

**RHEUMATOID ARTHRITIS, SOCIAL  
NETWORKS**

**AND SOCIAL SUPPORT**

**A CROSS-SECTIONAL SURVEY OF FEMALE  
PATIENTS WITH RHEUMATOID ARTHRITIS**

**AND**

**A CONTROLLED TRIAL OF  
A SOCIAL NETWORK INTERVENTION**

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## List of papers

- 1 Social network size of female patients with rheumatoid arthritis compared to healthy controls. *Scandinavian Journal of Rheumatology*, 29, 2000: 38–43.
  
- 2 Social support in female patients with rheumatoid arthritis compared to healthy controls. *Psychology, health and medicine*, 6(4), 2001: 429–439.
  
- 3 The impact of disability and disease duration on social support of women with rheumatoid arthritis. *Journal of Behavioral Medicine*, 25(3), 2002: 251–268.
  
- 4 The effect of social network intervention for women with rheumatoid arthritis. *Family Process*, 42(1), 2003: 71–89.

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With enthusiasm social network intervention was practised in all these institutions – somatic and psychiatric hospitals and special institutions. But obviously not everybody felt quite comfortable with this new adjuvant therapy to chosen groups of chronic patients. Summing up the project after two years work at Diakonhjemmet Hospital I talked to the medical director of medicine. He maintained that because the project had not included control groups the results did not represent a general value for the involved groups of chronic patients in the hospital. I would like to thank him for this response, although disappointing at the time, as it presented the challenge to start the work presented in this thesis.

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# 1. INTRODUCTION

## BACKGROUND

Social networks have been described extensively as a very basic factor in our lives. We know their importance for health, longevity and quality of life (Cohen & Wills, 1985; Berkman, Glass, Brissette, & Seeman, 2000), which is even more necessary for patients with chronic disease (Sorensen, 1994; Goodenow, Reisine, & Grady, 1990; Cohen & Wills, 1985; Fyrand, Wichstrom, Moum, Glennas, & Kvien, 1997). However, chronic disease is often associated with a decrease in both quantity (network size) and quality (social support) of social networks (Wortman & Conway, 1985). This process of network deterioration contributes to a more demanding life situation for people with chronic diseases, owing to diminished resources for coping with disease-related challenges (Schulz & Rau, 1985; Wortman & Conway, 1985). Schultz and Rau (1985) have coined the term “double jeopardy” to describe the chronic patient’s “situation where the joint effects of two variables doubly disadvantages one in terms of access to societal rewards”. “Social disability” is another term describing possible negative social consequences of having a chronic disease (Doeglas, Suurmeijer, Krol, Sanderman, van Rijswijk, & van Leeuwen, 1994).

### **Chronic disease—a challenge**

The phrase “when one in a family suffers, all suffer” is a saying based on people’s experience during their lifetime. It implies that when one in a family contracts a chronic disease, this will influence not only that individual’s different life arenas and functions, but also the other family members’ daily life (Revenson, 1993). Kleinman (1988) differentiates between the concepts of *disease* and *illness*. While disease is the problem defined from the biomedical and professional perspective, illness refers to “... how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability (p.3)”. The chronically ill patient experiences both the disease and the illness, and the rest of the family lives with the illness. Engel, in his article published in *Science*

in 1977 (Engel, 1977), proposes an alternative to the “single-effect model” of disease: the biopsychosocial model, which implies that emotional, behavioural, and social processes are implicated in the development, course, and outcome of most illnesses.

The term chronic illness seems to be commonly defined as “...a condition that interferes with daily functioning for more than three months in a year, causes hospitalization for 30 days or more per year, or (at the time of diagnosis) is likely to do either of these (p.4) “(Jennings, Callahan, & Caplan, 1988). Thus, the term chronic illness includes a very broad spectrum of diseases with regard to symptoms, causes and how they affect a person’s life (Christianson, Taylor, & Knutson, 1998). Conrad (1987) separates chronic illnesses into three groups: “lived-with illnesses”, “mortal illnesses”, and “at-risk illnesses”. Lived-with illnesses are usually not life threatening, but challenge the individual to adapt to, and live with, this particular type of disease in their daily life (e.g., arthritis, diabetes, asthma, epilepsy).

By definition, *chronic disease* represents the clinical challenge that medicine is not able to achieve a successful and happy ending. That does not imply that there is a lack of effort, or that medicine is without significant and very valuable steps forward. The pain and threat of the illness means that in many cases, medicine’s most imposing result is to avoid death—or to prolong life. The whole catalogue of ingenious interventions is implemented—for different kinds of outcome, which are more or less critical for the patient’s basic disease pattern. But as long as we are concerned with patients with a chronic disease, the interventions we know so far cannot solve the challenges of the disease and therefore the patient is left with many of the problems of her/his illness.

The health care system is, generally speaking, not ready to assume responsibility for this part of the patient’s problems. The health care system has not successfully developed interventions to meet this “residue”, left after the continuous fighting with the available biological interventions. Many efforts have been made in order to develop interventions that are trying to complement the extensive and vital efforts provided by biological interventions, so as to address

some of the illness consequences of the disease. Support groups and educational groups are among the interventions that have proved successful in helping patients address some of the challenges they often are left to confront alone. The need for flexibility from the health care system towards the chronic patient's different needs caused by an unpredictable disease, may especially challenge the structure of the health service system using other and new methods to understand more fully the patient and her family's daily challenges (Holman, 1994; Holman & Lorig, 1997).

### **The “Social Network Intervention Programme”—a pilot study**

From 1987 to 1989, Diakonhjemmet College, School of Social Work, developed a qualitative action-research programme called “Social Network Intervention Programme” for 32 professionals.<sup>1</sup> The aims were (1) education in social network interventions for these professionals, and (2) to trial and further develop these interventions in their particular field. Important experiences from this two-year project were (1) that individuals and families with severe problems (e.g., social problems, behavioural problems, psychiatric problems or chronic somatic problems—e.g., *patients with rheumatoid arthritis*), most often experienced a deterioration of their social network and a decreased amount of social support, and (2) furthermore, that social network intervention seemed to have a problem-solving role as well as the potential to change a dysfunctional network to a functional one, both in a crisis situation and/or to prevent an increase of dysfunctional coping for patients/clients living with different kinds of chronic problems.

### **Hypotheses of the thesis**

The focus of previous research has mainly been the health-related effects of social networks and social support. Few studies have investigated this topic from the

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<sup>1</sup> Seven institutions within the primary and specialist health and social services in Oslo, Akershus and Østfold Counties (Including a Psychiatric Clinic, Treatment Center for youths with psychiatric problems, Follow up Treatment Center for psychiatric patients, Somatic Hospital, Social Security

converse perspective: the impact of a chronic disease on social networks and social support. Therefore, in the present study, we decided to examine the social networks and social support of patients with a chronic disease. We formulated two main hypotheses. *First*, chronic disease may have weakening consequences for chronic patients' social network, social support and social activity. *Second*, social network intervention may (1) re-establish relationships and (2) improve functional coping with the chronic illness.

### **Social network and social support, and relevant concepts in exchange theory**

Social relationships have basically been assessed from two perspectives: structural (e.g., social network and social integration) and functional (e.g., social support) (Bolger & Eckenrode, 1991). While *social integration* is usually referred to as the existence and quantity of relationships, marital status and activity in social arenas and organizations, the structures existing among a set of relationships is referred to as *social network* (e.g., size, density, homogeneity or range). *Social support* most commonly implies the functional content in relationships (i.e., emotional, instrumental) (House & Kahn, 1985; House, Landis, & Umberson, 1988).

#### *Social network*

The term social network has been transformed from a metaphor (Barnes, 1954) to an analytical concept and characteristics (i.e., anchorage, size, density, range, content, directedness) (Mitchell, 1969; Boissevain, 1978). Social network may be defined as "... informal social relationships between people who interact more or less regularly with each other" (Finset, 1986).

Two leading perspectives in social network research can be distinguished. (1) The *ego-centred network*, where the focus is on the anchorage of an individual and the social processes on a micro level (also called personal network analysis), and (2) the *socio-centred network*, where the focus is directed towards a group of

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office, Treatment Center for youths with behavioral problems and a Senior Service Center). (The project is described in Fyrand, 1993; Fyrand, 1994.)

individuals and the social processes on different kinds of macro levels (also called partial or total network analysis) (Krol, Sanderman, & Suurmeijer, 1993).

Furthermore, the network analyses may focus on different *zones*, in which the individual may have a direct or an indirect relational contact. While an ego's direct relationships are in her/his *first-order zone (or primary zone)*, indirect contacts exist via the primary relations in the first-order zone to the next zone, named the *second-order zone*, and so forth (Barnes, 1969).

The different relationships in a person's social network may be seen as exchange channels for different kinds of resources between actors (Hall & Wellman, 1985). These actors may be identified by the *role-relation approach/method* (Van Sonderen, 1990), referring to members importance as potential sources of support owing to their specific role relation towards the respondent, such as for example partner, siblings, children, other family members, friends and acquaintances, neighbours, colleagues, etc. (Krol et al., 1993; Van Sonderen, 1990).

Thus, our study is based on *the ego-centred or personal network approach in the first-order zone (or primary zone)*, owing to the fact that the participants in our study were individual chronic patients with personal social networks. We included the *role-relation approach* (the patients were asked to mention persons most regularly seen and those who were most important to them, categorized into groups such as siblings, partner, children, friends, etc.), to identify how different subsets contribute to the amount of social support provided. In this personal network approach we focused only on *network size*, one of the important characteristic in a person's network, to identify possible resources for the exchange of social support between the network members and the patient. In addition to this, we had data on the network members' gender, age, marital and occupational status, travelling distance to the patient and frequency of two types of contact (telephone/letter and face-to-face), which might have given us further information on the patient's social network. Owing to the complexity of the present study, we decided to use this data in a later study only.

### *Social support*

Social support may be defined as resources provided by other persons (social network) in a reciprocal process according to the social-exchange (or equity) theory (Stewart, 1989). Thus, the different relationships in a person's social network may be seen as exchange channels for different kinds of resources between actors (Wellman & Wortley, 1990).

Social support has developed from a unitary to a multi-component construct (Sarason, Sarason, & Pierce, 1990). Social support research is now most frequently focused on different sources and types of support, owing to the fact that different types of support will most likely have different effects and impact in a person's life as the nature of the problem requiring support varies (House & Kahn, 1985). Both the need and provision of social support is for the greatest part determined by the situation in which the individual is involved. According to Stewart (1989), social support may be defined as resources provided by other persons (social network) in a reciprocal process according to social-exchange theory.

Suurmeijer, Doeglas, Briancon, Krijnen, Krol, Sanderman, Moum, Bjelle, and van den Heuvel (1995) distinguish between two main support types: (1) a social-emotional type (emotional and social companionship), and (2) an instrumental type (e.g., advice, practical help or financial help). While emotional and instrumental support often is provided in problem-based situations, social companionship represents social interaction for mutual enjoyment (Rook, 1987). Krol et al. (1993) emphasize the difference between daily and problem-oriented social support: While the daily support is provided by routine social interaction that is not considered as support until the individual is separated from her network, problem-oriented support is required when the individual needs to cope with a stressful situation.

The terms *received* and *perceived* support distinguish between the actual transference of advice, aid and affect through interpersonal networks (received support), and the perception of a hypothetical resource availability (perceived support) (Wethington & Kessler, 1986; Schwarzer, & Leppin, 1991). While

perceived support may be most important for a person's well-being and life quality in an everyday life, where people usually manage their challenges alone, activation of support (received support) is important in a problematic situation when support has to be mobilized (Schwarzer & Leppin, 1991). According to Sarason et al. (1990), a study of both types of support concludes that the two measures are distinct and clearly different from each other, which is confirmed by Schwarzer and Leppin (1991). Social relationships may also cause distress owing to disease-related challenges such as physical demands, emotional strain and a general feeling of uncertainty caused by altered roles and lifestyles, influencing in particular the closest relationships (Ell, 1996).

Social support can be obtained from both formal (i.e., doctor) and informal (i.e., friend) sources, which refers to both the provider of the support and the situation in which the two actors are involved (Krol et al., 1993).

We see a person's social network as exchange channels of social support interactions for resources exchanged between the person herself and her different network members, with the desire to uphold a balance (reciprocity) and equity in these exchanges (Stewart, 1989), preventing indebtedness of her significant others. Our study measured the amount of *daily and problem-oriented socio-emotional (emotional and social companionship) and instrumental support received*. We did not measure *perceived* support, or analyse our data regarding satisfaction with the amount of social support received.

#### *Relevant concepts in social exchange theory*

Because we have chosen to view relationships and social interaction in a person's social network as exchange channels for social support interactions exchanged between the person herself and her network members (Van Sonderen, 1990), *social exchange theory* was chosen as a framework. The theories of reciprocity, equity, dependence / indebtedness theory and social comparison are all components of social exchange theory, important to the understanding of human interaction and relationships (Miller, 1995). Empirical evidence shows that it is important to uphold a balance (*reciprocity*) or *equity* in these exchanges, to

prevent mental distress and withdrawal from inequitable relationships (Dunbar, Ford, & Hunt, 1998). Higher inequity scores in social relationships were found in a study comparing a disabled and a healthy sample, showing that a higher score was a consequence of the disabled sample “over-benefiting” from their social network (Dunbar, Ford, & Hunt, 1998). *Indebtedness/dependence* of the supportive others, due to an over-benefiting in relationships and caused by a progressing chronic illness, may determine the development of withdrawal between the patient and her significant others (DePaulo, 1982).

We have also included *social comparison theory* as a complementary theory to understand our results. Upward comparison from a chronic patient towards her healthy network members regarding their health status may threaten the patient’s self-esteem, thereby causing a reduced quality of life. Thus, withdrawal from interactions and relationships characterized by this kind of comparison may be seen as a self-protective strategy (Major, Testa, & Bylsma, 1991).

Retrospectively, we acknowledge that it would have been useful to investigate the patients’ perceived degree of reciprocity/equality and indebtedness in their social relationships, because this could have given us empirical evidence to confirm or reject the above hypothesis. Unfortunately, we were not sufficiently aware of the importance of this when we designed the study, thereby missing the opportunity to investigate this phenomenon empirically. Future research should include this perspective.

### **Social network intervention—a selected summary**

Social network intervention is seen as a model based on a traditional clinical psychotherapeutic model and a social systems model (Garrison & Howe, 1976). The interest in social systems represents steps in the evolution of intervention models beginning with dyadic psychotherapy, progressing through group and family approaches, to the clinical use of social networks (Pattison, 1973). According to Schoenfeld, Halevy-Martini, Hemley-Van der Velden and Ruhf (1985), network therapy as a model “... combines elements of family therapy, group therapy, and community organization into a single, cohesive, high-impact,



brief intervention (p. 281)". The main target in social network intervention is problem solving, resolution of tensions and untying relational misinterpretations between the patient and her network members, by releasing and channelling energy, ideas and empathy in a person's social network. This is a process that may develop the means to cope with the actual challenges and problems of living (Attneave & Speck, 1974).

The few evaluations in previous studies (mostly clinical evaluations without control groups) have concluded that social network intervention may be effective under certain conditions. In addition to direct problem solving, network intervention appears to foster larger networks, increase social support and improve social functioning, (e.g., for psychiatric patients (Speck, 1998; Gottlieb & Coppard, 1987; Schoenfeld et al., 1985), and for clients in child care and from multi-problem families (Forsberg & Wallmark, 1998).

#### *Network assessment: the network map*

A systematic network assessment assumes the use of a clinical network map. Carolyne Attneave (Attneave, 1976) was the first person to develop a network map as a systematic tool to map a person's own subjective perceptions of her social relationships and introduce this in clinical work. This was the starting point of systematic network mapping of a person's and her family's perceptions of their social relationships. This is also called the "affective" approach to social network mapping, assessing the most important network members in a person's social network (Van Sonderen, 1990).

According to Attneave (1976), the aim of constructing the network map is to make available a summary of the current social matrix within which the individual and the family lives (Figure 1). The lists of persons are arranged spatially on the map in relation to each other, connected with lines both inside and across the different spaces in the map to visualize their relationship, creating a kind of visual web. The map serves as a starting point for a deeper analysis of important characteristics in the network, such as the degree of reciprocity between the patient and the network members, frequency and durability of the different

relationships, geographical availability to the different persons in the network, degree of importance and social support (emotional, practical, informational, social companionship), etc.

After completion of the network diagram, the patient's perception of the significance of the providers of support is identified. This assessment identifies possible emotional and instrumental support, social companionship and the positive, negative or ambivalent feelings the patient has towards her significant others. This process helps the patient become more conscious about her own social world and, furthermore, helps the professional leader to understand the patient's social situation, to decide (1) whom to invite to the network meeting, and (2) important aims for the network meeting.

**Figure 1.** Example of a network map (Fyrand, 1994)

### *Network meetings*

The professional use of network therapy was developed and described in the late 1960s and early 1970s, in the field of psychiatry in the USA. The first definition of network therapy is “by simply gathering the network together in one place at one time with the purpose of forming a tighter organization of relationships, potent therapeutic potentials are set in motion (p.183)” (Speck & Rueveni, 1969). The professional network intervention is built on three basic principles: (1) that behaviour makes sense when one “... sees through the eyes and feels through the perception of the beholder”; (2) that people not only can, but will, help one another; and (3) that any help, to be useful, must be part of the social context of the person in distress (Speck & Attneave, 1973). Thus, network intervention is based on the assumption that the solution “... to a variety of human dilemmas lies within the expectations and collective resources of an individual’s social network (p. 330)” (Garrison & Howe, 1976). Long-lasting crisis and wearing problems due to chronic diseases, as is the case in rheumatoid arthritis, may cause dysfunctional, ineffective and unbalanced networks, indicating a structural unhealthy life situation that calls for a social network intervention.

According to Attneave and Speck (1974), this kind of intervention may be used both in crisis situations, and, furthermore, in “... repair of a social context that has gradually eroded away into a chronic problem state”, which most often will be the situation for patients with a long-term chronic disease. Tightening the bond between the patients and significant others in their social network may bind a fragmented network together, thereby increasing both the emotional involvement and the communication between the network members and the patient. This may help both the patient and the network members to modify or change behaviour and act more adequately towards each other’s needs, based on a new understanding of the situation. The effect of the network intervention on the client may also last over a longer period of time, owing to a constant reinforcement from the broader network system, which is more involved in the client and her family’s situation as a result of the intervention (Halevy-Martini,

Hemley-van der Velden, Ruhf, & Schoenfeld, 1984). The leader of the network meeting will not be the traditional therapist, but rather will assume the role of a catalyst, mobilizing and releasing the resources of both the patient and the larger network.

The network meeting typically produces a process that has been described as a six-cyclical spiral (Speck, 1998). According to Halevy-Martini et al. (1984), the first task in the network session is to convene the network.

The *first* stage, the opening of the meeting, was coined the “*re-tribalization phase*” by Speck and Attneave (1973). The conductor opens the meeting with an introductory talk about the goals and expectations (based on the investigation, discussion and agreement in the preparatory assessment meeting between the conductor and the patient herself) in front of the network group, encouraging all the participants to speak openly and to share their views on the problems displayed in the meeting. The network members are then asked to introduce themselves to the group and to share their view on how they see the patient’s (and the families’) problems and needs, as well as describe their hopes and expectations for the meeting. After the conductor or network members present themselves, the patient describes her situation as she experiences and perceives it.

The *second* stage consists of a free discussion on the most central topics presented, and focuses the group so that people can choose sides. This may create a “*polarization*” in the group process, where different views are displayed and discussed, raising emotional tension and energy in the assembly. In this process, outspoken persons, called “network activists”, gradually receive approval from other network members.

In the *third* and *fourth* stages, the network members gradually deal with the different problems and views raised, suggesting different kinds of solutions to the problems discussed, bringing the meeting into the “*mobilization stage*”. The network conductor(s) is monitoring interactions during these phases, giving space and time for each network member to contribute to the topic discussed, while also monitoring the resistance from the patient and her family (called the “*depression-resistance stage*”), towards the concrete suggestions arising in the group. These

phases ebb and flow in a spiral direction during the course of the meeting (Speck, 1998).

The *fifth* and the *sixth* stages are the “*breakthrough*” stage, where the patient (and the patient’s family) and the network can agree on relevant solution(s) suggested in the meeting, with the sixth phase, the “*exhaustion–elation*” phase, describing the network’s emotional drain after an intense process in the network meeting, as the last one. After the meeting, the network may be able to continue on its own, as a result of a more balanced and committed network, owing to the process created in the network session.

Empirical studies of relevant interventions are scarce. Schoenfeld et al. (1985) conducted a study of 12 clients, who attended two network meetings of three hours duration, at Mount Tom Institute for Human Services, an outpatient psychiatric clinic in Holyoke, Massachusetts, USA. The intervention group was compared with a historical comparison group, in which 12 clients were randomly chosen and originally referred for network therapy without receiving it. The results showed a significant difference between the groups, with the comparison group experiencing a decrease in service utilization of 17% after the date of referral, compared with the treatment group, who had a 76% decrease after the completion of network therapy. Keropuda Psychiatric Hospital in Western Lapland province in Northern Finland was developed from a traditional therapeutic psychiatric approach and organization to a family and network oriented approach, primarily based on network meetings in the patient’s home. Since 1992, they have completed a follow-up study of all psychotic patients referred for the first time, showing that hospitalization and heavy medication has mostly been redundant. In five years, there was a decrease in inpatient treatment beds from 320 to 66 in Keropuda Hospital, caused by this change in approach and organization of the professional psychiatric service system (Seikkula, 2000).

Even if there is no reason to question these results (and other clinical results not published in international journals), it is worth mentioning that this type of intervention has been insufficiently evaluated (not evaluated in a controlled trial) for any type of problem or diagnosis. Furthermore, systematic use

of social network intervention has mostly been practised in the psychiatric field and in the child-care sector (Speck, 1998), and its impact in somatic medicine is unknown, although there are chronic disorders in these fields as well. Therefore, there is a need to find out whether this kind of intervention is also clinically useful in somatic medicine. Thus, it seemed important to investigate, with a prospective, parallel-group design, whether this kind of network intervention had a positive, negative or no effect, within the somatic sector.

### **Rheumatoid arthritis, chosen as “the study illness”**

Rheumatoid arthritis (RA) is a chronic illness that is endured, according to the terms defined by Conrad (Conrad, 1987), characterized by unpredictability in the speed and consequence of its course, and with an unknown cause. It is a potentially disabling disease with pervasive negative impacts on the physical, psychological and social well being of the patients affected (Kvien & Smedstad, 2000). RA is characterized by pain caused by inflammation, swelling or joint deformity, limited motion, stiffness, fatigue and depression. Working activity, social roles and social interactions are affected, possibly causing social disability. It is three to four times more common in women than in men (Heath & Fortin, 1992). RA is the second most prevalent form of arthritis, occurring in 0.5–1% of the population (Uhlig, Kvien, Glennås, Smedstad, & Førre, 1998), having both direct and indirect costs to society (Callahan, 2000). Thus, this disease was chosen, as it represents general patterns and symptoms in chronic illnesses, making generalization to other endured illnesses possible.

### **Rheumatoid arthritis, social networks and social support**

“Chronic illness as biographical disruption” is the title of a paper reporting a study of the consequences of having a rheumatic disease such as RA (Bury and Michael, 1982). Bury conceptualizes chronic illness (like rheumatoid arthritis) as a particular type of “disruptive event” because the structures of everyday life are disrupted. Severe pain, physical deterioration, energy loss, social dependency and changes in self-concept commonly accompany a chronic disease such as RA,

imposing great demands on the patient's daily life (Evers, Kraaimaat, Geenen, & Bijlsma, 1997; Bury, 1991). "Loss of confidence in the body", caused by the disruptive processes and symptoms in the patient's everyday life, will most often lead to loss of confidence in social interactions (Bury, 1991).

Having RA may challenge the maintenance of both the quantity (network size) and the quality (social support) of the social network, when social relationships themselves are threatened by the illness (Affleck, Pfeiffer, Tennen, & Fifield, 1988).

RA seems to weaken the social network, reducing the *total network size* for patients with a disease duration of less than four years (Veenstra, 1996), the *network size of family and friends* for patients with a disease duration of less than one year (Evers, Kraaimaat, Geenen, & Bijlsma, 1998), or with a mean disease duration of 16 years (Fitzpatrick, Newman, Lamb, & Shipley, 1988; Fitzpatrick, Newman, Archer, & Shipley, 1991), and the *network size of neighbours* (Fitzpatrick, Newman, Lamb, & Shipley, 1988; Fitzpatrick, Newman, Archer, & Shipley, 1991).

Studies regarding deficiency in the amount of social support received due to negative consequences of RA show inconsistent findings. The results have ranged from moderate (12 months) (Brown, Wallston, & Nicassio, 1989) and fairly stable (12 months) (Evers, Kraaimaat, Geenen, & Bijlsma, 1998) support, to an extremely stable degree of emotional support received from the closest network members over a period of 18 months (Revenson, 1993). Furthermore, a stable degree of the number of measures of support (15 months) (Fitzpatrick et al., 1991) to a decline in "the overall level of social support" (Revenson, 1993) over an 18 month period was also found. Earle, Perricone, Maultsby, Perricone, Turner, and Davis, (1979) compared RA patients with non-patients, and showed that RA patients did not perceive social support from family and friends as an important problem.

Studies of the moderating effects of *disability* and *pain* connected to the disease/illness on the deterioration of RA patients' social network and social support also show inconsistent findings. While disability was found to be

negatively associated with the network size of friends and neighbours (Fitzpatrick et al., 1991), Brown, Wallston, and Nicassio (1989) and Smedstad, Kvien, Moum, and Vaglum (1995) did not find any association with total network size in their studies of RA patients. Furthermore, while two studies examining the relationship between social support and disability showed an inverse relationship between the two variables (Brown, Wallston, & Nicassio, 1989) (Evers, Kraaimaat, Geenen, & Bijlsma, 1998), a study by Doeglas, Suurmeijer, Krol, Sanderman, and van Leeuwen (1994) found no significant association. Affleck et al. (1988), in a study of 129 RA patients with a mean disease duration of 10 years, found that while more than 20% of the sample reported problems with disrupting relationships arising from their dependency on other people and/or from the stigma of joint deformity and disability, 12% answered that the disease had strengthened their relationship with family or friends. Patients in this study who had experienced disruption of their supportive providers had two main explanations for this: (1) network members withdrew personal contact owing to the stigma of joint deformity and disability, and (2) RA patients distanced themselves from supportive others because of a discomforting feeling of dependency on their relationships over a longer period of time.

The relationship between *disease duration* and social network/social support is not, to my knowledge, published in the RA literature.

The described inconsistency in results from the few studies investigating a possible deterioration of the social network and social support resulting from RA seems most likely to be due to methodological differences, such as study samples (i.e., different length of disease duration and degree of disability), variables measured and assessment instruments. Both the low number of studies, together with the inconsistent results found in the few studies completed, uncover a “hole in knowledge” regarding if and how rheumatoid arthritis deteriorates RA patients’ social network and social support, and if it is an indication of network intervention.



## **2. AIMS OF THE STUDY AND RESEARCH QUESTIONS**

The general aims of this study were, by examining patients with RA, to contribute to new knowledge relevant for an extension of clinical health care in the direction of a biopsychosocial approach for patients with RA and other patients who endure a chronic disease. Knowing more about a possible negative impact and its causes may increase the health care system's ability to help the patients take the necessary steps, preventing a process of social disability (decrease in the patient's social network, and reduced social support). Furthermore, if network intervention really has a clinically significant effect, it is a candidate for an adjuvant intervention to be considered as part of the clinical repertoire.

### **Main research questions**

In line with the hypotheses referred to above, our major agenda covers two main questions:

**(1) Does chronic illness such as rheumatoid arthritis deteriorate the social network and social support of female RA patients?**

- a. Whether and how RA influences social network and social support (Papers I and II)
- b. The influence of disease-related variables on social support (Paper III)

To address this question we conducted a cross-sectional study (Papers I, II and III):

**(2) What effect, if any, does “social network intervention” have on female RA patients?**

Is it possible, by social network intervention:

\*\* to maintain an effective and supportive social network, when the relationships are threatened by the illness?

\*\* to increase the patients' social functioning and their perceived overall health?

In order to address the second main question, a prospective intervention study was conducted (Paper IV):

### **Specific research questions**

The specific research questions were:

#### **Paper I:**

- Does health status (the term chosen to denote whether the subject has RA or not), the duration of the disease, and the degree of physical disability among female patients influence the size of the total social network and the size of the various subsets of the social network?
- If there is a relationship between RA variables (health status, disease duration, and disability) and network size, can that relationship be explained by higher levels of work activity and income among healthy controls and among RA patients with short disease duration and/or low degree of functional disability?
- Is the influence of disease duration and disability of RA on network size confounded by sociodemographic variables such as age, marital status and educational level?
- Are there any interaction effects between sociodemographic variables and health status, disease duration, and disability on network size?

#### **Paper II:**

- Does the presence of RA influence the amount of emotional and instrumental support and social companionship received?
- If so, is that relationship mediated by network size and occupational activity?
- Does marital status and age confound and/or modulate the abovementioned relationships?

#### **Paper III:**

- Does the degree of physical disability and duration of the disease influence the amount of social support received?

- Is the influence of disability and disease duration on social support confounded by sociodemographic variables such as marital status and/or age and/or personality variables such as extroversion and neuroticism?
- If there is a relationship between disease variables (physical disability and disease duration) and social support, can that relationship be explained by a larger network and higher levels of work activity for patients with a low degree of disability and/or shorter disease duration?
- Are there any interaction effects on social support between disability and disease duration on the one hand, and social network, sociodemographic and personality variables on the other?

**Paper IV:**

- To what extent—if any—will network intervention influence:
  - a) the total size of the patient’s social network;
  - b) the amount of the patient’s daily emotional support;
  - c) the patient’s social functioning; and
  - d) the patient’s perceived overall health?
- Are there different effects of network intervention in specific sociodemographic groups, defined according to marital and work status?

### **3. DESIGN OF THE STUDY**

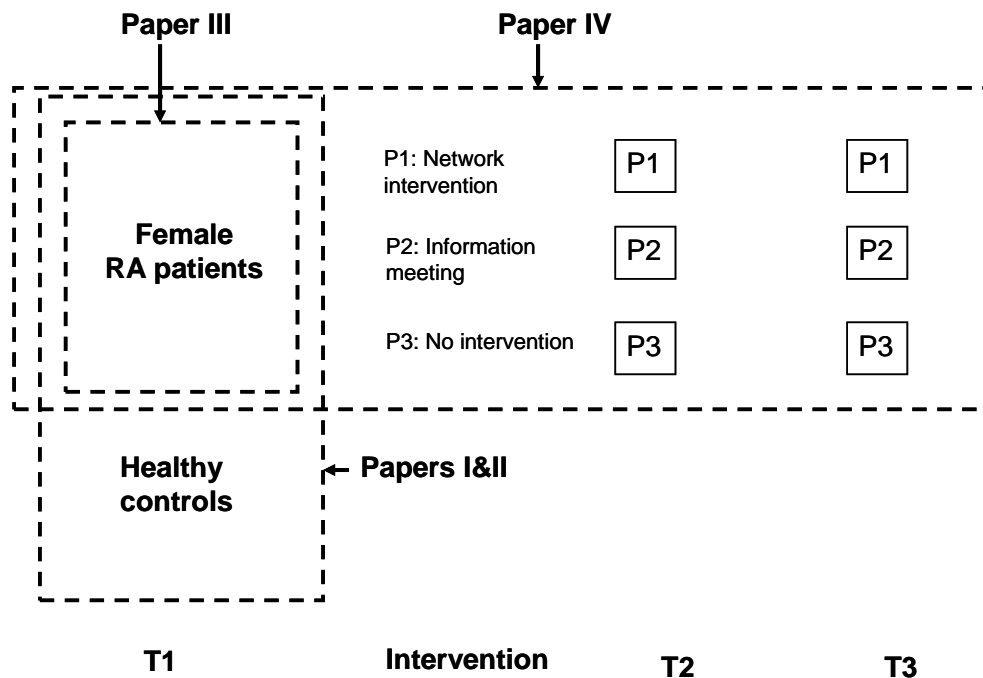
This thesis comprises two studies: a cross-sectional study presented in three papers (I to III) and a prospective intervention study presented in Paper IV.

The applied design of the cross-sectional study was both a case-control design (Papers I and II) and a one-sample design (Paper III). The case-control study was selected on the basis of whether or not the social network and social support were different between the two groups (RA patients and healthy controls), allowing elucidation of whether chronic disease influenced these variables negatively. While the cross-sectional case-control study consisted of 264 RA

patients and 61 healthy controls, the cross-sectional one-sample study was based on the same 264 RA patients only.

The network intervention study, described in Paper IV, was also based on analyses of the same 264 RA patients who were examined in the cross-sectional study. The intervention study had a prospective and parallel group design, with three cross-sectional data collections (baseline and 10-month (SD = 4 months) and 18-month (SD = 4 months) follow-ups) on stratified intervention groups and control group. The patients were allocated to three groups: (1) The *network intervention group* was offered the network intervention (N = 104); (2) patients in the *attention control group* were invited to join information meetings, which controlled for the “attention effect” (N = 85); and (3) the *no-treatment control group*, who received no intervention (N = 75). The patients in the attention group should control for a possible attention bias in the network intervention group caused by the network intervention. Furthermore, the no-treatment patients were included to control for the possibility of all patients showing the same pattern over time (e.g., a “regression to the mean”), i.e., that the results were general and not caused by the intervention itself. Patients were initially randomized to one of the three study groups and then stratified for the degree of physical disability and age, in order to ensure a balanced distribution of age and level of disability across the three groups.

The intervention study initially had a randomized controlled clinical study design (RCT), which was modified to a *partially* controlled clinical study, owing to consecutive replacement of attriters (dropouts not completing all three assessments) and non-compliers (completing the three assessments, but not the network intervention or the attention-control intervention) in the study. A high percentage (24.4%) of attriters and non-compliers resulted in our replacing these patients consecutively, with the aim of obtaining satisfactory power, by increasing the total number of RA patients from 180 (N = 60 in each of the three study groups) to 264 patients. Thus, it was the inclusion process of patients for the intervention study that also determined the final number of patients in the cross-sectional studies.



**Figure 2.** Observational time points for (1) the three assessments (T1 = baseline, T2, T3); (2) the RA patients allocated to the three study groups in the prospective intervention study (P1, P2, P3) after the baseline interview; and (3) the respective articles in the cross-sectional study (Papers I, II, III) and in the prospective intervention study (Paper IV).

## 4. MATERIALS

### Subjects

Subjects were female patients with RA, according to the ACR 1987 classification criteria (Arnett et al., 1988), selected from patient records at the Department of Rheumatology at Diakonhjemmet Hospital, The National University Hospital of Norway and Martina Hansen Hospital (serving the people of the Akershus county). RA patients between 20 and 70 years with a disease duration of more than six years were invited to complete the disability subscales of the Health Assessment Questionnaire (HAQ). Patients living in Oslo and neighbouring communities of Oslo were invited to participate in the study. Of the eligible patients between 20 and 70 years of age with a disease duration of more than six

years and with a HAQ disability score between 0.1 and 2.9, 264 (63%) consented to participate in the study.

The healthy controls comprised 61 females, sampled to represent the same distribution with respect to age (20–70 years) and residential area. The controls were selected from the Population Registry of Oslo.

### **Sampling procedure**

A total of 553 female RA patients living in the Oslo area, with a disease duration of more than six years, were invited to fill in the Health Assessment Questionnaire (HAQ). Ninety-eight (18%) did not respond and 36 (6.5%) patients were excluded, on the basis of a HAQ score of 0 or 3. We invited the 419 patients who scored between 0.1 and 2.9 on the HAQ to participate in the study. Of those 419, 155 (37%) refused and 264 (63%) agreed to participate. Of 211 eligible controls (sampled to represent the same distribution with respect to age and residential area as the RA patients), 133 (63%) refused to participate and 78 (37%) agreed to participate in the study. Of this sample, 17 were excluded owing to disabling diseases, resulting in a sample of 61 (29%) healthy controls.

Patients and controls who neither replied by letter nor made contact by telephone received one postal reminder. Patients willing to participate in the study signed a statement acknowledging their informed consent and declaration to participate. They were contacted by phone, and an appointment in their home or at the outpatient clinic of either the Oslo City Department of Rheumatology or Martina Hansens Hospital was organized.

Seventy-five per cent of the interviews took place in the home of the respondents. The interview comprised both self-administered questionnaires and personal interviews. All interviews were performed according to a structured interview guide, and the data were recorded during the interview in precoded responses. The total procedure took approximately two hours to complete. All patients and controls were assessed at baseline (T1) and then at the first follow-up assessment 10 months later (T2), and again at 18 months after baseline (T3).

The intentional time lag for the two interventions (the social network intervention and the information meetings for the attention control group) was three weeks after the first interview. The interviewer delivered a sealed envelope to each patient after the completion of the interview at baseline, informing her of the group to which she had been randomly allocated. The interviewer was not informed about the result of group allocation prior to the interview. The data collection and the interventions were performed between 1992 and 1994.

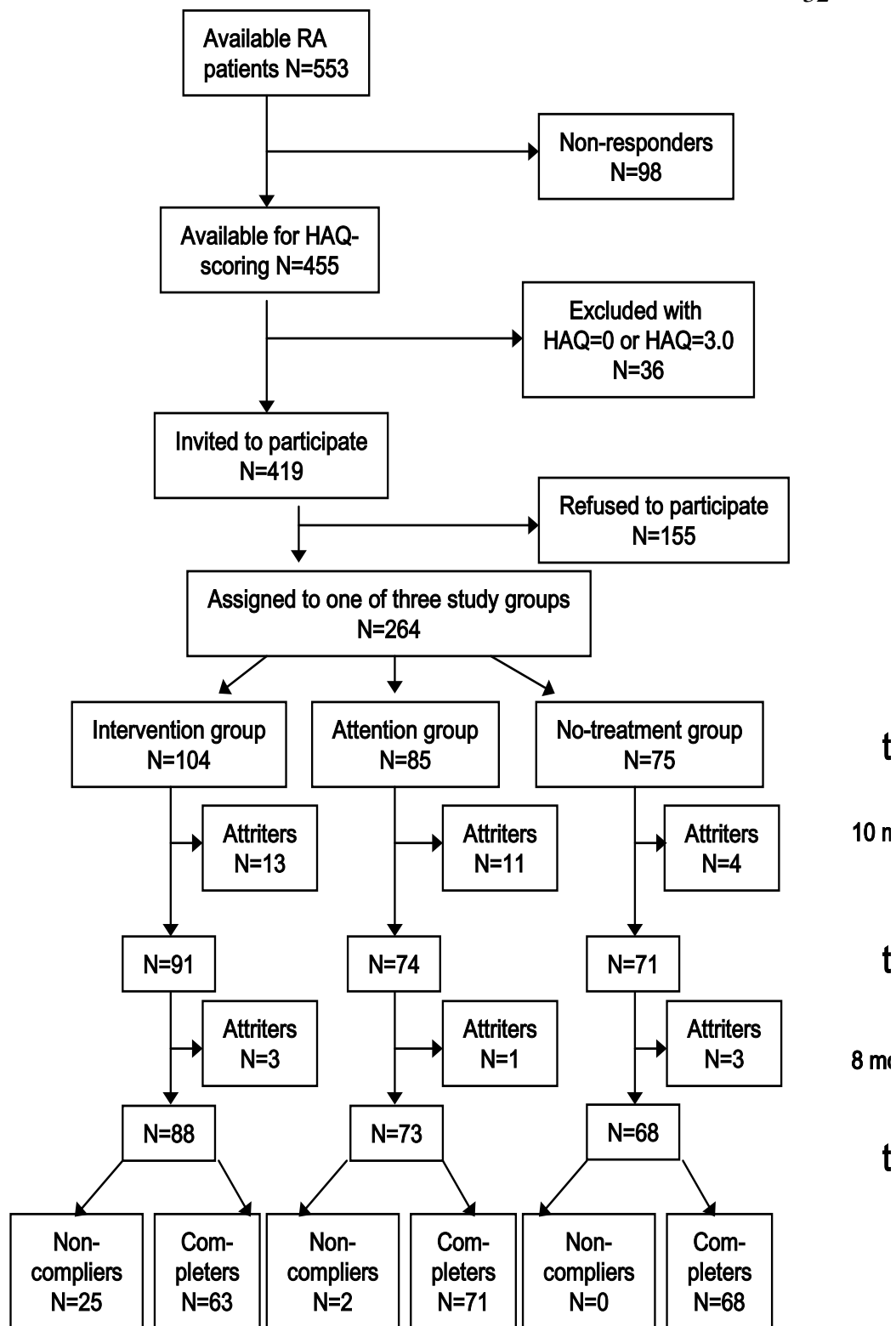
Meeting leaders produced structured reports and evaluation from both the preparatory assessment meeting and the network session. Furthermore, the patients completed in their own time a qualitative evaluation of the network intervention, consisting of relevant statements of possible positive or negative outcomes of the network meeting, with precoded responses and open-ended questions. Patients returned this evaluation by mail immediately after T2.

Four trained interviewers conducted the first baseline interviews, after which two trained interviewers conducted the rest of the baseline interviews and all the interviews at T2 and T3. All interviewers were trained by the leader of the project, including those who conducted pilot interviews.

The study was performed according to the guidelines of the Declaration of Helsinki. The regional government ethics committee for biomedical research and the Norwegian Data Inspectorate approved the project.

### **Attriters and non-compliers**

Sixty-two patients (23%) withdrew from the prospective intervention study. Of these, 35 patients, the attrition group, withdrew from assessment either after the baseline interview or after the first follow-up assessment at 10 months. Twenty-seven patients, the non-complier group, completed the three assessments, but failed to comply with the network intervention (N = 25) or the information meetings in the attention group (N = 2). They were all included in the Intention-to-Treat analysis.



**Figure 3.** Flow chart showing the patient selection process. Attriters did not complete the three assessments; non-compliers did not complete the network intervention (network intervention group) or the information meeting (attention group).



## **Inclusion criteria**

### *Disease*

Patients with *Rheumatoid Arthritis*, established according to the ACR 1987 classification criteria (Arnett et al., 1988), were chosen for the study, since RA is one of the most prevalent chronic diseases, affecting 0.5–1% of the population. The date of diagnosis was the date of fulfilling the ACR classification criteria, established according to the hospital medical file of the patient. Both inpatients and outpatients were invited to participate.

### *Sex*

Female patients were chosen for the study in order to eliminate the potential differential effects of gender, as RA is most prevalent in females (F:M = 3–4:1) (Heath & Fortin, 1992).

### *Age*

Since the level of social activity, need of different subsets in the network and different types of social support may be age dependent, we chose 20–70 years as the age range for inclusion in the study, thereby excluding the oldest RA patients. We also wanted to exclude children and adolescents suffering from Juvenile RA.

### *Domain population*

We included patients living in urban areas of Oslo and neighbouring urban/suburban zones in Akershus only, as studies have shown different network and social support structures for people living in urban compared with rural areas (Fischer & Claude 1982; O'Brien, Hassinger, & Dershem, 1996).

### *Disease variables*

*Disease duration:* Only patients with a disease duration of more than six years were included, assuming that a possible effect of RA on network size would only surface several years after the onset of the disease.

*Disability score:* Physical disability was assessed by the disability scales (0–3) of the Health Assessment Questionnaire (HAQ) (Fries, Spitz, Kraines, & Holman, 1980). Patients who reported no disability (HAQ score = 0) at the pre-inclusion screening were excluded, as the impact of their disease on daily life was considered minimal. Patients with the highest possible degree of disability (HAQ score = 3) were excluded, owing to anticipated compliance problems caused by the high degree of disability.

*Disabling diseases:* 17 healthy controls who exhibited various physically disabling diseases were excluded from the study.

## **5. METHODS**

### **Measures and instruments**

Except for the instruments measuring personality traits, we were granted permission to use the EURIDISS instruments and measures (Briancon et al., 1990).

#### **1) Dependent variables**

##### *Social support:*

Social support was measured by the Social Support Questionnaire of Transaction (SSQT) (Suurmeijer et al., 1995), which assesses global supportive interactions between the respondent and members of her social network. SSQT can be applied to all samples and is not a “disease-specific” questionnaire. The questionnaire measures both the amount of, and satisfaction with, social support received. The amount of social support received was a focus of our study. Five types of interactions are distinguished: (1) daily emotional support (five items; alpha = 0.70); (2) problem-oriented emotional support (six items; alpha = 0.68); (3) social companionship (five items; alpha = 0.70); (4) daily instrumental support (four

items;  $\alpha = 0.25$ ) and (5) problem-oriented instrumental support (three items;  $\alpha = 0.53$ ). The response categories are (1) seldom or never, (2) now and then, (3) regularly, and (4) often. The reliability of problem-oriented instrumental support was lower than desired ( $\alpha = 0.53$ ), but still acceptable for a three-item measure. Daily instrumental support was excluded from our analysis, because of an unacceptably low Cronbach's  $\alpha$  (0.25).

Reliability and validity tests in the EURIDISS sample of 744 RA patients (patients from four countries: the Netherlands, France, Sweden and Norway), showed that the scales "daily emotional and problem-oriented emotional support", "social companionship" and "problem-oriented instrumental support" demonstrated a relatively high intercorrelation of the items on each scale, thereby constituting a satisfactorily reliable scale (considering the number of items per scale), and had a consistent pattern of factor loadings (Suurmeijer et al., 1995; Doeglas et al., 1996). Regarding problem-oriented instrumental support, results from two pilot studies in the Netherlands and France particularly suggested a reconsideration of the formulation of the items in this instrument. The items were reformulated by assessing actual transactions against expectations about the instrumental support to be received in certain problematic situations *if these should occur* (Suurmeijer et al., 1995). The reformulation increased the validity of this subscale. Unfortunately, our study used the original version of the instrumental support subscale of SSQT, which may explain the rather low Chronbach's  $\alpha$  of both the "daily instrumental support" and "problem-oriented instrumental" support in our study. Tests regarding "daily instrumental support" were less consistent. Even if the three items in this scale had satisfactory factor loadings on the underlying dimension (between 0.47 and 0.75), inter-item correlations were close to zero, causing an unacceptably low Chronbach's  $\alpha$  for the four countries included in the study. An analysis of the possible impact of social desirability on the item response of the above mentioned support scales did not provide any evidence of such impact on the data (Van Sonderen, 1990). Provision of instrumental social support seems, in general, to be a more sensitive response to a concrete problem in a person's situation than provision of emotional

support (Cohen. & Wills, 1985), and social companionship. This applies especially to RA patients, such as the patients in our study, who have severe functional limitations with a mean disease duration of 20 years and a mean HAQ score of 1.5. A patient's need for practical help will always reflect her/his present life, which may be governed by sociodemographic factors, as well as mental and physical health. This is probably the most important reason for a lack of validated measuring instruments in this field.

The need for emotional support and social companionship seems to have a more general and overall character that is more independent of the patient's specific situation. This may require that instrumental support questionnaires should measure support that is provided in more concrete problem situations, either experienced or expected, than we did in our study. This difference should be taken into consideration when interpreting our results, indicating a possible Type II error regarding a lack of significant differences between RA patients and the healthy controls for problem-oriented instrumental support.

### *Social network*

Social network was measured by the Social Network Delineation Questionnaire (SNDQ) (Van Sonderen, 1990). Using self-reports of the respondents in face-to-face interviews, the SNDQ provides a broad range of information about the most important persons in their social network: subsets of the social network (family, friends, neighbours and "important others" (i.e., colleagues, club members and more distant acquaintances), the number of network members in each subset, their sex, age, travelling distance and the frequency of two types of contact (telephone/letter and face-to-face). The respondents were asked to state the names of the most important persons in the abovementioned subsets, allowing a maximum of nine (i.e., "Are there any neighbours with whom you have regular contact?" "If yes, could you mention the most important ones?") In the present study we chose data regarding network size—i.e., the number of individuals in each of the abovementioned subsets, as well as the total network size (the sum of all the members in the different subsets, excluding partners). The reason for this

choice was that most of the epidemiological studies investigating the main and/or buffering effect of social network and social integration on somatic and mental health use network size as the main network variable, together with marital status, organization activity and church membership (Berkman. & Syme, 1979) (House, Landis, & Umberson, 1988).

We removed spouse/partner from the SNDQ variable because we used “marital status” as a sociodemographic variable. The impact of spouse/partner on the amount of social support received was not part of the research questions in our studies, owing to the empirical data that already exist regarding this topic (Manne & Zautra, 1989; Ell, 1996) (House, Landis, & Umberson, 1988).

### *Social function*

The General Health Questionnaire (GHQ-28) is a self-administered generic instrument measuring mental distress, which includes four subscales: somatic symptoms, anxiety and insomnia, social dysfunction and depression (Goldberg & Williams, 1988). Of these four subdimensions, “social dysfunction” was most relevant, the main goal of our intervention study being to examine whether the network intervention had an effect on the “social world” of RA patients (e.g., social network, social support and social functioning). Social dysfunction was operationalized as a subdimension of the 28-item version of the General Health Questionnaire (GHQ-28). These subscales may be used separately, and/or may be added into one overall sum representing mental distress. The items were scored on a Likert scale, with integers from 1 to 4. Social dysfunction consists of seven items, demonstrating a Cronbach’s alpha of 0.85 in our study (Paper IV), representing a satisfactory internal consistency between the seven items, demonstrating the ability of the scale to measure the underlying subdimension. GHQ-28 has been extensively validated (Werneke, Goldberg, Yalcin, & Ustun, 2000).

The World Health Organization study of psychological disorders in general medical practice compared GHQ-28 in 15 different centres around the world, using the scale translated into 11 different languages, with 5,273 patients

completing the instrument. Important aims of the study were to examine whether GHQ-28 possessed reasonable factor invariance across centres and to establish whether the factor structure originally found for GHQ-28 (Goldberg & Hillier, 1979) was still stable. This study uncovered a stable factor structure for two of the four subdimensions of GHQ-28, namely social dysfunction and depression, indicating that social dysfunction may be used separately as a valid instrument to assess social function. According to a study by Sanderman and Stewart (1990), GHQ is not affected by social desirability, owing to the low and non-significant correlations between the social desirability scale in the Eysenck Personality Questionnaire (EPQ; Eysenck & Eysenck, 1975) and the GHQ, thereby supporting the validity of this instrument.

#### *Overall Health (OEHS)*

OEHS was measured by a 100 mm visual analogue scale (VAS), with the anchoring points of “very bad” to “excellent”, measuring the subjective assessment of present overall health status by the patient (Goldstein, Siegel, & Boyer, 1984). According to their study, this is the one-item measure of perceived health status sensitive to long-standing chronic illness, but not to short-term changes in objective health status, such as acute illness or the beginning of chronic illness. However, even if their study generally supports the utility of this measure, this instrument lacks an independent estimate of its reliability (Goldstein et al., 1984).

## **2) Independent variables**

#### *Sociodemographic variables*

*Marital status* was dichotomized into “living alone” (0) or “being married or living with a partner” (1).

*Work status* was dichotomized into unemployed (0) and full-time/part-time work (1).

*Income level* measured the net family income per year in Norwegian currency, and was assessed on a 10-point scale.

*Educational level* was recorded according to the International Standard Classification of Education (UNESCO, 1976) and then condensed into a three-point scale (Junior High School, Senior High School, College).

#### *Personality traits*

The personality traits of extroversion and neuroticism were measured by EPQ for Adults (Eysenck & Eysenck, 1975). Both scales showed an adequate reliability ( $\alpha = 0.84$  and  $0.86$ , respectively).

### **3) Qualitative measures**

#### *Structured reports and evaluation (completed by the leaders)*

Structured reports and evaluation of the preparatory assessment meeting and the network session were completed by meeting leaders. The leaders of the network intervention completed two standardized questionnaires about the structure and process of the meeting: (1) after the preparatory assessment meeting, e.g., whom to invite to the network session, topics discussed, goals for the network session; and (2) after the network session, e.g., number of persons attending the meeting, time used, topics discussed, concrete solutions/conclusions of topics discussed. Part of this qualitative evaluation is described in Paper IV.

#### *Qualitative evaluation (completed by the RA patients)*

Qualitative evaluation of the network intervention at T2 consisted both of statements with precoded responses and open-ended questions. The statements were relevant expectations of outcomes of the network session such as “easier to receive and not only give help”, “easier to share the challenges of the chronic disease with her network members” with “very important” “important” “not

important” as response categories. The open-ended questions were, for example, “which expectations did you have regarding the results of the network session?” “which, if any, positive consequences did the network session represent in your life?” and “which, if any, negative consequences did the network session represent in your life?” The patients completed this evaluation in their own time and mailed it immediately after T2. Space allows presentation of only some of the results from these two evaluations. A concentrated and selected summary from this qualitative evaluation is presented in Paper IV.

## **Data analysis**

### **Statistical analysis for the cross-sectional studies (Papers I, II and III)**

In Papers I and II, differences between patients and controls were tested for significance by t-tests for continuous variables and chi-square for categorical variables. Bivariate correlations (Pearson’s  $r$ ) and blockwise multiple linear regressions and ANCOVAs were used to estimate the relationships between dependent variables (network size and social support) and independent variables (health status, work status, marital status, age) (Papers I and II), and income and education level (Paper I). Health status was coded as a dummy variable, with the value of 0 for RA patients and 1 for healthy controls.

The same statistical procedures were applied in Papers I and II (with different outcome variables; network size (I) and social support (II)), owing to the fact that Papers I and II used the same case-control design, controlling for differences between RA patients and healthy controls. In Paper III, an investigation of the impact of disability and disease duration on social support for RA patients, the same statistical procedure as mentioned above was used, but without the case-control design. Bivariate correlations and blockwise multiple linear regressions were used to estimate the relationships between dependent and independent variables (physical disability (HAQ), disease duration, network size, work status, marital status, age and personality traits).



Possible interaction effects between every pair of independent variables were explored by entering multiplicative terms (one by one) along with all the main effects in the final regression equation. Only the significant interaction terms will be presented. All tests were two-tailed. The level of significance was set at 0.05 (Papers I, II, and III).

#### **Statistical analyses of the prospective intervention study (Paper IV)**

Data were collected at three time points: before the intervention (baseline = T1), approximately 10 months after the intervention (first follow-up = T2) and 18 months after the intervention (second follow-up = T3).

Because of the high number of non-compliers from the intervention group, we decided to perform the analyses on a sample including both the patients who were initially randomized for the study, and the replacements and non-compliers (thus performing an Intention-to-Treat analysis).

A number of statistical tests were employed to assess differences between and within groups across time points. One-way analyses of variance (F-tests) were used to assess possible mean differences in continuous variables between the study groups at baseline. Chi-square tests were used to assess possible baseline differences for categorical variables. Simple change within groups, from one time point to another, was assessed by paired t-tests. Differential change between groups was assessed by analyses of covariance (ANCOVAs), entering group membership (intervention group, attention control group, no-treatment control group) as the factor. Differential change between study groups was thereby assessed using the baseline value for any given dependent variable as the covariate (Cohen & Cohen, 1983). This procedure also protects against baseline differences between study groups that may be due to chance, and thus gives a stricter test of our hypotheses than a repeated measures procedure. Planned comparisons were the focus of analysis, and simple contrasts within ANCOVA procedures were used to assess differential change for pairs of groups (intervention group vs. attention group and intervention group vs. no-treatment group). A significant improvement (in the expected direction) at follow-up in the

intervention group compared with *both* the attention group and the no-treatment group considered individually was considered “strong” evidence in favour of our hypotheses, and a significant improvement in the intervention group compared with only one of the control groups (the attention group or the no-treatment group) was considered “moderate” evidence in favour of our hypotheses. No significant improvement in the intervention group compared with the two comparison groups was considered as “no” support for our hypotheses, and, finally, a significant deterioration in the intervention group compared with any or both of the comparison groups was considered as evidence “against” our hypotheses. These categories will be used when we summarize our findings.

Differential change between groups according to marital status was assessed by interaction terms (using centred variables to create the interaction terms). Interaction terms in the ANCOVAs (using the two groups individually) revealed that there were *significantly different effects of the intervention* within specific sociodemographic subgroups (as defined by marital status). We proceeded to carry out stratified analyses within the subgroup in question (within the group of married and unmarried separately to see if marital status was involved in the interaction) in order to assess the specific direction and magnitude of the intervention within each stratum.

## **Materials and methods—a discussion of selected topics**

### *Disease duration*

Since this was also a retrospective study, patients with a disease duration of less than six years were not included, assuming that a possible effect of RA on social network and social support would usually surface only after some years of disease. The mean disease duration for our study sample was 20 years (SD = 10 years). Retrospectively, we may argue that it would have been preferable to have the broadest variance in disease duration by including RA patients who were newly diagnosed, owing to the mental distress RA patients are facing during the

first years of the disease (Smedstad, Moum, Vaglum, & Kvien, 1996), which may also cause dysfunctional changes in their social network and social support.

A more practical reason for choosing RA patients with a disease duration of more than six years was that there were three parallel studies taking place within the same hospital. The EURIDISS study investigated RA patients with a disease duration of up to four years, and another investigated elderly patients (more than 60 years of age) with a disease duration of up to six months. Thus, there was a certain competition for patients.

#### *Disability score*

One may question the fact that 36 patients with a HAQ score of 0 or 3 were excluded from the study. We excluded (1) RA patients who possibly had no physical reductions due to the disease (HAQ less than 0.1), as this would have little or no negative consequences for the social network and social support of the patient, and (2) patients who were completely dependent on help from other persons (HAQ = 3), which may have caused compliance problems in the study for this group of RA patients. According to empirical studies, a change in HAQ score is clinically important after reaching a HAQ score greater than 0.17–0.25 (Redelmeier & Lorig, 1993). Inclusion of RA patients with a HAQ score of less than 0.1, independent of their level of physical functions, could therefore not be expected to uncover other results than found in our study of RA patients with a HAQ score of greater than 0.1.

#### *Patient selection process (dropouts and completers)*

Possible differences between responders and non-responders in the group of RA patients and in the group of healthy controls that could confound the results could not be analysed, as we had no data from the non-responders (Paper I and II). Furthermore, since non-participation was much higher among healthy controls than among RA patients, differential refusal may also have been conducive to Type II error by leaving us with a group of controls with apparently high levels of social support (Paper II).

Challenges arising from the dropouts in the intervention study were not sufficiently resolved during the data collection process. The impact was not fully acknowledged before we started analysing the longitudinal data from all three time points. As described under “Design”, owing to a lack of power, as well as a threat to the validity of the comparison, caused by the high percentage of dropouts in the intervention study, we modified the research design from a randomized controlled trial (with adequately concealed allocation) to a non-randomized controlled trial by replacing the dropouts consecutively and matching the dropouts with respect to age and level of disability, in order to safeguard the overall comparability of the study groups. Owing to a lack of marking of the replacements, we were not able to identify later which of the participants were replaced in each group, blocking our ability to identify possible selection effects in the final study sample.

We proportionally over-sampled for the intervention group to ensure that the intervention group was large enough to provide adequate statistical power, and included data from all participants in the analysis regardless of whether they attended the intervention or not. The intention-to-treat analysis helped to ensure a fair comparison, although we cannot be sure that the comparison groups were similar given the failure to maintain concealed random allocation.

In a review article comparing RCT and non-RCT clinical trials (eight evaluations of the same intervention), Kunz and Oxman (1998) found that, in five of eight studies, estimates of effect were larger in the non-RCT trials than in the RCT trials. However, outcomes in the RCT and non-RCT treatment groups were frequently similar. Kunz and Oxman (1998) points out that “on average, failure to use concealed random allocation results in overestimates of effect due to a poorer prognosis in non-randomly selected control groups compared with randomly selected control groups, but it can result in underestimates of effect, reverse the direction of effect, mask an effect, or give similar estimates of effect (p. 1189)”. In an update of this review article Kunz, Vist and Oxman (2002) emphasize that there is strong evidence that trials with inadequate concealment of allocation on

average yield larger estimates of effects than trials with adequately concealed allocation.

The patients who remained in the network intervention group throughout the duration of the study may have been more motivated for this type of intervention than the non-compliers, thereby representing a possible Type I error caused by this selection effect. Dropouts from the longitudinal sample (at the first (T2) and second (T3) follow-up) had a smaller network size than the patients who remained in the longitudinal study (Paper I). This fact may cause resistance to confront this phenomena in its full scope, both towards themselves and towards their significant others, in a network intervention. Thus, withdrawing from the network meetings may be seen as a self-protective strategy. Another reason may be the systematic selection of the completers. Analysis of the differences between the non-compliers and the completers in the intervention group showed that the non-compliers were significantly older (60 years) than the completers (56 years), received significantly more daily emotional support (non-compliers: 16.1; completers: 14.4) and had a non-significantly smaller total network (non-compliers: 12.3; completers: 14.7). This may indicate that older RA patients, who receive a high amount of daily emotional support, will refuse to participate in this type of intervention, even if they have a smaller social network than younger patients

The two-year project mentioned in the introduction may be seen as a pilot project. However, in retrospect in addition to testing the instruments and interviews on 10 patients, we should have had a small pilot study of the experiment as well. This probably would not have reduced the dropout rates, but probably would have ensured that we were more prepared for, and conscious of, the patients' resistance to participating in, and completing, the network intervention.

### *Time lag in the prospective study*

The anticipated time lags, described in the protocol, of six and 12 months between baseline and follow-ups, were impossible to accomplish, owing mainly to the patients' health and problems caused by their disease. The time lags between baseline and follow-ups were therefore 10 months (SD = 4 months) and 18 months (SD = 4 months).

Furthermore, the plan to run the network intervention for the intervention group and the information meetings for the attention control group three weeks after the baseline interview was also impossible to accomplish, for the reason mentioned above. The time lag between baseline and the two interventions in practice was changed from three weeks to three months (SD = 1.5 months).

### **Intervention effects**

Cohen (1988) suggests the following categories regarding effect size: small = 0.20, medium = 0.50 and large = 0.80. Most differences between the groups in our study were in the range from small to medium (between 0.13 and 0.57). The *effect size* will often be small when the phenomena that are studied cannot be brought into the laboratory (Cohen, 1988). This is because the influence of uncontrollable extraneous variables ("noise") makes the "signal"—i.e., the pure effect of the intervention—difficult to detect.

This is especially relevant in new areas of research inquiry, not least in (randomized) clinical trials in social medicine and within the field of social psychology. Another way to view the impact of the intervention is to look at the size of the effects actually observed in relation to the very brief (a few hours) intervention. The amount of time and resources used to complete the intervention is much smaller than for most clinical intervention studies in the social-psychological field with the objective of changing attitudes, behaviour and coping. This type of intervention therefore may be viewed as particularly interesting, even with limited effect for clinical settings with limited resources.

In some instances, intervention effects were found only in comparisons with one of the two control groups. The limited strength of the network

intervention, implemented as only one network meeting, may explain this finding. A booster network intervention with a series of network meetings (e.g., a preparatory assessment session and two network meetings with two, three or four weeks intervals as the first step, with a follow-up after some months as the next step, if needed) would be expected to increase the effect of this type of intervention. Moreover, an increase in the size of the sample would also possibly strengthen the statistical significance in the study.

### **Representativity**

The cross-sectional studies: Unfortunately, we have no data on the non-responders to help us identify a possible bias in selection of the RA group and the group of healthy controls in our study sample. However, owing to possible selection bias, we performed a logistic regression analysis, where we compared those who dropped out of the longitudinal study with those who remained, with network size and sociodemographic variables as independent variables. Dropouts in the RA sample were found to have a somewhat smaller network size than the patients who remained in the study (Paper I). This is supported by a study of Reisine, Fifield, and Winkelman (2000), which investigated characteristics of RA patients in long-term research, and the dropouts from these types of studies. Patients remained in the long-term studies if they were more socially integrated (married, a number of close friends, high frequency of contact, and with memberships in different types of groups). This may indicate that the study sample consists of patients with a somewhat larger network, losing important information about RA patients who were more isolated, and is therefore not representative of the most isolated female RA patients.

A selection bias caused by the fact that 37% of the invited patients refused to participate in the study may be present in our study. Since non-participation was much higher among healthy controls than among patients (63%), differential refusal may have resulted in our study examining a group of controls with a large network size (Paper I) and high level of social support (Paper II). Thus, the representativeness of the healthy controls could be questioned.

The prospective intervention study: By comparing the completers with the non-compliers (24%) in the intervention group, we identified the fact that older RA patients, who received a high amount of daily emotional support, refused to participate in this type of intervention even if they had a smaller social network than younger patients. Thus, as a result of the high percentage of non-compliers in the intervention study and the abovementioned difference between these two groups, we decided to use an Intention-to-Treat design, including the completers as well as the non-compliers in order to prevent a possible selection bias. However, the high number of non-compliers in the intervention group may have resulted in a Type II error caused by the high number of patients not attending the network intervention, thereby reducing the effect of the intervention.

Our results may only be regarded as representative for RA patients with disease duration of more than six years, while it is equivocal whether they can be generalized to patients with a disease duration of less than six years.

The sample was selected from patient records at the Department of Rheumatology that served all RA patients from Oslo city, and from patient records at Martina Hansen Hospital, which served RA patients in Akershus County. Our study is a “population-based” study with a sample representing RA patients living in *urban/suburban* areas, owing to different network and social support structures and patterns in urban versus rural areas (Fischer & Claude 1982; O’Brien, Hassinger, & Dershem, 1996).

RA is a so-called “lived-with” illness, according to the definition by Conrad (1987), which is not life threatening, but challenges the individual in her coping abilities every day. Even if other lived-with illnesses (i.e., diabetes, asthma and epilepsy) have different symptoms and manifestations, it appears that both the disease-related problems they face, and the strategies they develop to cope with the disease-related challenges, are similar (Conrad, 1987). Therefore, in addition to RA, our results may be generalizable to other lived-with illnesses.



## **The prospective intervention study—discussion of the method (Paper IV)**

### *The preparatory assessment session*

The *preparatory assessment session* constituted the crucial preparation, including an assessment of the patient's most important network members and necessary information about the motivation for the network meeting. The process in the assessment session challenged the leaders to meet the patient on her premises, and to understand as fully as possible how a chronic disease such as RA, since the onset of the disease, had influenced her daily life, including her social life and interactions in social relationships. This clarification represented the basis for conclusions on important topics presented in the subsequent network meeting. Seven patients withdrew before the preparatory assessment session, after being informed they were being randomized to the intervention group, and 18 patients withdrew after their assessment session. Despite providing written informed consent to participate in the study, the information about both the intervention programme and the background for the project that was given in the assessment session surprised some patients and caused a reluctance to participate further in the intervention programme. Even if several reasons were mentioned for this decision, the main arguments were related to a resistance to uncover their life as a chronic patient in front of their network members and, furthermore, anxiety about "bothering" their social network with their problems.

Avoidance as a coping strategy may be understood as a prevention of the perceived negative consequences of receiving help (i.e., indebtedness as a negative "cost"). Evidence seems to indicate that receipt of a benefit may easily generate feelings of indebtedness, which mediates subsequent cognitive and behavioural reactions (Greenberg, 1980). The withdrawal was, from the patients' perspective, probably such a "behavioural reaction" that protected them from an increasing feeling of indebtedness towards their network members, and thus from a decrease in their self-esteem caused by increased indebtedness (Dunbar, Ford, & Hunt, 1998).

When the patients were motivated and decided to complete the network meeting, most of the married patients met no opposition from their spouse/partner. However, a few patients met resistance from their spouse/partner, which in two cases led to our completing two preparatory sessions, but one without and one with her spouse. In some cases, the patient wanted to talk with her spouse before she finally decided to participate in the network meeting. In this case, the patient's spouse did not agree to his wife's participating in the network meeting, which was accepted by the patient, upon which she withdrew from the intervention. In one case, there was the opposite situation: while the patient was reluctant to participate in a network meeting, her husband begged her to do so, referring to the patient's extreme social withdrawal from her network owing to her disease. He hoped that such a meeting could help them both to turn the "negative relational spiral" into a positive one. Based on these experiences, one might question whether we initially should have invited the married couple to the preparatory assessment session, owing to the fact that the patient's chronic disease affected not only her own life in a negative way, but also the life of her partner (Revenson, 1993). In fact, the reluctant husbands seemed more anxious than their wives to confront their life-situation as "a chronic family" openly in front of their most important network members. The reluctance and denial of the abovementioned patient to participate in a network meeting may also be considered a symptom of problems in the extended family (i.e., between parents and grown-up children, between siblings, between his and her family), having nothing to do with the patient's disease. This was identified as the main reason for withdrawal from the intervention in at least one case. Inviting both the family network and friends together to a network meeting, with the aim of discussing the challenges in their common network caused by the patients chronic disease, may be too threatening in dysfunctional families.

#### *Network therapy (network meeting)*

Two teams of trained network therapists were responsible for the network intervention. Team I (a physiotherapist and an occupational therapist) conducted

network intervention for 20 patients, with seven of these interventions completed according to the protocol (i.e., two network meetings, with the second meeting held two to three weeks after the first one). Team II (a medical doctor and a nurse), carried out network intervention for 10 patients. This team broke the protocol in the first network meeting, changing the number of network meetings from two to one, owing to their evaluation of the process in the meeting. This resulted in our evaluating the number of meetings required in the intervention group. It was then decided that the leaders, in co-operation with the patient, should evaluate the need for one or two meetings after completion of the first meeting. Most of the patients preferred to hold one network meeting. Seven patients conducted two meetings, and 56 patients conducted one. They are all included in the final Intention-to-Treat analysis, thereby preventing possible bias problems. Mid way through the study, both leader teams withdrew from the leadership job owing to time limitations. Almost all of the meetings (the preparatory assessment sessions and the network meetings) were held in the evening in the patient's home. As the main researcher, I had planned not to lead any of the network interventions, on the principle of remaining a neutral researcher. Nevertheless, owing to the staffing situation, I had no choice but to complete the network interventions myself, which comprised 33 patients. Thus, the patients in the intervention group have had three leader teams. Owing to possible bias problems, I analysed the three groups, who had three different leader teams, separately, finding no significant differences. Retrospectively, I have learned that, in this kind of intervention study, assuming the responsibilities of a leader in addition to working in a full-time job is difficult. Owing to the process in this type of study, the neutral-researcher role is not relevant. On the contrary, owing to my leadership job for several network interventions in this study, I developed a unique understanding of the patients' life situation as chronic patients. This presented unique opportunities to understand more fully the results from the empirical data analyses.

Most of the patients did not want to invite any of their professional helpers to the network meeting. This probably reduced the effect of the network meeting,

owing to the fact that the professional helper could give information sought by the patient or the present network members, to understand better the nature of RA and how it was perceived to affect the patient's future life. Furthermore, by participating in the meeting, the professional would obtain access to important information about the chronic illness for future clinical work—i.e., how the disease affected the patient's and her family's daily life and her/their activity arenas. The patients' resistance to inviting, for example, their medical doctor, was mostly due to a feeling of distance and less contact with him/her, and anxiety about bothering the professional. While the rheumatologist participated in four network meetings, others refused to participate.

## **6. MAIN RESULTS AND SUMMARY OF PAPERS**

### *Paper 1: Social network size of female patients with rheumatoid arthritis compared with healthy controls*

This paper estimated how RA, disease duration and level of physical disability influenced the total size of patients' social network and the size of different subsets. Two hundred and sixty-four female patients (mean age = 57 years) with RA of more than six years' duration (mean = 20 years) were compared with 61 healthy controls matched for sex, age, and residential area. Network size was measured by the Social Network Delineation Questionnaire (SNDQ), while physical disability was assessed by the Health Assessment Questionnaire (HAQ). RA patients had a significantly smaller total network compared with healthy controls (RA: 15.8 persons; Controls: 18.1), mostly owing to a significant difference in the subset of important others in favour of the controls (RA: 1.1; Controls: 2.3). There were no significant differences regarding the network size of family, friends and neighbours. The same results remained after statistical control of sociodemographic variables. Neither disease duration nor physical disability had any significant association with network size. The interaction analysis did, however, show that unemployed patients with a long disease duration (more than 15 years) had fewer important others than occupationally active patients.

Furthermore, a high degree of physical disability was related to a smaller number of friends for patients aged more than 57 years than for equally disabled patients below this age. Most patients with RA seem to maintain contact with family network members, despite the challenges connected with chronic disease.

*Paper II: Social Support in Female Patients with Rheumatoid Arthritis Compared with Healthy Controls*

The objective of this study was to investigate the amount of social support received by female patients with RA compared with healthy controls. Two hundred and sixty-four patients and 61 healthy controls were assessed. Social support was assessed by the Social Support Questionnaire of Transactions (SSQT), measuring five different support types: daily and problem-oriented emotional support, social companionship, and daily and problem-oriented instrumental support. Compared with healthy controls, RA patients reported significantly less daily emotional ( $p = .024$ ) and problem-oriented emotional support ( $p = .024$ ), as well as less social companionship ( $p = .022$ ) when network size and sociodemographic variables were controlled for. Furthermore, among older subjects (aged more than 57 years), RA patients had a *lower* score on social companionship than controls. However, RA patients with few or no friends (less than four friends) received more problem-oriented instrumental support than controls.

*Paper III: The impact of disability and disease duration on social support of women with rheumatoid arthritis*

The objective was to investigate the impact of physical disability and disease duration on the amount of social support received by female patients with RA. Two hundred and sixty-four patients were assessed in a cross-sectional study.

- (1) Emotional support: Disease duration had a negative relationship to daily emotional support, indicating that the length of disease duration was inversely related to the degree of emotional support received. A combination of long disease duration (more than 12 years) and high

disability (a HAQ score of greater than 2) was related to a low degree of problem-oriented emotional support.

- (2) Social companionship: High physical disability was associated with less social companionship. Patients with high disability (a HAQ score of greater than 2) and few friends (fewer than 3), and patients with high disability (HAQ score greater than 2) and few neighbours (fewer than 2) reported less social companionship than patients with high disability and four or more friends or three or more neighbours.
- (3) Instrumental support: The combination of high disability (a HAQ score of greater than 2) and few friends (fewer than 3) was associated with less problem-oriented instrumental support.
- (4) The number of friends, age and personality types all contributed to the variance in social support.

*Paper IV: The effect of social network intervention for women with rheumatoid arthritis.*

We investigated the effect of network intervention on the social network size, social support, social functioning and perceived overall health of RA patients. A partially controlled intervention study with prospective design was performed. Female RA patients (mean age = 57 years, disease duration = 20 years and HAQ score of physical disability = 1.5) were allocated to three groups: the network intervention group (n = 104), the attention control group (n = 85; controlling for the Hawthorne effect) and the no-treatment control group (n = 75). The network intervention consisted of two elements: (1) an assessment session where the patient and the leader of the network meeting met to prepare, and (2) the main intervention, a network meeting. The patient invited the significant others from her network to her network meeting, sometimes including professional helpers. The scope of the network meeting was to provide a basis for open interaction between the patient and her network members, in order to help the chronically ill patients meet the emotional, social and practical challenges caused by their

disease. Patients were assessed, at baseline and at approximately 10 and 18 months after the intervention, by a structured interview and questionnaires.

The network intervention group as a whole reported an increase in network size. Daily emotional support increased for the intervention patients compared with patients in the attention control group. The degree of social dysfunction was reduced for patients in the intervention group compared with patients in the no-treatment control group. Furthermore, for patients living alone, the intervention significantly increased the social network size and improved the social functioning and perceived overall health compared with both to the attention control group and the no-treatment control group. The results suggest that the social needs of patients living alone should be given special attention in the clinical setting.

## 7. DISCUSSION OF RESULTS

### **I: Does an illness such as RA have a deteriorating effect on the patient's social network and social support? (Papers I, II and III)**

*The main results* are: Rheumatoid arthritis seems to have a more deteriorating effect on the *quality* of female RA patients' social network (i.e., social support), than on the size of the network *per se*, based on the following findings.

- (1) Having RA did not influence the total network size. The small network of RA patients was caused primarily by their status in the work place (Paper I). When we separated the four subsets in the total network, we found that:
  - a. the *family network* did not seem to deteriorate as a result of RA (Paper I);
  - b. RA did not have any significant impact on the *network size of friends and neighbours*, with the exception of older and highly

- disabled patients, for whom the network size of friends deteriorated (Paper I); and
- c. The *network size of important others (colleagues and other more distant acquaintances)* was significantly reduced by RA (Paper I).
- (2) RA had a negative impact on the amount of *daily and problem-oriented emotional support* and *social companionship* received (Paper II).
- (3) Degree of disability had a negative impact on *social companionship*, which increased with age. Having a high disability score and few friends or neighbours seems to have a negative impact on social companionship (Paper III).

#### *Social network and Rheumatoid Arthritis*

These results both confirm and contrast with other studies. Differences in study samples (different length of disease duration and inclusion of both males and females), variables measured and assessment instruments makes a comprehensive comparison difficult. While our study measured female RA patients with a mean disease duration of 20 years, a number of other studies have investigated both male and female RA patients with disease duration less than four years (Veenstra, 1996), less than one year (Evers, Kraaimaat, Geenen, & Bijlsma, 1998) and with a mean disease duration of 16 years (Fitzpatrick et al., 1991). Differences in network cultures and practices between the two sexes complicate comparison of mixed-gender samples. Compared with men, women seem to be more likely to identify persons other than their spouse as their confidant, and as a source of emotional support (Ell, 1996). While the availability of a good friend appears essential for female RA patients (Bury & Michael, 1982), for males, their wives seem to be the primary source of support (Ell, 1996). This concurs with a study by Shumaker and Hill (1991), which demonstrated that the spouse is the primary (and sometimes the only) social tie, and, furthermore, that men have fewer close ties than women and are less likely to seek support.



As the aforementioned studies did not differentiate the social network into network subsets as we did (friends, neighbours, work associates and more distant acquaintances), it is difficult to compare their results with our data (Paper I). A deterioration of the *total* network size, as found in a longitudinal Dutch study of a Norwegian and a Dutch sample (Veenstra, 1996), and a longitudinal study by Evers, Kraaimaat, Geenen, & Bijlsma (1998), was not supported by our study, which showed that the small network of RA patients was due to their status in the work place (Paper I). One may therefore question whether the results in the abovementioned studies are due to the work status of the RA patients. Our result of stability of the network size of the family (which is not deteriorating) is supported by Fitzpatrick et al. (1988; 1991). The rather stable network size of friends and neighbours found in our study is not found in the studies of Fitzpatrick et al. (1988; 1991), which revealed a deterioration of diffuse relationships as friends and neighbours. Their results, showing a deterioration of “diffuse” relationships for both male and female RA patients, contrasts with our data showing no deterioration of friends and neighbours, but a decrease for the subset of important others (colleagues and more distant acquaintances). This contrasting finding may be due to the different subsets measured. Thus, it may be that the group of work associates and more distant acquaintances accounts for the significant deterioration in the diffuse relationships found in different studies (Fitzpatrick et al., 1988; 1991).

The results from our statistical interaction analyses, showing that RA patients with a *high* degree of disability *above* 57 years, had fewer friends than patients below that age, is interesting owing to the fact that our study uncovered a correlation between age and the subset of friends and important others, but not between disability and any of the subsets of network size (Paper I). While this is in accordance with the studies by Smedstad et al. (1995) and Brown et al. (1989), it contrasts with the studies of Fitzpatrick et al. (1988, 1991), who found an inverse relationship between disability and the network size of the more diffuse relationships, such as friends and neighbours. Our findings that older patients with a high disability appear at

greater risk of losing important resources in their friendship network seems logical, resulting from the double jeopardy caused by the reduction in mobility, combined with the disability and increasing age.

### *Social support and Rheumatoid Arthritis*

The negative impact of RA on three types of social support (daily and problem-oriented emotional support and social companionship) found in our study seems only partly to support previous findings. Studies investigating the relationship between social support and RA have, for example, most often focused on one type of social support only, namely emotional support. While a moderate stability of the emotional support was found in a longitudinal study of RA patients (Brown et al., 1989), and perceived availability of social support (emotional and instrumental) for RA patients was also demonstrated (Evers, Kraaimaat, Geenen, & Bijlsma, 1998), the overall level of social support has been shown to decline in an unpublished, prospective study of psychosocial adaptation to the onset of RA (Revenson, 1993). Thus, the contrasting results between results found in our study (Paper II) and other studies regarding the possibility of decreased social support received by RA patients may be due to sample differences such as sample size, sex, age, disease duration, physical disability, different support type measured and different measures used. Even though there was a trend towards an increase in instrumental support received by the patients compared with healthy controls in our study, the lack of significant results for instrumental support may be caused by low reliability and questionable validity of the measure used.

The current inverse relationship found between disability and social companionship (increase in disability was followed by a decrease in social companionship; Paper III), generally supports results from a previous study on social integration for RA patients (Badley, 1995). This study showed that disability was negatively related to participating in social activities with family and friends, leisure activities, and other activities in different social arenas, indicating greater social isolation and less social integration in their community. However, the results from a study by Doeglas et al. (1994) on RA patients, using

the same measurement instruments as we did, did *not* find any relationship between disability and social companionship. Furthermore, the current lack of an association between disability and emotional and instrumental support (Paper III) also contrasts with other studies. While our results support the results of Doeglas et al. (1994), showing no association between disability and any of the same four support types measured, an inverse relationship has been found between emotional support and disability for RA patients (Brown, Wallston, & Nicassio, 1989; Evers et al., 1998), and between disability and emotional support (Fitzpatrick et al., 1991).

Thus, even if these studies demonstrate an inverse relationship between social support and disability (as we found between social companionship and disability), it seems difficult to draw any firm conclusion based on a comparison between our results and theirs, owing to differences in variables measured, measurement instruments used and RA samples. Furthermore, exclusively investigating female RA patients, as we did in our study, may yield results that are not comparable with studies investigating both males and females, owing to the priority placed by women on good friends as providers of emotional support, compared with men's view that the spouse is the primary provider (Ell, 1996). Furthermore, their findings may also be due to an association between a subdimension of social support (e.g., social companionship) and disability only (as found in our study), implying that disability has only a partial, but not general, weakening impact on the social support of RA patients.

Even though we found that RA patients received a higher amount of problem-oriented instrumental support compared with healthy controls, this difference was surprisingly not significant. This may, however, be due to a rather low reliability of this scale, indicating problems of developing valid and reliable questionnaires that measure instrumental support in chronically ill patients.

A lack of cross-sectional case-control studies with healthy controls and prospective and longitudinal studies, combined with different RA samples and measures of network size and social support, makes comparison between other studies and ours extremely difficult. Despite possible bias in our study regarding

the cut-off point for disease duration within the inclusion criteria, our study has uncovered more specific information regarding the impact of RA on the social network and social support received by the patient, than is shown in other studies. No other study has focused on the *impact of RA* and disease variables such as *disability* and *disease duration* on the *total* network and its *different subsets* and on *different* support types.

However, firm conclusions are dependent on further longitudinal studies regarding the possible impact of RA on the total network, the different subsets in a person's network and on different support types, to understand how a chronic disease such as RA influences the patient's social life.

## **II: Discussion of the effect of a social network intervention in a prospective design (Paper IV)**

Social network intervention, defined as a combination of a network assessment session and a network meeting, has never been investigated in a randomized controlled and longitudinal study, nor has it been used in the field of somatic medicine. Our study was therefore new in two ways: (1) we wanted to apply this kind of intervention in the field of somatic medicine, and (2) we wanted to investigate this type of intervention with a partially randomized controlled prospective research design. The sample in the study was composed of three groups: (1) the patient intervention group, who received the network intervention; (2) the patient attention-control group, who received another type of intervention (an information meeting) controlling for the "attention effect" (the Hawthorne effect); and (3) the patient control group, who received the questionnaires and interviews only.

The main results from the intervention study are as follows.

- (1) Patients in the intervention group reported an increase in their total network size.

- (2) Daily emotional support increased in the intervention group compared with patients in the attention control group.
- (3) The degree of social dysfunction was reduced in patients in the intervention group and in the attention group compared with patients in the no-treatment control group.
- (4) Patients *living alone* increased their network size, and improved their social functioning and their perceived overall health compared with the attention control group and the no-treatment control group.

(1) *Network size*: The increase of total network size for patients in the intervention group from baseline to T2 and T3 (10-month and 18-month time lags), may in part be due to regression to the mean. Patients in this group had fewer network members at baseline than patients in the attention control group (14/17), who experienced a borderline decrease of their total network size from baseline to T3. Thus, the within-group process in these two groups from baseline to T3 (without any between-group difference in change), may be due to a regression to the mean for both groups, which implies an approximation between the two groups to the mean for all three groups. However, the non-compliers (N = 25) in the intervention group tended to have a smaller total network size ( $p = .10$ ) than the completers (N = 63), indicating a possible Type II problem in our Intention-to-Treat analysis. This may indicate that the increase in network size observed in the intervention group is not only due to a regression to mean.

(2) *Daily emotional support*: While patients in the intervention group had an increase in the amount of daily emotional support received, the patients in the attention group had theirs reduced from baseline to T2. Given the fact that this difference was in relation to only one of the two control groups, the importance of the result may be reduced. Nevertheless, the opposite direction of change in the daily emotional support received from baseline to T2, between the groups, must be seen as an interesting result. Participants in the network meetings were generally family members and friends, with a predominance of the family subset. According to Suitor, Wellman, and Morgan (1997), the kin of people in

community studies tend to persist in emotionally supportive relationships. RA patients received less emotional support, both daily and problem-based, than healthy controls in our study, indicating a need for an increase of this type of support in patients (Paper II). In contrast to Sutor et al. (1997), we found that it was the network of friends who provided most of the daily emotional support. Thus, family and friends participating in a network meeting may have untied relational knots and experienced a re-opening of the support channels between the patient and her family members as a result of the meeting process. This may have increased the level of the family's emotional support, and possibly also increased the support provided from the friends present in the same meeting (Paper IV).

In agreement with most other researchers of support, Sutor et al. (1997) do not separate daily emotional support from problem-oriented emotional support, thereby missing an important difference in regard to emotional support that is given in a more everyday and ordinary situation, independent of having a chronic disease. It may be easier to develop reciprocal relationships that are based on equity within supportive relationships that provide daily emotional support, compared with the more problem-based types of support. Thus, the non-effectiveness of the more problem-based emotional and instrumental support in our intervention study may be due to the patients needing to be independent of their significant others, to prevent the possible consequences of indebtedness and lowered self-esteem (Dunbar, Ford, & Hunt, 1998).

The absence of significant differences in social companionship between the intervention group and either of the two control groups may be due to the fact that mostly family members were present at the network meetings. The fact that friends are the most important subset in a person's social network (Papers II and III) may indicate that a larger representation of friends in the network meetings may have improved the social companionship received. This is a hypothesis that should be tested in the future.

(3) *Social dysfunction*: The decrease in social dysfunction for both the intervention group and the attention group compared with the patients in the no-treatment control group (whose social dysfunction increased) may be due to the

“attention effect”, representing the attention given to the patient both in the network and information meetings.

However, this result may also (or in addition to the attention effect) be due to different processes in the two groups. A pattern of withdrawal from social arenas was found in RA patients in an eight-year follow-up study of the effect of RA on work status and social and leisure time activities (Fex, Larsson, Nived, & Eberhardt, 1998), and in the Canadian Health and Activity Limitation survey (Badley, 1995), indicating a need for more social activity. The inverse relationship found in our study, between the degree of functional disability and the degree of social companionship received (Paper III), indicates possible dysfunctional changes in the social activity of RA patients. Thus, the network intervention may represent a support that is needed to break through possible withdrawal and capture a more active social attitude caused by the dialogue and process in the network meeting.

Patients in the attention control group may have increased their ability to understand and cope with their life as chronic patients, owing to the process of the information meeting. The lecture from the rheumatologist, as well as the dialogue between the panel of professionals and the group of RA patients, and between the patients themselves, may have caused a more open and active social attitude. Information about the disease and the disease-related consequences seems to influence the ability of patients to cope with their disease in a positive way (Lindroth, 2000). Furthermore, interaction with other RA patients in this kind of meeting, with the aim of educating and solving problems regarding disease-related topics, may also have contributed to their social functioning (Holman & Lorig, 1997).

(4) The effect of *alone - living* patients from the intervention group increasing their social network, decreasing their social dysfunction and increasing their perceived overall health, may have been due to their needs that resulted from their status as single persons (discussed in Paper IV). However, why did *married* RA patients not benefit significantly from the network intervention? This raises the question of whether married patients need a booster network intervention, as our

study was relatively short, consisting of only one preliminary assessment session and one network meeting. Healthy spouses married to women with RA experience illness-related stressors (Revenson, 1993), as well as illness-related conflicts in their marriage (Manne & Zautra, 1990). Furthermore, while the spouse is the most important network member providing emotional support to married men, other women are also important providers of emotional support to married women (Shumaker & Hill, 1991), (Wellman & Wortley, 1990). Thus, the combination of illness-related stressors with a possible loss of emotional support from the spouse caused by her long-lasting disease may represent a doubly demanding situation for men married to women with RA. Thus, one network meeting is most likely an insufficient intervention to display and work through both the patients' and spouses' relationship challenges caused by a stress-producing chronic disease such as RA. While some husbands did not attend the network meeting, most agreed to participate. The topics covered in these network meetings supported the needs mentioned, according to their focus on how the disease also influenced the quality of life of the spouse, as well as their marriage.

Comparison of the network intervention used in our study with other network interventions seems very difficult, owing to differences in the method used, different study populations and different outcome results measured. Different problems and study populations seem to require different applications of the basic model of network therapy designed by Speck and Attneave (1973). The network method (described as network meetings) was initially used as a crisis intervention in the psychiatric and mental health field (Speck & Attneave, 1973; Pattison & Pattison, 1981; Halevy-Martini, Hemley-van der Velden, Ruhf, & Schoenfeld, 1984; Schoenfeld, Halevy-Martini, Hemley-van der Velden, & Ruhf, 1985; Lehtinen, 1994; Seikkula, 2000; Speck, 1998), as a tool for psychosocial rehabilitation for psychiatric patients (Weinberg & Marlowe, 1983; Gillies, et al., 1993; Forsberg & Wallmark, 1998) and crisis intervention in the field of child care and with multi-problem families (Gatti & Colman, 1976) (Klefbeck, Hultkrantz-Jeppson, Marklund, Bergherhed, & Forsberg, 1987; Forsberg & Wallmark, 1998). Only a few of these studies have included network mapping as



a part of their network intervention (Pattison & Pattison, 1981; Weinberg, & Marlowe, 1983; Klefbeck, Hultkrantz-Jeppson, Marklund, Bergherhed, & Forsberg, 1987; Forsberg & Wallmark, 1998).

The *similarity* between these studies and ours seems to be a basic understanding of the importance of opening up the boundary between the patient and the different social systems, of which the patient is a part (i.e., family system, other important network members, professional system), creating a larger network based on a co-evolution between these systems (Seikkula, 2000).

However, the primary goal for most of the described network interventions seems to be the development of treatment plans and the provision of solutions to basic problems in a co-evolution process, for which the patient and her/his family turn to the professional system for help. This is *different* from the status of our patients, who have a progressive, chronic somatic disease, resulting in dependence on the professional system over an unpredictable period. Thus, our network intervention must be seen as an intervention that is *additional to* medical interventions, providing an *adjuvant* supplement to help improve the patient's potential, incorporating a psychosocial rehabilitation process.

Despite all network meetings' having different goals, owing to different study populations, the most important and *common* therapeutic tool used in network meetings seems to be the generation of "*the polyphonic dialogues*" between the network members present at the meeting, which implies being interested in everyone's voice regarding the problem (Seikkula, Alakare, & Aaltonen, 2001). Promoting the dialogue may promote the necessary change in the life of both the patient and her/his family, allowing them to be "able to acquire more agency in their own lives by discussing the problems (p. 250)" (Seikkula, Alakare, & Aaltonen, 2001). The dialogue between the participants is the main opportunity and challenge in a network meeting. It is the channelling and releasing of resources from three different social systems—(1) the patient, (2) the informal network, and (3) the professional system—which, from their different roles and angles, engages both in the definition of the problem and in the problem-solving process itself. Even if the dialogue in network meetings is

practised differently, owing to the symptoms and problems of the individual patient, a common challenge is to generate a dialogue between the people present at the meeting so as to facilitate their support, thereby possibly attaining the desired changes in the patient's life. The dialogue in our study was primarily meant to re-establish relationships between the patient and her network members based on equity and reciprocal exchange, by disclosing important disease-related topics for an open dialogue in the meeting.

The high percentage of non-completers from patients assigned to the network intervention group may in part be due to the nature of problems caused by RA. Most network interventions described in the literature deal, more or less, with patients in acute crises, underscoring the necessity of an acute situation to get the patient and his family motivated to gather for network meetings. This is different from RA patients, who experience a series of crises over a longer period, owing to the loss of functions caused by a progressing disease. The patients are, over years, accustomed to participation in individually based treatments within the boundary of the health systems. Thus, it may seem rather scary and overly dramatic (compared with a crisis in acute care) to invite significant others to a network meeting, with the aim of disclosing disease-related challenges and participating in dialogue about how best to cope with these challenges.

## **8. CONCLUSIONS**

The main findings are summarized as follows.

- Having RA did not influence the total network size, in either a negative or a positive way.
- Separating the total network size into four subsets (family, friends, neighbours and important others), revealed that only the network of important others (colleagues and other more distant acquaintances) was reduced by RA.

- The degree of disability and the length of disease duration did not influence the network size.
- Patients who had a long disease duration (more than 15 years) and who were occupationally active had a larger network size of important others than unemployed patients.
- A high degree of disability (a HAQ score of greater than 1.5) was related to a smaller network size of friends in RA patients above the mean age of the sample (more than 57 years). In contrast, patients with the same disability score who were below the mean age had a larger network size.
- Having RA had a negative impact on the amount of *daily* and *problem-oriented emotional support* and *social companionship* received.
- The duration of the disease had an inverse association with the amount of daily emotional support received.
- Patients with a disease duration of less than 12 years and a high degree of disability (a HAQ score of more than 2) reported a high degree of problem-oriented emotional support. The opposite was true for patients with a disease duration of more than 12 years with the same HAQ score.
- The degree of disability was inversely related to social companionship. This inverse association was enhanced with increasing age
- Patients with few or no friends (0–3) received more instrumental support than the healthy controls, while there was no difference between patients and controls for those having four or more friends.

- Patients with high disability (a HAQ score of more than 2) and few friends (1–3) received less instrumental support.
- Patients with high disability scores (HAQ scores of more than 2) and few friends (fewer than 3) or few neighbours (fewer than 2) reported a lower degree of social companionship received compared with patients with a lower disability score (a HAQ score of less than 2) and the same number of friends and neighbours.
- The trends over time in the network intervention group were overwhelmingly in the expected direction (i.e., positive). In the two control groups, a trend in the negative direction regarding network size and perceived overall health was found.
- Patients in the network intervention group had improved scores for network size and daily emotional support, primarily at 10 months follow-up, whereas for the other two variables (social functioning and perceived overall health), scores tended towards improvement only after 18 months.
- Patient in the network intervention group increased their network size from baseline to the 10-month follow-up, with this continuing to the 18-month follow-up, at a borderline level of significance.
- The amount of daily emotional support increased for patients in the intervention group from baseline to the 10-month follow-up compared with patients in the attention group.
- Social dysfunction was reduced from baseline to the 18-month follow-up in patients of the intervention group compared with patients in the no-treatment control group.

- The social network intervention had the following effect for patients living alone, from baseline to the 18-month follow-up.
  - 1) It expanded their total network size.
  - 2) It reduced their social dysfunction.
  - 3) It improved their perceived overall health.

*In all, while female patients with RA, under the abovementioned assumptions, are at risk of experiencing a decrease in their network size, the quality of the social network—the degree of social support received—seems to be at greater risk of deterioration.*

*Even if there was an increase in daily emotional support and a decrease in the social dysfunction for all patients in the intervention group, the most convincing effect of the social network intervention was for alone-living patients, who experienced an increase in their network size, and demonstrated improved social functioning and perceived overall health.*

## **9. CLINICAL IMPLICATIONS**

The biopsychosocial model in medicine postulates that most illnesses, whether physical or psychiatric, are influenced and determined by biological, psychological, and social phenomena (Engel, 1977). However, these phenomena influence the predisposition, onset, course and outcome of most illnesses. It is also held that a doctor's ability to analyse the relationships between the different factors affecting the patient may improve interventions and help achieve better outcomes (Cole, Saravay, & Levinson, 1998).

The presented papers can be viewed as a piece of research with reference to such a model within somatic medicine. Furthermore, the findings of the papers provide empirical support and insight for clinicians to examine specific relationships between these factors, helping the clinician to understand the illness process for female patients with RA.

The clinician and the RA patient may engage in a psychosocial intervention, a network intervention, as an adjuvant to the biological therapy. Our results show that, for certain indications, the network intervention improves the subjective outcome for women with RA. This is particularly important for chronically ill patients, where biological medicine by definition has no cure to offer.

The different ways in which a clinician works with the patient to gather relevant information to obtain a mutual understanding of the balances and imbalances of the patient's effort to cope with her illness will have to be integrated into each clinician's practice. Furthermore, individual strengths, problems and solutions of the patient must of course be given significant attention.

In conclusion, however, certain generalities and some experiences may be summarized.

I. In clinical practice, the clinician should, in particular, give attention to:

- the workplace as an important social arena;
- older patients with high disability score, who are at risk of a reduction in the network size of friends;
- the importance of reciprocity in their relationships to prevent decreases in the amount of daily and problem-based emotional support, and of social companionship received, in particular for older patients with high disability and long disease duration; and
- in general, the patient's social network and social support—i.e. her relationships and social activity to prevent her withdrawing from her social world.

II. The clinician should consider *social network intervention* as an adjuvant part of the clinical repertoire. An increase in network size and daily emotional support received may imply more independence in relation to the professional health care system, owing to an increase in the patient's informal support systems.

In particular, for female RA patients living alone, a subjective increase in overall health caused by network intervention may indicate a possible reduction in the amount of professional health service needed. Furthermore, a decrease of social dysfunction may be seen as a presupposition both for the maintenance of important relationships providing support and social activity, and for the development of new relationships.

Even if it seems difficult to establish explicit indications for the use of network intervention, the following suggestions are offered on this background.

- Attention should especially be given for use with alone-living female RA patients.
- Dependent on the patient's reaction when receiving the diagnosis, network intervention could be useful as a social context for clarifying possible disease progress and both current and future disease-related challenges. This may include the patient, her significant others (for whom her disease will interfere in their life) and her professional helpers.

This may include how best to cope with disease-related challenges in the physical, psychological and social domains,

- when the disease is progressing, thereby challenging the ability to cope with daily life challenges (the aim might be to establish a context for an open dialogue between the three systems—the patient, her significant others and her professional system—for an exchange of information about the new situation and how to cope with the new challenges that the patients and her network must confront); and
- both before and after surgical interventions (in the rehabilitation situation), to establish co-operation and dialogue between the three systems, to increase the patients' ability to cope with the illness-related challenges.

## 10. REFERENCES

Affleck, G., Pfeiffer, C., Tennen, H., & Fifield, J. (1988). Social support and psychosocial adjustment to rheumatoid arthritis. *Arthritis Care and Research*, *1*, 71–77.

Arnett, F. C., Edworthy, S. M., Bloch, D. A., McShane, D. J., Fries, J. F., Cooper, N. S., Healey, L. A., Kaplan, S. R., Liang, M. H., & Luthra, H. S. (1988). The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. *Arthritis & Rheumatism*, *31*, 315–324.

Attneave, C. (1976). Social networks as the unit of intervention. In P. Querin (Ed.), *Family therapy: theory and practice* (pp. 220–232). New York: Gardner Press.

Attneave, C. & Speck, R. V. (1974). Social network intervention in time and space. In A. Jacobs & W. Spradlin (Eds.), *The group as agent of change* (pp. 166-186). New York: Behavioral Publications.

Badley, E. M. (1995). The impact of disabling arthritis. *Arthritis Care & Research*, *8*, 221–228.

Barnes, J. A. (1969). Networks and political processes. In J. C. Mitchell (Ed.), *Social networks in urban situations* (pp. 51–76). London: Butler & Tanner Ltd.



Berkman, L. F., Glass, T. A., Brisette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, *51*, 843–857.

Berkman, L. F. & Syme, S. L. (1979). Social networks, host resistance, and mortality: a nine-year follow-up study of Alameda County residents. *American Journal of Epidemiology*, *109*, 186–204.

Boissevain, J. (1978). *Friends of friends*. Oxford: Basil Blackwell.

Bolger, N. & Eckenrode, J. (1991). Social relationships, personality, and anxiety during a major stressful event. *Journal of Personality & Social Psychology*, *61*, 440–449.

Briancon, S., Doeglas, D., Guillemin, F., van den Heuvel, W., Krol, B., Sanderman, R., & Suurmeijer, T. P. B. M. (1990). European research on incapacitating diseases and social support (EURIDISS). Definite protocol. *International Journal of Health Sciences*, *1*, 217–228.

Brown, G. K., Wallston, K. A., & Nicassio, P. M. (1989). Social support and depression in rheumatoid-arthritis—a one-year prospective-study. *Journal of Applied Social Psychology*, *19*, 1164–1181.

Bury, M. (1991). The sociology of chronic illness—a review of research and prospects. *Sociology of Health & Illness*, *13*, 451–468.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4, 167–182.

Callahan, L. F. (2000). Health economics. In G. S. Firestein, G. S. Panayi, & F. A. Wollheim (Eds.), *Rheumatoid arthritis—new frontiers in pathogenesis and treatment* (pp. 443–449). New York: Oxford University Press.

Christianson, J. B., Taylor, R. A., & Knutson, D. J. (1998). *Restructuring chronic illness management*. San Francisco: Jossey-Baass Publishers.

Cohen, J. (1988). *Statistical power analysis for behavioural sciences*. New York: Academic Press.

Cohen, J. & Cohen, P. (1983). *Applied multiple regression/correlation analysis for the behavioural sciences*. New York.

Cohen, S. & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310–357.

Cole, S. A., Saravay, S. M., & Levinson, R. M. (1998). The biopsychosocial model in medical practice. In A. Stoudemire (Ed.), *Human behavior. An introduction for medical students* (pp. 36–84). Philadelphia/New York: Lippincott-Raven.

Conrad, P. (1987). The experience of illness: recent and new directions. *Research in the Sociology of Health Care*, 196, 1–31.

DePaulo, B. M. (1982). Social-psychological processes in informal help-seeking. In T. A. Wills (Ed.), *Basic processes in helping relationships* (pp. 255–279). New York: Academic Press.

Doeglas, D., Suurmeijer, T., Briancon, S., Moum, T., Krol, B., Bjelle, A., Sanderman, R., & van den Heuvel, H. W. (1996). An international study on measuring social support: interactions and satisfaction. *Social Science and Medicine*, *43*, 1389–1397.

Doeglas, D., Suurmeijer, T., Krol, B., Sanderman, R., van Rijswijk, M., & van Leeuwen, M. (1994). Social support, social disability, and psychological well-being in rheumatoid arthritis. *Arthritis Care and Research*, *7*, 10–15.

Dunbar, M., Ford, G., & Hunt, K. (1998). Why is the receipt of social support associated with increased psychological distress? An examination of three hypotheses. *Psychology and Health*, *13*, 527–544.

Earle, J. R., Perricone, P. J., Maultsby, D. M., Perricone, N., Turner, R. A., & Davis, J. (1979). Psycho-social adjustment of rheumatoid arthritis patients from two alternative treatment settings. *Journal of Rheumatology*, *6*, 80–87.

Ell, K. (1996). Social networks, social support and coping with serious illness: the family connection. *Social Science and Medicine*, *42*, 173–183.

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, *196*, 129–136.

Evers, A. W. M., Kraaimaat, F. W., Geenen, R., & Bijlsma, J. W. J. (1997). Determinants of psychological distress and its course in the first year after diagnosis in rheumatoid arthritis patients. *Journal of Behavioral Medicine, 20*, 489–504.

Evers, A. W. M., Kraaimaat, F. W., Geenen, R., & Bijlsma, J. W. J. (1998). Psychosocial predictors of functional change in recently diagnosed rheumatoid arthritis patients. *Behaviour Research and Therapy, 36*, 179–193.

Eysenck, H. J. & Eysenck, S. B. G. (1975). *Manual of the Eysenck Personality Questionnaire*. San Diego: EDITS.

Fex, E., Larsson, B. M., Nived, K., & Eberhardt, K. (1998). Effect of rheumatoid arthritis on work status and social and leisure time activities in patients followed 8 years from onset. *Journal of Rheumatology, 25*, 44–50.

Finset, A. (1986). *Familien og det sosiale nettverket*. Oslo: Cappelen.

Fischer, C. S. (1982). *To dwell among friends—personal networks in town and city*. Chicago: University of Chicago Press.

Fitzpatrick, R., Newman, S., Archer, R., & Shipley, M. (1991). Social support, disability and depression: a longitudinal study of rheumatoid arthritis. *Social Science and Medicine, 33*, 605–611.

Fitzpatrick, R., Newman, S., Lamb, R., & Shipley, M. (1988). Social relationships and psychological well-being in rheumatoid arthritis. *Social Science and Medicine*, 27, 399–403.

Forsberg, G. & Wallmark, J. (1998). *Nettverksboken*. Stockholm: Liber AB.

Fries, J. F., Spitz, P., Kraines, R. G., & Holman, H. R. (1980). Measurement of patient outcome in arthritis. *Arthritis and Rheumatism*, 23, 137–145.

Fyrand, L. (1992). *Perspektiv på sosialt nettverk*. (3rd ed.) Oslo: Universitetsforlaget.

Fyrand, L. (1993). *Samspill med sosialt nettverk*. Oslo: Universitetsforlaget.

Fyrand, L. (1994). *Sosialt Nettverk: Teori og Praksis*. Oslo: Tano.

Fyrand, L., Alm, G., & Aares, F. (1985). *Aktivitet og ansvar i eget bomiljø. Et forsøksprosjekt i naboskapsarbeid i en drabantby*. Oslo: Universitetsforlaget.

Fyrand, L., Wichstrom, L., Moum, T., Glennas, A., & Kvien, T. K. (1997). The impact of personality and social support on mental health for female patients with rheumatoid arthritis. *Social Indicators Research*, 40, 285–298.

Garrison, J. E. & Howe, J. A. (1976). Community intervention with the elderly: A social network approach. *Journal of the American Geriatrics Society*, 24, 329–333.

Gatti, F. & Colman, C. (1976). Community network therapy: an approach to aiding families with troubled children. *American Journal of Orthopsychiatry*, 46, 608–617.

Gillies, L. A., Wasylenki D.A., Lancee, W. J., James, S., Clark, C. C., Lewis, J., & Goering, P. (1993). Differential outcomes in social network therapy. *Psychosocial Rehabilitation Journal*, 16, 141–146.

Goldberg, D. & Williams, P. (1988). *A user's guide to the Goldberg Health Questionnaire*. Windsor: NFFR-Nelson.

Goldberg, D. P. & Hillier, V. F. (1979). A scaled version of the General Health Questionnaire. *Psychological Medicine*, 9, 139–145.

Goldstein, M. S., Siegel, J. M., & Boyer, R. (1984). Predicting changes in perceived health status. *American Journal of Public Health*, 74, 611–614.

Goodenow, C., Reisine, S. T., & Grady, K. E. (1990). Quality of social support and associated social and psychological functioning in women with rheumatoid arthritis. *Health Psychology*, 9, 266–284.

Gottlieb, B. H. & Coppard, A. E. (1987). Using social network therapy to create support systems for the chronically mentally disabled. *Canadian Journal of Community Mental Health*, 6, 117–131.

Greenberg, M. S. (1980). A theory of indebtedness. In K. J. Gergen, M. S. Greenberg, & T. A. Wills (Eds.), *Social exchange: advances in theory and research* (pp. 3–26). New York and London: Plenum Press.

Halevy-Martini, J., Hemley-van der Velden E. M., Ruhf, L., & Schoenfeld, P. (1984). Process and strategy in network therapy. *Family Process*, 23, 521–533.

Hall, A. & Wellman, B. (1985). Social networks and social support. In S. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 23–41). New York: Academic Press.

Heath, C. W., Jr. & Fortin, P. R. (1992). Epidemiologic studies of rheumatoid arthritis: future directions. *Journal of Rheumatology—supplement*, 32, 74–77.

Holman, H. R. (1994). Thought barriers to understanding rheumatic diseases. *Arthritis and Rheumatism*, 37, 1565–1572.

Holman, H. R. & Lorig, K. R. (1997). Patient education: essential to good health care for patients with chronic arthritis. *Arthritis and Rheumatism*, 40, 1371–1373.

House, J. S. & Kahn, R. L. (1985). Measures and concepts of social support. In S. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 83–108). New York: Academic Press.

House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science*, *241*, 540–545.

Jennings, B., Callahan, D., & Caplan, A. L. (1988). Ethical challenges of chronic illness. *Hastings Center Report, suppl.1*, 1–15.

Klefbeck, J., Hultkrantz-Jeppson, A., Marklund, K., Bergherhed, E., & Forsberg, G. (1987). Mobilisering av nettverk runt multiproblemfamiljer i krissituasjoner. *Fokus på Familien*, *2*, 59–74.

Kleinman, A. (1988). *The Illness Narratives: suffering, healing & the human condition*. Basic Books.

Krol, B., Sanderman, R., & Suurmeijer, T. P. (1993). Social support, rheumatoid arthritis and quality of life: concepts, measurement and research. *Patient. Educ. Couns.*, *20*, 101–120.

Kunz, R. & Oxman, A. D. (1998). The unpredictability paradox: review of empirical comparisons of randomised and non-randomised clinical trials. *BMJ*, *317*, 1185–1190.



Kunz, R., Vist, G. E. & Oxman, A. D. (2002). Randomisation to protect against selection bias in healthcare trials. (Cochrane Methodology Review). In: *The Cochrane Library*, Oxford: Update Software 2002.

Kvien, T. K. & Smedstad, L. M. (2000). Psychological and social aspects. In G.S. Firestein, G. S. Panayi, & F. A. Wollheim (Eds.), *Rheumatoid Arthritis: frontiers in Pathogenesis and Treatment* (pp. 415–426). Oxford, New York: Oxford University Press.

Lehtinen, K. (1994). Need-Adapted Treatment of Schizophrenia—family interventions. *British Journal of Psychiatry*, *164*, 89–96.

Lindroth, Y. (2000). Patient education. In G. S. Firestein, G. S. Panayi, & F. A. Wollheim (Eds.), *Rheumatoid Arthritis. New Frontiers in Pathogenesis and Treatment* (pp. 427–433). Oxford: Oxford University Press.

Major, B., Testa, M., & Bylsma, W. H. (1991). Responses to upward and downward social comparisons: the impact of esteem-relevance and perceived control. In J. M. Suls & T. A. Wills (Eds.), *Social comparison: contemporary theory and research* (pp. 237–260). Hillsdale, NJ: Lawrence Erlbaum Associates.

Manne, S. L. & Zautra, A. J. (1989). Spouse criticism and support—their association with coping and psychological adjustment among women with rheumatoid-arthritis. *Journal of Personality and Social Psychology*, *56*, 608–617.

Manne, S. L. & Zautra, A. J. (1990). Couples coping with chronic illness—women with rheumatoid-arthritis and their healthy husbands. *Journal of Behavioral Medicine, 13*, 327–342.

Miller, R. (1995). Exchange in social interaction. In F. N. Magill, H. L. Delgado, & A. Sica (Eds.), *International Encyclopedia of Sociology* (pp. 490–493). London, Chicago: FD.

Mitchell, J. C. (1969). The concepts and use of social networks. In J. C. Mitchell (Ed.), *Social Networks in Urban Situations* (pp. 1–50). New York: Manchester University Press.

O'Brien, D. J., Hassinger, E. W., & Dershem, L. (1996). Size of place, residential stability and personal social networks. *Sociological Focus, 29*, 61–72.

Pattison, E. M. (1973). Social system psychotherapy. *American Journal of Psychotherapy, 17*, 396–409.

Pattison, E. M. & Pattison, M. L. (1981). Analysis of a schizophrenic psychosocial network. *Schizophrenia Bulletin, 7*, 135–143.

Redelmeier, D. A. & Lorig, K. (1993). Assessing the clinical importance of symptomatic improvements—an illustration in rheumatology. *Archives of Internal Medicine, 153*, 1337–1342.

Reisine, S., Fifield, J., & Winkelman, D. K. (2000). Characteristics of rheumatoid arthritis patients: who participates in long-term research and who drops out? *Arthritis Care & Research.*, *13*, 3–10.

Revenson, T. A. (1993). The role of social support with rheumatic disease. [Review] [61 refs]. *Baillieres Clinical Rheumatology.*, *7*, 377–396.

Rook, K. S. (1987). Social support versus companionship: effects on life stress, loneliness, and evaluations by others. *Journal of Personality & Social Psychology.*, *52*, 1132–1147.

Sanderman, R. & Stewart, R. (1990). The assessment of psychological distress: psychometric properties of the General Health Questionnaire. *International Journal of Health Sciences*, *1*, 195–202.

Sarason, B. R., Sarason, I. G., & Pierce, G. R. (1990). Traditional views of social support and their impact on assessment. In B.R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: an interactional view* (pp. 9–25). New York: Wiley.

Schoenfeld, P., Halevy-Martini, J., Hemley-Van der Velden, E., & Ruhf, L. (1985). Network therapy: an outcome study of twelve social networks. *Journal of Community Psychology.*, *13*, 281–287.

Schulz, R. & Rau, M. T. (1985). Social support through the life course. In S. Cohen & S. L. Syme (Eds.), *Social Support and Health* (pp. 129–149). New York: Academic Press.

Schwarzer, R. & Leppin, A. (1991). Social Support and Health—a theoretical and empirical overview. *Journal of Social and Personal Relationships*, 8, 99–127.

Seikkula, J. (2000). *Åpne Samtaler*. Oslo: Tano Aschehoug.

Seikkula, J., Alakare, B., & Aaltonen, J. (2001). Open dialogue in psychosis I: An introduction and case illustration. *Journal of Constructivist Psychology*, Vol 14, 247–265.

Shumaker, S. A. & Hill, D. R. (1991). Gender Differences in Social Support and Physical Health. *Health Psychology*, 10, 102–111.

Smedstad, L. M., Kvien, T. K., Moum, T., & Vaglum, P. (1995). Life events, psychosocial factors, and demographic variables in early rheumatoid arthritis: relations to one-year changes in functional disability. *Journal of Rheumatology*, 22, 2218–2225.

Smedstad, L. M., Moum, T., Vaglum, P., & Kvien, T. K. (1996). The impact of early rheumatoid arthritis on psychological distress. A comparison between 238 patients with RA and 116 matched controls. *Scandinavian Journal of Rheumatology*, 25, 377–382.

Sørensen, T. (1994). The intricacy of the ordinary. *British Journal of Psychiatry*, 23, 108–114.

Speck, R. V. (1998). Network therapy. *Marriage and Family Review*, 27, 51–69.

Speck, R. V. & Attneave, C. (1973). *Family Networks*. New York: Pantheon.

Speck, R. V. & Rueveni, U. (1969). Network Therapy—a developing concept. *Family Process*, 8, 182–190.

Stewart, M. J. (1989). Social support: diverse theoretical perspectives. [Review] [50 refs]. *Social Science & Medicine*, 28, 1275–1282.

Suitor, J. J., Wellman, B., & Morgan, D. L. (1997). It's about time: how, why, and when networks change. *Social Networks*, 19, 1–7.

Suurmeijer, T. P., Doeglas, D. M., Briancon, S., Krijnen, W. P., Krol, B., Sanderman, R., Moum, T., Bjelle, A., & van den Heuvel, W. J. (1995). The measurement of social support in the 'European Research on Incapacitating Diseases and Social Support': the development of the Social Support Questionnaire for Transactions (SSQT). *Social Science and Medicine*, 40, 1221–1229.

Uhlig, T., Kvien, T. K., Glennås, A., Smedstad, L. M., & Førre, Ø. (1998). The incidence and severity of rheumatoid arthritis. Results from a county register in Oslo, Norway. *The Journal of Rheumatology*, 25, 1078–1084.

UNESCO. International Standard Classification of Education (ISCED).  
1976. Paris, Division of Statistics on Education. Ref Type: Generic

Van Sonderen, E. (1990). Measurement of social network and social support. Empirical results in relation to the Euridiss Instruments. *International Journal of Health Sciences, 1*, 203–216.

Veenstra, M. (1996). *Persoonlijke sociale netwerken van mensen met reumaïde artritis*. Vakgroep Sociologie, Rijksuniversiteit Groningen, Holland.

Weinberg, R. B. & Marlowe, H. A. (1983). Recognizing the social in psychosocial competence: the importance of social network interventions. *Psychosocial Rehabilitation Journal, VI*, 25–34.

Wellman, B. & Wortley, S. (1990). Different strokes from different folks—community ties and social support. *American Journal of Sociology, 96*, 558–588.

Werneke, U., Goldberg, D. P., Yalcin, I., & Ustun, B. T. (2000). The stability of the factor structure of the General Health Questionnaire. *Psychological Medicine, 30*, 823–829.

Wethington, E. & Kessler, R. C. (1986). Perceived support, received support, and adjustment to stressful life events. *Journal of Health and Social Behavior, 27*, 78–89.

Wortman, C. B. & Conway, T. L. (1985). The role of social support in adaptation and recovery from physical illness. In S. Cohen & S. L. Syme (Eds.), *Social support and Health* (pp. 281–298). New York: Academic Press.