We are the best to tell you what to improve! Users' perceptions about innovative resources to promote evidence-based manual wheelchair skills training in pediatric rehabilitation settings: a descriptive qualitative study

B. Ouellet^{1,2}, T. Dib^{3,4}, PW. Rushton⁵, KL. Best^{1,2}

¹Université Laval, ²Center for Interdisciplinary Research in Rehabilitation and Social Integration, ³Université de Montréal, ⁴CHU Sainte-Justine Research Center, ⁵Dalhousie University

INTRODUCTION

Manual wheelchairs (MWC) may help children and adolescents with mobility limitations to navigate their everyday life environments and participate in occupations (e.g. play, school, physical and social activities) contributing to their global development, health and quality of life [1]. However, many children and adolescents (pediatric MWC users [PMWUs]) require physical assistance from their caregivers to use their MWC [2], and may thus miss the benefits associated with independent mobility, such as opportunities for social participation [1].

User training is one of the 8 essential steps of the wheelchair provision process recommended by the World Health Organization, as it promotes safe and independent MWC mobility [3]. Training on how to use assistive devices, such as MWC, is also a right for people with disabilities [4]. Yet, 2 surveys conducted in Canada indicated that PMWUs receive little to no MWC skills training in pediatric rehabilitation settings [2,5]. In fact, because of lack of time, knowledge and resources, more than 50% of clinicians provide less than 3 hours of training to PMWUs and only teach basic skills for indoor mobility [2,5]. This may explain why PMWUs expressed feeling unconfident to overcome the obstacles they encounter in the community (e.g., holes, gravel) [6].

The Wheelchair Skills Training Program (WSTP), the gold standard for training indoor, community and advanced MWC skills, can be a helpful resource to support clinicians in their interventions [7]. Although 73 studies demonstrate the effectiveness of the WSTP with adults (n=69) and a positive influence on PMWUs' mobility (n=4) [7–9], this program remains underutilized in pediatric rehabilitation settings, as 75% of occupational therapists (OTs) reported not using a validated program when training MWC skills [2]. OTs expressed concerns regarding the lack of playfulness of the WSTP, the lengthy manual, the absence of tips and tricks to facilitate PMWUs' learning, and the training materials specific to adults (10). They perceived that knowledge transfer (KT) resources tailoring the pediatric population could promote the use of the WSTP and evidence-based practice [10].

To respond to this need, an interdisciplinary team of OTs (clinicians and students), MWC users (one adult and a 9-year-old child), rehabilitation services managers and researchers co-created a set of WSTP KT resources, including a storybook, posters and a training workbook for training 4 basic indoor MWC skills. Then, masters of OT students and researchers expanded the work of this team to create 2 additional sets of resources for training 9 more complex indoor and community MWC skills. Considering that clinicians' and patients' perceptions influence the adoption of evidence-based practice, this study aims to explore OTs' and PMWUs' perceived satisfaction with the 3 sets of resources and to describe these users' perceptions regarding their usability, relevance and feasibility in pediatric rehabilitation settings.

METHODS

A descriptive qualitative design was used to document users' perceptions, including online focus groups with OTs and semi-structured interviews with PMWUs. Ethics approval was obtained from the Sainte-Justine University Hospital Research Center Ethics Board (#2020-2828). OTs and PMWUs' parents provided written informed consent. PMWUs' assent was obtained verbally at the beginning of the interviews.

Participants

Participants were recruited from a Montreal rehabilitation center and its affiliated specialized schools (population with various physical disabilities \leq 21 years old) using convenience and purposive sampling strategies. OTs working with PMWUs and able to participate in an online discussion were eligible to participate in the focus groups. PMWUs between 5-15 years of age, who used a MWC (\geq 4h/day), and were able to participate in an online discussion were eligible to participate in an online discussion were eligible to participate in an online discussion were able to participate in an online discussion were able to participate in an online discussion were eligible to participate in the interviews.

Three sets of WSTP KT resources

Each set includes 3 complementary resources, a storybook, 4-5 posters and a training workbook. The 1st set addresses 4 indoor skills (rolls forward, rolls backward, turns while moving forward, reaches for objects), the 2nd 5 indoor and community skills (turns in place, maneuvers sideways, gets through hinged door, goes up and down slight inclines) and the 3rd 4 more complex community skills (goes up and down steep inclines, rolls on soft surfaces, gets over obstacles). The storybooks aimed to introduce the MWC skills in a playful way, to motivate PMWUs to engage in training and to raise awareness about PMWUs' potential to carry out activities with their MWC. The posters are visual aids based on motor learning principles. The skills are broken down into small steps (i.e., part practice) and explained using visual (e.g., rolls forward: rainbow illustration showing the hand position on the hand rims) or verbal cues (e.g., gets over obstacles: push, pop, lean). Posters can be used in training workbooks, which can be completed collaboratively by OTs, PMWUs and parents, include 4 sections: mobility goals, skills levels (scores to rate the capacity to perform the skills, level of assistance required [3rd set]), skill progression (tables in which smiley faces can be drawn when skill steps are mastered) and comments.

Procedures

A sociodemographic questionnaire was completed by OTs (e.g., sex, years of experience working with PMWUs, frequency of use of the WSTP) and PMWUs (e.g., age, years of experience using a MWC, previous training, frequency of assistance). Two 90-minute focus groups with OTs (2021: 1st set; 2022: 2nd and 3rd sets) and 60-minute semi-structured interviews with PMWUs were conducted on the Zoom videoconferencing platform. The resources were presented to the participants before the discussions to facilitate the expression of their points of view. Focus group and semi-structured interview guides included open-ended questions based on the 3 indicators of the *Guide to Monitoring and Evaluating Knowledge Management in Global Health Programs*: satisfaction (e.g., which element do you like most/least?), usability (e.g., how do you find the visual appearance or the presentation of the skills?) and relevance (e.g., how will you use the resources?) [11]. The feasibility to use the resources in clinical practice was also documented with OTs (e.g., which facilitators and barriers influence your capacity to use the resources?). Members of the interdisciplinary team who co-created the first set of resources pilot-tested the focus group (OTs and researchers) and interview guides (9-year-old MWC user).

Analyses

Sociodemographic data were summarized using descriptive statistics (medians, interquartile ranges [IQR], frequencies). Qualitative data were deductively analyzed using the Framework method, which involves the codification of the data in the categories (i.e., satisfaction, usability, relevance and feasibility) of a matrix [12].

RESULTS

Participants

8 OTs with a median experience working with PMWUs of 4.3 years (IQR=8.8) participated in the first focus group. 6 OTs with a median experience working with PMWUs of 4 years (IQR=0.4) participated in the second focus group. In both focus groups, only one OT reported often using the WSTP. 11 PMWUs ranging from 6 to 15 years of age participated in the interviews to share their perceptions about one or several sets of resources (n_{set 1}=5, n_{set} ₂=4, n_{set 3}=4). PMWUs had a median experience using a MWC of 6 years (IQR=3.8), the majority (n=7), sometimes required assistance and 5 of them previously received MWC skills training.

Satisfaction

OTs expressed satisfaction with the 3 sets of resources describing them as "*playful*", "*easy to use*" and "*helpful*". They had little suggestions for improvements for sets 1 and 2, but more for the 3rd set. They appreciated the continuity between the 3 sets since they could be used successively as PMWUs grow and improve. They noticed that the maturity of the themes and the difficulty of the skills increase progressively. Although the storybooks, posters, and training workbooks are complementary, OTs liked having various options: "*I like to have choices of different resources. It gives me flexibility in my interventions* [FG2: OT6]". PMWUs were satisfied with the resources but, regardless of the set, the training workbook was a favorite because of the section "skill progression". PMWUs liked drawing smiley faces to see their progress in the development of their skills. PMWUs would recommend all sets of resources to novice PMWUs, including those with community skills, as mentioned by PMWU3 when talking about the 2nd set: "*I would recommend the resources to help children understand their MWC when they receive them. It seems easy, but sometimes you have difficulty doing skills. It is normal.*".

Usability

OTs and PMWUs liked the aesthetics of the resources, especially because children and adolescents can recognize themselves in illustrations depicting adapted environments (sets 2 and 3; e.g., wheelchair swing) and characters of different genders, nationalities, and disabilities (e.g., different skin colours, various mobility options: MWC, walking aids and dogs). PMWUs mentioned anti-tippers should be added to the MWC for all skills to ensure safety, even when rolling on soft surfaces and getting over obstacles. Most suggestions for improvements were related to the presentation of the skills. For example, to facilitate the learning and integration of the skills sequence, OTs and PMWUs recommended changing the order of the steps to roll backward, simplifying the instructions of the skill maneuvers sideways and breaking down into sub-step the "pop step" of the skills rolls on soft surfaces and gets over obstacles. OTs acknowledged not frequently training the latter 2 skills and expressed the need for additional information to increase their confidence in teaching them.

Relevance

OTs expressed the desire to use the 3 sets of resources "*tomorrow morning* [OT]", feeling that they have a better knowledge of the skill techniques and are more competent to train them. They perceived the resources could be relevant to other stakeholders involved in training MWC skills (e.g., physiotherapists, physical education teachers), highlighting the training workbook could facilitate interdisciplinary collaboration by allowing everyone to follow PMWUs' progress. PMWUs found the resources were an appropriate method to train novice MWC users from 3 to 11 years of age but described them as "*too easy and childish* [PMWU1-4 sets 2-3]" for experienced and adolescent MWC users. While some PMWUs said they would use the resources to learn new skills or improve their techniques, others expressed reluctance to change, being already comfortable with their methods. Some PMWUs, like PMWU5 (set 3), who asked to write 12 mobility goals, were motivated to practice their MWC skills, whereas others expressed: "*I don't want to work on objectives, I want my MWC to stay fun* [PMWU1, set 1]".

Feasibility

For all sets, the main facilitator to the implementation of the resources identified by OTs is time. OTs described the resources as "*turn key* [FG1: OTs 1 & 4; FG2: OT6]" explaining they could decrease the time spent preparing fun interventions. While OTs mentioned having available space and materials to use the first set, those working in specialized schools did not for the 2nd and 3rd sets as the adapted environments are free of obstacles, such as ramps. Presenting only one technique to perform each skill was reported as a limitation since alternative methods may be favorable for PMWUs depending on the configuration of their MWC and their personal characteristics. Translating the resources in English may facilitate their use in the clinic as OTs mentioned offering services to a "*multicultural population* [FG1: OT6]" including "*families who are not fluent in French* [FG2: OT2]".

DISCUSSION

OTs' and PMWUs' perceptions suggest that the 3 sets of KT resources are a promising solution to promote the implementation of the WSTP in pediatric rehabilitation settings and to support the development of MWC skills in young and novice PMWUs. The results of the study highlight that the resources address several barriers to using the WSTP in pediatrics, particularly the lack of time to plan training interventions using the voluminous manual and the absence of pediatric-friendly training materials [10]. However, some barriers related to trainers' knowledge, skills, beliefs about capabilities and consequences remain to be addressed. In fact, OTs expressed that, although helpful, the information provided in the KT resources was insufficient to make them feel confident in training community and advanced MWC skills, such as getting over obstacles. Clinicians graduating from most rehabilitation university programs are insufficiently trained to provide high-guality MWC skills training, with 21% of institutions worldwide not providing any education on wheelchairs and only 5.1% of institutions in industrialized countries using the Wheelchair Skills Program to develop their content [13]. Moreover, as mentioned by OTs in the present study, lack of physical obstacles in the clinical practice setting may limit the training of community skills. However, since PMWUs encounter physical obstacles frequently when navigating in the community (e.g., parks, mall) [6], training interventions could be provided directly in various natural environments to overcome this barrier and also promote skills generalization [7]. Variability of practice is a motor learning principle in the WSTP and a component included in the most effective pediatric rehabilitation interventions [7,14]. In addition, exposure to real obstacles in natural environments may help PMWUs understand the relevance of training and make the skills practice more meaningful. Conversely, not all clinical contexts allow OTs to provide interventions outside their rehabilitation setting. As such, portable wheelchair skills obstacles could be interesting but, to our knowledge, this does not exist. Finally, to contribute to closing the gap between the evidence supporting the WSTP and its use in pediatrics, PMWUs' perceptions showed a need to develop KT resources tailoring experienced and adolescent MWC users. These specific users were not represented in our co-creation process,

which may explain why the resources may not reach them. In fact, involving these users right from the start may be a good strategy. For example, they could contribute to selecting the format (e.g., videos on social media), MWC skills important in their everyday life, or writing the content using their own expressions.

CONCLUSION

OTs and PMWUs perceive the KT resources (with small improvements to increase usability) have a great potential to enhance the use of the WSTP for training novice and young MWC users. Future efforts should contribute to reinforcing OTs' confidence in training community and advanced MWC skills and focus on the development of resources adapted to experienced and adolescent MWC users.

ACKNOWLEDGEMENTS

The authors thank the Canadian Institutes of Health Research for the financial support provided to Beatrice Ouellet by the Vanier Graduate Scholar Award. They also thank the Child-Bright Network for its financial support for this project.

REFERENCES

- [1] Rousseau-Harrison K, Rochette A. Impacts of wheelchair acquisition on children from a person-occupationenvironment interactional perspective. Disabil Rehabil Assist Technol. 2013 Jan;8(1):1–10.
- [2] Daoust G, Rushton PW, Demers L. Bridging the gap in wheelchair skills testing and training in a Canadian pediatric rehabilitation context. In Oceania Seating Symposium 2019. Melbourne: Australia; 2019.
- [3] World Health Organization. Guidelines on the provision of manual wheelchairs in less resourced settings; 2008. Available from: <u>https://www.who.int/publications/i/item/9789241547482</u>

[4] United Nations. Convention of the rights of people with disabilities; 2006. Available from: <u>https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf</u>

- [5] Best KL, Routhier F, Miller WC. A description of manual wheelchair skills training: current practices in Canadian rehabilitation centers. Disabil Rehabil Assist Technol. 2015 Sep 3;10(5):393–400.
- [6] Evans S, Neophytou C, de Souza L, Frank AO. Young people's experiences using electric powered indoor outdoor wheelchairs (EPIOCs): Potential for enhancing users' development? Disabil Rehabil. 2007 Jan;29(16):1281–94.
- [7] Kirby RL, Rushton PW, Smith C, Routhier F, Archambault PS, Axelson PW, et al. Wheelchair Skills Program Manual: Version 5.3; 2022. Available from: <u>https://wheelchairskillsprogram.ca/en/skills-manual-forms/</u>
- [8] Keeler L, Kirby RL, Parker K, McLean KD, Hayden JA. Effectiveness of the Wheelchair Skills Training Program: a systematic review and meta-analysis. Disabil Rehabil Assist Technol. 2019 May 19;14(4):391–409.
- [9] Ouellet B, Best KL, Wilson D, Miller WC. Exploring the Influence of a Community-Based Peer-Led Wheelchair Skills Training on Satisfaction with Participation in Children and Adolescents with Cerebral Palsy and Spina Bifida: A Pilot Study. IJERPH. 2022 Sep 21;19(19):11908.
- [10] Daoust G, Rushton PW, Racine M, Leduc K, Assila N, Demers L. Adapting the Wheelchair Skills Program for pediatric rehabilitation: recommendations from key stakeholders. BMC Pediatr. 2021 Dec;21(1):103.
- [11] Ohkubo S, Sullivan TM, Harlan SV, Timmons BK, Strachan M. Guide to monitoring and evaluating knowledge management in global health programs. Ward Rinehart; 2013. Available from: <u>https://www.msh.org/sites/default/files/km-monitoring-and-eval-guide.pdf</u>
- [12] Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013 Dec;13(1):117.
- [13] Fung KH, Rushton PW, Gartz R, Goldberg M, Toro ML, Seymour N, et al. Wheelchair service provision education in academia. Afr j disabil. 2017 Sep;6.
- [14] Novak I, Honan I. Effectiveness of paediatric occupational therapy for children with disabilities: A systematic review. Aust Occup Ther J. 2019 Jun;66(3):258–73.