Care for patients with rheumatoid arthritis
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Chapter 8

General discussion
In this thesis we aimed to gain comprehensive insight into the care for patients with rheumatoid arthritis (RA). We focused on health care utilization, access to health care, underuse of health care, quality of health care and informal caregiver burden among partners (Chapter 1).

The data for this research were supplied by the RA+ study, a longitudinal study among 882 patients with RA. These patients were recruited from the Jan van Breemen Institute, an outpatient clinic for rheumatology and rehabilitation, and its affiliated rheumatology clinics. Patients were randomly selected within strata of disease duration in order to cover the heterogeneity of RA within the group of selected patients. We followed these patients prospectively by questionnaire surveys in 1997, 1998, 1999 and 2001 and clinical examinations in 1997 and 1999 (Chapter 2). This longitudinal study included comprehensive assessments of health and health care.

In this final chapter, the main findings are presented and discussed. In addition, the generalisability of the findings and implications for health care and further research are addressed.

Main findings

Health care utilization

We observed that patients with RA use a wide variety of health care services (Chapter 3). As our patients were selected from the register of rheumatology clinics, we found that 97% of the patients received rheumatology care in 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 made use of physiotherapy, 17% of occupational therapy and 15% of chiropody. Of the patients, 18% received home help and 4% had nurse care at home. A social worker was consulted by 10% of the patients, and 6% received mental 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. With increasing disease duration, patients were more likely to use several health care disciplines simultaneously. While the percentage of patients receiving medical specialist care, home care and general
practice care increased, the percentage of patients consulting allied health care and psychosocial care decreased.

The percentage of these patients who use health care at least once a year is high compared to both the general Dutch population\textsuperscript{12} and patients with other chronic conditions.\textsuperscript{21-26} We may, therefore, conclude that patients with RA are among the highest users of health care.

**Access to health care**

We studied the equity in access to health care using the model of Andersen\textsuperscript{24,35} (Chapter 3 and 4). 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 in three types: predisposing variables (e.g. socio-demographic characteristics), enabling variables (e.g. socioeconomic characteristics), and need variables (e.g. health characteristics). With regard to socio-demographic characteristics, we found that men and patients older than 70 years of age were less likely to receive allied health care, and that married or cohabiting patients and patients older than 60 years of age were less likely to consult psychosocial care compared to patients with the opposite characteristics (Chapter 3). Focusing on the impact of socioeconomic status (SES), we observed that patients with low SES were less likely to visit allied health care and that with increasing disease duration patients with low SES made less use of medical specialist care compared to patients with high SES after adjusting for health outcomes (Chapter 4). So, our results show that the use of medical specialist care (other than rheumatology care), allied health care, home care and psychosocial care is not equally distributed among subgroups of RA patients.

Inequalities in access to health care are also reflected in the socioeconomic composition of our patient sample. As RA has a higher prevalence among patients with low SES,\textsuperscript{86} it was remarkable that we found fewer patients in the low SES group than was to be expected based on the SES distribution in the Dutch population.\textsuperscript{155} This might indicate to a problem, either in the access to primary care or in the referral from primary care to secondary or tertiary rheumatology centres.

Our results are in line with other findings from the Netherlands\textsuperscript{78,79} indicating that, although many efforts have been made to eliminate inequities from health care,\textsuperscript{64-68} these problems are persistent. In the Netherlands, financial barriers in access to health care ought not to be present, because of regulations of the Dutch health insurance system.\textsuperscript{47} The observed inequities could be due to patient characteristics, because patients with high SES or younger patients may be better equipped to negotiate for receiving health care, while these patients are not
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necessarily in more need for care. The inequities may also be induced by the health care system, if health care professionals are selective in assigning health care to various subgroups of patients, such as younger or single patients. Furthermore, the observed inequities may be related to the shortage in supply, as waiting lists and shortages of medical personnel, both doctors and nurses, are present for many health care services in the Netherlands.

Underuse of health care

We studied underuse of health care by determining patients' unmet demands for several health care services (Chapter 5). The advantage of this approach is that the perspective of patients is taken into consideration, which will reinforce patient-centred health care. Our results revealed that almost 30% of the RA patients reported an unmet health care demand for at least one of the four services under study. Unmet demands were reported by 13% of the patients for allied health care, by 10% for orthopaedic care, by 9% for home care, and by 6% for psychosocial care. For orthopaedic care and allied health care, there was approximately one unmet demander for every three health care users, while for home care one unmet demander existed on every two users. For psychosocial care, the group of unmet demanders was as large as the group of care users.

By comparing the health characteristics of unmet demanders, non-demanders and health care users, we explored if the reported unmet demands might indicate underuse. According to this approach we detected underuse for allied health care, home care and psychosocial care. For orthopaedic care the results were less conclusive.

Our findings raise concern as the group of underusers of health care services is relatively large. Especially for home care underuse seems a longstanding and persistent problem in the Netherlands as it has been observed previously in RA\textsuperscript{12} and in stroke.\textsuperscript{17} Moreover, these findings are supported by our results regarding access to health care: we also observed problems for allied health care and psychosocial care. These findings sustain the relevance of patients' unmet health care demands for identifying deficits in health care.

Quality of health care

We focused on the quality of health care services from the perspective of patients, using the method of the QUOTE-questionnaire\textsuperscript{55} (Chapter 6). The advantage of this method is, firstly, that the quality of care is obtained for a wide variety of health care aspects, regarding medical expertise, information, attitude, interpersonal relationships, organisation, autonomy, and privacy. Secondly, the performance of
health care providers on aspects of health care is weighted by the importance ratings of these aspects.

Of all health care providers, with exception of the rheumatologist, the rheumatic expertise was not up to standards according to the patients. The information received from health care professionals was also perceived to be of inadequate quality, especially information about concomitant use of medication, information on course of symptoms, information on adaptations and aids at home, and information provision in plain language. For the rheumatologists and the GP, the access to files of patients was of inadequate quality, and the accessibility of GP practices for physically disabled patients was not up to standards. Furthermore, we found no firm evidence that patients' ratings of quality of care were influenced by patients' health characteristics.

Our study implies that the quality of care could be improved further from the perspective of patients with RA. The inadequate quality of certain health care aspects may be related to knowledge problems both of health care providers and of patients. Educational programs specifically for arthritis patients have shown to improve patients' management of the disease, and educational programs for professionals have shown to be of value regarding arthritis related knowledge.

**Burden of informal care**

We investigated the burden of informal caregiving among partners of patients with RA (Chapter 7). We used a multidimensional instrument, the Caregiver Reaction Assessment, which included positive and negative dimensions. More than 51% of the patients received informal care, mostly from partners (i.e. 92%).

Many partners derived a high sense of self-esteem as a result of giving care. Negative aspects of caregiving were to a large degree caused by a disruption of the own schedule and to a smaller degree by lack of support, financial problems and loss of physical strength. Furthermore, partners who reported higher self-esteem perceived less lack of family support and loss of physical strength. These partners devoted a lot of time to giving care over a long period of time, on average 11 years over 6 days a week. Of the partners, 40% performed care tasks, such as help with personal care, 97% performed home tasks, such as fixing food or drinks, and 78% help tasks, such as accompanying or helping with visits or day trips. Health outcomes of partner and patient proved to be a strong predictor of the partners' caregiver burden.
Generalisability of the findings

To determine the generalisability of our findings some methodological issues will be addressed: the selection of patients, the response of patients and the data-collection based on self-report.

Selection of patients

The selection of patients may have introduced bias caused by unequal referral strategies (referral bias), and by the sampling procedure (sampling bias).

Referral bias
Patients were selected for the RA+ study from the patient-database of the outpatient clinic for rheumatology and rehabilitation in Amsterdam, the Jan van Breemen Institute (JBI), and its affiliated rheumatology outpatient clinics. The JBI is a tertiary health care centre specialized in rheumatic diseases. The affiliated outpatient clinics are secondary rheumatology clinics within hospital settings. Whether the RA patients from this patient-database represent patients with RA from the general Dutch population mainly depends on the presence or absence of referral bias. Bias related to referral strategies is present if unequal referral of subgroups of patients to secondary or tertiary health care centres (i.e. personal referral or GP-directed referral) leads to different findings in research.

Although current guidelines prescribe that patients with RA or with expected RA should be referred to a rheumatology clinic as soon as possible for early treatment with disease modifying anti-rheumatic drugs (DMARDs), it is unknown whether all eligible patients are referred. It may be expected that non-referred patients reflect mild cases of RA.

Sampling bias
For inclusion in this study, the selection criteria were a diagnosis of RA, an age of 16 years or older and at least one visit to the JBI or affiliated clinics in the two years previous to patient selection. Patients who fulfilled these criteria were randomly selected from the database within six disease duration groups. Because we used a random sampling procedure we assume that the selected patients reflect a representative sample of the patients in the database.
Response

Selective non-response of patients may have introduced bias at the study entry (refusal), at follow-up (lost to follow-up) or among participants who did not undergo clinical examination.

Refusal

Of the 1,200 invited patients, 14 patients could not be reached because of relocation to an unknown address, and 304 patients refused to participate in the RA+ study. The non-response study, that was performed among patients who refused to participate, showed that respondents were younger than non-respondents (i.e., on average 5 years), that respondents used more often health care services additional to rheumatology care, and that respondents more often reported to have pain. These results indicate that in our patient sample the eldest patients, patients who received rheumatology care only, and patients who never experienced pain might be underrepresented.

Lost to follow-up

In the first year of the study 882 patients participated. During the two-year follow-up, 30 patients were lost because of death and 11 patients because of relocation to an unknown address. Furthermore, 158 patients were lost during follow-up due to drop-out. Between respondents and drop-outs, no differences were found regarding age, gender or educational level, but these drop-outs were more likely to live alone, to report more pain, more disabilities, more depressive symptomatology, and a lower quality of life compared to respondents. These outcomes show that our findings of the follow-up years are based on a relatively healthy subgroup of RA patients.

Clinical examination

The clinical examinations at the JBI were, as far as possible, combined with appointments at the clinic. However, if patients were not under treatment at the JBI (anymore), they had to attend especially for our study. Some differences were observed between participants and non-participants of the clinical examinations. In 1997, non-participants to the clinical examination were significantly older and had worse disability than participants. In 1999, non-participants reported significantly worse disability, worse mental health, and lower quality of life than participants. Therefore, we can conclude that in the data of the clinical examinations healthier patients are overrepresented.
Data-collection based on self-report

The use of postal self administered questionnaires could have introduced bias caused by incorrect self-report. In questionnaire surveys, such incorrect self-report is mainly related to incorrect recall and to socially desired answering. Studies in this field have shown that patients regularly report health characteristics more positively, that patients usually underreport health care utilization, and that the underreporting is likely to increase as health care utilization increases. As our patients are high users of health care, we expect that underreporting of health care use may have occurred in this study.

Conclusion

In conclusion, we started our study with an underrepresentation of mild RA patients and the eldest patients, and we lost the most severe cases during follow-up. Note, these forms of bias might to some extent cancel each other out. In addition, both worse health problems and health care utilization might be underreported. These biases may have resulted in conservative estimates of health care needs and health care utilization in this study.
Implications for health care and further research

Health care utilization

We showed that patients with RA are high users of health care. In the years to come, an expansion of all types of health care services will be required to respond adequately to the health care needs of patients with RA, because it is expected that the RA prevalence will rise by 27% from 2000 to 2020 due to the growth and the ageing of the population.5

In addition, patients use a wide variety of health care services over a long period of time, varying from medical care, allied health care, and psychosocial care to home care. These findings stress the importance of continuity in health care and optimal communication both between the various health care providers, and between health care providers and RA patients. The use of electronic patient files may be of value in this respect.47-49

In this thesis, we have provided information on the diversity in health care use, but no information has been given on the frequency of this use. To predict future health care patterns more precisely, insight is needed into the frequency of the use of the various health care services.

Access to health care

Unequal access to health care was predominantly found for RA patients with low SES, older patients, and married or cohabiting patients. To strengthen equal access to health care, special attention should be given to the subgroups of patients who to date receive unequally less care from medical specialists (other than rheumatologists), allied health care and home care.

To enable health care professionals to refer patients to the appropriate health care services, multidisciplinary guidelines have to be developed and implemented for patients with RA. To assure that these guidelines are widely accepted, they should incorporate both the views of professionals and the views of patients.

Underuse of health care

We have shown that unmet health care demands of RA patients are relevant for identifying underuse of health care. If health care professionals will be more responsive to the health care demands of patients, the underuse of health care
services may be decreased. Especially demands for allied health care, home care and psychosocial care should be taken into consideration.

We studied underuse of health care by means of a single-item question. To gain more insight into patients' demands, a more elaborated instrument should be developed to gather more specific information on why and for what specific health problem patients report the demand.

We have provided information on the underuse of health care services from the perspective of patients. Identification of underuse should also incorporate the professional perspective. The perspective of professionals is usually reflected in guidelines. Deviation from optimal care as defined by guidelines may indicate suboptimal care. At this time no guidelines are available for the indication and referral to health care services, with the exception of referral criteria for patients with (suspected) RA from primary care to secondary or tertiary care. Therefore, other research techniques should be used to gain this information, for example focus groups among health care providers.

Our study showed that the use of health care services might increase considerably if the unmet health care demands of patients are taken into account. This increase is even higher than the increase as predicted by the epidemiological trend in the prevalence of RA.

Quality of health care

We showed that the quality of health care for patients with RA could be improved from the perspective of patients and we indicated on which aspects of care quality improvement may be most gainful. Special attention should be paid to the rheumatic expertise of health care providers, such as general practitioners, home nurses, home helps and allied health care providers and to the provision of information to patients regarding medication use, treatment strategies and home adaptations and aids.

Educational programs may be of value for the increase of arthritis-related expertise and for the improvement of information provision to patients. Many educational programs are available, but more efforts have to be undertaken to implement these programs in the Netherlands.

We provided information on the quality of health care from the perspective of patients. Previous studies have shown that patients and professionals disagree on the importance of aspects of care. It is therefore important to also investigate the quality of care from the viewpoint of health care professionals, and to study the extent of agreement between health care professionals and patients, to
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strengthen patient participation in daily clinical practice and to make sure that health care services are more responsive to the needs of patients.

Burden of informal care

Our study revealed that providing continuous informal care is burdening and that it has a large impact on the lives of partners. Informal caregiving not only induces negative experiences due to predominantly a disrupted schedule, but also leads to positive experiences, related to higher senses of self-esteem. Informal caregivers who experienced a positive impact of caregiving reported less caregiver burden.

It may be expected that the strain put on informal caregivers will increase significantly in the years to come due to the ageing of the population, the ensuing rise of chronic patients, the shift of health care to the ambulatory care settings, and the shortage of health care personnel. This strain will affect a large group: if we apply our findings to the general Dutch population, informal caregiving would concern almost 70,000 informal caregivers for RA patients. Further research should focus on gaining more insight into the impact of caregiver burden on the health and well-being of informal caregivers, and on developing support strategies which are especially focused on reducing the negative burden and simultaneously increasing the positive aspects of informal caregiving. More efforts are needed to strengthen the participation of informal caregivers in health care.