Care for patients with rheumatoid arthritis
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Summary
Care for patients with rheumatoid arthritis

Rheumatoid arthritis (RA) is a common, chronic and disabling rheumatic disorder that affects predominantly the joints of patients. The disease usually manifests itself between the ages of 40 and 60, but younger ages of onset are known. RA is a progressive disease, characterised by immune-driven chronic inflammation and a variable course involving exacerbations and remissions of disease activity, resulting in minor to severe disability and sometimes premature death. The progressive character of RA causes irreversible joint damage with consequences for physical, psychological and social functioning. The prevalence of RA in the Netherlands is estimated at 1.0% in the adult population, i.e. approximately 130,000 individuals. The number of RA patients is expected to rise by 27% in the period 2000-2020, due to demographic aging and population growth.

Because RA causes moderate to severe disability in many patients, these patients are a substantial target group for health care. The health problems that RA patients face are often complex and require treatment by a wide variety of health care disciplines. Because no cure for RA is as yet available, treatment and care are aimed at slowing down disease progression, maintaining the function of the joints, and optimising the patient’s quality of life. In addition to professional caregivers, informal caregivers, particularly partners, play an important role in caring for RA patients. As many different caregivers are involved in RA care, discrepancies may arise between health care needs and health care utilization.

This thesis aimed to quantify health care use and health care needs of patients with RA and to determine whether the use of health care corresponds with the need for care. The research aims of this thesis are elaborated in chapter 1. In this study, the RA+ study, a large group of patients with RA was followed over several years (chapter 2). We focused on health care utilization (chapter 3), access to health care (chapter 3 and 4), underuse of health care (chapter 5), quality of health care (chapter 6), and informal caregiver burden among partners (chapter 7). In the discussion, the main findings were presented and some methodological issues and implications for health care and further research were addressed (chapter 8).
Summary

The RA+ study

For the RA+ study, 1,200 patients with RA were selected from the patient database of the Jan van Breemen Institute, an outpatient clinic for rheumatology and rehabilitation in Amsterdam. In this patient database, patients from the affiliated outpatient clinics are also included. The selected patients were asked to fill in a questionnaire in 1997, 1998 and 1999 and to attend clinical examinations in 1997 and 1999. The questionnaires provided information regarding socio-demographic characteristics, health characteristics, health care needs, health care use, and quality of care. The clinical examinations comprised a 28-joint count, the erythrocyte sedimentation rate, and X-rays of hands and feet.

The response from patients was relatively high. In 1997, 882 patients (74\%) returned the questionnaire, and 735 (83\% of the respondents) underwent clinical examination. In 1998, 87\% of the baseline respondents (N = 755) completed the questionnaire. In 1999, 81\% of the patients (N = 683) responded by filling in the questionnaire and 76\% of these respondents (N = 530) underwent clinical examination.

In 2001 an additional study was performed, regarding informal care for patients with RA. Patients who had indicated in 1999 to receive informal care from their partners were asked to participate with their partners in an additional survey. The questionnaire for patients was used to collect information regarding socio-demographic characteristics, health-related quality of life, need for home care, and home care use. The questionnaire for partners provided information regarding socio-demographic characteristics, health-related quality of life, caregiver tasks, and informal caregiver burden.

Health care utilization

We studied health care utilization for a wide variety of health care services. As a consequence of the selection procedure of the study population, the majority of the patients (97\%) received rheumatology care within a 12-month period. In addition, 42\% of the patients visited a general practitioner (GP), 23\% an orthopaedic surgeon, 16\% a rehabilitation specialist, 10\% a plastic surgeon, and 30\% another specialist for RA related complaints. Regarding allied health care, 40\% of the patients received physiotherapy, 17\% occupational therapy, and 15\% chiropody. Of the patients, 18\% had home help, and 4\% nursing care at home. A social worker was consulted by 10\% of the patients, and 6\% received mental health care. Furthermore, we observed that apart from rheumatology care, almost half of the
patients received care from at least two different types of health care services simultaneously. As disease duration increased, patients were more likely to use several health care disciplines simultaneously. While the percentages of patients receiving medical specialist care, home care and general practice care increased, the percentages of patients consulting allied health care and psychosocial care decreased.

**Access to health care**

We studied the equity in access to health care using the model of Andersen. The advantage of this model is that it is especially designed to evaluate the access to health care and that it systematically arranges explaining variables into three groups: predisposing variables (e.g. demographic characteristics), enabling variables (e.g. socioeconomic characteristics), and need variables (e.g. health characteristics).

With regard to demographic characteristics, we found that men and patients older than 70 years of age were less likely to receive allied health care than women and younger patients. Married or cohabiting patients and patients older than 60 years of age were less likely to receive psychosocial care compared to single and younger patients. With regard to socioeconomic status (SES), we observed that low SES patients were less likely to use allied health care. With increasing disease duration, patients with low SES made less use of medical specialist care, compared to high SES patients with comparable health characteristics.

**Underuse of health care**

We studied the underuse of health care by determining patients’ unmet demands for four services: orthopaedic care, allied health care, home care and psychosocial care. Our results showed that almost 30% of the RA patients reported an unmet health care demand.

To explore whether the reported unmet health care demands indicated underuse of health care, patients were divided into three groups for each health care service: 1) patients who received care; 2) patients who perceived an unmet demand for health care; and 3) patients without a health care demand. Underuse of health care was determined by comparing the health outcomes of the three groups of patients. Underuse was detected for allied health care among 13% of the patients, for home
care among 9%., and for psychosocial care among 6%. For orthopaedic care the results were less conclusive.

**Quality of health care**

We studied the quality of health care services from the patients' perspective using the QUOTI-questionnaire method. We assessed the quality of care for a variety of health care aspects, i.e. medical expertise, information, attitude, interpersonal relationships, organisation, autonomy, and privacy. Quality ratings were obtained by weighting performance of health care providers on particular aspects of health care with patients' importance ratings of these aspects.

According to the patients, all health care providers, with the exception of the rheumatologist, were not up to standard regarding the rheumatic expertise. Information received from health care professionals, such as the rheumatologist and the GP, was also perceived to be of inadequate quality, especially information about medication, the course of symptoms, and adaptations and aids at home. We found no firm evidence that patients' ratings of quality of care were influenced by patients' health characteristics.

**Burden of informal care**

We investigated the burden of informal caregiving among partners of patients with RA. We used a multidimensional measure, the Caregiver Reaction Assessment, which distinguishes one positive dimension (care-derived self-esteem) and four negative dimensions (disrupted schedule, lack of family support, financial problems, and loss of physical strength).

Many partners derived a high sense of self-esteem from giving care. Negative aspects of caregiving were to a large degree caused by the disruption of the partner's own schedule and to a smaller degree by lack of support, financial problems, and loss of physical strength. Partners who reported higher self-esteem perceived less lack of family support and loss of physical strength.

Partners devoted a lot of their time to giving care over a long period of time; on average during 6 days a week over 11 years. Of the partners, 40% performed care tasks, 97% performed home tasks, and 78% help tasks. Health outcomes of partner and patient proved to be a strong predictor of partner's caregiver burden.
Discussion

After summarising the most important findings, some methodological issues were addressed, particularly regarding the generalisability of the findings. Implications for health care and further research were also discussed. Special attention was requested for enhancing the access to health care for specific subgroups of RA patients, improving the correspondence of health care demands and health care use, strengthening patient participation in daily practice, and additional support for informal caregivers.