

# Participatory research method to assess patients' needs for web-based self-management services: a pilot study.

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## Abstract

In this paper we study the potential of generative techniques to determine needs, barriers, perceptions and experiences of patients with coronary heart disease (CHD) in self-management of their health. Three patients that were previously hospitalized for a coronary event or intervention participated in this pilot study. The study consisted of a preparatory 'sensitizing package' and a generative session. During this generative session creative processes were used to discuss the experience of patients with their health. The results were compared to findings of published studies with similar objectives. This showed that generative techniques have considerable potential in participatory qualitative research in healthcare.

## 1. Introduction

Although web-based self-management services are seen as a promising solution to deal with the growing healthcare demand, the utilization of these services is disappointing. Chronic diseases, like coronary heart disease (CHD), impose a growing demand on the healthcare system. Patient self-management has the potential to relieve the demand as it can transfer tasks from medical professionals to patients. The last decade has witnessed an increasing interest in delivering support for self-management tasks through the web. Unfortunately, studies of web-based self-management services often report problems with poor uptake and high attrition [1].

One of the causes of this problem might be a lack of consideration of patients' needs in the development process. Participatory design methods originating from the field of product design, such as generative techniques, can alleviate this deficiency by involving users early onwards in the design process. Generative techniques use creative processes, like making collages and mindmaps, to access contextual and experiential information [2]. This kind of information is difficult to elicit as it is mostly situated in the tacit and latent dimensions of users' knowledge.

In this paper we study the potential of using generative techniques for determining the needs, barriers, perceptions and experiences of patients with CHD for self management. For this purpose we applied generative techniques in a pilot study and compared our results with studies that had a comparable objective.

## 2. Methods

We applied generative techniques as described by Sleswijk Visser et al. [2] to patients who were previously hospitalized for a percutaneous coronary intervention (PCI), a coronary artery bypass graft (CABG) or an acute myocardial infarction (AMI). Patients were recruited by their treating physician from an outpatient cardiology clinic or from an outpatient cardiac rehabilitation clinic. As the process of generative techniques was described extensively in Sleswijk Visser et al. [2], we will only report the specifics of our study here. Consistent with the approach of Sleswijk Visser et al. [2], participants first received a preparatory 'sensitizing package' consisting of a diary with small assignments and a notebook. An example of an assignment included in this diary is to describe the events of a typical day on a visual time line and explain the influence of your health on the events. This preparatory 'sensitizing package' was used to promote self-observation and self-reflection. It was used in the domestic environment of the participant during seven days, for approximately ten minutes a day. Participants subsequently participated in a focus group session in which they created and discussed collages concerning experiences with their health. This session, called a generative session, was used to become aware of and discuss ideas amongst group members. An example of an assignment they were given during this generative session was to create a collage of their experience with health and health information in daily life.

The generative session was videotaped after consent of the participants, and the audio of the videotape was transcribed verbatim and analysed qualitatively. The transcript was coded separately by two researchers, by selecting relevant sections and assigning topics to the sections. A thematic approach was applied and concurrence of key themes was verified in consensus meetings. In case of disagreement, a third researcher was consulted.

To evaluate the potential of using generative techniques, we compared the results of our study with the results of six recent studies concerning the needs, barriers, perceptions and experiences of patients with CHD for pursuing self management.

## 3. Results

Five patients were recruited and received a sensitizing package. Three of them participated in the generative session. The group consisted of two females (age: 65 and 53) and one male (49). Two of the participants had one AMI with a PCI in the last year; the other participant had two AMIs and six PCIs in the last nine years. The generative session lasted around three hours. During the analysis of the generative session four key themes were identified: (1) experience of having an AMI, (2) experiences in the period after their AMI, (3) experiences in their daily lives after having an AMI and (4) medication. All themes were described extensively in the context of the participants' daily lives. Furthermore, the majority of remarks or stories of participants were about barriers regarding self management. Table 1 summarizes our findings from this pilot study.

### Comparison between our findings and the findings of the selected studies

Six qualitative studies were included in this study. The objectives of these studies were to determine: (1) patient perceptions on CHD, cardiac rehabilitation, medication use, and lifestyle changes [3], (2) what is important after an AMI and for performing self-care [4], (3) patients' perspectives on making lifestyle changes following AMI [5], (4) patients' preferences for involvement and the type of information to make decisions [6], (5) barriers,

facilitators and sources of information with regard to suggested lifestyle changes and opportunities for nurse interventions [7] and (6) health and mental health information needs of patients with CHD [8]. The number of participants ranged from 12 to 62 patients. One study recruited patients via GPs, the other five recruited patients via hospitals. Four studies conducted semi-structured interviews and two studies used focus group discussions. All studies were analyzed by identifying emerging themes from the data (bottom-up analysis).

Many findings were congruent with the results of other studies. For instance, patients want to continue their lives without thinking of their disease every day [3, 4, 5]. Patients struggle with many questions, like How do I recognize symptoms of a recurring AMI? [4]; What are my physical limitations? [6]; Why do I have to take medication and how do I recognize side-effects? [3]; and What can I expect of the future? [6, 7, 8]. They also feel unable to stop disease progression [3, 7], felt physical or psychological discomfort in the period after their AMI or PCI [7, 4, 5], indicated that family can be over-anxious [6] and mispercept CHD as a disease for elderly people [5].

Unlike in other studies, participants in our study indicated that since their AMI or PCI they defined relaxation as an important part of their daily routines and that they have difficulties to get into their stride in the morning. Next to this, they indicated that health professionals sometimes fail to recognize the symptoms of an AMI. Similar to the study of White et al [3], participants indicated that they felt taking medication is inevitable, but they added that taking medication is an obligation that remembered them of their diseased status. Next to this, they struggled with effects of the disease on their social lives, for instance when they had to reject invitations to go out. As opposed to the study of Goyle et al [4], participants of our study found it difficult to adhere to medication. They had difficulties with medication adherence after their first AMI particularly, as they were not used to take medication. And where other studies found that patients did recognize that their disease was a consequence of an unhealthy lifestyle [3], the participants in our study believed that they always lived healthy. Other studies also described findings that were not mentioned by our participants, like the fact that patients often receive contradictory information [7, 3], the fact that friends and relatives need information about their disease [8], and the fact that relatives can be a barrier to implementing lifestyle changes [7].

**Table 1. Summary of findings; the table shows the four key themes, a description of the finding and a sample quote from a participant regarding this finding. The last column shows the type of finding, i.e. whether this finding is a need, barrier, perception or experience.**

<b>Theme</b>	<b>Finding</b>	<b>Sample quote</b>	<b>Type</b>
<i>Experience of having an AMI.</i>	Patients do not recognize symptoms of a first AMI.	<i>"I thought I had nausea due to a tough row training."</i>	Perception
	Patients indicated that health professionals some times fail to recognize the symptoms of a AMI	<i>"I went to the GP and he said that I was working too hard, I had to go to a social worker and received a sedative. But the pain remained and I subsequently had an AMI."</i>	Barrier
	Patients mispercept CHD as a disease for older	<i>"During cardiac rehabilitation I was surprised of how young</i>	Perception

	people	<i>people were there.</i> "	
	Patients describe their AMI as a freighting experience.	A picture of a nuclear explosion was representing the experience of having an AMI	Experience
<i>Experiences in the period after an AMI.</i>	Patients felt anxious or sad after their AMI, PCI or CABG	<i>"In the months after my AMI I felt emotionally weak."</i>	Experience
		<i>"I don't dare to go to such a country, because when I have to go to a hospital there..."</i>	Barrier
	Patients felt a diffuse sense of discomfort after their AMI	<i>"The main problem with my health is that I am feeling wearier."</i>	Experience
<i>Experiences in the daily lives of a CHD patient.</i>	CHD patients have many questions	<i>"Which activities am I still capable of, and how do I determine that?"</i>	Need
	Patients indicate that they want to return to and move on with their prior lives.	<i>"I don't want to think about it. I try to forget it and the better I feel, the less I think about it. "</i>	Barrier
	Patients indicated that since their AMI they defined relaxation as an important part of their daily routine	<i>"Since I had a heart attack I take more time to relax. "</i>	Need
	Patients feel powerless to stop disease progression	<i>"It is difficult; I don't trust that it stays away."</i>	Barrier
	Patients struggle with the effects of CHD on their social lives	<i>"I need to stand up for myself, because although I feel like I am doing too much, I am still saying yes to everyone who asks me to do things with them."</i>	Need
	Family and relatives of patients can be over-anxious	<i>"If I don't take up my mobile telephone, they become worried. They then start calling each other and ask: where is mom? While I walk outside with my dog. "</i>	Need
	Patients have difficulty with getting up	<i>"I am often still tired when getting up. I have difficulties to get into my stride in the morning."</i>	Barrier
<i>Medication</i>	Patients indicate that medication is important for their health	<i>"It gives you a higher chance to live longer"</i>	Perception
	Patients indicated that adherence to medication is especially difficult after their first AMI	<i>"After my first MI I found taking my medication very difficult. I wasn't used to taking medication"</i>	Barrier
	Patients indicate that a daily routine is useful to remember taking their	<i>"I have fixed times for taking medication"</i>	Experience

	medication		
	Patients indicate that although it is not realistic, they would prefer not taking medication in the future	<i>'I know I will always have to take medication, but it would be very nice to be able to stop taking them.'</i>	Barrier

#### 4. Discussion

We believe that generative techniques can aid in determining the needs, barriers, perceptions and experiences of patients with respect to self-management services. Although this pilot study consisted of only three patients, we found a number of results that were similar to those of other studies. Although the comparison showed that we also missed some information, our study provided a considerable amount of information about the patients' needs, barriers, perceptions and experiences. Moreover, this was accomplished with a relatively small investment compared to the other studies, in each of which at least 12 patients were included.

Although this study was mainly meant to study the needs, barriers, perceptions and experiences for self management, the results with the key theme "experience of having an AMI" are notable results and can be a barrier for primary prevention.

The largest difference between this pilot study and the studies selected for comparison was the research method, which included a sensitizing phase and generative techniques. Normally, information regarding the context of the patients' daily life in which self management takes place is difficult to acquire as patients can't take this with them to an interview or focus group meeting. By preparing patients with a sensitizing package to the topic, patients are supported to formulate and consider important changes, routines or aspects in their daily lives after their AMI, PCI or CABG. The differences in the study method might explain the discrepancies in the results of the studies. Our participants indicated afterwards that the preparatory 'sensitizing packages' and the process of creating collages during the focus group meeting helped them to recall things that were important. This suggests that generative techniques indeed did help elicit tacit and latent knowledge.

Our study has several limitations. First, there is not always a clear distinction between what needs, barriers, perceptions or experiences are. Second, we may have missed relevant studies for the comparison, because of constraints in the literature selection procedure. Third, the method that has been used to compare the pilot study and the other studies has its limitations as well. Our pilot study was analyzed according to different key themes than the studies we compared with. Next to this, the results of our study was compared to results sections of published articles instead of study transcripts due to time restraints and availability, this might have resulted in missing results. Finally, a limitation of our pilot study was the drop-out of two participants, because of a lack of interest and language barriers. Due to the use of visual stimuli and a certain request on creativity this method may not appeal to everyone. Also, similar to other qualitative methods, participants are asked to put quite some time and effort into the study.

As this study provided encouraging results, our next step will be to perform a more extensive study with patients in various phases of CHD. As information needs of patients with CHD are dependent upon the time passed since diagnosis [6], we will compare the needs, barriers, perceptions and experiences of patients in various stages of CHD.

## 5. Conclusion

In summary, the results of this small pilot study suggest that generative techniques can aid in studying the needs, barriers, perceptions and experiences of patients. It is a promising addendum to the design toolset of researchers and developers in the field of self management services.

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