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Strategies for patient education in rheumatic diseases

Aniek Claassen
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Colofon

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Chapter 1

General introduction
Introduction

In the Netherlands 1 out of 9 persons (1.95 million in total) has a rheumatic or musculoskeletal disease (RMD) such as osteoarthritis (OA) or rheumatoid arthritis (RA). Because of the aging population it is expected that in the Netherlands the prevalence of OA will increase with 92% from 1.2 million in 2015 to 2.3 million in 2040, becoming the most common chronic condition in the Dutch population (Figure 1). Globally hip and knee OA is ranked as 11th highest contributor to disability, whereas RA is ranked 42nd.

In the Dutch healthcare system General Practitioners (GPs) play a fundamental role as ‘gatekeepers’ in primary care; their central role is in favour of continuity of care. GPs are the first physicians to be contacted when patients experience health problems. They are usually responsible for making the first diagnosis, based on an evaluation of the medical and psychosocial aspects of the symptoms. Moreover, they may start initial treatment and coordinate treatments in primary care. Although primary care healthcare professionals like physiotherapists and dieticians can be directly accessed, GPs have an important role in advising patients about referrals to these healthcare professionals. In the Netherlands medical specialists in secondary care can only be consulted after referral of a GP.

For patients with RA the core element of their treatment takes place in secondary care under the overall guidance of a rheumatologist, as second-line medication is the core element of treatment in RA. In addition, as outlined in the Dutch guideline for the management of RA a specialized hospital-based nurse has a role in education and enhancement of self-management. For hip and knee OA, there are multiple effective non-surgical and surgical treatments available, delivered both in primary and secondary care. Treatment focuses primarily on reducing symptoms such as pain and functional limitations, reducing risk factors (e.g. overweight) for the progression of joint damage, and increasing coping skills to face disease consequences in daily life. Once non-surgical treatment options have been adequately tried and failed, a total joint replacement (TJR) is a cost-effective treatment option. However, TJR does not result in improvements for all patients and the lifespan of a prosthesis is not indefinitely. Therefore, treating patients with OA timely by means of lifestyle modifications (i.e. weight loss and physical activity) and conservative treatment options (e.g. education, physiotherapy and pharmacological treatment) is considered important. These conservative treatment options can all be coordinated in primary care. National guidelines provide recommendations for GPs and physiotherapists on patient education, physical activity and weight loss as well as the course of the condition. This structure of organization of care for patients with RMDs (including pharmacological, surgical and allied health care) makes it clear that most patients have contacts with a variety of healthcare professionals during the course of their condition.

Over the past decades healthcare has changed towards a less directive and more collaborative approach between healthcare professionals and patients, with patients wanting and expecting to take an active role in managing their own disease and treatment. Consequently, people with RMDs need a sufficient body of knowledge, skills, attitudes and coping abilities. This can be accomplished through patient education. Patient education comprises all educational activities provided for patients, including aspects of therapeutic education, health education and health promotion and can be considered a first step on the way to self-management.
Patient education

Patient education is therefore an important part of disease management of most RMDs and is recommended as core treatment in OA and RA\(^7,8,20,22\).

The overall aim of this thesis is to get insight in how patient education can be best delivered to patients with RMDs, in particular to those with hip and knee OA or RA, by identifying their informational needs and exploring the use and effect of educational interventions provided through different sources.

(Therapeutic) patient education as defined by the World Health Organisation:

"Therapeutic patient education should enable patients to gain and maintain abilities that allow them an optimal management of life with their disease. Therapeutic patient education is, therefore, a continuous process, integrated in health care. It is patient-centred; it includes organized awareness, information, self-care learning and psychosocial support activities, regarding disease, prescribed treatments, care, hospital and other health care settings, organizational information, health and illness behaviour. Its aim is to help patients and their families to understand the disease and the treatment, cooperate with healthcare providers, manage their own health and maintain and/or improve their quality of life."\(^23\)

Figure 1. Trend scenario for most common diseases in 2040 in the Netherlands\(^4\)

![Image of a pie chart showing the number of people with a specific disease in 2015 compared to 2040.]

Active patient role

Patients are expected to take an active role in their own care process as in everyday life they typically have to deal with the consequences of their disease in the absence of a healthcare professional.
Information on disease and medical care 

In order to be effective, patient education must emphasize the course of the disease, patients with OA and RA have high needs and expectations for their treatment. Despite the recommendations for patient education from an early stage on and throughout the course of the disease, patients need clear communication of health information, optimized from a joint perspective of healthcare disciplines, to improve their knowledge on OA and its management. Tailored to the individual needs of the patient is therefore encouraged in current models of care. However, a recent Cochrane review on the effect of educational self-management programs showed evidence for improving pain, functioning, self-management skills, or quality of life in OA is not always high. All interventions of included studies were considered to have an element of self-management. However, heterogeneity of the interventions was high, considering the variety of combinations with other interventions (e.g. exercise program), differences in mode (individual or group), supervision (healthcare professionals or trained facilitators), delivery method (face-to-face, telephone, internet) and duration, possibly explaining the finding of small effects.

Another explanation for the small effects found is the variety of outcome measures used across studies and the possible mismatch with the aim of the intervention. Most included studies used pain and functioning as outcome measure. It is questionable if those measures are the most suitable outcome measures if the aim of educational self-management programs is to change behaviour (e.g. increase in physical activity, changes in health care utilization, asking for social support, engage in social activities, etc.). Outcome measures that cover self-management skills like the Patient Activity Measure (PAM-13) have not been widely used yet and should be explored. Moreover, evaluation of patient educational self-management programs using outcomes matching the aim of the intervention is needed.

Decision making

In current patient-centred care, patients are expected to play an active role in deciding together with their healthcare professional what the best care will be. In order to actively participate in making treatment decisions patients need information on the options they have. A review of Smith et al. (2014) showed that attitudes of OA patients regarding the efficacy of conservative treatment options are often negative, and that patients tend to prefer surgical treatment. The trivialization of OA being a condition of normal ageing, and the perception that treatment options are limited, are misconceptions that are thought to contribute to patients not choosing recommended treatment options. Because beliefs about treatments are related to intended treatment choices, it is important to help patients form realistic expectations and make them aware of benefits and possible disadvantages of treatment options to make a well informed decision.

Aligning education to educational needs

Despite the recommendations for patient education from an early stage on and throughout the course of the disease, patients with OA and RA have high needs and expectations for information on disease and medical care. In order to be effective, patient education must be provided not only on what healthcare professionals think patients need to know, but also modified to patient's needs. In a recent review by Chou et al (2017) three main areas of perceived health information needs for OA were identified: 1) the need for health information content, 2) the desire for clear communication of health information, and 3) the need to obtain health information from a variety of sources.

Information content

Research has identified gaps in content of information regarding diagnosis, prognosis and management options for OA. Based on international recommendations OA professionals have identified key messages about OA that can be used in educational materials to ensure patients are educated about the most important aspects of OA and its management. However, these messages as well as most recommendations for information content are determined from the perspective of healthcare professionals and researchers. There may be differences between what patients and healthcare professionals consider important. Moreover, patients' preferences for information may go beyond information that is based on guidelines. As preferences and needs of the patient are an important aspect of their treatment choices, it is important to identify if patients' informational needs go beyond guideline recommendations and if there are differences between what patients consider important and what healthcare professionals think patients consider important.

Clear and consistent information

As patients have to deal with a number of informational sources, like healthcare providers, health-related websites, their social environment and informational leaflets, chances are high they encounter conflicting information. Receiving conflicting information has been associated with unfavourable outcomes such as non-adherence to medication. Moreover, it can be experienced as incompetence of healthcare professionals, resulting in not acting upon advice giving by the healthcare professional. Furthermore, in OA many terms used are often misunderstood by patients. For instance, the term “wear and tear” is being linked to normal ageing, and reinforces the thought that nothing can be done. Guidelines state that healthcare professionals should counter these misunderstandings. That may not always be easy however, as healthcare professionals not always believe in recommended treatments themselves. Providing clear and consistent information, optimized from a joint perspective of healthcare disciplines can improve patient knowledge on OA and its treatment, but may also optimize efficient information delivery.

Information from multiple sources

Educational interventions with similar content can be provided through a variety of sources, e.g. on paper, face-to-face or online. Research shows that patients have the desire to obtain information from a variety of sources in order to complement information to their individual situation. However, preferences may vary with regard to mode of delivery. Written information is highly rated by patients with RMDs as it provides the option to refer back and strengthen understanding. Previous studies have shown that written educational material is beneficial in various chronic conditions like low back pain and diabetes to improve knowledge and illness perceptions. Moreover, written information in form of interactive patient care booklets can assist patients with chronic conditions to get informed about their disease and treatment options, to monitor their symptoms and prepare consultations. They have shown to improve knowledge and treatment beliefs in OA and RA patients. Despite positive effects of the use of care booklets, use itself is often not very high. Strategies to disseminate written information to patients therefore need to be further explored to optimize use and target sub-groups.
Face-to-face educational interventions offer the benefit for patients to have direct interaction with healthcare professionals for advice and responses to their questions. Additionally, when provided in groups, interaction between patients has the major benefit of sharing ideas and learning from others\(^\text{39}\). Providing an educational intervention with consistent information supervised and provided by multiple disciplines guarantees better support to patients.

With the development of online resources new possibilities for patient education arise with major advantages. Information can be accessed by patients whenever, wherever they want, without the need to visit a healthcare professional, therefore having the potential to be cost-effective, time-saving and breaking down barriers. Online applications have shown to support the communication between patients and healthcare providers and seem effective at providing information, enhancing information exchange, and promoting self-management\(^\text{62,63}\). Evidence for the use of eHealth smartphone applications is starting to emerge in various chronic conditions\(^\text{64}\), including rheumatic diseases\(^\text{65}\). However, research on the development and evaluation of such applications is still in early stages\(^\text{66}\). There is some recognition that uptake and use of eHealth applications can be influenced by user characteristics\(^\text{64}\). Moreover, eHealth interventions can also have their downsides; low usability of technologies or limited access to these technologies can result in patients getting unmotivated and not using the intervention\(^\text{66}\). Evaluating usability, how applications are used and by whom can therefore be important for implementation and further optimization of developed eHealth interventions\(^\text{64}\).

Outline of this thesis

In order to improve education for patients with OA and RA the main objective of this thesis is to identify informational needs as starting point for the development of educational tools and to explore the use and effect of educational interventions disseminated through various sources. The content of the chapters in this thesis is outlined below.

Chapter 2 describes informational needs of patients with hip and knee OA that go beyond general guideline recommendations (based on information provided on Thuisarts.nl), in the form of most important frequently asked questions (FAQs). Differences between what patients consider important and what healthcare professionals think patients consider to be important are also described.

The identified FAQs were answered by health care providers from multiple disciplines involved in OA care and subsequently included in a multidisciplinary educational program delivered in the region of Nijmegen, the Netherlands. We describe the evaluation of this educational program and its preliminary effects on healthcare utilization in Chapter 3.

In Chapter 4 the results of a randomized controlled trial to evaluate the effect of an educational eHealth tool for patients with hip and knee OA to prepare a consultation with an orthopaedic surgeon on their experience with the consultation are presented. The use and usability of this application and factors related to its use are described in Chapter 5.

In the randomized controlled trial described in Chapter 6 we evaluate two distribution strategies of a care booklet for patients with RA on actual use of the care booklet. Differences between users and non-users are also explored.

Finally, in Chapter 7 the results of this thesis are summarized and discussed, and implications for clinical practice and future research are given.


Chapter 2

The most important frequently asked questions of patients with hip or knee osteoarthritis: a best-worst scaling exercise

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Abstract

Objective
To collect and prioritize the frequently asked questions (FAQs) that patients with hip or knee osteoarthritis (OA) and health care professionals consider to be the most important; to identify informational needs that go beyond guideline recommendations.

Methods
FAQs were collected among health care professionals and from the arthritis helpline of the Dutch Arthritis Foundation. After deleting overlapping FAQs, the remaining FAQs were prioritized by patients and health care professionals using a maximum difference scaling method. A hierarchical Bayesian method was used to calculate relative importance scores. Differences between health care professionals and patients were analyzed using independent t-tests.

Results
A total of 28 health care professionals and the arthritis helpline provided 393 FAQs. After deleting overlapping FAQs, 60 FAQs were prioritized by 94 patients (57 [60.6%] women, mean age 67.3 years) and 122 health care professionals (67 [54.9%] women, mean age 45.7 years). The FAQ “What can I do myself to decrease symptoms and to prevent the OA from getting worse?” was prioritized as the most important by both patients and professionals. FAQs that were highly prioritized by patients but significantly different from professionals were more directed toward treatment options offered by health care professionals, whereas highly prioritized FAQs of professionals were more often focused on treatment options involving self-management.

Conclusion
The health care professionals’ perspective on informational needs differs from that of OA patients. These differences are important to address in order to achieve more active involvement of patients in their own treatment process.

Introduction
Patient education is a cornerstone in the management of chronic conditions like osteoarthritis (OA). Providing relevant disease-related and self-management–related information helps patients become actively involved in their own care process. Moreover, research has shown that the need for information among OA patients is high.

A number of informational sources, including health professionals such as general practitioners (GPs) and physiotherapists, health-related web sites, patient information leaflets, and family and friends, are available for patients. When patients obtain information from more than 1 source, they may encounter conflicting information. Receiving conflicting information has been found to be associated with undesirable outcomes, such as reduced medication adherence in patients with vasculitis or arthritis and in pregnant women. Moreover, receiving conflicting expert opinions may be perceived as incompetence of the experts, which in turn has been associated with lower intentions to pursue health behaviors that are known to be beneficial.

National and international guidelines for hip or knee OA recommend the provision of accurate information about the condition and its management, to counter misunderstandings for all patients. Despite these recommendations, patients indicate that they do not always receive the information they need to manage their disease adequately. Barriers related to health care professionals can contribute to the lack of provision of consistent and sufficient information. In a systematic review, Egerton et al identified barriers for primary care health care professionals in providing the recommended management of OA to patients: OA was not always seen as a serious condition, but rather as a part of normal aging or as less important than other conditions; health care professionals felt underprepared, because of the lack of clarity and specificity of guidelines or because of their own lack of knowledge about OA treatments; personal beliefs about recommended treatments on effectiveness and patient adherence varied among health care professionals; and health care professionals were challenged by patients’ expectations that were other than their own views. These barriers underpin the importance of finding consensus among multiple health care professionals about the content and phrasing of information for OA patients and to formulate this information from a common perspective to make it consistent and clear for information transfer to the patient.

In a recent study, French et al used a multistage consensus process to identify key messages that are essential for patients to know, extracted from multiple guidelines about OA. After optimizing the wording of the key messages, an overall ranking of the messages averaged across all panel members was determined. These messages can be used in patient educational material because they are a translation of evidence-based information. However, although these statements are identified as being essential for patients, they do not necessarily cover patients’ needs and preferences for information on topics that go beyond what is covered in guidelines. Because the preferences and the needs of patients are important in their decision-making for treatments, such items are important to investigate. Porcheret et al found that patients considered information about the biomedical approach important for an OA consultation in primary care, while current psychosocial and behavioral approaches are recommended in guidelines. Therefore, there might be differences in what health care professionals consider important information and what patients want to know and what
patients in different stages of their disease consider important. 1

To make an inventory of the informational needs of OA patients that goes beyond guideline recommendations, and to evaluate whether those needs are perceived differently by health care professionals, the current study aimed to answer the following research questions: 1) What are the most important frequently asked questions (FAQs) of patients with hip or knee OA? 2) Are there differences in rating importance of FAQs between patients and professionals? 3) What is the difference in informational needs of patients and those perceived by professionals? and 4) Are there differences in informational needs among patients in different treatment settings?

Patients and Methods

The setting and context for the research was the region of Nijmegen in The Netherlands, where a collaboration among health care providers involved in the care of hip or knee OA set up a conjoint educational program for patients in several communities to harmonize care in the region. A 2-step approach was followed to make an inventory of the most important FAQs.

Step 1: inventory

Participants

The following stakeholders and health care professionals were invited by e-mail or newsletter to provide FAQs for the inventory: all orthopedic surgeons (n = 25; specialized in hip or knee surgery) from 3 hospitals in the Nijmegen area, i.e., Radboud University Medical Center (Radboudumc), Canisius Wilhelmina Hospital (CWZ), and Sint Maartenskliniek Hospital (SMK); rheumatologists from the Radboudumc and SMK (n = 10); nurse practitioners from CWZ (n = 2); GPs involved in this project, as well as colleague GPs working in their general practice (n = 24); primary care physiotherapists involved in this project or connected to a local OA network for health professionals specialized in rheumatic diseases (n = 188); and the Dutch Arthritis Foundation, which provided FAQs from OA patients made to the professionals on their telephone helpline.

Procedure

The Dutch College of General Practitioners (Nederlands Huisartsen Genootschap) recently launched the web site www.thuisarts.nl (i.e., home doctor), which provides information about OA (among other diagnoses). Questions and topics about OA covered on this web site include: What is OA?, What are symptoms of OA?, What causes OA?, How is OA diagnosed?, Medication and OA, and Exercise therapy and OA. The information on this web site is based on national and international guidelines. Our aim was not to restrict to FAQs on basic information about hip or knee OA, because these topics are usually covered on many web sites and in educational material. Therefore, we asked participating health care professionals to record 5–10 FAQs they often get from their patients about OA that are not covered on the web site www.thuisarts.nl. Two researchers evaluated all collected FAQs to reduce the total number when possible. First, duplicates were deleted. Next, the researchers individually identified FAQs that were similar in formulation, and based on discussion, we decided which could be combined. Last, FAQs that could be answered with the content of the web site mentioned above were also deleted. A total of 60 FAQs were included for the prioritization step.

Step 2: prioritizing

Participants

To prioritize the FAQs, a survey was developed and distributed among patients with hip or knee OA and health care professionals working in the field of OA. GPs from 2 local medical centers were asked to invite patients with an OA diagnosis by mail. These patients were selected through the GP’s information system. Inclusion criteria for patients were a diagnosis of hip or knee OA, age >18 years, ability to communicate well in Dutch, basic computer skills, having an email address, and a willingness to participate in the study and sign an informed consent. A total of 398 patients were sent an information letter about the study, with a reply card.

The same health care professionals who were asked for the inventory step were asked to participate in the prioritizing step. In addition, GPs from the Radboudumc Practice Based Research Network, Department of Primary and Community Care (n = 420) were invited to participate. To ensure diversity with regard to the type of discipline and setting, corresponding to the Dutch health care system, we aimed at including health care professionals in the following occupational groups: 35 primary care physiotherapists or exercise therapists, 35 GPs, 20 orthopedic surgeons (including physicians in training to be a specialist and nurse practitioners specialized in orthopedics), and 10 rheumatologists (including physicians in training to be a specialist and physician assistants specialized in rheumatology).

Overall we aimed at including 100 patients and 100 professionals. No guidance is provided in the literature regarding the minimal sample size for a desired statistical power for best-worst scaling methods16. Sample sizes of previous studies evaluated in a review ranged between 15 and 1,296 participants18.

Survey development and procedure

We developed an online survey consisting of 2 parts. In the first part, we assessed demographic characteristics of all respondents: age (years), sex (male/female), and education level (low/high). Patients were asked to answer additional questions on the affected joint (hip/knee/both), years since diagnosis (<1, 1-5, 5-10, >10), and setting (primary care, secondary care, or postsurgery) based on health care use (“Did you visit an orthopedic surgeon in the past?” [yes/no] and “Did you already have joint replacement surgery?” [yes/no]). In the questionnaire for health care providers, we assessed the occupation (GP, physiotherapist, rheumatologist, orthopedic surgeon, or other) and years in practice of professionals.

In the second part of the survey, we prioritized the FAQs from the inventory according to relative importance by means of a maximum difference scaling (MaxDiff) exercise (also known as best-worst scaling). In this methodology, participants are shown a subset of possible items and asked to indicate (among this subset) the most and least important item. Participants complete a number of these sets, an exercise in which each set contains a different subset of items (27). The MaxDiff method has been used successfully for research questions in rheumatology (18,19). In our study, all of the 60 FAQs were presented twice in subsets of 5 FAQs (20), resulting in 24 subsets for each participant. For each subset, participants were asked to indicate the most and least important FAQ that should be answered for all OA patients. In the current study, Sawtooth Software’s SSI Web platform (http://www.sawtoothsoftware.com/products/maxdiff-software) was used to develop the online questionnaire with the MaxDiff exercise. The software creates the optimal design of subsets based on 1,000 iterations. A total
of 300 versions was created to ensure a variety of combinations of FAQs and a randomized order among participants, to avoid higher importance being given to the first FAQ mentioned. An open link was created to be disseminated to patients and professionals.

Statistical analysis
Descriptive analyses were used to describe demographic characteristics of participants. The choices made by respondents in the MaxDiff exercise were analyzed using the hierarchical Bayesian (HB) method to estimate relative importance (RI) scores (Sawtooth Software). The HB method allowed us to estimate the individual level of importance by combining information from individuals’ specific choices with the distribution of importance across participants, computing individual-level weights under the logit rule. Raw scores were generated by iteration on an interval scale. To facilitate interpretation, the scores were subsequently rescaled to a standardized 0–100 ratio scale; the higher the score, the more important the FAQ. Furthermore, a FAQ with an RI of 5 is twice as important as a FAQ with a RI of 2.5. All RIs sum to 100 for each individual. Thus, the RIs represent the relative importance of an FAQ in relation to all other FAQs. The HB analysis provides a root likelihood (RLH) for random responders. Based on the number of items shown per set (5 in the current study) an RLH > 0.269 indicates that the responses appear thoughtful and consistent. The HB analyses were performed for patients and health care professionals separately, using the Sawtooth Software platform. Analyses were performed only on data of participants who completed the exercise. The software generated raw scores and RIs for each FAQ per individual respondent.

Potential differences in RIs between the patients’ and professionals’ top 5 FAQs were analyzed using independent t-tests, performed with Stata 13 software. For all analyses, a significance level of P less than or equal to 0.05 was assumed. Additionally, FAQs that differed by ≥1.67 in RI between patients and health care professionals were addressed. We considered a difference of 1.67 to be relevant, because this is the average score per FAQ when the total points (100) are distributed over the 60 FAQs. Differences in RIs in different settings were explored descriptively.

Ethical approval
This study protocol (no. 2017-3184) was presented to the Medical Research Ethics Committee, region Arnhem-Nijmegen, The Netherlands. An exemption was obtained, because this type of study does not require ethics approval according to Dutch law. All participants of the prioritizing step provided online informed consent.

Results
Inventory
A total of 28 health care professionals (11 rheumatologists, 7 orthopaedic surgeons, 1 nurse practitioner, 6 GPs, and 3 physiotherapists) took part, and the Dutch Arthritis Foundation provided 192 FAQs. From these FAQs, 104 were deleted because they were duplicates, they could be combined with another FAQ (n = 10), or they could be answered with the information on www.thuisarts.nl (n = 13). Another 5 FAQs were deleted because they were unclearly formulated (n = 3) or addressed other joints than the hip or knee (n = 2). The remaining 60 FAQs were used in the prioritizing step.

Prioritizing Participants
A total of 107 patients started the online questionnaire, and 99 completed the MaxDiff exercise. One patient had an RLH < 0.269 and was excluded. Four patients were excluded because they reported that their symptoms were caused by something other than OA. Characteristics of 94 participants (response rate of 24%) are shown in Table 1. Half of the patients had OA symptoms for ≤5 years. Approximately half of the patients had already had a joint replacement as treatment for their OA.

Table 1. Demographic characteristics of patients (n=94) and healthcare professionals (n=122) participating in the prioritizing-step

<table>
<thead>
<tr>
<th></th>
<th>Patients (survey)</th>
<th>Professionals (survey)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD), years</td>
<td>67.3 (8.1)</td>
<td>45.7 (10.8)</td>
</tr>
<tr>
<td>Sex, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>57 (60.6)</td>
<td>67 (54.9)</td>
</tr>
<tr>
<td>Educational level, n(%)</td>
<td>45 (47.9)</td>
<td>42 (34.4)</td>
</tr>
<tr>
<td>Low</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effected joint, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hip</td>
<td>41 (43.6)</td>
<td>18 (14.8)</td>
</tr>
<tr>
<td>Knee</td>
<td>46 (48.9)</td>
<td>25 (20.2)</td>
</tr>
<tr>
<td>Hip and Knee</td>
<td>7 (7.5)</td>
<td>43 (34.7)</td>
</tr>
<tr>
<td>Time since diagnosis, n (%)</td>
<td>25 (26.6)</td>
<td>26 (21.7)</td>
</tr>
<tr>
<td>≤1 years</td>
<td>8 (8.5)</td>
<td>25 (20.2)</td>
</tr>
<tr>
<td>1-5 years</td>
<td>42 (44.7)</td>
<td>30 (24.2)</td>
</tr>
<tr>
<td>5-10 years</td>
<td>19 (20.2)</td>
<td>25 (20.2)</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>25 (26.6)</td>
<td>25 (20.2)</td>
</tr>
<tr>
<td>Setting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care</td>
<td>25 (26.6)</td>
<td>25 (20.2)</td>
</tr>
<tr>
<td>Secondary care</td>
<td>26 (27.7)</td>
<td>25 (20.2)</td>
</tr>
<tr>
<td>Post joint replacement</td>
<td>43 (45.7)</td>
<td>25 (20.2)</td>
</tr>
</tbody>
</table>
A total of 140 health care professionals started the online questionnaire, of whom 124 finished the MaxDiff exercise. Two health care professionals were excluded because they did not fit the occupational categories, resulting in data of 122 health care professionals (response rate of 18%) usable for this study. The median years in practice of participating health care professionals was 15.5 years (interquartile range 6–25) (Table 1).

**Most important and least important FAQs**

Figure 1 shows the top 5 most important FAQs ranked by patients and health care professionals. The overall prioritizing of all 60 FAQs by patients and health care professionals is shown in Supplementary Table 1, available on the Arthritis Care & Research web site at http://onlinelibrary.wiley.com/doi/10.1002/acr.23719/abstract. The highest ranked FAQ both for patients and for health care professionals was “What can I do myself to decrease symptoms and to prevent the OA from getting worse?” Another FAQ that was prioritized in the top 5 for both groups but had significantly different RIs was “What is the natural course of OA?” FAQs that were in the patients’ top 5 but were not ranked in the top 5 of the health care professionals were: “What are the newest treatment options?”, “Is there any medication that can either slow down or stop OA?”, and “What are the latest research results concerning OA?” Three FAQs that were in the professionals’ top 5 but not in the patients top 5 were: “What can or can I not do in terms of exercise and physical activity?”, “I’m young and I have OA. What changes should I make to my life and what should or shouldn’t I do anymore?”, and “Can exercise or being physically active be harmful to my joints?”

Seven FAQs that differ by at least 1.67 in RI score between patients and health care professionals are shown in Table 2. Two FAQs that were scored considerably higher by patients than by health care professionals were “What are the latest research results concerning OA?” and “What are the newest treatment options?” The other 5 FAQs were scored higher by health care professionals than by patients (Figure 1).

**Table 2. Frequently asked questions (FAQs) that have an absolute difference of ≥ 1.67 in Relative Importance (RI) between patients and healthcare professionals.**

<table>
<thead>
<tr>
<th>FAQ</th>
<th>RI Patients</th>
<th>RI Healthcare professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can exercise or being physically active be harmful to my joints?</td>
<td>1.87</td>
<td>3.66</td>
</tr>
<tr>
<td>Can being overweight be harmful for my joints?</td>
<td>0.94</td>
<td>2.86</td>
</tr>
<tr>
<td>Can I continue doing my job or do I need to make certain adaptations to my working environment because of my OA?</td>
<td>0.71</td>
<td>2.71</td>
</tr>
<tr>
<td>Why do I have to try all these other treatment options, when surgery is also an option?</td>
<td>1.16</td>
<td>3.17</td>
</tr>
<tr>
<td>What are the latest research results concerning OA?</td>
<td>3.74</td>
<td>1.23</td>
</tr>
<tr>
<td>What are the newest treatment options?</td>
<td>4.47</td>
<td>2.14</td>
</tr>
<tr>
<td>I’m young and I have OA. What changes should I make to my life and what should or shouldn’t I do anymore?</td>
<td>0.78</td>
<td>3.88</td>
</tr>
</tbody>
</table>

**Exploring subgroup differences**

Exploration of subgroup differences between primary care, secondary care, and postsurgery patients did not reveal differences in RIs ≥1.67, indicating the absence of large differences in RI of FAQs between patient groups (Table 2).

**Figure 1A.** Relative importance scores (RIs) of both patients (black bars) and healthcare professionals (grey bars) of top 5 most important frequently asked questions (FAQs) as prioritized by patients.

**Figure 1B.** RIs of both patients (black bars) and healthcare professionals (grey bars) of top 5 most important FAQs as prioritized by healthcare professionals. Significant differences (p < 0.05) are indicated with a *.
Discussion

The FAQ “What can I do myself to decrease symptoms and to prevent the OA from getting worse?” was prioritized as most important by both patients and professionals in the current study. Other FAQs that were highly prioritized by patients were more directed toward treatment options offered by different health care professionals, whereas highly prioritized FAQs of professionals were more often focused on treatment options involving self-management.

The highest ranked FAQ by both patients and health care professionals, “What can I do myself to decrease symptoms and to prevent the OA from getting worse?” highlights the importance of patients’ need for information about OA and to feel confident in managing their condition. This need is in concordance with the guideline recommendation that self-management is important for patients with hip or knee OA. It is also in line with the nature of the key messages that French et al. reported to be essential for hip or knee OA patients, because 15 of those 21 statements covered treatment options and management in which the patients have an active role. This concordance between patients and health care professionals provides a good starting point for education and communication about treatment options. However, a recent review by Chou et al. showed that patients have a need for specific guidance. This need has also been seen in our results, where the majority of collected FAQs were very specific, i.e., “What sports can I still do? At what frequency and intensity?” and “What can the orthopedic surgeon or rheumatologist do for me?” Concrete recommendations about self-management, for instance about the type of exercise or how to navigate the health care system, should be handed to patients more directly. Providing this information not only in the consultation room but especially in an educational program provided by multiple health care professionals can be a good option to encourage patients toward the principles of self-management.

The importance of an active role by the patient is clearly found in the health care professionals’ top 5 choices. For instance “What can or can I not do in terms of exercise and physical activity?” and “Can exercise or being physically active be harmful to my joints?” can be seen as questions that illustrate the importance of conservative treatment options in which the patient plays an active role. This concern shows that health care professionals need to put effort into explaining the important active role patients can have in alleviating their symptoms and controlling their OA. Such an effort may be a challenge, because health care professionals themselves do not always have confidence in the outcome of conservative treatment options and in the willingness and capability of patients to play an active role. A lack of communication between health care professionals may contribute to low confidence in conservative treatment options. Collaboration among health care professionals to answer FAQs may improve insight among professionals on each other’s role and perspective on OA treatment. In addition, a joint endeavor of multiple disciplines to answer FAQs offers the opportunity to provide consistent knowledge about OA, which is important because patients report that they receive unclear and inconsistent information. The FAQs from our study offer a starting point for discussion to achieve consensus on the content of information and to improve patient education.

Two FAQs that were scored considerably higher by patients than by professionals were ”What are the latest research results concerning OA?” and “What are the newest treatment options?” These findings are in line with previous research showing that patients have an interest in recent developments and experimental treatments for their condition. Active information-seeking behavior of patients has developed in the past decades, and access to information on the internet may contribute to this behavior. Although information on experimental treatments is not applicable to all patients, for health care professionals to explicitly address this informational need could be worthwhile. Because effective management of OA requires actively involved patients, delivery of patient-centered care seems essential in this respect. After learning about the lack of new treatment options or the unknown effects of experimental treatments, patients may be more open to information about current conservative treatment options like physical activity and weight loss.

We explored differences between patient subgroups in different settings of treatment descriptively, but we did not find any large differences. One issue that should be taken into account is that patients with replaced joints seem to be overrepresented in our study population, because 47% of patients reported 1 or more joint replacements. However, participants were asked to take the perspective of all patients with OA, and FAQ ranking proved similar in those with and without replacements. This outcome suggests that information is important for every OA patient. Because of our small subgroups, this result should be interpreted with caution. Brembo et al. identified informational needs related to the disease continuum of hip OA patients. For instance, a key question during the phase when symptoms significantly decrease quality of life is: “I can’t stand the pain, is it time for surgery?” However, the researchers’ aim was specifically focused on identifying needs per stages of disease, rather than studying differences. Further research into informational needs at different stages of OA is therefore recommended.

There are several limitations to our study that should be mentioned. First, with a response rate between 18% and 24% there might be selection bias. We invited a large sample of patients from primary care and health care professionals from different settings, but we have no characteristics of the nonresponders and could not compare responders to nonresponders. Responders might have higher informational needs, but this possibility does not necessarily affect prioritization. Second, we included health care professionals from different disciplines, and there might be differences between these subgroups in prioritization. Although no clear guidelines for a minimal sample size for the MaxDiff method are given, in our view our sample size did not allow comparisons between subgroups of health care professionals. Health care professionals were invited from primary care and from 3 different medical centers: 1 university medical center, 1 specialized hospital for rheumatology, orthopedic surgery, and rehabilitation medicine, and 1 local general hospital. This variety of hospital types assures a good representation of The Netherlands. However, because of differences in health care systems, generalizability to other countries should be taken with caution. Last, because participants had to answer 24 subsets in the MaxDiff exercise, they may have given less attention at the end of the questionnaire, but using the RLH as an indicator should have limited this problem.

A strength of our study is that we included new FAQs based on input from a wide range of patients and health care professionals, from different fields in both primary and secondary care, that were not evaluated in previous studies and that are not mentioned in national and international guidelines. By investigating informational needs beyond guideline recommendations, we provided specific practical points for information that can be given
to patients in daily practice and in future interventions. In addition to providing basic
information, health care professionals can spend time on highly ranked topics at the expense
of identified topics that are considered less important.

This study provides informational needs of patients with hip or knee OA that go beyond
guideline recommendations. Our results provide starting points for optimizing patient
education and improving information given in daily clinical practice. A next step should be to
formulate answers for the most important FAQs, with health care professionals from different
disciplines, to provide patients with consistent information from a common perspective. These
answers can be used in educational programs and materials.

Funding

This project was funded by the healthcare insurance company Coöperatie VGZ.

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Supplementary Material

Total list of frequently asked questions (FAQs) (n=60) used in the MaxDiff exercise, ranked by patients and healthcare professionals, with relative importance scores (RI).

<table>
<thead>
<tr>
<th>Ranking patients</th>
<th>FAQ</th>
<th>RI</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>What can I do myself to decrease symptoms and to prevent the OA from getting worse?</td>
<td>4.81</td>
</tr>
<tr>
<td>2</td>
<td>What are the newest treatment options?</td>
<td>4.47</td>
</tr>
<tr>
<td>3</td>
<td>Is there any medication that can either slow down or stop OA?</td>
<td>3.77</td>
</tr>
<tr>
<td>4</td>
<td>What are the latest research results concerning OA?</td>
<td>3.74</td>
</tr>
<tr>
<td>5</td>
<td>What is the natural course of OA?</td>
<td>3.16</td>
</tr>
<tr>
<td>6</td>
<td>If the effects of medication are insufficient, what other treatment options do I have?</td>
<td>3.16</td>
</tr>
<tr>
<td>7</td>
<td>What can or can I not do in terms of exercise and physical activity?</td>
<td>3.04</td>
</tr>
<tr>
<td>8</td>
<td>What can the orthopaedic surgeon or rheumatologist do for me?</td>
<td>3.04</td>
</tr>
<tr>
<td>9</td>
<td>If I have OA in a certain joint, do I then have an increased chance to get OA in other joints?</td>
<td>3.00</td>
</tr>
<tr>
<td>10</td>
<td>What medication can the GP prescribe to alleviate my symptoms and in what timeframe can I expect results?</td>
<td>2.87</td>
</tr>
<tr>
<td>11</td>
<td>Can I expect a recovery of my activity-level within a certain period of time after my surgery?</td>
<td>2.40</td>
</tr>
<tr>
<td>12</td>
<td>What can a physiotherapist do for me?</td>
<td>2.39</td>
</tr>
<tr>
<td>13</td>
<td>Where can I find specialized treatments for OA?</td>
<td>2.36</td>
</tr>
<tr>
<td>14</td>
<td>Do injections with corticoids or hyaluronic acid have any effect?</td>
<td>2.27</td>
</tr>
<tr>
<td>15</td>
<td>What sports can I still do? At what frequency and intensity?</td>
<td>2.27</td>
</tr>
<tr>
<td>16</td>
<td>What can I expect from a joint replacement, and what can I do in terms of exercise and work?</td>
<td>2.24</td>
</tr>
<tr>
<td>17</td>
<td>When am I eligible for a joint replacement?</td>
<td>2.16</td>
</tr>
<tr>
<td>18</td>
<td>Can OA be cured?</td>
<td>2.05</td>
</tr>
<tr>
<td>19</td>
<td>How do I know what my physical limits are when I am on pain killers?</td>
<td>2.03</td>
</tr>
<tr>
<td>20</td>
<td>What is the survival in years of a prosthesis?</td>
<td>1.89</td>
</tr>
<tr>
<td>21</td>
<td>Can exercise or being physically active be harmful to my joints?</td>
<td>1.87</td>
</tr>
<tr>
<td>22</td>
<td>What specific aids can I use to alleviate my symptoms and who can help me with this?</td>
<td>1.87</td>
</tr>
<tr>
<td>23</td>
<td>There are stories going around about prosthesis breaking. How do I know if my prosthesis is of good quality?</td>
<td>1.85</td>
</tr>
<tr>
<td>24</td>
<td>Can the regular use of painkillers be harmful for the further development of my hip or knee OA?</td>
<td>1.80</td>
</tr>
<tr>
<td>25</td>
<td>I am so tired sometimes. Is that something that is a part of the OA? What can I do about it?</td>
<td>1.76</td>
</tr>
<tr>
<td>26</td>
<td>Can a certain type of diet or food influence my OA symptoms?</td>
<td>1.72</td>
</tr>
<tr>
<td>27</td>
<td>When will I be able to put full weight on my leg after a joint replacement surgery?</td>
<td>1.67</td>
</tr>
<tr>
<td>28</td>
<td>What is known about deacidification in OA?</td>
<td>1.58</td>
</tr>
<tr>
<td>29</td>
<td>What side effects can medication have?</td>
<td>1.56</td>
</tr>
<tr>
<td>30</td>
<td>What treatment options are covered by my insurance company?</td>
<td>1.52</td>
</tr>
<tr>
<td>31</td>
<td>What is the rehabilitation process after getting a joint replacement like?</td>
<td>1.51</td>
</tr>
</tbody>
</table>
1 Why does OA sometimes feel like an inflammation? 1.44
2 I have heard about special infusions for RA. Can't I get those for my OA? 1.43
3 What can I do when the pain wakes me up at night OA? 1.39
4 What is the best sleeping posture to relieve my OA-joint? 1.28
5 Can I use paracetamol for a prolonged period of time, or will my body become immune to the effect? 1.27
6 The use of physiotherapy increases my symptoms, what should I do? 1.23
7 What can I do when the pain wakes me up at night OA? 1.21
8 The orthopaedic surgeon suggests a joint replacement, but I do not want that yet. Can I postpone this until I am ready for it? 1.21
9 What is the difference between rheumatoid arthritis (RA) and OA? 1.20
10 Why do I have to try all these other treatment options, when surgery is also an option? 1.16
11 When will I be able to drive a car/work etc. after a joint replacement surgery? 1.05
12 How do I clarify to my surroundings that while I’m able to do something today, I might not be able to do the same thing tomorrow because of the variations in symptoms of my OA? 0.97
13 Can being overweight be harmful for my joints? 0.94
14 Will homeopathy help with my OA? 0.88
15 Why is OA also referred to as wear and tear of the joints if they are in fact increasing in size? 0.85
16 Is OA the same as osteoporosis? 0.80
17 I'm young and I have OA. What changes should I make to my life and what should or shouldn't I do anymore? 0.78
18 I can no longer reach my feet to put on socks or shoes. What can I do to solve this problem? 0.74
19 Where can I apply as a participant for research? 0.73
20 Can I continue doing my job or do I need to make certain adaptations to my working environment because of my OA? 0.71
21 My GP doesn’t take my symptoms seriously. What can I do? 0.62
22 What should I take in consideration when purchasing a new bed or matrass? 0.59
23 Losing weight is impossible, what should I do? 0.50
24 Why am I in so much more pain than my neighbour, who is also suffering from OA. 0.42
25 I cannot go to work because of my OA: Can I do what? 0.39
26 Can my company doctor approve my physical ability for all my work? 0.39
27 Should I inform my employer about my OA? 0.37
28 Because of the Dutch law for sick employees, I am currently not working. The medical officer informed me that I should be able to work a xx number of hours a week. I disagree. How can I deal with this? 0.37
29 Is it possible to operate two joints at the same time 0.28
30 Am I not much too young to suffer from OA? 0.23
FAQs from patients with hip or knee OA

Chapter 3

Preliminary effects of a regional approached multidisciplinary educational program on healthcare utilization in patients with hip or knee osteoarthritis: an observational study

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Abstract

Background
Providing relevant information on disease and self-management helps patients to seek timely contact with care providers and become actively involved in their own care process. Therefore, health professionals from primary care, multiple hospitals and health organisations jointly decided to develop an educational program on osteoarthritis (OA). The objective of the present study was to determine preliminary effects of this OA educational program on healthcare utilization and clinical outcomes.

Methods
We developed an educational group-based program consisting of 2 meetings of 1.5 hours, provided by a physiotherapist, a general practitioner (GP) and orthopaedic surgeon or specialized nurse. The program included education on OA, (expectations regarding) treatment options and self-management. Patients were recruited through searching the GP’s electronic patients records and advertisements in local newspapers. At baseline and at 3 months follow-up participating OA patients completed questionnaires. Paired-sample t-tests, McNemar’s test and Wilcoxon Signed-Rank test were used to estimate the preliminary effects of the program.

Results
A total of 146 participants in 3 districts attended the sessions, of whom 143 agreed to participate in this study: mean age 69.1 years (SD 10.2); 107 (75%) participants completed both baseline and follow up assessments. The proportion of participants who had visited their GP in the 3 months after the program was lower than 3 months previous to the program (40% versus 25%, p-value 0.02). Also, we observed a decrease in proportion of patients who visited the physio- and exercise therapist, (56.1% versus 31.0%, p-value 0.02). Both illness perceptions and knowledge on OA and treatment options changed positively (Δ0.8, 95%CI 0.4, 3.4 and Δ2.4, 95%CI -3.0, -1.6 respectively). No changes in BMI, pain, functioning and self-efficacy were found. However, a trend towards an increase in physical activity was observed.

Conclusions
Our results show that a multidisciplinary educational program may result in a decrease in healthcare utilization and has a positive effect on illness perceptions and knowledge on OA due to clear and consistent information on OA and it treatment options.

Background
Osteoarthritis (OA) is the most prevalent form of disability of posture and movement worldwide. OA of the hip and knee is characterised by pain and stiffness which can impair daily functioning, and decrease physical activity. This physical and accompanying mental burden influences the quality of life in patients with OA. Although there are no curative treatment options for OA, multiple effective non-surgical and surgical treatment options for reducing pain and improving movement ability and quality of life are available.

International guidelines recommend a combination of pharmacologic and non-pharmacologic modalities as primary approach for hip or knee OA. Non-pharmacological treatment modalities include psycho-educational interventions to improve self-management, physical activity and exercise therapy, and weight reduction. Recommended pharmacologic treatment consists of the use of acetaminophen (paracetamol), the use of non-steroidal anti-inflammatory drugs (NSAIDs) or, when the patient is not responding satisfactorily to oral analgesic/anti-inflammatory agents, intra-articular injections. Once non-surgical treatments become unsuccessful, joint replacement surgery is a cost-effective procedure that can be considered for patients with severe symptoms. However, joint replacement surgery is advised to be postponed as long as possible, as the lifespan of prostheses are limited and the results can vary.

In recent years the total number of hip and knee replacement surgeries increased with 50% and 196% respectively, especially in the age group of 75-85 years. Possible explanations for this overall increase are ageing of the population and increase in obesity resulting in more people suffering from symptomatic OA. Despite recommendations, conservative treatment modalities in hip or knee OA are underused while timely usage of these treatment modalities is advocated and may prevent untimely surgery.

The underuse of conservative treatment can be caused by healthcare providers related barriers for recommending conservative treatment modalities. Research shows that outcome expectations about conservative treatment options differ widely among healthcare providers and the confidence in competencies of other healthcare providers is low. As a result, patients with OA may not receive consistent information about effective, conservative treatment options. Receiving conflicting information is found to be associated with undesirable outcomes like non-adherence to treatment. Therefore, information on treatment options and strategies should be disseminated from a joint perspective of healthcare providers.

In addition, patient related factors might also influence the use of treatment modalities. Some patients are not aware of what they can do themselves and what conservative treatment options can be offered for their OA. Providing relevant disease-related and self-management related information helps patients to become actively involved in their own care process. Moreover, negative beliefs or unrealistic thoughts about different treatment modalities by patients might also influence the choice of treatment. A recent systematic review showed that OA patients have a negative attitude towards the efficacy of conservative treatment and tend to prefer surgical treatment. This emphasises the importance that patients are aware of benefits as well as possible disadvantages of both conservative and surgical treatment options, in order to have realistic expectations.
During a regional conference in the area of Nijmegen, the Netherlands, healthcare providers from different disciplines involved in the care for people with OA decided to develop a patient educational program with a multidisciplinary approach to tackle above outlined barriers for suboptimal care.

The aim of this program was to increase patients’ knowledge on OA, to stimulate self-management, to discuss benefits and disadvantages of treatment options, to promote the stepped care approach of treatments and to provide consistent answers to frequently asked questions by patients. The objective of the present study was to determine preliminary effects of this OA educational program on healthcare utilization (HCU) and clinical outcomes.

Methods

Design and setting
An observational pilot study was performed in three districts in the Nijmegen area, the Netherlands, to evaluate a knee and hip OA educational program at baseline, and 3 months after finishing the course. In the period of October 2015 – March 2016, the program was organized 11 times (3-4 times per district). According to the Central Committee on Research involving Human Subjects (CCMO), this type of study does not require approval from an ethics committee in the Netherlands. This study was approved by the local Medical Research Ethics Committee, region Arnhem–Nijmegen (protocol number: 2015-2024).

Study population
Patients were eligible for the program when they were aged 18 years or older and had a clinical diagnosis of OA in the knee or hip (diagnosed by a general practitioner (GP) or medical specialist). Exclusion criteria were inability to read or understand the Dutch language, and previous joint replacement surgery. A maximum of 20 people (including patients and their partner or other significant person) could participate in each of the 11 planned programs, in order to facilitate group interaction. We aimed to include a total of 110-132 patients with knee or hip OA (10-12 patients per program).

Procedure
GP’s and physiotherapists in the three different participating districts and several orthopaedic surgeons in de region were informed about the objectives, background and content of the study. They were asked to offer eligible patients a flyer with information about the knee and hip OA educational program. Additionally, a public health advisor attended the program. One of the healthcare professionals in each of the carried out meetings was part of the research team. They were asked to approach healthcare providers in their own district to help them carrying out the meetings.

The educational program was developed by an expert group working in the field of OA. The expert group consisted of 2 orthopaedic surgeons, 1 rheumatologist, 1 nurse practitioner, 3 physiotherapists, 1 GP and 2 physiotherapist-researchers. First an inventory of frequently asked questions (FAQs) about OA was made among local health professionals. Second, a prioritising exercise was used among OA-patients and health professionals to determine the most important FAQs. Finally, the expert group discussed and formulated answers to the 20 most important FAQs until consensus was reached. A detailed description of the process of inventory and prioritising of FAQs is described in Additional file 1. The content of the program was based on this structured inventory of informational needs and on consensus-based information addressing those needs. The FAQs and answers were incorporated in the course material. In line with current guidelines on education for patients with knee or hip OA, the program consisted of information on: OA and its disease course, evidence based tailored conservative treatment in a stepped-care format, and surgical treatment options. Moreover, education was given on outcome risks of treatment options and expectation management. This information provided patients with knowledge on where to find the (treatment) help they needed, at the time they needed it, with the appropriate expectations about this treatment. Additionally, the program included information on regional options to enhance self-management and physical activity, tips, practical assignments and mottos on OA.

To support the information given during the course, participants received a booklet consisting of information, monitoring forms, course handouts, the 20 FAQs, a pedometer and a list of useful websites, mobile applications and contact information of organisations.

Data collection

Baseline data
At baseline, patients’ characteristics were collected on: age, gender, the number of important comorbidities (ranging from 0 to 15) according to the Dutch Arthritis Impact Measurement Scales, living situation (alone / living with partner and/or family), education (low / high), ethnicity (native / foreign), employment (workless/paid work), duration of symptoms (<1 year / 1-5 years / 5-10 years / >10 years) and location of OA (hip and/or knee), and number of painful joints (including hip, knee, neck, back, shoulders, elbows, wrists, hands, ankle and feet).
Measurement instruments
Outcome parameters at baseline and 3 months follow-up were HCU, pain medication use, pain and functioning in daily living, illness perceptions, patient activation, knowledge, physical activity and patient satisfaction with the course. HCU was assessed with a self-developed questionnaire. Patients were asked which healthcare providers they visited in the preceding 3-month period related to their hip or knee symptoms (yes/no) and to indicate the number of contacts to these healthcare providers.

In addition, to record the use of pain medication, participants were asked if they used (yes/no) pain medication (paracetamol / non-steroidal anti-inflammatory drugs (NSAID) / other (i.e. tramadol, morphine)) in the past 3 months regarding their hip or knee OA. To calculate BMI (weight/height²) weight and height were self-collected. Two subscales of the Western Ontario McMaster University Index of osteoarthritis (WOMAC) were used to assess pain and limitations in functional activities. The WOMAC is a 24-item questionnaire, subdivided in 3 subscales: pain, stiffness and physical functioning. WOMAC pain and physical functioning subscales were calculated and presented as normalized scores (0 to 100, with higher scores indicating less pain and better functioning). Participants were asked to fill out the Dutch General Self-efficacy Scale (GSES) to measure self-efficacy. The GSES has 10 items of which a total score can be calculated ranging from 10 to 40. With higher scores indicating higher self-efficacy. The Brief illness perception questionnaire (IPQ) is a 8-item scale and was used to measure illness perceptions. It measures patient's cognitive and emotional perceptions with respect to their OA. The maximum score on the Brief IPQ is 80, with higher scores reflecting more threatening view of the OA. To assess patient activation, defined as patients' knowledge, skill, and confidence for self-management, the Patient Activation Measure (PAM-21) was used. A total score can be calculated ranging from 13 (low confidence for managing own health and healthcare) to 52 (high confidence for managing own health and healthcare).

Physical activity was measured using the Short Questionnaire to Assess physical activity and patient satisfaction with the course. HCU was assessed with a self-developed questionnaire. Patients were asked which healthcare providers they visited in the preceding 3-month period related to their hip or knee symptoms (yes/no) and to indicate the number of contacts to these healthcare providers.

Results
Patient characteristics
In total 146 patients with knee or hip OA and 54 of their partners participated in the educational program. Overall mean rating of satisfaction with the program was 8.0 (range 1-10). A total of 143 patients agreed to participate in the present study. 107 (75%) participants filled out both questionnaires, 4 were considered drop-outs, as they did not come to the intervention and did not want to continue with the study. Two participants had undergone surgery during the follow-up period and did not feel like to continue. One did have knee OA, but as symptoms of her hand OA were more severe, she did not feel like filling out another questionnaire. All other 29 participants were lost to follow-up without providing a reason. We found no differences on baseline characteristics between drop-out/loss to follow-up and those who completed follow-up questionnaires. Despite the exclusion criteria, 17 participants reported to have had previous joint replacement. Sensitivity analyses showed no differences on HCU regarding surgical visits. Therefore, these participants were not excluded from analysis.

The average age of participants was 69.1 years (SD 10.2), with the majority being female (62.9%). Fifty-six percent of the participants had experienced their OA symptoms for less than 5 years. Patient characteristics are presented in Table 1.

Table 1. Baseline demographic and clinical characteristics of participants (n=143)

<table>
<thead>
<tr>
<th>Social-demographic characteristics</th>
<th>Gender, n (%)</th>
<th>Age (years), mean ± SD</th>
<th>Ethnicity, n (%)</th>
<th>Living situation, n (%)</th>
<th>Level of Education, n (%)</th>
<th>Clinical characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>69.1 ± 10.2</td>
<td>Native</td>
<td>131 (91.6)</td>
<td>10 (68.4)</td>
<td>Location, n (%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>44 (30.8)</td>
<td>44 (30.8)</td>
<td>Hip</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>55 (38.5)</td>
<td></td>
<td>Kneel</td>
</tr>
<tr>
<td>Number of comorbidities (range 0-15); median (IQR)</td>
<td>5 (2-4)</td>
<td>3 (2-4)</td>
<td>3 (2-4)</td>
<td>3 (2-4)</td>
<td>3 (2-4)</td>
<td></td>
</tr>
<tr>
<td>Number of painful joints (range 0-10); median (IQR)</td>
<td>5 (0-10)</td>
<td>10 (0-10)</td>
<td>5 (0-10)</td>
<td>5 (0-10)</td>
<td>5 (0-10)</td>
<td></td>
</tr>
<tr>
<td>Duration of symptoms, n (%)</td>
<td>1-5 years</td>
<td>13 (9.2)</td>
<td>13 (9.2)</td>
<td>13 (9.2)</td>
<td>13 (9.2)</td>
<td></td>
</tr>
<tr>
<td>&gt; 10 years</td>
<td>30 (21.3)</td>
<td>30 (21.3)</td>
<td>30 (21.3)</td>
<td>30 (21.3)</td>
<td>30 (21.3)</td>
<td></td>
</tr>
<tr>
<td>Number of painful joints (range 0-10); median (IQR)</td>
<td>5 (0-10)</td>
<td>5 (0-10)</td>
<td>5 (0-10)</td>
<td>5 (0-10)</td>
<td>5 (0-10)</td>
<td></td>
</tr>
</tbody>
</table>

Statistical analyses
Baseline descriptive statistics were calculated as mean and standard deviation (SD), numbers with percentages (%) or median and Interquartile range (IQR). Changes over time in contacts with different healthcare providers were analysed using the exact McNemar's test and Wilcoxon Signed-Rank test. Difference between baseline and follow-up in secondary outcomes were analysed using the exact McNemar's test or Paired sample t-tests (two-sided). For all analyses a significance level of p ≤ 0.05 was assumed.
Healthcare utilization

Table 2 shows the HCU during the 3 months before baseline and during 3-months follow-up. Most common were visits to a physio- or exercise therapist, GP and orthopaedic surgeon regarding knee or hip OA. A significant decrease in proportion of patients who visited the physio- or exercise therapist and GP in the previous 3 months was observed. Although no changes in median number of contacts were seen, the total number of contacts increased. Small but non-significant changes in proportion of patients who visited a medical specialist were found. However, median number of visits to a medical specialist showed a small decrease, which was also seen in the total number of contacts in secondary care.

Table 2. Changes in proportion of patients visiting different healthcare providers and total number of contacts with healthcare providers between baseline and 3 months follow-up (n=107).

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>Follow-up</th>
<th>p-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>43 (40.2)</td>
<td>27 (25.2)</td>
<td>0.01*</td>
</tr>
<tr>
<td>Physio- or exercise therapist</td>
<td>39 (36.5)</td>
<td>26 (24.3)</td>
<td>0.02*</td>
</tr>
<tr>
<td>Dietician</td>
<td>3 (2.8)</td>
<td>3 (2.8)</td>
<td>1.00</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>2 (1.9)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Psychologist</td>
<td>1 (0.9)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Nurse (in GP practice)</td>
<td>6 (5.6)</td>
<td>5 (4.7)</td>
<td>1.00</td>
</tr>
<tr>
<td>District nurse/home care</td>
<td>1 (0.9)</td>
<td>2 (1.9)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total number of contacts</strong></td>
<td>258</td>
<td>327</td>
<td></td>
</tr>
<tr>
<td><strong>Secondary care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rheumatologist</td>
<td>6 (5.6)</td>
<td>3 (2.8)</td>
<td>0.25</td>
</tr>
<tr>
<td>Orthopaedic surgeon</td>
<td>20 (18.7)</td>
<td>15 (14.0)</td>
<td>0.30</td>
</tr>
<tr>
<td>Physician assistant / nurse practitioner</td>
<td>3 (2.8)</td>
<td>2 (1.9)</td>
<td>1.00</td>
</tr>
<tr>
<td>Multidisciplinary team care / pain clinic</td>
<td>1 (0.9)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total number of contacts</strong></td>
<td>46</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td><strong>Median (IQR)</strong></td>
<td>1 (0-2)</td>
<td>0 (0-3)</td>
<td>0.48*</td>
</tr>
</tbody>
</table>

* Exact McNemar significance probability  
b Wilcoxon Signed-Rank test  
Significant for p-value ≤ 0.05

Secondary outcomes

Changes in secondary outcomes are shown in table 3. Illness perceptions changed positively (Δ-1.8; 95% CI: -4.4, 3.4), and knowledge on OA and treatment options improved (Δ2.4; 95% CI: -3.0, -1.6). No changes in BMI, pain, functioning, self-efficacy and patient activation were found. However, a trend towards an increase in physical activity was seen.

Table 3. Differences between baseline and follow-up on secondary outcome measures (n=107 complete cases).

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>Follow-up</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI (kg/m²), mean (SD)</td>
<td>22.1 (4.4)</td>
<td>26.7 (4.1)</td>
<td>0.16*</td>
</tr>
<tr>
<td>WOMAC pain (range 0-100), mean (SD)</td>
<td>66.8 (21.4)</td>
<td>69.7 (20.1)</td>
<td>0.13*</td>
</tr>
<tr>
<td>WOMAC functioning (range 0-100), mean (SD)</td>
<td>83.1 (19.6)</td>
<td>67.8 (21.2)</td>
<td>0.78*</td>
</tr>
<tr>
<td>Medication use, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paracetamol</td>
<td>65 (61.9)</td>
<td>62 (59.1)</td>
<td>0.65*</td>
</tr>
<tr>
<td>NSAIDS</td>
<td>33 (31.4)</td>
<td>25 (24.5)</td>
<td>0.08*</td>
</tr>
<tr>
<td>Other</td>
<td>14 (13.1)</td>
<td>17 (15.9)</td>
<td>0.45*</td>
</tr>
<tr>
<td>SQUASH Total activity (min/week), mean (SD)</td>
<td>2128.9 (1023.1)</td>
<td>2349.2 (1246.8)</td>
<td>0.07*</td>
</tr>
<tr>
<td>IPQ Illness perceptions (range 0-100), mean (SD)</td>
<td>41.3 (10.5)</td>
<td>39.5 (10.3)</td>
<td>0.02*</td>
</tr>
<tr>
<td>GSES Self-efficacy (10-40), mean (SD)</td>
<td>32.1 (5.9)</td>
<td>32.2 (5.6)</td>
<td>0.85*</td>
</tr>
<tr>
<td>PAM-13, patient activation (13-52), mean (SD)</td>
<td>39.3 (9.5)</td>
<td>40.1 (9.5)</td>
<td>0.15*</td>
</tr>
<tr>
<td>Knowledge on OA (0-22), mean (SD)</td>
<td>10.5 (3.2)</td>
<td>12.9 (3.1)</td>
<td>0.001*</td>
</tr>
</tbody>
</table>

* Exact McNemar significance probability  
Wilcoxon Signed-Rank test, two-sided  
Significant for p-value ≤ 0.05

Discussion

Results of the present study show a decreased HCU, the proportion of patients having contact with a physio- or exercise therapist, or general practitioner decreased after following the educational program. We found an increase in knowledge on OA and patients’ perceptions towards their OA changed positively after the course. No significant changes were found in BMI, pain and functioning, physical activity, patient activation and self-efficacy.

Overall, our results are in line with the Cochrane review on self-management programs of Kroon et al.; we also did not find any changes on self-efficacy, pain and functioning. This review however, did not evaluate the effect of self-management programs on illness perceptions, OA knowledge and HCU. We believe that the changes in these parameters are relevant to patients. This is in line with a recent randomized controlled trial, evaluating the effect of a patient decision aid for patients considering joint replacement, (including patient education on treatment options, benefits and risks) that reported positive results on knowledge and illness perceptions. This is important to ensure realistic expectations of treatment outcomes in patients with hip or knee OA, and ultimately, to support self-management in the long-term.

The primary outcome in the evaluation of educational and self-management interventions is under debate. In the review by Newman et al. (2004) some included studies used outcome measures that are not specifically targeted at the intervention. They concluded that this may decrease the overall effectiveness of educational self-management programs. Similarly, Nolte et al (2013) argue to critically choose outcome measures which are linked to those targeted for in the intervention, in order to prevent incorrect interpretation of effectiveness. However, in general, multiple outcome dimensions are targeted in self-management interventions.
As a result across studies a wide variety of outcome measures is used to evaluate self-management interventions. Usually, pain and/or physical functioning are the primary outcome measures\textsuperscript{39}. However, it is questionable whether changes can be expected in these outcomes, when self-management programs are aimed at providing individuals with skills how to cope with symptoms, manage their disease in daily living and navigate the healthcare system\textsuperscript{39}. Knowledge on disease management is not the same as changing your behaviour into actually doing it yourself. Therefore, knowledge is often used as a process outcome, and seems more appropriate as secondary outcome. In contrast, HCU is more a measure for behaviour. Based on previous observations that self-management interventions can result in changes in healthcare utilization\textsuperscript{30,35} and the assumption that effective self-management ultimately impacts healthcare consumption our choice to explore HCU as primary outcome seems to be appropriate.

In our program we educated patients on what they can do for themselves, when to seek guidance for conservative treatment options and helped them to form realistic thoughts on the expected results of surgical treatment. Following this perspective, changes in HCU patterns could be expected. Our results showed a decrease in patients visiting primary care providers. However, only small non-significant changes in number of patients visiting secondary care specialists were found. Both observations may be explained by the short-term follow-up and small sample of our study. First, as we educated patients on what they can do for themselves (i.e. lifestyle advice on exercise, weight reduction and medication use), some patients may not have felt the need to visit a primary care healthcare provider on short-term, because they directly can put into practice what they have learned during the program\textsuperscript{30}. Second, it is possible that patients were already referred to secondary care previous to the intervention, resulting in no short-term changes in secondary care use. Besides, research has shown that education in combination with exercise therapy may postpone surgery in hip OA patients in the long term\textsuperscript{23,24}. This emphasizes the desirability to study long-term results of our educational program in a larger sample.

Remarkably, the total number of contacts in primary care increased whereas the median number of contacts did not change. This finding may reflect the great variability in HCU between participants and specifically the difference in treatment between healthcare professionals. For example, patients will visit their GP once or twice for OA within 3 months, whereas they may visit a physiotherapist once or twice a week. This can sum up to a total of 12-24 visits over 3 months. In the present study several patients started physiotherapy treatment 1-2 weeks prior to the intervention (1-4 visits in the previous 3 months) and continued this treatment after the intervention (1 visit in the 3 months post-intervention) (data not shown). This may have contributed to the increased number of total visits in our sample. However, the low number of participants and short-term follow-up of the present study do not allow firm conclusions on this aspect of HCU.

We chose a multidisciplinary approach; in both the developmental process as well as in the execution of the program. This approach is based on previous research which argues to focus on the communication between healthcare providers involved in OA treatment to improve prescription of non-surgical treatment options\textsuperscript{19}. In the process of achieving consensus on the content of the program and answering frequently asked questions on OA, we targeted differences in beliefs among healthcare providers regarding the efficacy of non-surgical treatments\textsuperscript{30,35} and clarified roles of different healthcare providers in the management of OA-patients\textsuperscript{51}. Consequently, this resulted in clear and consistent information that could be disseminated during the course. This could explain the increased knowledge of patients after participating in the program. So far, little research has been done on the impact of consistency of information on self-management skills across settings and across disciplines for patients with osteoarthritis. In our opinion this is an important area for future research.

Adapting to the program to local context and patients preferences as it is known that adapting to local context positively influences knowledge translation\textsuperscript{26,29}. We involved local health care providers in the development and the execution of the program to support the role that health care providers have in patients’ treatment consideration\textsuperscript{30} and offering patients options for local support. This may have contributed to the accessibility of the program and may have resulted that our educational program was highly valued by participants (satisfaction score 8 on a scale 1-10).

An important factor in the set-up of our program was the option for participants to bring their partner or a significant other person. Previous studies that focused on explaining reasons for underuse of conservative treatment, underline the importance of the social environment of patients to be involved their care process\textsuperscript{32}. Involving a spouse in an intervention may even enhance self-efficacy and improve coping abilities\textsuperscript{33}, and improve physical activity levels in in OA patients\textsuperscript{19}. Our results showed no improvement in self-efficacy after the intervention and only a small, but non-significant increase in physical activity. However, only one-third of the patients who participated in the educational program indeed brought their partner. Future improvements of our intervention should focus on ways to better involve patients’ social environment\textsuperscript{6}.

This study has several limitations that should be taken into account when interpreting the results. First, the uncontrolled design of the study and the small sample size urges that conclusions drawn about the effect of the intervention should be taken with caution. In our study we examined short-term preliminary effects of a multidisciplinary educational program. However, a controlled trial with long-term follow-up is needed to further explore effects on HCU behaviour in patients with hip or knee OA. Second, we had a 25% loss to follow up, despite reminder letters. The overall high age of our participants might have contributed to the loss. Last, there may be a matter of selection bias. Although we tried to minimize this in our procedure when inviting patients for our study, we have no data available of patients who did not respond to our invitation to participate in our study.

Conclusions

Our results suggest that a multidisciplinary educational program, may result in changes in HCU and have positive effects on illness perceptions and knowledge in patients with hip or knee OA. These results indicate that patients may better understand and adjust their health seeking behaviour as a result of the program. Especially, the collaboration between health professionals from different disciplines, both in developing and executing the educational program, provides in adequate and consistent information on OA, treatment and self-management options. A randomized controlled trial with long-term follow-up with larger number of patients is needed to confirm these results.
Funding

This project was funded by the healthcare insurance company Coöperatie VGZ.

Reference List


Additional file.

Process of inventory and prioritising of frequently asked questions (FAQs)

A five-step systematic approach was taken to determine important information that needed to be included in the educational program.

**Step 1 - Inventory**
An inventory of FAQs about OA was made among local health care providers. FAQs were collected among: 1) specialists from the Departments of Orthopaedic Surgery and Departments of Rheumatology in three local hospitals, 2) GP’s involved in the project, as well as GP’s within their network, 3) physiotherapists from local OA-networks, 4) the Dutch Arthritis Foundation. All health care providers were asked to record 5-10 FAQs they often get from their OA-patients, of which the answers are not covered on the website www.thuisarts.nl (Nederlands Huisartsen Genootschap, n.d.). This website already covers general information about OA, based on national and international guidelines. A total of 192 questions were collected among 28 health care providers. After deleting overlapping ones and questions covered by the before mentioned website, 99 FAQs remained for the prioritising step.

**Step 2 – Categorising**
The 99 FAQs were categorised into 9 categories by to researchers independently (7-14 FAQs per category). Categories were: “OA, cause, consequences and disease course”, “diagnostics”, “medication”, “health care providers”, “lifestyle”, “surgery”, “work”, “self-management”, “other”.

**Step 3 – Prioritising**
Health care providers who provided FAQs were asked to indicate a top 5 most important FAQs per category and divide 100 point among their top 5. Moreover, they were asked to prioritise the categories, with regard to importance for an educational program for patients with OA. Additionally, a call for patients with OA willing to prioritise those FAQs by patients with OA, was placed on several websites, a local OA-network website as well as on the website of a non-profit foundation, covering all patient organisations in the Netherlands (e.g. “Stichting Reumazorg Nederland”), and the websites of two local physiotherapy practice’s. The same prioritising method used for health care providers, was used among patients with OA. From the 5 highest ranked categories the 3 highest ranked scored FAQs were included. From the other 4 categories the 2 highest ranked FAQs were included. Based on overall highest scores, 7 more FAQs were added to complete a Top 30 of most important FAQs. This Top 30 was used for answer formulation.

**Step 4 – Answering FAQs**
An expert group was formed by 2 orthopaedic surgeons, 1 rheumatologist, 1 specialized nurse, 3 physiotherapists, 1 general practitioner and 1 researchers. Each member of the expert group answered 10 FAQs. They were asked to formulate answers as they would when answering a patients. Because every expert answered 10 FAQs, every FAQ was answered three times.

**Step 5 – Formulating definite answers**
In 3 consensus meetings with the expert group, answers were discussed and combined into one final answer per FAQ. Final answers were edited by a communication specialist.
Abstract

Objective
To evaluate the effect of a stand-alone mobile and web-based educational intervention (eHealth tool) compared to usual preparation of a first orthopaedic consultation of patients with hip or knee osteoarthritis (OA) on patients’ satisfaction.

Design
A two-armed unblinded randomized controlled trial involving 286 patients with (suspicion of) hip or knee OA, randomly allocated to either receiving an educational eHealth tool to prepare their upcoming consultation (n=144) or usual care (n=142). Satisfaction with the consultation on three subscales (range 1-4) of the Consumer Quality Index (CQI - primary outcome) and knowledge (assessed using 22 statements on OA, range 0-22), treatment beliefs (assessed by the Treatment beliefs in OsteoArthritis questionnaire, range 1-5), assessment of patient’s involvement in consultation by the surgeon (assessed on a 5-point Likert scale) and patient satisfaction with the outcome of the consultation (numeric rating scale), were assessed.

Results
No differences between groups were observed on the 3 subscales of the CQI (group difference (95% CI): communication 0.009 (-0.10, 0.12), conduct -0.02 (-0.12, 0.07) and information provision 0.02 (-0.18, 0.21)). Between group differences (95% CI) were in favour of the intervention group for knowledge (1.4 (0.6, 2.2)), negative beliefs regarding physical activities (-0.19 (-0.37, -0.002) and pain medication (-0.30 (-0.49, -0.01)). We found no differences on other secondary outcomes.

Conclusions
An educational eHealth tool to prepare a first orthopaedic consultation for hip or knee OA does not result in higher patient satisfaction with the consultation, but it does influence cognitions about osteoarthritis.

Introduction

Non-surgical treatments like lifestyle education, exercise therapy, weight loss and pain medication are recommended as a primary approach to manage hip or knee osteoarthritis (OA) in an early stage and can be organized in primary care. Once these conservative treatment options have been tried adequately and have failed, or in case of diagnostic uncertainty, referral to an orthopaedic surgeon should be considered for further evaluation and consideration of surgical interventions, e.g. a total joint replacement (TJR). To actively participate in the consideration of different treatment options, patients need to be informed of benefits and possible disadvantages of available treatment options.

Currently, half to two-third of patients referred to an orthopaedic surgeon are considered not (yet) eligible for a total joint replacement. This is in contrast with the observation that patients with hip or knee OA who are referred for a first orthopaedic consultation often expect action to be taken, in particular the planning of a TJR. It is thereby conceivable that in some patients the expectations they have about the consultation may not be met, resulting in patients being dissatisfied.

An appropriate preparation of the consultation is likely to streamline the patients’ expectations and increase their satisfaction, irrespective of whether the outcome is consideration of surgery or not. This hypothesis is supported by the literature, where in general, patients who are more knowledgeable, skilled and proactive before a consultation are more satisfied with their care experience because it is more likely that their needs are met. Interventions aimed at supporting the patients’ preparation of the consultation were found to improve self-efficacy in older patients. Moreover, educational tools have positive effects on patient knowledge, decision making, self-efficacy and number of questions asked during consultation, with high satisfaction-rates.

An educational eHealth application may be a suitable means to prepare patients for their consultation, because of the easy accessibility and the possibility to provide information that suits individual preferences and needs. Moreover, eHealth interventions have shown to enhance and supplement the communication between patients and healthcare providers and seem effective at providing information, enhancing information exchange, and promoting self-management in older adults. Recently it was concluded that the use of an educational website for patients with hip and knee OA improve important aspects of quality of care (i.e. self-management, lifestyle and physical activity). However, these results were based on an observational study and to our knowledge good quality randomized controlled trials evaluating educational eHealth tools with interactive parts are not available.

The aim of the present study was to evaluate the effect of a stand-alone mobile and web-based educational intervention (educational eHealth tool) compared to usual preparation of a first orthopaedic consultation of patients with hip or knee OA on satisfaction with the consultation. Secondary outcomes were knowledge, treatment beliefs and measures on the consultation from the patient and surgeon’s perspective.
Patients and Methods

Design and setting
This study was reported according to the CONSORT-EHEALTH checklist15. A two-armed unblinded randomized controlled trial was conducted. The study was performed at the outpatient departments of Orthopaedic surgery of the Sint Maartenskliniek Nijmegen and Boxmeer, the Netherlands from March 2017 to May 2018. The local Medical Research Ethics Committee, region Arnhem-Nijmegen (study no. 2016-3096) provided a waiver, as this type of study does not require approval from an ethics committee in the Netherlands according to the Central Committee on Research involving Human Subjects. The study was registered in the Dutch Trial Register (trial number NTR6262). All participants gave informed consent prior to the baseline data collection.

Participants
Patient with hip or knee OA, with a scheduled first-time visit for a new diagnosis at the outpatient department of Orthopaedic surgery of the Sint Maartenskliniek, were checked for eligibility. Patients were invited for participation when: 1) aged 18 years or older; 2) diagnosis or suspicion of OA in the knee or hip in the referral letter; and 3) no previous visit to the outpatient department of Orthopaedic surgery of the Sint Maartenskliniek for a complaint of the index joint. Exclusion criteria were: 1) unable to read and understand the Dutch language; 2) not in the possession of a smartphone, computer or tablet; or 3) did not have an e-mail address.

Interventions
The intervention and control group received the usual hospital procedure. Participants received a letter with date and time of their scheduled consultation along with a flyer named “Going prepared to the outpatient department of Orthopaedic surgery”. This flyer provides brief information on how to prepare for the consultation and information about logistic and practical issues regarding the hospital’s policy.

In addition the intervention group received a login and information to access the educational eHealth tool no more than two weeks before their consultation. The educational eHealth tool was developed following an iterative method of persuasive design in collaboration with OA patients16. Pilot-testing of the developed tool was done among patients and healthcare professionals. The tool could be consulted using a smartphone, a tablet or computer. The tool contained the following functionalities: (1) information on OA and treatment modalities, based on a stepped-care strategy for OA17; (2) preparation for the upcoming consultation consisting of predefined questions to answer, and space to record questions the patient would like to ask the orthopaedic surgeon; (3) the option to monitor pain and fatigue during 1 week prior to the consultation; (4) list medication use with the option to set reminders for intake; and (5) the option to create a visual timeline with the scheduled consultation, assessments and preparation. Further specifications and the developmental process of the tool are described in the supplementary material.

Procedures
Eligible patients were invited by information letter to participate. Patients were invited based on the referral letter of the general practitioner or referring specialist, which was screened by a research assistant on confirmed diagnosis or suspicion of knee or hip OA. Patients willing to participate were asked to contact the involved researcher by phone, by e-mail or by means of a reply card. After registering for the study, participants received information about the study by e-mail, along with a hyperlink to an online consent form and questionnaire for baseline assessment (T0). Once the questionnaire was completed, participants were allocated to the intervention or control group (allocation ratio 1:1, stratified by main OA-location hip or knee, using randomly varied block sizes (4 to 8)). Randomization was performed in an electronic data capture and management program; Castor EDC (www.castoredc.com) by the researcher (AAOMC). After allocation participants in the intervention group received an e-mail with information to access the educational eHealth tool. Other participants received an e-mail that they were assigned to the control group. One day after the consultation all participants received an e-mail with a hyperlink to the second questionnaire (T1). Non-responding participants received a reminder by e-mail after one week. Participants who did not go to their consultation were excluded. Diagnosis of all participants was checked after the consultation as indicated by the orthopaedic surgeon in the patient information system. Directly after the consultation the orthopaedic surgeon was asked to answer a question on their opinion about the degree of involvement of the patient during the consultation. All data, collected online, retrieved from the patient information system or filled out by the orthopaedic surgeon, were collected or processed in Castor EDC.

Measurements and outcomes
Data on demographic (gender, age, BMI, level of education, work status) and clinical (OA index joint, number of painful joints, duration of symptoms, pain and function) characteristics were collected at baseline (T0), 2-5 weeks prior to the consultation. To assess pain and function the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) was used18, with standardized scores being presented (0-100, higher scores indicating more pain and worse function). Primary and secondary outcome measures were collected during the week after the consultation (T1).

Primary outcome measure
The primary outcome was satisfaction with the consultation measured with an adapted version of the Consumer Quality Index (CQI), the Dutch standard for measuring patient experience with health care providers and health plans19. Because the CQI is available for several curative services, but not specifically for OA or a visit to an orthopaedic surgeon, we adapted three subscales of the CQI: 1) The subscale “physician-patient communication” from the ‘CQI-general practitioner care’ with the addition of 2 items from the ‘CQI-outpatient clinic’. 2) the subscale “conduct physician” from the ‘CQI-Rheumatoid Arthritis’ supplemented with two items from the ‘CQI-general practitioner care’ and 3) the subscale “information provision by the physician” from CQI-outpatient clinic. The three subscales are independently validated for the three mentioned CQI-indices20-22. For each subscale an indicator score can be calculated ranging from 1 to 4 (higher score indication higher satisfaction with care).

Secondary outcome measures
To evaluate the consultation several self-administered questions were used. Policy after the consultation was asked by means of the question: “What did you do next?” (the doctor referred me to another healthcare professional, namely …. / I’m getting surgery / the doctor described pain medication / I don’t know / We did not agree on a next step / wait and see / other, namely…). Satisfaction with the consultation and the policy after the
consultation could be scored on a Numeric Rating Scale (NRS) (0-10).

Based on identified frequently asked questions on OA in a previous study, 22 statements were self-administered to assess knowledge of participants on OA (treatment) at baseline (T0) and follow-up (T1). Total score ranged from 0-22, with higher scores indicating more knowledge. To assess patients’ thoughts and expectations regarding treatment options (physical activities, pain medication and joint replacement surgery), the Treatment beliefs in OsteoArthritis questionnaire (TOA) was used. Positive and negative treatment beliefs were measured at baseline (T0) and follow-up (T1). In order to facilitate interpretation mean subscale scores were divided by the number of items per scale, resulting in a standardized score ranging from 1 to 5. The TOA shows good internal consistency and reliability.

Orthopaedic surgeons were asked to score 2 statements about the consultation on a 5-point Likert scale (0 “completely disagree” – 5 “completely agree”): 1) “the patient gave the impression to be well prepared for the consultation” and 2) “The patient took an active role in the consultation”.

Statistical analysis
Based on previous research and collected unpublished data on the CQI in the Sint Maartenskliniek an a-priori sample size estimate indicated that 286 participants (143 per group) would provide 80% power at 5% level of significance (two-sided) to detect a treatment difference of at least 0.15 points on the CQI subscales between the two groups assuming a SD of 0.45. Accounting for 25% loss of follow up we aimed to include 382 patients.

Data were analysed using Stata 13.1. Primary analysis were done according to the intention-to-treat (ITT) principle. Secondary analyses included per-protocol analysis excluding protocol violators (i.e., patients who did not open the educational eHealth tool, based on log-file analysis). Additionally, we analysed differences in satisfaction between patients of whom the outcome of the consultation was surgery and patients with a different outcome of the consultation.

Post-intervention differences between groups were analysed using linear regression analyses, Chi-squared test and Mann-Whitney U test where appropriate. Data on knowledge and treatment beliefs were analysed with linear regression analyses, using follow-up scores as dependent variable and group (intervention/control) and baseline value as covariate. All linear regression analyses were corrected for outcome of consultation (surgery or not). Differences between groups and 95% CI were reported.

Results
Between March 2017 and March 2018, 836 individuals were invited to participate in the present study. A total of 293 (35%) participants filled in the first questionnaire and were randomized. No differences were found between the invited patients who did not participate and the study population with regard to age (P-value = 0.08) and sex (P-value = 0.61). Due to time constraints we needed to stop the inclusion after 293 out of the targeted 382 patients were enrolled. Data of 7 (2%) participants was excluded because they did not fulfil the inclusion criteria; 5 participants cancelled their appointment and 2 participants were wrongly included as it turned out they already had been to the clinic before for OA complaints in the same joint. Two hundred eighty-six participants were allocated to either the intervention (n=144) or control (n=142) group. Nineteen (7%) participants were lost to follow-up leaving data of 267 participants for the ITT analysis. Twenty-eight participants in the intervention group did not open the application and were therefore considered protocol-violators and excluded in the per-protocol analysis (Figure 1).
Baseline characteristics of the study population are shown in Table 1. The majority of patients was female (58%), more than half had complaints of their hip or knee less than 5 years and around 80% of patients had a consultation with regard to complaints on the knee.

Table 1. Baseline characteristics of participants allocated to the intervention and control group

<table>
<thead>
<tr>
<th>Social-demographic characteristics</th>
<th>Intervention group (n=144)</th>
<th>Control group (n=142)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female; n (%)</td>
<td>81 (57)</td>
<td>85 (60.7)</td>
</tr>
<tr>
<td>Age, years; mean (S.D.)</td>
<td>61.7 (10.4)</td>
<td>63.3 (10.1)</td>
</tr>
<tr>
<td>BMI, kg/m²; mean (S.D.)</td>
<td>27.9 (4.4)</td>
<td>29.0 (5.1)</td>
</tr>
<tr>
<td>&lt;12 years education; n (%)</td>
<td>57 (40)</td>
<td>56 (39.7)</td>
</tr>
<tr>
<td>Paid work; n (%)</td>
<td>58 (43)</td>
<td>47 (35.6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical characteristics</th>
<th>Intervention group</th>
<th>Control group</th>
<th>Group difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Index joint knee; n (%)</td>
<td>155 (80)</td>
<td>112 (78.9)</td>
<td></td>
</tr>
<tr>
<td>Number of painful joints (0-10); median (IQR)</td>
<td>2 (1-3.5)</td>
<td>2 (1-4)</td>
<td></td>
</tr>
<tr>
<td>Duration of symptoms; n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>14 (10)</td>
<td>19 (15)</td>
<td></td>
</tr>
<tr>
<td>1-5 years</td>
<td>69 (49)</td>
<td>64 (46)</td>
<td></td>
</tr>
<tr>
<td>5-10 years</td>
<td>20 (14)</td>
<td>22 (15)</td>
<td></td>
</tr>
<tr>
<td>&gt; 10 years</td>
<td>39 (27)</td>
<td>35 (25)</td>
<td></td>
</tr>
<tr>
<td>Pain, WOMAC (0-100); mean (S.D.)</td>
<td>50.9 (10.8)</td>
<td>47.6 (19.1)</td>
<td></td>
</tr>
<tr>
<td>Function, WOMAC (0-100); mean (S.D.)</td>
<td>55.0 (21.1)</td>
<td>48.5 (20.5)</td>
<td></td>
</tr>
</tbody>
</table>

Primary outcome

No relevant or significant differences between the intervention and control group were found on consultation satisfaction, as measured with all three subscales (communication, conduct and information provision) of the CQI (Table 2).

Table 2. Follow-up indicator scores and differences between groups on the subscales of the Consumer Quality Index.

<table>
<thead>
<tr>
<th></th>
<th>Intervention group</th>
<th>Control group</th>
<th>Group difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n Mean (S.D.)</td>
<td>n Mean (S.D.)</td>
<td>(95% CI)*</td>
</tr>
<tr>
<td>Communication, CQI(1-4)</td>
<td>129 3.69 (0.47)</td>
<td>118 3.66 (0.45)</td>
<td>0.009 (-0.10, 0.22)</td>
</tr>
<tr>
<td>Conduct, CQI(1-4)</td>
<td>133 3.78 (0.40)</td>
<td>124 3.76 (0.43)</td>
<td>-0.02 (-0.12, 0.07)</td>
</tr>
<tr>
<td>Information provision, CQI(1-4)</td>
<td>80 3.59 (0.69)</td>
<td>90 3.58 (0.65)</td>
<td>0.02 (-0.18, 0.21)</td>
</tr>
</tbody>
</table>

Secondary outcomes

In about one-fourth of patients in both groups it was decided on a joint replacement surgery (Table 3). In another one-third it was decided to wait and see how symptoms developed. Twenty-two percent of patients in the intervention group and 29% in the control group were referred to or received a conservative treatment option (physiotherapy, dietary therapy, pain medication, brace, etc.).

Table 3. Differences on secondary outcomes of the consultation for the intervention group and control group

<table>
<thead>
<tr>
<th></th>
<th>Intervention group</th>
<th>Control group</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=138</td>
<td>n=129</td>
<td></td>
</tr>
<tr>
<td>Patients’ outcomes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Able to ask what I wanted; n (%)</td>
<td>121 (88)</td>
<td>104 (81)</td>
<td>0.12*</td>
</tr>
<tr>
<td>Number of questions asked, median (IQR)</td>
<td>2 (1-3)</td>
<td>2 (1-3)</td>
<td>0.51*</td>
</tr>
<tr>
<td>Policy after consultation, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conservative</td>
<td>30 (22)</td>
<td>37 (29)</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>37 (27)</td>
<td>34 (26)</td>
<td></td>
</tr>
<tr>
<td>Wait and see</td>
<td>46 (33)</td>
<td>34 (26)</td>
<td></td>
</tr>
<tr>
<td>Other diagnosis</td>
<td>16 (12)</td>
<td>17 (13)</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with policy (0-10), mean (S.D.)</td>
<td>7.5 (2.7)</td>
<td>7.9 (2.3)</td>
<td>-0.4 (-1.1, 0.3)</td>
</tr>
<tr>
<td>Satisfaction with consultation (0-10), mean (S.D.)</td>
<td>8.0 (2.3)</td>
<td>8.3 (2.0)</td>
<td>-0.2 (-0.8, 0.4)</td>
</tr>
<tr>
<td>Surgeons’ outcomes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparedness of patient (1-5), median (IQR)</td>
<td>5 (4-5)</td>
<td>4 (4-5)</td>
<td>0.51*</td>
</tr>
<tr>
<td>Participation of patient (1-5), median (IQR)</td>
<td>5 (4-5)</td>
<td>5 (4-5)</td>
<td>0.82*</td>
</tr>
</tbody>
</table>

* Chi-squared test. * Mann-Whitney U test. * Linear regression analysis, adjusted for outcome of consultation (surgery or not), mean difference (95% CI).

Knowledge improved significantly more in the intervention group than in the control group (mean group difference (95% CI): 1.4 (0.6, 2.2)) (Table 4). Also, significant differences were found in negative beliefs regarding physical activities and pain medication between the intervention and the control group, with the intervention group having less negative beliefs (mean group difference (95% CI): -0.19 (-0.37, -0.002) and -0.30 (-0.49, -0.12) respectively). No other differences were found in any of the secondary outcome measures.
The results of this study show that using an educational eHealth tool to prepare a first orthopaedic consultation for hip or knee OA, does not result in higher satisfaction with the consultation regardless of the outcome being TJR or not. The results do not confirm our hypothesis, but are in line with a recently published RCT demonstrating no improvement in the appreciation of the first orthopaedic consultation, after the use of an educational smartphone app. However, secondary analysis showed that patients with a TJR planned as result of the consultation were significantly more satisfied than patients who had a different outcome, irrespective of the use of the tool. This confirms findings from previous qualitative studies that patients want action to be taken and prefer TJR as treatment. Previous research shows that expectations of TJR are often high and not always realistic, but are a key determinant of treatment satisfaction after TJR. Also, patients’ beliefs about conservative and surgical treatments options are an important aspect in the choice for a treatment. Our results are in line with recent findings showing that educational tools used either during or in preparation for the consultation improve knowledge and risk perception. However, effects of improvement in knowledge and risk perception on fulfilment of expectations and ultimately satisfaction still has to be investigated.

We hypothesized that when patients are better prepared for their consultation, have more realistic expectations of the consultation and possible treatment outcome, they are more satisfied with the consultation regardless of the outcome being TJR or not. The results do not confirm our hypothesis, but are in line with a recently published RCT demonstrating no improvement in the appreciation of the first orthopaedic consultation, after the use of an educational smartphone app. However, secondary analysis showed that patients with a TJR planned as result of the consultation were significantly more satisfied than patients who had a different outcome, irrespective of the use of the tool. This confirms findings from previous qualitative studies that patients want action to be taken and prefer TJR as treatment. Previous research shows that expectations of TJR are often high and not always realistic, but are a key determinant of treatment satisfaction after TJR. Also, patients’ beliefs about conservative and surgical treatments options are an important aspect in the choice for a treatment. Our results are in line with recent findings showing that educational tools used either during or in preparation for the consultation improve knowledge and risk perception. However, effects of improvement in knowledge and risk perception on fulfilment of expectations and ultimately satisfaction still has to be investigated.

The lack of positive effects of the tool on satisfaction may have several explanations. First, it may indicate that our intervention was not comprehensive enough to sufficiently change patients’ expectations towards other treatment options in order to improve their satisfaction. Although fulfilment of expectations is an important aspect of satisfaction, healthcare professional related aspects like trust, empathy, communication and relatedness, contact time and waiting time are important for satisfaction with the consultation as well. These aspects were not specifically targeted in our intervention. Second, in hindsight our choice for using the CQI as outcome measure may be questioned for several reasons. Because of missing values we could not calculate indicator scores for all participants. Moreover, it should be noted that satisfaction was high in all patients. Scores found in our study were even higher than previously reported CQI scores in orthopaedics setting (3.3 [hospital stay] and 3.5 [information at discharge]). Moreover, >15% of participants scored the highest possible CQI scores indicating a ceiling effect on our primary outcome. Last, the primary focus of our intervention was to target patient expectations. Fulfilment of expectations was not reflected in the CQI. A validated sensitive questionnaire to assess satisfaction incorporating fulfilment of patient expectations about the consultations and its outcomes is needed, but currently unavailable to our knowledge.

Based on the positive effects on knowledge and beliefs found in this study, we think that further implementation of the educational eHealth tool may be valuable for clinical practice. More guidance in the use of our educational eHealth tool and instruction for the orthopaedic surgeon to discuss the preparation during the consultation may result in better outcomes and should be a focus for further implementation of the tool. However, one of the advantages of eHealth interventions is that they can be used at any time at any place, without involvement of a healthcare professional. If the ultimate aim is to routinely use the educational eHealth tool, costs and benefits with regard to what is effective and what is practical should be weighted and further studied. Additionally, our intervention is already suited for preparation for the consultation and active participation of the patient in the consultation as evaluated by the orthopaedic surgeon.

Table 4. Differences in knowledge and treatment beliefs for the intervention group and control group

<table>
<thead>
<tr>
<th></th>
<th>Intervention group mean (S.D.)</th>
<th>Control group mean (S.D.)</th>
<th>Group difference (95% CI)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge (0-22)</td>
<td>11.2 (3.7)</td>
<td>12.9 (4.1)</td>
<td>1.4 (0.6, 2.2)*</td>
</tr>
<tr>
<td>Treatment beliefs, TOA (1-5)</td>
<td>Positive – PA: 3.63 (0.84)</td>
<td>3.88 (0.79)</td>
<td>-0.08 (-0.23, 0.06)</td>
</tr>
<tr>
<td></td>
<td>Negative – PA: 2.78 (1.00)</td>
<td>2.55 (0.92)</td>
<td>-0.24 (-0.36, -0.12)</td>
</tr>
<tr>
<td></td>
<td>Positive – PM: 3.35 (0.99)</td>
<td>3.63 (1.03)</td>
<td>-0.24 (-0.36, -0.12)</td>
</tr>
<tr>
<td></td>
<td>Negative – PM: 3.59 (0.81)</td>
<td>3.22 (0.82)</td>
<td>-0.37 (-0.55, -0.19)</td>
</tr>
<tr>
<td></td>
<td>Positive – TJR: 3.98 (0.70)</td>
<td>3.94 (0.68)</td>
<td>-0.10 (-0.21, 0.01)</td>
</tr>
<tr>
<td></td>
<td>Negative – TJR: 3.75 (0.79)</td>
<td>3.90 (0.73)</td>
<td>-0.12 (-0.24, 0.001)</td>
</tr>
</tbody>
</table>

* adjusted for baseline score of outcome (i.e. knowledge, TOA) and outcome of consultation (surgery or not). *Significant for P < 0.05. TOA: Treatment Beliefs in Osteoarthritis questionnaire; PA: physical activities; PM: pain medication; TJR: joint replacement surgery.

Secondary analysis

The per-protocol analysis was performed excluding 28 patients from the intervention group, all whom did not open the application. Experience with the consultation in the intervention group was found not to be significantly different than in the control group on all three CQI subscales. Only small differences were found on secondary outcomes compared to the ITT-analysis. The decrease of negative beliefs regarding physical activities in favour of the intervention group was not found statistically significant anymore (mean group difference (95% CI): -0.17 (-0.36, 0.03) and positive beliefs about total joint replacement surgery decreased in those who had used the intervention, compared to the control group (mean group difference (95% CI): -0.12 (-0.24, 0.001)).

Secondary analysis on satisfaction outcomes between patients scheduled for surgery versus those with a different outcome of the consultation revealed that patients scheduled for surgery were more satisfied as measured with the CQI subscales ‘Conduct’ and ‘Information provision’ (mean group difference (95% CI): -0.18 (-0.29, -0.07) and -0.32 (-0.53, -0.11), respectively). Also, satisfaction with the follow-up policy and the consultation as measured on NRS (0-10) was significantly higher in patients scheduled for surgery (mean group difference (95% CI): -1.1 (-1.8, -0.3) and -1.1 (-1.8, -0.5), respectively).

Discussion

The results of this study show that using an educational eHealth tool to prepare a first orthopaedic consultation for hip or knee OA, does not result in higher satisfaction with the consultation among patients but does result in more knowledge and less negative beliefs about physical activities and pain medication as compared to usual care. No other significant differences between the intervention and control group were found regarding outcome of the consultation (surgery or not), treatment beliefs about TJR, and preparedness for the orthopaedic consultation.
for consultation with other healthcare professionals (e.g. physiotherapist or general practitioner). It may therefore also be implemented in primary care, where it is likely that beliefs and expectations regarding treatments still are being formed and where use of the tool can contribute to providing consistent education throughout the treatment process for OA patients.

There are several limitations to this study that need to be addressed. First, we included fewer patients than intended which impacted the power of the study. The number of patients visiting our clinic with (suspicion) of OA was lower than expected, this resulted in a slower pace of inclusion and, due to time constraints, inclusion was closed after 293 out of 382 intended patients were enrolled. Although loss to follow-up rates were lower than expected (7% and 25%, respectively), the final number of participants of whom data could be analysed was slightly lower (n=267 instead of n=286) than aimed for based on sample size calculation. Considering the small differences found, it is not likely that we failed to detect an effect that was present (Type II error). Second, because the entire study was web-based we created bias against eHealth illiterate participants and may have excluded a relevant group of patients. We did not systematically examine reasons for not participating because of practical reasons. Although gender and age of responders did not differ significantly from non-responders, further research into factors associated with participating in eHealth studies and use of the educational eHealth tool could provide starting points for improvement of the application.

In this randomized controlled trial we demonstrated that an educational eHealth tool did not result in higher satisfaction with a first consultation in orthopaedics outpatient clinic setting for patients with possible hip or knee OA, but did result in small effects on knowledge and impact on involvement in primary care episodes. Considering the small differences found, it is not likely that we failed to detect an effect that was present (Type II error). Second, because the entire study was web-based we created bias against eHealth illiterate participants and may have excluded a relevant group of patients. We did not systematically examine reasons for not participating because of practical reasons. Although gender and age of responders did not differ significantly from non-responders, further research into factors associated with participating in eHealth studies and use of the educational eHealth tool could provide starting points for improvement of the application.

In this randomized controlled trial we demonstrated that an educational eHealth tool did not result in higher satisfaction with a first consultation in orthopaedics outpatient clinic setting for patients with possible hip or knee OA, but did result in small effects on knowledge and treatment beliefs. Future research is needed to evaluate if improvements of the educational eHealth tool and optimized implementation strategies in different care settings result in better outcomes.

Reference List

8. Greene J, Hibbard JH, Sacks R, Overton V: When seeing the same physician, highly activated patients have better care experiences than less activated patients. Health Aff (Millwood) 2013, 32: 1309-1309.


Supplementary material.

The educational eHealth tool

Development

Based on patient responses in daily practice to a previous implemented self-management booklet we choose to develop the educational eHealth tool. We followed an iterative method of persuasive design. Persuasive technology is the use of technology (internet, mobile devices like smartphones, tablets, e-mail) to change people's behaviour and influence their choices. Research shows that online applications, which are developed by using the methodology of persuasive design, are leading to better treatment adherence. A project group consisting of a project leader with expertise in persuasive design, a senior researcher, 4 students and 4 patients with osteoarthritis (OA) were responsible for the execution of the different steps. First, by means of individual interviews with a feedback group of 8 patients with OA information needs regarding 1) a previously developed multidisciplinary, guideline-based stepped-care strategy for patients with knee and hip osteoarthritis and health care providers and 2) preferences and barriers regarding the use of technology were examined. Main results regarding needs were “tailored information”, “assistance in preparing consultations with care providers”, “need for tool to log important health information related to osteoarthritis” and “need for tool to log appointments with care provider”. Next, based on the results of the interviews the primary goals of the tool were defined after discussion with all members of the project group. Those goals were translated to “actual target behaviours”, e.g. “start internet application”, “register for account”; “click for more detailed information” and “log questions for care provider”. Then, for each target behaviour a paper prototype was produced consisting of the different “screens” by the student members of the project group. These paper prototypes were iteratively tested on feasibility and clarity by the members of the patient feedback group, utilizing the “speaking aloud” method and adapted several times. The paper version was used to specify functionalities of the educational eHealth tool.

Based on specified functionalities a software development company (Comaxx – e-business) started the development of the tool using the project management method Scrum. The Scrum method is an iterative process in which the tool was developed in 4 sprints of 4-6 weeks. Each sprint followed the phases of development, user-testing, adaptation, re-testing and finalizing. In each user-testing phase a group of 5-10 patients and health care providers gave their feedback on the educational eHealth tool.

Functionalities

The final version of the educational eHealth tool as used in the study was available as native application for iOS and Android (Version 1.1, release date February 14th 2017), and online application (www.artrosewijzer.nl) free of charge. The tool can only be accessed with a username and password, provided by the researcher. The educational eHealth tool has the following parts:

1. “Information” (Figure 1). Information on OA and treatment modalities, based on a stepped-care strategy for OA, with additional information on surgical treatment.
2. “My consultation” (Figure 1). In this part the user gets the option to record a consultation by filling in date, time, location, healthcare professional and subject. Based on the type of healthcare professional (orthopaedic surgeon, rheumatologist, physiotherapist, other) questions can be answered that likely will be asked during the consultation. Additionally, users can record questions they want to ask themselves during the consultation. During the week before the upcoming consultation it is possible to daily monitor fatigue or pain on a numeric rating scale (0 to 10). Users receive a notification at the time they planned a measurement.
3. “Medication” (Figure 2). The possibility to list medication use (e.g. dosage) with the option to set reminders for intake
4. Achievements (Figure 2). It is possible to earn three achievements while using the educational eHealth tool. The first one can be earned when users read all the information parts in the tool. The second one can be earned when a consultation is planned. The last one is received when medication use is registered in the app.
5. Timeline (Figure 3). Based on a planned consultation a visual timeline is created in the tool, along with measurement moments and preparation. One day before the consultation the user receives a notification to prepare the consultation.

Figure 1. Screenshots of the stepped care strategy, providing information on treatment options for hip and knee OA (left) and consultation preparation (right) in the educational eHealth tool.
Reference List

Chapter 5

An eHealth tool to prepare for a first orthopedic consultation: a use and usability study

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Frank H.J. van den Hoogen
Cornelia H.M. van den Ende

Submitted
Abstract

Background

The use of eHealth technology to prepare patients with hip or knee osteoarthritis (OA) for their first orthopedic consultation seems promising. The exploration of the use and usability of an educational eHealth tool may highlight potential modifications that could increase patient engagement and effectiveness.

Objectives

1) to identify the use and usability of a standalone educational eHealth tool for patients with suspected hip or knee OA; 2) to explore whether the recorded questions in the eHealth tool were in line with an existing widely used question prompt list; and 3) to investigate whether user characteristics are related to use and usability.

Methods

We used data from 144 patients in the intervention group of a randomized controlled trial, who were asked to use the educational eHealth tool to prepare for their upcoming first orthopedic consultation. We defined ‘users’ and ‘non-users’ based on whether they had opened the tool at least once. ‘Users’ were characterized as ‘active’ or ‘superficial’ depending on the extent of their use of the tool. The recorded questions for the consultation preparation were categorized into themes fitting three predefined questions (“What are my options?”, “What are the possible benefits and harms of those options?” and “How likely are each of the benefits and harms to happen to me?”) or in a ‘remaining’ category. Usability was measured using the System Usability Scale (SUS, 0-100). Data were also collected on the patient demographic and clinical characteristics, knowledge of OA, and internet and smartphone usage in daily life. The characteristics associated with ‘users’ and ‘non-users’ were analyzed using a multivariable logistic regression analysis.

Results

A total of 116 (81%) participants used the educational eHealth tool, of whom 87 (75%) were ‘active users’. Of the three components of the tool (‘Information’, ‘My consultation’ and, ‘Medication’), ‘Medication’ was the least used (34%). Based on the recorded questions of the users a fourth predefined question could be proposed: “What is my situation at this moment?”. The mean (SD) SUS score was 64.8 (16.0). No difference was found between the SUS scores of superficial and active users (mean difference 95% CI: 0.04 (-7.69, 7.77)). Participants with a higher baseline knowledge of OA (OR (95% CI): 1.2 (1.0, 1.4)) and who used the internet less frequently in their daily lives (OR (95% CI): 0.6 (0.5, 0.9)) were more likely to use the educational eHealth tool. We found no differences between the demographics and clinical characteristics of the superficial and active users.

Conclusions

Based on the results of this study, it can be concluded that the use of an educational eHealth tool to prepare patients with hip or knee OA for a first orthopedic consultation is feasible. Our results suggest some improvements that should be made to the content of the tool to improve its usability. No clear practical implications were found to support the implementation of the educational eHealth tool in specific subgroups.

Introduction

Osteoarthritis (OA) is an age-related, degenerative joint disease and one of the most common causes of disability around the world. International guidelines recommend non-surgical treatments, such as lifestyle education, exercise therapy, weight loss if overweight, and pain medication, as a primary approach to manage hip or knee OA in the early stages. Once these conservative treatment options have been adequately tried and failed, or in the case of diagnostic uncertainty, a referral to an orthopedic surgeon should be considered for further diagnostic evaluation and consideration of surgical interventions, e.g. a total joint replacement. Patients with hip and knee OA often expect action to be taken when referred to an orthopedic surgeon; however, only one third to a half of referred patients are eligible for a joint replacement. It is therefore conceivable that patients’ expectations about the consultation may not always be met, resulting in patients being dissatisfied. A solid preparation for the consultation might help to streamline patient expectations.

In general, educational interventions can help patients to be more prepared for a consultation by providing information on treatment options and by assisting patients in reflecting on their own situation (e.g., monitoring symptoms, or recording medical history). Moreover, the use of self-prepared or provided question prompt lists for patients to ask, or questions to be expected from the health care provider, can facilitate the exchange of information during consultation. Previous research has shown that the use of conventional educational tools to prepare patients for consultations and to aid treatment decision making in OA is associated with lower health care costs because it may postpone unnecessary early surgery.

The growing and emerging opportunities in the use of eHealth can be harnessed to further develop educational interventions with the potential to improve efficiency and lower costs. To contribute to the emerging field of eHealth for OA and to support patients, an educational eHealth tool was developed to help hip and knee OA patients prepare for their first orthopedic consultation. This standalone smartphone and web-based intervention provides information on treatment options for hip and knee OA, the option to prepare for a consultation by preparing questions, and enables patients to monitor their symptoms and medication use. A randomized evaluation of this educational eHealth tool showed that it did not influence patient satisfaction with their consultation, but it did have small effects on patient knowledge of OA and treatment expectations (submitted). These results were less promising than expected; it seemed important to further explore the actual use of the intervention. Data on the use and non-use of (components of) an intervention and its usability can provide information on potential intervention modifications that increase engagement and likely, effectiveness.

The aim of the present study was to identify the use and usability of the afore mentioned educational eHealth tool. We therefore describe the user rates of different components of the tool and explore how the preparation component of the application is used (i.e., which questions do participants prepare) and whether these questions are in line with an existing widely used question prompt list. Our second aim was to investigate whether certain user characteristics are related to the use and usability of the educational eHealth tool, to provide points of support for its implementation.
Methods

Design and setting
The data for the present study were collected as part of a randomized controlled trial (RCT) evaluating the effect of an educational eHealth tool compared with standard care practices, which was carried out between March 2017 and May 2018 at the outpatient department for Orthopaedic Surgery at the Sint Maartenskliniek, Nijmegen, the Netherlands. Baseline and follow-up data for the intervention group and data retrieved from the backend of the educational eHealth tool were used in the present study. All patients gave their informed consent for participation. The Medical Ethics Committee on Research Involving Human Subjects (CMO) Region Arnhem-Nijmegen (study number 2016-3096) waived ethical approval because it is not required for this type of study under Dutch law. The RCT was registered in the Dutch Trial Register (trial number NTR6262).

Participants and procedure
Patients who had a scheduled visit for a new treatment episode at the outpatient clinic of Orthopedic Surgery at the Sint Maartenskliniek, Nijmegen, were checked for their eligibility. The inclusion criteria were: 1) aged ≥ 18 years or older; 2) the referral letter of their general practitioner or the referring specialist mentioned the (suspected) diagnosis of OA in the knee or hip; and 3) they had not previously visited the department of Orthopedic Surgery at the Sint Maartenskliniek for that index joint. The exclusion criteria were: 1) unable to read or understand Dutch; 2) did not possess a smartphone, computer, or tablet; or 3) did not have an e-mail address. Eligible patients were invited to participate in a letter providing information on the study. Patients who were willing to participate received further information about the study by e-mail and were asked to fill in a baseline questionnaire 2-5 weeks prior to their consultation. Once baseline data were collected, participants were allocated to the intervention or control group (allocation ratio 1:1, stratified by main OA-location hip or knee, using randomly varied block sizes (4 to 8)). Participants who were randomly assigned to the intervention group received an e-mail with personal login details and an information flyer about the installation and use of the educational eHealth tool. The tool could be used during the two weeks prior to the scheduled consultation. One day after their consultation participants received a link to a follow-up questionnaire.

Intervention
The educational eHealth tool was developed in collaboration with, patients with OA and healthcare professionals, following an iterative method of persuasive design19. The tool was available as a mobile application (Android and iOS) and in a web-based version. The tool consists of three parts: ‘Information’, ‘My consultations’, and ‘Medication’, covering the following functionalities: (1) short facts and information on OA and treatment modalities, based on a stepped-care strategy for OA20; (2) preparation for the upcoming consultation, consisting of predefined questions to answer, and space to record additional questions the patient would like to ask the orthopedic surgeon; (3) the option to monitor pain and fatigue during the week prior to the consultation; (4) a list of medication used (e.g., dosage), with the option to set reminders for intake; and (5) the option to create a visual timeline with the scheduled consultation, assessments and preparation. Users could earn three achievement awards while using the tool: one when they had scrolled through all information parts, one when a consultation was detailed in the educational eHealth tool, and one when medication use is registered in the tool.

Assessments
All clinical data were collected online using electronic data capture and management program Castor EDC. Demographic and clinical characteristics, knowledge, and frequency of internet and smartphone use in daily life were assessed at baseline. The usability of the intervention was assessed during the week after the consultation. Objective usage data was extracted from the backend of the educational eHealth tool on: (1) opening the tool and opening specific components, (2) information concerning a planned consultation (date, time, location, reason for consultation and consulting healthcare professional), preparation of the consultation (questions to ask during the consultation and answers to questions that can be expected to be asked by the orthopedic surgeon), measurements (pain and fatigue) and medication as recorded by the users and (3) earning of achievement awards.

Use
Based on the objective user data participants were classified as a ‘user’ or ‘non-user’. ‘Users’ of the educational eHealth tool were defined as ‘opening the tool at least once’, while ‘non-users’ were those participants who did not open the educational eHealth tool at all. ‘Users’ were further defined as ‘active’ or ‘superficial’. If a participant had opened the tool and earned at least one achievement award, they were defined as an ‘active user’. Participants were defined as ‘superficial users’ if they had used the tool but had not earned any achievements.

Preparation
The questions that patients recorded in the educational eHealth tool in preparation for their consultation were extracted from the backend of the applications. The questions were categorized into three themes based on the three good-preparation questions outlined by Shepherd et al. (2011): “What are my options?”; “What are the possible benefits and harms of those options?” and “How likely are each of the benefits and harms to happen to me?”18. For the latter question we used the Dutch version, which was translated into “What does this mean for my situation?” If the question did not fit one of the three themes, it was put in a ‘remaining’ category, which was subsequently further defined based on the nature of questions assigned to that category. This categorization was performed independently by a research assistant and a researcher. Any disagreement was resolved by discussion, and if consensus was still not met, a third researcher was consulted.

Usability
In the follow-up questionnaire, the usability of the educational eHealth tool was assessed using the 10-item System Usability Scale (SUS)21. The items, which covered complexity, ease of use, and willingness to use the tool, among other factors, were scored on a five-point Likert scale (‘strongly disagree’ to ‘strongly agree’). The final scores for the SUS could range from 0 to 100, with higher scores indicating better usability. The SUS is thought to be a robust, valid and versatile questionnaire22. The extent to which patients were satisfied with the tool was measured by asking the patients to rate their satisfaction on a NRS ranging from 0 to 10, with higher scores indicating a higher satisfaction.

Demographic and clinical patient characteristics
Demographic data were collected on the gender, age, body mass index (BMI), marital status, level of education and work status of the patients. Clinical characteristics were collected on the OA location (hip or knee) and duration of symptoms (years). To assess pain and function,
patients were asked to complete the Dutch Knee/Hip injury and Osteoarthritis Outcome Score (KOOS/HOOS)23. From the KOOS/HOOS, pain and function scores on subscales of the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) can be derived24. Scores were presented as standardized scores (0-100), with higher scores indicating more pain and worse function. Fatigue during the past week was assessed on a Numeric Rating Scale (NRS) from 0 (‘no fatigue’) to 100 (‘extreme fatigue’). To record the use of pain medication, patients were asked (yes/no) whether they had used pain medication in the past three months for their hip or knee symptoms.

Patient knowledge of OA (treatments) was assessed using a self-administered questionnaire. Based on the frequently asked questions on OA reported in a previous study26, 22 statements could be scored on a four-point scale (‘totally disagree’ to ‘totally agree’, with an additional option ‘I don’t know’). A total score (maximum of 22) was calculated by awarding one point for each correct response. Each incorrect or undecided (‘I don’t know’) answer was scored as 0.

Technology usage (frequency of internet and smartphone use in daily life) was assessed using two subscales of the Media and Technology Usage and Attitudes Scale (MTUAS)27. These scales use a 10-point frequency scale (1 = never, 5 = several times a week, 10 = all the time) to score possible activities on a smartphone (e.g. “using apps” or “listening to music”) and searching activities on the internet (e.g. “searching for information”). Mean scores can be calculated for each subscale.

Data analysis

Descriptive analysis
Baseline characteristics, user data, and usability were described descriptively using mean (SD), median (IQR), and number (%) where appropriate.

Statistical analysis
The demographic and clinical characteristics were compared between ‘non-users’ and ‘users’, and between ‘superficial’ and ‘active’ users of the educational eHealth tool using multivariable logistic regression analyses. First, the individual binominal associations between characteristics and the outcome variable (user or non-user) were calculated. Variables with a p-value ≤ 0.157 were selected for the multivariable logistic regression analyses28. By use of the Variance Inflation Factor (VIF, cut-off > 10) statistic, the remaining variables were tested for collinearity29. A backward selection (p-value < 0.10 for removal) was used to generate the final model.

For the logistic regression analysis, multiple imputation using Imputation by Chained Equation was used to estimate the missing values. A total of 20 imputed datasets were combined using Rubin’s rules30. These data were analysed using Stata 13.1.

Results
A total of 144 patients with knee or hip OA were included in this study. Their mean (SD) age was 61.7 (10.4), and more women (57%) participated than men. The mean (SD) BMI of the participants was 27.9 (4.4) kg/m². A total of 57 (40%) participants had a low educational level (<12 years) and 58 (43%) had a paid job at the time of inclusion. The majority of participants had a scheduled consultation for a knee joint (80%). The duration of symptoms was less than five years for the majority of participants (58%); however, patients had moderate to severe impaired functioning as reflected by the WOMAC (mean (SD): 50.6 (20.1) for pain and 55.1 (21.1) for functioning). Patient characteristics are shown in Table 1.

Table 1. Patient and clinical characteristics of users and non-users of the educational eHealth tool.

<table>
<thead>
<tr>
<th></th>
<th>Non-users (n=28)</th>
<th>Users (n=116)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (female), n (%)</td>
<td>14 (50)</td>
<td>67 (58)</td>
</tr>
<tr>
<td>Age (years), mean (SD)</td>
<td>59.4 (12.1)</td>
<td>62.2 (9.9)</td>
</tr>
<tr>
<td>BMI &gt; 25 kg/m², n (%)</td>
<td>18 (64)</td>
<td>78 (67)</td>
</tr>
<tr>
<td>Married, n (%)</td>
<td>20 (71)</td>
<td>86 (74)</td>
</tr>
<tr>
<td>Level of education (&gt;12 years), n (%)</td>
<td>17 (61)</td>
<td>67 (58)</td>
</tr>
<tr>
<td>Work status (paid), n (%)</td>
<td>11 (52)</td>
<td>47 (41)</td>
</tr>
<tr>
<td>Location (knee), n (%)</td>
<td>21 (75)</td>
<td>94 (81)</td>
</tr>
<tr>
<td>Duration of symptoms (&gt;5 years), n (%)</td>
<td>13 (48.1)</td>
<td>46 (39.7)</td>
</tr>
<tr>
<td>Pain, WOMAC (0-100), mean (SD)</td>
<td>81.1 (31.4)</td>
<td>49.1 (19.3)</td>
</tr>
<tr>
<td>Functioning, WOMAC (0-100), mean (SD)</td>
<td>62.4 (21.7)</td>
<td>53.5 (20.8)</td>
</tr>
<tr>
<td>Fatigue, NRS (0-100), mean (SD)</td>
<td>40.1 (20.2)</td>
<td>48.5 (25.1)</td>
</tr>
<tr>
<td>Pain medication use, n (%)</td>
<td>21 (81)</td>
<td>93 (81)</td>
</tr>
<tr>
<td>Knowledge of OA (0–22), mean (SD)</td>
<td>9.7 (3.2)</td>
<td>11.4 (3.7)</td>
</tr>
<tr>
<td>Smartphone usage in daily life, MTUASc (1-10), mean (SD)</td>
<td>6.1 (1.7)</td>
<td>5.0 (1.9)</td>
</tr>
<tr>
<td>Internet usage in daily life, MTUASc (1-10), mean (SD)</td>
<td>6.3 (1.9)</td>
<td>4.8 (1.7)</td>
</tr>
</tbody>
</table>

*WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index, †Self-administered, ‡MTUAS: Media and Technology Usage and Attitudes Scale.

Use of the educational eHealth tool
Among the participants, 116 (81%) were users and 28 (19%) were non-users of the eHealth tool (Figure 1). The group of 116 users, comprised 29 (25%) superficial users and 87 (75%) active users.

Among the users, 74 (64%) participants used the Android or iOS application and 57 (49%) used the web-version of the educational eHealth tool, with 15 participants using both platforms. The three main components of the tool (‘Information’, ‘My consultation’, and ‘Medication’) were all opened by the majority of users (91-95%) (Table 2) whereas the short facts on OA were opened by slightly fewer users (80%). The median number of opened components was two (IQR 1-3). The actual use (i.e., earning an achievement award) was highest for the preparation for the consultation (57%), followed by reading all the information on OA treatments (35%).
and listing one's medication (34%). A detailed look into the earned achievements revealed that participants who only earned one achievement, received the award for the 'Information' or 'My consultation' components. For those who earned two achievements, the combination of 'My consultation' and 'Medication' was most frequently earned. Our results also show that, of the 87 active users, 19 solely used the more passive component (i.e., reading information), while more than half chose to use the interactive components alone (i.e., preparing for a consultation only or in combination with listing medication).

Figure 1. Distribution of non-users and users (superficial and active) among the study population.

Table 2. Use of components of the educational eHealth tool among 116 users.

<table>
<thead>
<tr>
<th>Component</th>
<th>Frequency Median (IQR)</th>
<th>Earned achievement N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information</td>
<td>41 (35)a</td>
<td></td>
</tr>
<tr>
<td>Opened 'Information'</td>
<td>110 (95)</td>
<td>4.5 (2-10)</td>
</tr>
<tr>
<td>Read ≥ 1 short facts</td>
<td>93 (80)</td>
<td>7.5 (1.5-11)</td>
</tr>
<tr>
<td>My consultation</td>
<td>66 (57)a</td>
<td></td>
</tr>
<tr>
<td>Opened 'My consultation'</td>
<td>109 (94)</td>
<td>6.5 (4-35)</td>
</tr>
<tr>
<td>Answered ≥ 1 preparation questions</td>
<td>63 (54)</td>
<td></td>
</tr>
<tr>
<td>Recorded ≥ 1 questions for consultation</td>
<td>31 (27)</td>
<td></td>
</tr>
<tr>
<td>Scheduled pain and/or fatigue measurements</td>
<td>38 (33)</td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td>40 (34)</td>
<td></td>
</tr>
<tr>
<td>Opened 'Medication'</td>
<td>105 (91)</td>
<td>6.5 (2.5-14.5)</td>
</tr>
</tbody>
</table>

*Visited all pages with information. †Scheduled consultation date. ‡Listed medication use.

Questions in preparation for their consult
About one-quarter of users recorded one or more questions in preparation for their consultation. A total of 75 questions were recorded in the tool. Disagreement about the categorization of 20 questions was resolved by discussion. Two questions were excluded from the categorization because they were formulated as notes rather than questions. A total of 46 questions were categorized into three predefined themes: "What are my options?", "What are the possible benefits and harms of those options?", and "What does this mean is my situation?" (Table 3). When discussing the remaining 27 questions, a fourth theme was identified, "What is my situation at this moment?", with 15 questions added to this category. The other 12 questions were grouped into the 'remaining' category. These were mainly educational questions on how to deal with OA in daily life, some of which addressed the added value of experimental treatments.

Table 3. Categorization of questions prepared in the educational eHealth tool, with examples given for each theme.

<table>
<thead>
<tr>
<th>Themes (number of questions)</th>
<th>Example questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is my situation at this moment? (15)</td>
<td>• How far has the osteoarthritis progressed?</td>
</tr>
<tr>
<td></td>
<td>• What is the situation right now and what is the prognosis?</td>
</tr>
<tr>
<td>What are my options? (35)</td>
<td>• What is your advice in resolving the pain?</td>
</tr>
<tr>
<td></td>
<td>• What are my treatment options?</td>
</tr>
<tr>
<td>What are the possible benefits and harms of those options? (5)</td>
<td>• What can I expect if I had surgery?</td>
</tr>
<tr>
<td>What does this mean in my situation? (6)</td>
<td>• What is the recovery period of surgery?</td>
</tr>
<tr>
<td></td>
<td>• Is it still necessary to use orthopaedic shoes?</td>
</tr>
<tr>
<td>Remaining (12)</td>
<td>• Is it possible to get an injection in my knee one more time?</td>
</tr>
<tr>
<td></td>
<td>• At what level can I be physically active with regard to the wear and tear of my cartilage?</td>
</tr>
<tr>
<td></td>
<td>• Is it possible to inject cartilage into the knee?</td>
</tr>
</tbody>
</table>

Usability
The mean (SD) usability score among users, as measured with the SUS, was 64.8 (16.0). Moreover, patient satisfaction with the educational eHealth tool was 6.9 (1.7) on a scale from 0 to 10. No differences were found in the SUS and satisfaction scores between active and superficial users (mean difference (95% CI): 0.04 (-0.69, 0.77) and 0.3 (-0.50, 1.11) respectively).

Subgroup characteristics
Based on univariate binomial regression analyses, fatigue (P = 0.16), knowledge of OA (P = 0.04), and smartphone (P = 0.03) and internet (P = 0.009) use in daily life were included in a multivariable analysis. This analysis revealed that participants with a higher baseline knowledge of OA (OR (95% CI): 1.2 (1.0, 1.4)), and who used the internet less frequently in their daily life (OR (95% CI): 0.6 (0.5, 0.9)) were more likely to use the educational eHealth tool (Table 4). No statistically significant differences were found between the demographic and clinical characteristics of the superficial and active users.
tools had considerably higher SUS-scores\textsuperscript{36,37}. Scott et al.\textsuperscript{36} reported a median (IQR) SUS score of 95 (86-98) immediately after providing instructions about a mobile app for daily postoperative self-reporting after colorectal surgery; however, the majority of participants did not use the application after discharge or only used it once. This indicates that high usability alone is not sufficient to motivate people to use eHealth tools\textsuperscript{36}. Moreover, user rates in our study were reasonably high, indicating that patients see the benefits of using the eHealth tool in preparation for their consultation. It is therefore conceivable that improvement of the content might increase the usability. Frie et al.\textsuperscript{34} evaluated reviews of smartphone applications for monitoring weight loss and found that users had a preference for applications with a limited number of features. Our eHealth tool contained three components ('Information', 'My consultation', and 'Medication'), each of which contained multiple features (e.g., monitoring pain and fatigue, recording questions, and answering pre-defined questions). This may have unnecessarily complicated the tool. For the further improvement of the tool, the removal of the 'Medication' component should be considered, as this component was the least used by participants.

An important part of our intervention was the preparation for the consultation, which involved listing questions to ask during the consultation. Currently, three standardized questions ('What are my options?', 'What are the possible benefits and harms of those options?', and 'How likely are the benefits and harms of each option to occur?') are used in several national campaigns in England, Australia, and the Netherlands\textsuperscript{11}. It is not known to what extent these questions cover the essence of the questions patients want to ask, however. Here, we compared the listed questions to the three standardized questions. Our results showed that about a quarter of the questions listed by patients do not fit these three themes. A considerable number of these remaining questions were focused on the current status/situation that patients were in, e.g., ‘how far has my OA progressed?’ and ‘what is the prognosis based on my current situation?’\textsuperscript{39}. This shows that, although prompting pre-defined questions may result in patients considering novel topics\textsuperscript{39}, it may also miss patient’s individual information needs. This consideration is in line with a recent RCT performed by Bottachini et al.\textsuperscript{39} who compared the use of a question prompt list (pre-defined questions) with question listing in breast cancer patients and found that patients who used the prompt list were less satisfied with the information they received during their consultation. Our results support the extension of the three standardized questions to four, but also suggest the importance of finding ways to elicit the individual information needs of patients not covered in the pre-defined questions to optimize their preparation for consultations; for instance, by providing a space for a list of their own questions, as we did in our educational eHealth tool.

We found several differences between the characteristics of users and non-users. Our results show that the baseline knowledge of OA was lower among non-users than users, suggesting that some subgroups of patients may just not be as interested in learning more about their condition or are not able to\textsuperscript{40}. In clinical practice it is important to be aware of this subgroup of patients, which may need a different strategy to be educated. Additionally, we found that users were less familiar with using the internet in their daily life than non-users. Although only univariate, the same trend was seen for daily life smartphone usage ($P = 0.03$). A previous study on the determinants of adherence to an online component of a physical activity program in OA qualitatively identified internet skills as important for optimal adherence\textsuperscript{40}. On average, the users in our study indicated that they use the internet and smartphones several times a

### Table 4. Results from the multivariable logistic regression analysis for differences between users and non-users of the educational eHealth tool.

<table>
<thead>
<tr>
<th>OR (95% CI)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of OA (0-22)</td>
<td>1.1 (1.0, 1.4)</td>
</tr>
<tr>
<td>Internet usage in daily life, MTUAS (1-10)</td>
<td>0.6 (0.5, 0.9)</td>
</tr>
</tbody>
</table>

\textsuperscript{*Self-administered; MTUAS: Media and Technology Usage and Attitudes Scale.

## Discussion

This study explored the use and usability of a smartphone and web-based educational eHealth tool. The educational eHealth tool was used by 81% of the patients with knee or hip OA who were offered it. Among users, 75% actively engaged with the tool and used at least one of the components, with ‘Information’ and ‘My consultation’ being the most popular components. Questions that were recorded by participants in preparation for their consultation were mostly in line with a widely used question prompt list, although a considerable number remained, some of which could be categorized in a new additional theme ("What is my situation at this moment?"). Participants with a higher baseline knowledge of OA and who used the internet less frequently in their daily lives were most likely to use the tool. No other statistically significant differences were found between users and non-users of the educational eHealth tool.

To our knowledge, little is known about use of stand-alone eHealth interventions in OA. Our finding that 81% of participants used the educational eHealth tool is in line with the results of De Vries et al.\textsuperscript{33}, who evaluated adherence to an online component of a blended care physical activity program for patients with hip or knee OA. This study was part of a blended care intervention, involving interaction with a physiotherapist, so is not directly comparable with our study. One recently published RCT on the effectiveness of an educational smartphone and tablet app reported a 70% adherence rate\textsuperscript{31}. Compared with other eHealth stand-alone interventions these percentages are reasonably high\textsuperscript{33,34}. The relatively high usage rate in our study could be explained by the short timeframe in which the tool could be used (two weeks prior to the upcoming consultation) and the specific objective of the tool. Currently, there is no consensus about how to define and appraise eHealth use; measures used to define use include the frequency of logging in or using a tool, the number of components used or the time spent on the tool\textsuperscript{35}. Often the threshold for ‘use’ is drawn based on the concept that “more is better” or is not justified at all\textsuperscript{35}. Defining and operationalizing the elements and the measures that constitute eHealth “use” fitting the aim of the intervention would facilitate comparisons between studies.

Regardless of the high user-rates in our study our results regarding usability and patient satisfaction about the tool show that there is still room for improvement. The mean usability score of our educational eHealth tool was 64.8 on a scale from 0-100 as measured with the SUS. Although this score corresponds to being Fair to Good\textsuperscript{34}, it does not reach the acceptable score (i.e., 70) proposed by Bangor et al.\textsuperscript{35}. Previous studies on the usability of eHealth and mHealth campaigns in England, Australia, and the Netherlands\textsuperscript{12}. It is not known to what extent these questions cover the essence of the questions patients want to ask, however. Here, we compared the listed questions to the three standardized questions. Our results showed that about a quarter of the questions listed by patients do not fit these three themes. A considerable number of these remaining questions were focused on the current status/situation that patients were in, e.g., ‘how far has my OA progressed?’ and ‘what is the prognosis based on my current situation?’\textsuperscript{39}. This shows that, although prompting pre-defined questions may result in patients considering novel topics\textsuperscript{39}, it may also miss patient’s individual information needs. This consideration is in line with a recent RCT performed by Bottachini et al.\textsuperscript{39} who compared the use of a question prompt list (pre-defined questions) with question listing in breast cancer patients and found that patients who used the prompt list were less satisfied with the information they received during their consultation. Our results support the extension of the three standardized questions to four, but also suggest the importance of finding ways to elicit the individual information needs of patients not covered in the pre-defined questions to optimize their preparation for consultations; for instance, by providing a space for a list of their own questions, as we did in our educational eHealth tool.

We found several differences between the characteristics of users and non-users. Our results show that the baseline knowledge of OA was lower among non-users than users, suggesting that some subgroups of patients may just not be as interested in learning more about their condition or are not able to\textsuperscript{40}. In clinical practice it is important to be aware of this subgroup of patients, which may need a different strategy to be educated. Additionally, we found that users were less familiar with using the internet in their daily life than non-users. Although only univariate, the same trend was seen for daily life smartphone usage ($P = 0.03$). A previous study on the determinants of adherence to an online component of a physical activity program in OA qualitatively identified internet skills as important for optimal adherence\textsuperscript{40}. On average, the users in our study indicated that they use the internet and smartphones several times a...
week, which suggests that they likely had significant skills in using these media. The literature also shows that younger people are less likely to adhere to eHealth tools\textsuperscript{14,17}. Although, not statistically significant, the non-users in our study were slightly younger than the users. It is likely that younger adults, who in general use the internet and smartphones more often\textsuperscript{20}, have lost interest in new apps that are continuously being offered to them or already found similar apps or information about OA on the internet. Different strategies to target this subgroup should be explored.

Several limitations of this study need to be addressed. First, we do not know why some participants did not use the application or used it only in a superficial way. Qualitative research may provide additional insights into how we can further optimize the eHealth application. Second, it is important to note that our study sample consisted of patients willing to participate in a RCT evaluating an eHealth application. Although patients who were not willing to participate did not differ those who did in terms of their age or gender, we do not know the extent of internet use by the patients not willing to participate; therefore, it is not possible to generalize the user-characteristics we identified to the entire OA population. To consolidate our results in future research, we recommend the use of a study design in which every patient visiting for a first orthopedic consultation gets access to the educational eHealth tool. Finally, because there is no clear definition of ‘use’ in literature, we defined ‘users’ and ‘non-users’ based on whether they opened the application. Using another cut-off point to define these two groups might have resulted in different characteristics being significant for the use of the tool; however, considering the small differences found and the lack of differences detected between the active and superficial users, it is not likely that changing the cut-off point would have resulted in additional findings of interest.

Based on the results of this study it can be concluded that the use of an educational eHealth tool to prepare patients with hip and knee OA for their first orthopedic consultation is feasible; however, improvements to the content of the tool itself should be established to enhance its usability and user satisfaction. It is recommended that four predefined questions are included, and that space is provided for patients to list additional questions to support their preparation for their consultation. We found no clear practical indications that specific subgroups should be targeted for implementation. The literature on the use of eHealth and especially mHealth technologies in patients with OA is scarce. The results of this study therefore contribute to the body of knowledge for eHealth and mHealth in this population.

References


Chapter 6

How to best distribute written patient education materials among patients with rheumatoid arthritis: a randomized comparison of two strategies

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Abstract

Background

The aim of this randomized controlled trial was to evaluate the effect of a ‘supply on demand’-distribution strategy, compared to an ‘unsolicited supply’-distribution strategy, on the use of a care booklet and clinical outcomes among patients with rheumatoid arthritis (RA). In addition, differences in socio-demographic and clinical characteristics between users and non-users were explored.

Methods

As part of regular care the care booklet was distributed among RA-patients of two hospitals in the Netherlands. 1000 patients received the care booklet by mail, whereas another 1000 received an information letter with the option to order the care booklet. Four months after distribution, a random sample of 810 patients (stratified by hospital and distribution method) received a questionnaire on the use of the booklet, social-demographic and clinical characteristics. To compare effects between the two distribution strategies and differences between users and non-users univariate and multilevel regression analyses were performed. Secondary analysis included a per-protocol analysis (excluding participants who did not order the care booklet).

Results

194 patients in the ‘unsolicited supply’ and 176 patients in the ‘supply on demand’ group (46%) returned the questionnaire. In the ‘supply on demand’ group 106 (60.2%) participants ordered the care booklet. In total, no difference was found in use between the ‘unsolicited supply’-group (23.2%) and the ‘supply on demand’-group (21.6%) (OR 0.9; 95%CI: 0.6, 1.5). However, the proportion of users among patients in the ‘supply on demand’-group who ordered the booklet (55%) was significantly higher than in the ‘unsolicited supply’-group (OR 1.9; 95%CI: 1.1, 3.3). Regardless of distribution method, use of the care booklet was associated with being married (OR 2.4; 95%CI: 1.2, 4.6), higher disease activity (mean difference 0.5; 95%CI: 0.0, 1.1), more activity limitations (mean difference 0.2; 95%CI: 0.1, 0.4), use of corticosteroids (OR 1.9; 95%CI: 1.0, 3.2), perception of disease course as fluctuating (mean difference 1.4; 95%CI: 0.5, 2.3) and higher educational needs (mean difference 9.7; 95%CI: 2.9, 16.6).

Conclusions

From an economic and environmental perspective a ‘supply on demand’-distribution strategy could be recommended. Results of this study provide starting points to optimize further implementation strategies of a care-booklet in routine care.

Background

As a result of pain, fatigue and limitations in daily activities and participation, patients with rheumatoid arthritis (RA) have a significantly impaired health related quality of life. Apart from the consequences of the disease, patients with RA deal with different medical treatments and a variety of healthcare providers during their course of illness. Therefore, supporting self-management is an important element of non-pharmacological care. This encompasses activities, skills and interventions which allow patients to learn to cope with the consequences and treatment of their chronic illness and to take care of themselves. To enhance self-management, multiple interventions with similar content like face-to-face education and patient information booklets and leaflets, both on paper and online are available for patients with RA. Preferences may vary with regard to mode of delivery.

One strategy to augment effective self-management is the use of patient care booklets. A care booklet can support patients with a chronic condition to play an active role in managing their disease and treatment by providing information and tools for monitoring symptoms, prepare activities, skills and interventions which allow patients to learn to cope with the consequences and treatment of their chronic illness and to take care of themselves.

Patients7 and data on head to head comparison of different distribution strategies on the use of educational material is not available. Usage after ‘unsolicited supply’ (i.e. sending a care-booklet without being requested) may differ from that after ‘supply on demand’ (i.e. offering the option to order a care booklet), as patients who are offered the option to order a care booklet might be better motivated to use it, ultimately resulting in better outcomes.

In order to study the effect of different distribution strategies on the use of a recently developed care booklet for patients with RA, the aims of the present study were: 1) to evaluate the effect of a ‘supply on demand’ distribution strategy and an ‘unsolicited supply’ distribution strategy for an RA care booklet regarding its usage, and patients’ educational needs, self-efficacy and illness perceptions, and 2) to explore differences in patient and clinical characteristics between users and non-users of the care booklet.
Methods

Study design

In this multicentre randomized controlled trial two distribution strategies of a care booklet for patients with RA (‘unsolicited supply’ or ‘supply on demand’) were compared. The study was executed between September 2013 and May 2014 at the outpatient clinics for rheumatology of two hospitals in two regions of the Netherlands (Leiden University Medical Center (LUMC), Leiden and the Sint Maartenskliniek Hospital (SMK), Nijmegen). The Institutional Review Board of the University Medical Centre, Nijmegen (protocol number 2013/292) and the Medical Ethics Review Committee of the University Medical Centre, Leiden (protocol number: P13.202) both waived ethical approval, as the Medical Research Involving Human Subjects Act did not apply to this study.

The RA care booklet

The initiative to develop a care booklet for patients with RA was taken by regional patient organizations and further developed as a collaborative project of RA patients, healthcare providers and researchers. The process of development and content of the interactive self-management “RA care booklet” (Zorgwijzer Reumatoïde Artritis©) is described in an additional file [see Additional file 1].

Procedure

As part of regular care, the care booklet was distributed among patients with RA visiting the outpatient clinics of the departments of rheumatology of the LUMC and the SMK between September–December 2013. Because funding for printing booklets was restricted, for each outpatient clinic 1000 care booklets were available for distribution. Patients eligible to receive a care booklet were selected from the outpatient clinics’ registries by a data manager if they fulfilled the following criteria: 1) diagnosed with RA, 2) aged 18 years old and 3) having a future scheduled visit with a rheumatologist. Two distribution strategies were randomly applied by the researchers (AAOMC and SP) in each outpatient clinic concerned 1): ‘unsolicited supply’ of the care booklet free of charge to the home-address of patients accompanied by an introductory letter on behalf of the medical head of the department of rheumatology and 2) ‘supply on demand’: mailing an introductory letter about the care booklet on behalf of the medical head of the department of rheumatology to the home-address of patients with the option to order the care booklet free of charge. Patients could order the RA care booklet by sending back a reply card. Randomisation to the two distribution strategies in the outpatients of the LUMC was stratified for participation in an other ongoing study (yes/no), based on advise of the local review board of the LUMC.

Four months after distribution of the care booklet or the information letter about the care booklet, the subgroup of patients who were selected for the evaluation study received information about the study, a questionnaire, as well as a consent form. Reminders were sent after two weeks.

Participants

For the current study we planned on inviting half of the patients who were randomized to the two distribution strategies for the evaluation (500 from each outpatient clinic). However, patients from the LUMC who were participating in another on-going study were excluded (remaining participants n=310). A total sample of 810 patients (stratified by outpatient clinic) were randomly invited to participate in this study (Figure 2).

Assessments

The questionnaire comprised questions on the ordering and usage of the care booklet. In addition, a number of questions on demographic, clinical and psychosocial characteristics and educational needs were incorporated. The maximal time needed to complete the questionnaires was estimated to be 30–60 minutes.

Use of the care booklet

First patients were asked whether they had received the care booklet (in the ‘unsolicited supply’-group) or had received the care booklet after ordering it (‘supply on demand’-group). Second, patients were asked whether they used the care booklet in the past 4 months. Answer-options included: “no”; “yes, I read (parts of) the care booklet”; “yes, I made notes in the care pass”; “yes, I discussed (parts of) the care booklet/pass with my healthcare provider”; “yes, I used the care booklet in a different way, namely...”. Multiple answers were possible. Patients who answered “no”, or stated that they did not receive or ordered the care booklet were classified as “non-users”. Patients answering 1 or more of the “yes”-answers were classified as “users”.

Demographic characteristics

Demographic characteristics included age, gender, ethnicity (native or foreign, based on land of birth, land of birth mother and father), marital status (based on being married, divorced, widow/widower, never been married), education (<12 years of education, ≥12 years of education) and work status (based on having paid work or not (retired, unemployed, disabled, student, housewife/man) yes/no).

Clinical characteristics

Included disease duration (years since diagnosis) and medication use (yes/no of nonsteroidal anti-inflammatory drugs (NSAIDs), corticosteroids, disease-modifying anti-rheumatic drugs (DMARDs), biologicals, other).

The Rheumatoid Arthritis Disease Activity Index (RADAi) was used to measure disease activity4. The RADAi is a 5-item self-registered measure of disease activity, which include; “arthritis activity over the past 6 months”, “arthritis activity today”, “arthritis pain today”, “morning stiffness today” and “severity of pain per joint”. A total score can be calculated by dividing the sum of scores by 5. Total score ranges from 0 to 10 (higher score = more disease activity). Limitations in activities were assessed by the Health Assessment Questionnaire Disability Index (HAQ-DI)4. The HAQ-DI has 20-items. Daily activities are scored on a 4-point scale (0 “without difficulty” – 3 “unable to do”). Overall score can be computed as the sum of domain scores, divided by the number of domains answered. Total scores can range from 0 to 3 (0 = least difficulty, 3 = extreme difficulty). Educational needs were assessed using the Dutch version of the Educational Needs Assessment Tool (D-ENAT)19. The D-ENAT consist of 39-items, grouped into seven domains: managing pain, movement, feelings, arthritis process, treatments, self-help measures and support systems. RA patients are asked to indicate how important it is for them to know more about certain topics. A total score can be calculated, ranging from 0 to 156 (higher score indicate higher educational needs). The Dutch General Self-efficacy Scale
(GSES) was used to measure self-efficacy\(^\text{20}\). The GSES has 10 items of which a total score can be calculated. Patients are asked about the belief that their own actions are responsible for successful outcomes, on a scale from 1 (not at all true) to 4 (exactly true). Higher scores on the GSES, ranging from 10 to 40 reflect higher self-efficacy. To measure illness perceptions the Revised Illness Perception Questionnaire (IPQ-R) was used\(^\text{21}\). The IPQ-R has items divided into 7 subcategories, beliefs about: RA being acute or chronic (timeline; range 6-30), RA having a variety of consequences (consequences; range 4-20), RA having a fluctuating disease course (timeline cyclical; range 6-30), RA being under personal control (personal control; range 6-30), the ability to control one’s health due to treatment (treatment control; range 5-25), the level of understanding RA (illness coherence; range 5-25) and RA causing a variety of emotional states (emotional representation; range 6-30). High scores on the timeline, consequences, and cyclical dimensions represent strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness, and the cyclical nature of the condition. High scores on the personal control, treatment control and coherence dimensions, represent positive beliefs about the controllability of the illness and a personal understanding of the condition.

**Statistical analysis**

**Sample size**

To detect a 15% difference in proportions of users, assuming 40% use in the ‘unsolicited supply’-group versus 55% in the ‘supply on demand’-group, 372 participants (n=186 for per group) would be needed (power 0.8, alpha 0.05)\(^\text{22}\). Estimations of proportions of use were based on user-rates in previous studies, which varied between 36-55%\(^\text{12,14,15}\). A 15% difference between groups was considered to be relevant. Considering the comprehensiveness of the questionnaire we assumed a 45% response rate\(^\text{19,23}\), yielding a sample size of 810 patients to be invited for this study.

**Data analysis**

Data were analysed using Stata version 13.0 (www.stata.com). Descriptive statistics were provided as mean and standard deviation (SD) and numbers with percentages (%), where applicable. Imputed data were used for regression analyses. Missing data were imputed using Imputation by Chained Equations, which is an iterative multivariable regression technique, to obtain less biased results and preserve power\(^\text{24}\).

In order to analyse the effect of distribution strategy (“unsolicited supply” / “supply on demand”) on the use of the care booklet a multilevel logistic regression analysis was performed using “outpatient clinic” as a random effect, using “use of care booklet” as dependent variable and distribution strategy as independent variable (intention-to-treat analysis). Multilevel linear regression analyses were used to explore the effect of the distribution strategy on educational needs, self-efficacy and illness perceptions including “outpatient clinic” as a random effect. Additionally analyses were repeated on a per-protocol basis including only those participants in the ‘supply on demand group’ who indicated that they had ordered the care booklet. Finally, univariate logistic and linear regression analyses were used to explore the differences in age, gender, ethnicity, living status, level of education, work, disease duration, disease activity, activity limitations, use of medication, educational needs, self-efficacy and illness perceptions and between users and non-users of the care booklet. When needed analyses were corrected for “outpatient clinic” and “distribution strategy”. A statistical significance level of \(p < 0.05\) (two-sided) was adopted for all analyses.

**Results**

**Patients’ demographics and characteristics**

From the 810 invited patients, 194 patients in the ‘unsolicited supply’ group and 176 patients in the ‘supply on demand’ group (total 370 (45.7%)) provided written consent for participating in the present study and returned the questionnaire (Figure 1). Table 1 shows the patient characteristics per distribution-group. No significant differences were found between the two groups.

**Figure 1.** Participants selection from the Sint Maartenskliniek Hospital and Leiden University Medical Centre and response rate.

**Distribution strategy**

The ‘unsolicited supply’-group included 28 patients who did not recall to have received the care booklet, who were assigned as non-users. In the ‘supply on demand’ group 206 (60.2%) patients had ordered the booklet.

In the total study group, 79 patients (22.4%) used the care booklet, 42 (23.2%) in the ‘unsolicited supply’-group and 37 (21.6%) in the ‘supply on demand’ group (OR 0.9 CI: 0.6-1.5, (intention-to-treat analysis). Logistic regression analysis with “outpatient clinic” as a random effect, yielded similar results. In the total group, no differences were found between the two distribution strategies in any of the secondary outcomes (Table 2). Educational needs were slightly lower in the ‘supply on demand’-group, however this difference was not significant. A sensitivity analysis on complete cases yielded similar results.
A total of 37 (35%) of the patients who ordered the care booklet actually used the care booklet. In the per-protocol analysis a significant relation between distribution strategy and actual use of the care booklet (OR 1.9 CI: 1.1-3.2) in favour of the 'supply on demand' group was observed. Similar to the intention-to-treat analysis in the per-protocol analysis no differences were found in any of the secondary outcomes.

Table 1. Demographics and characteristics of patients allocated to the two distribution strategies and as total group.

<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>Group “unsolicited supply” N=194</th>
<th>Group “supply on demand” N=176</th>
<th>Total n=370</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (female), n (%)</td>
<td>137 (70.6)</td>
<td>114 (64.8)</td>
<td>251 (67.8)</td>
</tr>
<tr>
<td>Age (years), mean (SD)</td>
<td>65.0 (11.5)</td>
<td>65.3 (12.4)</td>
<td>65.4 (11.8)</td>
</tr>
<tr>
<td>Ethnicity (native), n (%)</td>
<td>175 (91.2)</td>
<td>157 (90.2)</td>
<td>332 (90.7)</td>
</tr>
<tr>
<td>Married, n (%)</td>
<td>132 (72.5)</td>
<td>122 (72.2)</td>
<td>254 (72.4)</td>
</tr>
<tr>
<td>Level of Education (&gt;12 years), n (%)</td>
<td>75 (40.1)</td>
<td>67 (39.0)</td>
<td>142 (39.6)</td>
</tr>
<tr>
<td>Work (paid), n (%)</td>
<td>46 (24.3)</td>
<td>37 (22.4)</td>
<td>83 (23.5)</td>
</tr>
<tr>
<td>Outpatient clinic (LUMC), n (%)</td>
<td>66 (34.0)</td>
<td>49 (27.8)</td>
<td>115 (31.4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical characteristics</th>
<th>Group “unsolicited supply” N=194</th>
<th>Group “supply on demand” N=176</th>
<th>Difference (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease duration (years), mean (SD)</td>
<td>17.5 (11.9)</td>
<td>16.4 (12.9)</td>
<td>17.0 (12.4)</td>
</tr>
<tr>
<td>Disease activity, RADAI (0-10), mean (SD)</td>
<td>2.5 (1.0)</td>
<td>2.8 (3.0)</td>
<td>2.6 (1.3)</td>
</tr>
<tr>
<td>Activity limitations HAQ-DI (0-3), mean (SD)</td>
<td>0.9 (0.7)</td>
<td>0.9 (0.7)</td>
<td>0.0 (0.7)</td>
</tr>
<tr>
<td>Medication, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSAIDs</td>
<td>66 (34.0)</td>
<td>62 (35.4)</td>
<td>128 (34.6)</td>
</tr>
<tr>
<td>Corticosteroid</td>
<td>33 (17.0)</td>
<td>27 (15.3)</td>
<td>60 (16.2)</td>
</tr>
<tr>
<td>DMARDs</td>
<td>131 (67.5)</td>
<td>123 (69.9)</td>
<td>254 (68.6)</td>
</tr>
<tr>
<td>Biologicals</td>
<td>82 (42.3)</td>
<td>87 (49.4)</td>
<td>169 (45.6)</td>
</tr>
</tbody>
</table>

| Care booklet            |                                  |                                |                     |
| Ordered the care booklet, n (%) | -                               | 106 (60.2)                     | -                   |
| Care booklet, n (%)     |                                  |                                |                     |
| Non-user                | 139 (76.8)                       | 134 (78.4)                     | 273 (77.6)          |
| User                    | 42 (23.2)                        | 37 (21.6)                      | 79 (22.4)           |

Comparison of users and non-users of the care booklet
Apart from self-ordering of a care booklet, a number of factors appeared to be associated with its eventual usage: the users were more often married (OR 2.4 CI: 1.2, 4.5) than non-users. Users had a higher disease activity (Δ 0.5 CI: 0.0, 1.1), more activity limitations (Δ 0.2 CI: 0.1, 0.4), used corticosteroids (OR 1.9 CI: 1.0, 3.5) more often, experienced the course of RA as fluctuating (Δ 1.4 CI: 0.5, 2.3) and had higher educational needs (Δ 9.7 CI: 2.9, 16.6) compared to non-users. No differences between users and non-users were found in other patient and clinical characteristics (Table 3).

Table 2. Differences in secondary outcomes between the two distribution strategies

| Educational needs, D-ENAT (0-156), mean (SD) | 81.3 (26.9) | 75.7 (22.5) | -4.2 (-9.9, 1.5) |
| Self-efficacy, GSES, mean (SD)               | 32.4 (5.7)  | 32.6 (5.4)  | 0.2 (-1.0, 1.3)  |
| Illness perceptions, IPQ-R, mean (SD)        |             |             |                  |
| Timeline (6-30)                              | 24.7 (4.6)  | 24.4 (5.4)  | -0.4 (-1.3, 0.6) |
| Consequences (4-20)                          | 18.9 (4.8)  | 18.8 (4.5)  | -0.1 (-1.1, 0.9) |
| Timeline cyclical (6-30)                     | 13.9 (3.4)  | 14.2 (3.5)  | 0.3 (-0.4, 1.0)  |
| Personal control (6-30)                      | 19.0 (3.6)  | 19.7 (3.6)  | 0.7 (0.0, 1.5)   |
| Treatment control (5-25)                     | 12.8 (2.9)  | 12.9 (3.0)  | 0.1 (-0.5, 0.7)  |
| Illness coherence (5-25)                     | 12.6 (3.8)  | 17.4 (3.6)  | -2.8 (-10.0, 4.6) |
| Emotional representation (6-30)              | 13.8 (4.8)  | 14.1 (4.4)  | 0.3 (-0.6, 1.1)  |

D-ENAT, (Dutch) Educational Needs Assessment Tool; GSES, General Self-efficacy Scale; IPQ-R, Revised Illness Perception Questionnaire.
Table 3. Differences in patient and clinical characteristics between users and non-users of the care booklet.

<table>
<thead>
<tr>
<th></th>
<th>Non-users</th>
<th>Users</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender (female), n (%)</td>
<td>182 (66.7)</td>
<td>58 (73.4)</td>
<td>1.4 (0.8, 2.4)</td>
</tr>
<tr>
<td>Age (years), mean (SD)</td>
<td>65.3 (12.2)</td>
<td>64.7 (9.6)</td>
<td>0.8 (-0.7, 2.3)</td>
</tr>
<tr>
<td>Ethnicity (foreign), n (%)</td>
<td>27 (10.0)</td>
<td>6 (7.7)</td>
<td>0.8 (0.1, 1.9)</td>
</tr>
<tr>
<td>Married, n (%)</td>
<td>181 (69.4)</td>
<td>64 (84.2)</td>
<td>2.4 (1.2, 4.6)**</td>
</tr>
<tr>
<td>Level of education (&gt;12 years), n (%)</td>
<td>106 (39.0)</td>
<td>32 (41.6)</td>
<td>1.1 (0.6, 1.8)</td>
</tr>
<tr>
<td><strong>Clinical characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease duration (years), mean (SD)</td>
<td>17.3 (12.8)</td>
<td>15.9 (11.2)</td>
<td>Δ -1.5 (-6.6, 1.7)</td>
</tr>
<tr>
<td>Disease activity, RADAI (0-10), mean (SD)</td>
<td>2.5 (1.9)</td>
<td>3.0 (2.0)</td>
<td>Δ 0.5 (0.0, 1.2)**</td>
</tr>
<tr>
<td>Activity limitations HAQ-DI (0-3), mean (SD)</td>
<td>0.9 (0.7)</td>
<td>1.1 (0.7)</td>
<td>Δ 0.2 (0.1, 0.4)**</td>
</tr>
<tr>
<td>Medication, n (%)</td>
<td>97 (35.6)</td>
<td>29 (36.7)</td>
<td>1.0 (0.6, 1.7)</td>
</tr>
<tr>
<td>NSAIDs</td>
<td>39 (14.3)</td>
<td>19 (24.1)</td>
<td>1.9 (1.0, 3.5)**</td>
</tr>
<tr>
<td>Corticosteroid</td>
<td>185 (67.8)</td>
<td>58 (74.4)</td>
<td>1.3 (0.8, 2.3)</td>
</tr>
<tr>
<td>DMARDs</td>
<td>185 (60.7)</td>
<td>58 (74.4)</td>
<td>1.3 (0.8, 2.3)</td>
</tr>
<tr>
<td>Educational needs, D-ENAT(0-156), mean (SD)</td>
<td>75.3 (27.5)</td>
<td>86.0 (26.6)</td>
<td>Δ 9.7 (2.9, 16.6)**</td>
</tr>
<tr>
<td>Self-efficacy, GSES, mean (SD)</td>
<td>32.3 (5.5)</td>
<td>33.1 (4.3)</td>
<td>Δ 0.8 (-0.6, 2.2)</td>
</tr>
<tr>
<td>Illness perceptions, IPQ-R, mean (SD)</td>
<td>24.5 (4.4)</td>
<td>25.1 (4.9)</td>
<td>Δ 0.6 (-0.5, 1.8)</td>
</tr>
<tr>
<td>Timeline (6-30)</td>
<td>13.6 (3.6)</td>
<td>15.1 (3.0)</td>
<td>Δ 1.4 (1.0, 2.8)**</td>
</tr>
<tr>
<td>Consequences (4-20)</td>
<td>18.6 (4.7)</td>
<td>19.8 (4.5)</td>
<td>Δ 1.2 (0.2, 2.3)</td>
</tr>
<tr>
<td>Timeline cyclical (6-30)</td>
<td>19.2 (3.2)</td>
<td>19.6 (3.3)</td>
<td>Δ 0.4 (-0.5, 1.4)</td>
</tr>
<tr>
<td>Personal control (6-30)</td>
<td>17.8 (3.0)</td>
<td>17.9 (2.7)</td>
<td>Δ 0.1 (-0.6, 0.6)</td>
</tr>
<tr>
<td>Treatment control (5-25)</td>
<td>17.4 (3.7)</td>
<td>18.0 (3.5)</td>
<td>Δ 0.5 (-0.5, 1.4)</td>
</tr>
<tr>
<td>Illness coherence (5-25)</td>
<td>13.9 (4.3)</td>
<td>14.0 (4.3)</td>
<td>Δ 0.1 (-0.1, 0.1)</td>
</tr>
</tbody>
</table>

**Significant for p-value ≤ 0.05.
D-ENAT, (Dutch) Educational Needs Assessment Tool; RADAI, Rheumatoid Arthritis Disease Activity Index; HAQ-DI, Health Assessment Questionnaire Disability Index; GSES, General Self-efficacy Scale; IPQ-R, Revised Illness Perception Questionnaire.

Discussion

This is the first study on the effect of distribution strategy on use of an interactive self-management care booklet for patients with RA. Overall 1 out of 5 patients (22%) used the care booklet. No differences were found in numbers of users of the care booklet between the two distribution methods (23.2% in the ‘unsolicited supply’-group, versus 21.6% in the ‘supply on demand’-group). Consequently, no differences between the distribution-groups were found on secondary clinical and patient related outcomes. However, the proportion of users was higher among patients who had ordered the booklet in the supply on demand group (35%) as compared to the unsolicited supply group. When comparing users with non-users, we found significant differences in marital status, disease activity, activity limitations, use of corticosteroids, educational needs and illness perceptions (timeline cyclical).

We hypothesized that patients in the ‘supply on demand’-group would use the care booklet more often than patients in the ‘unsolicited supply’-group. As patients who took the step of ordering the care booklet, might be more eager to use it. Indeed, when only including patients who ordered the care booklet, the relative percentage of users in this distribution group rises from 21.6% to 35%. This difference is relevant from an economic perspective. Considering that the costs of the care booklet are about €1.50, it seems to be a better strategy to only send the care booklet to patients who order it. Overall this may lead to less expenses in the distribution of the booklet, as less money is lost to sending care booklets to patients who do not use them [see Additional file 1]. This is also an important point from an environmental perspective. Not only less costs are made when distributing the care booklet on demand, but also fewer care booklets are unnecessarily printed and distributed, making the ‘supply on demand strategy’ more sustainable. Further research on cost-effectiveness of the care booklet should be done to confirm these results.

In total, only 22% of the participating RA-patients reported to have used the care booklet. This is even lower than use of care booklets reported in previous studies12,14,15. Low usage of the care booklet in the group of patients who ordered the care booklet might be caused by high expectations patients had when requesting the care booklet. Cuperus et al (2013) reported that patients’ perceptions about the usefulness of a care booklet has impact on the actual use of the booklet. However, in this previous study dissemination was incorporated in other intervention activities, in which the booklet was introduced by health care providers in an educational meeting14. In a second study on this diabetes patient booklet, implementation strategies were even more thoroughly: relevant patient data were recorded in the booklet before handing it to the patient and patients were asked to bring the booklet to every clinic visit. This led to a usage rate of 76%. These results suggest that to reach a higher uptake of care booklets a more enhanced dissemination strategy is needed and that the care booklet should be embedded in a larger intervention.
Different theories and methods have been developed to enhance and facilitate the adaptation or ‘uptake’ of new ideas or innovations like promoting self-management. In their description of the process of dissemination, Greenhalgh et al. suggested that identification and use of appropriate communication and distribution channels is important.\(^{\text{30}}\) To the best of our knowledge, the present study is the first to evaluate the effect of distribution strategies of a care booklet, on actual use among patients. A previous study on a cancer screening decision aid video did look at multiple strategies for distribution, including a supply on demand strategy\(^{\text{24}}\). They concluded that an automatic distribution strategy to all eligible patients is more effective than a strategy which relies on a patient’s initiative. However, they only evaluated the number of videos that were disseminated to eligible patients, not if the videos were actually used or watched. This could explain why their conclusion is not in line with our results, as we do not find an unsolicited supply strategy to be superior. Also, the screening decision aid was intended for patients to be seen before their doctor’s visit. The video was sent to all patients with an appointment and not necessarily to eligible patients. Screening for appropriate diagnosis before sending a care booklet or the option to order it seems therefore to be helpful in a distribution approach\(^{\text{31–2}}\).

In a recent review on strategies for dissemination of recommendations and guidelines towards patients, Schipper et al. showed that many ‘opinion’-papers have recommendations about dissemination strategies\(^{\text{27}}\). Only 1 out of 21 of the included studies in their review produced empirical evidence. In this respect, our study contributes to higher level of evidence for the effect of dissemination strategies on the uptake of patient information, and specific a care booklet. On the basis of the latter review, Schipper et al. described recommendations on how to involve patients in the development and dissemination process of guidelines to improve uptake\(^{\text{27}}\). The involvement of patients in health research is increasingly accepted and promoted, as a significant aspect of ensuring the development of high quality, relevant and necessary research\(^{\text{28}}\). In line with this development, a number of representatives from regional associations for patients with rheumatic diseases in The Netherlands were closely involved in the development of our care booklet. The active involvement of patients in the initiation and execution of the project assured that the perspective of patients was optimally taken into account resulting in a care booklet tailored to the preferences and perceptions of RA patients about the disease and options of self-management. The involvement of patients in the development of the care booklet may have led to the perceived usefulness of the booklet among users (mean rating 8 on a scale from 0–10).

We analysed differences between users and non-users of the care booklet, in order to explore if we could identify certain target groups based on patient and clinical factors. One difference that we found was that users were married more often, than non-users. It could be hypothesized that patients are motivated by their partner to use the care booklet. This is in line with previous research that RA-patients need social support to better manage their chronic condition and take an active role in their own care process\(^{\text{29}}\). Clinical outcomes showed that users had a higher disease activity, more activity limitations, used corticosteroids more often and experienced their RA as having a fluctuating disease course more often compared to non-users. We could hypothesize that these outcomes reflect more disease severity and that, thus, disease severity is associated with use of booklet. We also found that users of the care booklet had higher educational needs. Based on our study design, it is not possible to conclude whether these outcomes are a target group characteristic or changed because of use of the care booklet. However, these results do offer starting points for further research into identifying target groups when distributing care booklets.

This study has some limitations that need to be mentioned. First, although generalizability increases by including patients from two different outpatient clinics, there was a risk for selection bias. The LUMC had considerably fewer eligible patients (diagnosed RA) to be approached for the dissemination of the care booklet. Additionally, patients from the LUMC who were participating in another on-going study were not allowed to participate in the present study. This should be taken into consideration when interpreting the results. Second, our choice not to include a baseline assessment could be argued. As a result we were not able to analyse the effect of the care booklet over time. However, the dissemination of the care booklets prior to inviting patients to participate in the study prevented socially desirable use as part of a research project.

Conclusions

In conclusion, this randomized controlled trial shows that distribution strategy (unsolicited or supply on demand) does not influence the absolute number of RA patients eventually using a care booklet. Therefore, no influence of distribution strategy on clinical outcomes were found. The proportion of patients using the care booklet was somewhat higher in those who had ordered it on demand as compared to unsolicited supply. From an economic and environmental perspective a ‘supply on demand’ distribution strategy seems to be superior compared to a ‘unsolicited supply’ strategy. Our findings provide starting points to optimize further implementation strategies of a care-booklet by targeting specific subgroups of patients or by integrating the care booklet in the routine care.

Funding

This work was funded by the Dutch Arthritis Association [grant number IMP12–1-260]. The Dutch Arthritis Association was not involved in the work presented in this paper.
Additional file 1

The RA care booklet
A number of representatives from regional associations for patients with rheumatic diseases in The Netherlands expressed their need for a self-management tool. Therefore, the "RA care booklet" (Zorgwijzer Reumatoïde Artritis©) was developed as a collaborative project of healthcare providers and rheumatoid arthritis (RA) patients. We used a stepwise approach based on the developmental process proposed by Francis et al. (2008), which included: determining objectives and functionalities within a project team of researchers and patients, professional photography, graphic design and text editing, composing draft versions and consultation with stakeholders about the initial set up and draft versions. For the consultation 10 patients, 4 rheumatologists and 5 clinical nurse specialists were asked in multiple rounds for written feedback.

The care booklet comprises 60 pages of information about RA and its treatment, living with RA and self-management of RA. The care booklet also incorporates a separate hand-out, the "RA care pass" (Zorgpas RA, 26 pages), allowing patients to record personal information like medical history, use of medication and monitor symptoms like pain, fatigue and disease activity, using the DAS28-score. Additionally, points to consider for upcoming consultations with health care providers and goal setting can be recorded in the care pass.

In the present study the care booklet was distributed using two strategies. Table 1 shows an estimation of material costs per 100 approached patients following these two distribution strategies.

Table 1. Estimated costs when approaching 100 patients following the two distribution strategies.

<table>
<thead>
<tr>
<th></th>
<th>Unsolicited supply</th>
<th>Supply on demand</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Booklet + pass printing costs</td>
<td>€1.41</td>
<td>€1.41</td>
</tr>
<tr>
<td>Postage and package costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care booklet</td>
<td>€3.12</td>
<td>€3.12</td>
</tr>
<tr>
<td>Informational letter</td>
<td>-</td>
<td>€0.78</td>
</tr>
<tr>
<td>Reply card</td>
<td>-</td>
<td>€0.78</td>
</tr>
<tr>
<td>Total costs per patient that receives care booklet</td>
<td>€4.53</td>
<td>€6.09</td>
</tr>
<tr>
<td>Costs invested per 100 approached patients</td>
<td>€453.00$\text{a}$</td>
<td>€396.20$\text{b}$</td>
</tr>
</tbody>
</table>

$\text{a}$ €4.53 x 100 = €453.00
$\text{b}$ €6.09 x 60 (number of people who order the care booklet based on present study) + €0.78 x 40 (number of people who do not order the care booklet) = €396.20

Reference List

Summary and general discussion
Summary and general discussion

Rheumatic and musculoskeletal diseases (RMDs), such as osteoarthritis (OA) or rheumatoid arthritis (RA) are among the most prevalent disorders worldwide, with a large impact on individual patients as well as society. The pathogenesis of most RMDs is still unknown. Both OA and RA are characterized by painful joints, with reduced mobility and function, resulting in limitations in daily activities and societal participation. Although there are no curative treatments, depending on the condition, a number of effective pharmacological, surgical and non-pharmacological treatment options are available. Because of the chronic nature of RMDs patients have to cope with consequences of their condition in daily life and consult multiple healthcare professionals throughout the course of their disease.

Nowadays, patients take a more active role in the management of their own disease and want to actively participate in decisions that need to be made regarding their treatment. This active role of patients is also recommended in international guidelines. However, in order to do so, patients need to be appropriately informed so they can make appropriate decisions based on right expectancies and their personal needs. More knowledge on strategies to deliver education for patients with hip and knee OA and RA, that fit patients’ informational needs is needed. Therefore, this thesis focused on identifying informational needs of patients and exploring the use and effect of educational interventions provided through different strategies. In this chapter the results of this thesis are summarized and main findings, limitations, implications for clinical practice and directions for future research are discussed.

Summary

Informational needs among patients with hip and knee OA are often high. Currently, a number of informational sources are available to patients (e.g. healthcare professionals, websites, leaflets, friends and family). Despite their enormous value, these sources can provide conflicting information. Moreover, health and disease related information is often written from a healthcare professional’s perspective. In order to better tailor the provision of information to patients’ information needs, we collected frequently asked questions (FAQs) of patients with hip and knee OA that go beyond general guideline recommendations and could not be answered using the website Thuisarts.nl in Chapter 2. Subsequently, we used a best-worst scaling exercise to prioritize the FAQs among patients and healthcare professionals. A total of 60 FAQs were identified, and then used in the best-worst scaling exercise and prioritized by 94 OA-patients and 122 healthcare professionals. The FAQ “What can I do myself to decrease symptoms and to prevent the OA from getting worse?” was prioritized as most important by both patients and professionals. FAQs that were highly prioritized by patients and significantly different from professionals’ mainly concerned treatment options offered by different healthcare professionals, whereas highly prioritized FAQs of professionals were more often focused on treatment options involving self-management. These differences are important to address in the development and improvement of educational interventions, to better tailor them to patients’ needs.

Main finding I: This study identified informational needs that are considered important by hip and knee OA patients, but to a lesser extent by healthcare professionals.
Currently the use of conservative treatments in hip and knee OA is suboptimal. Providing tailored education to patients from a joint perspective of healthcare professionals may result in more realistic expectations about conservative treatments, and help patients to navigate the healthcare system better. Healthcare providers from multiple professional backgrounds involved in OA care provided unambiguous answers to the FAQs that were identified in Chapter 2. The answers were then included in a multidisciplinary group based educational program. We adjusted the program to the local context and offered it in one region in the Netherlands. In Chapter 3 the results of an observational pilot study to explore effects of this educational program are described. The educational program consisted of 2 meetings of 1.5 hours each, and was provided by a physiotherapist, a general practitioner (GP) and orthopaedic surgeon or specialized nurse. The aim of the program was to increase patients’ knowledge on OA, to stimulate self-management, to discuss benefits and disadvantages of treatment options, to promote the stepped care approach of treatments and to provide clear and consistent answers to the FAQs identified in Chapter 2. At baseline and at 3 months follow-up 107 participating hip and knee OA patients completed questionnaires on healthcare utilization (primary outcome), pain medication use, pain and functioning in daily living (Western Ontario and McMaster Universities Osteoarthritis Index, 0-100), illness perceptions (Brief Illness Perception Questionnaire, 0-100), self-efficacy (General Self-efficacy Scale, 10-40), patient activation (Patient Activation Measure-13, 13-52), knowledge (self-administered questionnaire, 0-22) and physical activity (Short Questionnaire to Assess physical activity, min/week). The proportion of participants who had visited their GP in the 3 months with OA related complaints after the program was lower than 3 months previous to the program (40% versus 25%, p-value 0.01). In addition, we observed a decrease in proportion of patients who visited the physiotherapist, (36.1% versus 25.0%, p-value 0.02). Although no significant difference was found for visits to the orthopaedic surgeon, rheumatologist or other medical specialists, the total number of secondary care contacts did decrease. Both illness perceptions and knowledge changed positively (Δ1.8; 95% CI: 0.4, 3.4 and Δ2.4; 95% CI: 3.0, -1.6 respectively).

**Main finding II:** A multidisciplinary educational program comprising clear and consistent information on OA and its treatment options, may result in a decrease in healthcare utilization and positive changes in illness perceptions and knowledge on OA.

Hip and knee OA patients who are referred to an orthopaedic surgeon often expect action to be taken. However, the majority of those patients is not (yet) eligible for a joint replacement. In Chapter 4 we describe a randomized controlled trial involving 286 patients with (suspected) hip and knee OA who were referred to an orthopaedic surgeon. They were randomly allocated to either receiving an educational eHealth tool to prepare their upcoming first orthopaedic consultation or usual care. We hypothesized that a solid preparation using the eHealth tool is likely to streamline patients’ expectations and increase satisfaction, irrespective of the outcome of the consultation. The tool consisted of three main components; 'Information' (information on OA and treatments), 'My consultation' (predefined questions, space to record questions to ask during the consultation and monitoring of pain/fatigue) and 'Medication' (option to record medication list). The primary outcome, satisfaction with the consultation, was measured with the Consumer Quality Index (CQI), one day after the consultation (follow-up). Secondary outcomes were knowledge (self-administered questionnaire, 0-22), treatment beliefs regarding physical activity, pain medication and joint replacement surgery (Treatment beliefs in OsteoArthritis questionnaire, range 1-5), assessment of patient’s involvement in consultation by the surgeon (5-point Likert scale) and patient satisfaction with the outcome of the consultation (numeric rating scale, 0-10). We found no differences between groups on the three subscales of our primary outcome measure. Between group differences (95% CI) were in favour of the intervention group for knowledge (1.4 (0.6, 2.2)), negative beliefs regarding physical activities (-0.19 (-0.37, -0.002) and pain medication (-0.30 (-0.49, -0.01)). We found no differences on other secondary outcomes.

**Main finding III:** An educational eHealth tool for hip and knee OA patients to prepare a first orthopaedic consultation does not result in higher patient satisfaction with the consultation, but it does influence cognitions about osteoarthritis.

Because we did not find an effect on our primary outcome in the RCT described in Chapter 4, and only small effects on secondary outcomes, we further explored the actual use of the educational eHealth intervention in Chapter 5. The use and usability of the educational eHealth tool, as well as factors related to its use were described in this study. We analysed objective user data of 144 participants. Participants were classified as ‘user’ or ‘non-user’ based on ‘opening the tool at least once’ ‘Users’ were further specified as ‘active’ if they actively used at least 1 out of the 3 main components. We used the System Usability Scale (SUS, 0-100) to assess usability of the eHealth tool and a numeric rating scale (0-10) to assess satisfaction. We collected data on demographic and clinical characteristics, knowledge on OA (self-administered questionnaire, 0-22) and internet and smartphone usage in daily life (Media and Technology Usage and Attitudes Scale, 1-10) to evaluate their association with use of the educational eHealth tool. Use of the tool was reasonably high (81% used the tool at least once and of those users 75% actively engaged in one of the three main components. However, usability and satisfaction of the tool were relatively low (mean (SD): 64.8 (16.0) and 6.9 (2.7) respectively). Based on the analysis of objective user data we could identify targets for improvement of the application: 1) the component least used was ‘Medication’, in which patients could record their medication use and setup reminders. To simplify the tool and thereby increasing its usability this component could be removed; 2) in the ‘Consultation’ component we provided space to record preparation questions for patients. Based on the questions users recorded we propose to provide 4 standardized questions to prepare and ask during a consultation (i.e. “What is my situation at this moment?”, “What are my options?”), “What are the possible benefits and harms of those options?” and “What does this mean in my situation?”), in addition to keeping the open space for users to come up with their own questions. Two factors were found to be related to use of the educational eHealth tool, namely, users of the educational eHealth tool having slightly more baseline knowledge on OA and users being less familiar with using the internet in their daily life compared to non-users. Hence, so far no clear subgroups could be identified to accomplish a targeted implementation.

**Main finding IV:** Despite relatively disappointing appreciation of its usability, our educational eHealth tool to prepare a first orthopaedic consultation is used frequently by the majority of patients willing to participate in our study.

As patients’ preferences regarding the mode of delivery of information and education can vary, the distribution method might also influence the eventual use of educational material. In the randomized controlled trial described in Chapter 6 we evaluated two distribution strategies of a care booklet for patients with RA i.e. ‘supply on demand’ versus ‘unsolicited supply’ on
patient reported use of the care booklet (yes/no, primary outcome), educational needs, self-efficacy and illness perceptions. We hypothesized that usage after a ‘supply on demand’ strategy (i.e. offering the option to order a care booklet) is higher than after an ‘unsolicited supply’ strategy. Patients who are offered the option to order a care booklet might be better motivated to use it, ultimately resulting in better outcomes. Differences in patient and clinical characteristics between users and non-users were also explored. No difference was found in use of the care booklet between participants given the option to order the care booklet (‘supply on demand’) and participants who received the care booklet anyway (‘unsolicited supply’) (OR (95% CI): 0.9 (0.6, 1.5)). However, when only looking at participants who actually ordered the care booklet in the ‘supply on demand’-group, this group used the care booklet more than the ‘unsolicited supply’-group (OR (95% CI): 1.9 (1.1, 3.3)). From the economic and environmental perspectives a ‘supply on demand’-distribution strategy could therefore be recommended. Regardless of the distribution strategy, use of the care booklet was associated with being married, more disease severity, higher educational needs and less positive disease perceptions. Results of this study provide starting points to further optimize implementation strategies of patient education materials.

Main finding V: The type of distribution strategy (‘unsolicited’ vs ‘supply-on-demand’) does not affect the use of an educational care booklet in RA patients.

Discussion

In this section main findings and methodological considerations of this thesis are discussed. Based on these considerations I propose recommendations for further research and clinical implications regarding patient education.

Patient education materials

Based on guideline recommendations high quality patient education materials have been developed in the past years to support patients to become more informed, and to support healthcare professionals in providing patient education. In the Netherlands, examples of three online evidence-based websites are Thuisarts.nl, Defysiotherapeut.com and ReumaNederland.nl (i.e. ‘Homedoctor’, ‘Physiotherapist’, ‘RMDs in the Netherlands’). We developed a multidisciplinary group-based intervention to provide patient education in primary care as described in Chapter 3. We chose a multidisciplinary approach; in both the primary care and OA patients with more baseline knowledge on OA and who used the internet less frequently (Chapter 5 and Chapter 6). The eHealth tool was used slightly more often by OA patients with more baseline knowledge on OA and who used the internet less frequently in daily life (Chapter 5). It can be suggested that some people are more eager to obtain knowledge or are more capable to do so. Moreover, in general older people use the internet less frequent than younger ones, but do adhere more often to eHealth interventions. Users in our study were slightly older (not statistically significant) possibly explaining the small difference we found in daily internet use between users and non-users. However, participants in this study were people who were willing to participate in an intervention study, which may have resulted in a selected group in the first place. We used a different approach in Chapter 6; we first distributed the care booklet and evaluated user characteristics afterwards. Patients who were married, with more disease severity, higher educational needs and less positive disease perceptions used the care booklet more often. Although small differences were found in patient and clinical characteristics between users and non-users of the educational eHealth tool and the RA care booklet, it is questionable if these ‘user’-characteristics are clinically relevant and need to be addressed. A recent review on educational needs among RA patients concluded that patterns of subgroup characteristics are not sufficiently robust to

disseminated during the course. This could explain the increased knowledge of patients after participating in the program. It could therefore be suggested to provide interdisciplinary patient education in primary care with multiple disciplines across settings with consistent information on self-management and available treatments (and a shared point of view about new and experimental treatments). Moreover, so far little research has been done on the impact of consistency of information across settings and across disciplines for patients with osteoarthritis on self-management skills. In my opinion this is an important area for future research.

Tailored information provision

In order to tailor interventions to patients’ needs and preferences we actively involved patients in the development process of all interventions described in this thesis. This may have contributed to the relatively high satisfaction rates of participants regarding some of our interventions (satisfaction score 8 on a scale 1-10 for the educational program in Chapter 3 and the RA care booklet in Chapter 6). However, satisfaction with our eHealth tool (Chapter 6) was somewhat lower (7 on a scale 0-10), which may be related to the usability of the tool that needs to be improved. Overall, user rates of the interventions varied greatly. The care booklet was used by 35% of those who ordered it, the eHealth tool by 81% of participants. Our results regarding satisfaction and differences in user rates of the different interventions may also indicate that one mode of education delivery may not be suited to one individual and the other way around; one individual may not prefer one specific platform. Aligning the content of information across a variety of interventions may be needed in order provide information fitting preferences for all patients. I therefore recommend head to head comparison of patient educational tools with different modes of delivery (paper, online and face-to-face) to usual care. When allocated to the intervention, one should choose his/her own preferred mode of education delivery.

One of the research questions of this thesis focused on the identification of subgroups of patients who used our different educational interventions. By identifying subgroups of users, modes of delivery can be improved and implementation can be more personalized. However, no clear indications for practical implementation points were found based on the results of this thesis (Chapter 5 and Chapter 6). The eHealth tool was used slightly more often by OA patients with more baseline knowledge on OA and who used the internet less frequently in daily life (Chapter 5). It can be suggested that some people are more eager to obtain knowledge or are more capable to do so. Moreover, in general older people use the internet less frequent than younger ones, but do adhere more often to eHealth interventions. Users in our study were slightly older (not statistically significant) possibly explaining the small difference we found in daily internet use between users and non-users. However, participants in this study were people who were willing to participate in an intervention study, which may have resulted in a selected group in the first place. We used a different approach in Chapter 6; we first distributed the care booklet and evaluated user characteristics afterwards. Patients who were married, with more disease severity, higher educational needs and less positive disease perceptions used the care booklet more often. Although small differences were found in patient and clinical characteristics between users and non-users of the educational eHealth tool and the RA care booklet, it is questionable if these ‘user’-characteristics are clinically relevant and need to be addressed. A recent review on educational needs among RA patients concluded that patterns of subgroup characteristics are not sufficiently robust to
Timing and setting of patient education

Results in Chapter 4 regarding the outcome of the orthopaedic consultation are in line with previous findings that more than half of patients with hip and knee OA are referred back to primary care with the prescription of conservative treatment or to wait and see how symptoms develop\(^{26,27}\). In addition, more than half of our study population had symptoms for a relatively short period of time (≤5 years). Although some of these patients may have been referred because of diagnostic uncertainty, these findings suggest that OA care is not in line with current guidelines\(^{41}\). Guidelines recommend non-surgical treatments starting in an early stage of disease, and can be organized in primary care\(^{42,43}\). However, patients may feel the need to consult an orthopaedic surgeon in an early stage or want action to be taken, thereby influencing the early referral process. Interventions targeting GPs in primary care to prevent unnecessary early referrals to secondary care have been tried in order to address this problem, but still have insufficient result\(^{22,24}\). Additional efforts to optimize the referral process from primary care to secondary care are therefore needed. Taken into account the patient-centred perspective of care, in which patients and healthcare professionals have a more collaborative approach, not only healthcare professionals but also patients should be targeted to optimize OA care in line with recommendations. This thesis shows that providing patient education may have the potential to increase patient knowledge and change treatment beliefs (Chapter 3 and 5). Treatment beliefs have shown to influence the intention to use a treatment\(^{15}\). Our results that patient education seems promising with regard to healthcare use (Chapter 3), supports this. If expectations regarding conservative treatment are positive, and patients feel informed about their conditions and treatment options, they might to a lesser extent feel the need to be referred in an early stage. Educational interventions targeting patients in an early stage before they are referred to secondary care are therefore recommended\(^{44}\).

At the time of initiating our studies the recommendations in Dutch guidelines for primary care GPs and physiotherapists included quite general advices regarding the actual provision of care (e.g. “advice the patient to be physically active regularly for at least 30 minutes at a moderate intensity level on at least 5 days of the week”). We showed that OA patients have a need for more specific information and guidance (Chapter 2). The updated guideline for treatment of hip and knee OA from the Dutch Royal Society for Physiotherapy is far more explicit in the provision of patient education\(^{46}\). The GP guidelines do also recommend to adjust information about how to exercise and reduce weight to patients’ preferences, motivation and availability of local services\(^{48}\). Nevertheless, research shows that time restraints are a major barrier for GPs to provide good quality patient education\(^{27,49}\) and to elicit patient’s preferences could be time consuming. Moreover, individual healthcare professionals themselves may not always have the knowledge or information to answer specific questions as “What is the optimal intensity and frequency of exercising?”. Processing consensus based information, adapted to local context (e.g. the availability of local health services, such as weight reduction programs and recreational exercising and its costs (Chapter 3)) into educational material could be valuable to address these preferences.

The responsibility of obtaining information

An important question regarding the provision of education and information is ‘Who is responsible that patients obtain information and increase their knowledge?’. The majority of patients wants to be informed about their disease and their options\(^{44}\). Therefore, to some extent they may have a responsibility themselves to search for the information they need. However, not all patient may have the capabilities to find this information and determine which information is trustworthy\(^{51}\). In that matter healthcare professionals have the responsibility and obligation to provide clear and credible information\(^{25}\).

In this thesis we evaluated multiple educational interventions, which were developed on the initiative of patients or healthcare professionals. The development of the RA Care booklet was initiated by patient organizations, the educational eHealth tool for OA patients was an initiative of patients to further develop a care booklet with digital advantages, and the educational program was developed after healthcare professionals expressed the need for improvements of the local OA care. The demand by patients for development of qualitative good educational material for patients with rheumatic diseases supports the thought that high quality material is needed. However, although response and first results to our interventions were positive, the next step of good implementation and further improvements of the interventions dissolved.

Healthcare professionals have the responsibility to inform patients about all available treatment options, even if these treatments are delivered by other professionals. Providing comprehensive, consistent information asks for collaboration with other professionals. This thesis shows that health care professionals take that responsibility, but that initiators are needed in a region to organize initiatives like this and enthusiast colleague professionals. Working together with healthcare professionals in a region can help optimize care for patients locally by providing consistent information and sharing extra workload. However, it is only to a certain extent that one can expect them to invest his/her own spare time. Financial incentives for local initiatives across settings in RMDs are currently not available in the Netherlands, but are very much needed. Once initiatives have shown to contribute to value based healthcare\(^{30}\) it should be supported financially on a regular basis. With the aging population and growing numbers of chronic diseases healthcare insurance companies need to take responsibility in providing these financial incentives. Insurance companies could for instance provide fixed subsidies for the initiation and piloting of local patient education initiatives, provided that the initiative is taken by multiple organizations across settings to secure a multidisciplinary approach that is supported regionally. When pilot results are promising, the educational intervention can be incorporated in the budget for prevention care in the health insurance. Currently, most supplementary health insurances include coverage of educational self-management courses for chronic conditions like chronic heart failure, diabetes and Chronic Obstructive Pulmonary Disease. Educational interventions for RMDs should be included in that coverage.
Methodological considerations

Study design
A point of consideration in the evaluation of eHealth interventions and especially smartphone interventions (apps) is the study design. A randomized controlled design is considered the primary study design to evaluate effect of interventions. However, the execution of a RCT in general is time consuming36, which is difficult to match with the rapid pace at which mobile interventions are developed and evolve. Evaluating a mobile intervention using a RCT design causes the risk of the mobile intervention turning to be obsolescence. Moreover, an iterative process of development is recommended for eHealth interventions, providing more challenges in the evaluation. Other study designs than a RCT with more flexibility should therefore be considered when evaluating eHealth interventions34. Although new frameworks and initiatives have been proposed, they are not adopted by researchers to evaluate eHealth interventions34. An example of such a methodological framework is the Continuous Evaluation of Evolving Behavioral Intervention Technologies (CEEBIT) (Figure 2). In this framework an intervention is implemented in daily practice and continuously evaluated among its users. When improvements are made and a newer version of the application is available, this is deployed alongside the older version and evaluated in the same manner. The same applies for subsequent versions. Because evaluation is consistent between the available versions, comparison is possible. Only if evaluation shows that one version is inferior to another, it should be eliminated from daily practice. For the evaluation and implementation of new eHealth interventions I recommend exploration of the use of the CEEBIT framework.

Figure 1. Continuous Evaluation of Evolving Behavioral Intervention Technologies (CEEBIT) framework. Versions A (VA) of the technology intervention is eliminated from use in daily practice at time point 5 when it is found to be inferior to Version D (VD). At time point 6 Version C (VC) is eliminated and at time point 7 Version B (VB). Both have shown to be inferior to Version D (VD) of the intervention.

Measuring successful patient education
A lesson learned in this thesis concerns measuring the outcome of patient education interventions. Two types of measures are discussed; process measures and outcome measures.

Process measures
For an educational intervention in general it is important to investigate if the intervention fit patients’ needs and therefore if and how it is used and what its usability is. In this thesis we showed that user-rates vary great among the offered interventions (22% used a care booklet (Chapter 6), 81% an eHealth tool (Chapter 5)). One of the issues in describing eHealth ‘use’ we ran into was the variety of operationalization of ‘use’ of eHealth intervention used in previous studies. Literature on the use of eHealth interventions is growing, however the operationalization of intended use is often based on the assumption that more use is better or a threshold is drawn without justification35. In a systematic review Sieverink et al. (2017) proposed to keep in mind the goal of the eHealth intervention and what use is necessary at minimum to establish new skills, when operationalizing use36. Subsequently, justified operationalization can be used to standardize use of eHealth interventions, making it easier to compare the user rates of different eHealth interventions.

Several validated questionnaires are available to measure the usability of eHealth interventions, like the System Usability Scale (SUS), the Questionnaire for User Interaction Satisfaction (QUIS), the Post-Study System Usability Questionnaire (PSSUQ), and the Computer System Usability Questionnaire (CSUQ)36. In Chapter 3 we used the SUS which has shown to be reliable37. Because the SUS is the most widely-used questionnaire for evaluating usability it is easy to compare it to other eHealth interventions38. However, the SUS as well as the other before-mentioned questionnaires are not specifically developed with a focus on healthcare settings. Therefore, there may be specific factors in some eHealth interventions that need to be measured along with the general usability attributes covered in the questionnaire. Open-ended questions can help to address these factors.

Outcome measures
Outcome measures of educational and self-management interventions should reflect the aim of the intervention. Pain and function are often used as outcome measures, however seem not to match the aim of educational self-management programs39. Other outcome measures used in evaluation of educational programs are knowledge and self-management skills or self-efficacy. However, these might also be considered process outcomes as they are concepts of cognitions with the eventual goal to change behaviour. We measured knowledge as secondary outcome in the evaluation of several of our interventions (Chapter 3 and Chapter 4). However, we did not use a validated questionnaire and to our knowledge this is not available. Because our interventions did change knowledge positively it shows to be an outcome measure that should further be explored. I therefore propose more research into how patients knowledge on OA and it’s treatments can be best evaluated. In Chapter 3 we measured self-efficacy and self-management skills, but did not find changes on these outcomes. However, the interpretation, validity and value of self-efficacy scales have been debated40. Moreover, we used the Patient Activation Measure (PAM-13) to measure self-management41. This questionnaire seems more appropriate for clinical practice as it classifies patients in 4 levels (reflecting patient progression from a passive therapeutic role (Level 1) to greater levels of activation (Levels 2–4)). Moreover, as every item of the questionnaire needs
to be scored to calculate a total score missing values are frequent. A questionnaire that should be further explored as outcome measure for evaluating educational interventions is the Health Education Impact Questionnaire (heiQ) [42]. The heiQ was developed from patients’ and clinicians’ perspectives on what valued outcomes of self-management programs are and covers areas such as behaviours, skills, attitudes, self-monitoring, health services navigation, and emotional distress. The heiQ is recently translated and validated for Dutch setting [43]. Ultimately, the aim of educational interventions is by improving patients knowledge and self-management skills that patients change their behaviour resulting in less healthcare use and use of healthcare that is better in line with recommendations (first conservative treatment and timely use of surgical options). In this thesis we evaluated healthcare utilization 3 months after the intervention in an observational design (Chapter 3). Although we did see some changes in healthcare utilization, it is likely that pay off will show in the long term. Moreover, long-term evaluation of healthcare utilization may provide better insight on patterns of use and whether these are in line with recommended treatments. In our study we saw a decrease in proportion of patients who visited a GP or physiotherapist because of their OA complaints. However, it is likely that some patients may not have felt the need to visit these healthcare professionals on short-term after just receiving education on what they can do themselves. We also did not find significant changes in proportion of patients visiting medical specialists. Because this was evaluated on short-term (3 months) it is possible that patients were already referred before we invited them for the study. Previous studies have shown that education in combination with exercise therapy may postpone surgery in hip OA patients in the long term [44, 45]. Moreover, the launch of website Thuisarts.nl, providing patient education on several available conditions has shown a trend to reduce nation-wide primary care consultations over a two-year period [46]. This supports the desirability to study long-term effects of educational interventions on healthcare utilization in a randomized study design.

To conclude
This thesis contributes to the insight on how patient education can be best delivered to patients with RMDs, and in particular to those with hip and knee OA or RA. This thesis shows that one mode of patient education delivery may not be suited for every patient. Offering different educational options (written, online and face-to-face) to patients, should be considered to allow patients to choose the mode of delivery they prefer. Finally, based on the results of this thesis some practical implications for the improvement of patient education can be given:

- Answering the FAQs in this thesis with healthcare professionals from multiples disciplines across settings in one region, can be a starting point to align content of patient education, support consistency of care and optimize collaboration among healthcare professionals.
- In order to meet patients’ educational needs, the highly prioritized FAQs by patients can be used in existing patient educational materials like Thuisarts.nl, Defysiotherapeut.com and ReumaNederland.nl to address topics that go beyond clinical guideline recommendation.
- The finding that patients highly prioritize questions on treatment options offered by healthcare professionals shows that patients have a need for clear information on available treatment options. It also indicates that patients need more specific guidance in where to find professionals who can help them in case they are not confident regarding their self-management skills [47]. Information about where and how to find guidance adjusted to a local context should be incorporated into existing patient education materials and in the development of new materials.

- Providing patient education may have the potential to increase patient knowledge and change treatment beliefs. Organizing patient education early in the disease process in primary care may ultimately support optimizing care in line with recommendations.


Hoofdstuk 1: inleiding

Reumatische aandoeningen, zoals artrose en reumatoïde artritis (RA) behoren tot de meest voorkomende aandoeningen wereldwijd. Deze aandoeningen hebben een grote impact op het dagelijks leven van de individuele patiënt, op hun omgeving en de maatschappij. De oorzaak van het ontstaan van de meeste reumatische aandoeningen is niet bekend. Zowel artrose als RA worden gekenmerkt door pijn en een beperkte beweeglijkheid van de gewrichten. Dit resulteert in beperkingen in dagelijkse activiteiten en sociale participatie. Ondanks dat er geen behandeling beschikbaar is die deze aandoeningen kan genezen, zijn er verschillende effectieve medicamenteuze, chirurgische en niet-medicamenteuze behandelopties beschikbaar. Gezien het chronische karakter van deze reumatische aandoeningen, is het voor patiënten belangrijk om te leren omgaan met de consequenties van hun aandoening in het dagelijks leven (zelfmanagement) en dienen zij hun weg te vinden in het zorglandschap.

Voor patiënten met RA vindt het zwaartepunt van hun behandeling in de tweede lijn plaats; zij hebben voornamelijk te maken met de reumatoloog, die hen medicatie voorschrijft. Voor patiënten met heup en knie artrose vindt de belangrijkste deel van de behandeling plaats in de eerste lijn, bij de huisarts, fysiotherapeut en/of diëtist. Deze behandeling bestaat uit leefstijladvies, het doen van oefeningen al dan niet onder begeleiding van een fysio- of oefentherapeut, afvallen bij overgewicht en pijnmedicatie. Pas als deze behandelingen niet of onvoldoende meer werken worden patiënten doorverwezen naar een orthopedisch chirurg voor mogelijk een gewrichtsvervangende operatie.

Gedurende de laatste decennia nemen patiënten een steeds actievere rol in het omgaan met hun eigen aandoening en willen zij actief deelnemen in de keuzes die gemaakt moeten worden ten aanzien van hun behandeling. Nationale en internationale richtlijnen bevelen een actieve rol van de patiënt ook aan. Echter, om een actieve rol in te nemen moeten patiënten voldoende geïnformeerd zijn over hun mogelijkheden, zodat zij een adequate beslissing kunnen maken op basis van juiste verwachtingen en hun persoonlijke behoeften. Meer kennis over strategieën om educatie/voorlichting aan patiënten met heup of knie artrose en RA over te brengen, passend bij hun behoeften is nodig. Dit proefschrift richtte zich daarom op het identificeren van informatie behoeften van patiënten en het evalueren van het gebruik en het effect van educatieve interventies die op verschillende manieren werden aangeboden.

Hoofdstuk 2: de meest belangrijke veel gestelde vragen van patiënten met heup en knie artrose

Informatiebehoeften van patiënten met heup en knie artrose zijn over het algemeen hoog. Er zijn veel verschillende informatie bronnen beschikbaar (bijvoorbeeld zorgverleners, websites, folders, ervaringsdeskundigen onder familie en vrienden). Informatie vanuit verschillende informatiebronnen kan tegenstrijdig zijn. Daarnaast wordt informatie over gezondheid en ziekte vaak gegeven vanuit het perspectief van zorgverleners. Om voorlichting beter af te stemmen op de behoeften van patiënten hebben wij in deze studie veel gestelde vragen (FAQs, “frequently asked questions”) verzameld van patiënten met heup en knie artrose. Het ging hierbij om vragen die verder gaan dan de algemene richtlijnen voor zorgverleners en die niet beantwoord konden worden met behulp van de informatie op de website Thuisarts.nl (www.thuisarts.nl). Vervolgens hebben we de zogenaamde best-worst scaling methode
gebruikt om te bepalen om de FAQs te prioriteren. Dit betekende dat we zowel aan patiënten als zorgverleners vroegen de meest en minst belangrijke vraag te kiezen uit een aantal sets van 5 vragen. Hiermee werd inzicht verkregen in welke FAQs het belangrijkst en minst belangrijk gevonden werden door patiënten en zorgverleners en een mogelijk verschil daarin. In totaal werden er 60 vragen geïdentificeerd, die vervolgens werden geprioritiseerd met de best-worst scaling oefening door 94 artrose patiënten en 122 zorgverleners. De FAQ “Wat kan ik zelf doen om mijn klachten te verminderen en te voorkomen dat de arthrose erger wordt?” werd door zowel patiënten als zorgverleners als meest belangrijke vraag bevonden. Overige FAQs die patiënten wel belangrijk vonden, maar die door zorgverleners als minder belangrijk werden beoordeeld, waren met name gericht op behandelmogelijkheden waarbij een zorgverlener betrokken is. De vragen die zorgverleners belangrijk vonden waren meer gericht op behandelingen waarbij zelfmanagement betrokken was. Deze verschillen zijn belangrijk om mee te nemen bij de ontwikkeling en verbetering van voorlichtingsmaterialen, zodat deze beter aansluiten bij de behoeften van patiënten.

**Hoofdstuk 3: een multidisciplinair voorlichtingsprogramma bij heup en knie artrose**

Momenteel is het gebruik van conservatiebehandelingen (leefstijlverbetering, fysiotherapie, afvallen, pijnmédicatie, etc.) bij heup en knie artrose niet optimaal. Het gezamenlijk geven van voorlichting door verschillende zorgverleners kan mogelijk resulteren in meer realistische verwachtingen van patiënten ten aanzien van verschillende conservatiebehandelingen en hen helpen om hun weg te vinden in het zorglandschap. Verschillende zorgverleners (huisartsen, fysiotherapeuten, verpleegkundigen, reumatologen en orthopedisch chirurgen) die betrokken zijn bij de zorg rond artrose hebben gezamenlijk de FAQs uit **hoofdstuk 2** beantwoord. De antwoorden werden gebruikt in een multidisciplinair groep voorlichtingsprogramma. Dit programma werd aangesteld aan de lokale context van de wijk waar het programma gegeven werd. In **hoofdstuk 3** beschrijven we de resultaten van de evaluatie van het programma in een observatieleide studie. Het voorlichtingsprogramma bestond uit 2 bijeenkomsten van ieder 1,5 uur, en werd begeleid door een fysiotherapeut, een huisarts en een orthopedisch chirurg of verpleegkundig specialist. De doelen van het programma waren kennis over artrose van de deelnemers te vergroten, het stimuleren van zelfmanagement, het bespreken van voor- en nadelen van verschillende behandelmogelijkheden, en het geven van duidelijke en consistente antwoorden op de veel gestelde vragen uit **hoofdstuk 2**. Voorafgaand aan deze maanden van het educatieronderdeel van de hoofdprogramma vulde deel deelnemers met heup of knie artrose een vragenlijst in. Hieruit bleek dat het aantal deelnemers dat de huisarts had bepaald voor hun artroseklachten in de drie maanden na het programma lag was in de drie maanden daarvoor (40% versus 25%). Daarnaast vonden we ook dat minder patiënten de fysiotherapeut bezoeken na het programma dan daarvoor (36.1% versus 25%). Het totaal aantal bezoeken van medisch specialisten nam ook af. Zowel opvattingen als kennis over artrose veranderden in positieve richting.

**Hoofdstuk 4: een app ter voorbereiding van een consult met de orthopedisch chirurg**

Patiënten met heup of knie-artrose die verwezen zijn naar de orthopedisch chirurg verwachten vaak dat er actie, dat wil zeggen een ingreep, wordt ondernomen. De meerderheid van deze patiënten is echter (nog) niet toe aan een gewricht vervangende operatie. Vaak omdat zij nog geen of slechts enkele conservatiebehandelingen gehad hebben. In **Hoofdstuk 4** beschrijven we een onderzoek met 286 patiënten die met (vermoedelijke) diagnose van artrose waren doorverwezen naar een orthopedisch chirurg. Zij werden willekeurig toegewezen aan twee groepen: één groep ontving toegang tot een educatieve eHealth applicatie om hun afspraak met de orthopedisch chirurg voor te bereiden, de andere groep kreeg geen of afzien op de reguliere zorg/voorbereiding. Onze aanname was dat een gedegen voorbereiding met behulp van de educatieve eHealth applicatie zorgt voor realistischere verwachtingen en tevredenheid vergroot, ongeacht wat de uitkomst van de afspraak is. De applicatie bestond uit 3 delen: ‘Informatie’ (over artrose en behandeling), ‘Mijn afspraak’ (vragen om te beantwoorden, ruimte om vragen te noteren die men tijdens de afspraak wil stellen, en bijhouden van pijn/vermoeidheidsscore) en ‘Medicatie’ (mogelijkheid om een medicatielijst bij te houden). Eén dag na de afspraak met de orthopedisch chirurg werd tevredenheid over de afspraak nagevraagd bij de deelnemers. We vonden geen verschil in tevredenheid over de afspraak tussen de patiënten die de applicatie hadden gekregen en de patiënten die deze niet hadden gekregen. Wel vonden we dat patiënten uit de ‘applicatie’-groep meer kennis over artrose hadden en minder negatieve opvattingen over fysieke activiteit en het gebruik van pijnmÉdicatie.

**Hoofdstuk 5: gebruik en gebruiksvriendelijkheid van een eHealth app**

Omdat we in **Hoofdstuk 4** geen verschillen vonden in tevredenheid maar wel kleine verschillen op andere uitkomsten, zijn we in **Hoofdstuk 5** verder gaan kijken naar het daadwerkelijke gebruik van de educatieve eHealth applicatie. In dit hoofdstuk worden het gebruik en de gebruiksvriendelijkheid van de applicatie beschreven, en ook factoren die gerelateerd zijn aan of proefpersonen de applicatie gingen gebruiken. Hiervoor analyseerde we de gebruikersgegevens uit de applicatie van 144 proefpersonen. We noemden proefpersonen een ‘gebruiker’ als zij de applicatie minimaal één keer geopend hadden. Zij dit niet gedaan dan noemde wij hen een ‘niet-gebruiker’. Wanneer een ‘gebruiker’ actief gebruik had gemaakt van ten minste 1 van de 3 onderdelen van de applicatie, dan noemde we hem een ‘actieve gebruiker’. We vonden dat de applicatie door relatief veel patiënten gebruikt was; 81% van de deelnemers was een ‘gebruiker’, waarvan 75% een “actieve gebruiker”. Echter, op gebruiksvriendelijkheid en tevredenheid scoorde de applicatie niet heel hoog (gemiddeld 65 op een schaal van 0-100 en een 6,9 op een schaal van 0-10). Op basis van hoe de app was gebruikt konden we een aantal aanbevelingen doen om de applicatie te verbeteren: 1) het onderdeel ‘Medicatie’ werd het minst gebruikt door deelnemers. Om de applicatie eenvoudiger te maken en mogelijk de gebruiksvriendelijkheid te vergroten zou dit onderdeel verwijderd kunnen worden; 2) in het onderdeel ‘Mijn afspraak’ konden proefpersonen zelf vragen noteren die zij tijdens hun consult wilde stellen aan de orthopedisch chirurg. Op basis van de genoteerde vragen, stellen wij voor om 4 standaard vragen te gebruiken bij de voorbereiding op een afspraak (namelijk: “Wat is mijn situatie op dit moment?”, “Wat zijn mijn mogelijkheden?”; “Wat zijn de voordelen en nadelen van deze mogelijkheden?” en “Wat betekent dat voor mijn situatie?”). Daarnaast moet er ruimte zijn om zelf vragen te verzinnen en te noteren. Twee factoren werden gevonden die gerelateerd waren aan het gebruik van de applicatie. Proefpersonen die de applicatie gebruikten hadden daarvoor al iets meer kennis over artrose dan proefpersonen die de applicatie niet gebruikten. Daarnaast waren gebruikers van de applicatie minder gewend om in het dagelijks leven het internet te gebruiken dan ‘niet-gebruikers’. Op basis van de resultaten kunnen we echter nog geen duidelijke subgroepen identificeren van patiënten, om het implementeren van de applicatie specifiek te maken.
Hoofdstuk 6: verspreidingsmethoden van educatiemateriaal

Omdat er verschillende voorkeuren kunnen zijn in hoe informatie en educatie overgebracht wordt, kan het ook zijn dat de manier van verspreiden van educatiemateriaal (de verspreidingsmethode) invloed heeft op of patiënten het materiaal gaan gebruiken of niet. In Hoofdstuk 6 hebben we daarom twee verspreidingsmethoden van een educatief zelfmanagement boekje, de “Zorgwijzer RA” met elkaar vergeleken. In de ene methode kregen 194 patiënten met RA de Zorgwijzer RA ongevraagd toegestuurd. In de andere methode kregen 176 patiënten met RA de mogelijkheid om de Zorgwijzer te bestellen. Patiënten die zelf een Zorgwijzer moeten bestellen zijn mogelijk meer gemotiveerd om deze ook daadwerkelijk te gaan gebruiken dan patiënten die hem zomaar toegestuurd krijgen. Wat uiteindelijk kan leiden tot betere uitkomsten. We vonden geen verschillen in het wel/niet gebruiken van de Zorgwijzer RA tussen de twee verspreidingsmethoden. Echter, wanneer we in de groep die de zorgwijzer kon bestellen, alleen keken naar de patiënten die de Zorgwijzer RA ook daadwerkelijk bestelde (je kan immers een zorgwijzer niet gebruiken als je hem niet besteld hebt) dan zagen we dat in de bestellers-groep de Zorgwijzer meer gebruikt werd dan in de groep die de Zorgwijzer ongevraagd ontving. Vanuit een economische en milieuvriendelijk perspectief kan de verspreidingsmethode waarbij men zelf een boekje moet bestellen worden aanbevolen. Los van de verspreidingsmethode werd de Zorgwijzer eerder gebruikt door patiënten die getrouwd waren, een hogere ziekteactiviteit hadden, meer educatie behoeften en die minder positieve percepties hebben van hun aandoening.

Hoofdstuk 7: discussie

In dit hoofdstuk worden de belangrijkste bevindingen van dit proefschrift en de methodologische overwegingen besproken. Op basis van deze overwegingen worden aanbevelingen gedaan voor verder onderzoek en implicaties voor de klinische praktijk. De onderzoeken in dit proefschrift dragen bij aan het inzicht dat er is over hoe we het beste voorlichting kunnen geven aan patiënten met reumatische aandoeningen. In dit proefschrift hebben we veel verschillende vormen van educatie/voorlichting onderzocht; een eHealth applicatie, een papier boekje en face-to-face groepsvoorlichting. In alle onderzoeken kwam naar voren dat deelnemers tevreden zijn over de verschillende materialen, maar het was niet altijd zo dat iedereen (optimaal) gebruik maakte van de materialen. Daarnaast hebben we onderzocht of er verschillen waren in bepaalde kenmerken tussen patiënten die wel of niet gebruik maakte van de voorlichtingsmaterialen. Hierbij kwamen geen duidelijke kenmerken naar voren. Dit laat zien dat niet één vorm van educatie geschikt is voor één type persoon. Daarnaast is het aannemelijk dat ieder persoon zijn eigen voorkeur heeft. Voorlichting aangeboden op verschillende manieren (op papier, online of face-to-face) zou beschikbaar moeten zijn voor alle patiënten, zodat zij zelf kunnen kiezen welke optie het meest aansluit bij hun voorkeur.

In dit proefschrift hebben we FAQs in kaart gebracht die belangrijk zijn voor patiënten. Deze vragen bieden zorgverleners de mogelijkheid om regionaal samen te werken en tot eenduidige antwoorden te komen die gebruikt kunnen worden in voorlichting aan patiënten. Het geven van eenduidige voorlichting heeft de potentie om de kennis van patiënten en hun opvattingen over behandeloptie te verbeteren. Voorlichting zou al vroeg in het ziekte proces aangeboden moeten worden, bijvoorbeeld bij de huisarts of fysiotherapeut. Wanneer patiënten beter inzicht krijgen in de behandelmogelijkheden die er zijn en wat zij hiervan kunnen verwachten, zal dit uiteindelijk bijdragen aan betere zorg.
Eindelijk is mijn proefschrift klaar! De afgelopen periode waren er ups en downs. Het was hard werken, maar vooral ook erg leerzaam en waardevol. Dit proefschrift als eindresultaat was niet mogelijk geweest zonder de inzet en hulp van een heleboel patiënten, zorgverleners, collega's en andere mensen om mij heen. Iedereen die heeft bijgedragen aan het tot stand komen van dit proefschrift wil ik dan ook hartelijk danken. Daarnaast wil ik een aantal mensen in het bijzonder bedanken.

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Lieve vriendinnen; Ilona, vanuit onze afstudeerstage bij de Hoogstraat hebben we elkaars carrière stappen gevolgd en een waardevolle vriendschap opgebouwd. Fijn dat ik bij jou altijd mag komen sparren als ik het niet meer trekt. Lieve Caroline, mijn ‘oudste’ vriendinnetje, ik ben blij dat we na al die jaren nog contact hebben en het altijd ‘goed’ is als we elkaar zien. Lieve Floorje, Sanne, Nienke en Sandra (en natuurlijk ook jullie lieve mannen en kids), na meer dan 10 jaar vriendschap ben ik nog steeds super blij met jullie! Heel fijn dat ondanks alle drukte van baan en gezin we toch altijd contact houden. Fijn dat jullie er altijd zijn in goede en slechte tijden, of als iemand een oppas nodig heb om een dankwoord te schrijven 😊. Lieve Nien, als vriendin en oud-collega ben ik ontzettend trots dat jij straks naast mij staat als paranimf. Bedankt!

Lieve schoonfamilie, wat ben ik blij met jullie aan de ‘koude kant’ , waar ik mij altijd thuis en welkom voel. Lieve Roelie en Max, de ‘Wet van Claassen’ is het net niet geworden, maar dan proefschrift komt een eind in de buurt.

Lieve Marije en Hans, grote zus en klein broertje, ik ben trots op jullie en jullie mooie gezinnen! Lieve bap en mam, bedankt dat jullie altijd klaar staan en mij onvoorwaardelijk steunen. Mam, jouw hulp en support is ontzettend waardevol voor mij geweest de afgelopen jaren. Het is fijn dat ik altijd bij je terecht kan. Pap, met jouw knieën was jij mijn voorbeeld patiënt, testervoor de interventies van mijn onderzoeken, en kritische sparringpartner als fysiotherapeut. Ik ben blij en trots dat jij mij haarfijn aan en houden jouw nuchtere karakter en de oneindige ‘komt wel goed schatje’-s mij met beide beenjes op de grond. Bedankt lieverd! Lieve Wouter en Bente, jullie zijn my sunshine, jullie maken mij gelukkig.

Dankwoord

Curriculum vitae
Curriculum Vitae


In mei 2015 ontstond de mogelijkheid om haar werkzaamheden bij de Sint Maartenskliniek uit te breiden tot een eigen promotietraject. In haar promotieonderzoek, waar dit proefschrift het resultaat van is, werd zij begeleid door Dr. Els van den Ende, Dr. Henk Schers, Prof. Dr. Frank van den Hoogen en Prof. Dr. Thea Vliet Vlieland.

Momenteel werkt Aniek als beleidsmedewerker bij de Nederlandse Vereniging voor Reumatologiete Utrecht waar zij zich richt op de ontwikkeling van nieuwe behandelrichtlijnen.

List of publications
List of publications

This thesis


Claassen AAOM, Vliet Vlieland TPM, Busch VJJF, Schers HJ, van den Hoogen FHJ, van den Ende CHM. An eHealth tool to prepare for a first orthopedic consultation: a use and usability study. (submitted)

Claassen AAOM, Schers HJ, Busch VJJF, Heesterbeek PJC, van den Hoogen FHJ, Vliet Vlieland TPM, van den Ende CHM. Preparing an orthopaedic consultation using an eHealth tool: a randomized controlled trial in patients with hip and knee osteoarthritis. (submitted)

Other publications


Conference abstracts


Research Data Management

All studies in this thesis were presented to the medical and ethical review board Committee on Research Involving Human Subjects Region Arnhem Nijmegen, Nijmegen, the Netherlands. On all studies the committee provided a waiver as these types of studies do not require approval from an ethics committee in the Netherlands according to the Central Committee on Research involving Human Subjects.

All projects are stored on the Sint Maartenskliniek, department server: (V:\) under reuma_research_studies and research_archief. In the studies of chapter 3 and 6 participants received questionnaire booklets containing written informed consent. The paper data were stored in the department archive (Sint Maartenskliniek, W-building). All paper data were entered into the computer by use of Microsoft Office Access. Data in the study of chapter 2 was collected online by the use of Sawtooth Software. Data were downloaded and converged from Microsoft Office Excel. Data in the study of chapter 4 and 5 were collected by use of Castor EDC.

The privacy of the participants in all studies of this thesis is warranted by use of encrypted and unique individual subject codes. This code corresponds with the code on the patient questionnaire booklets. The code was stored separately from the study data. All data where converged to Stata (StataCorp LLC, College Station, Texas, USA) for analyses.
**PhD Portfolio**

<table>
<thead>
<tr>
<th>Name PhD candidate: AAOM, Claassen</th>
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<tbody>
<tr>
<td>Department: Rheumatology</td>
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<td>Graduate School: Radboud Institute for Health Sciences</td>
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**PhD period:** 01-05-2015 – 15-02-2019

**Promotor(s):** Prof. F.H.J. van den Hoogen, Prof. T.P.M. Vliet Vlieland

**Co-promotor(s):** Dr C.H.M. van den Ende, Dr H.J. Schers

### TRAINING ACTIVITIES

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<th>Year(s)</th>
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<td>a) Courses &amp; Workshops</td>
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<tr>
<td>- Regression analysis (Erasmus Summer course)</td>
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<tr>
<td>- Epidemiologisch onderzoek: opzet en interpretatie (Epidem)</td>
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<td>- BROK course</td>
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<td>- Scientific Integrity</td>
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<td>- GIEP-cursus – Time/Project management</td>
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<tr>
<td>- Longitudinal data analysis (Epidem)</td>
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<td>- Loopbaanmanagement voor promovendi</td>
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<td>- Reumaclub/Kunst van het schrijven (journal club)</td>
<td>2015-2018</td>
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<td>- Researchlunch (journal club)</td>
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<td>- Work visit Keele University – Primary care sciences</td>
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### TEACHING ACTIVITIES

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<td>e) Lecturing</td>
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<td>f) Supervision of internships / other</td>
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