Experiences and Preferences of Patients Regarding a Rheumatology Interactive Health Communication Application: A qualitative Study

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Abstract – **Interactive Health Communication Applications (IHCAs) can make a valuable contribution to rheumatological care. The development of online health applications is moving quickly, and positive results have been shown. Yet solid research on use and acceptance of different information, communication and participation tools by patients is still lacking. In this qualitative study, we examined the health-related internet use of patients with rheumatic diseases, their motives for using or not using certain applications, and their needs and preferences with regard to a rheumatology IHCA. We conducted semi-structured individual interviews with eighteen patients, who were selected from a hospital's patient panel. Participants were diagnosed with eight different forms of rheumatism and their mean age was 50.7 years. The interviews were analyzed by two independent researchers. Results show that the applications most preferred by participants were: information provision on both medical and support topics, online communication with their doctor and insight in their personal health records. Patient support groups were less valued, as were participation tools such as symptom monitoring and online exercise programs. Patients reported clear preferences and pre-conditions that should be fulfilled in order for them to use the applications. A large discrepancy was found between patients' current use and their future preferences with respect to information about care and support, online access to medical health records and having online contact with their doctor. In conclusion, patients see great value in an IHCA provided by their own hospital, since it could increase reliability of the provided information, and would give them the confidence to use the application. Overall a rheumatology IHCA should contain communication and participation tools, both linked to the hospital, and information about disease, care and practical support. The reported motives and preconditions of the respondents outline key issues which should guide the development of an online application.**

Keywords – IHCA, rheumatism, patients, preferences.

I. INTRODUCTION

The internet is making an increasing impact on today's health care and the expectations about the effects of internet applications in health care are high. First, internet applications could support the growing need for health care resulting from both our aging population and the increasing number of people who suffer from one or more chronic diseases. Second, internet applications offer the opportunity to extend the patients' role in delivering health care [2][3]. Accordingly, such applications could support the transformation of the patient from passive receiver of care into an active participant in the management of one's illness, which is considered highly desirable in chronic health care [4][5][6].

Presently, patients with various chronic diseases can go online to find information, self-tests, and self-help tools or to get in contact with peer patients. In addition, health care organizations and health care providers are increasingly developing their own web applications for their patients. These applications sometimes provide – besides the above mentioned tools – opportunities for online contact with health professionals and/or access to patients' personal health records. Overall, three main categories of online health care applications can be distinguished: (1) information, (2) communication and (3) participation. Information applications mostly hold the provision of disease information and care information. Communication applications concern facilities for communication with peers or with health professionals. Participation – a broad area – concerns applications aimed at symptom monitoring, self-management and access to medical health records.

A. Interactive Health Communication Applications

Interactive Health Communication Applications (IHCAs) are operational software programs which combine the provision of health information with at least one of the above-mentioned communication or participation applications. Patients with chronic diseases, such as rheumatism, can benefit particularly from IHCAs, since such patients are often considered to be on an 'illness journey': as patients progress through their journey, they might have different needs with respect to information, self-management and support needs [7][8][9]. An IHCA has the potential to meet these multiple needs because it provides a wide range of information, communication and participation tools. It is accessible independent of time and place, and its content can be patient tailored – which also supports the patients' personal illness journey [3][10]. Moreover, the information

can be presented in accessible formats, such as video and audio clips, and graphics. Above all, two recent systematic reviews suggest that chronic health care IHCAs are effective in improving knowledge, perceived social support, and health behavior for various kinds of chronic diseases, as asthma, diabetes and heart failure [11][12].

B. Lack of supply and acceptance

Despite these benefits, online applications for rheumatic patients remain scarce. Murray's systematic review included 24 randomized controlled trials on IHCAs, but no rheumatology application [11]. Another systematic review of online self-management systems by Solomon also did not include a rheumatology application in any of the 28 articles reviewed [13]. Our own literature search revealed only one study about a website for patients with rheumatic diseases that combined information, patient-provider communication and health assessment tools [14]. Other existing online rheumatism applications are single applications focusing mainly on participation, such as symptom monitoring, exercise support, or overall self-management [15][16][17].

Whereas IHCAs thus seem to be effective, it is still unclear which combination of tools contributes to these successes [18]. Moreover, not all applications on an IHCA are equally well used [19]. It seems that simply developing and implementing online applications does not suffice. Roughly, the often experienced lack of acceptation seems to be related to the patient on the one side, and to the technology on the other side [20][21]. Usability problems often occur; applications are not being developed patient-centered and are not being tested by users before implementation. Furthermore, it is often reported in studies that patients experience an overload of websites containing information and support possibilities. Yet internet applications are often not initiated from the demand side of the patient, so they do not meet patients' needs. In sum, often it is not known whether the services offered on the internet are services that patients actually desire. Furthermore, acceptance problems are often explainable by patients' existing (negative) attitudes towards innovations [22]. Many people experience doubts on reliability when it comes to health related technology, for the large amount of supply causes confusion on what sources are trustworthy. Furthermore, privacy issues are of large concern to patients when it comes to private health information that is communicated via The Web. Overall, it is important to carefully match the applications on an IHCA to the needs of the patients, so that the offer is patient-centered and actually valuable for them [1].

C. Interview study

In summary, while studies on the needs of patients regarding online applications have been conducted for other chronic diseases [8], within rheumatism there remains a gap in this kind of knowledge. The aim of this study was to perform a needs assessment among patients with rheumatic diseases regarding an IHCA. Our study focused on four questions: (1) Which (information, communication and participation) support applications do rheumatism patients already use on the internet? (2) What are their attitudes about available online support applications? (3) What are their preferences and demands for a rheumatology IHCA? And most importantly, (4) What are their reasons for preferring or not preferring certain applications? This paper will give an expansion on earlier presented work [1] and describes an overview of the methods used in our study, the results that were found in the three main categories of applications and a discussion on each category, including study limitations and a conclusion.

II. METHODS

A descriptive qualitative design was used, since this study was explorative. We preferred the use of individual semi-structured interviews to get the best understanding of patients' experiences, needs, motives and preferences for a selection of widely used internet applications.

A. Selection of participants

Participants were selected from an existing patient panel, which was initiated in cooperation between the University of Twente and Twente's largest clinical hospital. Patients registered on this panel are willing to volunteer in rheumatology research. The criteria for patient participation for the present study were: willing to participate in interviews, contactable by e-mail and not older than 60 years. The interviews took place at the university or at people's homes, at each participant's choice. In total, 18 interviews were conducted, after which data saturation was reached; meaning that no more new information of value was obtained [23, 24].

B. Interview structure

Each interview started off broadly, by asking participants about their internet use. Both general internet use and health and rheumatism related internet use was asked about. Subsequently, participants were asked to reflect freely about their ideas and preferences for a rheumatology IHCA. The interview continued by discussing 7 types of widely-used applications within the three main categories of online health support: information, communication and participation. For each type, a prototype card was made which showed representative examples of existing internet applications and websites. The participants were asked about their current use, their needs and their attitudes regarding these applications. Also important were their motives for use or nonuse and their preferences for the applications. The 7 illustrated cards showed: (1) information about disease and treatment; (2) information about care and support; (3) peer support groups; (4) e-consultations via e-mail or online chat; (5) symptom monitoring (scoring of variables such as pain, swollen joints, mood and activity through which is visualized in graphs); (6) exercise programs; and (7) access to medical health records (the ability to give patients access to their own medical files, with information about their diagnosis,

treatment plan and latest lab results). The interviews took one to two hours, depending on the patient. The interviews were audiotaped, provided patients had given permission beforehand.

C. Data-analysis

The audiotapes of the interviews were transcribed verbatim. Current use and needs were extracted, and citations about attitudes and motives for use, nonuse and preferences or pre-conditions were selected and coded into categories by two independent researchers (RvdV, CHCD). The final categories were defined by consensus between the two researchers. Next, the first researcher examined the raw data again to ensure the robustness of the analytical process and to confirm that all the data were indeed reflected in the coding [24]. During this process, only the participant numbers were used to protect the anonymity of the participants.

III. RESULTS

This section gives an overview of participants' current (health related) internet use and their attitudes towards future use of applications on a rheumatology IHCA.

A. Characteristics and internet use

Eighteen participants were interviewed: five male and thirteen female, with a mean age of 50.7 years (SD = 9.27). Participants interviewed had been diagnosed with eight different forms of rheumatic diseases: more than half of the participants were diagnosed with rheumatoid arthritis (n = 10), two with osteoarthritis. The remaining participants were all diagnosed with a less common rheumatic disease. All participants owned a computer and had home access to the internet. They used the internet on a regular basis, generally for several hours a day. The internet was mainly used for e-mail, obtaining information, purchasing goods and banking. All the participants reported that they had used the internet for health-related purposes, usually to search for information.

B. Utilization of and attitudes toward health related internet applications

Overall participants saw great value in an IHCA provided by their own hospital. They reported it would lower barriers such as unreliability of information, and would give them the confidence to use the IHCA. When asked an open-ended question about which applications participants would like to find and use on a rheumatology IHCA, participants mentioned various topics. Most frequently mentioned were: information on the latest developments in treatment and medication, insight into hospital procedures, and tips to cope with troubles in daily life (e.g., at work, when shopping or doing household chores). All these topics were covered in the themes that were discussed using the prototype cards. Table 1 shows an outline of participants' current use and needs, and their motives for use or nonuse on the 7 themes. Table 2 shows an outline of the preferences that patients reported for each support tool. Both of these tables are being extensively clarified in this section, using participants' quotes.

The applications most preferred by participants were information provision on both medical and support topics, online communication with the doctor and insight in their medical health record. Patient support groups were less preferred, as were participation tools such as symptom monitoring and online exercise programs. What stands out is the discrepancy between current use and future preferences on information about care and support, online communication with the doctor and access to medical health records.

TABLE I.   CURRENT USE, NEEDS AND MOTIVES OF PARTICIPANTS TOWARDS ONLINE APPLICATIONS (N = 18)

Application	Use[a]	Needs[a]	Motives pro	Motives con
Information about disease and treatment	high	high	- easy and fast - can read what one wants - can read it when one wants	- information overflow - can be unreliable - confrontational/can cause worry - already has all the necessary information - gets information otherwise
Information about care and support	moderate	high	- structured and complete - overview - helpful in decision-making - good reference tool	- no additional care necessary - current health professionals recommend or refer to supplementary care
Patient support groups	moderate	moderate	- recognition - support in coping - giving and receiving advice - anonymous	- unreliable information/advice - complaining people - confronting - impersonal - not wanting to spend much time on the

				disease
Ask your doctor	low	high	- accessible and easy - reliable - enables time to write down questions and (re)read answers - could save visit to doctor	- non synchronous communication - waiting time for a response
Symptom monitoring	low	moderate	- better disease insight for one self and the doctor - new and fun to try - shows patterns over time	- confronting - time consuming - gets one too focused on pain and signs
Exercise programs	moderate	moderate	- help maintain self-respect - comfortable to exercise and get support at home	- no self-discipline - already exercises by themselves/at a therapist - doubtful accuracy and safety
Access to medical health record	low	high	- more involvement in treatment - overview of appointments - overview of previous and current (lab)results	- too difficult to understand

a. Low: < 6 participants reacted positively; Moderate: 6 - 12 participants reacted positively; High: > 12 participants reacted positively

TABLE II.   PREFERENCES AND PRE-CONDITIONS OF PARTICIPANTS FOR ONLINE APPLICATIONS (N = 18)

Applications	Preferences and Pre-conditions
Information about disease and treatment	Information on three topics: - disease (diagnosis, symptoms, heredity) - treatment (medication, therapies, protocols) - coping (psychological, social, tips and tricks)
Information about care and support	Information on two topics: - medical care (job description, specializations, hospital procedures) - practical support (tools, insurances, facilities for e.g. work, housekeeping)
Patient support groups	- positive topics; tips & tricks - divers target groups - good control and protection on posts and privacy
Ask your doctor	- valuable extension to current care but no replacement - contact with own health professional - use for minor/non-urgent questions - quick handling of e-mails
Symptom monitoring	- tele-monitoring by doctor - use in consult and treatment - overview in graphs
Exercise programs	- solution to self-discipline barrier - safe exercises - online coach
Access to medical health record	- clear information and instructions - good protection

1) Information about disease and treatment

Every participant reported having searched for information on rheumatism on the internet. Most of the topics patients had searched for were related to medication, such as user instructions, side-effects and the development of new medications. Participants also went online when they felt pain, when they had doubts about their symptoms or when they had noticed new symptoms. Furthermore, the internet was used to gather information after participants had been given their diagnosis and when they heard or read something interesting. A final reason to search the internet was when a person had forgotten to ask the doctor something. The greatest reported benefits of online information were that it is easy, fast and one can decide for oneself what to read and when to read it. Whereas most participants had used the internet to obtain information, some participants did not have (or did no longer have) the urge to use the internet for health information because they believed it was too confrontational or led to unnecessary worry about their disease.

"It's fine by me, I can think of so many other things to search for and giving myself a hard time about. I live my life now and I don't want to think about it daily [Female, 40 years, RA]."

Also, many participants already felt that they knew everything they wanted to know. Some participants reported that they felt there is an overflow of information on the internet, which can make it hard to find relevant information, judge the reliability of information and interpret the information correctly. Other participants reported obtaining their information in alternative ways, such as through their doctor or from patient organization magazines. Information provision via a rheumatology IHCA from their own hospital provoked enthusiasm, since it could overcome the problem of information unreliability.

The information participants preferred the most could be classified into three categories. The first category is disease information, which contains topics such as the symptoms of the disease, the diagnosis, heredity and related symptoms, such as fatigue. Some patients mentioned that they want to be kept up to date on rheumatology research, to know about the latest results and developments.

"That is just keeping up with the newest developments within the field, as a patient. [Male, 55 years, Arthritis Psoriatica]."

Second, information about treatment was preferred, such as medication, therapies and protocols. The final category concerns information about how to cope with rheumatism, which involves topics such as dealing with the psychological and social consequences relating to family, friends and work, how to keep exercising, and tips and tricks to overcome the difficulties in daily life that rheumatism can cause.

2) Information about care and support

Participants were asked to what extend they used or were interested in a 'care guide': an overview of all the rheumatism care and support available in the region. Half of the participants reported knowing of, and using existing care guides. Participants thought that these tools gave structured and complete overviews of health care and support services, and that they were helpful in making informed choices concerning health professionals. The most important reason participants mentioned not to use a care guide was that they did not need any additional care, and if necessary current health professionals usually made recommendations. However, a care guide from a rheumatology IHCA from their own hospital would be appreciated by most participants; it was seen as a potentially good reference tool in healthcare and support.

"I used one (care guide, ed.) to find a physiotherapist in [small town] who was specialized in rheumatic diseases. Through this website I got the therapist I have now [Female, 53 years, RA]."

An effective care guide includes two kinds of information, according to the participants. The first type is aimed at medical care; the second type at support services and local resources. Regarding the medical care information, participants expect job descriptions and specializations of all health care facilities, including psychological and familial help. Each facility should show a complete overview of all its health care professionals. Also, information about accessibility, waiting periods, and hyperlinks to the web pages of each health professional is valued. A few participants would additionally like to read about experiences and opinions of other patients about particular professionals. Regarding the hospital participants wanted information about procedures, reciprocal expectations between the hospital and the patients, any changes in the rheumatism department and announcements of activities and meetings involving rheumatism. The preferred information on support services and local resources varied from household services to work reintegration authorities and health resorts for vacations. Participants also expressed a need for clear information about the options and financial help for home adjustments, support tools, health insurances and tips for disabled-friendly shopping, dining and entertainment in the region.

"It is not just the medical part that counts, but also the coping in daily life. Where can you find information? Which regulations are important for you? How are things covered financially? [Female, 57 years, Forestier's Disease]."

3) Communication with peers

One-third of the participants reported using online peer support groups or looking at support message boards occasionally. Participants identified advantages in online support groups since they can supply recognition, advice and support in coping with the disease. Furthermore, such groups

are anonymous, which reduces the reluctance to discuss personal topics.

"Larger issues you discuss with your doctor, but for me it is very nice to read about the little things and think 'oh, all those other people experience that too' [Female, 57 years, RA]."

Reasons for not using online support groups were that the information can be unreliable and some participants felt that people who are active in online support groups tend to complain a great deal or will only talk about their own problems. Also, some messages about the scope of the disease could be confrontational. Furthermore, some participants reported that they did not fit into the target group represented by the online support group.

"I searched a lot in the beginning, when I was just diagnosed with rheumatism, and then I stumbled upon a rheumatism peer support forum. That's when I thought that if this is where I'll end up, then I'm never looking again. I was really shocked by it [Female, 40 years, RA]."

"I know these (peer support groups, ed.), but they didn't appeal to me because there were mainly younger people posting on them, struggling with kids, getting married and jobs, but I already had all of that covered, so that wasn't an issue for me anymore [Female, 43 years, Ankylosing Spondylitis]."

Some participants added that they perceived online communication as impersonal, that they didn't want to hear strangers' stories or advice, and that they didn't want to spend too much time reflecting on their disease; because they did not want to feel like being a patient all the time. However, because of the large amount and large diversity of pros and cons for peer support groups, most people found it difficult to give a clear opinion or preference about the desirability of such an application within a rheumatology IHCA.

"Personally, I don't want to be occupied with my disease too much. But on the other hand, I don't want to miss valuable advice [Female, 57 years, Forestier's Disease]."

Participants reported that there should be clear value for them in the online support groups: messages should be positive, and the exchange of tips and tricks should be the main function of the group. Other important pre-conditions were that there should be accurate control of posts as well as on privacy, and participants thought it was important to have a variety of topics and target groups on a forum.

To the question if a peer support group should be national or regional opinions split two ways. Half of the patients thought such a forum should be national, because they felt it could provide more information about how treatment and coping differs around the country. One participant even mentioned a world wide forum to learn more about current research and treatment development globally. Furthermore, patients saw more value in a national forum to be able to speak to new people; instead of to people they can also visit face-to-face.

"Yes, than I would use it more. See, I already have my contacts with rheumatic patients in the neighborhood [Male, 59 years, RA]."

Regional cultural differences were also mentioned; people in the region of Twente are known to be more introvert and down to earth than patients in southern or western regions of the Netherlands. A national forum could enrich the information flow, because more (different types of) patients can contribute. However, the other half of the patients reported to be more in favor of a regional forum. This might provide more recognition between patients from the same hospital, with the same doctors. Also, it would keep things small and orderly when not too many patients have access to the forum and can post messages. Furthermore, it would be easier to meet each other in person when desired. Strikingly, the regional characteristics were mentioned in this context as well; patients mentioned it would be nicer to talk to other patients who think and communicate alike.

4) Communication with the health professional

The majority of participants had never used e-mail to contact a doctor, either online available doctors or their own doctors. Almost all participants would never consider consulting an online doctor which they did not know, for it might be unreliable and it would feel as a betrayal to their own rheumatologist. However, there was a significant discrepancy between actual and preferred use of online contact with their own care provider in the hospital. Nearly all participants felt that this facility would be a valuable addition to the current care, since it is accessible, reliable and easy. Moreover, participants mentioned that e-mail allows them to take time to formulate a question and to carefully read or reread a doctor's answer. Participants would use e-mail mainly for minor, non-urgent questions, mostly instead of using the telephone to ask a question. Yet some patients mentioned it could stretch the time between two visits or it could possibly even save a visit to the hospital.

"Sometimes I just have a short question and it's not necessary to make an appointment. Something I just want to check. I don't have to make a telephone call for it either, there's no rush. Sending an e-mail would suffice [Male, 58 years, SLE]."

Despite their positive views, disadvantages were also mentioned: one disadvantage is the lack of immediacy in the communication, which inhibits both doctors and patients from directly asking a follow-up question for clarification. Also, patients would have to wait a while for a reply e-mail, while face-to-face or telephone contact is both direct and in real time.

Overall, participants thought that e-consultations could be a valuable extension of their current healthcare. The most important criteria for this tool are that the e-mail contact occurs with the rheumatology department of their own hospital and that it should not replace their regular contacts with their doctor. Moreover, participants expect a quick response of e-mails in a protected environment.

Some patients also mentioned to bundle abound questions to form a 'frequently asked questions'-tool (FAQ), or to create such a tool in advance, to avoid a lot of the same questions. Most patients reported they would use such a tool because the threshold would be very low. Furthermore, they reported that these tools often provide a lot of useful information. It could also contribute to the recognition that patients feel, because they are not the only one with those kind of questions.

"Those are things (FAQ's, ed.) I read a lot, and then I feel like 'oh, I am not the only one with these questions and they are already answered' [Female, 28 years, Fibromyalgia]."

Yet an important precondition is that the list of frequently asked questions does not become too large, which causes overkill and disrupts the orderly presentation of information.

Using a chat function to communicate with their care provider causes enthusiasm for almost half of the respondents. It would save patients the stress of visiting the hospital, including finding a parking space, sitting in the waiting room and absorb all the information of the doctor in one time. Still, it would be one step to far for a lot of patients. They are afraid the conversation would get too chaotic or they would not know how to use the tool properly. An important precondition would also be that the amount of offered chat sessions by the care providers could cover the demand by patients.

5) Participation by symptom monitoring

Half of the participants did not have experience with symptom monitoring. The other half had some experience in various ways, for example using a diary or during a treatment. Reasons mentioned for using a symptom monitoring tool were that it could give both the participant and the doctor a better insight into the disease, which could benefit communication and treatment. Also, it was considered to be good to be open-minded about new approaches and methods, and it can be fun to use the tool and see patterns emerge over time.

"You get a much better idea of what your bottlenecks are, and then you can explain it a lot better to the rheumatologist [Female, 40 years, Osteoarthritis]."

Some participants were not able to grasp the use and the extra value of regular monitoring. Often because they felt they did not have complaints that were severe enough to be worth monitoring or because their complaints had been stable for a longer period of time. Other reasons for not using symptom monitoring were that it could be confrontational, participants didn't want to spend too much time thinking about their disease and some patients feared it could be counterproductive if one becomes too focused on pain and symptoms.

"I just don't want to know. Ignorance is bliss; if I'm feeling good on a day, then I live it to the fullest. If I feel miserable the next day, then that's the way it is. I don't think about it too much [Female, 57 years, RA]."

Participants particularly appreciated the value of symptom monitoring when the data would not just be for their own knowledge, but when their doctor also receives the data and uses it to improve treatment. For example, a doctor could adjust treatment or medication according to reported complaints by patients, or a doctor could go deeper into conversation about monitored problems during consultation. An advanced way of getting the monitored information from the patient to the care provider would be via tele-monitoring. The IHCA could offer an application with which it is possible to get the patients' data directly to their own care providers. This way it could be a valuable addition to regular care.

"For me personally it would only work when it would benefit me, when I could improve something with it (symptom monitoring, ed.). But if I would only be scoring all my pains en symptoms, that would not do any good for me personally [Female, 56 years, Sjögren's Syndrome]."

Symptoms that participants would like to monitor were primarily inflamed and swollen joints. Furthermore, the monitoring of pain, overall health, and exercise is important to patients. Stress, fatigue, medication and nutrition were also mentioned. Furthermore, the participants thought it was important to see possible correlations between these various factors in graphs. For example the effect of exercising on perceived pain, or the effect of sleep on the amount of stiffness. Symptom monitoring would mainly be used semi-regularly in times of high disease activity, and before a consult. Participants also mentioned that it could be a very valuable tool for patients who were recently diagnosed, for exactly than it can give good insight in the variability and fluctuation of symptoms and pain.

6) Participation by exercise programs

Most participants did not have any experience with online exercise programs. They mentioned not having enough self-discipline to persist and they mostly preferred visiting the physiotherapist. Some participants regularly exercised by themselves, through daily activities such as walking or cycling, visiting the gym or using exercises from a self-help book or on a game computer. Still, these people

also mentioned having self-discipline problems in regulating their behavior.

"One time I got a booklet with exercises from the Dutch Arthritis Association. I started it, but on some point in time the motivation slipped away and I thought 'well, never mind then' [Female, 50 years, Osteoarthritis]."

Some participants reported that using an online exercise program might, in comparison to physiotherapy, help to maintain a sense of self-respect: doing things on your own. Furthermore, being able to exercise at home and get tips and support via the internet would be comfortable. Still, almost half of the participants did not see any value in an exercise program on a rheumatology IHCA. They did not think the tool could address the need for self-discipline. They were afraid of the accuracy and the safety of the exercises, and of doing them without a supervisor.

"It all depends on proper supervision. I can and I want to exercise, but if I do things the wrong way I get injured easily. When a healthy person does something incorrectly, he gets muscle aches, but if I do something incorrectly I can't walk for a week. To prevent this, I want a physiotherapist next to me. I want to keep on exercising, but in a healthy way [Female, 43 years, Ankvlosing Spondylitis]."

These barriers might be overcome by an online coach, someone who can watch the patient via a webcam, so that the coach can look along and give tips and advice. For some participants, this seemed like a good idea. Furthermore, patients would appreciate information and tips and tricks considering exercising. They would like to know which exercises are good, and which are not, or which could even be bad. They would also like advice on which exercises are good for what specific problems or for what specific parts of the body. Participants reported that this information would lower thresholds for them to start exercising in their own pace and convenience.

"I would indeed look up which exercises they recommended, and I can imagine that I would also actually use them [Female, 56 years, RA]."

7) Participation by access to medical health record

The most enthusiastically identified example of an online application by participants was access to their personal health record. Fifteen out of eighteen participants were positive about this; they would like to have access to their complete personal health record, including previous and current test and lab results, their treatment plans and an overview of all the upcoming appointments. The most important reason why they wanted this was to feel more involved with, and in control of, their disease and treatment.

"It would mean more involvement in myself. It concerns information about me, so I would like that very much (insight in personal health record, ed.) [Male, 59 years, RA]."

Also, it would give a good overview of the entire treatment, both back in time and in the future. Patients could see how their lab values and their disease activity have been changing over time, and they could see how their treatment is going to proceed and what they can expect from the hospital in the upcoming months.

"According to my treatment plan I have to give blood every 4 weeks and I have to get a consultation every 6 months. If I could see that in a schedule, I would never have to ask myself anymore 'How did this work again?' [Male, 59 years, Osteoarthritis]."

One reason for not desiring access to their personal health record would be that participants feel it is too difficult to understand all the information. Participants argue that it is the doctor's information and they would not know how to interpret it. Therefore, an important pre-condition is that the personal record should contain enough clear information and instructions to allow the patient to correctly interpret all the results and information.

"How is that score calculated and what is good or bad? I would not know, the nurse always scores everything and than says 'Well, you are doing fine' [Female, 39 years, RA]."

Furthermore, it is important that the records are safely secured. Patients want the information to be only accessible for themselves and for their care providers.

IV. DISCUSSION

To the best of our knowledge, this is the first study to identify a broad overview of use, needs, motives and preferences of rheumatism patients on a full spectrum of online support applications. Results reveal that the provision of an IHCA by ones' own hospital causes enthusiasm. With a hospital based IHCA barriers of online applications, such as information overflow or doubts about the reliability, could be overcome. Overall, participants were most interested in receiving information on both medical and support topics, online contact with their doctor and access to their personal health record. Patient support groups were less preferred as well as participation tools such as online symptom monitoring and online exercise programs. Furthermore, a significant discrepancy between current use and future preferences was seen in information about care and support, online communication with the doctor and access to a personal health record.

A. Information

Presently, participants used the internet predominantly to search for information. Previous research among rheumatism patients, as well as among those suffering from other diseases, has shown similar findings [25][26][27]. In this study the emphasis was on the kind of information and the

reasons for which patients searched the internet. We found that the participants were predominantly interested in disease information, treatment information and information on care, which was also reported by Gordon [28] and Hay [29]. Still, many participants reported searching for other information than the aforementioned subjects, which is not reflected in earlier studies. First, many participants emphasized information about coping: how to deal with psychological and social consequences relating to stress, family, friends and work, how to keep engaged in exercising, and tips and tricks to overcome the small difficulties in daily life that rheumatism can cause. Second, information on support services and local resources was valued, such as on household services and financial support for home adjustments. Overall, participants seem to want rheumatism information in a broader spectrum, while on the other hand many participants mentioned that they often experience an information overload. This is widely described in the literature, moreover, the available health information is often unreliable or biased [21][30]. Information provision by way of a hospital IHCA, could meet the preferences of patients by overcoming the problem of a doubtful information overload, while still offering a wide amount of information.

B. Communication

Participants were asked about online communication possibilities with both their doctors and their peer patients. The reported overall current use of communication tools by participants is limited. Much is written about the possible positive results peer support groups can give [31][32]. Still, actual usage of online support groups seems to be moderate [24][33][34][35][36]. The current study shows that most participants do not immediately reject the concept of online peer support groups, but they only want to participate under certain conditions. Participants would like to read positive messages and practical tips from other patients. Communication with health professionals shows a large discrepancy between current use and needs for the future. This is also shown by Van Lankveld in a study on current and expected use of online health applications by the chronically ill [27]. This discrepancy is largely due to lack of opportunity. Most participants have never communicated with their doctor online [33], because such applications were not available. Still, when offered, e-mail contact appears to be a popular facility [13][18][34][35][37]. Our study reveals that rheumatism patients thought it would be an accessible, reliable and easy way to improve their current care. However, patients do not want e-mail communication to replace consultations or other face-to-face contact. Moreover, practical implementation might be difficult as e-mail communication might be impeded by legal, budgetary and motivational barriers [38].

C. Participation

The current use of self-management or exercise programs is reported as moderate by patients. Many of our participants did not see the purpose of these applications, or they

believed it would demand too great a time investment without clear benefits. Previous trial studies concerning self management and physical activity in rheumatism showed good results using computer-based technologies [15][31][39]. However, despite of promising results, the predicted use of suchlike tools on an IHCA is still moderate. Reported explanations for this are barriers in both self-discipline and accuracy, and safety of the exercises.

On symptom monitoring patients stated that their motivation to use the application would definitely increase if their doctor would use the information for treatment purposes. Therefore, the greatest promise of these tools is when linkage to the treatment can be realized. The perceived usefulness for themselves and for their treatment is a large motivator for use: this raises interesting questions about the possible future use of these applications. For example, tele-monitoring, in which the doctor applies a patient's self-reported data on monitoring and management during the consultation.

Finally, a participation tool with great potential is online access to medical health records. Previous studies have shown that this application is well received by patients [18][37][38][40] and the participants in this study also report enthusiasm. This application would give patients the sense of being involved in, and in charge of, their own disease and treatment. Motivations such as this are very important because they demonstrate the value an IHCA can have in involving patients in their care process.

D. Preferences

Results show that patients mentioned a lot of pre-conditions which should be fulfilled in order for them to use the various support tools, especially for the communication and participation tools (Table 2). Often, the reported motives for not using the support tools could be overcome when the patients' demands on possibilities, quality and care provider involvement for each online support tool are met. Therefore, it is very important to meet these pre-conditions when developing a rheumatology IHCA; this is what makes the application patient-centered. If we wish to overcome the current acceptance problems that many online applications face when it comes to actual use, patients' wishes should be complied with as much as possible and feasible. Still, it should be noticed that many patients have not yet had the opportunity to use most of the participation applications, so their preferences and pre-conditions are not based on experience, but on expected usefulness [41].

E. Study limitations

There are limitations to this study. This qualitative study may not be representative for all patients. The participants were volunteers who, being more actively involved in research than usual patients, may not represent typical patients. Furthermore, the participants had mostly suffered rheumatism for a longer time. This can influence their needs and preferences; they are in a later stage of their illness

journey than recently diagnosed patients. In a quantitative follow-up study these limitations will have to be averted.

V. CONCLUSION

Patients see great value in an IHCA provided by their own hospital, since it could increase reliability of the provided information , and would give them the confidence to use the application. The current study shows a significant discrepancy between current use and future preferences rheumatism patients have regarding online communication with their doctor, online symptom monitoring and access to their medical health record. Furthermore, our results provide an overview of important preferences and pre-conditions that patients have for each support tool in order to improve intention to use the application. Overall, patients prefer a rheumatology IHCA that contains both communication and participation tools, which are linked to the hospital, and information about disease, care and practical support.

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