

## 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.

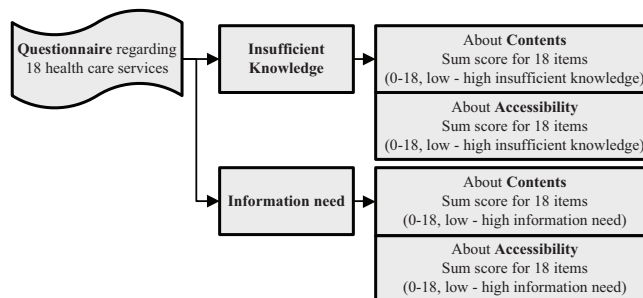
## 3. Results

### 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.

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