Exploring Ethical Design Dimensions of a Physiotherapeutic mHealth Solution through Value Sensitive Design

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Abstract

With the advent of smartphones, wearable sensors, and health tracking devices, mobile technologies providing healthcare services increasingly interfere with the users’ daily routines. In particular, mHealth solutions enable spatially independent health assessment and therapy monitoring, resulting in more efficient treatments and less clinical visits. However, due to these technologies being highly interwoven with the patient’s everyday life, mHealth technology designers need to factor in individual values and attitudes towards health-related technologies. In this paper, we propose a Value Sensitive Design approach for the design of a digital assistance for physiotherapeutic treatments. We present a three-step approach comprising focus groups, narrative and semi-structured interviews, and design workshops with relevant stakeholders to develop a system design that supports human values. First empirical findings suggest that autonomy, competence, privacy and diversity are key values forming the baseline for future work.

Keywords


Introduction

mHealth systems such as mobile rehabilitation solutions for treating patients at home are receiving increasing attention (Tang et al. 2015). When the patient’s condition requires ambulatory treatment, therapy interferes with the everyday life of individuals and their peers. Much research has been conducted within design-oriented disciplines exploring and evaluating technological designs of assisting healthcare systems from the user perspective (Noble 2015). However, especially in the private life context of users, human values underlying the use of mHealth technologies remain rather unexplored. Following the ethical stream of design-oriented disciplines, Berry et al. (2017) state that “[u]nderstanding patients’ values is key to the provision of high quality patient-centered care” (p. 1). Evidently, human values gain a major momentum regarding medical practices (Kelly et al. 2015) and digitalized support of healthcare services. Design processes are not value-neutral (Friedman et al. 2013) and require a sensitive design-lens.

Friedman et al. (2013) define a value as “what a person or group of people consider important in life” (p. 2). Values depend on the needs of individual human beings. In this vein, health is a fundamental value. Contrary to the context-specific, situative importance of values, many studies on digital health systems have been conducted within artificial settings neglecting the strong influence real-life settings have on the way patients manage their conditions (Berry et al. 2017). Healthcare comes with different sets of values, demands and concerns. The context of professionalized healthcare services and private life exhibits frictions between (1) different stakeholders (e.g. physicians and patients) and (2) value systems with regard to wellbeing, quality of life and therapeutic efficiency and effectiveness. This implies a high need for normative
considerations. A promising methodological framework for investigating individual and context-dependent value systems is Value Sensitive Design (VSD) (Friedman et al. 2002, 2013). VSD aims for identifying human values within the context of a specific technology. It provides tools to systematically identify and analyze stakeholders, their respective value systems and ways to transform the normative insights into design choices and system features (Friedman et al. 2002, 2013). The case study presented in this paper proposes conceptual, empirical and technical investigations as suggested by VSD. The investigations take place within a project on the development of an ambulatory, sensor-based system intended to assist physicians and caregivers within clinical and home settings. The purpose of this study is to identify stakeholders and pursued values in order to identify value conflicts between stakeholder groups and values. Based on these conflicts, concrete design requirements and guidelines can be elaborated aiming for solving the conflicts. We propose the following research questions:

**RQ1:** What constitutes the heterogeneous value-systems forming the normative conceptualization of ambulatory mHealth systems for physiotherapeutic purposes from different stakeholder perspectives?

**RQ2:** What design implications for the technological development of ambulatory mHealth systems for physiotherapeutic purposes can be derived from the unveiled value systems?

## Theoretical Background

**Ethically driven healthcare systems design**

The design of healthcare technologies demand ethical considerations, since they address fundamental intrinsic human values such as health and well-being. In particular, due to the advent of mobile technologies, mHealth systems increasingly interfere with the patients’ everyday routines, effecting their perceived health status and quality of life (Kreps 2017). In contrast, designers are prone to impose their own values when making design choices, which in turn might stand in conflict with the patients’ value systems, calling for ethical pluralism (Barry et al. 2017). The need for ethical considerations within design processes has already motivated many researchers to conduct dedicated studies on the interplay of values and technology (Knobel and Bowker 2011; Shilton et al. 2013). Barry et al. (2017) report on ethical design activities of a mHealth self-reporting app to support pregnant women with depression, fostering psychological well-being. Berry et al. (2017) explored values around the collaboration between patients with chronic conditions and their caregivers in an ambulatory setting. Research demands “perspectives that draw more attention to the local values [and the] highly heterogeneous user groups” (Barry et al. 2017) (p. 3). Many design techniques have been developed accounting for values in design, for instance reflective design and participatory design (Barry et al. 2017). Beyond that, Value-Sensitive Design (VSD) (Friedman et al. 2002, 2013; Friedman and Kahn Jr 2003) is a promising methodology to address value issues by identifying stakeholders, values, occurring conflicts, and design choices contributing to solving these issues.

**Value Sensitive Design**

The VSD approach is appropriate to illuminate ethical issues for sensor-based mHealth solutions for physiotherapeutic purposes. VSD is a methodology unveiling human values underlying the usage of IT. It enables developers to implement identified values within technological design decisions by prioritizing features to satisfy the stakeholders’ interests. VSD has been applied within studies on digital healthcare, leading to concrete designs. Research areas amongst other cover patient self-management (Dadgar and Joshi 2018), ageing support (Detweiler and Hindriks 2012), and cyber-physical systems (Denning et al. 2014). However, the healthcare domain lacks value-sensitive studies on supporting therapeutic treatments by laypersons at home. This context involves many stakeholders and value conflict potentials, hence calling for appropriate design guidelines.

VSD suggests three forms of investigations. Conceptual investigations seek to identify relevant stakeholders (e.g. users, designers, society) and the respective values these stakeholders hold, resulting in an initial conceptual value set. Hence, this step covers “philosophically informed analyses of the central constructs and issues under investigation” (Friedman et al. 2002) (p. 2). Commonly, this can be done by adapting the value classification scheme developed by Friedman and Kahn (2003), which involves a set of “human values with ethical import”, each holding distinctive relevance when it comes to IT design (Deng et al. 2016; Friedman and Kahn Jr 2003). Empirical investigations focus on the human context. The goal is to
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empirically investigate human reactions to and opinions on an artifact (Deng et al. 2016; Friedman et al. 2002, 2013). The way people prioritize values when it comes to using a certain technology is of major interest during the design process, since favored values can be implemented over others (Friedman et al. 2002). Technical investigations seek to elaborate technological designs that incorporate the previously identified and empirically refined values. Developers can retrospectively evaluate and modify existing technologies. Also, technical investigations allow for a more proactive design of system properties by deriving design requirements from values (Friedman et al. 2013). However, the re-organization of these steps seems reasonable. Empirical investigations are suitable for exploring prevalent values within the user’s context, which inform further conceptual and technical investigations (Le Dantec et al. 2009). Conceptual activities are prone to import preconfigured values in order to align further research activities (Le Dantec et al. 2009). Closely related, researchers have suggested moving away from sole solutionism, which is intended to produce tangible outcomes (e.g. a user interface). Instead, highly explorative and unbiased investigations of users’ values and real-life contexts promise deeper insights motivating further design considerations (Le Dantec et al. 2009). Within our study, we begin with explorative empirical investigations to avoid the potential induction of bias and import of pre-conceptions.

Methodological Approach

Case Description

The study at hand is part of a research project on the development of a sensor-based assistance system, aiming for supporting physiotherapeutic treatments following the Vojta principle. This therapy is applied to patients with a malfunctioning central nervous system (CNS), often resulting in an impaired locomotor system. By stimulating the patient’s CNS through the application of pressure to defined body zones (reflex locomotion), the therapist tries to provide access to elementary movement patterns (e.g. standing upright). The therapeutic treatment has additional effects on the patient’s body such as an altered blood pressure and breathing, which implies novel ways of sensory measurement techniques. Three usage scenarios form the foundation of the project: (A) Caregivers (here: parents) perform therapeutic treatments on the patients (here: infants) at home, since the treatment needs to be applied daily, rendering steady clinical visits unfeasible. The system aims to support these ambulatory treatments by providing contextual feedback regarding the treatment execution (e.g. appropriate advice), based on data (e.g. sensory data). (B) The utilization of hardware (e.g. acceleration sensors) allows for a detailed capturing of movements and physiological data. Its analysis enables the measurement of quality and quantity of treatment sessions. This enables the therapist to control the therapy progress more effectively, potentially accompanied by higher patient compliance. (C) The guidance of therapy sessions is suitable for educational purposes, representing a teaching and training tool for apprentices. Regarding these scenarios, different stakeholders have been identified, i.e. caregivers, physicians and therapists, and apprentices. To address these usage scenarios, the values within each group need to be analyzed.

Research Agenda

The case study presented in this paper comprises three sequential steps: (1) An exploration phase comprising focus group sessions engaging technological, medical, social and computer science experts. The goal is to unveil an initial set of ethical issues as well as correlating values and possible conflict-resolving design approaches. (2) A subsequent empirical phase incorporating narrative and semi-structured interviews with caregivers to investigate the user’s context (especially at home), individual value systems and normative assessments. This step also delivers system requirements with regard to desired and unwanted features. The phase concludes with a triangulation of the qualitative data. (3) A conclusive design-oriented phase in which concrete design features and system properties are elaborated within focus group sessions and specified based on the values found. The three steps are briefly described below, followed by interim findings from the focus group study we conducted to date (Mueller et al. 2018).

Explorative focus groups. As a first step, we conducted four focus group workshops engaging 19 expert stakeholders from relevant domains (i.e. IT development, medicine, social and computer sciences). We carried out an initial workshop in order to discuss ethical challenges and questions regarding the design of the mHealth system, leading to initial values and potential designs. Subsequently, we conducted three workshops, each incorporating a subset of the stakeholders from one specific domain. The goal was to
enrich each value by focused, multi-perspective discussions and iterative data analysis. This resulted in an integrated scheme covering four main values and respective subcategories (Mueller et al. 2018). Data analysis was performed in two steps: (1) Each value discussion cycle within a single workshop session was analyzed independently, resulting in a set of subthemes. (2) We analyzed similarities and dissonances between the subthemes. The interim findings are briefly described below.

Narrative and semi-structured interviews. We propose a second phase involving empirical investigations illuminating the patient-sided context. The goal is to develop a holistic value scheme covering multiple relevant perspectives. We plan to conduct interviews consisting of both open-ended and semi-structured questions (Deng et al. 2016). Open-ended questions aim for externalizing individual narratives and inherent values, asking the interviewees about everyday life situations, their handling of the condition, and salient feelings, needs and concerns. Semi-structured questions seek to explore the digitization of the treatment regarding the mHealth system aiding the caregivers at home and the benefits or trade-offs coming with it. This structured part of the interviews involves pre-conceptions on possible technological ways of supporting the treatment in order to circumvent a possible lack of imagination due to the absence of experiences relating to mHealth systems. The interview procedure resembles an indirect approach by asking interviewees about everyday life situations encompassing the values to be unveiled (Friedman et al. 2013). By that, researchers avoid priming the participants with pre-conceptualized values and enable people to explore the context in a differentiated and open-minded way. For data analysis, we adopt the coding procedure by Deng et al. (2016). The procedure involves three steps: (1) Each researcher codes every interview independently. (2) The researchers discuss their codes and occurring disagreements. (3) Each researcher re-codes the interview data according to the elaborated scheme.

Design-oriented focus groups. Within the third phase, we plan to conduct focus group sessions consisting of design-oriented workshops with the purpose of unveiling concrete design features and system properties that are able to support identified values. While particularly engaging design and IT experts (e.g. interaction designers), we will use the triangulated findings as a basis for discussion and design elaboration. This approach relates to the technical investigations within VSD, as it seeks to proactively construct novel ways to address human values (Friedman et al. 2013). The data analysis will be performed in two steps comprising (1) the analysis of each workshop session and (2) the analysis of similarities and dissonances.

Interim Findings and Future Work

Four key values emerged from analyzing the initial focus group workshops, forming a superordinate valuesystem (Mueller et al. 2018), which incorporates the following: Autonomy: The degree to which the user is able to autonomously control the system behavior during a therapy session. Competence: The degree to which the system utilization preserves or increases the individual competence and skill level of the user. Privacy: The degree to which the system safeguards the user’s privacy and protects data from unauthorized access. Diversity: The degree to which the system is designed for a heterogeneous population.

For each value, we derived technical manifestations that exhibit concrete implications for future system design (Mueller et al. 2018). Each manifestation represents a system feature that supports the respective value within the technology. For instance, Individualization (autonomy) describes a system property offering different forms of guidance according to the user’s preferred level of autonomy during the treatment. Low levels of guidance allow individual approaches, such as personal treatment paths that work best for the user. With regard to competence, different forms of Feedback (e.g. audio, video, haptic) during the treatment can lead to higher levels of competence and confidence on the side of the user. For example, subliminal feedback (e.g. vibration of a body-worn device) can lower the level of distraction of the user, increasing the focus during the treatment and learning potential. Simulation (privacy) describes how data captured by the sensors can be visualized and stored, for instance by utilizing a generic, humanoid model instead of real video footage. Hence, sensible data can be obfuscated in accordance with to the user’s privacy settings. Data Heterogeneity (diversity) implies the system’s ability to capture multiple data via distinct sensors, enabling a broader population to use the system while not relying on a single source measurement. For example, the patient’s physiology (e.g. in case of amputation) does not lower the system functionality.

The study proposed contributes to the body of knowledge in the field of mHealth technology design for assisting physiotherapeutic treatments at home. The values to be identified represent the complexity of multiple desires and interests of relevant stakeholders, which have to be considered when designing
technical solutions. The design features to be derived pave the way for future technology development and evaluation. From a practical point of view, the inclusion of values as additional goals of mHealth technology design can lead to innovative design solutions to improve user experience and technology acceptance. Our next steps are threefold: (a) Conduct interviews engaging caregivers as potential future users of the mHealth system, (b) triangulate the empirical data from the focus groups and interviews in order to construct a holistic value-system, (c) elaborate concrete design principles through focus group workshops.

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**REFERENCES**


