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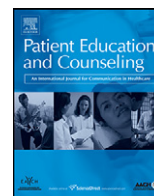
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Short communication

Unmet information needs about the delivery of rheumatology health care services: A survey among patients with rheumatoid arthritis

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ABSTRACT

Objective: To measure patient-perceived knowledge and information need regarding regional health care services and their determinants among 400 patients with rheumatoid arthritis (RA) and to identify the preferred method of information provision.

Methods: Postal survey on knowledge and information need (content and accessibility) of 18 regional health care services and preferences for the mode of delivery of information. Logistic regression analyses determined which factors were associated with insufficient knowledge and information need.

Results: Two-hundred and thirty-seven (94%) patients reported insufficient knowledge about the contents and 235 (94%) about the accessibility of at least one health care services, whereas 172 patients (69%) reported an information need about the content and 154 (61%) on the accessibility. Age was significantly associated with knowledge whereas both age and physical functioning were significantly associated with information need. Seventy-nine percent of the patients mentioned written information, 21% the Internet and 12% personal contact with a professional as a preferred method of information delivery.

Conclusion: Many RA patients reported a lack of knowledge or information need concerning the contents and accessibility of regional health care services.

Practice implications: Active strategies to provide practical information about health care services are needed for RA patients.

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1. Introduction

Self-management strategies are important for patients with rheumatoid arthritis (RA) to cope with the consequences of their disease [1–5]. A formal body of knowledge is a prerequisite for effective self-management [6]. Several studies in RA patients demonstrated a considerable lack of knowledge or information need about the disease [1,2,7–9], medical care [1,7–9], drug therapy [1,2,7,9,10] or treatment from health professionals [11]. The few studies on determinants of information need indicated that lower age, longer disease duration [11], more disease severity, pain and a greater learning interest [7] were associated with a higher information need among RA patients. Knowledge and

information need on practical aspects of health care delivery (i.e. where, how and by whom) have not yet been addressed.

Patients' preferences regarding the method of information delivery have hardly been examined, except for the Internet being an important source of information [12–15].

Given the scarcity of data on RA patients' knowledge and information need, this study aimed to investigate the level of patient perceived knowledge and information need on local and regional health care services and their determinants, and patients' preferences regarding information delivery.

2. Methods

2.1. Study design and patients

This cross-sectional study was part of a larger study also including RA patients' lifestyle [16,17]. It was conducted in April 2004 at the Leiden University Medical Center (LUMC), The Netherlands and judged to be non-medical research according

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to the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee of the LUMC.

Subjects included a random sample of 400 patients with RA according to the 1987 ACR criteria [18], obtained from a registry of 1500 outpatients. All patients received a questionnaire and an information letter explaining the aim of the study by mail.

2.2. Measurements

2.2.1. Socio-demographic variables

Socio-demographic variables included marital status, employment status and educational level.

2.2.2. Health-related quality of life

A validated Dutch version of the Short Form 12 health questionnaire (SF-12) was used [19,20], yielding mental and physical component summary scores (range 0–100, higher scores indicating better quality of life).

2.2.3. Knowledge and information need about regional rheumatology health care services

Patients' self-perceived knowledge and information need were measured with a self-developed questionnaire. For 18 regional health care services, patients indicated their knowledge on content and accessibility (sufficient = 0, insufficient = 1) and their information need on content and accessibility (no information need = 0, information need = 1), resulting in 4 total scores, all ranging from 0 to 18 (insufficient knowledge contents, insufficient knowledge accessibility, information need contents, and information need accessibility) (see Fig. 1).

Patients were also asked how they preferred to receive information: by written leaflets, electronic information via Internet or e-mail, information via a telephone helpline or by personal contact with a professional (more than one answer possible).

2.3. Statistical analysis

Differences between responders and non-responders were analysed with the Mann–Whitney *U* or Chi-Square tests where appropriate.

Correlations among the insufficient knowledge and information need scores were computed by Spearman rank correlation coefficients with the 95% confidence interval (CI).

Associations between patient characteristics and the four knowledge and information need scores were examined by univariate logistic regression analyses. For this purpose, insufficient knowledge and information need scores were dichotomized according to the median. Subsequently, multivariate logistic regression analyses were performed with all significant explanatory variables from the univariate logistic regression analyses as independent variables. Results were expressed as odds ratios (OR) with the 95% CI. For all analyses, $p \leq 0.05$ (2-tailed) was considered the criterion for statistical significance.

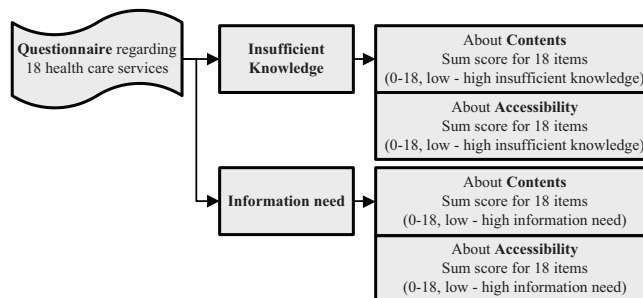
3. Results

3.1. Patient characteristics

Two hundred and fifty-one of the 400 patients (63%) completed the questionnaire (Table 1). Their sex, age and disease duration did not differ significantly from the 149 non-responders: 104 (70%) female ($p = 0.68$); mean age 62.4 years (SD 14.7, $p = 0.17$), and mean disease duration 12.5 years (SD 8.5, $p = 0.15$).

3.2. Knowledge and information need

Two-hundred and thirty-seven (94%) patients reported insufficient knowledge about the contents and 235 (94%) about the accessibility of at least one health care service. The median



The use of a questionnaire to score knowledge and information need regarding the contents and accessibility of 18 health care services.

Subsequently 4 sum scores are computed that represent a patient's level of:

- insufficient knowledge contents,
- insufficient knowledge accessibility,
- information need contents, and,
- information need accessibility.

Example 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?"*

Fig. 1. Knowledge and information need questionnaire.

Table 1
Characteristics of 251 outpatients with rheumatoid arthritis.

Age in years; mean (standard deviation)	60.5 (11.5)
Disease duration in years; mean (standard deviation)	12.5 (8.5)
Female	181 (72)
Level ^a of education	
Low	122 (49)
Medium	94 (38)
High	34 (14)
Living alone	46 (18)
Employed	67 (27)
SF-12 ^b (range 0–100)	
Physical functioning; mean (standard deviation)	36.8 (10.2)
Mental functioning; mean (standard deviation)	49.5 (9.8)

All results are presented in absolute numbers (%) unless stated otherwise.

^a 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.

^b Short Form 12: higher scores indicate a better health status.

insufficient knowledge scores on content and accessibility were 11 (range 0–18), and 10 (range 0–18), respectively.

One hundred and seventy-two patients (69%) reported an information need about the content and 154 (61%) about the accessibility of at least one health care services. The median information need scores on content and accessibility were 3 (range 0–18), and 2 (range 0–18), respectively. Table 2 shows the patients indicating insufficient knowledge and an information need regarding the contents and accessibility of 18 health care services.

3.3. Correlations among knowledge and information need scores

There was a significant relationship between the insufficient knowledge scores on content and accessibility ($r = 0.76$, $p = 0.00$) and between the information need scores on content and accessibility ($r = 0.84$, $p = 0.00$). A weak, yet statistically significant relationship was found between the insufficient knowledge and information need scores regarding content ($r = 0.15$, $p = 0.02$); but not for accessibility ($r = 0.11$, $p = 0.09$).

3.4. Factors associated with knowledge and information need

In the univariate analyses higher age was significantly associated with more insufficient knowledge and a lower information need score, whereas living together and being employed were significantly associated with a lower insufficient

knowledge score (Table 3). In addition, better physical and mental functioning were associated with a lower information need score.

In the multivariate logistic regression analysis higher age was associated with more insufficient knowledge, whereas both higher age and better physical functioning were associated with less information need.

3.5. Method of information provision

Written leaflets were most often mentioned as the preferred method for information provision (178, 79%), followed by the Internet or e-mail (48, 21%), personal information by a health care provider (28, 12%), and information by a telephone helpline (13, 6%).

4. Discussion and conclusion

4.1. Discussion

This cross-sectional study among Dutch RA patients shows a considerable lack of knowledge and need for information about practical aspects (contents and accessibility) of regional and local health care services.

Our findings are complementary to the available literature, showing that 70% or more of patients with RA or other rheumatic diseases have a general lack of knowledge or information need about their disease and its treatment [1,7,8,11,21]. In our study 60–70% of RA patients indicated a need for practical information about rheumatology health care services, including information on what health services offer and how to access them.

We found that a perceived lack of knowledge does not automatically imply an information need, since fewer patients reported an information need than a knowledge deficit and correlations between knowledge and information need were weak. An important finding, because forcing information to patients who are not open for it may diminish the chance of a successful behavioral change [5].

In line with previous research [12], higher age was related to a lesser information need in the present study. In addition, we found that better physical functioning was associated with less information need. In contrast to previous studies [1,8,11], we did not find an association between education level, gender or disease duration and insufficient knowledge or information need. The observation that disease duration neither associated with

Table 2
Numbers (%) of 251 rheumatoid arthritis patients indicating insufficient knowledge and/or an information need regarding the content and accessibility of 18 health care services.

	Insufficient knowledge		Need for information	
	Content	Accessibility	Content	Accessibility
1. General practitioner	46 (18)	12 (5)	36 (14)	11 (4)
2. Rheumatologist	17 (7)	23 (9)	45 (18)	17 (7)
3. Orthopaedic surgeon	145 (58)	124 (50)	51 (20)	41 (16)
4. Physical therapist	48 (19)	23 (9)	59 (24)	35 (14)
5. Specialized arthritis physical therapist	181 (72)	168 (67)	90 (36)	83 (33)
6. Occupational therapist	144 (57)	147 (59)	46 (18)	45 (18)
7. Clinical nurse specialist	121 (48)	106 (42)	74 (30)	68 (27)
8. Orthopaedic shoe technician	92 (37)	91 (36)	37 (15)	31 (12)
9. Podiatrists	170 (68)	160 (64)	54 (22)	54 (22)
10. Home nurse	158 (63)	135 (54)	44 (18)	42 (17)
11. Home help	121 (48)	110 (44)	45 (18)	38 (15)
12. Social worker	160 (64)	152 (61)	42 (17)	43 (17)
13. Psychologist	179 (71)	161 (64)	36 (14)	34 (14)
14. Patient education and self-management	175 (70)	167 (67)	80 (32)	71 (28)
15. Local/regional consumer organization	107 (43)	95 (38)	47 (19)	35 (14)
16. Hydrotherapy	154 (61)	163 (65)	78 (31)	82 (33)
17. High-intensity group exercise therapy	184 (73)	188 (75)	78 (31)	76 (30)
18. Supervised exercise for chronically ill people	201 (80)	199 (79)	75 (30)	74 (30)

Table 3
Results of the univariate and multivariate logistic regression analyses.

	Logistic regression analysis	Insufficient knowledge contents odds ratio (95% CI) ^a	Insufficient knowledge accessibility odds ratio (95% CI)	Information need contents odds ratio (95% CI)	Information need accessibility odds ratio (95% CI)
Age (years)	Univariate	1.05 (1.02–1.07)	1.03 (1.01–1.06)	0.98 (0.96–1.00)	0.99 (0.97–1.01)
	Multivariate	1.05 (1.02–1.07)	1.03 (1.01–1.06)	0.97 (0.95–0.99)	–
Male	Univariate	1.22 (0.70–2.12)	1.13 (0.65–1.97)	0.61 (0.35–1.06)	0.71 (0.41–1.24)
	Multivariate	–	–	–	–
Disease duration (years)	Univariate	1.00 (0.97–1.03)	0.99 (0.96–1.02)	1.02 (0.99–1.05)	1.00 (0.97–1.03)
	Multivariate	–	–	–	–
Higher education	Univariate	0.88 (0.62–1.25)	0.77 (0.54–1.10)	1.33 (0.93–1.90)	1.17 (0.82–1.66)
	Multivariate	–	–	–	–
Living together	Univariate	0.47 (0.24–0.91)	0.61 (0.32–1.16)	1.20 (0.63–2.28)	1.20 (0.63–2.28)
	Multivariate	0.63 (0.31–1.27)	–	–	–
Employed	Univariate	0.66 (0.37–1.15)	0.51 (0.29–0.91)	1.22 (0.70–2.14)	1.04 (0.59–1.81)
	Multivariate	–	0.72 (0.37–1.42)	–	–
SF-12 Physical (0–100, worst–best)	Univariate	0.99 (0.97–1.02)	1.01 (0.98–1.03)	0.97 (0.94–0.99)	0.97 (0.94–0.99)
	Multivariate	–	–	0.96 (0.93–0.99)	0.97 (0.94–0.99)
SF-12 Mental (0–100, worst–best)	Univariate	1.01 (0.98–1.03)	1.02 (0.99–1.04)	0.99 (0.96–1.01)	0.97 (0.94–1.00)
	Multivariate	–	–	–	0.98 (0.95–1.00)
<i>R</i> ² ^b		0.08	0.04	0.08	0.03

Associations between socio-demographics and disease characteristics on the one side and insufficient knowledge and information need about the contents and accessibility of health care services on the other side. The knowledge and information need scores were split at their median scores. The independent variables that were significantly associated with knowledge or information need in the univariate analyses ($p \leq 0.05$) were entered into the multivariate logistic regression model with the same dependent variable.

^a 95% confidence interval.

^b $R^2 = \text{Nagelkerke } R^2 = \text{pseudo measure for proportion explained variance; bold significant result } (p \leq 0.05)$.

knowledge nor with information need, could be explained by the relatively long average disease duration in our sample, implying that patients with early RA were underrepresented.

Overall the explained variance of information need was very low, underlining the difficulty to identify subgroups of patients with higher information need. For tailored information delivery, active strategies from professionals will be required, including a definition of the patients' specific problems, their knowledge deficit [22] and their educational needs and to negotiate relevant learning objectives. For diagnostic purposes, the arthritis-specific Educational Needs Assessment Tool is usable [8,11].

The proportion of patients preferring paper leaflets as found in our study may currently be lower because Internet usage increased in The Netherlands from 83% to 93% between 2005 and 2009 [23]. Moreover, the preference for written leaflets may in part be due to patients' lack of experience with information on the Internet. To customize the information to the individual patient's knowledge, abilities and behavior, several media, such as group sessions and workshops, leaflets via paper or the Internet, individual face-to-face consultations, or DVD's must be considered.

This study had a number of limitations. The sample was a cross sectional selection from one university hospital. Moreover, the patients' level of disability was not measured with the Health Assessment Questionnaire score but with the generic SF-12. In addition, we used a self-developed questionnaire to measure patient-perceived knowledge and information need.

4.2. Conclusions

- A considerable proportion of Dutch RA patients have a lack of knowledge and a need for information on practical aspects of regional and local health care services.
- Lower age and worse physical functioning were significantly associated with more information need, but overall the explained variance of information need was small.

4.3. Practice implications

- In daily practice, informing RA patients about the practical aspects of regional health care services is needed.
- Identifying subgroups of patients with higher information needs requires an active and individual approach.

- Several media must be considered in order to tailor the delivery of information to the individual patient's knowledge, abilities and behavior.

Conflict of interest statement

The authors have declared no conflicts of interest and they confirm that all patient identifiers have been removed so the patients described are not identifiable.

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