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PAULA MÄKELÄINEN

Rheumatoid Arthritis Patient Education and Self-Efficacy

Doctoral dissertation

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Department of Nursing Science
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ABSTRACT

Background of the study: The purpose of rheumatoid arthritis patient education is to increase the patients' knowledge levels, and to improve their self-management strategies by influencing their self-efficacy.
Purpose of the study: The purpose of this study was to describe current rheumatoid arthritis patient education provided by rheumatology nurses, how much patients know about their disease and its treatments, and what kind of self-efficacy they have when no intervention has been used.
Data and methods: The data were collected from 80 rheumatology nurses. The data were also collected from rheumatoid arthritis patients at baseline (n = 252), and after three and six months (n = 223). In addition, 173 patients described and/or evaluated patient education. The data were collected using self-reported questionnaires, and analysed using descriptive and non-parametric statistical tests.
Results: Rheumatology nurses informed the patients mostly about medical treatment, and used the one-to-one patient education method. Only 45% of the nurses discussed self care at home. The patients' knowledge of their disease and its treatments varied from poor to good, and their self-efficacy from weak to strong. The patients' uncertainty level increased when they had to reduce their arthritis pain using non-medical techniques. The patients' good knowledge and their strong self-efficacy did not correlate with each other. Weak patient self-efficacy correlated with a high degree of disability. The patients' knowledge scores increased, and their self-efficacy scores decreased during the six-month period. Half of the patients were satisfied with patient education provided by rheumatology nurses. However, every fourth patient was not satisfied; the main reason for the dissatisfaction being that nurses did not focus on the patient's emotional support.
Conclusions and practical implications: The results provide a useful insight into current patient education. It is important that rheumatology nurses plan the content and methods of patient education with the patients so that it is based on the patients' individual information needs and their need for support. Nurses should teach self-care to patients and concentrate on supporting those patients whose self-efficacy is weak. Especially with newly-diagnosed patients, nurses should the take time to discuss the patient's feelings caused by the disease.

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Medical Subject Headings: Arthritis, Rheumatoid; Patients; Patient Education as Topic; Arthritis, Rheumatoid/nursing; Self Efficacy; Patient Satisfaction

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TIIVISTELMÄ

Tutkimuksen tausta: Nivelreumaa sairastavan potilaan ohjauksen tarkoituksena on antaa potilaalle riittävästi tietoa sairaudesta ja sen hoidosta sekä vahvistaa sairastuneen hallinnan tunnetta. Hallinnan tunne edesauttaa sairauden kanssa toimeen tulemista arkielämässä.
Tutkimuksen tarkoitus: Tämän ei-kokeellisen tutkimuksen tarkoituksena oli kuvata, mistä asioista reumahoitajat antavat ohjausta nivelreumapotilaille ja mitä ohjausmenetelmiä he käyttävät. Lisäksi tavoitteena oli kartoittaa, miten paljon potilaat tietävät sairaudestaan ja sen hoidosta sekä millainen heidän hallinnan tunteensa on.
Aineisto ja menetelmät: Tutkimukseen osallistui 80 reumahoitajaa ja 252 nivelreumapotilasta eri sairaaloista ja terveyskeskuksista. Potilailta aineisto kerättiin myös kolmen ja kuuden kuukauden kuluttua ensimmäisestä aineiston keruusta (n = 223). Lisäksi 173 potilasta kuvasi ja/tai arvioi saamansa ohjauksen sisältöä. Aineisto kerättiin käyttämällä kyselylomakkeita. Aineisto analysoitiin käyttämällä kuvailevia ja ei-parametrisia tilastollisia menetelmiä.
Tulokset: Reumahoitajat antoivat nivelreumapotilaille ensisijaisesti ohjausta lääkehoidosta. Vain 45 % hoitajista mainitsi, että he keskustelevat itsehoidosta potilaiden kanssa. Yksilöllinen ohjaus oli eniten käytetty ohjausmenetelmä. Potilaiden tieto sairaudesta ja sen hoidosta vaihteli vähäisestä tiedosta hyvään tietoon. Samoin potilaiden hallinnan tunne vaihteli heikosta hallinnan tunteesta vahvaan hallinnan tunteeseen. Potilaat kokivat kivun hallinnan tunteensa heikommaksi, jos he joutuivat käyttämään ei-lääkkeellisiä menetelmiä nivelkipunsa hoitamiseen. Potilaiden hyvä tietämys sairaudesta ei korreloinut vahvan hallinnan tunteen kanssa. Potilaiden heikko hallinnan tunne korreloi heikon toimintakyvyn kanssa. Potilaiden tieto heikkeni ja heidän hallinnan tunteensa vahvistui puolen vuoden aikana. Puolet potilaista oli tyytyväisiä reumahoitajalta saamaansa ohjaukseen. Kuitenkin joka neljäs potilas ei ollut tyytyväinen ohjaukseen, ja suurin syy tyytymättömyyteen oli hoitajalta saadun emotionaalisen tuen puute.
Johtopäätökset ja suositukset: Tämä tutkimus antaa uutta tietoa nykyisestä nivelreumaa sairastavan potilaan ohjauksen sisällöstä. Tulosten mukaan reumahoitajien tulisi suunnitella potilasohjauksen sisällöt ja käytettävät ohjausmenetelmät yhdessä potilaan kanssa, jotta ne perustuvat potilaan yksilöllisen tiedon ja tuen tarpeeseen. Reumahoitajien tulee lääkeohjauksen lisäksi opettaa potilaille myös itsehoitomenetelmiä, jotka auttavat potilasta selviytymään sairauden oireiden kanssa. Lisäksi hoitajien tulee keskittyä erityisesti niiden nivelreumapotilaiden tukemiseen, jotka kokevat hallinnan tunteensa heikoksi. Reumahoitajien on varattava aikaa varsinkin vastasairastuneen potilaan ohjaukseen, jotta potilaalla on riittävästi aikaa käsitellä tunteitaan, joita nivelreumaan sairastuminen hänessä herättää.

Yleinen suomalainen asiasanasto: nivelreuma; potilaat; ohjaus; sairaanhoitajat; potilasohjeet; kokemukset; itseluottamus; tyytyväisyys

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Mikkeli, March 2009

Paula Mäkeläinen

ABBREVIATIONS AND DEFINITIONS

AIMS2 = Arthritis Impact Measurement Scale, version 2

ASES = Arthritis Self-Efficacy Scale

ASMC = Arthritis Self-Management Course

ECTS = European Credit Transfer System

FSE = Function Self-Efficacy

HAQ = Health Assessment Questionnaire

OSE = Other Symptoms Self-Efficacy

PKQ = Patient Knowledge Questionnaire

PSE = Pain Self-Efficacy

RA = Rheumatoid arthritis

RN = Registered nurse

VAS = Visual Analogue Scale

LIST OF ORIGINAL PUBLICATIONS

I Mäkeläinen P, Vehviläinen-Julkunen K, Pietilä A-M. 2007. Rheumatoid arthritis patients' education – contents and methods. Journal of Nursing and Healthcare of Chronic Illness in association with Journal of Clinical Nursing, 16, 11C, 258 – 267. DOI: 10.1111/j.1365-2702.2007.01953.x

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CONTENTS

1 INTRODUCTION 15
2 BACKGROUND LITERATURE 18
2.1 Rheumatoid arthritis and patients' experience of living with it 19
2.2 Rheumatoid arthritis patient education 22
2.2.1 Definition of patient education 22
2.2.2 Types of RA patient education 23
2.2.2.1 Current RA patient education 25
2.2.2.2 Rheumatology nurse and RA patient education 27
2.2.2.3 RA patients' satisfaction with patient education 29
2.2.3 Increasing RA patients' knowledge through patient education 30
2.3 Rheumatoid arthritis patient self-efficacy 31
2.3.1 Definition of self-efficacy 32
2.3.2 Strengthening RA patient self-efficacy through patient education 35
2.4 Summary of the background literature 38
3 PURPOSE OF THE STUDY 40
4 MATERIAL AND METHODS 41
4.1 Setting and sampling 43
4.1.1 Sample of rheumatology nurses 43
4.1.2 Sample of RA patients 43
4.2 Data collection and analysis 44
4.2.1 Data concerning the rheumatology nurses 44
4.2.2 Data concerning the RA patients 47
4.3 Ethical considerations 55
5 RESULTS 57
5.1 Contents and methods of RA patients' education provided by rheumatology nurses 57
5.2 RA patients' knowledge of their disease and its treatments, and how it changed during the six months 59
5.3 The nature of RA patients' self-efficacy and its connection to their knowledge of RA and its treatments, and how it changed during the six months 61
5.4 RA patients' evaluation of patient education provided by rheumatology nurses 63
5.5 Summary of the main findings of the study 64

6 DISCUSSION 67
6.1 Discussion of the results 67
6.2 Limitations of the study 70
7 CONCLUSIONS AND SUGGESTIONS FOR FURTHER RESEARCH 73
7.1 Conclusions and practical implications for RA patient education 73
7.2 Suggestions for further research 74
REFERENCES 75
APPENDICES

1 INTRODUCTION

Patient education is an ethical and legal obligation, and health care professionals should provide patients as much information as they require using the kind of terminology they understand (Finlex, The Act on the Status and Rights of Patients, Section 5, 785/1992). Patient education, in general, has been one of the main interests in nursing science in Finland since 1990 (e.g. Heikkinen et al. 2006). In addition, nursing scientists, researchers from other disciplines and multi-disciplinary research teams in other countries (1991, Lorig et al. 1993, Riemsma et al. 1997, Hammond & Freeman 2004) have been interested in rheumatoid arthritis (RA) patient education studying, for example, how arthritis patients' knowledge and self-efficacy can be increased by patient education. Patient education is an important part of RA patients' treatment, and it has been recommended as a routine in the management of arthritis.

Patient education is a multi-stage learning process. The purpose of RA patient education is to improve patients' knowledge levels and to influence their health behaviour positively. On the basis of this information, patients are supposed to be capable of monitoring the disease and managing with it (e.g. Hill 2003, Schrieber & Colley 2004). Nowadays, patient education is, as it was in the 1950s and 1960s, one of the non-pharmacological treatments in RA (Sarkio 1996, Goldring 2000). Even though there are new medications, RA patients' self-care is important and patients should learn self-care skills so that they could cope at home with the varying symptoms caused by the disease (Barlow 2001, Riemsma et al. 2003b). Patients use various coping strategies to manage the stress associated with RA (Melanson & Downe-Wamboldt 2003).

RA is a painful long-term disease which causes pain, early morning stiffness, joint swelling, malaise and fatigue. It may also cause functional disability and thereby difficulties in managing at home and at work (Young et al. 2002, Dubey & Gaffney 2005). About 0.8% of adults in Finland suffer from RA, and so does 0.5 – 1.0% of the population of Northern Europe. It is more prevalent among women (sex ratio of 3:1); the typical age at onset is 60 to 70 years (e.g. Symmons et al. 2000, Isomäki 2002, Working group established by the Finnish Society for Rheumatology in 2003). Physical disability caused by RA is one of the important predictors of RA patients becoming incapable of working, for example (Young et al. 2002).

Typically, RA patient education is planned and provided by multidisciplinary teams consisting of physicians, nurses, physical and occupational therapists, pharmacists, social workers, psychologist and dieticians (Sheepy 2000, Schrieber & Colley 2004). In this study, 'patient education' is defined as '*a planned educational process with the purpose of influencing the patients´ health behaviour and quality of life. This educational process is related to the context and interaction relationship of the patients and the educators (e.g. a rheumatology nurse)*' (e.g. Ramos-Remos et al. 2000, Kääriäinen & Kyngäs 2005b).

Patient education programs have become one way to provide information for patients. There are several descriptive and evaluative studies on RA patient education programs and their influence on patients´ knowledge level, compliance and self-care (e.g. Brus et al. 1998, Riemsma et al. 2003a, Lorig et al. 2004). Patient education can be delivered in one-to-one (individual) education sessions or as group education, and education programmes can be structured or informal. A key concept in the management of RA patients and their educational programmes is the need to improve 'self-efficacy'.

The concept of *perceived self-efficacy* referring to one of the control concepts developed by Albert Bandura in 1977. On the basis of the previous studies (e.g. Taal et al. 1993, Barlow et al. 1999, Hammond & Freeman 2004), self-efficacy is an important predictor of the future behaviour of patients with a long-term disease; self-efficacious patients are more confident of managing with their disease and it thus influences their physical functioning. When one suffers from a long-term disease such as RA, a change may be necessary in the patient's behaviour when he or she is learning self-care at home (e.g. pain management). The concept of 'self-efficacy' was used in nursing science for the first time when Kate Lorig examined osteoarthritis and RA patients' self-efficacy and its influence on their health behaviour (Lorig et al. 1989). She also developed an instrument with her colleagues, the Arthritis Self-Efficacy Scale (ASES) that has been used in several international studies since 1990.

In Finland, there has been nursing research into patients' and nurses' experiences of patient education in general. However, there is lack of knowledge of the contents of patient education and how the current patient education influences RA patients' knowledge and self-efficacy. Therefore, more research is necessary for developing nursing practices and patient education methods for chronically ill patients. Chronic illnesses and evidence-based clinical practices are also priorities in international nursing research (Callister et al. 2006).

The aim of this cross-sectional and longitudinal study is to describe the current RA patient education provided by rheumatology nurses in different public health care units in Finland. In addition, the aim is to describe how much RA patients know about their disease and its treatments, and what kind of self-efficacy they have without any educational intervention. Previous studies have shown that patient education intervention (e.g. group education) increases RA patients' knowledge and self-efficacy. This kind of research is missing in Finland. The findings of the study can be used for enhancing RA patient education. In addition, the results can be used when developing curricula for nurse education programmes and supplementary courses in rheumatology nursing.

2 BACKGROUND LITERATURE

The literature for this study covers the period from 1966 to 2008. RA patient education and patient self-efficacy has interested researchers in different countries in Europe, North-America, Asia and Australia. Especially the concept of 'self-efficacy' seems to have attracted wide interest in different disciplines, since a search with the keyword 'self-efficacy' gave 72 711 references from Nelli from all areas of human life (e.g. education, social psychology, psychology, medicine). In this study, the search after studies utilized the keywords 'self-efficacy', 'rheumatoid arthritis', and 'patient education', and it was conducted into the electronic databases Cinahl, PubMed, and Nelli, the latter including PsycINFO and MEDLINE. Table 1 shows the results of the search.

Table 1. Literature search from electronic databases.

Electronic database	Keywords	Number of references	From years
PubMed	rheumatoid arthritis and nursing	679	1966 - 2008
	rheumatoid arthritis and patient education	434	1978 - 2008
	rheumatoid arthritis and self-efficacy	186	1987 - 2007
	rheumatoid arthritis and nurse	293	2003 – 2008
	rheumatology nurse and patient education		
	rheumatology nurse and patient education	7	1996 – 2005
	and rheumatoid arthritis	3	2000 - 2003
CINAHL	rheumatic disease and patient education	89	1994 - 2008
	rheumatic disease and nursing	160	1994 - 2008
	individual education and rheumatoid arthritis	12	1997 - 2007
	rheumatoid arthritis and nurse educator	16	1990 - 2008
	self-efficacy and nurse educator	64	1986 - 2008
	self-efficacy and nurse educator and rheumatoid arthritis	4	1996 - 2004
Nelli -nursing science;	individual patient education and rheumatoid arthritis	127	1993 - 2006
references from databases e.g.	rheumatoid arthritis and patient education and nurs?	85	1995 - 2008
Cinahl, PsycINFO,	patient education and self-efficacy	210	1992 - 2007
PubMed, Medline	patient education and self-efficacy and rheumatoid arthritis	114	1993 - 2008
	self-efficacy and rheumatoid arthritis and nurs?	71	1997 - 2006
	Total number of accepted studies	**33**	**1991 - 2008**

The criteria for accepted studies were that (1) the article was published in a journal that is considered scientific, (2) the article was available as 'Ovid full text' or printable from the journal, (3) the article concerned RA patient education or self-efficacy. However, fewer

studies were found using the keywords ‘nurse educator’, ‘individual’, ‘nursing’, ‘nurse’ or ‘rheumatology nurse’ combined to RA patients’ education. The studies have concerned more multi-disciplinary patient education. Altogether 33 studies from 1991 to 2008 were chosen.

2.1 Rheumatoid arthritis and patients’ experience of living with it

Previous studies show, RA influences many areas of a patient’s life. RA is evident throughout the world and it affects all races. In Finland, approximately 0.8% of adults suffer from RA and about 0.5 – 1.0% of the population in Northern Europe suffer from it (Sangha 2000, Symmons et al. 2000, Isomäki 2002). RA is a chronic, multi-systemic and autoimmune long-term disease of unknown cause. It usually begins in the small joints of the hands and feet, spreading later to the larger joints, causing joint deformity and progressive physical disability. The incidence was 29.1/100 000 in the year 2000 in Finland, the trend declining from 1980 (Kaipiainen-Seppänen & Kautiainen 2006).

However, the prevalence of RA is generally lower in developing countries. The prevalence increases in older population: the typical age at onset is 60 to 70 years of age. RA is more prevalent among women (sex ratio of 2.5:1). The reason for the greater female gender prevalence is not clear, but hormonal reasons may be one of the obvious causes for the predominance. In addition, smoking, socio-economic status, education and stress may constitute risks (Symmons et al. 2000, Sangha 2000, Working group established by the Finnish Society for Rheumatology in 2003). Symptoms of RA may vary from arthritis pain, stiffness, swelling and fatigue to malaise, and thereby cause functional impairment and reduced general health (e.g. Fransen & van Riel 2005).

Treatment of RA is typically targeted toward symptoms and disease modification. RA patients’ treatment is provided by multi-disciplinary teams, and the purpose of treatments is to slow down the disease progression using medical and non-medical treatments (Working group established by the Finnish Society for Rheumatology in 2003). RA treatment was conducted by multi-disciplinary teams as early as the 1950s, with patients included in the teams when their disease was concerned. Gold was used for medical treatment in the 1930s and cortisone in the 1950s (Sarkio 1996). Nowadays, anti-rheumatic and non-steroidal anti-inflammatory drugs, but also gold and cortisone are used to reduce inflammation and arthritis pain (Working group established by the Finnish Society for Rheumatology in 2003).

Physical therapy is used to reduce patients' arthritis pain and maintain their functioning (Working group established by the Finnish Society for Rheumatology in 2003). In the 1950s, too, it was important to support patients' physical functioning by encouraging them to self-care (e.g. to make their beds). In addition, healthy nutrition, mobilizing and rest were important parts of RA patients' treatment (Sarkio 1996). Today, occupational therapy is tailored to teach patients joint protection and energy conservation. The purpose of surgical treatment is to return RA patients' functioning in case joints have been damaged (Working group established by the Finnish Society for Rheumatology in 2003).

RA causes expenditure to the national economy, health care system and also the patients themselves. In the study of Laajalahti and Sintonen (2005), 51% of the costs *for patients* were caused by the social services required to support their day-to-day activities. The other 49% were caused by their use of health services (treatment in in-patient and out-patient departments, medication etc.) (Laajalahti & Sintonen 2005).

RA lead to many limitations for patients: social life, hobbies, everyday tasks, personal and social relationships, and physical contact, such as hugging and lovemaking. RA patients have experienced uncontrollably severe pain caused by the disease (e.g. Hwang et al. 2004, also Laajalahti & Sintonen 2005), and this can increase with age and disease duration (Jacobsson & Hallberg 2002). Painful joints and stress can lead to sleeping problems. Night pain, for example, is a significant problem that causes worry and stress for patients (Jump et al. 2004, Treharne et al. 2007, Coady et al. 2007). According to the study by Vaajoki et al., RA patients' pain causes them emotional discomfort (Vaajoki et al. 2004). Arthritis pain is reported to be related to a decrease in a person's satisfaction on his or her health status (Minnock et al. 2003), and restricted joint mobility and increased perception of pain have been reported to be the most determining factors in predicting concurrent disability (Holm et al. 1998). Pain patients may have to give up, for example, tasks that require hands such as writing or holding a book to read (Whalley et al. 1997).

A common consequence of RA is the limitation of physical activities and decrease of physical strength (e.g. Melanson & Downe-Wamboldt 2003, Hwang et al. 2004). The physical limitations caused by the illness form patients' most frequently identified stressors. RA patients often experience that their limited mobility makes them dependent on others, leading to feelings of helplessness and lack of control or independence (Taal et al. 1993, Whalley et al. 1997, Melanson & Downe-Wamboldt 2003, Vaajoki et al. 2004). This influences patients' mood and self-esteem. Female patients have more difficulties in

this respect than male patients, because they have the responsibility for housework and childcare (Hwang et al. 2004). Functional limitations have also been found to decrease patients' quality of life (Jacobsson & Hallberg 2002) and psychological well-being (Nagyova et al. 2005).

RA patients also express feelings of tiredness or fatigue. Fatigue can be intermittent or continuous. Many patients experience 'flares', but fatigue is not always related to flares (Jump et al. 2004, Treharne et al. 2007). Fatigue has also been described as general lethargy or exhaustion after activity. Patients need to plan their days so that they have time to rest. Pain and tiredness cause them to have to stop doing household tasks, for example. RA patients have described negative feelings such as anger, frustration, depression, irritation (Whalley et al. 1997), anxiety, shame, suffering, sadness, guilt or uncertainty (Hwang et al. 2004).

Disease status has been found to predict illness-related functioning but not emotional or social adjustment (Curtis et al. 2005), and the reported feelings of depression have been more generalized with no specific cause (Whalley et al. 1997). Perceived stress has been a good predictor of positive and negative emotionality, more so than disease severity (Curtis et al. 2005), and illness acceptance beliefs have been identified as significant predictors of anxiety and depression (Barlow et al. 1999). According to previous studies (e.g. Jump et al. 2004), RA patients seem to find themselves in a vicious circle because the higher levels of affective disorders (depression, anxiety) are likely to increase their somatic awareness and tendency to focus on sensations of pain, stiffness and fatigue (Jump et al. 2004). In the study of Conner et al. (2006), RA patients who had been depressed experienced difficulties in managing with their chronic pain (Conner et al. 2006). Iire found in her study (1999) that RA patients' knowledge of the disease and depression were the most important factors predicting the development of uncertainty.

However, RA patients' self-esteem and adjustment to the disease seem to be related to their psychological well-being (Nagyova et al. 2005). When suffering of RA, patients' own abilities to cope with the symptoms in their everyday lives are very important and patients use different coping strategies to manage the stress associated with RA (Melanson & Downe-Wamboldt 2003). Coping efficacy was significantly related to pain, mood, and social support. According to the study of Keefe et al. (2001), RA patients experienced much less joint pain and negative moods and much more positive moods if they could control and decrease pain using spiritual or religious coping methods (Keefe et al. 2001). In the study

of Leino-Kilpi et al. (1999), Finnish RA patients stated that their positive thoughts and perseverance helped them to cope with the disease. In addition, patients said that social support from family and friends increased their satisfaction with their health status (Leino-Kilpi et al. 1999, also Minnock et al. 2003). Social support has been linked to levels of social activity (Curtis et al. 2005).

2.2 Rheumatoid arthritis patient education

2.2.1 Definition of patient education

The terms 'patient education', 'health education' and 'counseling' have been used side-by-side in nursing practice. The choice of the term seems to depend on the situation in which education or counseling is delivered (hospital or primary health care unit), because the purpose of the activity varies, in practice. Ramos-Remus et al. (2000) defines *health or patient education* as 'any combination of learning experiences designed to facilitate the voluntary adoption of behaviour conductive to health', or 'to improve patients' behaviour and through it, their health status and ultimately long-term outcome'.

Patient education can be a combination of methods, such as provision of information, teaching, counselling, social support and cognitive behavioural treatment with the purpose of influencing a patient's knowledge and health behaviour. This view involves the assumption that patients participate actively in caring for their health (Lorig 2001, Schrieber & Colley 2004, Taal et al. 2006). *Counseling* is defined as 'professional activity or a process that is delivered between educator and patient and is active target-oriented action'. Counseling can also include concepts such as 'guidance', 'education' and 'information', and counseling is before patient education (Kääriäinen & Kyngäs 2005b). In addition, counseling can include social support and giving patients the opportunity to discuss their problems (Riemsma et al. 2002).

Poskiparta (1997) defined patient education as a 'reflective process in which educator and patient co-operate together and try to find the solutions together'. The purpose is that patients become more self-piloting and through that their life-control increases. Also Vänskä (2000) emphasizes the patient's active role, and in her view, an educator's role is to empower the patients to find suitable techniques to promote the desirable aspects in their lives (Vänskä 2000). Patient-centred counseling enables the patient's participation and gives the patient the responsibility of the decisions that concern his or her own health

or illness. Patient-centred counseling also increases the patient's independence (Kääriäinen et al. 2005). Kettunen (2001) emphasizes the process of communication: the educator and patient can reciprocally share experiences that lead to both learning. Sharing encourages patients to ask the right questions and allows them to interrupt the educator when necessary.

In conclusion, one of the differences between the definitions presented above is the issue of the purpose of patient education: is the purpose to promote patients' health by preventing possible diseases, or to teach patients to cope with their diseases, such as RA, so that the patients can live as normal an everyday life as possible. The second difference we find is whether the role of the educator is to act as a specialist who leads the discussion while the patient acts as a passive listener, or is the patient expected to be active participant in the conversation.

In this study, we define the concept of 'patient education' as *a planned educational process with the purpose of influencing the patients' health behaviour and quality of life; the educational process is related to the context and interaction relationship of the patients and the educators*. This definition is derived from the definitions of Ramos-Remus et al. (2000), Riemsma et al. (2002) and Kääriäinen and Kyngäs (2005b).

2.2.2 Types of RA patient education

Patient education can be delivered in one-to-one education sessions given by specialists or in group education sessions given by multi-disciplinary teams of health care professionals. Education programmes can be structured or informal. An arthritis self-management programme (or course) is a structured programme that can be delivered by lay people and health care professionals (Hainswort & Barlow 2001, Hill 2003, Schrieber & Colley 2004, also Lorig et al. 1989). Structured educational programmes are planned educational activities designed to teach patients knowledge, beliefs and behaviours, such as adherence to health recommendations, self-management and coping strategies (Taal et al. 2006).

One-to-one and group education have advantages and disadvantages: one-to-one patient education is flexible and can be adjusted to an individual patient's needs, with topics tailored according to the patient. Patients can decide the order of the topics and determine the pace of teaching. The advantages of group education are found in that other patients can act as powerful role models, and patients can learn from each other.

Group education also facilitates social interaction. Another advantage is that group sessions are less labour intensive, because one person can give information for many patients at the same time. Groups are also good for teaching general principles such as disease process, treatments, physical exercise and relaxation, exercise therapy, diets and nutrition (Hill 2003, also Lindroth et al. 1997, Oh & Seo 2003). RA patients have been known to consider that emotional issues are better dealt with among other RA patients who understand their feelings and to whom one does not need to explain why one feels the way one does (Barlow et al. 2002).

A disadvantage of one-to-one patient education is that it does not facilitate sharing experiences or reaching solutions to any problems because there is no interaction with other patients. Disadvantages of group education include the facts like some patients do not want to join groups, people have different learning rates and skill levels, and some may even fear criticism. Also, one articulate patient can dominate the whole group (Hill 2003). Group education may also increase newly diagnosed RA patients' anxiety and depression (Brus et al. 1997).

One-to-one education may suit RA patients best when they need individualized exercise or joint protection programmes, or information concerning e.g. a new drug treatment prescribed to them. It is also necessary to pay attention on the patient's ability to take in information in early RA, for example, when the patient is in shock and may need emotional support more than information (Hill 2003). In certain studies, RA patients preferred education about the disease and its treatments to be delivered on one-to-one basis by health care professionals (Barlow et al. 2002). Patients stress the importance of there being enough time for dialogue to take place. An encouraging atmosphere motivates patients to express their feelings and to ask questions (Kyngäs 2003, Haugli et al. 2004).

Written materials, such as leaflets and booklets, are often used to supplement one-to-one and group education, but it must be of high quality and easily understood before it is useful (Arthur & Clifford 1998, Hill & Bird 2003, Walker et al. 2007, also Kyngäs et al. 2004). RA patients can receive information from leaflets on medication prescribed to them, for example (Barlow et al. 2002, Hill & Bird 2003, also Kyngäs et al. 2004). Leaflets can be effective in promoting longer term increases in knowledge (Barlow & Wright 1998), and they are memory aids giving general information such as names and side-effects of medication. However, leaflets alone are not sufficient to convey information (Barlow et al. 2002).

Other sources of information include patients' relatives, TV, books, videos, computer programs, the Internet, and telephone helplines (e.g. Hugles et al. 2002, Neame et al. 2005, and Wilson et al. 2001). The study of Brown et al. (2006) showed that RA patients were satisfied with a rheumatology helpline which they could call when they needed information on their diagnosis, drugs, understanding their symptoms, advice on changing conditions or pain management, for example. However, a telephone helpline should be provided all days a week, and patients should receive a call back the same day they leave a message to an answering machine. According to Brown's study (2006), the patients preferred to speak with a rheumatology nurse rather than other health care professionals when contacting the rheumatology helpline (Brown et al. 2006, also Hugles et al. 2002). In the study by Barlow et al. (2002), RA patients considered videos good visual aids for demonstrating how aids and devices could be used or how families coped in the home environment. Computer programs were not experienced as good sources of information (Barlow et al. 2002).

2.2.2.1 Current RA patient education

One-to-one patient education is the most commonly used method in Finland (Kyngäs et al. 2004, Heikkinen et al. 2006, Kääriäinen et al. 2006, Juhola et al. 2007). Typically, RA patient education is carried out in hospitals and health centres during and different health care professionals' teach RA patients on one-to-one basis during their consulting hours. For the first two years, newly-diagnosed RA patients have their follow-up controls in hospitals, and later, in health centres. However, controls continue taking place in hospitals if the patient's disease is active. Rheumatology or district nurses monitor an RA patient's disease in health centres when it is in remission (Figure 1).

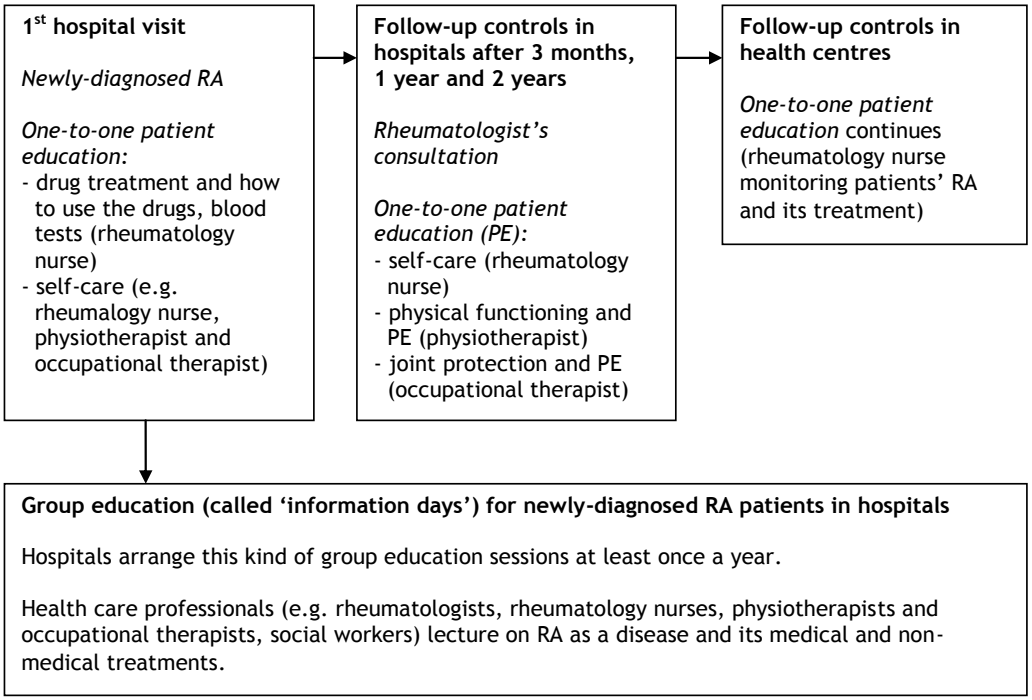

Figure 1. RA patient education provided in public health care organizations (e.g. Hakola et al. 2004).

After receiving the diagnosis, patients are invited to join a group education session within three months. Hospitals arrange this kind of sessions at least once a year, and patients can participate in the session if they so wish but it is not compulsory. In these sessions, multi-disciplinary teams (rheumatologist, rheumatology nurse, physiotherapist and occupational therapist, social worker) deliver lectures on RA as a disease and its medical and non-medical treatments (e.g. Hakola et al. 2004). Certain Finnish hospitals have developed models of group education for RA patients (Liimatainen & Stenbäck 2005). The models differ from the group education (e.g. Arthritis Self-Management Course) that has been more common in other countries.

In Finland, patient education methods such as providing audiovisual materials have been less used (Lipponen 2008). In addition, Kääriäinen found in her study (2007) that one third of the Finnish patients had not received any written materials. According to the study of Laiho et al. (2008) the content, structure and language used in current written materials would need to be clarified to make it more patient-oriented.

2.2.2.2 Rheumatology nurse and RA patient education

Rheumatology nurses typically mention patient education as being of primary importance in their work, and studies have shown that nurses have an important role in educating RA patients to cope with their RA and to increase their personal control over it (e.g. Newbold 1996, Ryan et al. 2005). In Finland, 'rheumatology nurse' is not an official title. Finnish nurses graduate as registered nurses (RN) and have the possibility to specialize (in e.g. district nursing). In this study, the term 'rheumatology nurse' means *a registered nurse (RN) involved in rheumatology patient treatment in public health organizations*. These nurses may have taken a supplementary nursing course in rheumatology or not. Different health care units nominate nurses involved in rheumatology to work as rheumatology nurses. However, many nurses are involved in rheumatology nursing without any nomination.

Even though there are rheumatology nurses (or rheumatology nurse practitioners/specialists) working in many countries (e.g. Europe, America, Asia), a nurse practitioner's **training** usually differs from the training in Finland. The role and practice of nurse practitioner depends on the country's legislation (Gardner et al. 2004). The education required is the master's level (American Academy of Nurse Practitioners, 2003, The National Organization of Nurse Practitioners Faculties, 2006, also Gardner et al. 2004). However, there is a limited amount of studies available in English concerning the extents of curricula (ECTS) of master's degree programmes for nurse practitioners. Therefore, the level of education of rheumatology nurse practitioners/specialists cannot be directly compared to the level of rheumatology nurses' education in Finland.

Finnish nurses have certain opportunities to train themselves in rheumatology nursing. Polytechnics, in particular, organize different kinds of supplementary courses and specialization studies in rheumatology nursing (30 ECTS; one ECTS means 26.6 hours of student work) (e.g. Juhola et al. 2007). However, the Rheumatism Foundation have regularly organized a supplementary course in rheumatology nursing since 1995 (9 ECTS), carried out in three sessions, three days per session (http://www.reuma.fi, 2008).

In the U.S.A., nurse practitioners' curriculum includes, for example, domains such as teaching and coaching. This means assessing the patient's educational needs, creating an effective learning environment, designing a personalized plan for learning, providing health education, coaching the patient towards behavioural changes, and evaluating the

outcomes of patient education (American Academy of Nurse Practitioners, 2003, The National Organization of Nurse Practitioners Faculties. 2006). The Finnish supplementary course in rheumatology nursing includes patient education, too, but it is not as encompassing as in the U.S. nurse practitioner's curriculum (http://www.reuma.fi, 2008, also Juhola et al. 2007).

The nurses' **role** in RA patient education often means advising and educating their patients concerning their drug management (Tijhuis et al. 2002). Other educational content involves supporting and motivating patients in their self-care, educating them regarding medication, nutritional counseling, physical exercise and joint protection (e.g. Juhola et al. 2007). Rheumatology nurses often succeed not only in increasing RA patients' knowledge of RA significantly, but also in improving the patients' psychological status by teaching them how to manage their symptoms (Hill et al. 1994).

Emotional support and helping patients to cope with their disease have always been an essential part of nurses' work. Nurses learn about patients' fears and worries and encourage them to make their own choices in order to be comfortable in their disease situations (Long et al. 2002, Arvidsson et al. 2006). A nurse's emotional support and motivation often is an important predictor that young RA patients comply with their health regimens (Kyngäs 2002). Empathetic listening, for example, can encourage RA patients to manage their RA during activities of daily living (Iaquinta & Larrabee 2004).

Previous studies have shown that nurses can provide a holistic perspective, influencing positively patients' perceived ability to cope with their RA and increasing patients' personal control over their RA. Nurses can also influence patients' perceived level of well-being positively in this way (Barry et al. 1998, Ryan et al. 2005). According to the study of Arvidsson et al. (2006), patients stated that it was easier to ask a nurse about the effects and side-effects of drugs than it was asking other professionals. In addition, the patients found it easier to understand nurses' terminology, and this facilitated their understanding of how the prescribed drugs worked. RA patients also experienced that nurses in nurse-led clinics offered a holistic outlook to their disease and that they were seen as whole persons.

According to the review by Virtanen et al. (2007), nurses are able to empower patients if the nurse-patient relationship is balanced and respectful and the nurses know the patient and his or her needs and view the patient as an equal and competent participant in the discourse. However, Finnish studies (e.g. Kääriäinen 2007, Lipponen et al. 2008) have

shown that it is difficult for nurses to identify patients' information needs, since patients' backgrounds and health vary, and because time constraints have been a typical problem in one-to-one patient education situations (e.g. Kääriäinen & Kyngäs 2005a, Kääriäinen et al. 2006, Kääriäinen 2007, Lipponen et al. 2008, also Long et al. 2002). Some Finnish nurses consider their skill to perceive patients' fears and non-verbal communication insufficient (Lipponen et al. 2008).

2.2.2.3 RA patients' satisfaction with patient education

Studies surveying patients' satisfaction with patient education (e.g. Ahlmén et al. 2005) have shown that a good relationship with health care professionals plays a prominent role in the degree of patients' satisfaction. In addition, patients tend to be satisfied if the content of patient education is tailored to the patients' educational needs. The patients' satisfaction increases also if the rheumatology staff members respect the patients as experts on their own body and on living with arthritis. This increases the patients' trust in the treatment (Johansson et al. 2003, Haugli et al. 2004, Ahlmén et al. 2005).

On the other hand, dissatisfied patients have felt they have not been given the opportunity to explore their personal views and feelings about the objectives of patient education, and that the education provided has met the needs of the nurses rather than the patients (Kyngäs 2003, Johansson et al. 2003). RA patients have also experienced that poor communication is the problem when discussing sensitive issues such as RA causing the patient sexual problems: patients have been reluctant to approach health professionals and vice versa (Hill et al. 2003).

In the study of Kääriäinen (2007), the patients in a certain Finnish hospital regarded nurses' attitudes as partly negative. One fifth of these in-patients was of the opinion that patient education was not patient-oriented. Patients' social and psychological support, for example, was insufficient. Also Johansson (2006) found in her study that within the current Finnish practice of patient education nurses do not assess what the patients themselves want or need to know about their recovering or coping. Ramos – Remus et al. accentuate that the content of patient education is supposed to be a balance of what health care professionals want to teach, what educational needs the professionals think the patients have, and finally, what the patients want and think they need to know (Ramos-Remus et al. 2000).

2.2.3 Increasing RA patients' knowledge through patient education

Previous studies have shown that patient education has expanded RA patients' knowledge. Questionnaires have been used to assess specific knowledge of RA, such as anatomy, inflammation, aetiology, symptoms and blood tests, medications and how to use them, exercise, joint protection and energy conservation, pain relief and treatments (Hill et al. 1991, Lindroth et al. 1997, Hennell et al. 2004). RA patients' knowledge has often been assessed using the Patient Knowledge Questionnaire (PKQ) which was developed by Hill et al. in 1991. The studies have evaluated RA patients' knowledge levels regarding RA at the baseline, after an education programme and after three or 12 months. The PKQ has been in use in various studies after the year 2000 as well, but not for the same purpose (e.g. Minnock et al. 2003). The studies concerning the relationship between patient education and RA patients' knowledge are shown in the Table 2.

Table 2. Studies concerning the relationship between patient education and RA patients' knowledge of RA and its treatments (years 1991 – 1999; source MEDLINE, CINAHL).

Authors	Purpose of the study	n	Data collection	Main findings
Hill et al. 1991 UK	Develop the Patient Knowledge Questionnaire (PKQ) and test RA patients' knowledge of RA and its treatments	n = 40 + 29 for developing and testing the questionnaire n = 70	Questionnaire	General knowledge; mean 4.7 (max 9) Drugs: mean 3.3 (max 7) Exercise: mean 4.0 (max 7) Joint protection and energy conservation: mean 3.9 (max 7) Total score: 16 (SD 5.3; range 3 – 28) (max 30)
Davis et al. 1994 Canada	Evaluate the effect of an education programme on RA patients' knowledge and self-efficacy	n = 51	Baseline, after the programme and 3-month follow-up Questionnaires (e.g. PKQ)	Knowledge increased significantly ($p < 0.05$) Self-efficacy increased from baseline to follow-up ($p < 0.05$). Knowledge and self-efficacy did not correlate with each other at the baseline or after the education programme.
Barlow et al. 1999 UK	Compare patients of 1. short disease duration (< 1 years) 2. long disease duration (> 10 years) in terms of RA knowledge, symptoms of anxiety, depression and disease acceptance.	n = 102 n = 33 (group 1) n = 69 (group 2)	Questionnaires (e.g. PKQ)	No statistically significant differences between the groups as to knowledge, anxiety, depression or acceptance of illness. The needs of education did not differ between the groups. Illness acceptance beliefs were identified as a significant predictor of anxiety and depression.

Table 2 continues

Helliwell et al. 1999 UK	Examine the effect of an educational programme on RA patients' radiological damage and quality of life.	n = 77 n = 43 intervention group (1) n = 34 control group (2) Randomised controlled trial	Baseline, 4 weeks and 12 months Questionnaires (e.g. PKQ) Hand and wrist radiographs Laboratory tests	No significant difference between the groups as to Larsen scores, social functioning and general health perceptions (SF-36, HAQ). The educational group had more disease specific knowledge than the control group at 12 months ($p < 0.002$)

These studies showed that RA patients' knowledge increased significantly on the basis of patient education (also Lindroth et al. 1997, Kyngäs et al. 2004). This was the case with disease specific knowledge especially, and the influence lasted over 12 months. The duration of RA did not influence knowledge levels (also Hennell et al. 2004). Patients' good knowledge and their self-efficacy did not correlate.

2.3 Rheumatoid arthritis patient self-efficacy

Even if patient education increased RA patients' knowledge, Riemsma et al. (2002) found in their review that neither information only nor counselling programmes showed any significant effects as to RA patients' health behaviour. Also Taal et al. (1996) suppose that RA patient education should lead not only to changes in knowledge, but also to changes in behaviour (e.g. exercising, coping, problem-solving) and health status (e.g. pain, disability, depression).

The self-efficacy theory has given raise to a number of studies from different disciplines and countries in Europe, North-America and Asia since 1989. Individual researchers and research teams have been interested in, for example, chronically ill patients' (e.g. RA, diabetes) self-efficacy and how patients' self-efficacy can be increased by patient education. In Finland, some studies have been conducted in health psychology concerning a person's self-efficacy. For example, Järvilehto (1997) studied the self-efficacies of the participants on a rehabilitation course and found that increased self-efficacy influenced the respondents perceived functioning positively and decreased the perceived pain caused by work.

2.3.1 Definition of self-efficacy

The term ’self-efficacy’ has not got any one translation into Finnish. Ready-made translations cannot be found in dictionaries (e.g. MOT WSOY Enteka 4.0 suomi-englanti). The word ‘*self-*‘ means ‘itse-, oma-‘ or ‘automaatti-‘, and the word ‘*efficacy*’ means ‘teho[kkuus], vaikutus’. In Finnish studies, the concept of ‘self-efficacy’ has been described using terms such as ‘pystyvyysodotus', ’pystyvyyskäsitys’, ’pystyvyys’ or ’oma toimintakykyisyys’ (capability, ability, competence), ’omahallinta’ (self-control) or ’hallinnan tunne’ (“sense of control”). In this study, we think of the Finnish words ’hallinnan tunne’, because they describe well the content of ‘self-efficacy’.

Albert Bandura developed the theory and concept of ‘perceived self-efficacy’ in 1977, and he defines perceived self-efficacy as ‘*a judgement of one’s ability to organize and execute given types of performances, whereas an outcome expectation is a judgement of the likely consequence such performances will produce’*. The concept is not concerned with the skills individuals have but with their judgements of what they can do with their skills. In other words, individuals all have their own conceptions about how well they can perform certain behaviours regardless of what skills they actually have. Individuals can, for example, judge themselves to be very competent in a specific field, but less competent in another field (Bandura 1977, 1986).

According to the self-efficacy theory, there is a difference between the subskills individuals have and how well they can use them under different circumstances. Competent functioning requires both the appropriate skill and the self-efficacy belief. Thus, perceived self-efficacy is a major determinant of intention and motivation, because efficacy beliefs affect performance both directly and also by influencing the individual’s intention (Bandura 1977, 2002).

Individuals choose what challenges to undertake, how much effort to expend in the struggle, how long to persevere in the face of obstacles and failures, and whether failures are motivating or demoralizing (Bandura 2001, 2002). The individual may consider a certain behaviour more or less challenging. The more valuable the outcome of the behaviour, the more motivated he or she is to reach it. If the individual succeeds in reaching it, this strengthens his or her certainty to perform the behaviour. Individuals with strong self-efficacy are more persistent in the face of difficulties than those with weak

self-efficacy. Individuals with weak self-efficacy give up more easily than those with strong self-efficacy (Bandura 1986).

According to Bandura, self-efficacy is a uniformly good predictor of diverse forms of behaviour. Self-efficacy thus contributes to the development of individuals' subskills as well as draws upon them in fashioning new behaviour patterns. However, Bandura himself brings out that it is not possible to talk about a general self-efficacy as self-efficacy is related to specific situations and tasks (Bandura 1986, 2002).

Bandura has distinguished efficacy expectations from outcome expectations. Efficacy expectations vary in three dimensions that are magnitude (or level), generality and strength. In addition, outcome expectations can take three major forms: physical effects, social effects and self-evaluative reactions. Positive outcome expectations serve as incentives and negative ones as disincentives. If individuals judge themselves incompetent in performing certain behaviour they tend to avoid performing it (Bandura 1986, 2002).

An individual's efficacy expectations (self-efficacy) can be **strengthened** through performance accomplishments (practicing), modelling, verbal persuasion and reinterpretation of psychological symptoms. Practicing is the most important source of self-efficacy, because it is based on the individual's own experience. However, if the individual does not have particular experiences himself or herself, seeing others perform successfully can also form an important source of self-efficacy.

The second-best way to strengthen an individual's self-efficacy is through observing others. When the individual forms a conception of how new behaviours are performed, the symbolic construction serves as a guide for action on later occasions. The individual's self-efficacy can be increased by verbal persuasion also. The final and weakest source of self-efficacy is the individual's own physiological and emotional situation. The feed-back the individual receives either strengthens or weakens his or her self-efficacy (Bandura 1977, 1986, 2002). Figure 2 shows the modified theory of self-efficacy, the dimensions of efficacy and outcome expectations, and how an individual's efficacy expectations (self-efficacy) can be strengthened.

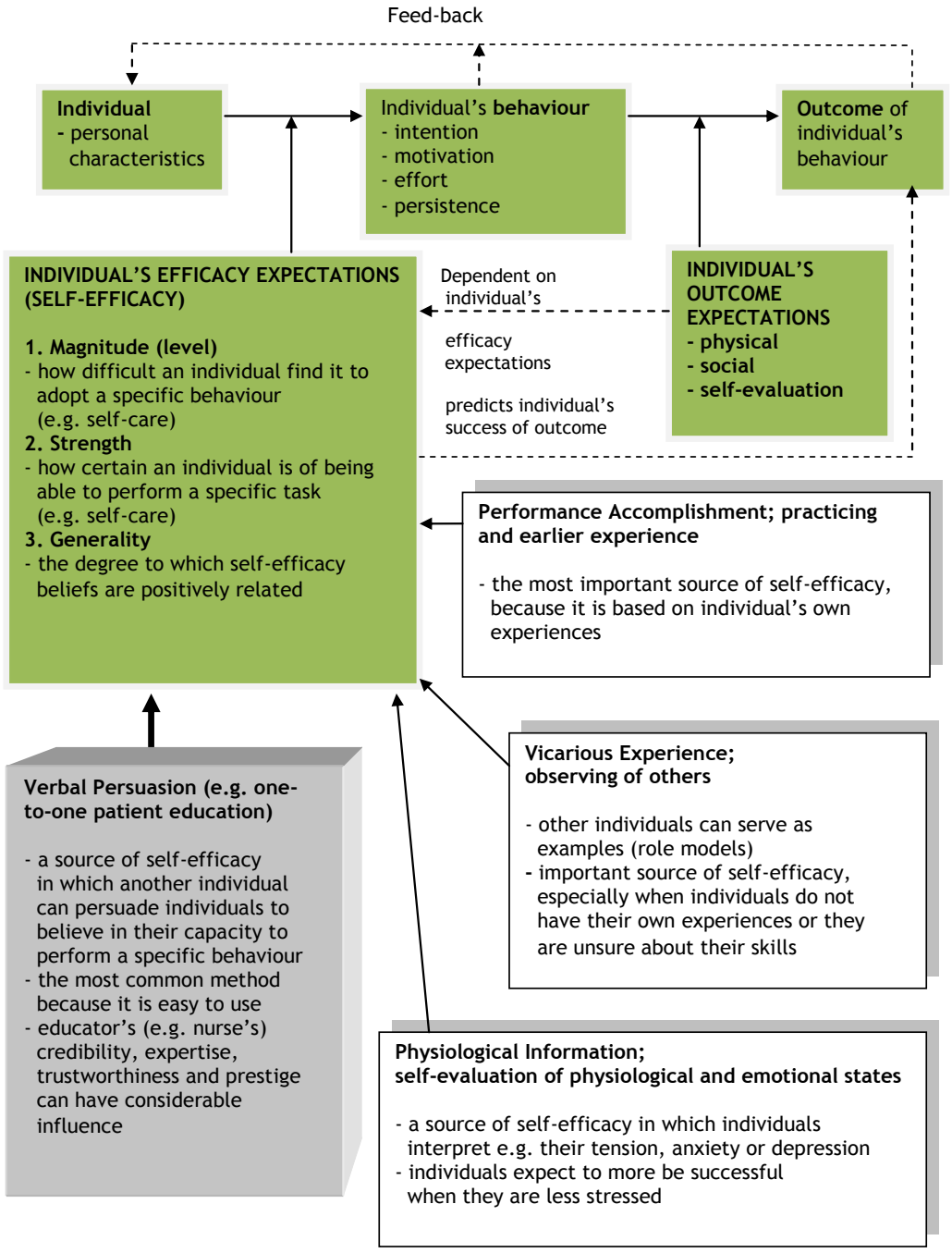

Figure 2. Modified self-efficacy theory (e.g. Bandura 1977, 2002, van der Bijl & Shortridge-Baggett 2002).

2.3.2 Strengthening RA patient self-efficacy through patient education

Previous studies have shown that, besides their knowledge levels, psycho-educational group education influences RA patients' self-efficacy positively and thus changes their behaviour (practicing self-management abilities). The patients' self-efficacy has been evaluated using the Arthritis Self-Efficacy Scale (Lorig et al. 1989) and compared to their pain, fatigue, psychological and physical functioning, and health status. Measures have been taken at the baseline and after one week to four years after the educational programme. Studies concerning the relationship between patient education and RA patients' self-efficacy are presented in Table 3.

Table 3. Studies concerning the relationship between patient education and RA patients' self-efficacy (from years 1993 – 2004; source PubMed, CINAHL, PsycINFO).

Authors	Purpose of the study	n	Data collection	Main findings
Lorig et al. 1993 USA	Determine the effects of an Arthritis Self-Management Program 4 years after participation in it.	n = 401 intervention group n = 567 (control group)	4-year follow-up Questionnaires (e.g. ASES) Self-reports of visits to physicians	Over the first 4-month after the ASMC, treatment subjects experienced significant increase (p< .01) in taught behaviour (e.g. exercise and practice of relaxation) and significant decrease (p< .05) in pain and depression. After 4-year follow-up, the trainees' pain had declined a mean of 20% and visits to physicians 40%, while physical disability had increased 9%. Among the RA patients in the study, disability actually declined during the 4 years. Estimated 4-year savings were $648 per rheumatoid arthritis patient and $189 per osteoarthritis patient.
Taal et al. 1993 Holland	Evaluate a group education programme and its effect on patients' self-efficacy and self-management behaviour (e.g. pain, functional abilities)	n = 38 intervention group n = 37 control group	Baseline, 1 and 4 weeks and 14 months after intervention Questionnaires (e.g. ASES) Joint tenderness score Laboratory tests Self-reports of performance of exercise, times/weeks	Group training (ASMC) influenced positively (p < .03; p < .02) functional disability, joint tenderness, practice of relaxation and physical exercises, self-management behaviour, outcome expectations, self-efficacy function and knowledge. After 14 months there were still effects seen as to practise of physical exercise, self-efficacy function and knowledge.
Barlow et al. 1998 United Kingdom	Determine the effectiveness of self-management training (ASMP) among people with RA and OA delivered in community settings	n = 117	Baseline and 4-month follow-up Questionnaires (e.g. ASES) Open ended questions concerning the patients views of the ASMP	Participants demonstrated significant increase in arthritis self-efficacy (p< .0005), cognitive symptom management (p<.0005), communication with doctors (p< .001), use of flexible exercises (p< .0001), strengthening exercises (p< .00008) and relaxation (p< .00005). Significant decreases were found in terms of pain (p< .002), fatigue (p< .002) and anxiety (p< .002).
Hammond & Freeman 2004 United Kingdom	Evaluate the long-term effects of joint protection on health status of people with early RA	n = 127 n = 62 standard program n = 65 joint protect. program	4-year follow-up Questionnaires (e.g. ASES) Joint count	At four years, the joint programme group continued to have significantly better joint protection adherence (p= .001), early morning stiffness (p = .01), AIMS activities of daily living (p = .04). Joint protection group had significantly fewer hand deformities.

The studies show that psycho-educational group education influenced the practice of relaxation and physical exercises positively (also Brus et al. 1998). This improved the RA patients' physical functioning, decreasing their arthritis pain, depression and anxiety (also Smarr et al. 1997). In addition, the RA patients in a joint programme group had significantly better joint protection adherence than others, and they had significantly fewer hand deformities. The results showed that the RA patients' self-efficacy was still strong six to 14 months after the programme (also Chui et al. 2004).

Group education has been shown to improve RA patients' coping strategies and to decrease their helplessness (Rhee et al. 2000). RA patients who had strong self-efficacy were less stressed and depressed by their condition and used better coping strategies than those with weak self-efficacy (e.g. Taal et al. 1993, Riemsma et al. 1998). In addition, the studies of Chui et al. (2004) and Cross et al. (2006) show that RA patients with strong self-efficacy used fewer health-care services than the other RA patients.

Some studies show (Smarr et al. 1997, Brekke et al. 2003, Chui et al. 2004, Cross et al. 2006) that there is a relationship between enhanced self-efficacy and physical and psychological health status. However, in the study of Freeman et al. (2002), cognitive-behavioural education did not have a significant effect on the health status of newly diagnosed RA patients. In addition, in the study by Kirwan et al. (2005), the RA patients who had participated in a self-management group did not maintain their pain self-efficacy after four months, with no difference to the controls. The researchers found that those patients who accepted the educational programme showed improvements in self-efficacy immediately after the educational intervention. Further, in the study by Riemsma et al. (1997), one-to-one patient education did not influence RA patients' self-efficacy when they were educated during routine consultation hours.

2.4 Summary of the background literature

As previous studies show, RA influences many areas of a patient's life. Patients give arthritis pain and fatigue as the most difficult symptoms caused by RA and their influence is most severe on patients' physical and psychological well-being (e.g. Whalley et al. 1997, Hwang et al. 2004). Patients develop different coping strategies using for example spiritual or religious methods (e.g. Keefe et al. 2001), or positive thoughts can help them survive (Leino-Kilpi et al. 1999). RA patient knowledge and coping strategies (self-efficacy) can be increased via patient education. The most common patient education methods are one-to-one and group education with written materials supplementing.

The self-efficacy theory has raised number of studies from different disciplines and countries in Europe, North-America and Asia since 1989 (e.g. Lorig et al. 1989, Taal et al. 1993, Barlow et al. 1998, Rhee et al. 2000). Individual researchers and research teams who have been interested in arthritis (e.g. RA) patient education have studied especially how arthritis patients' self-efficacy can be increased by patient education. The studies have shown that multi-disciplinary health care teams have succeed in increasing patients' self-management by strengthening their self-efficacy especially when using group education (ASMC) where patients also receive peer support. Self-efficacy theory, developed by Bandura in 1977, is one of the concepts of control, such as 'locus of control'. However, self-efficacy is of a more specific nature, whereas the other concepts are more general. Self-efficacy expectations refer to patients' beliefs in their capacities to successfully execute a certain behaviour.

In this way, RA patients benefit of group education. They learn to manage with pain, for example, using non-medical methods such as exercise besides medical treatment. In addition, patients learn to solve problems caused by RA and arising from their everyday lives. Peer support is invaluable (e.g. Barlow et al 1998, Rhee et al. 2000). Even though the relationship between self-efficacy and patients' health status is not clear, strong self-efficacy has been shown to increase RA patients' physical functioning and thus also their physiological well-being (Riemsma et al 1998, Levebvre et al. 1999). RA patients with strong self-efficacy use less health care services than those with weak self-efficacy (e.g. Cross et al. 2006).

The number of studies concerning the relationship between self-efficacy and one-to-one patient education is minimal. Therefore, the relationship between one-to-one patient

education and RA patients' self-efficacy is unclear. One-to-one education is the most commonly used method in Finland (e.g. Heikkinen et al. 2006). Previous studies have shown that patient education increases RA patients' knowledge levels, enhancing especially their disease specific knowledge (e.g. Helliwell et al. 1999), but the relationship between patients' knowledge of RA and its treatments and self-efficacy is unclear (e.g. Davis et al. 1994). Figure 3 summarizes the theoretical frame of this study.

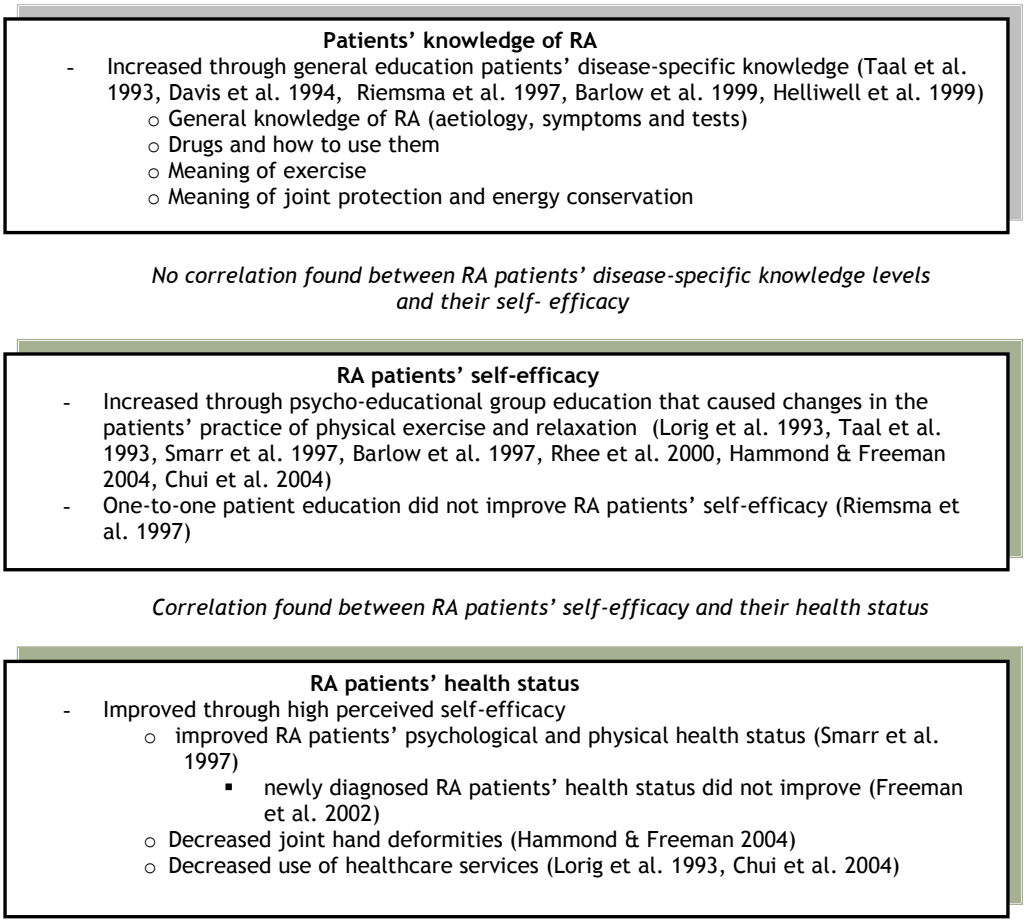

Figure 3. Summary of the theoretical frame of the study.

3 PURPOSE OF THE STUDY

The purpose of this non-intervention study was to describe current RA patient education provided by rheumatology nurses in different public health care units, and how much RA patients know about their disease and its treatments, and what kind of self-efficacy they have. The results can be used in developing RA patient education. In addition, the results can be used when enhancing the contents of curricula of nurse's training programmes and supplementary courses in rheumatology nursing.

The research questions were:

1. What are the contents and methods of RA patients' education provided by rheumatology nurses, in general, during their consulting hours? (Articles I, V)
2. What do RA patients know about RA and its treatments, and how does their knowledge change in six months? (Articles II, IV)
3. What is the nature of RA patients' self-efficacy? (Articles III, IV)
    a. How does RA patients' self-efficacy change in six months?
    b. What kind of relationship exists between RA patients' knowledge and their self-efficacy?
4. How do RA patients evaluate the patient education that they receive from rheumatology nurses? (Article V)

4 MATERIAL AND METHODS

The design of this study was both cross-sectional and longitudinal. Cross-sectional design allows studying phenomena at one point of time (baseline), and in our case, data was also collected during a six-month period gathering it from the same respondents for studying the same phenomena (e.g. Polit & Beck 2004). The reason for this was the wish to study how RA patients' knowledge and self-efficacy changed without any specific patient education intervention during the follow-up, since previous studies have shown that certain interventions increase RA patients' knowledge and self-efficacy. In this study the data was collected at the baseline and at three and six months, because that time was considered enough long to show the change. In previous studies, the follow-up designs have been from one month to five years (e.g. Brekke et al. 2003, Hammond & Freeman 2004). The phases of the study are shown in Table 4.

Table 4. Phases of the study.

Purpose	Sample	Data collection	Data analysis
Phase 1			
Describe the contents and methods of RA patient education (Article I)	n = 80 rheumatology nurses from - 12 special health care units - 40 primary health care units	Self-reporting questionnaire developed for the study and based on earlier studies *Data collection: 2003 - 2004*	The open-ended questions were transcribed, quantified and categorized. Descriptive and non-parametric statistical methods.
Phase 2			
(1) Describe RA patients' knowledge of RA and its treatments, and their self-efficacy (Articles II, III), **(2)** Describe the relationship between patients' knowledge and their physical function (Article II) **(3)** Describe the relationship between patients' knowledge and their self-efficacy (Article III) **(4)** Describe the relationship between patients' self-efficacy, physical function and health status (Article III)	n = 252 RA patients from - 11 special health care units - 23 primary health care units	Questionnaires: **1)** Patient Knowledge Questionnaire (PKQ) **2)** Arthritis Self-Efficacy Scale (ASES) **3)** Health Assessment Questionnaire (HAQ) **4)** Arthritis Impact Measurement Scale, version 2 (AIMS2), only sections: - RA patients estimations about their present health status and what they thought it would be in 10 years - RA patients satisfaction with their health status **5)** Visual Analogue Scale (pain, fatigue) (VAS) *Data collection: 2004*	Descriptive and non-parametric statistical methods.
Phase 3			
(1) Describe how RA patients' knowledge and self-efficacy changed during the six months (Article IV) **(2)** Describe how RA patients experienced patient education provided by rheumatology nurses (Article V)	n = 223 RA patients, who participated in all three data collections n = 173 RA patients, who evaluated patient education	See phase 2. In addition, open-ended questions concerning changes in medication, follow-up visits and patient education provided by rheumatology nurses, during the six-month period *Data collection: 2004 - 2005*	Descriptive and non-parametric statistical methods.

4.1 Setting and sampling

4.1.1 Sample of rheumatology nurses

Rheumatology nurses (n = 80) working in public health care units in Finland were asked about the contents and methods of RA patient education (Article I). The sample of rheumatology nurses was drawn from a list of nurses who had taken a rheumatology nursing course (organized by the Rheumatism Foundation) during the years 1995 – 2003 and were working in public (special and primary) health care organizations in Finland. Another source was the head nurses in the public health care organizations in Finland (Stakes 2002) who were asked for the names of nurses involved in rheumatology patient care in the organization.

The reason for the sampling method was that there was no register of nurses involved in rheumatology nursing in public health care in Finland (in spring 2003). Another reason was that we also wanted to include nurses in our sample who had not attended the particular rheumatology nursing course (9 ECTS). The purpose of including 'educated' and 'non-educated' nurses (or ones who had attended a different course) into the sample was to test how a certain supplementary course influenced the contents and methods of rheumatoid arthritis patient education.

After the research permissions were received from the appropriate organizations, the sample consisted of 164 nurses from 79 special and primary health care organizations. However, a total of 80 nurses were included in this study of the contents and methods of RA patient education (n = 80); 27 respondents were excluded because their questionnaires were either incompletely filled or the nurse's job description had changed and he or she did not treat rheumatology patients any more (response rate 65.2%) (Article I).

4.1.2 Sample of RA patients

The sample of RA patients was recruited from the nurses' offices who participated in the first data collection. The nurses (n = 80) were asked to estimate how many RA patients they met during one week or month, because it showed how many RA patients the nurse met on average. For the study, the criteria were that the nurse met at least one RA patient per week or four per month. The reasoning was that if the nurse met RA patients he or she also educated them in certain periods of their disease history (see Figure 1).

Another reason was that the nurses could be asked to recruit RA patients to participate in the study by giving them consent forms. In this way, we could be sure the participating patients actually met rheumatology nurses. This might not have been the case had we pulled the patients' names from the register of RA patients.

Sixty-eight nurses from 48 special (university, central and local hospitals) and 23 primary health care organizations fulfilled the criteria. The nurses were asked to present written consent forms for 500 RA patients. This number was approximately 60% of all the RA patients these rheumatology nurses estimated that they met during one week in these 47 organizations. The nurses got 1-29 consent forms each depending on how many RA patients they expected to meet during the week. The inclusion criteria were: 1) the patient had RA as the main disease, and 2) the patient was willing to participate in the study. The nurses handed out the forms to potential volunteers in the order they came in. Those who were willing to participate took the forms home, filled them in, and returned them to the nurse. The nurse then returned the completed consent forms to the researcher. A total of 299 RA patients from 11 special and 23 and primary health care organizations were willing to participate in the study.

4.2 Data collection and analysis

4.2.1 Data concerning the rheumatology nurses

The data concerning the rheumatology nurses was **collected** by a self-reporting questionnaire developed on the basis of earlier studies (e.g. Hill et al 1991). The form was developed because there were no valid instruments available for dealing with the contents and methods of rheumatoid arthritis patient education. The themes of the contents in the questionnaire were categorized on the basis of the Patient Knowledge Questionnaire (Hill et al. 1991), because the same instrument was also used in the patient data collection. The questionnaire included background information and seven open-ended questions about the content of RA patients' education and the methods used. The content-related questions were grouped per topic: information on RA (general knowledge of RA), treatments, self-care and other issues which nurses include in the education they provide for RA patients.

The nurses were asked to give short descriptions under every topic, because the purpose was to analyse the data using statistical methods. Demographic information was gathered

on age, education as an RN, supplementary course in rheumatology nursing (9 ECTS), work place, work experience as an RN and rheumatology nurse, and how many RA patients the nurse met per week. The questionnaire was pilot-tested in autumn 2002 by ten nurses who had taken a rheumatology nursing course. After the unclear questions were corrected, the questionnaire was re-tested in March 2003 with another ten nurses who were participating in a supplementary course in rheumatology nursing.

The questionnaires were coded based on the course and work place, and mailed out during the period of October 2003 to February 2004 to the nurses' work places after the research permissions were received. There was two weeks allowed to complete the questionnaire. There was no reminder for those who did not return the questionnaire, because it was not certain that the attendee list of the rheumatology nursing course was up to date, and nurses might have changed their work places. As indicated by the background information as well, nurses in primary health care units did not meet rheumatology patients as often as expected.

The data was **analysed** using descriptive and non-parametric statistical methods. The open-ended questions were transcribed, getting 46 single-spaced pages. The texts were quantified (Robson 1997, Burns & Grove 2001, Polit & Beck 2004), getting 83 different mentions under the aetiology, character, symptoms, treatments, follow-up of RA and self-care and 12 mentions under methods. Further coding gave 24 nominal variables (0 = not known, 1 = taught by the nurses) (Article I), as follows:

- information on RA (i.e. general knowledge of RA) (3); aetiology, characteristics, symptoms
- treatments (6); anti-rheumatics, side-effects, pain treatments in general, importance of mobilizing, importance of joint protection, importance of energy conservation
- follow-up of RA (2); blood tests, follow-up controls
- self-care (6); follow one's own health condition, self-care at home, cold as pain relief, effects of RA on one's life, information about social assistance and/or rehabilitation, information of other professionals (e.g. physiotherapists or occupational therapists)
- the teaching methods (7); verbal individual education, group education, discussion (emotional support), other methods besides verbal or group education, leaflets

(from local hospitals or the drug industry), material from rheumatic associations, treatment card

The demographic variables of age, education, work experience as an RN and rheumatology nurse and the number of RA patients per week, were changed into dichotomous variables. The correlations between the variables were tested statistically using cross-tabulation and x^2-test (SPSS 11.5 for Windows). The background information concerning the nurses is shown in Table 5.

Table 5. Background information of the rheumatology nurses (means, SDs, percentages, ranges, n = 80 (Article 1).

Background information	**n = 80**
Age	
Mean ± SD	47.2 ± 7.6 years
Min - max	27 – 60 years
Education n (%)	
RN (2.5 years)	15 (20)
RN (2.5 years) + specialization (1.0 year)	40 (50)
RN (3.5 years)	16 (20)
BNSc	8 (10)
Rheumatology nursing course (4.5 credits) n (%)	
Yes	44 (55)
No	36 (45)
Work experience as an RN	
Mean ± SD	20.7 ± 7.6 years
Min - max	2 – 40 years
Work experience as a rheumatology nurse	
Mean ± SD	7.1 ± 6.2 years
Min - max	1 – 27 years
Work place n (%)	
Special health care (12)	21 (26)
University hospital (4)	6 (8)
Central hospital (5)	9 (11)
District hospital (3)	6 (8)
Primary health care (40)	59 (74)
Number of RA patients treated per a week	
Mean ± SD	11.8 ± 13.7 patients
Min – max	1 – 55 patients

4.2.2 Data concerning the RA patients

The baseline data concerning the RA patients was **collected** using two questionnaires and three scales. The questionnaires were coded on the basis of the rheumatology nurse from whom the RA patients received the consent forms, and also whose clients they were. The assumption was that the nurses also had educated the RA patients during their follow-up controls. The instruments are shown in Table 6.

Table 6. Instruments used in the study and their validity and reliability (n = 252/223 RA patients).

Questionnaire	**Areas covered**	**Internal consistency**[1] n = 252	**ICC; 95% CI**[2] n = 223
Patient Knowledge Questionnaire (PKQ) (Hill et al. 1991)	16 questions subdivided into four subscales: 1) general knowledge (max 9 score) 2) drugs (max 7 score), 3) exercise (max 7 score) 4) joint protection and energy conservation (max 7 score) Each question comprises 5 – 7 statements, 1 – 3 of which are correct (correct statement = one score). Max score 30.	*Pilot study (n = 34):* *α = 0.60* Total α = 0.75	Total 0.76 (0.70 to 0.81)
Arthritis Self-Efficacy Scale (ASES) (Lorig et al. 1989)	20 items subdivided into three subscales: 1) pain self-efficacy (PSE) (5 items), 2) function self-efficacy (FSE) (9 items) and 3) other symptoms self-efficacy (e.g. fatigue) (OSE) (6 items) Scale 0 – 100-mm (0 = very certain, 100 = very uncertain)	*Pilot study (n = 34):* α = *0.94* Total α = 0.93 PSE: α = 0.86 FSE: α = 0.90 OSE: α = 0.90 Inter-total correlations[3] PSE: 0.57 FSE: 0.63 OSE: 0.64 Inter-item correlations[3] varied from 0.51 to 0.65	PSE: 0.61 (0.52 to 0.69) FSE: 0.78 (0.72 to 0.82) OSE: 0.70 (0.62 to 0.76)
Visual Analogue Scale (VAS), pain and fatigue (e.g. Clark et al. and Wolfe)	100-mm horizontal line (0 = no pain/fatigue, 100 = the worst pain/fatigue imaginable)		Pain: 0.59 (0.48 to 0.66) Fatigue: 0.51 (0.40 to 0.60)

Table 6 continues

Health Assessment Questionnaire (HAQ) (Fries 1983)	8 items that have an overall disability score covering activities of daily living: walking, hygiene, getting up and eating. Scale 0 – 3 (0 = good physical functioning, 3 = poor physical functioning)	Total α = 0.96	0.78 (0.72 to 0.82)
Multidimensional, and disease-specific Arthritis Impact Measurement Scale, 2 version (AIMS2) (Meenan et al. 1984)	Only parts in use: 1) RA patients' estimations about their present health status and what they thought it would be in 10 years Scale 1 – 4 (1 = good health status, 4 = poor health status). 2) RA patients' satisfaction with their health status Scale 1 – 5 (1 = very satisfied, 5 = very unsatisfied), and demographic data		

[1] Cronbach's alpha, [2] Intraclass correlation coefficient, [3]Spearman rho

The Patient Knowledge Questionnaire (PKQ) measures the correctness of the patient's information on RA and its treatments. The subscale 1) 'general knowledge of RA' contains four questions about the aetiology and symptoms of RA and the blood tests that must be taken for follow-up controls (maximum score 9). The subscale 2) 'drugs and how to use them' contains four questions about non-steroidal anti-inflammatory (NSAID) and anti-rheumatic drugs, the side-effects of NSAIDs, and about how to use them (maximum score 7). The subscale 3) 'physical exercise' contains four questions about physical exercising and RA, activities which must be carried out when the joints get painful and stiff, the most suitable ways to take regular exercise, and what one should do if the wrists become painful (maximum score 7). The final subscale 4) 'joint protection and energy conservation' contains four questions about the most practical ways to protect the joints and the most suitable activities and methods to conserve energy (maximum score 7).

The Arthritis Self-Efficacy Scale (ASES) measures the magnitude, strength and generality of self-efficacy. It measures situation-specific perceptions of control rather than generalized or trait measures such as mastery or locus of control (Brady 2003). The patients are required to indicate how certain they are of performing specific tasks with regard to pain, function and other symptoms. The ASES comprises items such as, 'How certain are you that you can make a large reduction in your arthritis pain by using methods other than taking extra medication?' (PSE); 'How certain are you that you can walk 30m on

flat ground in 20 seconds?' (FSE); and 'How certain are you that you can do something to help yourself feel better if you are feeling blue?' (OSE) (Lorig et al.1989).

The PKQ has been tested and found to be valid and reliable (Hill et al. 1991) and it has been used in studies in Europe (e.g. Barlow et al. 1999, Minnock et al. 2003). The ASES is the dominant measure of self-efficacy in arthritis and it has been widely used in the U.S.A., Europe, Asia and Australia since 1990 (e.g. Brekke et al. 2003, Chui et al. 2004, Cross et al. 2006) and found to be valid and reliable (Lorig et al. 1989, also Taal et al. 1993, Strahl et al. 2000, Brady 2003). Swedish, Norwegian and Spanish versions of the ASES have been developed and evaluated (Brady 2003). Also other self-efficacy scales have been developed, such as Self-Efficacy Scale (SES) (see Brady 2003) and Rheumatoid Arthritis Self-Efficacy Scale (RASE) (Hewlett et al. 2008). In this study, we used the original Arthritis Self-Efficacy Scale (ASES; Lorig et al. 1989).

The PKQ and the ASES were used in this study for the first time in Finland. The required permissions to use the scales were requested and received via e-mail from Jackie Hill (September 24, 2002) and Kate Lorig (October 29, 2002). The questionnaires were translated word for word from English into Finnish and nurses, physiotherapists and occupational therapists involved in rheumatology patient treatment were asked to assess whether the translation was in line with RA patients' education in Finland. In light of the assessment, in the PKQ, the statement 'plasma viscosity (PV)' under the subscale of laboratory tests was changed to 'haemoglobin'. In addition, two statements were changed under the subscale of drugs. The statement 'D-penicillamine (also called Distamine, Pendramine)' was changed to 'Metotreksaatti (kauppanimi[1]: Methotrexate tai Trexan), and the statement 'Sulphasalazine, also called Salazopyrin, E/C, Salazopyrin' was changed to 'Hydroksikloridi (kauppanimi: Oxiklorin)', because they are the medicines in use in Finland. The questionnaires were translated back into English and evaluated to ensure that the meanings in the translations had not been changed. Finally, the questionnaires were translated back into Finnish and tested by 34 RA patients in the Rheumatism Foundation Hospital. No more changes were needed in the Finnish PKQ.

In the original ASES the scales read from 10 to 100 (Lorig et al. 1989) or from 1 to 10 (http://patienteducation.stanford.edu/ research/searthritis.pdf). However, after testing the ASES with 34 RA patients, the scales were changed to 100mm scales and turned into the same direction as the scales in the other instruments (e.g. VAS) (0 = very certain; 100 =

[1] kauppanimi = 'trade name', tai = 'or'

very uncertain). The patients felt it was confusing to have scales in opposite directions in one questionnaire.

The RA patients' physical functioning was measured using the *Health Assessment Questionnaire (HAQ)* (Finnish version, 1994), and their pain and fatigue using *the Visual Analogue Scale (VAS)*. The physical functioning, pain and fatigue were then compared to the patients' knowledge of RA and its treatments and their self-efficacy. From the HAQ, only the function scale index (0 – 3) was used, not the subscales under 'additional help from other person or aids needed'. The HAQ contains 20 statements under eight subscales, the scale being from zero to three: zero (0) indicates that the respondent could perform a certain activity without any difficulty during the previous week, for example, opening a car door. One (1) indicates that the respondent could perform the activity with minor difficulty; two (2) indicates that the respondent had great difficulties, and three (3) indicates that the respondent could not perform the activity at all. In the analysis, the greatest number chosen (0 – 3) under a subscale represents the whole subscale. For the HAQ index, the highest scores from the subscales are summarized and divided by the number of the subscales (8).

The VAS is a 100-mm horizontal line where zero means no pain or fatigue and 100 means the worst pain or fatigue imaginable. The VAS has been deemed an instrument suitable for measuring RA patients' pain and fatigue (e.g. Clark et al. 2003, Wolfe 2004). From *the AIMS2* (Finnish version, 2001) we used only the subscales that contain patients' estimations and satisfaction with their health status. As to the HAQ and AIMS2, the Finnish version has been tested on Finnish RA patients and found to be reliable and valid (Arkela-Kautiainen et al.2001, Arkela-Kautiainen 2006). Internal consistencies were assessed using Cronbach's coefficient and test-retest reliability using Intraclass correlation coefficient (ICC 95% IC). In the ASES inter-total correlations and inter-item correlations were tested using Spearman's rho (Table 6).

The voluntary patients (n = 299) had questionnaires mailed to them with two weeks to complete them. For the first data collection (August 2004) 250 patients returned the completed questionnaire, and after one reminder, 16 more patients did so (n = 266, response rate 53.2% (266/500)). However, 33 patients dropped out the study even though they had returned the consent forms. In addition, 14 questionnaires were excluded because the patients had a rheumatoid disease other than RA, so the total sample comprised 252 RA patients (Articles II, III). The second data collection had 234 participants and the third had 223 RA patients all of whom also participated in all three data

collections (n = 223) (Article IV). A total of 173 participants described and/or evaluated patient education provided by rheumatology nurses (Article V).

The second and third sets of data were collected using the same questionnaires and scales but also including additional open-ended questions which the RA patients were asked to answer shortly or give a concise description (1 = 'No', 2 = 'Yes'; if 'Yes', what kind of). The first (1) question was: 'Have you had changes in your medication?' The reason for the question was to evaluate how changes influenced the RA patient's knowledge and self-efficacy. The second and third questions concerned RA patient education, and they were: 2) 'Have you been educated by a rheumatology nurse concerning your RA or its treatments?', and 3) 'How was the patient education you received from the rheumatology nurse - please evaluate'. Figure 4 shows the data collection of the study, and the instruments used.

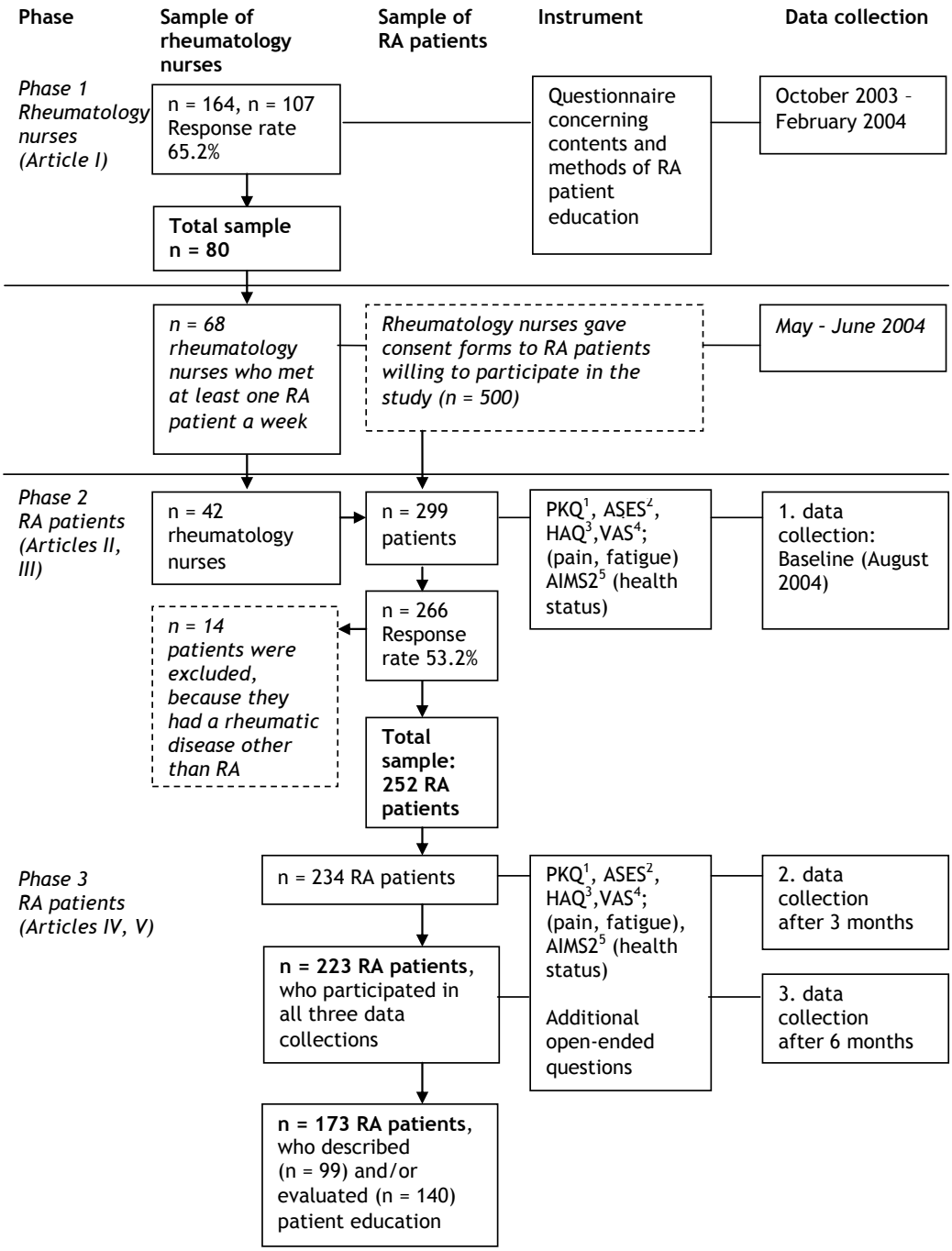

Figure 4. The data collection process of the study ([1]Patient Knowledge Questionnaire; [2]Arthritis Self-Efficacy Scale; [3]Health Assessment Questionnaire, Finnish version; [4]Visual Analogue Scale (pain, fatigue); [5]Arthritis Impact Measurement Scale2, Finnish version).

The data was **analyzed** using descriptive and statistical methods (SPSS for Windows, version 11.5 and 14.0). The HAQ index was calculated (Articles II, III). For the further analysis the PKQ scores were calculated and subdivided into three subscales: 1) poor knowledge (score 0 – 10), 2) moderate knowledge (score 11 – 20) and 3) good knowledge (score 21 – 30) (Article IV). The subscales of the ASES (Pain Self-Efficacy = PSE, Function Self-Efficacy = FSE and Other symptoms Self-Efficacy = OSE) were summarized and subdivided into four subscales for further analysis: 1) very certain (0 – 25mm), 2) quite certain (26 – 50mm), 3) quite uncertain (51 – 75mm) and 4) very uncertain (76 – 100mm) (Articles III, IV).

The open-ended questions concerning changes in patient medication (Article IV) were categorized under two nominal variables: follow-up controls, and changes in medication in general (0 = no, 1 = yes). The answers to the open-ended questions concerning content and evaluation of patient education (Article V) were transcribed, getting 14 single-spaced pages. The answers varied from three to 300 words depending on whether the patient only shortly described the content or if he or she also evaluated the patient education. The texts were quantified (e.g. Polit & Beck 2004), arriving at 15 different mentions under content and 45 mentions under evaluation.

The content of patient education was subdivided into four variables: 1) information on RA, 2) information on treatments, 3) motivation to self-care, and 4) other issues of which nurses informed RA patients. In addition, the evaluations were subdivided into four variables: 1) satisfied with patient education, 2) dissatisfied with patient education, 3) information unnecessary, and 4) opinion not known. Age was dichotomized (≤ 57 years, > 57 years) and disease duration categorized into three classes: 1) 1–5 years, 2) 6–15 years, and 3) over 15 years (Article V).

The normality of demographic and dependent distributions was tested using the Kolmogorov-Smirnov test. Because the curves were strongly skewed and did not get corrected through transformations, non-parametric techniques were used. The correlations between the PKQ, PSE, FSE and OSE scores and the respondents' age, disease duration, and HAQ index were calculated using Spearman's rho (e.g. Burns & Grove, 2001). The differences between the independent groups were analysed by the Kruskall-Wallis (ASES and health status and satisfaction with health status) and the Mann-Whitney *U*-test (ASES and gender) (Articles II, III).

The Mann-Whitney *U*-test was also used to test the differences between the PKQ and ASES scores (after six months) of those RA patients who had had follow-up controls during the six months and those who had had no controls. The Friedman two-way analysis of variance by ranks was used to test the magnitude of difference of the PKQ and ASES scores in six months. The Wilcoxon matched-pairs signed-ranks test was used to test the difference in ranks of the PKQ and ASES scores from baseline to three months, from three to six months, and from baseline scores to six month scores (e.g. Polit & Beck, 2004; Munro, 2005) (Article IV). A x^2-test was used to test differences in dissatisfaction with education between long and short-term sufferers (Article V).

The results are expressed as frequencies, percentages and ranges for categorical data, means, standard deviations for interval or ratio level data, and medians and interquartile ranges (IQR) for ordinal data. The results are noted only when significant ($p < 0.05$). Table 7 shows the background information on the RA patients.

Table 7. Background information on the RA patients (means, SDs, medians, IQRs, percentages, min – max).

Background information	**n = 252** (Articles II, III)	**n = 223** (Article IV)	**n = 173** (Article V)
Age			
Mean ± SD	56.1 ± 12.4 years	56.6 ± 11.9 years	57.0 ± 11.5 years
Min - max	20 – 81 years	27 – 81 years	27 – 81 years
Gender n (%)			
Female	199 (79)	179 (80)	137 (79)
Male	53 (21)	44 (20)	36 (21)
Duration of RA			
Mean ± SD	13.5 ± 11.1 years	13.7 ± 11.3 years	
Median			11.0
IQR			4, 22
Min – max	1 – 46 years	1 – 46 years	1 – 46 years
Physical functioning (HAQ)			
Median (scores 0 - 3)[a]	0.5		
IQR	0.13, 1.0		
Min – max	0 – 3		
Pain (VAS; scores 0 – 100) [a]			
Mean ± SD (Range)	35.8 ± 24.9 (95)		
Fatigue (VAS; scores 0 – 100) [a]			
Mean ± SD (Range)	46.1 ± 28.6 (99)		
Health status (Scale 1- 4; estimated by RA patients) [a]			
At present			
Median	3.0		
Min – max	1 – 4		
In 10 years			
Median	3.0		
Min – max	1 – 4		
Satisfaction with health status at present (Scale 1– 5; estimated by RA patients) [a]			
Median	2.0		
Min – max	1 – 5		
Follow-up controls (%)		61	
Changes in medication in 6 months (%)		46	

[a]Low score = good functioning, health status or satisfaction

4.3 Ethical considerations

The permission to carry out the study was obtained from the organizations concerned (n = 79) and the ethical commissions of the hospital districts (n = 7) in June 2003 – February 2004. The verbal permission to carry out the pilot study of RA patients was obtained from the Rheumatism Foundation in the spring of 2003, and the written permission on 11 February 2004. In addition, all patients completed and signed two consent forms: one for the researcher and one for themselves. Patients could consider at peace at home if they wanted to participate in the study and return the filled consent form to the nurse (procedure in accordance with the guidelines of The Royal College of

Nursing Research Society); they gave their addresses where they wanted the questionnaires to be mailed. The nurse returned the consent forms to the researcher.

The consent forms included information about the study and data collection as well as how to acquire more information from the researcher if necessary. It was emphasized to the respondents (nurses and patients) that participation in the study was voluntary and confidentiality was assured, and participants could leave the study without any explanation (procedure in accordance with the guidelines of The Royal College of Nursing Research Society 2003, World Medical Association Declaration of Helsinki 2004, Kalra et al. 2006, Kuula 2006).

The questionnaires of the patients were coded based on respondents consent forms so that it was possible to remind those who did not return the questionnaire in time. Even if the respondents' personal details were not asked for in the questionnaires, it was not possible to reach full anonymity of the respondents (Polit & Beck 2004, Kalra et al. 2006, Kuula 2006). However, the codes were created and known only by the researcher, and they, and also names and addresses of the respondents were destroyed after they were not needed for the study. Consent forms and questionnaires were kept in a place where they could be reached only by the researcher (Finlex, Personal Data Act, Section 14, 523/1999).

5 RESULTS

5.1 Contents and methods of RA patients' education provided by rheumatology nurses

Rheumatology nurses gave the most information for the RA patients about anti-rheumatic medication prescribed for them and blood tests as follow-ups. Almost every second nurse taught self-care to the patients. A minority of the nurses gave information also about RA as a disease and physical and relaxation therapy (Articles I, V). One-to-one patient education with supplementary written materials was the most common methods used by nurses. Other methods, such as pictures, demonstrations or multiple methods together were used by every third nurse (Article I). Almost half of the nurses said that they conversed with their patients and supported them emotionally, whereas only 15% of the patients mentioned it (Articles I, V).

The key factors influencing the content of RA patient education and the methods used include the following: rheumatology nurse's age over 45, education that of a specialized RN, over 21 years of work experience as an RN and over 6 years as a rheumatology nurse, working in a special health care unit and meeting over 11 RA patients a week. The nurses fulfilling these criteria taught the content mentioned most extensively or used more extensive methods than other rheumatology nurses. Supplementary courses in rheumatology nursing (9 ECTS) did not influence the contents or methods used. Table 8 shows a summary of the content and methods of RA patient education as described by the rheumatology nurses (Article I; n = 80) and RA patients (Article V; n = 99).

Table 8. Content of RA patient education as described by the rheumatology nurses (n = 80) and RA patients (n = 99), and influence of the rheumatology nurses' backgrounds (%).

Content and methods of RA patient education provided by rheumatology nurses	**n = 80** %	**n = 99** %	**Influence of rheumatology nurses' backgrounds on content and methods used** (Article I)
CONTENT			
1.General knowledge of RA (aetiology and symptoms)			
- RA is an autoimmune disease, it is long term, cause unknown	< 10	8	
- Symptoms (characteristics) of RA in general	56		RN (2.5 years) + specialization (1.0 year) (p = 0.005) Special health care unit as the work place (p = 0.010) Nurse met >11 RA patients a week (p = 0.021)
2. Treatments			
- anti-rheumatic prescribed to patient	76	26	RN (2.5 years) + specialization (1.0 year) (p = 0.019)
- blood tests as follow-ups	64		
- importance of mobilizing	29	17	RN (2.5 years) + specialization (1.0 year) (p = 0.047) Special health care unit as the work place (p = 0.047) Nurse met >11 RA patients a week (p = 0.014)
- importance of joint protection	23	9	Nurse met >11 RA patients a week (p = 0.015)
- pain management, in general	15	5	Work experience as a rheumatology nurse > 6 years (p = 0.005)
3. Self-care			
- motivating and teaching self-care methods, in general	45		Special health care unit as the work place (p < 0.001) Nurse met >11 RA patients a week (p < 0.001)
4. Other issues			
- social assistance	20		
- rehabilitation given by local Rheumatic associations	15	3	
- meaning of follow-up controls			Special health care unit as the work place (p = 0.013)
METHODS			
- one-to-one education	88		
- group education	4		
- discussion about the patient's experiences (and emotional support)	43	15	Age >46 years (p = 0.004) Work experience as a RN > 21 years (p = 0.009)
- other methods besides one-to-one education (e.g. pictures, demonstrations)	38		Age >46 years (p = 0.037) Work experience > 21 years as an RN (p = 0.034)

Table 8 continues

			Work experience as a rheumatology nurse > 6 years (p = 0.015) Special health care unit as the work place (p = 0.038) Nurse met >11 RA patients a week (p < 0.001)
Written materials	71	3	Work experience as a rheumatology nurse > 6 years (p = 0.019) Special health care unit as the work place (p = 0.026) Nurse met >11 RA patients a week (p = 0.022)

5.2 RA patients' knowledge of their disease and its treatments, and how it changed during the six months

RA patients' knowledge of RA and the treatments was, on average, good, since the median score was 20 (max score 30). However, the patients' knowledge varied from poor to good in all subscales, and no one got the maximum score in the subscale of 'drugs and how to use them'. At the baseline the best knowledge was general knowledge of RA (aetiology and symptoms of RA and blood tests) and exercise, and the poorest knowledge levels were found in drugs and joint protection and energy conservation.

Even though most of the patients knew correctly the aetiology of RA, a little more than half (54%) of the patients believed that they had inherited their disease from their parents. Most of the patients were also well informed about their medical and non-medical treatments. However, every fifth patient did not know the reason for exercising, and 62% of the patients confused joint protection with energy conservation (Article II).

The patients' knowledge of exercise and joint protection and energy conservation increased during the six months. However, the total scores decreased because the general knowledge scores decreased significantly during the follow-up. Drug scores did not differ from baseline to six months. However, those patients' knowledge of drugs was better whose medication (e.g. anti-rheumatics, pain medication) were changed during the six months (Article IV).

The RA patients' background influenced their knowledge level so that women's and young patients' knowledge of RA and its treatments was significantly better than that of men and elderly patients. In addition, the longer the patients had suffered from RA, the better

knowledge they had. However, the statistical correlation was not very strong (Articles II, IV). The relationship between the patients' knowledge and their physical function was significant but weak. The poorest knowledge was held by the RA patients whose physical functioning was good (Article II). Table 9 summarizes the RA patients' knowledge and its change, and also their background that influenced their knowledge positively or negatively.

Table 9. RA patients' knowledge of RA and its treatments and the change during the six-month period (medians, IQRs, min-max; n = 252 / 223 RA patients).

Subscales of the Patient Knowledge Questionnaire (PKQ)	**Baseline** Median (IQR) Min - max n = 252	**Baseline** Median (IQR) Min - max n = 223	**Difference between medians at six months** n = 223	**Influenced RA patients' knowledge positively** (Articles II, IV)	**Influenced RA patients' knowledge negatively** (Article II)
General knowledge of RA; aetiology, symptoms and blood tests (max 9 score)	7.0 (6.0, 8.0) 0 – 9	7.0 (6.0, 8.0) 0 – 9	-1.0 ***	- follow-up visit at six months (p = 0.029)	
Drugs and how to use them (max 7 score)	4.0 (3.0, 5.0) 0 – 6	4.0 (3.0, 5.0) 0 – 6	No difference	- medication was changed during the six months (p = 0.004)	
Exercise (max 7 scores)	5.0 (4.0, 6.0) 0 – 7	5.0 (4.0, 6.0) 0 – 7	+ 1*		
Joint protection and energy conservation (max 7 scores)	4.0 (3.0, 5.0) 0 – 7	4.0 (3.0, 5.0) 0 – 7	+ 1**	- medication prescribed to patient (p = 0.022)	
Total score (max score 30)	20.0 (17.0, 23.0) 2 – 29	19.9 (17.0, 23.0) 4 – 27	No difference (max score -1)***	- female gender (p < 0.001) - young age (r = 0.35; p < 0.001) - long disease duration (r = 0.24, p < 0.001) - follow-up visit at six months (p = 0.026) - medication was changed during the six months (p = 0.003)	- good physical functioning (HAQ) (r = 0.17, p = 0.009)

***Friedman Test: Chi-Square (Asympt Sig.) is significant at the 0.001 level, **Friedman Test: Chi-Square (Asympt Sig.) is significant at the 0.01 level, *Friedman Test: Chi-Square (Asympt Sig.) is significant at the 0.05 level.

5.3 The nature of RA patients' self-efficacy and its connection to their knowledge of RA and its treatments, and how it changed during the six months

The RA patients' self-efficacy was, on average, strong as regards management of function (FSE) and other symptoms (e.g. fatigue, frustration) (OSE), and moderate as regards pain management (PSE). However, the patients' uncertainty increased when they had to reduce their arthritis pain using methods other than taking extra medication (Article III). All patients' self-efficacy got stronger during the six-month period (Article IV).

There was a weak but statistically significant relationship between the RA patients' background and their self-efficacy; the women had stronger pain self-efficacy than the men; the shorter the disease duration, the stronger the patients' pain (PSE) and function self-efficacy (FSE). The younger patients also had stronger function self-efficacy (FSE) than the older ones. The strongest self-efficacy was held by the RA patients who estimated that their physical function (HAQ) was good. Correspondingly, the RA patients who estimated that their health status was poor at present and would also be so in future (in 10 years) had weak pain (PSE), function (FSE) and other symptoms self-efficacy (OSE). Moreover, those patients' self-efficacy was weak who were very dissatisfied with their health status at present (Article III).

Even if the patients' knowledge of RA and its treatments was, on average, good, there was no significant relationship between patients' knowledge and self-efficacy, in general. However, there was a weak linear but statistically significant correlation between the patients' good knowledge of joint protection and energy conservation and their strong function self-efficacy (FSE) during the six-month period. Further, the patients' good knowledge of exercise and their strong other symptoms self-efficacy (OSE) correlated weakly with each other (Article IV). Table 10 shows a summary of the RA patients' self-efficacy, its change during the six months, and the connection of these to the patients' backgrounds and their knowledge of RA and its treatments.

Table 10. RA patients' self-efficacy and the change during the six-month period; the connection of these to the patients' backgrounds and their knowledge of RA and its treatments (medians, IQRs; n = 252 / 223 RA patients).

Subscales of the ASES[1]	**Baseline** Median (IQR) n = 252	**Baseline** Median (IQR) n = 223	**Difference between medians during the six months** n = 223	**Influenced RA patients' self-efficacy positively** (Articles III, IV)	**Influenced RA patients' self-efficacy negatively** (Articles III, IV)
Pain self-efficacy (PSE)	35.5 (16.7, 48.2)	35.5 (15.4, 48.2)	-7.6 **	- short disease duration (r = 0.20, p = 0.002) - good physical functioning (HAQ) (r = 0.47, p < 0.001) - less pain (VAS) (r = 0.52, p < 0.001) - less fatigue (VAS) (r = 0.39, p < 0.001) - follow-up controls during the six months (p = 0.020) - good knowledge of joint protection and	- male gender (p = 0.15) - poor health status at present (p < 0.001) - poor health status in 10 years (p < 0.001) - dissatisfaction with health status at present (p < 0.001)

Table 10 continues

				energy conservation (r = 0.14, p	
Function self-efficacy (FSE)	18.4 (7.7, 34.3)	18.4 (7.8, 33.1)	-4.2*	- short disease duration (r = 0.30, p < 0.001) - young age (r = 0.20, p = 0.002) - good physical functioning (HAQ) (r = 0.77, p < 0.001) - less pain (VAS) (r = 0.51, p < 0.001) - less fatigue (VAS) (r = 0.39, p < 0.001) - good knowledge of joint protection and energy conservation (r = 0.18, p = 0.009)	- poor health status at present (p < 0.001) - poor health status in 10 years (p < 0.001) - dissatisfaction with health status at present (p < 0.001)
Other symptoms self-efficacy (OSE)	24.7 (10.3, 40.3)	25.3 (10.3, 41.1)	-6.6**	- good physical functioning (HAQ) (r = 0.44, p < 0.001) - less pain (VAS) (r = 0.45, p < 0.001) - less fatigue (VAS) (r = 0.56, p < 0.001) - follow-up controls during the six months (p = 0.020) - good knowledge of exercise (r = 0.16, p = 0.019)	- male gender (p = 0.45) - poor health status at present (p < 0.001) - poor health status in 10 years (p < 0.001) - dissatisfaction with health status at present (p < 0.001) - medication was changed during the six months (p = 0.010)

[1] Range 0 – 100; low score = strong self-efficacy
******Friedman Test: Chi-Square (Asympt Sig.) is significant at the 0.01 level, *Friedman Test: Chi-Square (Asympt Sig.) is significant at the 0.05 level

5.4 RA patients' evaluation of patient education provided by rheumatology nurses

A little more than half (57%) of the RA patients was satisfied with the patient education they received from rheumatology nurses: they felt that they got enough information or they did not need any information because they had had RA for so long. The main reason for the patients' satisfaction was that rheumatology nurses gave information on the disease and its treatments without the patient needing to ask and used terminology that the patients understood. In addition, the patients had the feeling that nurses arranged their matters for them and had time to converse with them in an unhurried way.

However, every fourth RA patient was not satisfied with patient education. The main reason for dissatisfaction was that the information they received from rheumatology nurses was not tailored to their needs or they did not receive any information after they had had the diagnosis of RA. In addition, one reason for dissatisfaction was that patients felt that rheumatology nurses treated them with a workmanlike routine and did not concentrate on their emotional well-being. Patients under 57 years of age were slightly more dissatisfied than the older ones (x^2 (3) = 9.3, p = 0.026). In addition, patients who had suffered from RA less than six years were more dissatisfied than those who had suffered from RA for longer (x^2 (3) = 13.8, p = 0.003). The patients' gender did not influence their satisfaction with patient education (Article V).

5.5 Summary of the main findings of the study

The sum total of the main findings of the study was that rheumatology nurses mostly informed their RA patients as to how to use medication prescribed to them. Both nurses and RA patients brought this up. One-to-one patient education was the commonest method used. Nurses 1) who were qualified as RNs (2.5 years) and specialized, 2) worked in special health care organizations or 3) met more than 11 RA patients weekly informed their patients more often about such topics as symptoms of RA, anti-rheumatic drugs, the importance of mobilizing and joint protection, self-care and meaning of follow-up controls. They also used multiple methods besides one-to-one education more often than other nurses. Nurses who were 1) over 45 years old or 2) had over 21 years work experience mentioned more often that they discussed patients' experiences with the patients and supported them emotionally.

RA patients' **knowledge** of their disease and its treatments was, on average, good. However, the range was wide - there were patients whose knowledge was poor. Patients who did not need to visit health care professionals because of their RA knew less than the RA patients who had controls in special or primary health care units. The patients' knowledge of exercise and relaxation techniques increased, and general knowledge of RA (aetiology, symptoms) decreased during the six-month study period. The women and young RA patients knew more about their disease than men and elderly patients.

The RA patients' **self-efficacy** was, on average, strong as regards function (FSE) and other symptoms (OSE, e.g. fatigue) self-efficacy and moderate as regards pain self-efficacy (PSE). Patients' uncertainty increased when they had to use non-medical pain treatment

methods. Patients' self-efficacy got stronger during the follow-up study period. Women had stronger pain self-efficacy (PSE), and young patients stronger function self-efficacy (FSE) than men or elderly patients. In addition, the shorter the disease duration the stronger pain (PSE) and function self-efficacy (FSE). The RA patients' self-efficacy correlated strongly or moderately with their physical functioning (HAQ), pain and fatigue (VAS). There were also weak linear but statistically significant relationships between the RA patients' knowledge of the meaning of exercise, joint protection and energy conservation and their self-efficacy after the knowledge scores had increased during the six-month follow-up period.

Every second RA patient was satisfied with the patient education they received from rheumatology nurses. However, every fourth patient was not satisfied, and the reason for dissatisfaction was that patients felt that nurses did not support them emotionally. Patients who had suffered from RA less than six years were more dissatisfied than the other patients. Figure 4 shows the main findings of the study. The arrows represent the correlations between the variables.

Current main contents of patient education provided by rheumatology nurses in public health care units in Finland

- aetiology and symptoms of RA
- anti-rheumatic drugs prescribed to patients, and blood tests as follow-ups
- importance of mobilizing and joint protection
- pain management in general
- motivating and giving information about self-care
- information about social assistance and rehabilitation
- meaning of follow-up controls
- emotional support

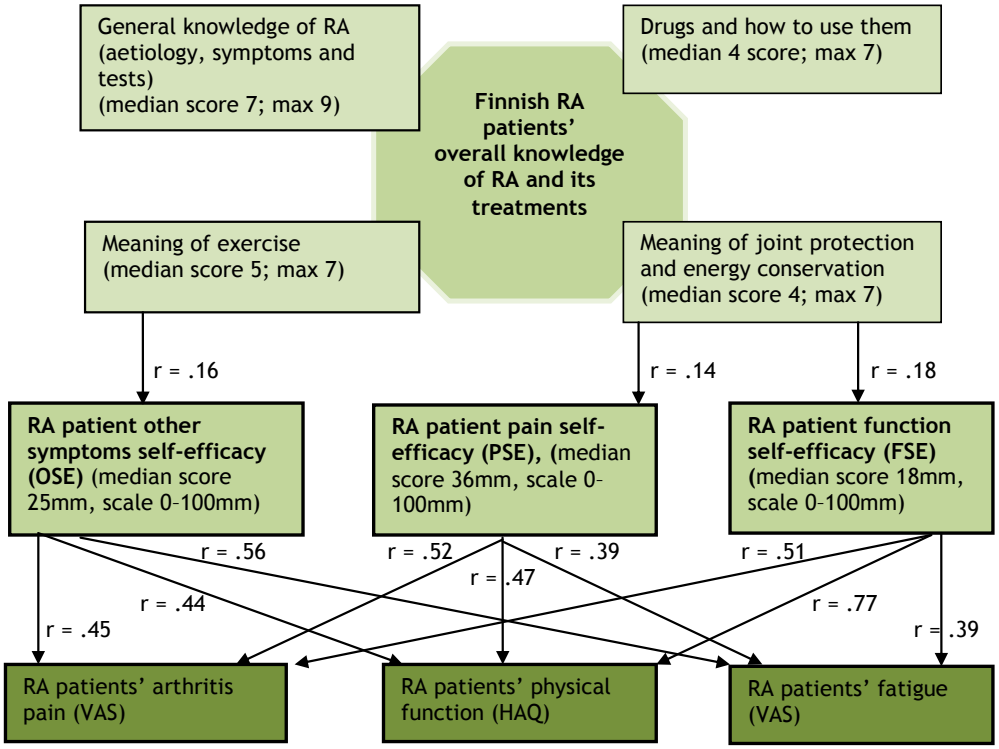

Figure 5. Summary of the main findings of the study.

6 DISCUSSION

6.1 Discussion of the results

This study confirmed the results of some previous studies conducted in Finland (e.g. Heikkinen et al. 2006), namely that one-to-one patient education with supplementary written materials is the most commonly used method. The present findings show that rheumatology nurses mostly inform their RA patients about medical treatment and blood tests which must be taken as follow-ups. This result can be considered reliable because the RA patients brought the topic up as well. In addition, almost half of the nurses mentioned that they discuss the importance of self-care at home. This study does not show why self-care was not considered as important a content as medical treatment even though rheumatology nurses recognize the importance of supporting and motivating RA patients to use self-care management techniques at home (e.g. Ryan et al. 2005), raising it to the position of the first aim of patient education (Juhola et al. 2007). One reason for this finding may be that most of the nurses who participated in this study worked in health centres and, according to the results, it seems that RA patients are mostly taught in hospitals. However, self-care is a very important area of RA patient education, enabling patients to learn self-care so that they can live as full a life as possible regardless of RA (e.g. Riemsma et al. 2003b, Lorig et al. 2004).

According to this study, only every fifth rheumatology nurse and every sixth patient was of the opinion that nurses supported patients emotionally. Especially the patients emphasized the meaning of emotional support, and it increased their satisfaction (or dissatisfaction) with the patient education they received from the nurses. Also nurses consider the emotional support of the patient a very important part of the work (e.g. Iaquinta & Larrabee 2004). The reason for the finding may be that the reality and the working pace in current health care units are not as they might be in an ideal situation, as many nurses work under pressure (Partanen 2002), and there may not be enough time to converse with the patient in peace (e.g. Kääriäinen 2007, Lipponen et al. 2008, also Long et al. 2002). On the other hand, the hurry during nurses' busy working hours was not always a hindrance; more often the hindrance was formed by the nurses' attitudes towards patients' needs of information. The present findings show that patients sense it easily if the nurse is genuinely interested in their well-being.

This study shows that a Finnish RA patient's knowledge of RA and its treatments is good in comparison to the findings of previous studies (e.g. Barlow et al. 1999). However, the range in this study was very wide since as many as every the tenth RA patient demonstrated poor knowledge. In addition, there were RA patients whose knowledge of the aetiology and symptoms of RA decreased significantly during the follow-up study period. One reason for this may be that the patients were not absolutely sure about the aetiology of RA (e.g. Symmons et al. 2000).

Surprisingly, every second patient thought that they had inherited their disease from their parents. The reason for this finding may be that the questionnaire did not allow the respondents to proffer their own views as to the cause of the disease, only to choose from the selection of given statements. However, there were also patients who did not know the reason for physical exercise, or confused joint protection and energy conservation. It can be speculated if those patients' disease was in remission and did not cause any health problems and, thus, the patients did not know the aetiology or treatments of RA. On the other hand, patients may hold to their own beliefs about what has caused their disease or what is the best treatment to it, as Kirwan et al. (2005) brought up in their study.

The present study showed that Finnish RA patient self-efficacy, in general, is strong as regards management of function (FSE) and other symptoms (e.g. fatigue, frustration) self-efficacy (OSE). Previous studies have not reported on the level of self-efficacy, so it was not possible to compare whether Finnish RA patients had stronger or weaker self-efficacy than RA patients in other countries. However, the range was very wide and there were also patients whose self-efficacy was very weak.

An important result was that the patients' uncertainty increased when they had to treat their arthritis pain using non-medical methods. As shown in previous studies, arthritis pain increases RA patients' stress and feelings of discomfort, and stress has a negative influence on self-efficacy (e.g. Yucum et al. 2000, Hwang et al. 2004). In addition, another important finding is that the RA patients who estimated their current health status to be poor and also to stay poor in the future had weaker self-efficacy than others. According to the study of Brekke et al (2003), baseline self-efficacy influences future self-efficacy. As in Bandura's self-efficacy theory (1977), patients with low self-efficacy tend to generalize from one experience to another and will attribute failures to their own incapacity.

This study confirmed the findings of the study of Davis et al. (1994) that RA patients' knowledge and their self-efficacy do not correlate, in general. The weak correlation shown

in this study can result from statistical fluctuation (Article IV), and the results can not be generalized without further study. According to this study, there were many RA patients whose self-efficacy was poor even though their knowledge level was good. The present findings are important because one-to-one patient education is the commonest method in Finland. One-to-one education suits RA patients when they need, for example, individualized information regarding a new drug treatment (Hill 2003). The current method is sufficient for increasing RA patients' knowledge of the medication prescribed for them.

However, giving information individually about different kinds of self-care methods may not be enough for RA patients to start using them in practise. This holds true for especially those patients who require persuasion and additional support from other people. As shown in the study of Riemsma et al (1997), one-to-one patient education only had a small effect on RA patients' behaviour, self efficacy and therefore, their functional disability. Because of this, these RA patients need to be taught by other methods than one-to-one patient education.

Nurses as a members of multi-disciplinary teams play an important role in RA patient education (e.g. Madigan & FitzGerald 1999, also Arvidsson et al. 2006), and successful patient education requires nursing care of a high level. Therefore, it is important that rheumatology nurses either have the time to concentrate on supporting and persuading verbally the patients who have weak self-efficacy, or they have a chance to include supplementary teaching methods in their one-to-one education such as videos that show other RA patients' behavioural solutions (e.g. Barlow et al. 2002).

Anyway, RA patients with weak self-efficacy should not be left alone. Pain management, for example, may require multi-disciplinary teamwork, and nurses can either consult other professionals (e.g. physiotherapists or occupational therapists) or guide the patient to them. These patients need special attention to enable them to find suitable self-management methods such as how to decrease arthritis pain with non-medical methods. In addition, this study shows that strong self-efficacy correlates with good physical functioning, as has been found in previous studies also (e.g. Smarr et al 1997, Cross et al. 2006). Previous studies (e.g. Chui et al. 2004, Cross et al. 2006) have also shown that RA patients with strong self-efficacy are more confident in coping with their disease, and thereby do not use health care services as much as those whose self-efficacy is weak. Therefore, it is important to strengthen RA patients' weak self-efficacy by the use of appropriate teaching methods.

In this study, rheumatology nurses rarely participated in group education. However, the Finnish type of group education differs from group education in other countries (e.g. Liimatainen & Stenbäck 2005), where psycho-educational training has been reported good for learning self-care abilities and problem-solving (e.g. Lorig et al 2004, Riemsma et al 2003b). Psycho-educational group education could be a method worth considering in Finland. In the frame of the self-efficacy theory (Bandura 1977), patients who do not have their own experiences about successful behaviour benefit from models of other patients. In groups, RA patients can also receive psychological support from their peers (e.g. Barlow et al. 2002), whereas time constrains tend to cause problems for the provision of support in one-to-one education situations (e.g. Kääriäinen et al. 2006).

This study confirms the results of previous studies (e.g. Neame et al. 2005) that women and young patients know more about their disease than men or elderly patients, and they also have stronger self-efficacy. It is worth considering whether current RA patient education is too female oriented, as shown in the study of Hennell et al. (2004). However, in this area, multidisciplinary teamwork could be necessary as it might lead to better quality of RA patient education. The co-operation of nurses and other members of multidisciplinary teams might lead to finding more ways suitable for educating patients, especially men and elderly patients, so that they would get information and support based on their individual needs.

It would also be necessary that health care professionals would share the topics on which they provide information for their RA patients, so that the patients would know from whom they are expected to receive a certain piece of information. In addition, rheumatology nurses in hospitals and health centres could parcel out what issues to teach in hospitals and what issues to leave for rheumatology nurses in health centres. When developing educational methods, attention should be paid on patients' individual ways of learning.

6.2 Limitations of the study

As with any study, also this study has limitations. The first limitation was set by the questionnaire for rheumatology nurses developed for the purposes of this study. The open-ended questions in the patients' questionnaire set another limitation. The nurses and patients were asked for short verbal descriptions of the contents and methods of RA patient education under themes based on earlier studies (Hill et al. 1991). Even if open-ended questions allow a richer perspective on respondents' views, however, the

disadvantage of this kind of questionnaire is that it demands more of the respondents' time than answering structured questions (e.g. Burns & Grove 2001). Respondents who have a rich capacity of expression give much information answering open-ended questions, but it is more difficult to interpret the views on the contents of patient education of those patients that have a poorer capacity of expression. It was impossible to use some contents for further statistical analysis, because there were not enough observations to be placed in any categories (on the formation of categories, see e.g. Polit & Beck 2004).

The second limitation was that the response rate from the rheumatology nurses was only 65.2%. Reasons for this could be that some rheumatology nurses had changed working units or resigned and therefore did not receive the questionnaire at their work places. However, the response rate is usually lower when questionnaires are mailed out (Burns & Grove 2001, Polit & Beck 2004). As to the generalization of the contents of RA patient education, it is not known what the opinions of those are who did not participate in the study (Article I).

The third limitation of this study was that this was not an intervention study and respondents were not selected randomly. In other words, those patients who volunteered to participate in the survey may have more extensive knowledge of RA and stronger self-efficacy than RA patients usually. This may cause the curves to be strongly skewed, allowing the use of non-parametric tests only. As for the generalization of the study, it is not known what the knowledge levels or self-efficacy of those are who did not want to participate in or dropped out the study (46.8%), so further studies are needed.

Three data collections in six months may not have been necessary; the baseline and a six-month follow-up could have been enough. Three data collections may have caused the patients to tire of filling the PKQ, for example, every three months. This may be deduced from the fact that the scores in the different sections of the PKQ increased after three months but then decreased again after six months (Article IV).

However, strength of this study was that the sample size of RA patients was good. The amount of non-respondents during the follow-up data collection was only eleven per cent (n = 29), and they did not differ any from the respondents who returned the questionnaires in all three data collections. The large sample size increases the power of the test and reduces the risk of committing Type I error. However, for any further study, it is necessary

to calculate a power analysis in order to avoid Type II error (e.g. Polit & Sherman 1990, Lenth 2001, Munro 2005).

Another strength of this study was that the instruments of RA patient data collection were reliable and valid and had been used in previous studies (e.g. the HAQ). The PKQ and the ASES were used for the first time in Finland. The reason for their use was that they were found to be valid and reliable in test-retest settings, and developing other instruments for this study was not considered necessary. Valid and reliable measures increase the validity of the results. For the purposes of this study, the instruments were translated from English into Finnish making sure the concepts were as similar as possible and semantically equivalent compared to the original instruments (e.g. Polit & Beck 2004).

However, the instruments were developed for a culture other than the one in which the data was collected and the terminology may have been unfamiliar for some patients decreasing their knowledge scores, for example. There were some concepts that were not in line with the Finnish culture and may have confused the respondents and thereby influenced their responses (e.g. the subsection on joint protection and energy conservation: 'use of dish cloth rather than sponge'). The confusing statements may have increased the systemic error seeing that Cronbach's alpha remained under 0.80 that is considered to be the lowest acceptable value for a well-developed instrument (Burns & Grove 2001). In this study, Cronbach's alpha in the baseline data collection was 0.76 and 0.60 in the pilot study. Therefore, further development and testing are necessary as well as multidisciplinary co-operation in which also RA patients are included as team members.

The ASES proved to be valid in this study except for the pain subscale (PSE) in test-retest data collection. This instrument might also have had some statements that the respondents did not understand because of the language. In the Finnish version the scale was changed from the original so that it ran from 0 – 100mm on a horizontal line (VAS), turned into the opposite direction compared to the original instrument. In the original ASES the scale runs from one to ten (1 = very uncertain, 10 = very certain). The reason for the changes was that the respondents had it easier to fill the questionnaire with the scales of all instruments in the same direction; low scores meant good functioning (the HAQ), health status (the AIMS2) and certainty (the ASES). In the pilot testing, the respondents confused the different scales and the directions in them thereby decreasing the validity of the results. Even though the ASES was valid and reliable in this study, except for the pain self-efficacy subscale in test-retest setting, the ASES also needs further testing.

7 CONCLUSIONS AND SUGGESTIONS FOR FURTHER RESEARCH

7.1 Conclusions and practical implications for RA patient education

The findings of this study provide new information concerning the content of current RA patient education, RA patients' knowledge of their disease and its treatments, and their self-efficacy. 1) The rheumatology nurses informed the RA patients mostly about medical treatment and blood tests as follow-up controls. Less than half of the nurses discussed self-care at home. One-to-one patient education was the mostly used method. 2) The RA patients' knowledge of their disease and its treatments varied from poor to good. 3) The RA patients' self-efficacy varied from weak to strong. The patients' uncertainty level increased when they had to reduce their arthritis pain using non-medical techniques. 4) Weak patient self-efficacy correlated with a high degree of disability. 5) The RA patients' good knowledge and their strong self-efficacy did not correlate with each other. 6) Half of the RA patients were satisfied with patient education provided by rheumatology nurses. However, every fourth patient was not satisfied; the main reason for the dissatisfaction being that nurses did not focus on the patient's emotional support.

The present findings can be used for enhancing RA patient education. Our recommendations for practice, nurses' training and administration are the following:

1. It is important that rheumatology nurses plan the content of patient education with the patients so that it is based on the patients' individual information needs and their need for support. Rheumatology nurses should concentrate on supporting those patients whose self-efficacy is weak using alternative teaching methods in addition to one-to-one patient education (e.g. videos, teleinformatics, psycho-educational group education).
2. Rheumatology nurses should teach self-care abilities to RA patients. In addition, they should teach alternative pain management methods to patients with weak self-efficacy in using pain-reducing methods other than medication.
3. Rheumatology nurses should notice the importance of supporting patients, especially newly-diagnosed ones, emotionally to help them gain satisfaction and psychological well-being.
4. The contents of rheumatology nursing courses should be enhanced further to stress the importance of appropriate teaching methods and to help point out the importance of self-care to RA patients. When developing the curricula of

supplementary courses and nursing training programmes, it is important to differentiate between patient education in acute and long-term disease situations.

5. Health care organizations and administrations should support rheumatology nurses in developing RA patient education by arranging the required time and training. Administrations (e.g. head nurses) should notice that one-to-one patient education may not be sufficient when teaching patients with long-term diseases.

7.2 Suggestions for further research

This study was a descriptive study presenting the contents and methods of RA patient education provided by rheumatology nurses in different health care units in Finland. For further study, a concept analysis is needed of the concept *perceived self-efficacy* (i.e. self-efficacy) to ascertain that the Finnish translation describes the content and real use in nursing science. So far, the concept has been used in health psychology and the present translations are based on the needs of disciplines the other than nursing science.

Longitudinal research would be necessary to study how RA patients' self-efficacy develops during the course of the long-term disease. Voluntary patients with short disease duration at present could be measured for a longer period; it could offer important insights into how to enhance RA patient education. In addition, interviewing RA patients would benefit the enhancement of patient education programmes: how would it be possible to strengthen patients' self-efficacy via patient education, where do patients receive the peer support they need, and what kind of support do they want from rheumatology nurses? It would be necessary to interview RA patients with strong self-efficacy and find out what has caused their self-efficacy to increase.

The questionnaire of patient education contents and methods must be developed further, piloted and data collected using a bigger sample. This instrument could be developed together with the Patient Knowledge Questionnaire to make them measure the same topics better for the ease of analysis. The PKQ as well needs further development and testing.

An intervention study is needed to test the relationship between individual education and RA patients' self-efficacy. It is also important to evaluate how other current teaching methods in Finland (e.g. group education) influence RA patients' self-efficacy. Further randomized and controlled intervention research is also important for evaluating current individual education programmes in different health care units.

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APPENDICES

Appendix 1 Original publications

Kuopio University Publications E. Social Sciences

E 146. Kemppainen, Ulla. Ninth-grade adolescents´ health behavior in the Pitkäranta district (Russian Karelia) and in Eastern Finland.
2007. 149 s. Acad. Diss.

E 147. Pusa, Anna-Kaisa. The right nurse in the right place: nursing productivity and utilisation of the RAFAELA patient classification system in nursing management.
2007. 111 s. Acad. Diss.

E 148. Antikainen, Mari. Sosiaalityöntekijän asiantuntijuus lapsen huolto- ja tapaamissopimuspalvelussa.
2007. 199 s. Acad. Diss.

E 149. Hujala, Anneli. Johtamisen moniäänisyys: johtaminen vuorovaikutuksena ja puhuntana hoivayrityksissä.
2008. 146 s. Acad. Diss.

E 150. Kiviniemi, Liisa. Psykiatrisessa hoidossa olleen nuoren aikuisen kokemuksia elämästään ja elämää eteenpäin vievistä asioista.
2008. 119 s. Acad. Diss.

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