1 Functional ability, social support and quality of life

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1.1 Introduction

1.1.1 Rheumatoid Arthritis

Rheumatoid Arthritis (RA) is a chronic-progressive disease of the auto-immune system. In western countries, about 1% of the population has RA; twice as many females as males are afflicted. The disease has an unpredictable course with no general pattern as well as an uncertain speed of deterioration (Brown et al. 1989, Pincus and Callahan 1989, Wright 1983, Zvaifler 1984). There is no cure for rheumatoid arthritis, and sooner or later all patients will be confronted with the physical consequences of the disease, and will become more or less disabled. Chronic diseases like RA will change life completely.

Inflammation of the joints is the main characteristic of RA, which leads to damage of the joints in a varying degree and progression. The disease is furthermore characterized by ‘flare-ups’ alternating with remissions. During this process and especially in times of flare-ups, the patients suffer from pain, stiffness, and lack of energy, while during remissions they seem to recover, although the affected joints never again reach the state from which the destruction started. As a result of the destruction of the joints, bodily functions are disturbed, which inevitably results in further impairment (i.e. physical incapacity of the body). In turn, impairment may lead to disability (i.e. the inability to use bodily functions in a normal way without restrictions). This process not only often implies a gradual deterioration of the body but, as a consequence, also the patient’s self-image and social relations. Hence, besides leading to physical restrictions, RA often has social consequences as well. As a result of their disease, sooner or later, patients with RA lose the ability to perform adequately the tasks and roles they used to perform, such as household activities, occupational tasks, or leisure activities. Patients with RA may find themselves in a disadvantaged position with respect to the availability of resources for the achievement of valued goals and interests. According to the disease-handicap model, on which the International Classification of Impairments, Diseases and Handicaps (ICIDH) is based, this is called a handicap (Meenan 1984, Verbrugge and Jette 1994).

As a result of their rheumatism and of its physical implications, patients are confronted with uncertainty, threat, and ambiguity, partly due to the unpredictable course of RA. As a consequence,
many psychological problems may occur in addition to the physical and social difficulties, like a decrease in self-esteem or in psychological well-being. It can therefore be concluded that RA is a chronic disorder that will affect the lives of patients in many respects: physically, socially and psychologically. Since the disease cannot be cured, and the prospects for chronically ill patients are rather poor, social sciences can help to find factors that counterbalance or break the negative spiral of the disease and its consequences. These factors are probably responsible for differences in the course of disease between patients of the same age who are completely comparable on the level of the disease characteristics; one patient is able to maintain performance of his activities of daily living and social roles, while the other patient is not able to maintain his independence in performing daily activities and needs the help of others. Apparently, disease characteristics are not a good predictor of outcome for either the level of physical restrictions or psychosocial consequences. For this reason, the EUropean Research on Incapacitating DIseases and Social Support (EURIDISS 1990) was started.

The goal of the EURIDISS-project is to understand the role of informal and formal care systems in managing chronic, incapacitating diseases and how both systems (formal and informal) affect the course of the chronic disease process. The study aims to explore and explain how people cope with an incapacitating disease and, in particular, the role formal and informal care systems play with regard to the physical and social functioning of the patient (EURIDISS 1990). To investigate the influences of the distinct care systems, the study was internationally designed. The influence of formal and informal care systems can be studied by means of an international comparison of the courses of disease in the various countries, and by comparing the effects of the formal and informal care systems upon the course of disease and management of a chronic disease such as RA. An important condition for international comparison is the availability of valid and reliable instruments especially suited for international comparison. Since such instruments either do not exist or have not yet been tested in an international context, another major aim of the EURIDISS-project was to develop and test instruments that could be used for international comparison.

A third major aim of the EURIDISS-project is to study the effect of intervening (mediating and moderating) variables on daily functioning. During the last decades, two major fields of intervening variables have received special attention. These are, on the one hand, personality characteristics such as self-esteem, locus of control, neuroticism and extraversion, and, on the other hand, the influence of social support. The study on the effect of personality characteristics (neuroticism and extraversion) on quality of life, using data of the EURIDISS-project, was carried out by Krol (1996). In the
present thesis, the direct and buffering effect of social support is one of the major issues.
In section 1.2, the conceptual model underlying the EURIDISS-project is presented, followed by a discussion of the concept of quality of life (section 1.3) and the concept of social support and its direct and buffering effect (section 1.4). The research questions are presented in section 1.5. In section 2, the design of the study and the international context of the EURIDISS-project is described.

1.1.2 The disease-handicap model
The Disease-Handicap Model (DHM; see figure 1), on which the ICIDH is based, was published in 1980 (WHO 1980). The original goal of the DHM was to provide a framework to organize information about the consequences of diseases, i.e. to clarify the consequences of the disease in terms of resulting impairments, disabilities and handicaps.

Figure 1 The disease-handicap model

The DHM is composed of four related but distinct concepts: disease, impairment, disability and handicap (Verbrugge and Jette 1994). Disease refers to the intrinsic pathology or disorder, while pathology refers to cellular and tissue changes, caused by disease, infection, congenital conditions or other agents. Pathology is often a reflection of the mobilization of the body’s defense against abnormalities. It is often possible to identify a disease by its particular manifestations, e.g. as a result of the destruction of normal cell architecture. Impairment is defined in the context of health experience as any loss or abnormality in psychological, physiological, or anatomical structure or function. Impairment includes losses caused by all forms of pathology. A specific impairment might have different etiologies and different types of pathology. All pathologies are accompanied by impairments. Impairments include anomalies, defects, or losses and relate to the specific functioning of an organ or organ system but not to the organism as a whole. Examples of impairments are absence or displacement of body parts, reduced blood flow, mechanical problems of joints, paralysis, stiffness, pain and numbness. Disability is the effect manifested in the performance capacity of the person as a whole, to perform activities which are considered normal for one’s age and gender group. Disability is defined in the context of health experience as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. All disability results from impairments, but not all impairments lead to disability. Furthermore,
two individuals having the same level of impairment of a certain bodily function do not necessarily have the same level of disability; one may be able to perform an activity such as walking upstairs, while the other cannot. Handicap is defined in the context of health experience as a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual. People with certain functional restrictions are not inherently disabled, that is, incapable of carrying out their personal, familial, and social responsibilities. It is the interaction of their physical or mental restrictions with social, psychological and environmental factors that determines whether they have a handicap. Disease, impairment, and disability depend on the physical constitution of the body, while handicap is more socially determined. Or, to put it differently, disease, impairment, and disability all involve different levels of organismic functions, while handicap refers to socio-cultural factors rather than to organismic functions. In this respect, disability is also related to a social-cultural component. To understand ‘handicap’ as it is defined here, one must also understand the concepts of roles and tasks, and how they relate to each other. In this respect, Pope and Tarlov (1991) refer to Parsons, who has stated that roles - such as being a teacher, researcher, parent, or civic leader - are organized according to how individuals participate in a social system. Tasks are specific physical and mental actions through which an individual interacts with the physical and social world and fulfils his or her roles. In the DHM, handicap refers to the disadvantage due to impairment or disability that limits or prevents fulfilment of a normal role for the person (Verbrugge and Jette 1994, WHO 1980).

The DHM is based on the perception that every complaint of some importance (caused by a disease) interferes with daily life, and therefore has social consequences. In this respect the model is too static. As such, the model is often incorrectly interpreted as ‘causal-deterministic’, while it should be perceived as a chronological model, in which disease may lead to impairment and disability and finally may result in a possible handicap and, secondly, in which also social, psychological and environmental factors should be used to explain differences in experienced disability and handicap. Such an elaboration of the DHM was undertaken by Pope and Tarlov (1991) and in particular by Verbrugge and Jette (1994). This elaboration was based on the basic framework of Nagi (1965), who already in the sixties developed a model that is very similar, but not identical, to the DHM of the WHO. It is concentrated on other variables in addition to those already mentioned in the DHM: social, psychological, environmental and other variables, in order to explore and to explain the pathway from disease to disability and handicap,
as well as to psychosocial well-being. Since so many variables influence the pace and direction of this pathway, Verbrugge and Jette speak of the disablement process. These additional variables that influence the pathway from disease to disability and handicap may vary between patients and thus be responsible for differences in outcome of the DHM, which can not (solely) be explained by differences in disease or impairment characteristics. Since disability is a central concept of this study, the question arises how to measure disability in such a way that it can be used as an explanatory factor in, for example, the DHM or disablement process, and can be used for international comparative studies.

1.1.3 Quality of life

As indicated before, as a result of a chronic condition, like RA, life will change considerably. Since the consequences of RA are much more far-reaching than only the physical aspects, a broad approach of the conceptualization and assessment of Quality of Life (QoL) in RA (and in other chronic illnesses) is often strongly advocated: one which includes not only the assessment and evaluation of aspects in the physical domain, but also of other life domains such as emotional functioning, role activities and social functioning, health perceptions and general satisfaction with life (Hermann 1992, Spilker 1990, Suurmeijer and Hermann 1992, Bergner 1989). A chronic illness may not only mean a (gradual) deterioration of the body but, as a consequence, also of someone’s self-concept and social relations (Charmaz 1983, Wiener 1975, Bury 1991). Basically, this pleads for a multi-dimensional approach to the consequences of chronic disorders. In her overview, De Haes (1988) gives four different dimensions on which the characteristics of QoL can be divided. These different dimensions are 1) objective versus subjective, 2) affective or cognitive, 3) positive or negative, and 4) global or multidimensional. The first refers to whom observes the situation as well as to the use of factual or perceived information. The second refers to the difference between emotional (being happy) and rational aspects (satisfied or not satisfied). The third aspect refers to the question whether or not positive and negative QoL can be conceived as two extremes of one underlying construct, or as two separate dimensions of the global concept. With respect to the last dimension of QoL, distinction is made between satisfaction with life as a whole and satisfaction with respect to a number of relevant domains. Furthermore, besides a more ‘global’ overall assessment of QoL, defined as ‘an individual’s overall satisfaction with life, and one’s general sense of personal well-being’; also more specific domains of QoL can be discerned (Spilker 1990, De Haes 1988).

The QoL construct and more particularly ‘health-related quality of life’ (HRQL), was introduced to assess and evaluate more
comprehensively the outcomes or effects of (chronic) illness and medical interventions. The World Health Organization Quality Of Life (WHOQOL 1995) group has defined QoL, as ‘the individuals’ perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns’. The patient’s perspective on QoL is central in this definition; it encompasses his or her personal assessment of his/her physical health status (e.g. physical functioning or disability) and of his/her psychological and social functioning (e.g. mood, companionship, recreational activities). The individual’s perceptions are at the core of this conceptualization of QoL and, it is consequently subjective or, more adequately phrased, subject-bound.

In line with other studies, three separate domains of QoL will be distinguished: a physical, a psychological and a social domain (Spilker 1990, Krol et al. 1994a, König-Zahn et al. 1993). These domains correspond with the main components of health in the WHO’s definition of health: physical health, mental health and social health. The physical component of QoL is related to the whole of physical functions of the human body. It refers to the physical functioning of the patient as a consequence of his illness and treatment. Patients with a chronic condition like RA are often confronted with the physical effects of the disease: pain, fatigue, joint destruction leading to restrictions in performing activities and threatening one’s independence (Riemsma et al. 1998a, Krol 1993). The psychological component of QoL refers to an individual’s mood in a global sense, as a result of an emotional evaluation of a specific situation. In this respect, uncertainty is a major threat to mental health. Patients with a chronic condition are confronted with uncertainty about the future course of the disease and its consequences for daily life (Dildy 1996). For patients with RA, the uncertainty pertains to: ‘1) whether there will be any pain, swelling or stiffness; 2) the area of involvement; 3) the intensity of the disability; 4) whether onset will be gradual or sudden; 5) how long it will last; and 6) how frequently flare-ups will occur’ (Wiener 1975). As a result, a decrease in self-esteem, a decline in psychological well-being, or the occurrence of depressive symptoms are commonly reported in patients with RA (Brown et al. 1989, König-Zahn et al. 1993, Anderson et al. 1985, Wolfe and Hawley 1993, Eberhardt et al. 1993, Revenson et al. 1991, Hurwicz and Berkanovic 1993, McEvoy DeVellis 1993). Some studies reported depression in more than 40% of the patients involved (Frank et al. 1988, Rimón and Laakso 1984). The social component of QoL refers to the way a person is anchored to society. Two important elements of the social component are: social participation and role activities. Social participation is an important aspect of (daily) life. Being meaningful to someone is only
possible as a result of a social relationship, while social relationships, on the other hand, are an important source of social support. Physical restrictions, fatigue and pain caused by a chronic condition may disturb these important social relationships, which could lead to the loss of sources of social support. Every human being performs many social role activities in life, for example age roles, family roles, or occupational roles (Allen and Van de Vliert 1984). The impact of a chronic disease on the performance of social roles depends on both the type and flexibility of that role and may vary from no influence at all to major role changes, or even loss of a certain role. Occupational roles fulfil an important function in daily life and are associated with social position, income and social status, while colleagues at work are part of someone’s social network of and thus relevant for the provision of social support. Several studies have demonstrated the consequences of RA for the performance of the occupational role; after a mean disease duration of about ten years, 50-60% of the patients had stopped working (Meenan et al. 1981, Pincus et al. 1984, Yelin et al. 1987, Callahan et al. 1992, Doeglas et al. 1995b). Recently, Jaarsveld et al. (1998) found similar percentages among patients with a recent onset (≤ 3 years) of RA. As a result, one is confronted with great losses in earning power, with psychological distress and changes in one’s identity (Charmaz 1983, Rimón and Laakso 1984, Allen and Van de Vliert 1984, Eerdekeens 1989, Mitchell et al. 1988). The QoL model assumes that the variables measuring more specific aspects of QoL (at a ‘lower’ level) more or less determine those at a more general or overall level and ultimately determine, as a general evaluation, the overall assessment of quality of life. Also it is assumed that the different aspects of the QoL concept are interrelated. This means, for example, that the physical restrictions caused by the chronic disease possibly play an important part in the decline of the psychological as well as the social component of QoL. Integrating the disablement process model as presented in figure 1 and the hierarchical QoL model of Spilker provides us with the following figure (figure 2).
From figure 2, it follows that the different components of the DHM can be recognized in the components of the QoL model. Furthermore, in figure 2 it is assumed that each component in the DHM may affect, or is an indicator of, someone’s QoL as defined by Spilker (1990) and the WHOQOL group (1995). Partly, this is comparable to Ebrahim’s umbrella view (1995) on the relationships between the two models. If one component of the QoL concept is affected it will have direct consequences for the other components. Deterioration in function or the occurrence of disability, as is the case in many patients with RA, must be viewed in the context of how QoL is affected. Figure 2 also implies that from a social science point of view, i.e. when one is primarily interested in the interrelations between the various aspects of QoL, the QoL concept should be analyzed at its basic level and the components should be hypothetically related to each other (Rogerson 1995, Suurmeijer et al. 1998). In a social science model of chronic disorder, it is assumed that physical illness, particularly chronic disorders, can be considered one of the main causes of a net loss of (access to) valued resources and consequently of the achievement of valued objectives. The loss to the individual involves, for example, loss of independence, social mobility, companionship, capacity to work etcetera (Devins et al. 1993, Hobfoll and Stephens 1990). Several of these phenomena have been observed in patients with RA. Therefore, besides examining the effect of the physical context on the social aspects as well as on the psychological aspects of QoL, also the effect of the social context on the relationship between the physical aspects and the psychological aspects of QoL is examined in this study. The availability of a supportive social network helps people to cope with difficult situations and both directly and indirectly affects health and well-being (De Haes 1988, Cohen and Hoberman 1983, Funch and Mettlin 1982, Revenson et al. 1983, Kessler et al. 1985, Sarason et al. 1985, Wortman and Conway 1985, Thoits 1982, 1986, 1995). In this study, the emphasis is on the direct effect of social support and on the buffering effect of social support on QoL. In the next paragraph, these two functions of social support are outlined.

1.1.4 Social support

It is assumed that social support has a beneficial effect on well-being through two mechanisms (Hurwicz and Berkano 1993, McEvoy DeVellis 1993, Thoits 1982, 1986, 1995, Vaux 1988, Cohen and Syme 1985, Sarason et al. 1990). First, social support has a direct (or main) effect on the well-being of individuals. People who meet warmth and affection in their relations with others, who are helped in case of need, and who have social companionship once in a while, are better off than people who are not supported in any of these ways. On the other hand social support has a stress-reducing or buffering effect. The traditional buffering hypothesis states that the impact of stress
on mental health is stronger under conditions of low support than of high support (Kessler and McLeod 1985). This indirect effect implies that people who receive support in stressful situations will have a greater sense of security, an increased feeling of self-esteem and less psychological distress, than persons who lack support in stressful situations.

Generally, the dimensions of social support are classified into social-emotional support (love and affection) and instrumental support (helping hands). Another frequently used distinction is made by distinguishing daily emotional support from problem-oriented emotional support and daily instrumental support from problem-oriented instrumental support. Social-emotional support can further be divided into emotional support and social companionship (social activities with other people). Different types of social support will be beneficial for different types of needs and, therefore, will have different places in the social support process.

Also from this discussion the question arises how to measure social support in such a way that it can be used in international comparative studies or as an explaining factor in, for example, the stress-buffering model. Although the theoretical effects of social support are generally accepted and its dimensions largely agreed upon, less consensus exists about which aspect of social support exactly should be provided or measured in research. Some transactions are intended to be supportive, but it is up to the receptor of support to evaluate the worth of the actual transactions. In this respect, some studies have indicated that perceptions of social support were related to health-outcome (Sarason et al. 1990, Procidano and Heller 1983, Schwarzer and Leppin 1991, Sherbourne and Sterwart 1991, Van Sonderen 1990, Helgeson 1993). Perceptions of social support can be conceived as expectations about ones social support resources in case of need, and must be distinguished from actual supportive transactions and from support satisfaction. So far, however the separate effects of actual supportive transactions and support satisfaction have not been well elaborated although they seem to be at least as relevant as the perception of being supported. At least one study has indicated that perceptions of support, supportive transactions, and satisfaction are only weakly related to each other (Van Sonderen 1991).

In this study, the focus is on actual social supportive ‘transactions’ and on ‘satisfaction with the supportive transactions provided’. Perceptions of social support are left out of consideration. Furthermore, social support is conceived as part of the social component of the quality of life concept. The following five dimensions of social support will be distinguished: daily emotional support, problem-oriented emotional support, social companionship, daily instrumental support and problem-oriented instrumental
support. As part of this study, both the direct and buffering effect of each of the five dimensions of social support will be examined.

1.1.5 Research questions
In early RA, the variance in disease characteristics, as measured with the Ritchie Articular Index (RAI), is large, but only weakly related to health-outcome measures (Zeben et al. 1993, Young 1995). Therefore, these characteristics are not a good predictor for outcome in terms of either functional ability (disability) or QoL (Krol et al. 1994a, 1998), it was decided to concentrate in this study less on the disease characteristics (disease and impairment) and more on disability. In this thesis, the physical component of QoL, e.g. disability, has become the central concept and its effect is studied on both psychological and social components of QoL (see figure 3).

Figure 3 The effect of the physical component of quality of life on both the psychological and social components of quality of life

Figure 3 comprises the relationship between the physical component of QoL and both the psychological and social component of QoL. The physical component of QoL is operationalized as functional ability or disability in terms of the DHM. In this study, functional ability is measured by means of the Groningen Activity Restriction Scale (GARS). In most analysis, the level of depressive feelings is used as an indicator for the psychological component of QoL. Depressive feelings are measured by means of the severe depression subscale of the General Health Questionnaire 28 items version (GHQ-28). In chapter 6 also the other three subscales of the GHQ-28 are used: somatic symptoms, anxiety and insomnia and social dysfunctioning. To study the effect of the physical component of QoL on the social component of QoL, we investigated to what extent patients with early RA have met work disability as a result of their rheumatism. Colleagues may form an important part of someone’s social network. When social relationships diminish as a result of work disability, an important source for social support is threatened. Furthermore, as another indicator of the social component of QoL, a twofold social support instrument was used, measuring supportive interactions; the
Social Support Questionnaire for Transactions (SSQT) as well as the satisfaction with the support provided; the Social Support Questionnaire for Satisfaction with the provided supportive transactions (SSQS). Also the effect of functional ability on social support was studied.

Finally, the effect is studied of the social component of QoL, i.e. social support, on the relationship between the physical component (disability) and the psychological component of QoL (depressive feelings) is studied (see figure 4). This effect is known as the buffering effect of social support. Besides the buffering effect of social support, also the direct effect of social support on depressive feelings is studied. To test these effects, both cross-sectional and longitudinal data were used.

**Figure 4** The effect of the social component of quality of life on the relationship between the physical and psychological component of quality of life

Before the relationships between the several components of the QoL concept were studied, first some psychometric studies were performed in order to test the (psychometric) qualities of instruments that we intended to use in our study. In this thesis, three instruments are central in the described models: the GARS, the SSQT together with the SSQS, and the GHQ-28. The psychometric properties of the GHQ-28 and the SSQT have already been described elsewhere (Krol et al. 1994b, Suurmeijer et al. 1995). In this thesis, a psychometric study of the GARS and the SSQS is included.

Based on the preceding discussion, three research questions have been formulated. The first research question is twofold:

1a What are the psychometric properties of the GARS as a measure for disability?
1b What are the psychometric properties of the SSQS as a measure for the satisfaction with the social support provided?
The second research question is also twofold:

2a What is the impact of the physical component of quality of life (disability) on the psychological component of quality of life (depressive feelings)?
2b What is the impact of the physical component of quality of life (disability) on the social component of quality of life (work disability)?

Finally, the third research question reads as follows:

3 What are the direct and buffering effects of the social component of quality of life (social support) on the relationship between the physical (functional ability) and the psychological component (depressive feelings) of quality of life?

1.2 Design of the study

1.2.1 International context of the study

By the end of 1990, the EURIDISS-project -which stands for the European Research on Incapacitating Diseases and Social Support- was started, in which the following countries were involved: Belgium, France, Germany, Northern-Ireland, Norway, Slovakia and Sweden. By means of identical studies in these countries, a large international database could be set up. In first instance the EURIDISS-project was focused on patients with RA with the option to involve other chronic diseases as well. The Dutch part of EURIDISS, called ‘Social Support and Chronic Disease - Rheumatoid Arthritis (SSCD-RA)’, was started in the Netherlands with a pilot-study in 1989. Next, in november 1990, the main study was started. This study had a longitudinal design, consisting four waves of data collection with a one-year interval after each wave. The fourth wave was finished in the summer of 1995. This thesis is partly based on only Dutch data (SSCZ-RA project) and partly on data of other European countries (EURIDISS data). These latter data were used to test the psychometric properties of the GARS and the SSQS.

1.2.2 Patient selection

In order to sample comparable groups of patients in the Netherlands and the participating European countries, a number of inclusion and exclusion criteria were formulated. Firstly, only those patients were included that fulfilled four out of seven ARA criteria, formulated and revised by the American Rheumatism Association in 1987 (Arnet et al. 1988). These ARA criteria are: 1) morning stiffness in and around the joints lasting for at least one hour before maximum improvement
and present for at least six weeks; 2) swelling of three or more joint areas simultaneously for at least six weeks; 3) swelling of the wrist, metacarpophalangeal or proximal interphalangeal joint for at least six weeks; 4) symmetric joint swelling; 5) rheumatic noduli; 6) serum rheumatoid factor detected by a method positive in less than 5% of the normal population; and 7) RA-typical changes in hand roentgenogram, including erosions or unequivocal bony decalcification.

To optimize the comparability of patient groups in the various countries, the patients had also to fit additional inclusion criteria. These inclusion criteria were: 1) both sexes; 2) 20 to 70 years old at the onset of the study; 3) interval between inclusion in the cohort and time of RA diagnosis less than or equal to four years; 4) patient’s willingness to sign a form of informed consent.

Furthermore, another five criteria were formulated to exclude a number of patients from the sample. The exclusion criteria were: 1) existence of another physical disorder prior to the onset of RA; 2) association with any other severe disease which might affect the autonomy of the patient; 3) malignant RA with systemic vasculitis; 4) very disabling RA (stage IV according to Steinbrocker functional classes, 1949); and 5) any identified reason for being unavailable for follow-up.

Before the main study started (in 1990), two pilot studies were conducted, one in the Netherlands (see 2.1) and one in France, in order to test the instruments and the research protocol. For the Dutch pilot study, 65 RA patients were randomly selected from the files of the Department of Rheumatology of the University Hospital Groningen (the Netherlands), according to the described sampling procedures. For various reasons, eleven of these 65 patients refused to participate or were excluded for not fulfilling the ARA criteria. The other patients fulfilled at least 4 out of 7 ARA criteria and all had a disease duration of more than 4 years. Accordingly, the sample used in the pilot study consisted of 54 patients: 35 women (65%), and 19 men. The mean disease duration of this group was 8.2 years, while the mean age of the patients with RA was 53 years.

After the pilot study, the main study started in the Netherlands in 1990. The patient files of five hospitals were screened by the research team. These five hospitals were the Groningen University Hospital (AZG), the Martini Hospital in Groningen, the Wilhelmina Hospital in Assen, the Refaja Hospital in Stadskanaal, and the Scheper Hospital in Emmen. The rheumatologists examined the year of RA onset, the presence of sufficient ARA criteria, and whether or not the patients fulfilled the medical inclusion and exclusion criteria. After this selection, a sample of 331 patients remained for inclusion in the research project. Only 39 of these 331 patients (11.8%) did not respond to the initial request to participate in the study, for which no

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As a result, the first wave of data collection (T1) started with 292 respondents. Due to various reasons, there was an additional loss in follow-up of 12 (4.1%) patients between T1 and T2, leaving 280 patients in the sample. Between T2 and T3, another 6 (2.1%) patients were lost due to follow-up, which left a sample of 274 patients. In total, 268 patients completed all four waves of data collection (91.7% of the original T1 sample). The mean non-response per year was 2.7%.

To test the psychometric properties of the GARS across countries, data of 116 patients from France, 124 patients from Norway, 98 patients from Sweden, and 292 patients from the Netherlands were used. To test the psychometric properties of the SSQS (and the SSQT), the same samples were used except for the sample of Norway, which was extended to 238 patients. To test the sensitivity to change of the GARS and the Health Assessment Questionnaire (HAQ), longitudinal data were used of 104 French patients, 190 Norwegian patients, and 271 Dutch patients. Owing to a lack of Swedish longitudinal data, these patients were omitted from this latter analysis on the GARS.

1.3 Outline of this thesis

Three chapters of this thesis are devoted to the development of two measuring instruments; two are on the development of an instrument measuring disability, and another on the measurement of social support. By means of psychometric analysis, an attempt was made to obtain reliable and valid instruments. Within the framework of the EURIDISS-project, both instruments were tested for their appropriateness in international comparative studies.

Chapters two and three both focus on the measurement of disability. Chapter 2 is devoted to the GARS, a generic instrument for the measurement of functional restrictions. It was developed to measure activities of daily living (ADL) as well as instrumental activities of daily living (IADL). The psychometric properties (the unidimensionality and hierarchical order of the scale items) of the GARS were tested and the scale construct validity was explored in an European sample with data from France, Norway, Sweden and the Netherlands. This chapter has been published in the American Journal of Public Health (1994). In chapter three, the psychometric properties of the GARS were compared with those of the HAQ, a disease-specific instrument for the measurement of functional status in RA. In this study, both cultural and longitudinal differences between the two instruments were examined in a sample with data from France, Norway, and the Netherlands. Chapter three has been published in The Journal of Rheumatology (1995).

The first aim of chapter four is to examine the structure and psychometric properties of the SSQS, which was developed parallel
to the SSQT. The second aim was to explore whether it is preferable to use the SSQT and/or the SSQS separately and/or simultaneously. Also in this study data from France, Norway, Sweden and the Netherlands were used. This chapter was published in Social Science and Medicine (1996).

In chapter five, the impact of early RA on work status was assessed. To this end, the employment status of 119 Dutch patients who had jobs before the onset of RA was examined. Secondly, the patients with work disability were compared to those without, on several disease characteristics, therapeutic regimen, and educational level and age. This article has been published in the Annals of the Rheumatic Diseases in 1995.

Chapter six was based on the data of the pilot study of the SSCD project (performed in the Netherlands in 1989) and is the first study to explore the direct and buffering effects of social support on psychological well-being. The buffering effect was studied by computing stress by support interaction terms, and subsequently testing the significance of these interaction terms by means of a regression analysis on depressive feelings. This part of the study was published in Arthritis Care and Research (1994).

Also chapter seven (which is submitted for publication) is about the relationship between functional ability, depressive feelings and social support. In this chapter, longitudinal data from the Dutch part of the EURIDISS-project were used to assess the buffering effect of social support on depressive feelings at T4. Furthermore, in this chapter the level of depressive feelings was related to changes in functional ability and social support.

Finally, in chapter eight, the results of this thesis will be reviewed and discussed.

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1 In literature on the consequences of (chronic) diseases, many different terms are used for what was defined in the DHM as disability. In this thesis the following terms are used as equivalents: functional capacity, functional ability, functional status, physical limitations, physical restrictions, physical functioning, disability and social disability. In this study, the term ‘disability’ (or its counterpart in terms of ‘functional ability’) is preferred.