Is a smartphone application useful for self-management support in patients with a rheumatic disease?

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Submitted

ABSTRACT

Aims

This study 1) investigates whether the use of an app improved patients' self-management 2) investigates which factors are associated with the use of the RD-app, 3) explored patients' experiences with this RD-app.

Background

Self-management is an important aspect in the care for patients with a rheumatic disease (RD). To support patients' self-management, we developed and implemented a smartphone-application (RD-app).

Design

A prospective before-after study was performed among patients with a RD.

Methods

The primary outcome was patients' self-management measured with the Partners in Health-scale (PIH). Survey questions addressed whether the RD-app had contributed to get more hold on the disease and how. A paired t-test was used to evaluate changes in the PIH-scale score after three months. Logistic regression analyses served to investigate variables that are important for using the RD-app.

Results

Of the 1511 eligible patients, 397 completed both the baseline and the follow-up surveys. Participants with positive expectations of the RD-app for getting hold on the disease were more likely to use the RD-app. 114 participants used the RD-app, of which forty-two percent of the app-users perceived that use of the RD-App had contributed to get more hold on the disease. This percentage was higher for those who used the RD-app more frequently ($p=0.04$). The PIH-scale score in the app-users group had not changed after 3 months. Receiving tips, information on exercises and gaining insight in self-reported disease activity contributed to get more hold on the disease.

Conclusion

Almost one third used the RD-app. If they used the RD-app, almost half experienced more hold on the disease. Positive expectations are an important factor for the use of the app.

Relevance to clinical practice

The RD-app can be useful for additional self-management support in a clinical practice.

INTRODUCTION

Patients with rheumatic disease (RD) can face several physical (e.g. pain, stiffness, disability and fatigue) and psychosocial problems that might influence their activities in daily life (Abraido-Lanza & Revenson, 2006). Sometimes emotional, psychosocial adjustments and behavioral changes are needed (Dures et al., 2014; Homer, 2005). This might require a great effort; patients daily have to make decisions to self-manage the disease and are expected to take an active role in this process. Self-management is considered highly in chronic care and it needs to be integrated in a patient's life (Anderson & Funnell, 2005; Glasgow, Jeon, Kraus, & Pearce-Brown, 2008; Wagner et al., 2001).

Self-management is not clearly defined; a commonly used definition is: 'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition' (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178). Effective self-management approaches might result in physical and psychosocial benefits and improve quality of life (Barlow et al., 2002; Lorig & Holman, 2003). Self-management in RD has primarily been seen as patient's own task, although receiving support to optimise self-management behaviour is appreciated (Been-Dahmen et al., 2017; Dwarswaard, Bakker, van Staa, & Boeije, 2016; van Eijk-Hustings et al., 2013)

Self-management support can be defined as the provision of interventions to increase patients' skills and confidence in managing their chronic condition (Institute of Medicine Committee on Identifying Priority Areas for Quality, 2003). Patients are activated and facilitated to play an active role concerning living with a chronic disease. Besides the support given by nurses in daily care, an additional way to assist self-management support is by using a health-related application (App).

Background

Apps are becoming a part of the nursing practice and it has been suggested that 'nurses must be able to recommend and integrate apps into their clinical practice' (Ferguson & Jackson, 2017). Health-related apps might contribute to assisting self-management by providing information, advice, support, encouragement and tools for monitoring the disease activity and might overcome several barriers like time and distance (Garabedian, Ross-Degnan, & Wharam, 2015; Patrick, Griswold, Raab, & Intille, 2008; Whitehead & Seaton, 2016). Furthermore, apps can provide efficient and individual tailored information at the time suitable for patients (Azevedo, de Sousa, Monteiro, & Lima, 2015; Wang et al., 2014), and a way for patients to become more involved with their self-management of the disease (Grainger, Townsley, White, Langlotz & Taylor, 2017).

There are many commercial health-apps available, however, most of the apps have a paucity of high-quality and the content is not evidence based (Bhattarai, Newton-John,

& Phillips, 2018; Grainger et al., 2017). Only a few studies have been done on health-apps for patients suffering from a RD (Nishiguchi et al., 2014; Yamada et al., 2012). These studies showed that apps can be useful to assess gait pattern in rheumatoid arthritis patients (Yamada et al., 2012) and to predict the disease activity by combining subjective measurements of joint symptoms, degree of disability and objective gait balance measurements (Nishiguchi et al., 2014; Yamada et al., 2012). Patients with rheumatoid arthritis stated they would certainly use an app for self-management support (Azevedo, Bernardes, Fonseca, & Lima, 2015).

In 2015, the Rheumatology department in the Erasmus University Medical Center, Rotterdam, the Netherlands, developed and implemented an app for patients with a RD with the purpose of assisting patients get more hold on the disease. The aim of this study was 1) to investigate whether the implementation of this newly developed RD-app can help improve self-management of patients with a RD and 2) to investigate which factors are associated with use of the RD-app, 3) to explore patients' experiences with this RD-app.

METHODS

Design and data-collection

A before-after study was designed to measure the effects of use of the RD-app on patients' self-management behavior after implementation of the RD-app.

We recruited patients with RD from the outpatient rheumatology clinic of the Erasmus University Medical Center in Rotterdam between August 2015-July 2016. All eligible patients whose email address was noted in the electronic patient record received an invitation by email to participate in this study (n=1511) (figure 1). After they confirmed to be willing to participate, they received a questionnaire before (baseline) the launch of the RD-app. All patients who participated at baseline received a second questionnaire three months after the launch of the RD-app. Reminders to return the questionnaire were sent after one and two weeks at baseline and after the second questionnaire by email. At baseline, demographic data, working status, diagnosis and time since diagnosis were obtained.

No extra instructions were given on how to use the app, as we thought it was self-explanatory. Furthermore, no instructions were provided to the (minimum) number of times participants had to use the app nor which categories they had to use specifically.

The study protocol was approved by the Medical Ethical Committee of the University Medical Center Rotterdam (MEC-2015-317). All participants gave written informed consent before completing the baseline questionnaire.

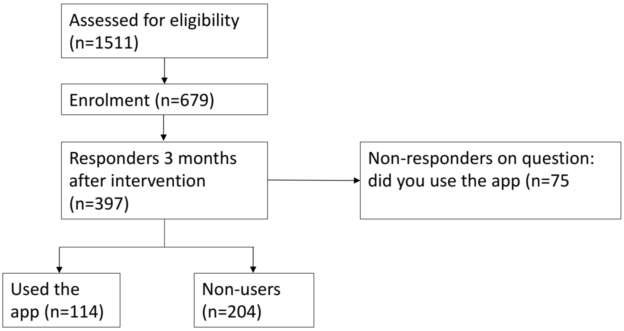

Figure 1. Flowchart inclusion

Development of the RD-app

The RD-app was developed by a team of specialist nurses, rheumatologists, a professional software developer and patients. Different self-management components were incorporated, such as education with disease-specific information, self-monitoring and medication tools, as suggested by studies on self-management interventions (Barlow, Wright, Sheasby, Turner, Hainsworth 2002). The development of the app started by creating a functional design by the team mentioned above. To make sure the design fulfilled the needs and expectations of patients with a RD, a total of 61 patients completed a questionnaire asking for their opinions. This design process resulted in a definitive design consisting of the following six functionalities:

1. Patients can monitor the disease activity using specific self-reported outcomes (e.g. Rheumatoid Arthritis Disease Activity Index, Bath Ankylosing Spondylitis Disease Activity Index, Health Assessment Questionnaire). Thus, this category can be used for self-monitoring the disease.
2. Overall wellbeing and activity level are each rated on a visual analog scale (VAS). The ratings over the last week or months can be visualized. This category is trying to gain more insight information on the course of the overall wellbeing in combination with perceived physical activity level.
3. Different physical exercises, explained with video's, are provided to stimulate activity. Promoting healthy moving by evidence based exercises might be helpful for patients to change their physical activity.
4. The app also provides reminders for medication intake and appointments. With this category the adherence of medication as well as appointments are addressed.
5. A game was developed to increase patients' knowledge about the process of inflammation. Education and understanding the disease is a part of self-management.
6. Tips and health information form the last category. To tailor this app, information categories (tips and health information) can be switched on or off. This tailored evidence-based information is divided into 10 categories: exercises for joints, fatigue,

more hold on the disease, medication, pain, sexuality, tips using hands, holidays, working tips and pregnancy. To perform in daily life and incorporate the disease many tips are provided monthly.

Feedback of the patients was used to develop the app and therefore this is an user driven approached app. Thereafter, a prototype of the app was used for the test rounds, to get feedback on the functionality and missing topics, in two rounds, by 30 and 40 patients, respectively. The first test round resulted in modifications in functionality, minor additions and textual adjustments. After the second test round no more adjustments were made. This app does not include a feedback function, due to privacy legislation.

The RD-app was incorporated in the usual nursing care: patients received information and explanation about this app during nursing consultations, were given written information and received a newsletter from the department of rheumatology to inform them about the app. Furthermore, the app was launched on several different (social) media platforms. The RD-App (Dutch: Reuma app) is freely available from both the iOS and the Android store, thus not only for patients treated in this hospital.

Outcome measures

The primary outcome of this study was the self-management knowledge and behavior as measured by a generic validated 12-item self-rated scale, the Partners in Health scale (PIH scale), with total score ranging from 12 to 96 points. Higher scores indicate better self-management behavior (Battersby & Markwick, 2003; Petkov, Harvey, & Battersby, 2010; Smith, Harvey, Lawn, Harris, & Battersby, 2017). The PIH scale is a reliable and valid instrument for measuring self-management of chronic conditions, including arthritis. Additionally, participants were asked if the app helped them to get more hold on their disease with one dichotomised question, yes or no.

The secondary outcomes were health-related quality of life (HRQOL), self-efficacy, pain, fatigue, and experiences with the app. HRQOL was scored with the validated SF-36 (range score 0-100). A higher score indicates a better HRQOL. It assesses eight health concepts: physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems, emotional well-being, social functioning, energy/fatigue, and general health perceptions, which are summarised in a physical component summary and mental component summary score (Ware & Sherbourne, 1992). Self-efficacy was measured with the validated Dutch version of the arthritis self-efficacy scale, which consists of two subscales related to self-efficacy to deal with pain and to deal with other symptoms (depression, fatigue, frustration) (Taal et al., 1993). Self-efficacy is 'the belief of patients in their own capability to perform activities to produce a desired outcome' (Bandura, 2001). Pain and fatigue were each measured with a visual analogue scale (VAS) ranging from 0-10, where higher scores are regarded as more fatigue or pain. The VAS scale is valid to detect changes in pain and fatigue in RD patients (Hewlett, Dures, & Almeida, 2011; Wolfe, 2004).

Experiences with the app

To measure experiences of the participants who used the RD-app (app-users) an open-ended question was asked: How did the app help you to gain more hold on your disease? Participants who did not use the app (non-users) were asked to state the reason why they did not use the app.

Statistical analysis

Quantitative data

We used descriptive statistics to describe the study sample. Because not all participants used the RD-App, we divided the participants in two groups: app-users and non-users. A paired T-test was used to investigate whether the use of the RD-app had contributed to an increase in the PIH-scale score and other patient reported outcomes (PROs).

Logistic regression analyses served to investigate variables that are important for using the RD-app. First, univariate analyses were performed. All significant variables were put in the full models; thereafter backward elimination was performed. Results were considered statistically significant when the p-values were less than 0.05. STATA version 13.0 was used to analyze data.

Qualitative data

Answers to the open questions about the experience of the app were labeled and grouped. Two researchers (JB, MW) independently analyzed answers to the open-ended question. Differences were discussed until consensus was reached.

RESULTS

At baseline, 679 of the 1511 eligible patients, participated (response rate 43%). Of those 679 participants, 397 also filled in the second questionnaire. The latter were older ($p<0.01$), more often unemployed ($p=0.04$), had higher expectations the app would help them to get more hold on their disease ($p=0.01$), and had higher scores on the PIH scale ($p=0.08$) than those who responded only at baseline. All other baseline characteristics and PRO did not show differences.

Participants who completed questionnaires ($n=397$) at both periods were most frequently diagnosed with RA, 65% was female, the mean age was 52.0 (SD15.6) years and 71% was higher educated (table 1). Almost all participants had a smartphone (89%). At baseline, 70% thought they would use the RD-app for self-management support and 63% expected it would give them more hold on the disease (table 1).

Of the 397 participants, 19% (n=75) had missing data regarding the question "did you use the app?". Of those participants who missed this question 72% (n=54) did not possess a smartphone. Furthermore, there was a difference between the participants who did or did not answer this question, participants with the missing data worked less often (p=<0.001) and were less highly educated (p=0.006). Further analysis did not show differences on demographics and patients reported outcomes (PROs).

Table 1. Demographics baseline of participants who filled in both questionnaires, app-users, non-users

	Total n=397	
Age (mean, SD)	52.0 (15.6)	
Gender (Female) (n; %)	258	(65)
Education (College or higher) (n; %)	284	(71)
Employed (yes) (n; %)	180	(45)
Diagnosis (n; %)		
Rheumatoid arthritis	163	(41.2)
Spondyloarthritis	23	(5.8)
Systemic Lupus Erythematosus	15	(3.8)
Juvenile arthritis	9	(2.2)
Fibromyalgia	24	(6.1)
Osteo-arthritis	37	(9.3)
Gout	20	(5.0)
Arthritis psoriatic	54	(13.6)
Other (e.g. PMR, arthritis eci, sarcoidose)	51	(12.9)
Time since diagnosis (n; %)		
<6 months	7	(1.8)
6 months-1 year	20	(5.0)
1-2 years	46	(11.6)
2-5 years	69	(17.4)
>5 years	254	(64.1)
Nationality (Netherlands) (n; %)	383	(96.4)
Smartphone present (Yes) (n; %)	344	(89.3)
Intend to use the app (Yes) (n; %)	242	(70.4)
Expect the app will increase the self-management skills (Yes) (n; %)	242	(62.7)

App users

After three months, almost one third (n=114) of the participants used the app. App-users had a mean age of 51.3 (SD 16.4). Eighty-eight percent of the app-users (n=98) who had responded positively to the baseline question "do you think you will use the app", actually used it after three months. App-users who used the app five times or more were younger (44.4 vs. 52.1; p=0.03) and were higher educated (p=0.001). Eighty-two percent of the app users would recommend this app to others. Almost all who used the app five times or more (96%) recommended this app to others.

To investigate who did use the RD-app univariate analysis showed a role for gender, positive expectations of the RD-app, help needed to get more hold on the disease and the VAS global as associated factors with actually using the RD-app. In the multivariate analysis only expectations of the RD-app remained significantly associated with actually using the RD-app (p=<0.001) (table 2). Thus, if participants had positive expectations of the RD-app for getting more hold on the disease, they were more likely to use the RD-app compared to those who did not believe the RD-app would help them to get more hold on their disease.

Evolution of self-management and PRO over time

One hundred eleven app-users completed the PIH-scale at baseline and after three months. After three months, the mean score and the subscale scores had not significantly changed (p=0.8) (table 3). Forty-two percent of the app-users agreed the app had contributed to get more hold on the disease. This percentage was significantly higher for app-users who used the app five times or more compared to those who used it less frequently (59% vs. 37%; p=0.04).

Table 2. Prediction model for using the RD-app

Used the RD-app	Uni variate			Multi variate		
	Coef.	95% CI	P value	Coef.	95% CI	P value
Age	-0.0008	-0.004-0.002	0.62			
Gender	0.11	0.008-0.22	0.03	0.09	0.01-0.20	0.1
Time since diagnosis	0.01	-0.03-0.06	0.60			
Employed	0.02	-0.08-0.12	0.42			
Education	-0.04	-0.16-0.07	0.42			
Self-efficacy	0.03	-0.29-0.09	0.31			
Expectations of RD-app	0.21	0.11-0.32	<0.001	0.20	0.10-0.31	<0.001
VAS global	-0.02	-0.05-0.0002	0.05			
SF-36 PCS	-0.003	-0.008-0.0005	0.08			
SF-36 MCS	-0.002	-0.008-0.002	0.25			
Partners in Health scale	-0.0005	-0.005-0.004	0.82			
No help needed	-0.11	-0.22- -0.007	0.03			

*VAS: Visual Analog Scale; SF-36: 36-Item Short Form Survey; PCS: Physical Component Summary; MCS: Mental Component Summary.

The secondary outcomes self-efficacy, VAS pain and VAS fatigue, and SF-36 also did not change over time (table 3).

Experiences with the app

The answers to the question: How has the app helped you getting more hold on the disease, could be divided into three categories: 1) receiving tips, 2) information on exercises and 3) gaining insight into the self-reported disease activity.

Table 3. Patients reported outcome at baseline and after 3 months

Outcome variables	App Users (n=114)		
	Baseline	Post test	P-value
Partners in Health scale (12-96)	79.47 (11.75)	79.20 (11.55)	0.8
VAS fatigue (0-10)	6.07 (2.39)	6.03 (2.22)	0.8
VAS pain (0-10)	4.96 (2.25)	4.97 (2.18)	0.9
SF-36 PCS (0-100)	36.44 (11.39)	36.73 (11.12)	0.7
SF-36 MCS (0-100)	48.44 (10.64)	48.37 (10.72)	0.9
Self-efficacy (1-5)	2.55 (0.83)	2.48 (0.77)	0.1
More grip on Rheumatic disease due to app (yes, %)		42% (48)	
Recommended app to others		82% (94)	

* PIH: Partners in Health Scale; VAS: Visual Analog Scale; SF-36: 36-Item Short Form Survey; PCS: Physical Component Summary; MCS: Mental Component Summary

App-users stated that practical tips were helpful, for example to learn more about the disease and how to gain more control in daily life, and how to deal with fatigue or devices in daily life. Some app-users mentioned that they could use the tips whenever necessary. App-users mentioned that video instruction on physical exercises stimulated them to do more exercises. Lastly, app-users appreciated that the evolution of their self-reported disease activity could be visualized.

Reasons for not using the app

Non-users (n=208) mentioned different reasons for not using the RD-app. The most stated reasons were ‘no interest at all’ or ‘low disease activity. Other reasons were; ‘not any added value due to e.g. online information sources’, ‘not wishing to be confronted with the disease’, and ‘no time for downloading the app’. Although, some of them stated they want to download the app later on. Some non-users struggled with technical issues as they did not know how to download or did not have enough remaining space on their phone.

DISCUSSION

This study aimed to evaluate if the RD-App had a positive effect on patients’ self-management behavior. It appeared that use of the app helped 42% to get more hold on the disease by the provided tips, exercises and the insight in self-reported disease activity. This percentage was even higher for those used the app more frequently. However, a beneficial effect on self-management behavior three months after the launch of the RD-App could not be shown.

Self-management is a complex concept and the assessment of interventions on self-management is complex as well (Nolte & Osborne, 2013). A review on evaluation of self-management support by using apps in chronic illnesses showed conflicting results: only three out of the nine studies demonstrated an improvement in symptom management through self-management when the intervention comprised an app only, thus without a feedback tool integrated in the app (Whitehead & Seaton, 2016). Another review showed that apps were rarely successful in improving self-efficacy or quality of life (Garabedian et al., 2015). In the present study, of the absence of improvement in the PIH scale might be explained by app-users being convinced they had sufficient self-management skills, since most of them had an established RD. On the other hand, it cannot be excluded that the PIH scale fails to pick up any changes important for a patient's experience to get more hold on the disease. Interestingly, almost half of the app-users, even those with an established RD, responded positively to the question: "Did the RD-app help you to get more hold on the disease". Thus, the perception of more hold on the disease increased by using this RD-app. Therefore, this RD-app must not be dismissed as it might be useful for self-management support from the perspective of the users, which is something that is not picked up in the used questionnaires. Besides, app-users appreciated the received tips and information on exercises and gaining insight into the self-reported disease activity. This is in line with a study on users' perceptions of apps, which found that personalised and tailored information was a motivator for using apps (Peng, Kanthawala, Yuan, & Hussain, 2016).

The second aim of the study was to investigate which factors were associated with the use of the RD-app. In the multivariate analysis, only having positive expectations beforehand was found to be associated with actually using the RD-app. This is in line with other studies on smartphone apps, they found that positive expectations and a positive attitude were of great importance for the utilization of apps (Huygens et al., 2016; Wang et al., 2014). Nurses may play a role here by recommending, integrating and communicating positively about the app. However, assessing the quality of existing apps can be difficult (Grainger, Townsley, White, Langlotz, & Taylor, 2017). Nurses can take the lead in integrating technological possibilities, like health-related apps, and using them to improve care targeted at supporting self-management.

In this study, we found a remarkable discrepancy in the willingness to use the app and the actual use. At baseline, 70% of all participants indicated they would use the app. This compares well with a study in patients with epilepsy, in which 65% were willing to use an app for self-management support (Liu, Wang, Zhou, & Hong, 2016). This percentage was higher in a study of willingness of using apps for patients with RA (85%), even if they had to pay for it (Azevedo et al., 2015). In the present study, however, only one third of the participants did actually use the app after three months. A similar gap was seen in a study in patients with diabetes (Frandes, Deiac, Timar, & Lungeanu, 2017), which identified a lack of time and insufficient technological skills as influential factors (Frandes et al., 2017). These factors were also mentioned by the non-users in our study. But, non-users also stated, in the qualitative analysis, that they did not need an app because they had already received enough information. This finding was confirmed in the univariate analysis, an association for the use of the RD-app was found if participant did not need help at all. Similarly, in a study investigating the needs of patients toward self-management and eHealth for self-management, patients had already received most information from health professionals (Huygens et al., 2016).

Some limitations of this study need to be addressed. First, we had missing data, with regard to the question "did you use the app?". This might have affected the outcomes. However, of those who missed this question almost three quaters did not possess a smartphone. After adding these participants to the non-users group, no different outcomes were found for the prediction of the use of the RD-app. The other participants who missed this question had similar results on the of the PIH scale and expectations compared to the other participants. Second, we additionally used a dichotomous question for measuring the feeling of getting more hold on the disease. Self-management is a difficult construct and moreover it is difficult what outcomes must be used (Bykerk, Lie, Bartlett, Alten, Boonen, Christensen, Furst, Hewlett et al.,2014; Trappenburg et al., 2013). Patient reported outcomes should provide key information of the perspective of the patient of getting more grip on the RD. The use of a one single question provided an overall image of the feeling of more grip on the RD, while an extended questionnaire may be useful to address more specific issues. Therefore, we feel that the used single item question is informative to measure how patients perceived hold on their disease. Finally, the effects of the app were measured three months after it was launched. This period may have been too short to detect changes in complex outcomes like self-management. App-users who used the app more often than average found they were getting more hold on the disease. Thus, more long-term evaluation, after 6 and 12 months for example, might show changes in outcomes.

Relevance to clinical practice

Although patients feel self-management has been seen as patient's own task, patients appreciate support on self-management. The RD-app can be useful for additional self-management support in clinical practice. The results are important as they help understand how new technology can improve patients' self-management in daily care.

CONCLUSION

The RD-app seemed to be of benefit to participants in their need to get more hold on the disease. Positive expectations are an important factor for the use of the app, which might increase by better communication about the app.

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