

Participation Overload in Physical Rehabilitation

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Abstract. In this paper, we discuss the merits and difficulties of establishing a culture of participation in the context of physical rehabilitation. We describe our own efforts in and experiences from deploying an end-user extensible technology for rehabilitation in a clinical setting. Finally, we discuss how some of the challenges that we have faced could be resolved, and how they are applicable to a wider range of domains.

Keywords Cultures of participation, healthcare, end user development, meta design, TagTrainer

1 Introduction

The rising incidence of age-related diseases such as stroke puts an ever increasing pressure on the healthcare system. Not only does this increase threaten the financial viability of high-quality healthcare, it also puts medical professionals, such as doctors and therapists, under great pressure to cope with the increasing number of patients. Arguably this can lead to patients receiving less treatment than they should and therefore achieve less than optimal results from their rehabilitation. The use of technology can potentially alleviate some of these burdens, since it can be used to provide more intensive, variable and fun treatment and hopefully, increase the effectiveness of treatment. As technology can guide and even monitor how patients carry out rehabilitation, it can potentially support independent training, or at least reduce the need for supervision by healthcare professionals. Technology can potentially reduce the dependency of patients on traditional healthcare environments such as hospitals and rehabilitation clinics.

In our research, we focus on the application of end-user adjustable technology for physical rehabilitation. Providing adaptable technology is especially important in the domain of physical rehabilitation, since the needs of individual patients can differ greatly. In order to provide every patient with the best possible treatment, it is therefore imperative that the technology is adjustable, and that therapists can themselves design and implement patient tailored exercise content. Such adjustment can vary in its extent, starting from simple adaptations of parameters such as number of repetition, level of challenge, and the collection of exercises carried out for rehabilitation. At the other end, adjustment may concern the very content of rehabilitation exercises, and their purpose

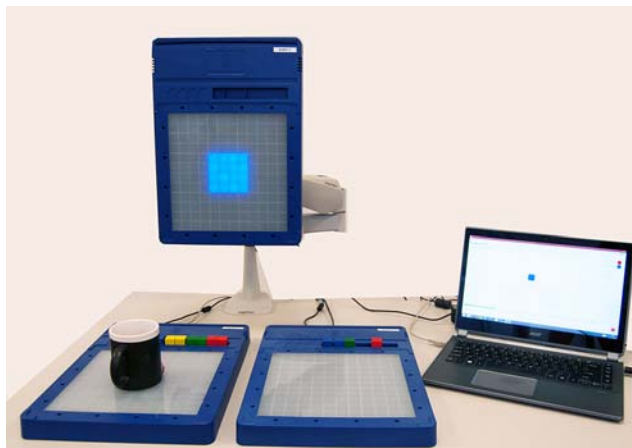


Fig. 1. A TagTrainer setup with three TagTile boards connected to a laptop.

which could be made to fit the individual wishes for patients. Exercises created specially for a specific patient could be programmed by therapists allowing thus end-user development practices to emerge.

In the remainder of this paper, we discuss the design and evaluation of TagTrainer, an end-user extensible technology for physical rehabilitation. Specifically, we focus on the impact of the introduction of end-user development (EUD) practices and establishing a culture of participation [1] in a clinical context.

2 A case study: TagTrainer

At the Eindhoven University of Technology, we have developed TagTrainer, an end-user extensible, interactive technology for physical rehabilitation training [3]. In this section we describe the technology, and four studies in which we deployed TagTrainer in a clinical setting. These studies are described more extensively in [2].

2.1 Design & implementation

TagTrainer (see **Fig. 1**) consists of:

- One or more interactive tabletop surfaces (TagTiles) that are able to detect RFID-tagged objects, and provide visual and auditory feedback
- An extensible and customizable collection of objects with RFID-tags attached to them, and
- Software that allows therapists to run therapy exercises on the TagTile board(s), and to extend, modify and create therapy exercises for TagTrainer.

An example exercise that could be performed with TagTrainer is one where the patient trains wrist rotation in order to be able to drink from a cup. In this case, a therapist would attach a RFID-tag to the bottom, left and right side of a cup. The exercise could then be as follows:

- An area lights up at the center of the board, indicating to the patient that the cup needs to be placed here.
- The patient places the cup on the lit up area. TagTrainer confirms the correct placement of the cup by flashing the area in green.
- Another area lights up in blue, indicating to the patient that the cup needs to be turned on its right side in order to touch the lit-up area. The patient touches the area with the right side of the cup.
- Finally, a yellow area lights up on the board, and the patient touches the area with the left side of the cup. From here, the exercise is repeated a number of times, to provide the patient with sufficient training intensity.

Therapists can modify, extent, or create exercises by using the TagTrainer Exercise Creator (TEC). TEC provides a visual programming interface that allows therapists to easily modify or construct exercises by composing a sequence of actions (e.g., ‘place object’, ‘lift object’, ‘playback sound’) and by specifying the objects to be used in the exercise. All exercises are currently stored in a local database and are accessible to any therapist using that specific TagTrainer system.

2.2 Evaluation

Method

We evaluated TagTrainer by performing four deployment studies in three rehabilitation clinics in Belgium and The Netherlands (see [2]). 24 therapists participated in these studies that lasted for three to eight weeks. These deployment studies were aimed at studying the uptake of TagTrainer as a tool for physical rehabilitation therapy, and at studying the uptake of EUD practices by rehabilitation therapists. We conducted interviews and observations, administered questionnaires measuring technology acceptance, self-efficacy and clinical credibility, and collected log-data on the use, modification and creation of therapy exercises.

Results

In total, over the four studies, 45 patients performed 466 therapy exercises with TagTrainer. Further, 35 new exercises were created and 5 exercises were modified by the participating therapists.

In general, therapists reported that the application of TagTrainer as a technology for physical rehabilitation provided them with important benefits. For example, it allowed them to provide patients with tailored exercises that increased the motivation and treatment compliance of their patients. Similarly, it allowed patients to work more independently, enabling therapists to attend to other patients requiring their assistance. Though the possibility to modify and create exercises appeared valuable, therapists remarked that it put them under severe time pressure. Currently, therapists are paid for

patient treatment only, and not for auxiliary tasks that might eventually provide higher treatment quality. Any such activities, like creating an exercise with TagTrainer, had thus to be performed at the expense of patient treatment time, or during breaks and afterhours.

In this regard, it is paradoxical that therapists were inclined to create new exercises rather than to reuse peer-created exercises. One therapist remarked, for example: “*Finding out the details about a peer-created exercise would take me more time than creating a suitable exercise myself.*” Therapists expected reuse to be difficult, since exact knowledge about an exercise (e.g., tag placement on an object) is required to get the desired effects of an exercise. Additionally, they envisioned problems in standardizing the categorization of exercises. Nevertheless, they used extensively the exercises pre-installed in TagTrainer at the start of the study, which had been created by other therapists.

Therapists reported that in principle they had no objections to sharing their creations with colleagues within or outside their own clinic, as long as other therapists would share as well. One participant especially liked the idea of other therapists being able to review the exercises that she created, such that she would learn to create better exercises. However, they doubted the further usefulness of sharing, since they expected that working out the details of a colleague’s exercise would cost them more time than creating an appropriate exercise from scratch. Additionally, participants expected that a lack of knowledge about the local patient population would make it harder for external colleagues to interpret the meaning and value of a given exercise. Rather than sharing exercises, therapists proposed an inter-clinic collaboration aimed at identifying ‘gaps’ in the exercise database that could be filled by the therapists themselves.

3 Discussion

Our studies have revealed interesting aspects about the introduction of EUD in a highly professional and time-constrained domain, such as physical rehabilitation. Our participants constantly faced a tradeoff decision between providing improved treatment quality and patient motivation by providing customized training exercises, and not having to invest in additional work to be performed in breaks and afterhours.

Given these findings, we expected that therapists would prefer the use of existing exercises over creating new exercises. One of the long-term goals of introducing TagTrainer in multiple rehabilitation clinics our studies was to facilitate the forming of a community of TagTrainer users, such that these users could engage in the exchange of end user developed rehabilitation exercises, and knowledge on the application of TagTrainer in physical rehabilitation therapy.

In view of a possible *participation overload*, it is interesting that sharing exercises was not at all considered to be problematic by the participants. Therapists were willing and able to share their creations, not even expecting their peers to act reciprocally. However, therapists had several objections against the reuse of peer created content. They expected that reuse would be time-consuming (difficult to judge an exercise’s content), and also expected that peer created exercises would not provide the same

treatment quality as exercises they could create themselves. The latter, interestingly, was not reported to be an issue of trust, but rather one of ignorance by peers of a therapist's local patient population.

Despite the reported difficulties, we do believe that TagTrainer can provide important benefits to physical rehabilitation therapy. One of the difficulties of our case is that the benefits of engaging in a culture of participation surrounding TagTrainer do not accrue to the same people that have to perform additional effort to provide these benefits (patients vs. therapists). We believe that a healthier culture of participation might develop if patients themselves (or their caretakers) can take an active role within our ecosystem, possibly providing some relief to the therapists. Instead of a 'mono-culture' of participation, we believe that a 'multi-culture' of participation is required, with several different stakeholders that can equally contribute to and benefit from the TagTrainer ecosystem.

Notwithstanding the benefits of a 'multi-culture' of participation, we believe that especially in a professional context such as that in our studies, it is of crucial importance that contributing to a culture of participation is recognized as an essential part of professionals' work, before such professionals can fully partake as active members of a culture of participation.

4 Conclusion

In this paper, we have described a case study of the implementation and deployment of TagTrainer, an end-user extensible technology for physical rehabilitation. Though TagTrainer was received positively by the therapists, their engagement in a culture of participation surrounding TagTrainer could have been even greater. An interesting challenge that remains for cultures of participation in specialist contexts such as ours is how to facilitate reuse of peer-created content. Moreover, we propose that to avoid a possible participation overload, multiple stakeholders should be enabled to actively participate in a culture of participation, especially if the benefits of participation do not in first instance accrue to those that provide effort to achieve those benefits. Finally, we propose that in a professional context, the management should acknowledge in certain cases that contributing to a culture of participation can be an essential part of a professional's tasks.

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