

Mapping the Health Technology Needs of Congestive Heart Failure Patients: User Needs vs. Feasibility

Karin Slegers
Meaningful Interactions Lab
(Mintlab), KU Leuven - imec
Leuven, Belgium
karin.slegers@kuleuven.be

Maarten Van Mechelen
Meaningful Interactions Lab
(Mintlab), KU Leuven - imec
Leuven, Belgium
maarten.vanmechelen@
kuleuven.be

Jeroen Vanattenhoven
Meaningful Interactions Lab
(Mintlab), KU Leuven - imec
Leuven, Belgium
jeroen.vanattenhoven@
kuleuven.be

ABSTRACT

In health technology projects, user-driven requirements and ideas for functionalities often pose a challenge for research and development teams. Some of these are typical for the context of research projects while others are related to implementation in healthcare settings. In research projects, such challenging issues are sometimes disregarded so that one can focus on the project scope, which, from a user point-of-view, may cause sub-optimal project results. Additionally, disregarding requirements and ideas that are important for end-users in early project stages, hinders the development of in-depth understanding of such issues, which may become a serious barrier for health technology adoption in general. To prevent these risks, we present user requirements that were especially challenging in a research project on disease management for people with congestive heart failure (CHF). By sharing examples like these, we aim to contribute to building intermediate knowledge related to health technology design in general.

Author Keywords

Health technology; User research; Human-centered design; Requirements; Congestive heart failure;

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

INTRODUCTION

In this paper we present research that was carried out to identify user requirements for a personal disease management system to support people suffering from congestive heart failure (CHF). Congestive heart failure is a

disease that is characterized by the fact that one's heart cannot pump enough blood to properly supply the body with oxygen and nutrients. The main symptom is the inability to be physically active, which makes the disease quite debilitating. In most developed countries, 1-2% of the population suffers from CHF [1]. The disease cannot be cured (but can and does get worse over time), so treatment is mostly focused on mitigating the symptoms. CHF patients must take various medications, monitor their weight, exercise appropriately, watch what they eat and drink, and make other changes to their lifestyle. All this makes CHF management very complex, and to make matters worse, each patient is different and may have to manage the disease differently.

Although research into the beneficial role of health technology for CHF patients is increasingly being reported in literature, most of this research focuses on technical aspects, such as classifying and predicting patients' condition severity [2, 6], automated vital sign monitoring [8] or improving disease outcomes [5]. Research focusing on heart patients' needs is mostly done with people suffering from other types of heart disease, or patients with cardiovascular disease in general [e.g. 4,10].

The work that we describe in this paper is part of the human-centered design research that was carried out in the first phases of a project called HeartMan. In this paper we specifically focus on research findings regarding user needs of CHF patients towards health technology that caused challenges regarding the feasibility of the corresponding user requirements within the HeartMan project. Some of these challenges are especially relevant within the context of research projects with limited timeframes and budgets, while others are more generally related to implementing health technologies in mainstream healthcare, e.g. integration with medical practice, legal issues, user adoption issues, etc. Although our research focused primarily on CHF patients, many of the challenges we identified are more generally applicable to health technology initiatives for any group of patients dealing with complex disease management. As such, these challenges

are relevant for any researcher, designer and developer in the broader field of health technology.

HEARTMAN

The HeartMan project¹ is a European (H2020) research project in which companies and research institutions collaborate to design a personal health system to help congestive heart failure patients to manage their disease. Based on predictive mathematical models, the HeartMan system will suggest individual patients which actions they can take in case their condition worsens. These suggestions concern actions related to medication, food and fluid intake, physical exercise, etc. Principles from cognitive behavioral therapy are used to help patients make changes towards a healthier lifestyle (e.g. by giving users attainable, personalized goals and help them to reach those goals). The HeartMan system will consist of a smartphone or tablet app as well as a wristband monitoring patients' physical state.

Diary & interview study

As the HeartMan project follows a human-centered design approach, heart failure patients were involved in the design process from the beginning of the project. The first research activity in this respect was a diary and interview study. The purpose of this study was to analyze the users and the context of use to identify problems, needs, wishes etc. of CHF patients, and to understand how their characteristics, environment and tasks should be considered in the design of the HeartMan system. By using qualitative and generative methods, including cultural probe like diaries and in-depth interviews, we follow an approach often referred to as context mapping [7]. Subsequent steps of the human-centered design process (not extensively reported in this paper) include ideation sessions, participatory prototyping sessions and prototype evaluations with both patients and caregivers.

The study was carried out in Belgium and in Italy and involved a total of 42 CHF patients. Two weeks before they were visited at home by a researcher for a semi-structured interview, all participants received a diary booklet. These diaries contained several assignments (see some examples in Figure 1) that allowed participants to collect data themselves about a variety of relevant topics, including technology use, patient experience, therapy adherence, lifestyle (e.g. diet and exercise behavior), medication, social support, medical life events, etc. During the interview, the diary was used as a starting point and researchers would ask further questions to gain in-depth understanding of the world of experience of heart failure patients.

This paper is based on the findings of the Belgian participants (n=23). Audio recordings of the interviews were transcribed and the participants' diary entries were digitized. To analyze the data, the three researchers who

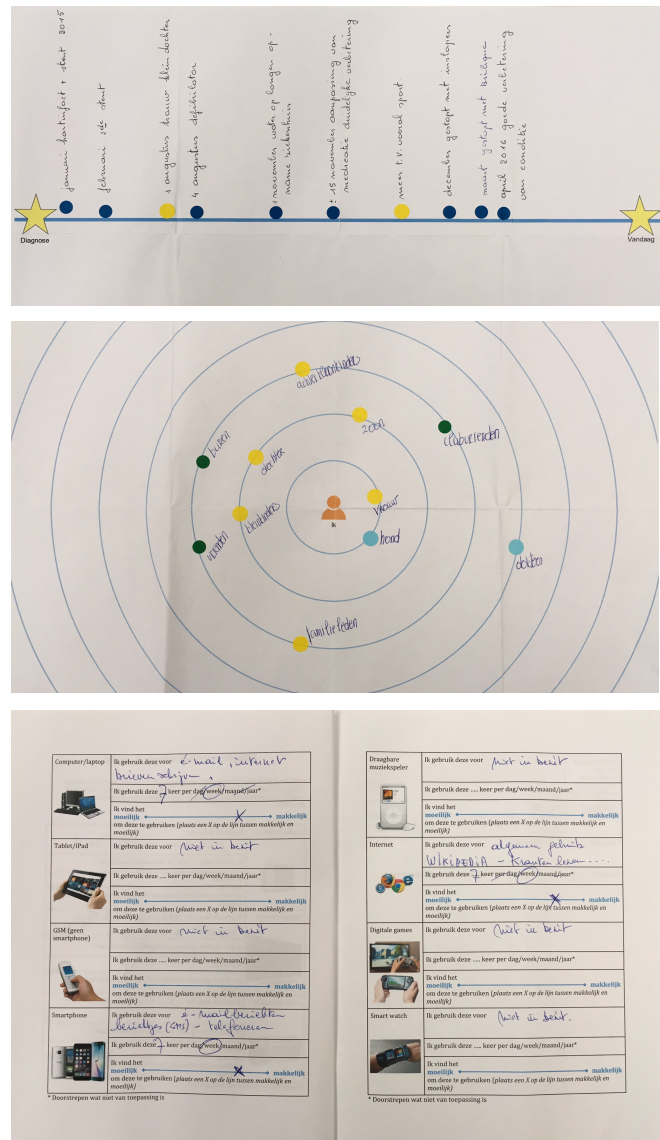


Figure 1 Diary assignments (from top to bottom): a timeline with personal (yellow dots) and medical events (blue dots) from diagnosis to today; a visualization of one's network of people who are important in disease management (people closer to the center are more important to the participant); and one's technology use.

conducted the interviews created a list of codes. This list was initially based on the aims of the HeartMan project (as these are described in the official project proposal) and the topics addressed in the diaries and interviews. Each researcher added further codes to the list while coding one or two interview transcripts, after which the researchers discussed the codes they added, and agreed on a final code list. This list was used to code all interview transcripts. Diary data were analyzed per assignment by summarizing the data of all participants.

The analysis resulted in a collection of rich insights into the everyday experiences, problems, needs and wishes of heart

¹ <http://heartman-project.eu/>

failure patients. These insights were subsequently translated to user requirements for the HeartMan system.

CHALLENGES

In this section, we present a selection of findings from the Belgian diary and interview study. For each selected finding, we briefly discuss the user requirement and its underlying problem or need, as well as what it is exactly that makes this requirement a challenging one for both the HeartMan project and for health technology development in general. Whenever possible, we also discuss how this challenge is dealt with within the HeartMan project.

Alarming

When we explained the concept of the HeartMan system to CHF patients (both in the interviews described in this paper as well as in ideation sessions with patients and caregivers organized later in the project), several patients immediately recognized the opportunities that wearable technology may offer in terms of alarming others in case of emergency. Many patients mentioned that their partner and other family members worry a lot about them. Some were never left home alone, or were not allowed to go out on their own, which severely limits their autonomy. Based on patients' need to be independent and to reassure their loved ones, we formulated the user requirements that the HeartMan system should: allow users to actively alert specific persons when they feel the need to; automatically alert specific persons when critical values of monitored data (e.g. heart rate) are reached; and allow users to inform specific persons that they are all right.

The user requirements related to these alarm functionalities caused quite some discussion in the HeartMan consortium. There were worries about legal issues such as liability, and in the end, it was decided that these issues were too complicated to solve within the scope of the project and that no alarm functionalities would be included in the HeartMan system as it will be developed for the project field trial. Reasoning from the goals of a specific research project, it may make perfect sense that some functionalities are out-of-scope, however, for heart failure patients, as well as for other patients suffering from potentially life-threatening illnesses, these functionalities might be more essential than those that a consortium decides to focus on, which may seriously lower the chances that users adopt the technology once it is launched.

Dietary monitoring and advice

Since one of the goals of the HeartMan system is to provide lifestyle advice to heart failure patients, dietary requirements related to CHF were discussed in-depth with participants. We learned that patients are convinced that they are well-aware of all dietary restrictions and the consequences of not adhering to such restrictions. However, when we asked more specific questions, patients seemed to overestimate their knowledge and skills in this respect. Therefore, detailed monitoring of food and fluid intake was considered an important requirement for the HeartMan

system, as well as highly personalized advice based on such monitoring (e.g. strategies for grocery shopping and cooking).

Unfortunately, in contrast to monitoring physical exercise, for which an abundance of technological solutions is on the market in the form of activity trackers and smartphone apps, automatically monitoring dietary intake in a reliable way is much more difficult. Although manual 'workarounds' (e.g. food diaries or regular questionnaires) are possible, these aren't always desirable as they require quite a lot of work and motivation on behalf of the end-users. Since developing a dietary monitoring system is not the main goal of the HeartMan project, the consortium decided to drop the requirements related to monitoring food intake on a daily basis. This caused a dilemma for the HeartMan project: how can the system help heart failure patients to make lifestyle changes regarding their diet while it can't gather reliable data about dietary behavior? Such a dilemma is likely quite common for health technology projects: patients have a need for 'holistic' health technology solutions, while projects typically focus on just one or a few technological advances to keep the project aims feasible. Although such projects may bring forward advances regarding their main focus, the resulting solution may not provide sufficient added value to patients in real life.

Technology experience

A more general challenge when designing health technology, especially for relatively older target groups, is the users' level of technology experience. Almost all the participants in our diary and interview study were light technology users at the most. They use technology, but usually on a very basic level. For instance, most of them own a mobile phone, but use it only to be able to make a phone call when they are away from home. Also, most have a computer or tablet to send an occasional email or to read the news. Smart televisions are mostly used in the same way as traditional televisions were used.

As the HeartMan system will run on a smartphone or a tablet, the consortium needs to take into account that several potential users have limited or no experience with using such technology. Even though some patients might be willing to learn how to use the technology, adoption may be low. This is a general challenge in health technology. Although innovative initiatives in health technology aim to empower patients and to make healthcare more accessible, recent research [7] suggests that eHealth may only reach assertive patients and requires quite some motivation on behalf of patients (e.g. to learn how to use the technology, to manually monitor data on a daily basis, etc.).

Within the HeartMan project, we are currently spending quite a lot of effort in thoughtfully designing and iteratively evaluating the architecture, interactions and interfaces of the system to make it as simple as possible, even for users with little or no technology experience. In this design,

gradual introductions to new system features as well as different levels of interaction complexity and feature richness are considered. Although such design solutions might not make the final system usable for every heart failure patient, we hope to lower potential barriers as much as possible.

Support with disease management

A consistent finding amongst almost all participants in the diary and interview study was that patients usually don't manage their disease on their own. In addition, family members are considered incredibly important in terms of support with the emotional consequences of CHF. Patient's partners especially seem to be actively involved in daily care activities such as taking medication, managing doctors' appointments and administration. The majority of the Belgian participants were male (22 out of 23), and most of them indicated, for instance, that their spouses were the ones who would prepare the medication they had to take for the whole week, and who would take into account dietary requirements while preparing meals.

In terms of HeartMan user requirements, this means that patients should be able to grant their partners access to the system. This of course has an impact on issues related to patient privacy. The current choice made by the consortium is that the patient will be the one who controls who has access to which parts of their data in the system, and that a partner can be given their own user account. Data access and data sharing is highly relevant for any health technology project, as it is likely that any patient suffering from a disease that impacts their life gets support from informal caregivers. The question whether, how, and to what extent such informal caregivers should have access to personal health information solutions should be thoroughly addressed by all researchers, designers and developers involved in health technology development.

Mental model of monitoring

When we discussed the HeartMan concept with heart failure patients during the interviews, we noticed that many patients seem to have a mental model of monitoring technology that may not match the real-life situation. Many participants expressed that being monitored by a system like HeartMan would make them feel much more reassured, and that they would worry less. When we asked them why, they seemed to assume that the data gathered by the HeartMan system would be constantly monitored by someone in the hospital who could take action if this would be necessary. In reality, however, even though doctors and nurses may be granted access to their patients' data via the HeartMan system, real-time monitoring will not happen. It is more likely that doctors will only access the data during consultations with their patients.

Initially, we did formulate a user requirement for the HeartMan system to send automatic alarms to medical staff in case certain monitored parameters would reach critical values, but this requirement was disregarded by the

consortium due to legal considerations. The design challenge of making patients aware that their data will not be actively monitored by hospital staff has not been tackled yet at the moment of writing. More dedicated research into the different mental models end-users of health technology may have about data monitoring would be required in order to properly design such monitoring technology, especially regarding realistic expectation management on the end-users' behalf. Again, this does not only apply to CHF patients, but to any patient whose health condition needs constant monitoring.

Therapy adherence

Improving therapy adherence (in terms of medication, physical exercise, dietary intake and mental wellbeing) is an important goal of the HeartMan project, as it is to many other health technology projects. Most guidelines that patients need to adhere to in this respect, however, are purely medical guidelines that don't take into account the everyday context of patients. We found that patients are in general quite motivated to stick to the guidelines, but that they also need to be flexible in real life sometimes. For instance, they would like to know how bad it really is to have one tiny glass of alcohol on New Year's Eve, or to eat a piece of cake on a grandchild's wedding day.

To accommodate this need, we formulated the (rather abstract) user requirement that the HeartMan system should support users to make decisions about occasional flexibility regarding adherence to doctors' advices. This support should entail different levels of flexibility for (e.g.) medication, nutrition and exercise guidelines, as some guidelines require stricter adherence than others. We haven't figured out yet, however, how to exactly implement this requirement. As such, technology-enhanced therapy adherence, an increasingly popular domain within health technology, should take into account (and find design solutions for) the common patient need for flexible adherence and more research is needed as to how to design for such flexibility.

Comorbidity

A challenge that is relevant to many patient populations, and therefore to health technology in general, is comorbidity. Many of the participants in our study (and caregivers who were involved in later ideation sessions in the project confirmed that this is indeed common in the CHF patient population) suffered not only from CHF, but also from other conditions, such as diabetes progressive lung diseases. The main problem in this respect is the fact that most medical health technology apps – including HeartMan – focus on one specific condition and may give advice that conflicts with advice users get for other conditions. Related to this is the fact that many health technology apps tend to focus on the physical aspects of a condition, while many conditions, CHF included, are also known to have mental consequences. Participants in our study, for instance, indicated that they experienced heart

failure incidents (e.g. heart attacks or surgery) as quite traumatic, and that the idea of having become a chronic (heart) patient is difficult to get used to.

HeartMan explicitly includes mental issues related to CHF (e.g. depression) and aims to support patients in coping with their condition. It does this, amongst others, by assessing users' psychological status and adapting the presentation of personal advice accordingly. Comorbidity, however, is considered out-of-scope of the HeartMan system. As health technology solutions aimed at specific diseases or impairments commonly target people with frail health conditions, comorbidity is likely to occur. Therefore, designers and developers of such systems should not only acquaint themselves with the requirements related to the condition their solution addresses, but with the requirements caused by other conditions their patient group may suffer from as well. Since medical and user requirements of multiple conditions often conflict, however, combining these is highly challenging.

DISCUSSION & CONCLUSION

As we mentioned before, several of the insights we gained from our diary and interview study posed quite a challenge for the HeartMan consortium. In our experience, this is quite common for any health technology development project. Even though human-centered design approaches are getting more common, compromises are always made. Although such compromises may offer a solution within the timeframe and scope of the project, from an end-user point-of-view, the resulting technology may not provide a full solution to essential real-life problems. As a result, adoption of such technologies may be low. An additional risk is that those user-driven issues regarding health technology that are often disregarded are never addressed appropriately, especially in research. Therefore, knowledge on such issues is not being built, which may hinder the design, development and implementation of any future health technology.

In the HeartMan project, we explicitly aim to contribute to knowledge building on the user-driven issues mentioned above, even when compromises were made or when the consortium decided to disregard them. In the user research and participatory design phases of the project, we explicitly include user requirements or ideas for functionalities that the consortium has decided not to develop further. The upcoming phase in the project, for instance, includes the iterative (participatory) design and evaluation of the HeartMan system architecture and design ideas for interfaces and interaction. In the first version of the HeartMan prototypes that will be evaluated with both CHF patients and caregivers, several functionalities have been included that will, in the end, not be developed in HeartMan's final system.

An example of such a functionality is the alarming discussed in the previous section. Since the participants in the diary and interview study indicated that such

functionalities would especially have an added value, we would like to further research how such functionality could be designed properly. Although the functionality will not be implemented in the HeartMan system, reporting on the knowledge we gain by designing and evaluating it with end-users (e.g. in the form of papers like this) may help to create better health technology in general. As such, we would like to encourage any (user) researcher within the domain of health technology to do the same. To not immediately disregard functionalities or requirements that may be out of scope of the particular projects they work on, but to keep doing (and reporting) research, at least as long as designs are still low fidelity, such as paper prototypes, and the research doesn't require much development effort anyway. By researching and reporting these issues, even if they are out of the project scope, researchers can contribute to what Höök and Löwgren [3] refer to as 'intermediate knowledge' in design-oriented research, providing a bridge between insights gained in relation to specific research and design activities and more general theoretical models. We hope that the challenges and suggestions for future research we have made in this paper will provide some focus for researchers in the health technology domain in this respect.

Another opportunity to keep building knowledge of frequently disregarded, but therefore not unimportant, user-driven issues in health technology is to map the issues that are frequently disregarded. We think it would be interesting to analyze a considerable amount of health technology research and development projects concerning disregarded user-driven requirements and ideas for functionalities. A systematic review and deep understanding of such disregarded issues may considerably increase the chances of successfully implemented and adopted health technology in the future.

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