PPP-ARM: A QUALITY IMPROVEMENT BY INCORPORATING PATIENT INVOLVEMENT AND BY ADDING A DECISION AID FOR TERMINAL DEVICES

Paula A. Wijdenes, OT[1, *]; Nienke Kerver, MSc[1, *]; Sacha van Twillert, PhD[2]; Laura Boerema, MSc[1]; Michael A.H. Brouwers, MD[3]; Professor Corry K. van der Sluis, MD PhD[1]

* These authors contributed equally to this work

[1] *University of Groningen, University Medical Centre Groningen, Department of Rehabilitation Medicine, Groningen, The Netherlands*
[2] *University of Groningen, University Medical Centre Groningen, UMC Staff Policy and Management support, Groningen, the Netherlands*
[3] *Rehabilitation centre De Hoogstraat, Utrecht, The Netherlands*

ABSTRACT

Introduction: The Prosthesis Prescription Protocol of the upper limb (PPP-Arm), is a digital tool to structure, underpin and evaluate the prescription of upper limb prostheses (ULPs) in rehabilitation centres in the Netherlands that prescribe ULPs. The results of evaluating five years of PPP-Arm use, the recently developed Dutch Quality Standard for Prosthetic Care (D-QSPC) and the wish for facilitating shared decision-making led to this study. We aimed to develop and implement quality improvements and a patient decision aid (PDA) to the national digital protocol PPP-Arm.

Methods: Improvements for PPP-Arm were identified by an evaluation with clinicians after five years of PPP-Arm-usage and based on the recommendations described in the D-QSPC, focussing on new elements that should be incorporated in PPP-Arm. The PDA about Terminal devices for people with Upper Limb Absence (PDA-TULA) was developed in a systematic co-creation process following the steps described by the International Patient Decision Aid Standards. The improved PPP-Arm and the newly developed PDA-TULA were pilot-tested in the real-life national rehabilitation setting.

Results: The following improvements were made to PPP-Arm: the option to add images to the prosthesis application for the health care insurer, access for patients to PPP-Arm in order to complete surveys, digitally signing prosthesis applications, view educational material, and more structure was integrated in the description of the stepped care process. Furthermore, the PDA-TULA was added to PPP-Arm, which informs patients about available Terminal Devices (TDs), then stimulates the patient to consider their own preferences regarding the TD options, and lastly provides an overview of the patients' preferences in relation to the available TD options. Implementation of the pilot-test regarding the improvements of PPP-Arm is ongoing, we expect it will lead to better usability, modernization, and increased patient involvement in the treatment process. Pilot-testing of the PDA-TULA showed that patients and clinicians experienced benefits from the PDA-TULA regarding the prosthesis selection process.

Conclusion: PPP-Arm has been improved, adjusted to the renewed D-QSPC, and supplemented with the PDA-TULA. Results emphasize the importance to cooperate with all stakeholders and pilot-test changes and new products in the real-life setting to develop and improve products that suits the needs of all stakeholders.

INTRODUCTION

The Prosthesis Prescription Protocol of the upper limb (PPP-Arm) is a national tool to structure, underpin and evaluate the prescription of upper limb prostheses (ULPs). The protocol creates a uniform and structured, nationally applicable, prescription policy and is based on the World Health Organization's criteria of the International Classification of Functioning (ICF; Figure 1). PPP-arm was initiated in 2009, digitalized in 2012, and implemented into all ten rehabilitation centres that prescribe ULPs in the Netherlands in 2016. PPP-Arm has been co-created by patients, rehabilitation teams, orthopaedic workshops, and health insurance companies, collaborating in the working group PPP-Arm [1]. After five years of nationwide use, the users expressed a need to evaluate and improve PPP-Arm.

Additionally, the publication of the new Dutch Quality Standard for Prosthetic Care (D-QSPC) [2], which should be implemented into the Dutch health care process, affirmed the need to update PPP-Arm. Furthermore, shared decision making is becoming increasingly important in clinical practice, especially regarding preference-based decisions such as ULPs [3]. A patient decision aid (PDA) could support the shared decision-making process between patient and clinicians by informing the patient about available options and helping them to clarify their values related to those options [4]. Therefore, this study aimed to develop and implement quality improvements and a PDA to the national digital protocol PPP-Arm.

Figure 1: Structure of PPP-Arm

METHOD

Adjustments to PPP-Arm

Adjustments to PPP-Arm were based on 1) an evaluation among clinicians and 2) recommendations provided by the recently published D-QSPC.

1) The evaluation consisted of collected feedback and suggestions from clinicians of ten rehabilitation teams during the last five years and discussion during several meetings of the national working group amputation and prosthetics of the upper limb (WAPA).
2) The recommendations of the renewed D-QSPC were analysed focussing on elements that should be incorporated in PPP-Arm, for example: PPP-Arm should be more patient oriented, more structured in the application of the stepped care process and should use the same terminology as the D-QSPC.

A proposal for adjustments was presented to and approved by the WAPA members. After incorporation of the improvements to PPP-Arm, the protocol was implemented and tested in clinical practice by ten rehabilitation teams. In each team a knowledge broker (KB; a member of the prosthetic team, mostly a therapist) was responsible for the implementation of the new version of PPP-Arm within his own centre. A national project coordinator was appointed, who maintained contact with all parties involved, collected questions and problems regarding the improved PPP-Arm, and organized meetings to further implement the PPP-Arm.

Development and pilot-test of PDA-TULA

The local Medical Ethics Review Board of the University Medical Centre Groningen waived formal study approval regarding the PDA-TULA (METc 2018/582). Participants of focus groups, surveys and interviews provided written informed consent. The documentation template of the International Patient Decision Aid Standards was used to develop the PDA about Terminal devices for people with Upper Limb Absence (PDA-TULA) [5]. First, the scope was determined. A focus group among clinicians was organized and the target audience for the PDA-TULA was determined: people with major unilateral upper limb absence. Second, a steering group with patients, clinicians, a prosthetist, researchers, an ICT expert, and implementation experts was assembled. Third, the contents and design of the PDA-TULA were elaborated. The contents were based on a qualitative meta-synthesis [6], a focus group with patients [6], a survey among patients [7] and prosthetists, a nationwide digital meeting with clinicians, information from manufacturers, and discussions with the research team and steering group. To determine the design, drafts of the PDA-TULA were made, improved based on the feedback of the steering group, and the PDA was integrated into the software. Fourth, the PDA-TULA was alpha tested by patients, clinicians, health care insurers, researchers, and an implementation expert. All feedback was processed, resulting in the beta-version of the PDA-TULA, which was implemented and pilot-tested for five months in nine rehabilitation centres. To support the implementation process, the following actions were taken: co-creation of the PDA-TULA, usage of the network of KBs of PPP-Arm, option

for financial support for KBs, organization of meetings with the KBs, assignment of a project coordinator for technical support and questions during the pilot, provide updates about the PDA-TULA on national meetings and in newsletters for stakeholders. Telephone interviews with patients, KBs and clinicians were conducted to evaluate the PDA-TULA.

RESULTS

Implementation of adjustments to PPP-Arm

Based on the feedback derived from PPP-Arm users (ten rehabilitation teams) and analyses of the D-QSPC, the following improvements were made to PPP-Arm:

- Creation of a patient hub, a digital environment that can be accessed by the patient in order to exchange questionnaires and entry the PDA-TULA.
- Addition of the option to provide a digital signature for patients and professionals in order to digitally approve the prosthesis application.
- Integration of the Dutch version of the Quebec User Evaluation of Satisfaction with assistive technology (D-QUEST). Via the patient hub, D-QUEST can be sent digitally, completed and stored in PPP-Arm.
- Creation of easier access and management of the prosthesis information folder in the protocol: Administration page for content managers to add/remove educational materials for patients.
- Addition of the option to add photos to the prosthesis application report.
- Addition of the option to define the function of all separate users (i.e., doctor, occupational therapist, physiotherapist, hand therapist, prosthetist) to guarantee safety and transparency.
- Application of the terminology of the D-QSPC in PPP-Arm.
- Structuring and improvement of choices in the stepped care process.
- Development and integration of the PDA-TULA (see below).

Currently, pilot-testing is ongoing. We expect the adjustments will lead to a quality improvement of PPP-Arm: better usability, more structure, modernization, better access to educational material and increased patient involvement in the prosthesis selection process. Pilot-test results will be revealed at the conference.

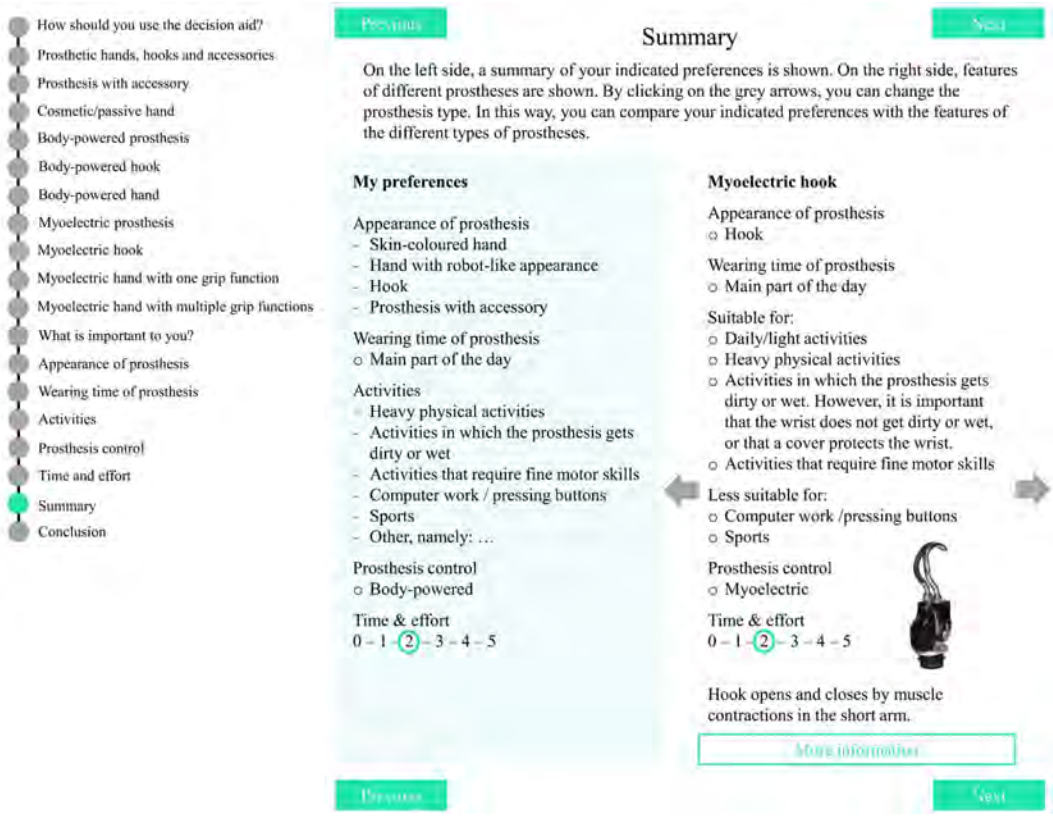

Figure 2: Example of the summary page of the last part of the digital PDA-TULA.

Development and pilot-test of PDA-TULA

The PDA-TULA consists of four parts. In the first part, patients are asked to enter personal information, which can be imported into the patient's file by the clinician. In the second part, general information about seven Terminal Device (TD) categories is provided: prosthesis with a tool/accessory, cosmetic/passive hands, body-powered hooks, body-powered hands, myoelectric hooks, myoelectric hands with one grip, and myoelectric hands with multiple grips. To fulfil the need of experienced ULP users, more detailed information can optionally be consulted by accessing underlying pages within the PDA-TULA. In the third part, patients are stimulated to consider what is important for them regarding their ULP. Information about five prosthetic aspects is provided (appearance, wearing time, activities, prosthesis control, time and effort), each followed by a question about the patient's preferences regarding that aspect. In the last part, a patient profile is created based on the patient's preferences. This profile can be compared with the profiles of the TD options (Figure 2). A PDF with a summary of the results and the patient's questions for the next consultation is available for the patient and clinician.

Patients were enthusiastic about the PDA-TULA, they stated that the PDA helped them to get an overview of the available TD options and go through the information at their own pace. Additionally, KBs and clinicians indicated that the PDA-TULA was of added value and could be used as educational material in the prosthesis selection process. However, some patients needed help to go through the PDA (e.g., non-Dutch speakers, insufficient digital skills). Provided feedback from the telephone interviews were discussed with the steering group and subsequently final refinements were made to the beta-version of the PDA-TULA (e.g., addition/change of some pictures, textual clarifications).

CONCLUSION

PPP-Arm was modernized, improved, adjusted to the new D-QSPC, and supplemented with the PDA-TULA. Clinicians, KBs, and patients were involved in the development of the PDA-TULA and update of PPP-Arm. Pilot-testing of the PPP-Arm improvements is still ongoing. However, the pilot test in the real-life rehabilitation setting enabled further improvements of PDA-TULA based on the experiences of the different stakeholders, which resulted in many positive responses from the involved stakeholders. This study, therefore, emphasizes the importance to cooperate with all stakeholders and pilot-test changes and new products in the real-life setting to make a product that suits the needs of all stakeholders.

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