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User involvement in the co-design of self-care support systems for heart failure patients

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Abstract

In this paper the nature of user involvement in a co-design process will be explored. The outlines of a research project aiming at developing support systems for self-care inpatients suffering from chronic heart failure will be presented. The project is planned to perform a co-design effort where users (patients and healthcare professionals) will be given the opportunity to influence the development of support systems. We will discuss a number of possibilities and challenges that lie in the design of this kind of project and also some findings from its early stages. This report presents the experiences of users' input, which are discussed in the context of previous research on benefits of user contributions in systems development.

Keywords: Heart failure; Patient-centred care; Self-care support; User involvement; Co-design.

1. Introduction

The involvement of patients has for a very long time been suggested as a method for improving the quality of a final system and increasing the likeliness of actual use in the long term[1]. However, how to actually and effectively

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allow patients to influence the systems development project is far from being an easy task. For a project to achieve the involvement of users in a process of providing ideas, influencing the design and seeing some of their visions become reality in a useful product is challenging. In focus of this paper is a research and development project in the area of heart failure self-care management support, including a discussion about a co-design approach, its background, planning, general layout, and reflections on the challenges of involving patients and health-care personnel in systems development. The organization of the paper looks as follows. In Section 2 we discuss the needs of self-care support and the current theory of the benefits of involving users in the development process. In Section 3 we describe the user involvement method applied. Section 4 contains results in the form of the experiences of working with patients in co-design processes. The concluding Section 5 presents a comparison between the current theory on user involvement and our experiences and, finally, a list of issues for future studies.

2. Background and theoretical standpoints

Person-centred care is a trend involving many aspects of the health care of today[2]. The number of elderly persons with chronic health problems increases, which puts higher demands on health-care systems. E-health solutions are often suggested as one path forward for tackling these problems. This includes both technological and organizational innovation together with clinical testing in order to achieve a proper impact on patient and health-care system. The use of information technology is expected to enable patients to become more active and responsible for their everyday self-care. This is one approach that could reduce the problems of increasing costs for people with a chronic disease.

This particular project focuses on the area of heart failure, a condition where the heart muscle cannot pump enough blood to the tissues of the body, because of structural changes in the heart. Heart failure is a chronic condition leading to a number of symptoms, including e.g., tiredness, shortness of breath, and oedema in the legs or in other parts of the body. There is often a preceding or underlying medical problem that causes the heart failure, typically a heart attack, high blood pressure, a valvular or heart muscle disease (cardiomyopathy). Depression and cognitive problems could also appear among conditions alongside heart failure. Chronic heart failure changes the patients' lives, limiting what activities they are able to perform. It is a lifelong health issue, which gradually becomes more problematic. Self-care is important for avoiding or mitigating problems in connection with heart failure[3]. Typical recommended self-care activities include adhering to pharmacological and non-pharmacological treatment, monitoring and managing symptoms, and exercising[4,5].

For effective self-care, some technological support system or changes in the care /self-care processes could be of use. However, to actually achieve long-term usage and maintain the effect when implemented in the health care at large is a challenge. A possible approach for this is the application of co-creation or co-design[6] and the use of focus groups. In the area of e-Health, special considerations must be taken when using patients in the design process[7]. Das and Svanaes[7] argue that the vulnerable situation of patients must be well understood by the system developers. Elg et al.[8] report the successful use of co-creation in generating and collecting patient ideas for health-care services. The procedure of the project was conducted along the following steps:

- Preparation: Selecting care process, design process and diary, selecting medium.
- Execution: Recruiting patients, supporting patients writing diaries etc.
- Learning: Patients' ideas, summary report, patient narratives.

The use of patient diaries was central to the collection of ideas. The patients were asked to write down everyday situations and contacts with the health care for 14 days in a row. Patients could select medium by choosing among writing by hand, blogging and using the telephone. Elg et al.[8] argue that the proposed method allows the developer to obtain a deeper understanding of the situations of the patient and the patient to appear as a whole person in a broader context.

Different approaches to user involvement have been suggested, including focus groups. One example presented by Townsend et al.[9] is where focus groups were used to understand how patients with chronic illness utilize e-Health in their daily lives, including patient-provider relationships and the connections between patients, providers, and service delivery. Another example comes from Donnelly et al.[10], who present a focus-group study of how internet sources are used to gather health-care information, and how this affects patient identities and challenges expert powers. Noordegraaf et al.[11] used focus groups to understand patient needs in an intervention, mapping protocol and

literature search to develop an e-Health intervention to enable patients to improve their recovery from gynaecological surgery. Focus groups were also formed to better understand how to apply IT for obtaining health information from adolescents in a study by Skinner et al.[12]. Van Velsen et al.[13] included focus groups as a step in a requirements development process for e-Health systems.

User involvement is an old approach[1,14,15] to improving the usability of information systems. Bano and Zowghi[16] present an overview of current benefits of involving users in the development process. In a study of 87 publications concerning projects that include users' involvement, a number of benefits of such involvement are presented. Of these studies, 56 reported a positive relationship between user involvement and successful software systems. On the basis of an analysis of the studies, a categorization of types of benefits is presented in five perspectives, each of them containing a number of concrete benefits[16]. Briefly, the factors look as follows:

- Psychological (user system satisfaction, user system acceptance, facilitating change, user attitude, user motivation, customer loyalty and long-term user relationships);
- Managerial (better communication, improved management practice, realistic expectations, reducing cost of system, conflict resolution);
- Methodological (understanding user requirements, quality of resultant application, improving quality of design decisions, overcoming implementation failures);
- Cultural (increased system usage, facilitating knowledge sharing, improving user skills);
- Political (workplace democracy).

Since the background of these studies lies in traditional organizations, businesses etc., differences from these are expected in comparison with patients as intended users.

3. Project outlines

The project included three development phases conducted between 2014 and 2015. The solutions would not necessarily be to introduce brand-new systems, but could consist of new ways of working, new organizational arrangements, and the adjustment or packaging of existing systems or services. The first phase contained a series of focus group meetings with patients and care personnel, with the aim to form a core set of prioritized situations as bases for the creation of solutions. Next, a process of working with these ideas started, producing a number of testable solutions. In the last phase, these solutions were tested in an organizational development project involving both patients and health-care professionals.

The first step consisted of five rounds of meetings involving different focus groups. There were two groups, one with patients (8-10 patients and family members) and one with health-care professionals (10 people from different health-care and community organizations with different professions and work roles). The first three meeting rounds were designed to ask people to give their views on being ill or caring for family members with heart failure. Between each round all people were asked to write down important things experienced or remembered, using diaries or e-mails. A telephone number connected to an answering machine could also be used as a spoken diary. Patients could also request to be interviewed as a way of better explaining their situation.

Both health-care professionals, patients and family members were given a lecture on heart failure and self-care for heart failure during their first meeting. The following two meetings were structured around two themes, the care process and a four-stage patient experience model of "pre/symptom, diagnosis, normalization and relapse stages". From each of these meetings researchers gathered suggestions for when and how self-care actions could improve the patient situation. The fourth meeting was an integration meeting where health-care professionals, patients and family members discussed the identified situations and looked at possible types of support technologies. An individual voting session produced a priority list of situations which needed further attention and which could form the basis for developing IT solutions. In the fifth round, all patients, family members and health-care professionals came together to present the situations ranked as the most important in the form of scenarios before an audience of IT technology experts. In the second phase, solutions were selected matching the patients', family members' and health-care professionals' needs. In two work meetings these were presented to the user group and discussed in focus groups. Hands-on sessions were arranged with evaluations of the usefulness and likelihood of actual use. The users were interviewed about which solutions they would envisage coming into actual use and how they should be deployed. On the basis of these activities, a package of self-care support was constructed, containing both technical

and non-technical artifacts. Adjustments were made to the solutions, both with regard to how they worked and to how they were planned to be implemented, on the basis of feedback from users. Phase 3 consisted of a test implementation of what had been developed in a real-time situation. This process was managed by the hospital development department and was conducted as a regular part of the development work of the health-care regions. Depending on the outcomes of this process, future projects were targeted at clinical trials, while anticipating wider implementation.

4. Possibilities and challenges of user involvement

During the active co-design phases of the project a number of possibilities and challenges for how to work with user involvement emerged. Involving users in all phases of the project was the key idea. During these steps we experienced some encouraging aspects of the project actions as well as some challenges. The data gathered in this section build on participatory observations and field notes, backed by audio/video recordings of the meetings. As the group was diverse, several patterns of behaviour and attitudes could be detected. More or less opposite views were displayed by different people. Here we report experiences of two types, even though they may be seen as contradictory.

On the positive note, a number of experiences made indicate the benefits of involving users.

1) The high level of patient involvement was a very positive experience. Those who chose to take part were bursting to tell their stories, and did so with fervour. As their situational and personal stories were very detailed, they provided a great opportunity for understanding the plights of a heart failure patient.

2) The same goes for the health care professionals, who were all deeply engaged in sharing their experiences of different parts of the care process. Gathering health-care professionals from different parts of the care system at large, representing a number of separate care organizations, proved very fruitful.

3) The patients' willingness to be part of a change process and of improving the system of care that they had been subjected to was impressive. Many of the participants clearly expressed a wish to give something back to the care system, from which they had both received high-quality care and, sometimes, experienced flaws or problems.

4) The groups also seem to have created a meeting place for sharing mutual patient experiences, thus creating a dialogue that in itself seems important to them. The process translates into a learning experience involving facts about heart failure, which turned into a learning process that changed the patients and the way they perceived the situation of suffering from heart failure. This learning experience also had an effect on how the patients engaged in the project, making them more interested in self-care and IT support.

5) The use of a two-track meeting schema, with parallel groups of patients and family members in one and health-care professionals in another, gave interesting results. To contrast the two views has been highly rewarding for both research and development processes. It underlines the differences in the life-worlds and lived experiences of the groups. Interconnecting patients and care personnel showed that the differences are very substantial. Patients are for most of the time preoccupied with coping with their daily life (most of them having left work) trying not to think of their medical problems more than necessary. Health-care professionals focus on work tasks at hand, and the encounters with patients might be very brief and episodic. Having separate meeting tracks and joining them together later on seems to be of great benefit for this kind of project.

6) The project works as a process of creating expert patients. After a full year of many meetings and workshops the patients are well trained and have been given time to create a personal understanding. As the abilities of patients to contribute change greatly during the year, this effectively creates a Super User.

Many challenges were anticipated in the project planning, and some of these have materialized during the process.

1) The challenges of bridging from situational stories to an innovation process became apparent during the first couple of phases, since the users (both patients and personnel) are experts on their own situation.

2) The consequences of the low level of technical expert involvement might tilt the project too much in the here-and-now direction. This choice might limit the participants' views of what is important and interesting. Possible futures are illusive to the patients, especially when it comes to novel IT solutions.

3) Patients find it surprisingly easy to tell their stories but have a really hard time looking forward to and understanding the continued process. This is a state that seems to remain, despite efforts of trying to explain the full

project idea and the way different phases connect to each other. Patients have a very strong interest in understanding their own personal situation and creating a personal care situation. The driving forces behind this must therefore be elaborated to create an interest and a driver for the patient to contribute.

4) The selection of patients was made with regard to the expected quality of their contributions and to their willingness to take part in the research. However, this also means limiting the views that are included. The information gathered in the current setting seems to be of great importance, but there always remains a question of what is not captured.

5) Making the project objectives concrete to the users is a challenge. Moving a patient that has a hard time keeping everyday life working into a position of being a co-designer is difficult. To understand the purpose of the project and how the patient can contribute is important. The information that prepares the patient must therefore be well presented, explaining what contributions are expected and how they will be used later on, during and after the project.

6) As the language barrier may be a problem, it is necessary to use everyday language. This becomes apparent even before the project starts, in the initial contacts with the patient.

7) Feedback about the progress of the project and about how the contributions of the patients have been used is important. However, this is clearly difficult to provide in the course of the process, especially in a more open-ended project.

8) Although care professionals had a positive approach to taking part, some of them maintained a guarded attitude deriving from earlier experiences of how hard it can be to actually find acceptance for new solutions and achieve change in general.

9) The interaction between health-care professionals and patients/family members at times became somewhat uncomfortable for the former. When more personal care-oriented questions happened to slip into the discussions, the risk of turning them into a care-giving session increased.

5. Discussions

The focus of this paper is on the creative part of the project's co-design process and on the ways patients and health-care professionals were involved. The general idea was that patient and health-care professionals (users) should become drivers of the needs analysis and take part in the continued design and construction processes as guarantors of its long-term functionality. In this paper we have detailed the planning process, with the aim of ensuring the influence of patients and personnel. This experience offers a number of lessons to be learned.

In comparison with the systematic review made by Bano and Zowghi[16], there are some benefits that can be recognized and others that are not relevant due to the limitation of our study, as well as some that work differently because of the nature of the patient. Benefits deriving from actual use (for example, user system satisfaction) are not relevant to discuss. When it comes to effects like "user attitude towards systems", "better user attitude towards systems", "user motivation" and "long-term relations with users", these could be seen to be developing in the course of the project. The many genuinely open and user-focused meetings really encouraged and informed the patients. Both patients and care professionals did undergo a process of change and came out with a new understanding of self-care and support systems. This is, on the other hand, an expensive process in terms of time and resources. Managerial and methodological benefits are not equally relevant, due the limitations of the action of the project. Still, a benefit like "developing realistic expectations" is not unlikely to appear in the long run. The cultural benefit of "facilitating knowledge sharing" and "improving user skills" has clearly emerged in the process. The final political perspective includes the "democracy in workplace" benefit, which is of some relevance to in our project. Although patient centredness does include some democratization of the relation between patients and care professionals, these issues of patient empowerment require a further and deeper analysis of the material.

During this research we have found a number of issues and discussion areas to work with. One is the clear difference between users in an organizational setting and those in a setting where the user is a patient. Power relations between an employer and an employee obviously differ from a patient-developer relation. The driving forces for a patient to engage in the process are different and to some extent more altruistic, in that they imply wanting to contribute to better care for patients in the future. Sometimes there seems to be a need for correcting problems that patients have perceived during their own encounters with the care system. We conclude that a better

and more detailed understanding of patient motivation is needed. There are, for example, indications that some patients shun away from their health problems, preferring not to think too much about them. Even taking part in information or discussion meetings may be an undesired reminder. This is a mixed picture, with some patients being seriously engaged. However, just catching those who are interested is not enough, since the full spectrum of patients should be represented.

What determines the long-term sustainability of ideas coming from patients and personnel, and which ideas will prevail in the end? On this journey there will be many factors contributing to the final result, as a co-design process is in danger of becoming myopic in practise. Although the current project attempted to work with as many of the actors as possible, the experience is that even more should be done in this direction. A broader understanding of the network of actors that are engaged in the process is needed, including categories like patients, personnel, institutions, informatics researchers, IT experts, companies, clinical researchers and health care politicians.

A co-design process must find a balance between a situational understanding of users (patients and health-care professionals) and the understanding of possibilities that IT experts can contribute with. Which interests should guide the process and lead to systems that really come into effective use? There is a possibility when the users are too dominant that the focus might still be on old and well-known problems and solutions. On the other hand, the reverse situation could also cause problems, if the project ends with adopting the most recent technology but remains unused because it is not related to users' needs.

The co-design process includes a strong learning component. It comprises the people involved, both patients and professional caregivers, continuously changing their understanding, perception and engagement. This is a slow process and actions repeated over an extended period of time have a clear impact on interest and engagement. For these and other reasons, this learning aspect of a co-design process needs to be further developed.

Acknowledgement

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