Patient Values Associated with an Exergame Supporting COPD Treatment

Kira OBERSCHMIDT[a,b,1], Marijke BROEKHUIS[a,b], and Christiane GRÜNLOH[a,b]

[a] *eHealth Department, Roessingh Research and Development, The Netherlands*
[b] *Biomedical Signals and Systems Group, University of Twente, The Netherlands*

Abstract. Exercise games (exergames) can help COPD patients stay active and prevent exacerbation. When evaluating such exergames, patient values are an important variable to take into account. In this study, seven COPD patients used an exergame technology at the physiotherapist for six months. Their values regarding treatment and the exergames were identified in interviews. Values were very stable throughout the study, and closely interconnected. Personal Guidance and Independence were important values. Additionally, patients sometimes held conflicting values that they prioritized differently at different times or based on specific events. As the study identified important values that appeared stable over a period of time, albeit with different prioritization, they are worth considering when designing new technology. However, values cannot be looked at in isolation because of the strong connection between values.

Keywords. Patient values, COPD, eHealth, Value sensitive design, Exergames, Rehabilitation, Physical therapy, Value tension

1. Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a common, preventable and treatable disease that is characterized by persistent respiratory symptoms and airflow limitation, a major cause for chronic morbidity and mortality and is among the top three causes of death worldwide (1). Being a chronic condition, many people suffer from COPD for years with respiratory symptoms such as dyspnea, cough and/or sputum production and periods of acute worsening of these symptoms called exacerbations (1).

It is important for COPD patients to stay active and keep exercising. Research suggests that exergames (exercise games) can be a good way of engaging COPD patients to exercise and stay active (2). When developing these games, much attention is paid to ensure safety, adherence and enjoyment (e.g. (3,4)), however, it is also important to investigate whether the technology supports the values of patients, as this might be a deciding factor whether the technology will be adopted and used. Value sensitive design (VSD) is an approach that addresses human values in the design process (5). While the word 'value' can refer to something of economic worth, VSD uses a broader meaning in which human values are defined as "what is important to people in their lives, with a focus on ethics and morality" (6) (e.g., trust, privacy, autonomy, identity). As values are contextual, may change over time or come into conflict (within an individual, among

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[1] Kira Oberschmidt, Corresponding author, eHealth Cluster, Roessingh Research and Development, Postbus 310, 7500 AH Enschede, The Netherlands; E-mail: k.oberschmidt@rrd.nl.

individuals or groups, creating so-called value tensions) (6), it is important to conduct empirical investigations to examine which values are affected in the distinct setting, i.e. how they are lived and experienced in a particular context at a particular point in time. It is therefore also important to evaluate in which way the values are supported or hindered in a particular setting. This study therefore aims to answer three research questions: (1) Which values are important for COPD patients in physical therapy? (2) How are their values supported when using the exergame? (3) How and to what extend do these values change over time?

2. Method

This study was part of an AAL project (Active Assisted Living) which evaluated an exergame technology installed at a physiotherapist's office in the Netherlands, where patients perform physiotherapy exercises in a large room, sometimes in groups. Patients used the exergame as an integrated part of their treatment, not as an addition on top of the regular care. The technology consisted of a TV screen on which videos and games were shown, and a motion-sensing camera that captured the participants' movement. When detecting that a patient was carrying out an exercise incorrectly, an audio-visual notification was provided. However, sometimes these notifications erroneously occurred even though the exercises were correctly performed.

Patients were recruited by their physiotherapist and interviewed four times within a period of six months (T1 start of the project, T2 6 weeks, T3 12 weeks, T4 24 weeks after starting). In each interview, their perceived values concerning (a) their physiotherapy in general, and (b) the use of the exergame were discussed. Because the patients had not experienced the exergame at the time of the first interview, it was possible to discuss the topics of values and technology more broadly. In this first interview (T1), open questions were asked about what is important to the patients in their treatment, and with regard to technology. Based on the T1 interviews and previous research within the researchers' institution, a list of nine values that seemed important for COPD patients in rehabilitation care was created. In all following interviews (T2-T4) participants were presented with this list and asked to select a maximum of three values that were the most important to them. For each selected value, participants were asked to describe what that value means for them, how that value is reflected in their treatment (generally and specifically with the exergame) and how this could be improved.

3. Results

Seven COPD patients took part in this study, of which two completed the whole six-month study. Most dropouts occurred after the third interview (between week 12 and 24). These dropouts happened mainly due to exacerbation or co-morbidities, except for one patient who dropped out because they disliked the exergames. Participants' age ranged between 55 and 74, and five of them were male. Most had been diagnosed with COPD between four to eight years ago, and most were also following physiotherapy (group) training for as long. The GOLD status (i.e. severity of airflow limitation) of all but one patient was 2 (moderate), for the last patient this was between 3 (severe) and 4 (very severe). Based on the initial interviews and previous research conducted in the rehabilitation center, nine values were identified in relation to rehabilitation care and the

exergame that were used as prompts in the follow-up interviews: Personal Guidance, Challenge, Trust, Independence, Contact with Others, Seeing Results, Regularity, Quality of Care and Privacy.

Important values, interconnection and tensions: Patients valued INDEPENDENCE and PERSONAL GUIDANCE highly, which was shown by the fact that these values were mentioned the most and most consistently over time. PERSONAL GUIDANCE was closely related to the values QUALITY OF CARE and TRUST. Some patients mentioned that QUALITY OF CARE improved when they received PERSONAL GUIDANCE. Although TRUST was not explicitly selected, participants talked about the trust towards their therapist when being personally guided.

The two most important values, INDEPENDENCE and PERSONAL GUIDANCE, seem to be contradictory, and one patient indeed described them as "*yin and yang*", meaning that they sometimes needed a lot of support, but at other times preferred to be left alone during their treatment. One patient selected INDEPENDENCE, because "*I have difficulty asking others for help. And if I am independent [working with the exergame] I don't need to do that*". However, in the next interview, the same participant mentioned needing PERSONAL GUIDANCE while working with the exergame[2]. Two other values that were interconnected and seem contradictory are REGULARITY and CHALLENGE. Patients liked having a fixed schedule and exercise pattern but also enjoyed being tested and pushed out of their current flow from time to time.

Values that increase motivation for treatment: For some patients, CONTACT WITH OTHERS was also important. Many of the participants were part of COPD treatment groups and highly valued the contact with peers who "*know each other well*" and "*all have the same problem*". Being able to exchange experiences and feeling understood when something was not going well were the main benefits of being part of a group. However, the exergame was used by one participant at a time, and thus did not allow for interaction with peers during the session. This was especially negatively remarked upon by one participant, for whom the group was what motivated and pushed them to do their training. A value that connected to this motivating experience when being in a group was that of CHALLENGE. The participants enjoyed the competition element in the exergame and perceived it as a way to either compare themselves with other users or others in their therapy group or to challenge their own score from the previous week.

These challenges also pushed them to do better and see the effect that this had on their condition, which was reflected in the value SEEING RESULTS. Patients were motivated by seeing the effect of their treatment, especially because for some of them it was crucial to keep being active. Additionally, when seeing these positive results, they knew that they were not wasting their time. Some of the patients also mentioned REGULARITY to be important during their training. For some the regular training schedule was needed as a motivational push, because "*sometimes I don't want to, but the appointment is set and so I go*", and that in the end "*it's always nice*". Concerning the exergame in this study, this patient added that the fixed time for each game made them stick to it instead of taking a break.

Values as a barrier: PRIVACY was mentioned specifically regarding the exergame technology. Prior to the third interview with one patient, there was an issue, where a photo of another participant was accidentally uploaded to their profile by the therapist. This made the participant think about PRIVACY, because they were now concerned that

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[2] This was related to the notification from the exergame about incorrectly performing an exercise, when according to the therapist, they were doing the exercise correctly.

"*somebody else can see my session*". While this was not explicitly mentioned by the participant, this situation also relates to TRUST in the system as the participant now was doubting. Additionally, this patient did not like being watched while doing the exergame and the loud notifications drew the attention of others in the room. These notifications made the patient self-conscious, even when being aware that they were often unjustly displayed.

Value change over time: Overall, the values that patients selected were relatively stable over time. The two participants who completed the study of 6 months, selected the exact same values each time, even though they were not aware of this and even surprised themselves. For another participant that dropped out after T3 the change in selected values was based mainly on the privacy issue that was described above.

4. Discussion

This study looked at important values of patients with COPD related to their treatment and the exergame that was tested. Additionally, the value change over time was investigated. Nine different values were identified and discussed by patients: Personal Guidance, Challenge, Trust, Independence, Contact with Others, Seeing Results, Regularity, Quality of Care and Privacy. Within their treatment in general, the symbiosis between PERSONAL GUIDANCE and INDEPENDENCE was deemed very important, as was CONTACT WITH OTHERS, especially others with COPD who experience the same problems. This is supported by (4) who notes that patients with COPD are often isolated due to their condition, and benefit from social contact. The exergame supported some of the patients' values (e.g. INDEPENDENCE, CHALLENGE, REGULARITY), but it did not support or even hindered other values (e.g. PERSONAL GUIDANCE, CONTACT WITH OTHERS, PRIVACY).

From the values that patients mentioned, selected and how they described them, it became apparent that a personalized approach to care is necessary. Not only can two patients have very different needs when it comes to PERSONAL GUIDANCE, but there can also be a vast difference for the same patient. Given the different situations at different times they might need a lot of support or prefer to be independent. This is supported by literature that says that suitable support from healthcare professionals increases the motivation of COPD patients to follow an exercise program (3,7). A similar personalized approach is needed when it comes to technology. Exergames support certain values but not others, so they might be more suited to a patient who for example values INDEPENDENCE highly.

Similar to (6), we also observed that values do not exist in isolation, but are interconnected. Some values are closely related and support or even depend on each other (e.g. TRUST and PRIVACY), others seem contradictory and create value tensions (e.g. PERSONAL GUIDANCE and INDEPENDENCE; REGULARITY and CHALLENGE). Most patients seemed unaware of the tension that appears between the values they chose. In addition to being very interconnected, values were also stable over time, even though the reasoning and prioritization might change, allowing patients to hold seemingly contradictory values. The interconnection between values shows that it is necessary to take a holistic approach to VSD instead of only designing for one value, e.g. INDEPENDENCE. It also shows that not all value tensions must be resolved, as people are able to balance and prioritize their values in a particular situation, especially when this flexibility is supported by the context, which is also described by (6).

A limitation of this study is the timeline of six months. To investigate the long term consistency of human values, a longer study would be needed. We did however see that, even though patients were not aware of it or consciously doing so, they selected the same values throughout the course of this study. Nonetheless, following patients for an even longer period of time could be valuable to learn more about the consistency and changes of values over time. In addition, many patients had to drop out due to exacerbations, which is something that needs to be accounted for with COPD patients. Participants who experienced exacerbations were unable to continue using the system, and in some cases also felt unable to partake in the interviews. As technology use was a main reference point for the patient values and out of respect for their wishes, the researchers did not try to convince dropouts to continue participation.

5. Conclusion

COPD patients hold a variety of different, but interconnected values. The most important values are PERSONAL GUIDANCE from their healthcare professional and keeping their INDEPENDENCE. While exergames can support some patients and patient values, others are not supported or even inhibited by technology. Even if values stay consistent over time for an individual, the value set may include values that seem to be in tension and are then prioritized given the current situation or specific important events. Generally, the values a person holds are often interconnected and relate to each other, so values should not be looked at in isolation. Therefore, when designing technology, the interconnections, dependencies and tensions between human values of stakeholders should be taken into account. This study is conducted within Active Assisted Living (AAL) project SALSA (project number: 2018-5-46-CP).

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