Care for patients with rheumatoid arthritis
Jacobi, C.E.

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Chapter 1

Introduction
This thesis describes a longitudinal study on health care among patients with rheumatoid arthritis (RA). The high impact of RA on physical and psychosocial functioning often leads to long-term dependency on a wide variety of health care services. We have studied several health care issues to gain better insight into RA health care. Patients with RA were studied over a five year period, using questionnaire surveys in 1997, 1998, 1999 and 2001 and clinical examinations in 1997 and 1999. This chapter serves as an introduction for this thesis and is structured as follows. First, the clinical and epidemiological aspects of RA are addressed. Second, the health care disciplines for RA are described. Third, the health care issues and the study objectives are discussed. And finally, the outline of this thesis is presented.

Rheumatoid arthritis

Rheumatoid arthritis (RA) is a common, chronic and severe rheumatic disorder that affects predominantly the joints of patients. It is a progressive disease, characterised by immune-driven chronic inflammation and a variable course involving exacerbations and remissions of disease activity. The progressive character of RA causes irreversible joint damage with consequences for physical, social and psychological functioning, resulting in minor to severe disability and sometimes premature death. The American College of Rheumatology (ACR) has specified seven classification criteria for the diagnosis of RA: morning stiffness, arthritis in at least three joint areas, arthritis in the hands, symmetric arthritis, the presence of rheumatoid nodules, the presence of the rheumatoid factor, and radiographic changes in the joints. Of these seven criteria at least four must be fulfilled for the diagnosis of RA.

The annual incidence of RA in the Netherlands is estimated at about 0.38 to 2.42 per 1000, with increased incidence at higher ages. Women are two to three times more affected than men. The prevalence of RA is estimated at 1.0‰ in the adult population of the Netherlands as well as in diverse other populations worldwide. To date, RA affects about 130,000 individuals in the Netherlands, and the absolute number of RA patients is expected to rise due to demographic aging and population growth. According to the Public Health Forecasts of the Netherlands the prevalence of RA is expected to rise by 27‰ from 2000 to 2020. In 2000, RA was registered as the primary cause of death in 1.17 per 1000 deaths.
RA causes pain and physical and psychological impairments. In many patients these impairments may result in disabilities, leading to restrictions in housekeeping, walking or in personal care. RA was found to be one of the largest causes of disability world-wide. Follow-up studies among RA patients have shown that the decrease in functional ability during the course of the disease varies widely between individuals. After ten to twenty years of follow-up about 20% of the patients had no or minor disabilities and could still perform all daily activities, the majority of the patients was moderately disabled, and about 10% of the patients suffered from severe disablement.

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 therefore treatment and care from several health care disciplines.

Health care for patients with RA

A wide variety of health care services is available for patients suffering from RA. Each of these services has specific goals and treatment strategies. These health care services encompass medical care, allied health care, psychosocial care, home care, and institutionalised care. In addition to professional health care services an important and substantial part of the needed care at home is provided by informal caregivers.

Medical care

Rheumatologists and general practitioners focus on diagnosing the disease followed by pharmacological therapy, guidance, support, and care co-ordination. The main goals of pharmacological therapy include a reduction of pain and inflammation, maintenance of functional ability, and slowing disease progression. Related specialists, such as orthopaedic surgeons, plastic surgeons and rehabilitation specialists, provide treatment strategies that are directed on improving or maintaining the functional abilities of patients.

Allied health care

Allied health care services include physiotherapists, occupational therapists and chiropodists. Physiotherapists focus on preservation of the muscle strength and the use of the joints. Occupational therapists aim to assure independent functioning of patients by teaching them to reduce the strain on the joints during
daily activities and by recommending assistive devices. Chiropodists aim to decrease changes in the position of the feet which cause pain or rigidity by providing aids or shoes that improve the foot function or foot position.

**Psychosocial care**

Psychosocial care is provided by social workers, psychologists and psychiatrists. Social workers can be consulted to help patients with tasks related to employment mediation, disability or benefit payments and financial grants. Psychologists and psychiatrists provide mental care to help the patient with problems in disease-related coping or depression.

**Home care**

Home care services are involved when disabilities bring about problems in self care activities or other activities in the home situation. Home nurses help predominantly with self-care activities, whereas home helpers predominantly attend to the household activities.

**Informal care**

Informal care is provided by family, friends, relatives and voluntary workers, but mostly by the partner. These caregivers provide a substantial part of the care in the home situation.

**Institutionalised care**

Institutionalised care comprises care in homes for the elderly and in nursing homes.

In this thesis, all these services are studied with the exception of institutionalised care, because of the small number of institutionalised patients in the study population.
Health care issues

This thesis aims to gain further insight into RA health care by investigating health care issues which cover important areas of the care as provided to patients with RA. The following aspects were taken into consideration in this investigation: 1) the treatment of RA patients involves a wide variety of medical and non-medical health care services with chronic and acute health problems alternating, and 2) professionals and patients have complementary knowledge because RA patients become experts of their disease. First, we studied the health care use of multiple disciplines. Second, we evaluated three issues that are important in chronic care: access to health care, underuse of health care and the quality of health care. And finally, we focused on informal caregiving, namely on informal caregiver burden among partners.

Information on the use of multiple health care services may serve as a basis for developing long-term health care programs. Information on the access to health care, on underuse of health care and on the quality of health care could be used to make health care more responsive to the personal needs of patients. Information on the impact of caregiving on the health and well-being of partners may be helpful for optimising care provision in the home situation.

Health care utilization

Previous studies revealed that patients with rheumatic diseases use a wide variety of health care services, and have a higher use of health care than patients with other chronic diseases. In these studies no information was given for RA specifically.

Studies directed to patients with RA focused predominantly on societal costs of the illness burden, on the effectiveness of multidisciplinary team care, and on the use of a single discipline, such as rheumatology care, occupational therapy, or home care. This thesis aimed to quantify the use of multiple health care disciplines in RA.

Access to health care

Equal access to health care is considered a key indicator of high quality care. Equity in access to health care is usually studied with the model of Andersen. According to this model access to health care depends on three types of factors: predisposing characteristics, enabling characteristics and need factors. Predisposing characteristics refer to demographic and social characteristics, such as age, gender and marital status. Enabling characteristics, such as educational
level, income, health insurance, and costs of health care services, reflect the ability to use health care. Need factors represent the most immediate cause for health care use, reflected by symptoms, diagnosis, and disability. The purpose of this model is to find evidence for equity or inequity in access to health care. Equity in access to health care is demonstrated when the use of care is primarily determined by need factors; this is an indication that patients receive the care they need. Inequity in access to health care is demonstrated when the use of care is merely explained by enabling characteristics or predisposing characteristics.

The health care insurance system of the Netherlands is designed to supply equal care for equal needs. However, this principle of equity in access to health care has not always shown to be self-evident in daily practice. Previous studies observed inequity in access to health care related to socio-economic status for home care among stroke patients, and for specialist care among individuals in the general population.

Equal access to health care is especially important in RA, because recently it is acknowledged that early and intensive treatment of RA is of utmost importance for better health outcomes in the long-term. Therefore we studied socio-economic inequalities in access to health care.

**Underuse of health care**

Underuse of health care refers to the discrepancy between health care needs of patients and the actual health care utilization. Underuse of health care can be studied from two perspectives: the professional perspective and the perspective of patients. The professional perspective is usually reflected in guidelines. The perspective of patients is related to personal views of patients, their health care expectations and experiences.

Studying underuse of health care for patients with RA according to the professional perspective is hampered, because the guidelines that have been developed for RA mainly focus on pharmacological therapy rather than on criteria for referral to multiple health care services. Several researchers have stressed the importance of assessing the patients' perspective in health care by stating that professionals are unable to recognize aspects of the disease that are important to patients. Moreover, insight into the perspective of patients is needed to adjust treatment and interventions to patient-centred care. Therefore, we studied underuse of health care from the perspective of patients.
Quality of health care

The importance of good health care quality has increasingly been recognized in health care organizations, resulting in quality assurance programs. Induced by the strong move towards patient-centred care the views of patients on the quality of health care are considered important components of quality assurance.

Quality of care has been the subject of studies for many years. For the assessment of quality of care, Donabedian distinguished three categories in health care: structure, process and outcome. Structure refers to the attributes of the settings in which health care occurs; process reflects what is actually done in giving and receiving care; and outcome denotes the effectiveness of care on the health status of patients and populations. The views of patients are usually defined as outcome indicator relating to both health care structure and health care process.

Patients' views on quality of care are usually investigated with patient satisfaction questionnaires. Patient satisfaction questionnaires have been criticized because these questionnaires mostly provide information on a general level of quality of care. To be able to use the information from patients for improving or sustaining quality of health care, more specific information on several aspects of health care is needed. Recently, an instrument has been developed to assess the quality of care from the perspective of patients: the QLOT-approach. With this questionnaire, the quality of care is assessed combining patients' views on the importance of care aspects and patients' views on the performance of health care professionals on the same aspects. By means of the QLOT-approach we studied the quality of health care for both medical and non-medical health care services.

Burden of informal care

Patients with RA have to adjust their lives to pain and discomfort and to changes in their capacity to perform formerly routine tasks. These adaptations affect not only the patient, but also close family members like the partner. The partner, in most cases, is the one to take over the tasks at home which the patient can no longer perform.

A number of studies have indicated that the occurrence of serious illness creates several adverse health outcomes for the partner, but also positive influences have been found. To gain further insight into the burden of caregiving, we assessed both the positive and the negative aspects of caregiving among partners of patients with RA.
Outline of this thesis

The aforementioned health care issues will be successively addressed in this thesis. In chapter 2, the study design and the research population of the RA+ study are presented. Chapter 3 describes the health care utilization among patients with RA for a wide variety of health care services. Chapter 4 deals with equity in access to health care, focusing on the impact of socioeconomic status on health care utilization in relation to health characteristics. Chapter 5 addresses the issue of underuse of health care. We analysed the discrepancies between health care utilization and health care demands of patients. Chapter 6 focuses on the quality of professional health care services from the perspective of patients. We quantified the importance of several aspects of care and the performance of health care professionals on these aspects. Chapter 7 describes the burden of caregiving among partners of patients with RA, focusing on both the positive and the negative impact of caregiving. Finally, in chapter 8, the main findings will be presented and discussed, and the generalisability of the findings and implications for health care and further research will be addressed.