Cultures of Participation in Healthcare: A Healthy Idea?

ABSTRACT

Healthcare has been named as one of the most promising domains for the application of end-user development (EUD) and cultures of participation. The specific nature of a patient's conditions often requires tailored treatment that calls for end-user adaptive technology. We have studied the establishment of cultures of participation in the domain of physical rehabilitation. In this paper we explore some of the issues related to introducing a culture of participation in the healthcare domain by reviewing experiences from our research, providing fuel for a broader discussion.

Categories and Subject Descriptors

J.3 [**Life and medical sciences**]: Health, K.4.3 [**Organizational impacts**]

Keywords

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

1. INTRODUCTION

Healthcare has been named as one of the most promising domains for the application of end-user development [3] and cultures of participation [4]. In many cases, patients have such specific conditions that they are in a 'universe of one' [2]: a unique case. Therefore, standardized technologies and treatments might not deliver an optimal solution and it seems only logical to allow doctors, therapists, caregivers and even patients to adjust these technologies to better fit the needs of the individual patient.

Guided by experiences from our own research in the domain of physical rehabilitation, we want to fuel a discussion about the feasibility of cultures of participation in the healthcare domain. After a short introduction to the domain of our research, we share some issues that we encountered during our studies.

2. PHYSICAL REHABILITATION

Patients who suffer from conditions such as stroke, spinal cord injury or multiple sclerosis are often faced with limited physical functionality. Usually, some of the lost functionality can be regained by intensive physical therapy. We have deployed the TagTrainer system [5], an end-user extensible physical

rehabilitation technology, in three clinics in the Netherlands and Belgium (see Figure 1). TagTrainer offers rehabilitation exercises on a tangible interactive board, and therapists can modify existing exercises, or create additional exercises to better fit the needs of their individual patients.

Figure 1 : Patient performing training with TagTrainer.

In studies performed at the various clinics, we observed and interviewed therapists working with TagTrainer. The therapists are highly motivated to improve the rehabilitation process of their patients and think that TagTrainer can play an important role herein. However, they also encountered a number of issues regarding the modification and creation of exercises that, we think, carry general applicability for cultures of participation in the healthcare domain.

3. PARTICIPATION IN HEALTHCARE

3.1 Quality and security

The healthcare sector is known to be relatively change resistant (e.g. [1]) – introducing new technologies and treatments usually involves going through long and complicated approval processes. There is of course a good reason for this: the risks associated with healthcare are extremely high. A wrongfully applied treatment or a poorly designed technology might at best not help a patient's recovery, but potentially leads to worsening of a patient's condition, or even death.

In the domain of our research, the consequences of design failures by end-user developers are fortunately limited. Still, we observed cases in which design failures of therapists led to patients getting stuck in the execution of their training programs. Therapists generally have good domain knowledge, but are not trained programmers or software designers. Without some form of quality control on their creations, it is likely that their solutions will not always produce the intended result – even though the principle behind an exercise might be perfectly adequate.

3.2 Workload and revenue models

The therapists in our studies were highly motivated to help their patients, and hence were willing to modify existing and create new exercises to better fit their patients' needs. However, the revenue model of their clinics is not centered on end-user development, but instead favours providing rehabilitation training to as many patients as possible. Any time therapists spend on end-user development tasks is time they cannot spend on patient treatment. Hence, therapists often settled for using existing, but less optimal exercises rather than creating new ones.

Although the participation of therapists in the adaptation of the TagTrainer system bears some potential advantages to their organizations (e.g. self-guided rehabilitation training, higher treatment quality), the clinics were hesitant to give up treatment time for therapists to engage in EUD. It is reasonable to believe, given the overloaded state of the healthcare sector in many countries, that this issue will appear in almost any healthcare organization where EUD is introduced.

3.3 Patient involvement

As we have experienced during our studies, therapists were very involved with the fate of their patients. Patient requests motivated therapists to engage in the creation of new exercises, and a positive patient response on such creations had a positive impact on therapists' attitude towards exercise creation and modification. While this example shows that patients do have an important, but relatively passive role within a culture of participation, it remains unclear to what extent patients can have a more active role within such a culture. Initiatives such as websites where patients with similar conditions exchange experiences and knowledge regarding living with, and treatment of their conditions (e.g. www.patientslikeme.com) enable patients to take on a more proactive role. However, they can at the same time be perceived as a threat by medical professionals, undermining their authority as domain experts. A similar response was observed during our studies, when therapists were asked as to what they thought could be the role of patients within a culture of participation. None of the therapists envisioned roles that involved domain expertise for the patients or their caretakers. We believe that this shows that the boundaries of patient involvement in cultures of participation need to be explored, allowing for a more active role of patients, while retaining some of the authority of medical specialists.

3.4 Sharing and reuse

One of the benefits of a thriving and open culture of participation is the possibility to exchange knowledge, ideas and creations in order to profit from 'the power of the crowd'. Although there are no reasons to believe that this benefit does not exist for the case of healthcare, there are a number of issues specific to the healthcare sector that influence the way in which sharing could and should take place:

1) Although the fact that patients often present a universe of one is a strong argument for the applicability of a culture of participation, it also presents a threat. It inherently means that solutions that are designed for a specific patient will carry less value for other patients. Well-designed abstraction and specification mechanisms could play a critical role here, since they would enable sharing overarching concepts while still allowing for patient tailored solutions.

2) With the high stakes at play in healthcare, trust and quality become very important factors in sharing solutions. After all, who would blindly accept medical advice, or even a treatment suggestion from a complete stranger? Before sharing solutions, especially between organizations, can be an effective mechanism in the healthcare sector, the quality of the solutions needs to be guaranteed. Fortunately, there are many ways to achieve this, such as by using peer-reviews, an independent validation body, or mutual development. Still, issues of liability might play a prohibitive role in sharing content between healthcare organizations.

3) An issue that might not be specific to the healthcare sector, but nonetheless bears great importance, is the transferability of concepts. In our studies, we often noticed that creations that were shared by therapists were not picked up by other therapists, because it was unclear to the others what exactly the therapeutic concept was that an exercise was addressing. If we aim to develop prolific cultures of participation, we need to give serious considerations to this particular issue.

4. CONCLUSION

The healthcare sector is generally regarded as a promising domain for cultures of participation. However, as we have illustrated with experiences from our own research, several issues exist that make healthcare an especially difficult domain for the application of cultures of participation. The potential gains are high, but so are the risks. We urge the community to discuss in what way these risks can be mitigated, how patient and caretaker involvement can be increased, and to what extent cultures of participation are a feasible concept in the healthcare domain.

5. ACKNOWLEDGMENTS

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