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The Design Process of an mHealth Technology: The Communicative Constitution of Patient Engagement Through a Participatory Design Workshop

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Abstract: The aim of this article is to allow for a better understanding of how patient engagement is progressively constituted through interactions during a participatory design workshop. We will present a research project (based on a Participatory Design Approach) with the objective of creating an mHealth technology to encourage post-myocardial infarction (MI) patients to manage their condition, and learn more about their sudden cardiac death risk. The analysis will allow us to reveal the communicative constitution of patient engagement during the design process. We will illustrate patient engagement "in-the-making" by revealing 3 interactional processes: (1) the collective constitution of "experiential knowledge", (2) the enaction of a "mutual learning space", and (3) the co-creation of a prototype that embedded the patients' voices.

Keywords: health technology, mHealth, participatory design, dialogical space, patient engagement

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Le processus de conception d'une technologie mHealth. La constitution communicative de l'engagement des patients lors d'un atelier de conception participative

Résumé : Le but de cet article est d'avoir une meilleure compréhension de la façon dont l'engagement des patients dans le design d'une technologie de e-santé se constitue progressivement au cours des interactions s'accomplissant lors d'un atelier de conception participative. Nous présenterons un projet de recherche (fondé sur une approche de conception participative) dont l'objectif est de créer une technologie de e-santé visant à encourager les patients ayant subi un infarctus du myocarde à mieux comprendre leur maladie et gérer leurs facteurs de risque. L'analyse nous permettra de révéler la constitution progressive de l'engagement des patients au cours du processus de design. Nous illustrerons l'engagement des patients « en train de se faire » en révélant 3 processus interactionnels : (1) la constitution collective d'un savoir expérientiel, (2) l'émergence d'un espace d'apprentissage mutuel et (3) la co-création d'un prototype matérialisant les voix des patients.

Mots-clés : e-santé, application mobile, design participatif, espace dialogique, engagement, patient

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Introduction

The design of health technology (such as health information systems, telehealth, telemedicine) is not new (Fitzpatrick & Ellingsen, 2013)[1]. However, there has been growing interest in healthcare design research for so-called mobile health applications or mHealth (Cajita, Hodgson, Budhathoki, & Han, 2017; Davis et al., 2017). As stated by Zapata, Fernandez-Alemàn, Idri, & Toval (2015):

> The release of smartphones and tablets, which offer more advanced communication and computing capabilities, has led to the strong emergence of mHealth on the market. mHealth applications are being used to improve patients' lives and their health, in addition to facilitating communication between doctors and patients. (p. 1)

In the last decade, the number of mHealth technologies for managing patients with chronic diseases has increased. Devices for self-monitoring imply new responsibilities for the patients, as well as the healthcare professionals (Oudshoorn, 2011). In this new "geography of responsibilities", the patient becomes a "diagnostic agent" (Oudshoorn, 2008). In other words, "patients are not just users of a new technology that requires instrumental skills, but should be considered as agents who have to perform all manner of articulation work required to carry out the responsibilities delegated to them" (Oudshoorn, 2011, p. 149). In this context, what

[1] For an extensive overview of design research in healthcare see Fitzpatrick & Ellingsen (2013).

role does the patient play in the design of mHealth technology? There is a growing consensus that patient participation or patient engagement in the design of mHealth tools is a crucial factor for improving the implementation of the technology (Pagliari, 2007).

1. Patient engagement in the design process: From testers to design partners

We note that numerous health technologies are developed without any real form of patient involvement (Oudshoorn & Somers, 2006; Vosbergen et al., 2013). Historically, the design process in telemedicine and telecare has rested mostly on top-down approaches that can be characterized as "technocentrically oriented" (Bonneville & Grosjean, 2008). The end user, i.e. the patient, is conceptualized as a "human factor"—at most an informant—rather than a real stakeholder, partner in the design process (Kanstrup, Bertelsen, & Nøhr, 2015). Patients do not play an equal role to software developers, engineers, and healthcare providers who make crucial decisions regarding the form and content of health technologies. Consequently, patients are consulted by the developers to give their opinion on a technology already designed. Often, patient involvement is sought to validate an already preconceived design to give it further legitimacy. Patients are perceived as testers of the prototype (Pagliari, 2007).

As suggested by Lundin & Mäkitalo (2017):

> A new kind of relation has been claimed urgently required between health services and the persons with whom they have long-term relations. What has been suggested is for health "users" to become more actively involved as "co-producers" at all levels and in all aspects of health system development and functioning. (p. 18)

In the past years, there has been a growing interest in the integration of patients in the design process, from user-centered design to the co-design of devices (Sanders, 2003; Bjerkan, Hedlund, & Hellesø, 2015; Kanstrup et al., 2015; Span et al., 2018). Patient-centered care implies fundamental changes in the way that mHealth technologies are designed. The involvement of the patients (as real partners) is considered vital to achieve this goal (Lundin & Mäkitalo, 2017).

However, several researchers pointed out the various conceptions of patient engagement[2] or patient participation in the design process (Bélanger, Bartlett, Dawes, Rodríguez, & Hasson-Gidoni, 2012; Andersen, 2010; Demiris et al., 2008; Yuan, 2016). For example, Das & Svanæs (2013), based on the work of Druin (2002), established a distinction between 4 types of end users:

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[2] In this paper, the term patient engagement is used to illustrate the active role played by patients in the design process. In the literature, various terms are used such as: patient involvement, patient participation, patient collaboration. We will use the term "engagement" to emphasize two elements: (a) the processual dimension of patients' participation and (b) the agency of patients in the design process.

> (…) user, tester, informant and design partner. In the role of *user*, end-users contribute to the research and development process by using technology, while the researcher may observe, videotape or test for skills. This is done to try to understand the technologies' impact on the user with the aim that future technologies can be changed or future environments enhanced. In the role of *tester*, end-users test prototypes and are observed with the technology to capture their experiences, and observation of participants with existing technologies or they may be asked for input on design sketches or low-tech prototypes. In the role of *informant*, end-users have an important part in the various stages of the design process, based on when the researcher believes that the participants can inform the process. This may involve observation of participants with existing technologies or they may be asked for input on design sketches or low-tech prototypes. In the role of *design partner*, end-users are considered to be equal stakeholders in the design of new technologies throughout the whole process. (p. 1077)

But patients are much more than "users", much more than their relation to a technology (Bannon et al., 2012). If we want to understand the complexities of the "figure of the user" (Suchman, 2007) in the design process, we must understand the multiple practices and experiences by involving patients as co-designers. In this context, design requires engagement, participation and creativity, as well as methods and techniques to transform needs and ideas into concrete solutions (Simonsen & Robertson, 2012).

For many authors, a participatory design approach appears to be the most effective way to include patients in the design process (Bjerkan et al., 2015; Noergaard et al., 2017; Sparud-Lundin et al., 2013). Participatory design is not only a technique to gather input, but a holistic approach that entails multiple steps through which patients are considered full-fledge partners (Smith, Bossen, & Kanstrup, 2017). In the same vein, patients are regularly invited to share their ideas, opinions, and views on the design of the technology. Patients are seen as a fundamental resource in the design process because of their first-hand experience with specific diseases and treatments. These patients develop an "experiential knowledge" (Blume, 2017) specific to their daily life with their condition. It must be stressed that this knowledge should be considered as important as the healthcare provider's biomedical expertise, and should consequently be included in the design process. This can be done by establishing a real and durable partnership between patients as end users on the one hand, and healthcare providers on the other. "The partnership paradigm credits patients with an expertise similar in importance to the expertise of professionals. This paradigm implies that while professionals are experts about diseases, patients are experts about their own lives" (Bodenheimer, Lorig, Holman, & Grumbach, 2002, p. 2470). However, the current lack of focus in contemporary work on the role of the patient as an expert (i.e. as possessing useful

knowledge to design health technologies) signals an underestimation of the patient's capacity to fully contribute in the design process (Kanstrup et al., 2015).

As researchers who participated in the conception of an mHealth application for post myocardial infarction (post-MI) patients, we adhere to the principle of engaging patients as partners. The patients (as future users of a technological solution) should "have a say" in the design of the mHealth. As stated by Bratteteig (2017), having a say is more than having a voice. It implies a real involvement throughout the design process, and the power to make a difference. However, in practice, the degree of patient engagement or patient participation (the two notions are used in the literature) varies throughout the development of mHealth technologies (Grosjean, Bonneville, Redpath, Mayère, & Marrast, 2017). How patients are involved, and the meaning of engagement or participation differs in the literature (Anderson, 2010; Bratteteig & Wagner, 2016) and "there is little explicit analytical attention directed at what constitutes participation" (Anderson, Danholt, Halskov, Hansen, & Lauritsen, 2015, p. 253).

1.1. *The purpose of the paper*

As suggested previously, the notions of patient engagement or participation are somehow taken-for-granted in the literature. What this engagement process might look like at the empirical level, and how patients may participate and contribute to the design process in concrete ways remains unclear. As mentioned by Lundin & Mäkitalo (2017): "Although users (such as patients) have been recognized as part of the design collective in the development of medical innovations, the interaction in design meetings with patients has not been explored to any extent" (p. 20). The role of patients and their involvement in the design process of mHealth is gradually becoming an important issue, but we must gain an in-depth understanding of how patients could contribute to the development of mHealth technologies. This points to a need for empirical studies of the design process, where patients' contributions are looked into thoroughly.

In order to address this knowledge gap, we aim to understand patient engagement by focusing on the communicative constitution of various acts of involvement that occurred during interactions in a participatory design workshop. This implies, as we will illustrate, that we conceptualize patient engagement as an ongoing and communicative process throughout the design of an mHealth application. We will clarify our approach in the next few pages. We will present our research project of designing an mHealth application—in which post-MI patients were actively engaged from the initial phase as experts sharing their experience of the illness, thereby co-constructing collectively a prototype. We will focus on a participatory design workshop for describing the ongoing process of patients' engagement through the interactions. We will follow patients' engagement "in-the-making" by revealing 3 interactional processes: (1) the collective constitution of "experiential knowledge", (2) the enaction of a "mutual learning space", and (3) the co-creation of a prototype that embedded the patients' voices.

2. Participatory Design: A communicative and collaborative approach

2.1. *Participation and communication at the heart of Participatory Design*

Originally, Participatory Design was developed by researchers in Scandinavia to support the development of technologies and information systems in the workplaces (Greenbaum & Kyng, 1991; Gregory, 2003; Bødker, Kensing, & Simonsen, 2009; Halskov & Hansen, 2014). "The dominant driving forces were the aims to focus on democratic approaches, including the user perspective, and to ensure that new technology enabled people, rather than constrained" (Bjørn & Østerlund, 2014, p. 20). The workers were involved as co-designers and the focus was to embrace an end-user perspective by understanding the work practices in which the technology should be used.

This approach was applied to new contexts, such as the design of technology for healthcare professionals or patients (Ackerman et al., 2018). Participatory Design is grounded in a democratic vision of empowering users by having them participate in the design and development of technology. The main purpose of the Participatory Design approach is to create a collaborative partnership with the people destined to use the technology.

> [This approach] refers to a set of theories, practices, and studies on how to include the end users as active *design partners* in the design process (Muller, 2009). The purpose of including the future users is to ensure that the final product is usable and meets the users' needs. [So] in PD, the research and design work are done *with* the users, while in related approaches within user-centered design, this work is done on *behalf* of the users. (Das & Svanæs, 2013, p. 1077)

The notions of collaboration and engagement are at the heart of the participatory design approach, and may be understood as the complex process that combines doing, talking, thinking, feeling, and sharing experience and knowledge. For Muller and Druin (2012), Participatory Design is described as the enactment of a "third space", maybe the space of the participatory design workshop (Muller, 2009); a dialogical space where participants are involved in the collaborative construction of a prototype (Béguin, 2003). Various tools and techniques are developed to involve users in co-design dialogues (Sanders, Brandt & Binder, 2010). These tools and techniques combine 3 elements (Brandt, Binder & Sanders, 2013): telling (e.g. sharing experiences, challenges and dreams), making (e.g. sketches, mock-up for externalizing and embodying ideas in an artefact) and enacting possible futures (e.g. imagine and act out future solutions, scenarios of use).

The participatory design process implies a succession of activities to stimulate interaction between the participants and to support users' involvement in producing interpretation, sharing knowledge and making choices and decisions. In a book on Participatory Design, edited by Simonsen and Robertson (2012), the authors state

that at the heart of participatory design is the user's voice in the design process, through interaction with humans (various stakeholders) and non-humans, such as prototypes (Rice, 2018). Participatory Design is also defined by mutual learning through collective "reflection in action" (Bratteteig & Wagner, 2016). Many authors describe design as a communication process or dialogical process (Béguin, 2003). For Lawson (2005), design is a conversation between participants, but also a conversation with the situation (involving space, objects). For Schumacher (2016), the design process is an ongoing process of communication between various actors and a "dialogue with the situation" (Schön, 1988).

2.2. *A theoretical framework to study patient engagement in the design process*

As suggested previously, various authors assert that communication in participatory design is constitutive of an organization involving heterogeneous actors (humans and non-humans), and design practices are constituted by both discursive and material practices (Jackson & Aakhus, 2014). Some authors use the term "sociomaterial-design" (Bjørn & Østerlund, 2014) to describe the entwined nature of the social and the material in the participatory design process. "The two are inseparably, constitutively entangled. Sociomateriality highlights the nexus of doings, materialities, and discourses that people carefully enact" (Bjørn & Østerlund, 2014, p. 8). As mentioned, various tools and techniques (such as CARD sorting, personas, mock-ups, etc.) are used to facilitate the generation and communication of ideas between participants and stimulate collaboration and engagement in participatory design. Various techniques of facilitation, tools and artefacts are needed to conduct the design activities in order to support all the participants in both creating collective understanding and supporting participation. For example, Brandt, Binder and Sanders (2013) have highlighted the performativity of tools used in participatory design that contribute to engaging users in enacting solutions.

Therefore, the CCO framework[3] will be useful to understand the constitution of patient engagement through the design process by studying the "constitutive entanglement" between discourse and materiality (Ashcraft, Kuhn, & Cooren, 2009; Orlikowski & Scott, 2015). This theoretical framework could contribute to the study of patient engagement "in-the-making" (i.e. in a processual perspective), by offering a way of understanding how patient engagement is being made and shaped through material-discursive practices.

[3] For further information on the Communicative Constitution of Organization (CCO) approaches see Cooren (2015) and Brummans, Cooren, Robichaud & Taylor (2014). The CCO frameworks "do not focus solely on human interactions and sensemaking activities; they extend the concept of communication to what non-humans do" (Giordano, 2015, p. 323)

3. Methodology

3.1. *Context of the research project*

In this research project, we followed the development of an mHealth application aiming to empower post-MI patients in tackling their cardiac risk factors.

Over seven million North Americans are MI survivors and have a fourfold higher risk of sudden cardiac death (SCD) compared to individuals without prior MI (Kannel, Gagnon, & Cupples, 1990). A recent meta-analysis emphasized the fact that β-blockers reduced the risk of SCD for post MI patient by 31% (Al-Gobari, El Khatib, Pillon, & Gueyffier, 2013). Randomized trials indicate that implantable cardioverter defibrillator (ICT) therapy reduces the risk of SCD by over 50% and increases overall survival by more than 25% in individuals at risk of SCD due to severe left ventricular (LV) systolic dysfunction, which is generally defined as a LV ejection fraction (EF) <30%. Despite strong evidence that knowledge of one's ejection fraction is beneficial to the patient's health, LVEF is poorly understood, infrequently measured, and SCD prevention therapies (β blockers and ICDs) remain underused (Chew et al., 2013).

To address this need in terms of patient education, the main objective of this project was to create an mHealth application that would encourage patients to learn more about their SCD risk following an MI event. We collected data relative to the generation of system requirements specifications; we sought to first understand the context of use through patient engagement in the design process of a healthcare device.

3.2. *Data Collection*

Our participatory design approach involved multiple methods such as semi-structured interviews and a participatory design workshop (Figure 1). Various tools and techniques were employed during the workshop as a means to directly engage patients in the design of the mHealth technology they will later use (Sanders & Stappers, 2014). Post-MI patients were invited in the early stages of the design process to share their experiences managing their medical condition, and to generate the features of the technology.

To understand the experience of post-MI patients with a high risk of SCD, we recruited a specific group of patients to participate in semi-structured interviews and in a design workshop. Our sample includes post-MI patients over the age of 18 years with an ejection fraction of less than or equal to 40%. To have a better understanding of the post-MI patients' needs, we also recruited healthcare professionals (through purposive sampling) to participate in semi-structured interviews.

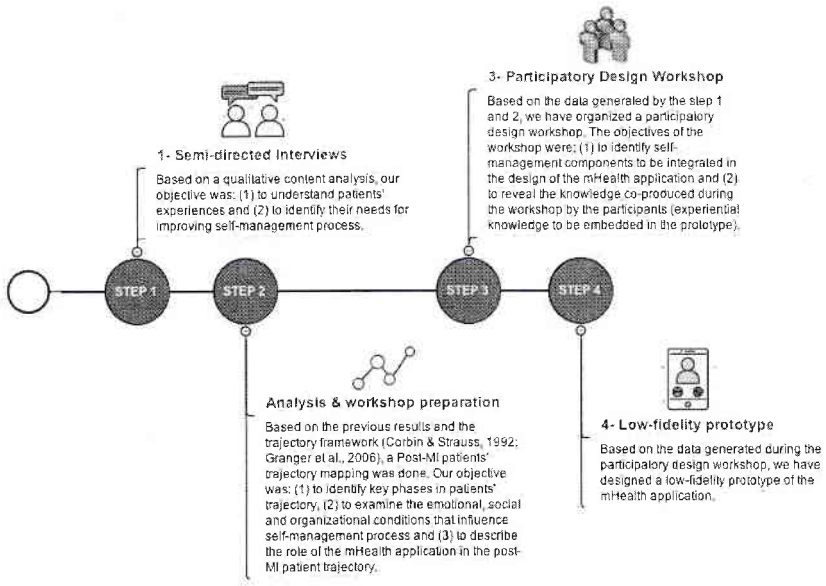

Figure 1. *Overview of the Participatory Design Approach*

After conducting interviews and gaining preliminary insight, we organized a three-hour participatory design workshop. Participants included post-MI patients (N=7), software designers (N=3), and one nurse. The objectives of the workshop were: (a) to understand the patient expectations (needs) in terms of support, information, and knowledge; (b) to identify the effective components of an mHealth application. The workshop was facilitated by a moderator; facilitation techniques were used to encourage the expression of individual needs, but also to contribute to the creation of a prototype that embedded patients' expectations to support self-management (Table 1). Consequently, the goal was to generate ideas for self-management resources and tools to be added in the design of an mHealth application to be used by post-MI patients. The workshop was audio recorded; notes and pictures were taken by two of the researchers.

Table 1. *Tools and techniques used during the participatory design workshop*

Tools and techniques	Instructions to participants
CARD sorting activity The goal of this activity was to identify the most important	***1- Small Group (20 minutes)*** Keep in mind the following question: What topics/content would people who have had a heart attack like to see on the mobile application?

information and resources for post-MI patients. Participants collaboratively combined cards in order to capture a sense of priorities, and to identify resources and tools necessary to support the self-management of the disease. This process was initiated by a discussion in which participants established a shared understanding of the cards' meaning and relevance.	We suggested 3 topic areas: (1) Medical information and advice to understand my disease (2) Tools and resources to manage my disease and (3) Support/communication to assist me with my disease. Each card represents a piece of information which could be important for understanding and managing your condition over time. 1) Select 10 cards for each topic areas; the most important in your opinion. 2) Rank the cards in order of importance (the most important on the top). ***2- Plenary session (15 minutes)***
Paper prototyping The goal of the second task was to gain further insight on the users' preference regarding the interface. Patients designed paper prototypes during the workshop. We asked participants to project themselves using the broad features/components they previously identified as relevant, by placing them onto a separate screen that would represent the final interface of the mHealth application.	***1- Small Group (40 minutes)*** Papers representing screens are placed on the table. Each paper has been designated as one screen. Your role: (1) To identify the components/information to include under each screen (2) to describe the organization of the content and the desired "look" of the user interface you would want to see on the screen. ***2- Plenary session (10 minutes)***

All the interviews were transcribed, and a qualitative content analysis was done in order to identify categories and themes. We used the trajectory framework (Corbin, 1998; Granger, Moser, Germino, Harrell, & Ekman, 2006) to inform our thematic analysis and to map the post-MI patients' trajectory in the healthcare system and throughout their recovery at home. Two complementary types of analysis were conducted with the data collected during the workshop: a) a qualitative content analysis, and b) the analysis of interactions. As mentioned by Brassac & Gregori (2001), there is logic underlying this type of analysis: it is possible to describe human cognitive processes by analyzing speech patterns produced through an interaction, in the context of a given situation. A fine-grained description of the interaction contributes to revealing the production of knowledge by the participants, and understanding patient engagement in the design process (Grosjean, Fixmer, & Brassac, 2000). For the purpose of this article, the analysis presented will solely focus on the participatory design workshop.