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ORIGINAL ARTICLE

Evaluation of a website providing information on regional health care services for patients with rheumatoid arthritis: an observational study

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Abstract Studies on the effectiveness of information provision for patients with arthritis through the Internet are scarce. This study aimed to describe rheumatoid arthritis (RA) patients' knowledge and information needs before and after launching a website providing information on regional health care services for patients with rheumatic conditions. The intervention consisted of a weekly updated website comprising practical information on regional health care services for patients with arthritis. In addition, patients were offered information leaflets and an information meeting. Before (T1) and 24 months after (T2) the website was launched, a random sample of 400 RA patients filled in a questionnaire regarding knowledge and information need (scores 0–18) about accessibility and contents of 18 regional health care services. Two hundred and fifty-one patients returned the questionnaire (response rate 63%) at T1 and 200 patients (50%) at T2, respectively, with 160 paired observations (112 females (70%), mean age 60.4 years (SD 9.9)). The total score for insufficient knowledge about contents decreased from 9.3 (SD 4.9) to 8.5 (SD 4.8; $p=0.03$) and for accessibility from 8.6 (SD 4.7) to 8.4 (SD 4.9; $p=0.59$). Total score for information need about contents decreased from 4.2 (SD 4.5) to 1.9 (SD 2.9; $p<0.01$) and for accessibility from 3.6 (SD 4.5) to 1.4 (SD 2.4; $p<0.01$) (paired *t*-tests).

After the administration of a website comprising practical health care information, RA patients' information need and to a lesser extent their perception of having insufficient knowledge on relevant regional health care services decreased significantly. The results of this descriptive study suggest that the use of the Internet to inform patients may be effective, although controlled studies are required to evaluate and optimize web-delivered information.

Keywords Consumer health information · Health care services · Health services accessibility · Information need · Internet · Rheumatoid arthritis

Introduction

In the past decade access to the Internet has grown worldwide [1], and analogously the patient's use of online health services increased rapidly [2–5]. In arthritis care, the Internet is used in various ways: for communications between patients and health care providers, in the form of e-mail or online help lines or consultations [6, 7]; structured

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interventions to enhance self-management including physical activity [8]; medical treatment adherence [9, 10] or patients' self-management attributes [11, 12]; online tools for decision support [13]; patient support groups [14] and disease-oriented social networks [15]. Moreover, the Internet is an important source of information for patients with arthritis [16–19].

Despite the enormous amount of disease-related information on rheumatic diseases on the Internet, the availability of studies on the effectiveness of information delivery by means of websites for patients with arthritis is limited. Young et al. in 2002 showed a significant increase in disease-related knowledge in patients with systemic lupus erythematosus (SLE) using a website providing information on this specific condition [20]. Most other studies on online health information for patients with arthritis focus on the quality of the contents rather than their effectiveness, concluding that the quality of the information on the internet varies widely [21] or needs improvement [17, 22].

In patient populations other than those with arthritis, studies on the effects of online health information showed a positive effect on the collaboration between patients and health professionals [2] and the patients' understanding and use of treatments, lifestyle and ability to manage their condition [23]. An evaluation of an educational website on diabetes mellitus showed significant improvement in disease-related knowledge among its visitors [24].

In their review Lustria et al. [25] studied randomized controlled trials concerning online behavioural interventions and concluded that these interventions showed a large diversity with respect to formats, features and underlying theoretical frameworks. The most frequently used underlying theoretical frameworks for the interventions were: the trans-theoretical model [26] and the social–cognitive theory [27]. The social–cognitive theory is often used in online health promotion and distinguishes between two pathways through which communication can alter health habits [28]. Using the direct pathway the media promote changes by informing, modelling, motivating and guiding personal changes. By the indirect, socially mediated pathway the media link participants to social networks and community settings. The evaluation of structured Hip Fracture Prevention Website for elderly, which was developed based on the social–cognitive theory and employed both direct and indirect pathways, showed a significant improvement in knowledge regarding hip fractures and osteoporosis [29].

In the literature there are few studies describing the impact of information delivery via Internet in patients with arthritis. Therefore, this study aimed to describe knowledge and information needs of patients with arthritis before and after launching a website providing information on regional health care services for patients with rheumatic conditions. The study was confined to patients with rheumatoid arthritis (RA).

Methods

Study design and patients

This pre-test post-test study was part of a larger, observational study also including RA patients' lifestyle [30, 31]. Apart from the intervention described in this paper, no co-interventions were involved. The study was conducted from April 2004 until June 2006 at the Leiden University Medical Center (LUMC), The Netherlands, and judged to be non-medical research according to the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee of the LUMC.

A random sample of 400 RA patients with RA according to the 1987 ACR criteria [32] was selected from a registry of 1500 outpatients. All 400 patients received a questionnaire and an information letter explaining the aim of the study by mail before the information intervention (T1) and 24 months thereafter (T2). The patients were asked to fill in the questionnaire and return it via postal mail in a pre-stamped envelope. If after 4 weeks the questionnaire had not been returned, the participant was contacted by telephone, with the request to return the completed questionnaire. Details concerning baseline data on knowledge and information need have been published in a separate paper [33].

The intervention: a planned, multi-component information intervention

To enhance RA patient's self-management abilities by improving knowledge and diminishing information need regarding the complex and extensive range of health care services, a website was developed.

The website contained information regarding practical aspects of health care services for patients with rheumatic diseases in the region South-Holland North. The website was also accessible from a computer in the waiting area of the rheumatology outpatient clinic.

The website offered a large variety of practical and trustworthy information for patients with rheumatic diseases and their relatives, divided in six areas: "Health care services", "Health professionals", "Rheumatic diseases and physical activity", "Information and support", "Local consumer organization" and "Assistive devices".

In particular, the website included information on the health services' or health professional's names of the contact persons, addresses, telephone numbers, e-mail addresses, internet sites and opening hours. Visitors to the website could subscribe to a newsletter for example to receive the announcement of relevant regional events. Moreover, a telephone number and an e-mail helpline to contact a clinical nurse specialist (MB) for questions regarding regional health care services were provided. The website was updated on a weekly basis by the clinical nurse specialist (MB) in collaboration with the project coordinator (IGdB). For the updates and maintenance of the website a content management protocol was developed.

The development of the contents and structure of the website was done in close collaboration with four regional patient organizations (Reumapatiëntenverenigingen Leiden, Katwijk, Wassenaar and Alphen aan den Rijn). They facilitated the institution of small committees of RA patients who commented on the general design and the main information categories and their contents. In addition, a group of health care providers including a rheumatologist, physical therapist, occupational therapist and clinical nurse specialist reviewed the website contents. The patients involved in the project pilot-tested the pre-final version of the website and reviewed all contents of the website on a yearly basis.

The regional informative website was launched in January 2004 on www.reumanet.nl. For practical reasons the contents of the website were transferred to the website of the Leiden University Medical Center in 2010. All patients with RA of the outpatient clinic of the rheumatology department were informed about the introduction of the website via a postal mailing. In addition, the website was announced via a PR campaign, including the distribution of 3000 information leaflets and 200 posters to regional health care services and local consumer organizations. Moreover, all 400 patients in the present study had the possibility to request additional written information about health care services or attending a one-time information meeting by filling in a pre-stamped reply card. During the information meeting, patients were given information on the website and an update on treatments provided by rheumatologists and various health professionals by means of a plenary session and workshops.

Measurements

Sociodemographic variables

Sociodemographic variables were collected at baseline and included age, gender, disease duration, educational level, marital status and employment status. Of the patients who did not return the questionnaire, data concerning age, gender and disease duration were collected.

Health-related quality of life

A validated Dutch version of the Short Form 12 health questionnaire (SF-12) was used [34, 35], to compute mental and physical component summary scores ranging from 0 to 100 with higher scores indicating better quality of life.

Knowledge and information need about regional rheumatology health care services

Patients' self-perceived knowledge and information need regarding 18 regional health care services addressed on the website were measured with a self-developed questionnaire. The questionnaire was developed by two of the authors (IGdB and TVV). The content of the questionnaire matched the contents of the website, so that patients' perceived knowledge and information needs regarding all health care services included in the website would be examined. Regarding their knowledge (Fig. 1) about regional health care services, patients indicated their knowledge concerning content and accessibility on a 4-point Likert scale (insufficient=1, moderate=2, sufficient=3 and good=4; later dichotomized into sufficient=0, insufficient=1). In addition, patients rated their information need on content and accessibility as either "no information need (0)" or "information need (1)". Results were summarized in two total scores for insufficient knowledge (i.e. regarding the contents and accessibility) both ranging from 0 to 18, equaling the number of health care services about which patients reported insufficient knowledge. The questionnaire also yielded two total scores for information need (i.e. regarding the contents and accessibility), both ranging from 0 to 18, equaling the number of health care services about which patients reported an information need (see Fig. 1). In a previous study [33] in 251 patients with RA using this questionnaire, it was found that a higher insufficient knowledge score was associated with higher age and a lower information need score was associated with higher age and better physical functioning. Moreover, correlations between insufficient knowledge and information need scores were weak (r=0.15, p=0.02 for content and r=0.11, p=0.09 for accessibility, respectively), indicating that lack of knowledge and information need scores represent different constructs.

Statistical analysis

All analyses were performed using the Statistical Package for the Social Sciences (SPSS 17.0 for Windows, Chicago IL, USA).

To analyse differences in age, gender and educational level at baseline between patients who did return the questionnaire at T1 and T2 and those who returned zero or one questionnaire, the Mann–Whitney test for continuous variables and the chi-square for discrete variables were applied.

Descriptive statistics were used to summarize demographic characteristics and data regarding knowledge and needs of rheumatology health services.

To analyse the differences in knowledge and information need regarding contents and accessibility of the separate health care services before and after the information

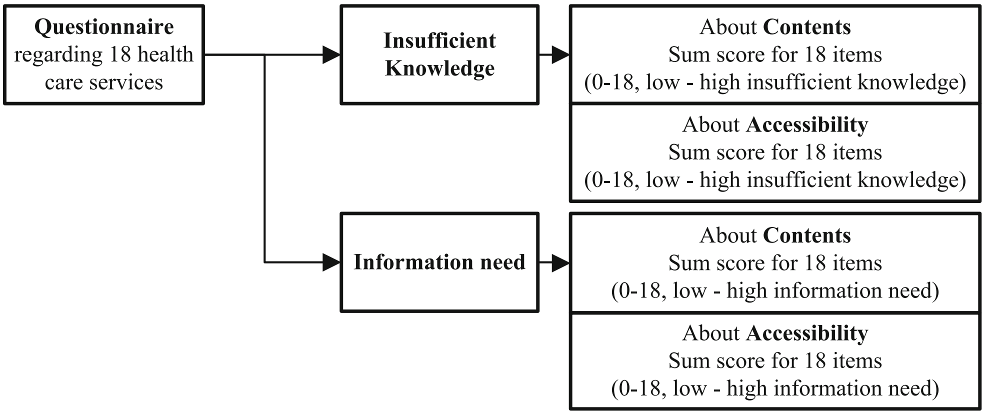

Fig. 1 Knowledge and information need questionnaire. The use of a questionnaire to score knowledge and information need regarding the contents and accessibility of 18 health care services that were represented in the website (i.e. general practitioner, rheumatologist, orthopaedic surgeon, physical therapist, specialized arthritis physical therapist, occupational therapist, clinical nurse specialist, orthopaedic shoe technician, podiatrist, home nurse, home help, social worker, psychologist, patient educational programs, consumer organization, hydrotherapy, high-intensity group exercise therapy and supervised exercise for chronically ill people). Subsequently four sum scores are computed that represent a patient's level of insufficient knowledge contents, insufficient knowledge accessibility, information need contents and information need accessibility. Questions regarding the knowledge about regional health care services: Contents: "To what extent are you familiar with what the following health professionals or health care services in your place of living or region actually do for patients with arthritis?" Accessibility: "To what extent are you familiar with how to get access to and contact the following health professionals or health care services in your place of living or region?"

intervention, the McNemar test for paired observations was performed for each of the 18 health care services. The differences in total scores for knowledge and information need were analysed with the paired samples *t*-test. For all analyses, a *p*-value of less than 0.05 (two-tailed) was adopted as the criterion for statistical significance.

Results

From January 2004 until June 2006 there were on average 471 users of the website per month. In that period, in total 169 telephone calls and 131 e-mails to the clinical nurse specialist were registered. Thirty-nine patients out of 251 patients (16%) subscribed to the information meeting, organized in the hospital in 2005. One-hundred and eighteen (30%) out of 400 patients requested and received additional information leaflets.

Response

Of the 400 patients who received the questionnaires, 251 patients (response rate of 63%) sent back the questionnaire at T1, and 200 patients (50%) sent back the questionnaire at T2. One hundred and sixty (40%) patients returned the questionnaire at both T1 and T2. The latter patients were defined as paired observations.

Patient characteristics

Table 1 shows the characteristics of the 251 respondents at T1, and the 160 paired observations. The distribution of age, gender and disease duration of the 251 patients responding at baseline did not differ significantly from that of the 149 patients who did not respond to the questionnaire at baseline.

Knowledge of regional and local health care services

Table 2 shows the proportions of patients ($n=160$, representing the patients who responded at both T1 and T2) reporting moderate or insufficient knowledge of the content and accessibility of health care services before the information intervention (T1) and 24 months thereafter (T2), and the *p*-values of the changes between T1 and T2.

At baseline, 50% or more of the patients reported insufficient knowledge regarding contents and the accessibility for 11 out of 18 health care services. In total, 150 patients (94%) reported insufficient knowledge about the contents and 149 (93%) about the accessibility of at least one of the 18 health care services.

After the information intervention, insufficient knowledge about the contents decreased significantly for four of the 18 health care services, and insufficient knowledge about the accessibility decreased significantly for two of the 18 health care services.

The total score for insufficient knowledge about the contents of health care services decreased significantly from 9.3 (SD 4.9) to 8.5 (SD 4.8; $p=0.03$), whereas the decrease of the total score for insufficient knowledge about the accessibility of health care services from 8.6 (SD 4.7) to 8.4 (SD 4.9; $p=0.59$) did not reach statistical significance.

Table 1 Patient characteristics, scores on the SF-12 before the intervention (T1) and the paired observations (T1+T2)

	T1	Paired observations (T1+T2)
Number of respondents (%)	251 (63)	160 (40)
Age (years), mean (SD)	60.5 (11.5)	60.4 (9.9)
Female	182 (72)	112 (70)
Disease duration (years), mean (SD)	12.1 (8.9)	12.7 (8.3)
Level of education		
Low	122 (49)	72 (45)
Medium	94 (38)	63 (39)
High	34 (14)	24 (15)
Living alone	46 (18)	32 (20)
Employed	67 (27)	49 (31)
SF-12, (0–100) mean (SD)		
Physical	36.8 (10.2)	36.9 (9.6)
Mental	49.5 (9.8)	51.0 (9.6)

Results are presented as absolute numbers (%) unless specified otherwise. Level of education: Low: up to and including lower technical and vocational training; Medium: up to and including secondary technical and vocational training; and High: up to and including higher technical and vocational training and university

SF-12 Short Form 12 health questionnaire

Need for information on regional and local health care services

Table 2 also shows the proportions of patients reporting an information need of the content and accessibility of health care services before the information intervention (T1) and 24 months thereafter (T2) and the *p*-values of the changes between T1 and T2.

At baseline, 25% or more of the patients reported an information need regarding the contents and the accessibility for the specialized arthritis physical therapist, clinical nurse specialist, patient education programs and on all three exercise activities.

In total, 114 patients (71%) reported an information need about the contents and 102 (64%) about the accessibility of at least one of the 18 health care services.

After the intervention, the information need regarding the contents decreased significantly for 16 out of 18 health care services, and information need regarding the accessibility decreased significantly for two out of 18 health care services.

In addition, the total scores for information need about the contents and accessibility of health care services decreased significantly, respectively from 4.2 (SD 4.5) to 1.9 (SD 2.9; $p<0.01$) and from 3.6 (SD 4.5) to 1.4 (SD 2.4; $p<0.01$).

Discussion

This descriptive, observational study found a significant decrease of RA patients' information need and, to a lesser extent, their perception of having insufficient knowledge after the institution of a website providing information on regional health care services for patients with arthritis.

The positive effect of online information increasing knowledge is in line with the results of studies in patients with SLE [20] and DM [24]. In addition to the effects of the website on knowledge, this study shows that the intervention decreased the information need regarding practical aspects of regional health care significantly. To our knowledge, the effects of an informative website on patient's information needs have not yet been studied. The concept of information need is very important in the light of the growing emphasis on self-management in arthritis care. For adequate self-management in arthritis, patients are not only in need of information on the disease and its management but also on practical aspects regarding the availability of and access to relevant health care services.

Although informing patients via the Internet is increasingly important in health care and the availability of Internet in the Netherlands and many other countries is very common [36], patients preferences regarding the method of information provision may include other means [33, 37]. This is supported by our observation that a considerable proportion of RA patients requested paper information leaflets and some of them took part in an information meeting. Information leaflets and individual or group information meetings of information proved to be effective in improving knowledge and therapy adherence [38] in arthritis patients. In addition, 169 patients from the subgroup of website users contacted the clinical nurse specialist by telephone.

Although our baseline findings regarding information need and level of knowledge are in line with previous studies [5, 39, 40], our results show that the information need (four services) is substantially lower than lack in knowledge (nine services), implying that patients do not need to know about all they do not know. Moreover, the decrease in information need was substantially larger than on insufficient knowledge. The mechanisms behind these are not clear, but it appears that information need and knowledge are not interchangeable. It has indeed been observed that patients are not always

Table 2 The numbers (%) of patients (n=160) reporting insufficient knowledge and information need, respectively, regarding health care services before (T1) and after (T2) the information intervention, and the p-values from the McNemar test

	Insufficient knowledge						Information need					
	Contents			Accessibility			Contents			Accessibility		
	T1	T2	*p*	T1	T2	*p*	T1	T2	*p*	T1	T2	*p*
1. General practitioner	24 (15)	36 (23)	0.11	6 (4)	9 (6)	0.51	22 (14)	16 (10)	0.27	8 (5)	5 (3)	0.51
2. Rheumatologist	8 (5)	16 (10)	0.19	9 (6)	9 (6)	1.00	26 (16)	22 (14)	0.58	12 (8)	9 (6)	0.63
3. Orthopaedic surgeon	90 (56)	93 (58)	0.89	75 (47)	72 (45)	0.77	35 (22)	9 (6)	0.00*	25 (16)	4 (3)	0.00*
4. Physical therapist	31 (19)	28 (18)	1.00	11 (7)	17 (11)	0.12	38 (24)	18 (11)	0.00*	22 (14)	4 (3)	0.00*
5. Specialized arthritis physical therapist	114 (71)	100 (63)	0.82	107 (67)	105 (66)	0.77	62 (39)	30 (19)	0.01*	59 (37)	19 (12)	0.00*
6. Occupational therapist	90 (56)	94 (59)	0.75	93 (58)	98 (61)	1.00	33 (21)	14 (9)	0.00*	31 (19)	10 (6)	0.00*
7. Clinical nurse specialist	79 (49)	56 (35)	0.00*	69 (43)	56 (35)	0.12	51 (32)	25 (16)	0.00*	45 (28)	19 (12)	0.00*
8. Orthopaedic shoe technician	49 (31)	7 (4)	0.69	48 (30)	53 (33)	0.39	24 (15)	10 (6)	0.00*	18 (11)	5 (3)	0.00*
9. Podiatrists	105 (66)	78 (49)	0.00*	95 (59)	92 (58)	0.47	37 (23)	11 (7)	0.00*	33 (21)	4 (3)	0.00*
10. Home nurse	101 (63)	98 (61)	0.45	86 (54)	84 (53)	1.00	29 (18)	7 (4)	0.00*	28 (18)	4 (3)	0.00*
11. Home help	76 (48)	79 (49)	1.00	67 (42)	69 (43)	0.89	32 (20)	12 (8)	0.00*	24 (15)	8 (5)	0.00*
12. Social worker	99 (62)	93 (58)	0.61	96 (60)	88 (55)	0.37	25 (16)	11 (7)	0.01*	26 (16)	9 (6)	0.01*
13. Psychologist	113 (71)	111 (69)	0.61	98 (61)	104 (65)	0.63	21 (13)	6 (4)	0.00*	21 (13)	7 (4)	0.02*
14. Patient education and self-management	109 (68)	111 (69)	0.78	102 (64)	106 (66)	0.67	53 (33)	26 (16)	0.00*	49 (31)	19 (12)	0.00*
15. Local/regional consumer organization	67 (42)	68 (43)	1.00	58 (36)	64 (40)	0.24	32 (20)	16 (10)	0.01*	22 (14)	8 (5)	0.01*
16. Hydrotherapy	91 (57)	91 (57)	1.00	100 (63)	92 (58)	0.35	51 (32)	26 (16)	0.00*	54 (34)	29 (18)	0.00*
17. High-intensity group exercise therapy	112 (70)	90 (56)	0.01*	115 (72)	96 (60)	0.03*	54 (34)	19 (12)	0.00*	56 (35)	26 (16)	0.00*
18. Supervised exercise for chronically ill people	127 (79)	108 (68)	0.02*	127 (79)	109 (68)	0.02*	51 (32)	33 (21)	0.02*	50 (31)	35 (22)	0.07
Total score; 0–18; no. of health care services (SD)	9.3 (4.9)	8.5 (4.8)	0.03*	8.6 (4.7)	8.4 (4.9)	0.59	4.2 (4.5)	1.9 (2.9)	0.00*	3.6 (4.5)	1.4 (2.4)	0.00*

The total scores for insufficient knowledge and information on T1 and T2 and the p-values from the paired samples t-test

*$p<0.05$

aware of their knowledge and structurally they tend to overestimate their level of knowledge [41], and analogously patients are not fully aware of their information needs. It is therefore advocated that tools are used to identify the individual information needs of patients [39, 40], but also tools need to be developed to raise awareness of gaps in knowledge and information needs [41]. In addition, potential adverse and harmful effects due to online health information should be taken into account. However, Crocco et al. found only a few cases of harm in their disease-independent analysis of cases of harm associated with use of health information on the internet [42].

The collaboration with patients to develop the contents and structure of the website was an essential point in the conducted study. First, patients were included in the development of the design and the contents of the website. Subsequently, patients were involved in the testing of the pre-final version of the website and reviewed all contents of the website on a yearly basis. The involvement of the patients in this project was in line with five out of eight of the European League Against Rheumatism (EULAR) recommendations for the inclusion of patients in scientific projects [43]. In our study and the development of the website, the role of patients with rheumatic diseases, the phase of involvement, the recommended number of patients, support of the patients and acknowledgements were addressed. These recommendations aim to achieve a better representation of patients needs in scientific projects and thereby enhancing the chances for implementation and patient empowerment.

In their review regarding online behavioural interventions, Lustria et al. conclude that tailoring of web-based interventions is important and that tailoring is a complex multidimensional and multi-step process [25]. Moreover, it is concluded that the social–cognitive theory is often used in online health promotion, using both direct and indirect pathways. Although our website did not primarily intend a behavioural change, it did comprise some important modalities that were identified in this review: informative web content, an e-mail and a telephone helpline, and an online newsletter. However, our website used direct pathways only and did not comprise other potential modalities like animations, online quizzes or games, video contents, chat sessions or moderated discussion boards. The latter two modalities were used in the social–cognitive theory-based website for hip fracture prevention developed by Nahm et al. [29]. This study showed a substantial effect on people's knowledge. Expanding our website with chat sessions and moderated discussion boards and thereby incorporating the social–cognitive theory by personalizing information and positive role-modelling [44], as well as by using indirect pathways of health promotion, could probably have led to larger effects on knowledge and information need than the benefits we observed. It remains to be established, however, to what extent the additional learning effect would be justified by the relatively large investments in time, resources and maintenance that would be required.

This study had a number of limitations. The sample was a cross-sectional selection from one university hospital. From the original sample of 400 patients, we ended with a limited response of 160 paired observations.

In addition, we used a self-developed questionnaire to measure patient-perceived knowledge and information need. This questionnaire needs to be further validated in other populations of RA patients. Although in 2006 80% of the Dutch households had access to the Internet [36], the intervention may have reached only a selected group of patients. As we did not collect data regarding the actual utilization of the website by the respondents, we cannot further analyze the association between website usage and the changes in knowledge and/or information needs. Moreover, we did not take potential side effects [42] into account.

Although the website in this study clearly fills a gap in the current spectrum of health-related information, it remains unclear whether our results actually affect the health care utilization. Baker et al. [23] in their study after the effects of health care information from the Internet concluded that the actual effects on health care utilization were very limited.

Based on the results of this study, we can conclude that the provision of practical information about health care services should play a greater role in daily care for RA patients. The use of the Internet to inform patients via a web site seems to be very effective. Since there is a discrepancy in the effects on information need and the effects on knowledge, the identification of information needs is very important.

Therefore, further research is needed in controlled studies with respect to the intervention, the sample and the outcome measures used. A possible outcome measure to reliably assess the patient's information need is the Educational Needs Assessment Tool [39, 40].

Informing patients about practical aspects of health care via the Internet is feasible and contributes to the information position of patients, and should therefore play a greater role in daily care. More and better-controlled evaluations should be included in projects aiming to provide online health information to analyze the effects of online health-related information and the determinants of patients most susceptible for this type of information.

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