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

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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.

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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.