The Value of Active End-User Participation in Rehabilitation Technology: A Co-creation Workshop

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Abstract. To design effective rehabilitative technology, stakeholders (e.g., professionals from hospitals, universities, and industries) must empathize with end-user experiences and actively involve them throughout the design process. This approach can ensure the understanding of their complex needs. Yet end-user involvement is often limited to testing only. Technology developers often underestimate the valuable insights end-users gain during their recovery, which extend beyond technical knowledge. To address this, our international team of designers, engineers, and clinical personnel proposes a participatory design workshop involving acquired brain injury patients and their caregivers. Patients and caregivers work in groups with workshop participants to address specific needs and use methods like personas, MoSCoW prioritization, and prototyping to co-create solutions to meet those needs. We aim to illustrate the benefits of this approach and encourage participants to adopt participatory design in their future developments.

1 Introduction

Recent developments in rehabilitation technology have shown promising results in delivering high-intensity therapy after acquired brain injury, crucial for restoring cognitive and sensorimotor function [1]. However, the successful implementation of these technological solutions in everyday rehabilitation remains limited due to inaccessibility, difficulty of use, and resistance and abandonment of the technology [2]. The barriers to the widespread adoption of this technology may

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This work was supported by the Health and Technology Convergence Alliance of TU Delft, Erasmus MC, and Erasmus University Rotterdam and the Dutch Research Council (NWO) Talent Program VIDI TTW 2020.

J. L. Pons et al. (Eds.): ICNR 2024, BIOSYSROB 32, pp. 636–640, 2024.
https://doi.org/10.1007/978-3-031-77584-0_124

be due in part to the limited involvement of the end-users, such as patients and their caregivers, in each phase of the design process [2].

Understanding the diverse and complex needs of end-users is critical to designing more inclusive and human-centered technology; for example, the needs of patients can differ based on their specific impairments, family and friends' involvement in their care, emotional support, and personality traits, among other factors [3]. The active participation of end-users in the development process can be achieved through research approaches such as participatory design. This collaborative approach involves end-users in the design process and is built on the principles of inclusion, collaboration, co-creation, and empowerment [4].

Here, we describe the participatory design workshop we proposed for the 6th International Conference on NeuroRehabilitation (ICNR2024) titled: *Co-creating with patients: does it really matter? A Participatory Design Approach for Developing Rehabilitation Technology.* This workshop intends to engage the attendees (e.g., engineers, physiotherapists, researchers) in hands-on activities with acquired brain injury (ABI) patients and their caregivers to demonstrate the value of participatory design in rehabilitation technology and educate participants on various methodologies.

2 Methods

The workshop uses the *Double Diamond design process model* (Fig. 1), which consists of two diamonds —the problem and the solution space— and four phases: Discover, Define, Develop, and Deliver [5].

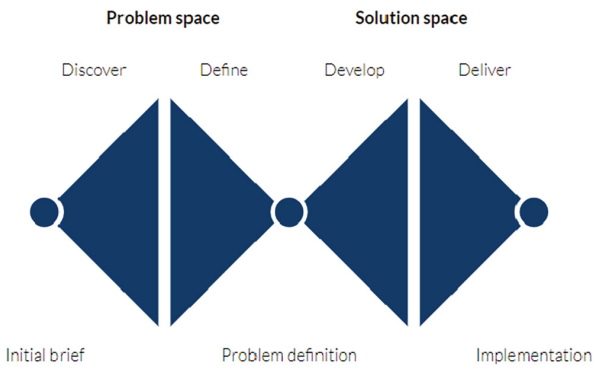

Fig. 1. The Double Diamond Design Process Model.

In the *Discover* phase, workshop participants gather insights from and empathize with ABI patients and their caregivers' needs. Participatory design methods, such as *bodystorming* —the act of physically experiencing a situation to immerse oneself in the users' shoes [6]—, or *digital storytelling* —short videos

capturing and sharing participants' lived experiences as narratives [7]—, are employed to enhance empathy as they could depict physically challenging situations that an ABI patient commonly faces when using rehabilitation technology, using a first-person perspective.

Participants then converge in the *Define* phase to identify the problem. By using methods like *Personas* —fictional characters created to help people empathize with end-users needs, experiences, behaviors, and goals to guide product development [8]—, or the *Point of View* —a meaningful and actionable problem statement that combines user needs, insights, and the design challenge to guide the product development [9]—, workshop participants determine together with ABI patients and their caregivers how they would behave and respond to a specific interaction with rehabilitation technology. These activities allow them to identify the needs, such as making the technology more accessible or training more motivating, and formulate a problem statement or the challenge to address in the following phase.

In the *Develop* phase, workshop participants brainstorm ideas with ABI patients and their caregivers by using brainstorming techniques to prioritize the ideas for final requirements. Examples of such methods are the *MoSCoW prioritization technique* to manage requirements and categorize them into must-have, should-have, could-have, and won't-have initiatives [10], and the *SCAMPER* technique to explore challenges and generate ideas from different perspectives, using the approaches *Substitute*, *Combine*, *Adapt*, *Modify*, *Put to another use*, *Eliminate*, and *Rearrange* [11].

In the final phase of the double diamond, *Deliver*, workshop participants build low- or high-fidelity prototypes together with ABI patients and their caregivers. They use methods like *Storyboarding* —a low-fidelity prototyping method consisting of visual representations of a hypothetical user's journey through a

Fig. 2. Example of the *Deliver* phase. Two groups of therapists co-created high-fidelity VR training prototypes for ABI patients with developers in a previous participatory design workshop at a Dutch rehabilitation institute conducted by the same research team [13].

product [12]—, or high-fidelity prototyping methods such as *Product mockups* —simplified representations of systems used to gather usability feedback, particularly when functional prototypes are impractical or when modifications are needed from non-experts [12] (Fig. 2).

3 Discussion and Conclusion

The value of collaborating with end-users during the design process has long been documented [4]. In rehabilitation technology, therapists, caregivers, and patients are increasingly involved (e.g., [2,13,14]). Integrating this design approach at every development stage could lead to broader acceptance of promising rehabilitation technology.

In the proposed ICNR2024 workshop, we hope for participants to embrace collaboration with end-users in their future endeavors by experiencing the value of active participation throughout the design process. Participants will engage in hands-on activities based on participatory design principles, bridging theory and practice. Including ABI patients and their caregivers from the start allows us to leverage their individual insights into how acquired brain injuries affect them. This fosters empathy and a deep understanding of their complex needs.

Insights from the workshop will be shared in the special session titled *Understanding the Value of Co-Creating Technology with Patients*, where we will discuss our problem-solving approaches and the outcomes of the workshop.

We encourage participants to include end-users from the beginning of their design process in future research. Active end-user participation can inspire new ideas that enhance accessibility, usability, and acceptance of the technology, ultimately improving ABI patients recovery.

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