A qualitative participatory study to identify experiences of coronary heart disease patients to support the development of online self-management services

Sandra Vosbergen [a,*], Jolien Janzen [a], Pieter Jan Stappers [b], Myra C.B. van Zwieten [c], Joyca Lacroix [d], Karin Idema [e], Inge van den Broek [e], Hareld M.C. Kemps [a,f], Roderik A. Kraaijenhagen [g], Niels Peek [a]

[a] Department of Medical Informatics, Academic Medical Center, Amsterdam, The Netherlands
[b] Department of Industrial Design, Delft University of Technology, Delft, The Netherlands
[c] Department of General Medical Practice, Academic Medical Center, Amsterdam, The Netherlands
[d] Department of Brain, Body & Behavior, Philips Research, Eindhoven, The Netherlands
[e] De Hart&Vaatgroep [Dutch Patient Association for Cardiovascular Disease], The Hague, The Netherlands
[f] Department of Cardiology, Máxima Medical Centre, Veldhoven, The Netherlands
[g] NIPED Research Foundation, Amsterdam, The Netherlands

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ABSTRACT

Objective: Web-based self-management services remain underutilized in current practice. Our aim was to gain insight into disease and self-management experiences of patients in early and progressive stages of coronary heart disease (CHD), to understand moderating effects of daily life experiences on the utilization of web-based self-management services and preconditions for use.

Methods: We applied generative research techniques, which stem from the field of product design and are characterized by the use of creative processes. Three groups of patients with CHD received a sensitizing package to document and reflect on their health, and were subsequently either interviewed or participated in a focus group session.

Results: In total, 23 patients participated in this study. Emerging themes were (1) fear for recurrent events, (2) experiences with professional care, (3) the perceived inability to prevent disease progression, (4) the desire to go on living without thinking about the disease every day, (5) the social environment as a barrier to or facilitator for self-management, and (6) the need for information tailored to personal preferences.

Conclusion: How patients experience their disease varies between stable and post-acute stages, as well as between early and progressive stages of CHD. Patients in post-acute stages of the disease seem to be most amenable to support, while patients in stable stages want to live their life without being reminded of their disease. In the context of self-management, web-based services should be adapted to the variation in needs that occur in the different stages of CHD and new strategies to fit such services to these needs should be developed.

* Corresponding author at: Academic Medical Center – University of Amsterdam, Department of Medical Informatics, P.O. Box 22660, 1100 DD Amsterdam, The Netherlands. Tel.: +31 20 56 66 179; fax: +31 20 69 19 840.
E-mail address: s.vosbergen@amc.uva.nl (S. Vosbergen).

Furthermore, they should be tailored to patients' individual health situation and preferences, support patient empowerment, and manage expectations regarding the progression of their disease.

1. Introduction

Self-management is becoming an integral part of care for chronically ill patients, such as patients living with diabetes or coronary heart disease (CHD). According to Barlow, self-management can be defined as the individual's ability to manage a disease's symptoms, its medical treatment, and its physical and psychological consequences, and to pursue lifestyle changes necessary for living with a chronic condition [1]. In the Netherlands, self-management education to CHD patients is mostly provided during cardiac rehabilitation, by general practitioners (GPs) or by nurse practitioners. The main goals are risk factor reduction (e.g. behaviour change), medication adherence, monitoring of disease parameters (i.e. blood pressure), and coping [2,3]. Given the prominent role of the internet in many people's lives nowadays, information technology is increasingly considered as the key medium to support patients in their self-management at home. For example, information technology is one of the main components of the Chronic Care Model [4]. It has been shown that web-based services for patients with chronic disease can have a positive effect on knowledge, social support, clinical outcomes and health behaviours [5].

However, many studies report poor utilization of existing web-based self-management services [6–8]. While few studies have thoroughly investigated the causes for this poor utilization [6,9], critics of existing self-management services have postulated that this can be explained by insufficient adaptation of these services to patients' needs and daily routines. This explanation corresponds with Rogers, who states that the rate of adopting an innovation is positively related to a variety of characteristics, including the degree to which an innovation is perceived as being consistent with the existing values, past experiences, and needs of potential adopters [10]. Additionally, Van 't Riet et al. found that their electronic patient information system was underutilized due to the lack of fit between system content and the needs and capacities of the target group [11]. However, assessing information to develop products that fit the values, experiences and needs of patients is not easy, as this information is often concealed in tacit knowledge and latent needs. The field of product design has developed methods that can be used to explore such tacit knowledge and latent needs [12]. We believe that insights into patients' experiences, assessed with these methods, can help to provide an understanding of the moderating effects of service utilization and the preconditions for use.

Previous studies have examined the needs for and barriers to self-management from a patient perspective [13–19]. They showed that patients have unmet information needs [13,15–19], psychological and physical barriers to self-management [15], and problems accessing health care [15,19]. Furthermore, Decker et al. have shown that the information needs of patients who experienced an acute myocardial

infarction (AMI) depend on how much time has passed since initial diagnosis [17]. Although we can derive from this that the stage of the disease influences the kind of support needed for self-management, previous studies have only explored the needs of patients in a relatively short period of CHD. Little is known about the way patients experience the disease and treatment from diagnosis of early-stage CHD until progressive CHD.

1.1. Objective

The aim of this study was to gain insight into disease and self-management experiences of patients in various stages of CHD. We explored the experiences of such patients to get a broad-based view of how their disease intertwines with their daily lives, to understand moderating effects of daily life experiences on the utilization of web-based self-management services and preconditions for these services.

2. Methods

2.1. Participant selection and recruitment

To study the experiences of patients in various stages of CHD, we recruited three separate groups of patients to participate in this study:

- Group A – patients who are receiving medical treatment for hypertension or hypercholesterolaemia and have never been hospitalized for an acute coronary syndrome (ACS), percutaneous coronary intervention (PCI), coronary artery bypass grafting (CABG), or cerebrovascular accident (CVA), and have an estimated individual risk of 5% or higher for a fatal cardiovascular event within the next ten years (SCORE risk) [20]. This group is characterized as "early-stage CHD."
- Group B – patients with progressive CHD who were recently (less than six months ago) hospitalized for the first time for an ACS, PCI, or CABG.
- Group C – patients with progressive CHD who were hospitalized for an ACS, PCI, or CABG more than six months ago, more than once, or both.

All recruited participants were 18 years or older. People with chronic heart failure (systolic left ventricular dysfunction; New York Heart Association (NYHA) Functional Classification III or IV) and congenital heart disease were excluded from the study. Patients with NYHA-III or IV were excluded, because there exists an extensive literature specifically focused on self-management of chronic heart failure, and because these patients are treated with separate guidelines. Also, heart failure is not only an end-stage of CHD but also of other diseases, and it has a different, more pronounced symptomatology than the CHD stages studied here.

Participants were recruited through two outpatient cardiology clinics and one cardiac rehabilitation clinic, and by advertising on the website and in the magazine of De Hart&Vaatgroep, the Dutch patient association for cardiovascular disease. Participants recruited through outpatient clinics were invited by their cardiologist, nurse practitioner, or physiotherapist. A questionnaire on demographic factors, medication use, risk factors, health literacy, and disease history was used to verify eligibility and to collect participants' background information. Recruitment ended when at least eight participants were included in each study group. The Institutional Review Board of the Academic Medical Center waived formal approval for this study as this is not required by Dutch law. All participants gave written consent for their participation in the study.

2.2. Design

Generative techniques are exploratory qualitative research methods from the field of product design [12,21,22]. They belong to the broader fields of co-creation and participatory design research, and are used in the early stages of product development to provide a rich, situated understanding of the user, so that designed products are suited to that user's personal situation. Generative techniques differ from the traditionally used qualitative methods in that they sensitize participants before interviews or focus group sessions take place, and use creative processes. We used generative techniques in this study, as the values, needs, preferences and experiences of patients which we aim to study here, are often concealed in tacit knowledge and latent needs. The use of creative tools in this approach supports participants in their process to assess this tacit knowledge and latent needs. By making objects (e.g. collages, mindmaps) participants are forced to take into account competing ideas, resolve ambiguities and make statements [22]. This prevents them from 'hiding into abstracts' [22]. The fundamental starting point of generative techniques is that users are the experts of their own experiences [12]. To enable them to play that role, they are guided along a process of self-observation and reflection, and given tools to express specific aspects of their own experiences (depending on the study aim). Users are led through this process to construct a view of the future product and its context [12].

In this study, we deliberately chose to widen the scope of our research by not focussing specifically on self-management or information technology. This is a common strategy in generative design research, as it allows to explore a broader scope of values, ideas, preferences and experiences [22]. Important user needs may be missed when focusing on technology, because this will often constrain users to think within the limits of their knowledge and experiences with this technology. To make our scope not too wide, medical goals described in clinical practice guidelines were taken into account when developing the assignments and the interview or focus group scripts [2,23]. Furthermore, we deliberately chose to focus on wellness and health rather than on disease, in order to induce mind frames conducive to exploring improvements and directions for solutions.

Fig. 1 depicts the design of our study. The generative techniques design consists of two subsequent phases: (1) a sensitizing phase and (2) a meeting with the research team. Both phases are described in detail below.

2.3. Phase 1: sensitizing phase

The sensitizing phase is meant to encourage participants to reflect on past and current experiences of daily life regarding the complete scope of the study before the Phase 2 meeting [12]. One week before the meeting, participants received a package containing a diary, a photo camera, and a notebook (Fig. 2). This allowed patients to get a feeling for the goals and topic of the study and to increase their understanding of their experiences regarding this topic [22]. The package allowed them to capture observations, anecdotes, and reflections to share during the meeting.

The diary contained several assignments (see the supplementary materials (Appendix A)) to be performed at home, spread out over several days. Participants were for example asked to describe a day in their life, the course of their health over the years, and the role health plays in their life. In addition, they were requested to take pictures of such things as items they bring along when they visit their doctors, places they relax, their computer environment, tools for self-management support and objects or persons who motivate them to have a healthy lifestyle. The notebook could be used to write down their thoughts about health during the day.

The sensitizing package was designed in an iterative process, with the method of Sleeswijk Visser et al. [12] as the starting point. To our knowledge, Sleeswijk Visser et al. [12] were the first to extensively describe guidelines for the development of generative tools. To summarize, they describe that sensitizing packages should contain a series of assignments that explore present and past experiences around the central topic of study. In these exercises participants should express their memories, opinions, dreams etc. They furthermore recommend that these packages have a broader scope than the scope covered in the sessions. The activities should be inspirational and provocative, stimulate participants to reflect on a daily pattern over a few days, take no more than 5–10 min a day, and the design of the package should invite them to write ideas or impromptu comments.

The assignments we included in the package are standard, frequently used assignments (e.g. [22,24]). The assignments were chosen and adapted based on the context and aim of this study in two steps. First, the subjects of the assignments were chosen from clinical goals described in medical guidelines [2,23]. Second, to further adapt the diary assignments to the study groups and context of the study, one person from each study group was interviewed. Then, the package was shown to and discussed with a specialist in generative techniques (PJS), a member of the Dutch patient association for cardiovascular disease (De Hart&Vaatgroep), and a cardiologist (RAK). This feedback was used to redesign the sensitizing package, which was then tested in a pilot study [25]. Participants in this pilot study evaluated the complete sequence of the package, and we used this feedback to redesign the package one more time. Participants for both the interviews and the pilot study were
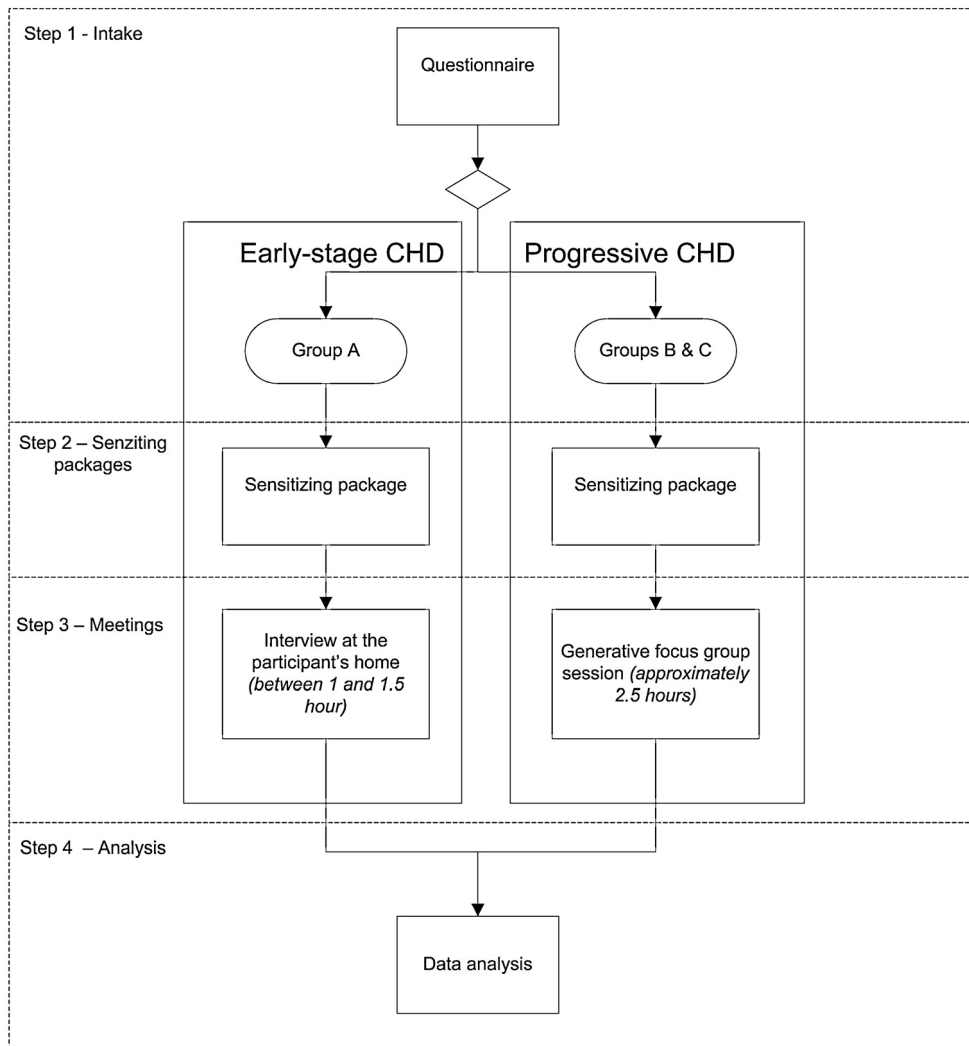
Fig. 1 – Outline of our study design. There were four steps to this process: verifying eligibility and collecting background information, sensitizing packages, meetings, and analysis.
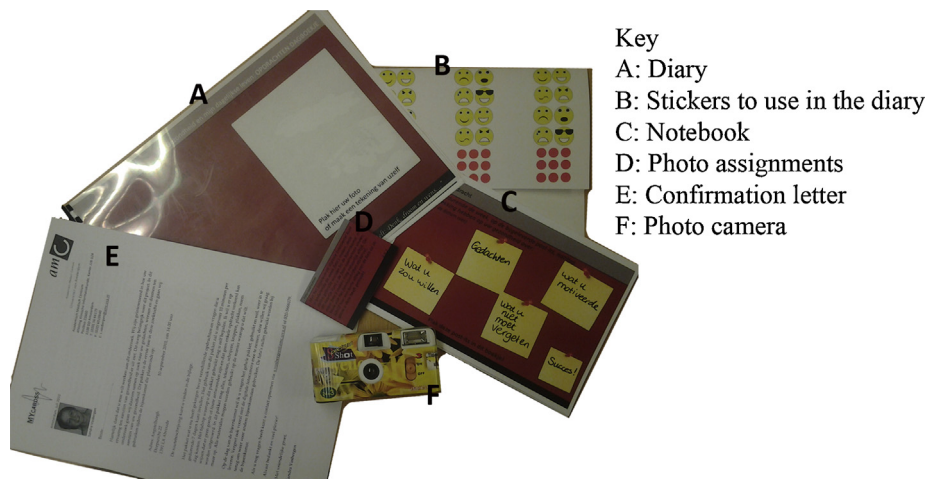

Fig. 2 – The sensitizing package sent to participants in the focus group sessions, consisting of a diary, a photo camera, and a notebook.

Fig. 3 – Examples from the set of pictures provided to study participants during the interviews and/or generative focus group sessions and used to illustrate feelings and experiences. Most pictures in the set were intended to be ambiguous. The first picture was chosen by many participants to depict the experience of a cardiac event. The second one depicted "I'll see what happens – I don't want to think about the disease too much." Most participants associated the third picture with health, and one of the participants described it as "living in the healthiest way possible." The last one was chosen to represent "looking ahead." [1]Copyright information, from left to right: ©Depositphotos/Khackimullin, ©Depositphotos/Zezulka, ©Depositphotos/Karandaev, ©Depositphotos/Baha.

recruited separately, and were different from the participants recruited for the present study.

Because the packages were primarily meant to sensitize participants and not to collect data, we did not analyze the packages that were used by participants or report on their results.

2.4. Phase 2: meeting with the research team

During the second phase, the sensitized participants share their stories, experiences and thoughts with each other and the research team [12]. It consists of either a one-to-one interview or a focus group session. In our study, it was hard to motivate patients from Group A (early-stage CHD) to participate in a focus group session. Therefore, we decided to interview these patients in their homes, while the other patients attended a focus group meeting.

During the meetings and interviews, participants carried out expressive tasks, such as making collages. The tools for carrying out these tasks included sheets the participants used to complete the assignments and sheets with preselected pictures (see Fig. 3 for examples of the pictures).

Interviews were semi-structured, and followed a topic list that included diagnosis, activities, health routines, ways to improve health, medical professionals, obtaining information about health, social relationships, and useful hints for other patients. The full topic list is found in the supplementary materials (Appendix B). At the end of the interview, patients were asked to make a collage with the preselected pictures on a magnetic collage board. The assignment was to create and explain their collage about "*my past, present and future (ideal) health situation in ten years time.*"

Participants from Groups B and C (i.e. progressive CHD) attended focus group sessions; the sessions followed a script that included, for example, making a photo album telling the story of participants' week, and a collage of their experience with their health and health information. The complete script is found in the supplementary materials (Appendix A). Separate sessions of approximately 2.5 h were organized for the two groups. Each session took place in an informal, homelike environment. The sessions were moderated by one researcher (SV) and assisted by another member of the research team. During the sessions, the participants presented their photographs, drawings, and collages to one another and discussed experiences with their health. The moderator only intervened when it was time to explain another assignment, to start the discussion, when there were additional questions, or when there was a lull in the conversation.

The script used in the generative focus group sessions was based on assignments commonly used during such meetings, and the guidelines described by Sleeswijk Visser et al. [12]. In summary, these sessions generally consist of a warm-up, closing, and two or three assignments, lasting about 2 h. The first assignment is mostly about memories, and participants should, during the continuation of the meeting be triggered to express deeper levels of feeling and knowing [12]. The commonly used assignments were adapted to our study aim and context in the steps described previously in paragraph 2.2; topics and questions were adapted according to the guidelines, interviews, expert feedback, and the pilot study. The tools used during the sessions and interviews were also designed and chosen according to the guidelines [12]. These guidelines describe that preselected tools should differ in content and context, and should be chosen to be open to more than one interpretation. The tools were changed based on the feedback of the experts and the participants in the pilot study.

Audio recordings were made of all interviews and video recordings were made of all focus group sessions with the participants' consent. Interviews were not recorded on video, because, unlike in focus groups, there is no interaction with other participants, and it is less likely that the interviewer misses particular (important) information.

2.5. Data analysis

The audio and video recordings of the interviews and focus group sessions were transcribed verbatim and analyzed qualitatively, using the MAXQDA 10 software package [26]. We

aimed to describe the experiences of patients in various stages of CHD that might influence adoption of self-management services. Accordingly, the process of data analysis was as follows. Our analysis was based on the steps described in the handbook of Boeije, with a thematic description of the data as outcome [27]. Exploration of the data was done by means of line by line coding by two researchers independently (SV and JJ). In this exploration phase, the common elements of chronic disease management described by Swendeman et al. [28] were used as 'sensitizing concepts' [27]. These elements were used, as these elements focus specifically on the broad range of patients' tasks in the context of disease management. These elements were found to fit the topics addressed in preliminary phases of this study (i.e. pilot and preliminary interviews) best. Differing opinions were resolved by consensus, and if there was disagreement, a third researcher (NP) was consulted. Following this initial coding, common themes and/or concepts were identified within and between groups by using constant comparison. This was done by one researcher (SV). Afterwards, the process was assessed by two researchers independently by critically reviewing several source documents (NP one transcript of a generative focus group session and HK two interviews) together with the interpretations and thematic analysis, as a quality check on the data.

3. Results

3.1. Participant demographics and health-related characteristics

A total of 23 eligible patients agreed to participate; 19 patients (16 men, 3 women) were eventually either interviewed or attended a focus group session. Table 1 presents a summary of the demographics and health-related characteristics of all participants; one person did not return the background questionnaire. Of the participants in Group A (i.e. early-stage CHD; $n = 6$), two indicated they have diabetes, five hypercholesterolaemia, and five hypertension. The majority of participants in Groups B and C (i.e. progressive CHD; $n = 13$), had had a single ACS and one or more cardiac interventions. Sixteen sensitizing packages were returned. Fig. 3 shows some of the pictures used by participants during focus groups.

3.2. Patient experiences: interviews and generative focus group sessions

Our analysis yielded six core themes: (1) the emotional impact of CHD, (2) experiences with professional care during recovery and follow-up treatment, (3) perceived inability to prevent progression of the disease and recurrent events, (4) experiences with the impact of having CHD on daily life, (5) the social environment as potential barrier or facilitator in managing the disease, and (6) information needs and preferred sources of information. Every theme first describes the participants' health-related experiences in the various study groups, followed by a description of participants' needs and preferences.

Table 1 – Characteristics of the patients included in this study ($n = 19$). Group A consisted of patients with early-stage CHD, Group B of patients with progressive CHD who had recently had their first cardiac event or intervention, and Group C of patients with progressive CHD who had had multiple cardiac events or interventions, or had one more than six months ago.

Participants, n[*]	
Group A	6
Group B	5
Group C	8
Age, mean ± SD[†],[a]	64.6 ± 10.2
Gender, n (%)	
Male	16 (84%)
Female	3 (16%)
Country of birth, n[*] (%)	
Netherlands	19 (100%)
Other	0 (0%)
Education, n[*] (%)	
Low (elementary and lower secondary education)	7 (37%)
Middle (upper/post-secondary education)	4 (21%)
High (tertiary education)	8 (42%)
Medication usage, n[*] (%)[a]	
Beta-blockers	11 (58%)
ACE inhibitors/angiotensin II receptor	13 (68%)
Diuretics	6 (32%)
Other antihypertensive drugs	5 (26%)
Anti-platelet drugs	12 (63%)
Anticoagulants	4 (21%)
Nitrates	4 (21%)
Lipid-lowering drugs	15 (79%)
Anti-diabetics	5 (26%)
Other medication not related to CHD	11 (58%)
Marital status, n[*] (%)	
Married or living together	13 (68%)
Single	6 (32%)
Work status, n[*] (%)	
Paid	9 (47%)
Voluntary	2 (11%)
Retired/no work	8 (42%)
Diabetes, n[*] (%)[b]	6 (35%)
Body mass index, mean ± SD[†],[a]	28.1 ± 3.3
Alcoholic drinks per week, median (IQR)[‡],[a]	4 (0.3–9.5)
Smoking status, n[*] (%)[a]	
Never	4 (22%)
Former smoker	12 (67%)
Current smoker	2 (11%)
Days per week with exercise, mean ± SD[†]	
30 min, moderately intensive[a]	3.9 ± 1.9
20 min, intensive[b]	2.3 ± 1.0
Health perception, n[*] (%)[a]	
Excellent	2 (11%)
Very good	8 (44%)
Good	6 (33%)
Moderate	1 (6%)
Poor	1 (6%)

[a] One participant did not provide information on medication usage, age, diabetes, body mass index, alcohol, smoking, exercise, or health perception.

[b] Two participants did not provide information.

[*] n, number.

[†] SD, standard deviation.

[‡] IQR, interquartile range.

3.2.1. The emotional impact of CHD

A majority of the participants in Groups B and C had experienced an acute cardiac event at least once. Such events were frequently depicted as atomic bombs in the collages participants made during the focus group (Fig. 3). They reported having experienced the event as sudden, unexpected, and frightening. After an acute event or cardiac intervention, some participants felt disappointed or angry with their bodies for letting them down. Many participants expressed an intense fear of recurring cardiac events:

> 3-3: The fear I had then, after the heart attack, [...] I had it again after the operation. You kind of think, gosh, my heart's going to stop working any time now.

Participants in all groups felt that during such periods they needed to keep a positive mindset and search for distractions. Most participants from Group C (i.e. progressive CHD with multiple events or interventions, or one more than six months ago) indicated that the fear had diminished or faded away over time:

> 3-1: In the end it took about two years before I was really over it. It really scared me. But okay, that's completely behind me now, that feeling is completely gone.

3.2.2. Experiences with professional care during recovery and follow-up treatment

In general, participants in all groups were satisfied with the professional care they received. Most participants from Group B (i.e. progressive CHD, recent first event, or intervention) had recently attended a cardiac rehabilitation programme. They expressed satisfaction with this programme and described having benefited from it because the controlled environment satisfied their need to feel more secure and recover physically. Participants from the various groups appreciated the regular visits to their cardiologist. The main benefits they described were feeling reassured and the opportunity to ask questions. Participants from Group B added that they had learned how to recognize symptoms that indicate a recurrent cardiac event. However, some participants from Group C doubted the usefulness of these regular visits, as they experienced no benefits from them:

> 3-6: As far as I'm concerned, the check-ups with the cardiologist could stop now, because they don't mean very much. He makes an ECG, but that just shows one moment in time. [...] And often it's like, you go in one door and out the other.

All participants indicated they had unanswered questions. For example, most participants from Group B said they did not get information about what to expect after discharge. Participants from Group A (i.e. early-stage CHD) indicated that the information provided about their treatment (i.e. medication) or condition (i.e. hypercholesterolaemia and hypertension) was limited, and that they primarily discussed other health problems. Additionally, they often felt there was not enough time to ask all their questions.

3.2.3. Perceived inability to prevent progression of the disease and recurrent events

A majority of the participants in Groups B and C perceived themselves as unable to prevent disease progression and recurrent events. Only in Group C did participants clearly vary in this regard, with some participants acknowledging that the risk of recurrence could be reduced by a healthy lifestyle. However, most of the participants from Groups B and C felt they had always lived healthy lives and therefore did not understand why they had become ill:

> 2-1: Of course it's different for everyone, but I've never had any health problems, that's what's so strange. [...] I got sick in May for the first time. I feel like I've always lived a fairly healthy life. I've never smoked, and I drink very little.

Several participants from Group A showed an awareness of the importance of exercise, a healthy diet, and medication adherence. Still, this group did not discuss whether they felt they could control progression from early-stage CHD to progressive CHD.

Participants in Groups B and C expressed a need to understand the causes of their illness. Many of them were bewildered by the mechanisms that lead to CHD, and reported knowing people with cardiac disease who had seemed to have had healthy lifestyles. Others saw explanations in work-related or other types of stress.

3.2.4. Experiences with the impact of having CHD on daily life

The majority of participants from Groups B and C felt that – except for the first period following their ACS, which brought with it physical and emotional discomfort and fear – nothing had really changed:

> 2-4: I think it's been three months since I also noticed I'm now actually fully recovered and can do whatever I like. Like it was a bad dream I had a while back.

Some of them even said they felt better physically after their cardiac event or that they enjoyed life more than before. When asked about their experiences with their health, participants from Group A only brought up experiences with conditions other than CHD (e.g. being admitted to intensive care for respiratory problems). These experiences often had more impact on their lives than their heart disease, because they felt more threatened or needed acute care. Participants from Groups A and C in particular did not consider themselves to be "patients."

All groups of participants expressed a dislike for medication. Groups B and C explained that having to take medication reminded them of their disease, and felt this was all that remained of their CHD:

> 2-4: I decided to draw the picture at the bottom [in which the participant made a drawing of a number of pills] because that's my main memory of the heart attack: taking pills twice a day. I carry around one of those sprays for under the tongue, which I've never had to use and hopefully won't need.

Some participants in Group A disliked medication because they believed it was prescribed more than necessary, or perceived them to be unhealthy substances.

Participants from Groups B and C expressed the desire to continue living their lives without worrying every day about their disease, and indicated they disliked being regarded as a "patient" by others. Furthermore, participants in all groups indicated they would prefer to take less medication. One of the participants in Group A explained that this motivated him to change his dietary habits, as his physician had said the amount of medication would be reduced if the patient succeeded in making lifestyle changes:

> 1-6: A while back I got to stop taking one, and I really enjoyed that. "Hey, that's one less pill." Just because my weight went down a bit, I could take less of one of the medications. That felt like kind of a victory.

3.2.5. *The social environment as a potential barrier or facilitator*

When considering the initial period following an acute cardiac event or cardiac intervention (hospitalization and recovery), participants from Groups B and C experienced their partners, friends, and family as supportive. For example, participants from Group B asked their friends to keep an eye on them during the period following the cardiac event. Furthermore, they had friends or family members with whom they exercised. Participants from both Groups B and C added that distraction was important to them after the event, and that family and friends were helpful in this regard.

In contrast, in both Groups A and C (where the disease was less acute), some participants complained that their friends and family were overprotective. Some of these participants described their partners as being more worried than they were. Furthermore, some participants from Group A described friends as being meddlesome, and focusing too much on risk factors and their health:

> 1-2: The first question is, "What's your cholesterol level? How's your blood pressure?" Then I think, "Here we go again, give it a rest, will you?" All that harping on about diseases and blood pressure and… I get tired of it.

3.2.6. *Information needs and preferred sources of information*

Participants in all groups described health professionals as their primary and preferred source of health information. A few participants preferred the internet. Information from health professionals was frequently supplemented with written information provided by a variety of other sources, such as magazines, books, and the internet. When participants used the internet to find health information, they usually searched for information about medication, acute treatments in the hospital (such as a CABG or PCI), or for clarification of something they heard during a medical visit. Participants who did not use the internet gave various reasons, such as not needing supplementary information, disliking the internet, or not knowing what to search for.

There was variation in the amount and type of health information participants needed. In Groups A and C the need for information was relatively low, because at that stage, CHD no longer affected their personal situation. Additionally, most of the participants in Group C felt they knew enough about their disease. If participants in Groups A and C needed information, this was primarily about medication, co-morbidities, and how to deal with acute health problems should they occur. In Group B, participants had more questions and concerns about their disease. They expressed a need for background information, understanding the mechanisms of disease, and insight into their prognosis.

Participants expressed a preference for information relevant to their individual situations. They wanted information about CHD only when they were prepared for it, or at a time and place of their choosing, because information about CHD could be unsettling. In the focus groups, we observed various differences between participants in the preference for information provision. This included variation in preferences for a delivery method (e.g. health professional, internet), the content of messages (e.g. information about whether there were side effects), the level of detail of the messages, and the amount of information provided. If anything were possible in terms of health information, one participant would prefer the following:

> 3-6: Then what I would really like would be, say, to get exactly the information I need when I want something, and not have it come along with a lot of extra information I don't need.

This need for personalized information was also reflected in problems with finding and interpreting health-related information. Participants reported problems applying information to their individual situations and evaluating the reliability of the information. They also felt the written information provided in hospitals (such as leaflets) was often formulated too negatively. As to information available on the internet, participants indicated they only visited websites they believed to provide objective information. They felt discussion boards contained information that had an unsettling impact, and that this information did not reflect their personal situations.

4. Discussion and conclusions

4.1. *Discussion*

In this study, we explored the experiences of patients in various stages of CHD, to understand moderating effects of daily life experiences on the utilization of web-based self-management services and preconditions for use. Using the qualitative analysis of transcripts from focus group meetings and interviews, we identified six themes that described these patients' experiences with their health and well-being.

The post-acute stage (i.e. the first months following the cardiac event or intervention) was often characterized by fear for recurrent cardiac events. Although the fear typically diminished after a while, the feelings of uncertainty brought about a need for reassurance and information about the causes of the disease. In the literature, this has been reported as an opportunity for motivating patients to make lifestyle changes [29]. Self-management services should seize this opportunity and provide patients with education and

behavioural management support. Both elements often recur in various self-management interventions [6,30]. Additionally, these findings suggest a need for emotional support in the post-acute stage to reduce anxiety and unnecessary stress; an element that has been implemented less often in general or cardiac-disease specific self-management interventions [6,30].

Many participants had the feeling that they could not prevent disease progression or recurrence of events. Participants were confused by the fact that they had become ill despite their perception of living healthy. This perceived lack of control is in line with the findings of Sullivan et al. in patients with stroke [31]. It suggests that a precondition for effective self-management is that patients are aware of risk factors and the influence they can exert on disease progression. In addition, patients should be empowered to take control over their health; a notion that is described extensively in the literature and is a common element in various self-management models [4,32,33], including the framework used in this study [28]. Patient empowerment has also been the focus of various chronic disease management interventions [34–36] and has shown to increase the uptake of control consultations for secondary prevention of CHD [37]. Providing these services through information technology has already shown positive results [35]. A perceived lack of control might also have a moderating effect on the utilization of self-management services; patients who do not believe that they can govern their health will not be inclined to use these services. These patients might therefore first need support in increasing their empowerment, before they will be deemed eligible for self-management.

In stable stages of CHD, participants expressed the desire to lead normal lives, not being reminded of their disease. Participants with early-stage CHD were more focused on diseases other than CHD, which could be explained by the fact that both hypertension and hypercholesterolaemia are "silent," asymptomatic diseases [38] and do not play a major role in the daily lives of patients. Patients in early-stage CHD might therefore be amenable to more generic self-management interventions [e.g. 39] that can focus both on CHD and co-morbidities. Furthermore, it seemed that for participants in the stable stages, questions only emerged in specific situations (e.g. when someone experienced a side effect from medication). These finding are in line with findings of Kerr et al., who found a direct link between the use of a web-based intervention for heart disease self-management and patients' time since diagnosis [40]. If patients were diagnosed with cardiac disease longer ago, their need for information, advice and support has reduced, and so has their need for self-management support. The disease stage of the patients seems to be a clear moderator for the utilization of self-management services. This suggests that for patients in stable stages of CHD different strategies to support self-management are needed. Services should either (1) accommodate this desire to lead a normal life by smoothly integrating them into patients' daily routines and avoiding explicit references to their patient status, or (2) focus on occasions when specific needs emerge, or (3) use strategies to motivate these patients to participate in self-management.

Although in all patient groups participants were satisfied with the professional care they received, they did have unmet information needs. This failure to meet patients' information needs supports findings from earlier research [13,15–19]. Concordant with Decker et al. [17], we observed that these information needs differed between the stages of CHD, with the strongest information needs being observed during the initial period following the cardiac event or intervention. This might be explained by the findings described above. Current disease management programmes have already successfully implemented elements of patient education and of training patients in communication with health professionals [39,41].

Participants in stable stages often perceived their social environment as a barrier, while in post-acute stages it was perceived as supportive. This is in line with other studies, which reported overprotection by significant others [18,42]. Some authors have suggested that family-centred care following cardiac events should receive more attention [42,43]. To our knowledge, this is not implemented in any of the current web-based interventions. Our findings suggest that it might be advantageous to explore the effects of family-centred care in the post-acute disease stage and explore potential strategies to eliminate the perceived threshold in stable stages.

Finally, participants in all groups reported to have problems with applying generic health-related information, and expressed a desire to receive information that is tailored to their individual situation and preferences. This finding is consistent with findings of Kehler et al. [44] who found that patients had problems with recognizing the relevance of the generic information provided and were unable to apply it to their personal situation during preventive consultations with GPs. These findings suggest that a precondition for patient self-management is that patients be provided with tools that translate, or support them in translating health-related information to their personal situation and preferences. An extensive literature suggests that tailoring health-related information to patients' individual characteristics, information needs or preferences might be a promising strategy [45–49]. However, few studies have integrated the concept of tailoring into self-management services, and most tailoring strategies focus on patient characteristics, health behaviours, willingness to change behaviour, risk factors, or information needs. Our findings indicate that information should also be tailored to personal preferences concerning information content, message complexity, and level of detail. There is a need for user models which can incorporate these preferences and patients' personal situation.

Commonly used qualitative research methods such as interviews are limited in their abilities to reveal tacit knowledge and latent dreams [12]. Our study is different from other studies with chronically ill patients because we used participatory qualitative methods from the field of product design [12], characterized by a sensitizing step that precedes the meeting with the researchers and by the use of creative processes during the meeting. We found that these methods evoked appropriate awareness and expression in the participants. Participants referred to the sensitizing packages during the meeting and used the images to explain their experiences. The use of other explorative research techniques (such as

observations in the participants' home) were either not feasible, or had particular limitations for achieving our study goal.

In the data analysis of this study, we used the elements of Swendeman et al. [28] to inform our thematic analysis. Other models, like the Chronic Care Model [4] or the components of self-management described by Lorig and Holman [30] and Barlow et al. [41] could also have been used. However, as there is a large overlap in concepts that are covered by these models, we do not expect that using these alternatives would have resulted in different findings. Similarly, we chose to adopt the analysis method described by Boeije [27], where a grounded theory approach [50,51] would also have been appropriate. Again, we do not expect that this has influenced our findings.

Our study also has several limitations. First, to study experiences in various stages of CHD, one would ideally follow the same patients as they progress from one stage to another. This would, however, take many years. Therefore, we chose to recruit different patients for each of the disease stages. Second, our sample is small and might be biased. Patients with demanding jobs, those who do not see themselves as patients, or who have many co-morbidities may have been less inclined to participate. Third, for pragmatic reasons, we interviewed patients with early-stage CHD rather than having them participate in a group meeting. Finally, the generative approach used in this study is an explorative method. It is characterized by developing a broad perspective of users' experience and personal situation, instead of immediately focusing on the future product and considering all current knowledge on the topic at hand. Consequently, this might not directly result in concrete requirements for the future product and might make it more difficult to interpret the findings in light of the future product (i.e. web-based self-management); both were the case in this study.

4.2. Conclusion

The experiences of CHD patients with their disease varies between stable and post-acute stages, and between early and progressive stages of CHD. Post-acute stages are characterized by the strongest needs for support, with a specific need for reassurance and sense-making. In this stage, patients seem to be most amenable to initiate self-management activities. In stable stages, patients want to live their lives without being reminded of their disease. These patients only want to focus on the disease during pre-arranged meetings or when concrete questions occur. Strategies are needed to develop web-based self-management services that anticipate the variation in experiences and needs in these different stages of CHD. Many patients throughout all groups feel unable to prevent disease progression and have a need for information that is tailored to their individual health situations and preferences.

4.3. Practice implications

Our findings suggest that self-management services should allow for differences between the stages of CHD and that to improve the utilization of web-based self-management services different strategies to support patients in self-management are needed for at least stable and post-acute disease stages. Strategies that are currently deployed by web-based self-management services might be best fitted to patients in the post-acute stages, as patients in the initial period following a cardiac event seem to be most amenable to support. For patients in stable stages of CHD new strategies need to be developed that either (1) smoothly integrate services into patients' daily routines, or (2) focus on occasions when specific needs emerge, or (3) motivate patients to participate in self-management. Health professionals and researchers who participate in developing self-management services should keep in mind that patients in these stable stages of CHD may be reluctant to use them.

Furthermore, for all patient groups web-based self-management services should be complemented with tailored approaches to match these services to patients' preferences and personal health situation. Also, in line with current self-management models, web-based self-management services should, for all patient groups, aim to increase patient empowerment, so that patients are supported in exerting control over their health and well-being; and in managing their expectations regarding the progression of their disease. Developing solutions that are focused on patients' personal needs and that are offered to them in a way they feel comfortable with may increase the perceived support and thereby the utilization of these services.

Author contributions

Conflicts of interest

No conflicts of interests.

Acknowledgements

Summary points

What was already known on this topic:

- Web technology is considered well suited to support chronically ill patients in self-management at their homes, but utilization of existing web-based self-management services is disappointing.
- Critics of existing self-management services have postulated that this is due to insufficient adaptation of these services to patients' needs, experiences, values and daily routines.
- The field of product design has developed methods, called generative research techniques, that can be used to explore experiences of potential product end-users, including tacit knowledge and latent needs.

What this study added to our knowledge:

- Among coronary heart disease patients, marked differences exist between the experiences of stable and post-acute patients, and between patients in early and progressive stages.
- Patients have a need for information that is tailored to individual preferences, for support to regain control over their health and well-being and for expectation management regarding the progression of the disease.
- Patients in the initial period following a cardiac event have the highest need for support, and seem to be most receptive to start using web-based self-management tools.
- Patients in other stages of the disease may be reluctant to use them and services should either (1) smoothly integrate into patients' daily routines, or (2) focus on occasions when specific needs emerge, or (3) motivate patients to participate in self-management.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.ijmedinf.2013.09.001.

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