



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 from 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 ≥ 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 (@reumaitgedaagd). 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

Table 1

Demographic characteristics of participants in the online focus group and the card sorting task group.

	Focus group (n = 35)	Card sorting task (n = 24)
Female sex, n	33	21
Age, mean (min-max) in years	42 (26–74)	48 (28–62)
Education, n ^a		
Low	1	2
Middle	15	7
High	19	15
Disease, n		
RA (Rheumatoid Arthritis)	13	10
SpA (Spondyloarthritis)	5	2
OA (Osteoarthritis)	3	–
FM (Fibromyalgia)	4	3
PsA (Psoriatic arthritis)	4	3
Sjögren's syndrome	–	2
Systemic Sclerosis	1	–
Palindromic rheumatism	1	1
Comorbid diagnoses ^b	4	3
Mean duration of the disease (min, max) in years	10 (0–48)	16 (1–48)
Under treatment by a rheumatologist, n	29	21
Once participated in a self-management training, n	6	7

^a Low = primary School or lower vocational secondary education, intermediate general secondary education; Middle = intermediate vocational education, higher general secondary education; High = higher vocational education or university education.

^b PsA in combination with FM and OA, FM in combination with Tietze's syndrome and hypermobility syndrome, SpA in combination with OA and RA.

'content'. The fragments on structure were categorized and discussed in the project group until consensus was reached.

Regarding the fragments on content, corresponding needs were put together, and ambiguous and abstract needs and needs that did not relate to online self-management support were removed. The remaining needs were evaluated by the project group on their suitability and comprehensibility for the card-sort task until consensus was reached.

2.3.3. Step 3: Grouping the needs by similarity and importance in a card sorting task

The selected needs on content (step 2) were numbered randomly and written on separate cards for use in the card sorting task. Each content need fitted the format "I have a need for . . .". The card sorting task was performed at Utrecht University or, when the patient could not attend this session, at home. Each participant performed, individually, two types of sorting tasks on a table and wrote down the results on a score form. In the first task, participants individually sorted the needs into piles according to similarity of contents. To prevent that too few or too many piles were formed, the following rules applied: all needs had to be placed in a pile; each need could be placed in one pile only; each pile could contain 2–25 needs; and 4–20 piles could be formed. The participants gave the piles a label that could be used by the researchers to interpret the sorting. In a second task, the participants individually sorted the needs based on importance. For this task, the following rules applied: all needs had to be placed in a pile; each need could be placed in one pile only; exactly five piles had to be formed from the least important needs (Pile 1) to most important needs (Pile 5); and needs had to be distributed equally across the five piles.

2.3.4. Step 4: Classifying the needs content into clusters by Hierarchical Cluster Analysis

Hierarchical cluster analysis in SPSS statistical software version 21.0 (SPSS, Chicago, IL) [23] was used to classify needs that were individually sorted by the participants during the card sorting task according to similarity of meaning in a hierarchy of clusters. In cluster analysis, the cells of the input matrix of needs comprised

the number of times that two needs were *not* sorted in the same pile. Squared Euclidean distances were computed between each pair of needs and Ward's method was used to derive the hierarchical structure of needs. The main criterion to decide on the number of clusters was that the clusters should reflect distinct components of needs. The final number of clusters was set by all the members of the project group, guided by the dendrogram and the agglomeration schedule produced by the statistical software program showing which statements were being combined at each stage of the hierarchical clustering process.

In the first stage we used a top-down interpretation starting with two clusters, then three and so on until additional clusters did not yield new content. In the second stage, the contents of both a lower and a higher number of clusters were compared to finally decide on the number of clusters, based on consensus of the project group.

The scores of the second sorting task were used to calculate for separate needs and clusters a mean importance score and standard deviation.

3. Results

3.1. Participants

Two men and 33 women participated in the online focus group, and 21 women (of which 3 had also participated in the online focus group) and 3 men participated in the card sorting task (Table 1). Fourteen participants performed the card sorting at Utrecht University and 10 participants at home.

3.2. Results focus group (step 1 and 2)

The research team derived 146 topics from the focus group (preferences for structure and content needs).

3.2.1. Preferences for structure

The 43 topics relating to the preferred structure of the program were categorized into six components. These components and some examples of quotes are outlined in Box 1.

Box 1. Components of the online training: preferences (in bold) and example quotes regarding the structure.

Suited to individual needs

“... I think it is important to choose something that suits your life and your needs ... that varies per person, per phase. One person might only want to learn more about having arthritis while others want to share their life experiences ... (woman, 26 years old)

‘...I want to work on issues that matter most in my life at the moment ... children, pregnancy, being a mother in combination with having a rheumatic disease ...’ (woman, 30 years old)

“... I know I made the right decision (not having children) ... but I am still sad about it ... but we are now living our own life, my husband and me ... slowly ... but we are not receiving any help ... how can I ask for help? ... (woman, 38 years old)

Suited to life stage

“...I think my problems differ from older people. I was just looking for people who work, for people with young children and how they manage their lives while having a rheumatic disease. I also wonder how I could combine work and home ... (woman, 37 years old)

“...Some themes are not always, at all times, relevant. Especially for the ‘younger’ generation ... also, it depends on the stage where you are with regard to your illness ... (man, 52 years old)

Share experiences and have contact with other people who have a rheumatic disease

... “I would very much like to hear experiences of others ... Maybe I still have something to learn, to adapt better to the situation ... (woman, 43 years old)

“...Being ill asks for adjustment ... having a chronic disease asks for change. Healthcare providers give information and advice. To apply this advice to your own life is something different ... by working together (with other patients) and sharing successes, I experience that you can make that change ... It can be refreshing ... (woman, 47 years old)

Expert patient as trainer

“...I think having a rheumatic disease is not a special quality, being empathic is ... (woman, 42 years old)

“...An expert patient who dares to share his experiences ... is more a facilitator than a leader. He or she does not pretend that he knows everything ... he helps you to work towards your own goals (woman, 47 years old)

Own pace

“...I want to work at my own pace ... behavioral change asks for time and practice ... ” (woman, 42 year old)

Limited in time

“...Well, I think it’s important to set a time limit (to actually end the training) ... to keep me motivated ... ” (man, 60 years old)

3.2.2. Needs regarding contents

The 103 topics that were identified as needs for the online program were reduced during the consensus meetings to 55. These final needs are shown in the first column of [Table 2](#).

3.3. Results card sorting task (step 3)

Participants individually sorted the 55 cards with needs regarding content into piles. The mean number of piles was 8 (range 4–12). The number of cards per pile varied from 1 to 22. Individual participants used 56 labels to describe the piles. Frequently chosen labels were: *knowledge about the disease, treatment, medication, psychological problems, sharing experiences, emotions, work, relationships, pregnancy and children, keeping control, self-control, physical consequences, leisure time, sports, exercise and standing up for yourself*. These multiple labels were used by the team to interpret the hierarchical cluster analysis and to choose the final labels of the clusters.

3.4. Results hierarchical cluster analysis (step 4)

Based on the dendrogram that was produced by the hierarchical cluster analysis, the number of clusters was set to eleven. A schematic drawing of the dendrogram is shown in [Fig. 1](#). [Table 2](#) shows which needs are included in the eleven clusters on the right of [Fig. 1](#). Increasing the number of clusters from eleven to twelve or thirteen divided the clusters ‘psychological distress’ and ‘having children’ into new clusters referring to professional help versus learning from peers. As these deviations referred to the process instead of content, we decided to limit the clusters to eleven. Decreasing the eleven clusters to ten combined the clusters ‘dealing with rheumatism’ and ‘communication’, which were clearly distinct needs. Thus, the final number of clusters was set to eleven.

[Fig. 1](#) shows that in the hierarchical structure of clusters, at the highest level, ‘self-management needs’ were divided into the categories ‘self’ and ‘system’. ‘Self’ included both ‘knowledge’ about the treatment and ‘competencies’ to self-manage the consequences of the disease. ‘System’ divided into the broader ‘social network’ and ‘home’ including needs relating to the immediate (family) environment.

3.4.1. Importance of the clusters

The importance attached to needs is shown in the right column of [Table 2](#). The mean importance rating per cluster varied from 1.9 (sd 1.6) for the cluster ‘having children’ to 4.1 (sd 0.5) for the cluster ‘self-efficacy’ ([Table 2](#)).

4. Discussion and conclusion

4.1. Discussion

This study yielded an extensive overview of the individual preferences regarding the structure and the needs regarding content of an online self-management program to support patients with a rheumatic disease: six preferences and eleven needs were identified.

Concerning the *structure* of the training, patients emphasized that account should be taken of individual needs and the stages of their disease and life, and that they should be able to follow the program at their own pace and within a limited time period. This is in line with previous studies in which people with arthritis expressed the need for taking individual experiences and an individualized approach as points of departure [6,9,14,15,17] as well as with the ongoing emphasis on customizing training and exercises to the individual [2,7]. As a positive example of customized treatment, participants reported ‘how arthritis affected their lives’ after which the knowledge was used to direct the

Table 2

The eleven clusters of needs regarding content for an online self-management program with the mean (standard deviation) importance rating of each cluster and statement. All statements started with “I have a need for . . .”.

Cluster Treatment knowledge	2.8 (0.9)
16. Knowledge about pain and fatigue caused by the rheumatic disease	3.8 (1.3)
20. Understanding why you have to take the prescribed medication	3.3 (1.4)
41. Understanding how the arthritis medication works	2.9 (1.5)
43. Knowing how best to maintain adherence to the medication	3.0 (1.5)
31. Knowledge of all possible treatments for arthritis	3.0 (1.5)
28. Information about the use of alternative medicine (for example homeopathy and acupuncture) in arthritis	2.2 (1.2)
44. More information in order to judge whether an alternative method is safe and appropriate.	2.0 (1.0)
42. Information about how to get extra help and treatment (for example home care, physiotherapy, psychologist)	2.7 (1.3)
Cluster Societal procedures	3.0 (0.6)
52. Knowledge of the laws and regulations that pertain to having a rheumatic disease	2.7 (1.5)
10. Learning how to deal with lack of understanding on the part of social service organizations	3.0 (1.5)
49. Information on accommodations that would make work easier	3.3 (1.2)
50. Information on how to function at work with a rheumatic disease	3.2 (1.2)
37. Hearing how others manage work and chores	3.2 (1.4)
35. Learning how to tell others about your disease at work or school	2.9 (1.2)
27. Finding out how to acquire enough income despite the limitations of arthritis	2.6 (1.4)
Cluster Physical activity	3.1 (0.9)
5. Discovering which physical activities or sports are suitable for me	3.5 (1.2)
39. Discovering how much physical activity is healthy with arthritis	3.2 (1.3)
23. Discovering how to keep up physical activities or sports	3.1 (1.1)
36. Information about sports that are possible for people with a rheumatic disease	2.8 (1.3)
Cluster Psychological distress	3 (0.7)
33. Learning how to deal with anger, embitterment, irritation and frustration	3.6 (0.9)
54. Learning how to deal with helplessness and sadness	3.5 (1.3)
38. Professional help with psychological or emotional problems caused by the rheumatic disease	2.9 (1.5)
34. Testing to evaluate how serious my psychological problems are	2.2 (1.5)
9. Hearing how others deal with (negative) emotions	2.9 (1.5)
Cluster Self-efficacy	4.1 (0.5)
7. Discovering how to remain in control of my life	4.8 (0.5)
30. Discovering how to set boundaries	4.4 (1.1)
18. Learning to set attainable goals	4.2 (1.1)
53. Learning to give direction to your life with arthritis	4.1 (1.3)
19. Learning to say “no” without feeling guilty	4.0 (1.1)
47. Learning how to ask friends, acquaintances and neighbors for help	2.9 (1.0)
Cluster Provider	3.0 (1.2)
51. Learning how to best talk to your medical professional	3.2 (1.4)
40. Learning how to express dissatisfaction with the treatment	2.9 (1.3)
Cluster Fluctuations	3.5 (1.0)
46. Learning how to control your arthritis or symptoms yourself	3.7 (1.3)
48. Learning how to fit the treatment into daily life	3.3 (1.4)
13. Learning what to do if the arthritis or the symptoms change	3.3 (1.3)
Cluster Dealing with a rheumatic disease	3.5 (0.8)
25. Hearing how others keep up their energy all day	3.6 (1.0)
55. Hearing from others how they function with arthritis in daily life	3.6 (1.2)
29. Hearing how others deal with pain and fatigue	3.6 (1.2)
26. Hearing from others how they deal with arthritis in daily life	3.4 (1.3)
24. Hearing from others how they have learned to accept the consequences of a rheumatic disease	3.3 (1.3)
Cluster Communication	3.0 (0.9)
2. Learning how to explain to others what it means to have arthritis	3.3 (1.4)
3. Learning how to deal with a lack of understanding on the part of friends, relatives and neighbors.	3.5 (1.2)
4. Learning from others how to maintain a social life while taking account of your arthritis	2.9 (1.3)
17. Hearing from others how they explain what rheumatic disease is	2.4 (1.2)
Cluster Intimate relationships	2.4 (0.7)
22. Information about the influence of arthritis on sexuality and intimacy	2.3 (1.1)
32. Information on having sexual relations without pain or discomfort	2.1 (1.1)
11. Getting tips from others on how they deal with sexuality, intimacy and arthritis	2.6 (1.4)
45. Discussing with other patients the influence of arthritis on the partner relationship	3.1 (1.2)
14. Hearing from others what they do with their leisure time and holidays, taking account of their arthritis	2.0 (1.1)
Cluster Having children	1.9 (1.6)
1. Expert advice about heredity and rheumatic diseases (for example when hoping to become pregnant)	1.9 (1.3)
15. Information about medication before, during and after a pregnancy	1.8 (1.1)
8. Discussing with others how best to talk to your children about your rheumatic disease	2.1 (1.2)
12. Finding out how to get help with child care	2.0 (1.0)
21. Hearing from others how they involve their partner in child care	2.0 (1.1)
6. Hearing from fellow patients how they decided whether or not to have children	1.8 (1.4)

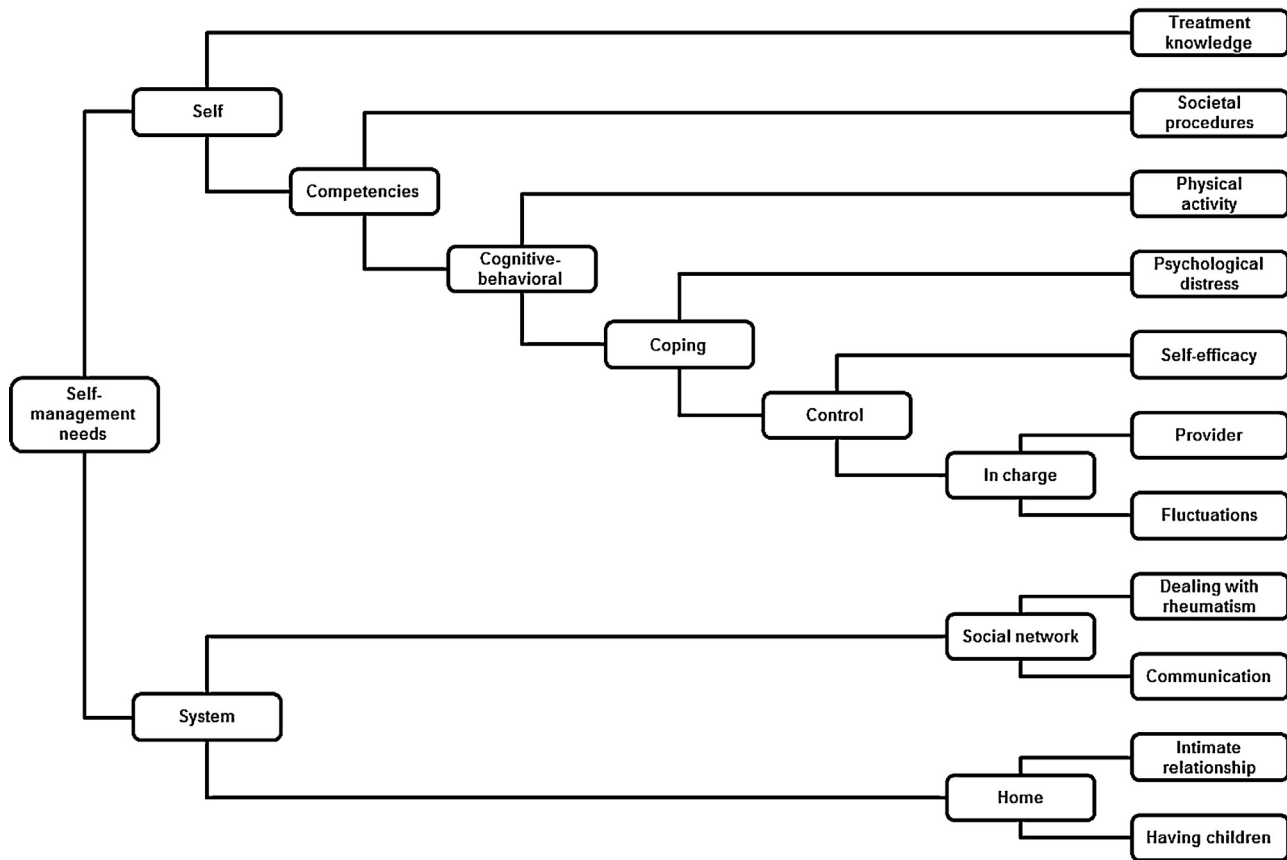


Fig. 1. Schematic drawing of the dendrogram showing the hierarchical structure with needs regarding the content of an online self-management support program.

participants to different parts of a 'Toolkit' of self-management interventions [24]. However, although many self-management programs emphasize individual goals of the participant at the start of the program [1,2,25] the structure and content are mostly predetermined, protocolled, and based on group preferences [2,25,26]. Our study emphasized the importance of customizing both structure and content of the program to personal preferences and needs.

The participants in our study also expressed a preference for being guided through the program by a trained patient instead of a professional tutor such as a nurse, psychologist, or social worker, in agreement with the Arthritis Self-Management Program [26] and Dutch Self-management Program for young adults with a rheumatic disease [27]. Programs with a patient "expert" as trainer were observed to be effective [2,26,28]. This suggests that this wish of patients can be granted, although –to be certain that both are equally efficacious – programs with an expert-patient trainer and a professional trainer should be compared.

Although during recent decades the treatment of rheumatic diseases has improved considerably and psychological distress and physical disability have decreased [18], patients still express the need to have knowledge about their disease, physical activity, managing emotions, and self-regulating their own life, family, work and leisure time. Moreover, having a rheumatic disease affects the patient's family, friends, and coworkers [15,18,29,30]. Our respondents expressed the need to include relational needs in the self-management support program by working on concrete issues such as asking for help or support from a husband or coworkers, communicating with experts, and dealing with pregnancy or intimacy.

Needs within clusters differentiated between getting help from professionals versus peers, in agreement with previous studies [14,26]. Also in a study on self-management support from the perspective of patients with a chronic condition [31], the need for support of different sources (professionals and peers), each with its unique contribution, is recognized. This combination of support from professionals and peers reflects that besides increase of competencies (with help from professionals and peers), social relatedness (with peers) is also an important aspect of behavioral change as is emphasized by self-determination theory [10].

Considering *importance* of the content-needs, the clusters 'self-efficacy', (being in charge of) 'fluctuations' and 'dealing with rheumatic disease' (in the social network) are rated high on average, but the mean importance ratings of most clusters is rather similar which indicates that individuals rate the importance of needs differently. A cluster of needs that is rated less important on average by our sample, can for an individual patient be of primary importance. A strength of the overview of needs in our study is that its comprehensiveness makes it suitable to also quickly screen for needs that are considered important by only some individual patients.

Strengths of this study are that experiences and perspectives of patient were used as input materials and that the project team consisted of patient representatives and professionals that took decisions based on consensus and collaborated during all phases of the study. Moreover, the method that was used allowed a description beyond the subjective interpretation of the researchers, because the patients categorized the needs in meaningful constructs. A limitation of the current study could be that input was especially provided by patients who were interested in

contributing to the development of an online self-management intervention. Having a volunteer group, can have resulted in information bias. Moreover, only a few men participated. However, this selection bias that is inherent to a convenience sample might also give a good reflection of the actual participants. In an intervention that was built using the insights of the current study also volunteers are invited to participate [32]. Another limitation is that the wording of the needs may have influenced the sorting by patients. Words in the phrasing of needs such as 'knowledge', 'hearing' or 'learning' were sometimes sorted in the same cluster by patients. However, while some patients used these kinds of process variables to sort needs, others used the contents of needs. With respect to sample size, although 10–20 people are suggested to be a suitable number for card sorting [19], we noticed that the structure of the hierarchical cluster solution slightly changed by reanalyzing the data while excluding few participants; this was especially true for the higher order structure. Therefore, we focused our results and discussion mainly on the eleven lowest order clusters. Finally, the participation of three participants in both the interviews and the card-sorting is not considered a great problem because these two parts of the study appealed to distinct areas of knowledge of participants.

4.2. 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, which is an area of future research.

4.3. Practice implications

The current overview of preferences and needs can be used to build a self-management support program, to help in identifying needs at the beginning of the program, and to customize the program to the individual patient.

Disclosure

All authors have approved the final article. "I confirm all patient/personal identifiers have been removed or disguised so the patient/person described is not identifiable and cannot be identified through the details of the story."

Contributors

JA, HvO, NdB, BM and RG designed the study. JA and LS collected the data. JA, HvO, NdB, BM, LS and RG analysed the data under supervision of RG and all authors contributed to interpreting the analysis. JA, HvO and RG produced the initial draft and all authors contributed to subsequent drafts and approved the final version.

Conflicts of interest

None.

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