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Conceptual paper

Preferences and needs of patients with a rheumatic disease regarding the structure and content of online self-management support

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ABSTRACT

Objective: Aim of this study was to investigate preferences and needs regarding the structure and content of a person-centered online self-management support intervention for patients with a rheumatic disease.
Methods: A four step procedure, consisting of online focus group interviews, consensus meetings with patient representatives, card sorting task and hierarchical cluster analysis was used to identify the preferences and needs.
Results: Preferences concerning the structure involved 1) suitability to individual needs and questions, 2) fit to the life stage 3) creating the opportunity to share experiences, be in contact with others, 4) have an expert patient as trainer, 5) allow for doing the training at one's own pace and 6) offer a brief intervention. Hierarchical cluster analysis of 55 content needs comprised eleven clusters: 1) treatment knowledge, 2) societal procedures, 3) physical activity, 4) psychological distress, 5) self-efficacy, 6) provider, 7) fluctuations, 8) dealing with rheumatic disease, 9) communication, 10) intimate relationship, and 11) having children.
Conclusion: A comprehensive assessment of preferences and needs in patients with a rheumatic disease is expected to contribute to motivation, adherence to and outcome of self-management-support programs.
Practice implications: The overview of preferences and needs can be used to build an online-line self-management intervention.

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1. Introduction

Patients with a rheumatic disease face the challenge of managing their disease and its consequences for daily life. Self-management is the individual's ability to deal with symptoms, treatment, physical and psychosocial consequences, and life style changes inherent to a chronic condition [1]. Self-management interventions often combine information-based and cognitive-behavioral strategies [2]. In rheumatology, especially self-efficacy theory [3] has guided self-management programs intended to improve the skills necessary to deal with disease-related problems. With the growing opportunities and use of the internet, self-management programs are becoming available online as well [4,5].

There is, however, no consistent (long-term) evidence of the effectiveness of self-management programs for chronic patients in general [2,6]. This might be due to diversity of interventions in terms of format and contents, insufficient theoretical fundament, and heterogeneity of patient populations [2,6,7]. Moreover, positive mean group outcomes sometimes disguised the substantial proportion of patients who did not comply with or respond to the intervention [2,6].

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A basic assumption in initiating self-management interventions is that the patient will be more motivated, adhere better and benefit more and for a longer time when the intervention is customized to the individual needs and preferences of the patient [6,8,9]. For instance, while a young parent with a rheumatic disease may want to learn and practice skills needed to raise children, an older person may want help in dealing with frailty due to the disease and old age. A theory, consistent to this assumption, is self-determination theory [10] which emphasizes the importance of keeping goals of behavior change close to the autonomous motivation of people. Behavior change and long-term adherence to changed behavior are expected to be larger when a patient conceives a meaningful rationale for change, values the changed behavior, and aligns it with other central values and lifestyle patterns. Support for this assumption has been offered [11] and emphasizes the need for an individualized and engaged approach to patient guidance, taking their individual needs and circumstances as point of departure.

The contents of self-management interventions that mostly originated form self-efficacy theory comprised elements such as mastering experiences, role modelling, reinterpretation of symptoms, psychological consequences, and provision of information from a persuasive or credible source [1,12]. In the past decade, some studies examined individual and group needs of patients regarding self-management support. Patients with rheumatic diseases wanted health professionals to help them with self-management in general [13] and more specifically, they wanted health professionals to provide information and support to manage pain [14]. One study using a scoping review method concluded that patients with RA have informational, emotional, social and practical support needs [15]. Another study based upon a study of barriers to self-care proposed that four dimensions should be included in self-management interventions: medical management, communication with healthcare providers, coping with consequences, and lifestyle changes [16]. Other needs regarding self-management mentioned in literature were e.g., dealing with limitations [17], working together with health professionals, getting psychosocial support [18], empowerment, and dealing with emotional responses [13,18].

We wanted to extend these previous findings 1) by adopting a truly open approach with individual patients collaborating during the whole research cycle from defining research goals, to choosing the design and offering input, and analyzing and describing the results, 2) by examining specifically needs and preferences of patients with rheumatic diseases, 3) by including not only needs regarding content but also preferences regarding the structure, which was not done before, 4) by offering an overview of needs and preferences that are expressed in a concrete and specific rather than an abstract and global way, and 5) by choosing a method that inventories what kind of self-management support needs an individual patient may have instead of summarizing what a group needs. Therefore, the aim of the present study was to examine the individual needs concerning content and preferences regarding the structure of person-centered online self-management support training in adult patients with a rheumatic disease. To that aim we used a concept mapping technique [19] consisting of online focus groups, card sorting tasks, and hierarchical cluster analysis.

2. Methods

2.1. Design

A four step procedure was used. First, focus group interviews with adult patients with rheumatic diseases yielded needs and preferences. Second, a project group consisting of patient representatives and professionals from rheumatology, communication sciences, nursing sciences and psychology, analyzed the results of the interviews to differentiate preferences regarding structure and needs regarding content, and summarized the 'preferences for structure' during consensus meetings. Third, in a card sorting task, patients with a rheumatic disease grouped the selected content needs by similarity and importance. Fourth, hierarchical cluster analysis was used to classify the needs into clusters.

2.2. Patient selection

Adult (age $\geq$ 18 yrs) patients, diagnosed with a rheumatic disease and able to speak and read Dutch, were recruited for a focus group and card sorting task separately through announcements on the website of the Dutch Arthritis Foundation and Twitter (@reumauitgedaagd). This announcement asked for patients who wanted to help with the development of an online self-management intervention. Patients were asked to share their needs, preferences and thoughts on contents, structure and layout of the new to develop online intervention. Thus, a volunteer convenience sample was used. For focus groups a sample size of at least twelve participants has been suggested to provide a variety of perspectives [20]. A sample size between 10 and 20 people has been suggested to be a workable number for a card sorting task [19] and as few as 25–30 participants will likely yield results similar to those of several hundred, provided these participants are representative of actual users and are familiar with the domain being considered [21]. All participants received an information letter explaining the aim of the study and a brief self-report questionnaire for demographic characteristics, and all provided written informed consent. The study was conducted according to the principles of the Declaration of Helsinki [22]. The medical-ethical review board of the University Medical Center Utrecht decided that the Medical Research Involving Human Subjects Act did not apply to this study.

2.3. Variables, data collection and analyses

2.3.1. Step 1: Identifying content needs and preferences regarding the structure in a focus group

Participants were asked to join a closed, private focus group on Facebook during four weeks. The online focus group was facilitated by two moderators (LS, JA) who guided and stimulated the online, written discussion. They encouraged each participant to elaborate on his or her answer and to react to each other's comments by using question words like 'what', 'if' and 'how'. The discussion started with an open question. The leading question with respect to content needs was "If you want to work on improvement of your self-management skills, what themes should the self-management training consist of?" Examples of questions to identify preferences for structure were: "would you like to do the training on your own or in an online group?" and "what skills should a trainer have to guide you through the training?". To ensure that the discussion yielded as much as possible needs and preferences, the moderators, summarized regularly and checked if there was anything else the participants wanted to discuss about the subject of self-management.

2.3.2. Step 2: Analyzing the results of the focus group on preferences for structure and content needs

A generic qualitative approach [20] was used for data analysis, including coding, categorizing, and discussion by the project group members. First, the written transcripts of the focus group were copied and sent out to the group. After reading the transcript and assessing the whole scope of the interviews, each member individually coded fragments of the transcript on 'structure' and

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