Marja Arkela-Kautiainen

Functioning and Quality of Life as Perspectives of Health in Patients with Juvenile Idiopathic Arthritis in Early Adulthood

Measurement and long-term outcome

JYVÄSKYLÄN YLIOPISTO

ABSTRACT

Arkela-Kautiainen, Marja
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First aim of this study entity was to evaluate the results of treatment and rehabilitation in patients with juvenile idiopathic arthritis (JIA). The long-term health outcomes in the early adulthood were evaluated in the framework of the International classification of functioning, disability and health (ICF). The second aim of this study entity was to evaluate the psychometric characteristics of two multidimensional measures of functioning which were used in the outcome evaluations. For the outcome evaluations young adult patients with JIA were gathered from the patient files of the Rheumatism Foundation Hospital (RFH), Heinola, Finland. The patients were evaluated during a one-day visit to the RFH by a multidisciplinary team. Patients completed Finn-AIMS2, Finn-MDHAQ and the quality of life (QoL) (RAND-36) questionnaires. Age-, sex- and domicile matched controls were gathered from the Finnish population registry. The validity and reliability of the Finnish versions of the Arthritis impact measurement scales 2 (AIMS2) and the Multidimensional health assessment questionnaire (MDHAQ) were evaluated in two Finnish adult rheumatoid arthritis (RA) populations. Sixty-three per cent of young adult patients with JIA had active disease at a mean age of 23 years after a mean follow-up of 16 years. Patients experienced more pain, had lower levels of mobility and social life than controls. In patients with active disease versus controls the differences became even more conspicuous. In all, 20% of the patients had uveitis diagnosed during the course of the disease. Levels of education and employment in patients with JIA were similar to controls. Patients rated their QoL similar to controls except in one sub area of physical health. In the areas of mental health patients with JIA and controls evaluated their QoL similarly. Patients with active disease rated their QoL lower in all areas of physical health compared to patients in remission and controls. On the contrary mental health was found to be similar between all patient groups and controls. Finn-AIMS2 and Finn-MDHAQ were found to be valid, reliable and applicable for outcome studies in adult RA age groups. In conclusion, gaining remission and active treatment and rehabilitation interventions designed to maintain functioning should be a high priority in clinical practice in young adult patients with JIA. ICF can offer a promising tool in providing a wide perspective on health outcome evaluations and a unified language between different health professionals nationally and internationally. Minor modifications suggested in the Finn-MDHAQ would benefit application of the instrument in the future. The appropriateness of both measures, Finn-AIMS2 and Finn-MDHAQ, for the young adult age groups should still be reinforced in further studies.

Keywords: juvenile idiopathic arthritis, young adult, functioning, disability, health, quality of life, ICF

Author's Address   MSc, PT Marja Arkela-Kautiainen
MedCare Ltd
Torikatu 4
FI-44100 Äänekoski
FINLAND
marja.arkela-kautiainen@medcare.fi

Supervisors   Professor Esko Mälkiä
Department of Health Sciences
University of Jyväskylä

Professor Marjatta Leirisalo-Repo
Department of Medicine, Division of Rheumatology
Helsinki University Central Hospital

Lic Soc Sc Ilpo Vilkkumaa
Merikoski Rehabilitation and Research Centre

Reviewers   Docent Pekka Lahdenne
Children's Hospital
Hospital District of Helsinki and Uusimaa

Associate professor Christina H. Stenström
Karolinska Institutet, Division of Physical therapy
Huddinge, Sweden

Opponent   Professor Alan Jette
Health & Disability Research Institute
Boston University
USA

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LIST OF ORIGINAL PUBLICATIONS

This thesis is based on five original publications, which will be referred to in the text by the following Roman numerals:

I   Arkela-Kautiainen M, Kauppi M, Heikkilä S, Kautiainen H, Mälkiä E, Leirisalo-Repo M: Evaluation of the Arthritis Impact Measurement Scales 2 (AIMS2) in Finnish patients with rheumatoid arthritis. Scand J Rheumatol 2003;32:300-305.

II   Arkela-Kautiainen M, Kautiainen H, Uutela T, Laiho K, Blåfield H, Leirisalo-Repo M, Hakala M: Evaluation of the Multidimensional Health Assessment Questionnaire in Finnish patients with rheumatoid arthritis. J Rheumatol 2005;32:1426-1431.

III   Arkela-Kautiainen M, Haapasaari J, Kautiainen H, Leppänen L, Vilkkumaa I, Mälkiä E, Leirisalo-Repo M: Functioning and preferences for improvement of health among patients with juvenile idiopathic arthritis in early adulthood using the ICF model. (submitted)

IV   Kotaniemi K, Arkela-Kautiainen M, Haapasaari J, Leirisalo-Repo M: Uveitis in young adults with juvenile idiopathic arthritis. A clinical evaluation of 123 patients. Ann Rheum Dis 2005;64:871-874.

V   Arkela-Kautiainen M, Haapasaari J, Kautiainen H, Vilkkumaa I, Mälkiä E, Leirisalo-Repo M: Favourable social functioning and health related quality of life of patients with JIA in early adulthood. Ann Rheum Dis 2005;64:875-880.

ABBREVIATIONS AND DEFINITIONS

ADL	Activities of daily living
AIMS2	Arthritis impact measurement scales 2
ANA	Antinuclear antibody
ANOVA	Analysis of variance
ARA	American Rheumatism Association
CI	Confidence interval
CRP	C-reactive protein
DMARD	Disease-modifying antirheumatic drug
ESR	Erythrocyte sedimentation rate
EULAR	European League Against Rheumatism
FN	Function scale (in the MDHAQ)
HAQ	Health assessment questionnaire
HLA	Human leukocyte antigen
HRQoL	Health-related quality of life
IBD	Inflammatory bowel disease
ICC	Intraclass correlation coefficient
ICD	International classification of diseases
ICIDH	International classification of impairments, disabilities and handicaps
ICF	International classification of functioning, disability and health
ILAR	International League of Associations for Rheumatology
IQR	Interquartile range
JAS	Juvenile ankylosing spondylitis
JCA	Juvenile chronic arthritis
JIA	Juvenile idiopathic arthritis
JPA	Juvenile psoriatic arthropathy
JRA	Juvenile rheumatoid arthritis
MANOVA	Multivariate analysis of variance
MCS	Mental component scales (in RAND-36)
MDHAQ	Multidimensional health assessment questionnaire
MHAQ	Modified health assessment questionnaire
PS	Psychological scale (in the MDHAQ)
PCS	Physical component scales (in RAND-36)
QoL	Quality of life
QOLS	Quality of life scale
RA	Rheumatoid arthritis
RF	Rheumatoid factor
RFH	Rheumatism Foundation Hospital
SD	Standard deviation
TNF	Tumor necrosis factor
VAS	Visual analogue scale
WHO	World Health Organization

CONTENTS

1   INTRODUCTION

Early adulthood is an important developmental period for all young persons and their families. Especially in young people having chronic disease, e.g. juvenile arthritis, the importance of transition from childhood home to an independent member of society and adult subject has been recognized (Quirk and Young 1990). A chronic disease during this period may interfere with the developmental transition. In this respect a coherent picture of one's health, a knowledge of disease management and future prospects to the adolescent and parents is essential part of patient information in all chronic diseases (Barlow et al. 1999, Ravelli 2004).

All members of the multidisciplinary care and rehabilitation teams treating children and adolescents with juvenile arthritis need a wide scale of feedback on the outcomes of their interventions to develop the health care of patients in accordance with their treatment and rehabilitation goals. From the viewpoint of society the need for outcome research has rapidly risen during the last decade, when health care costs continually escalated (Maloney and Chaiken 1999). Therefore, also the Finnish government as one of the main institutions financing the health care system pinpointed research on the health and well-being of children and adolescents as a particularly important area of outcome research in the development programme for rehabilitation research in Finland (Ministry of Social Affairs and Health 2004).

Background to the present work is the writer's wish to view the health and functioning, treatment and rehabilitation from the multidimensional standpoint. The importance of multidisciplinary work in the health care and support of juvenile arthritis patients and their families has also been recognized in the literature (Hagglund et al. 1996, Aasland et al. 1997, Davidson 2000, Petersson 2005). In research on the outcomes of patients with juvenile idiopathic arthritis (JIA) the multidimensional approach is manifested as various effects of the disease on growth, body composition and function as well as social participation in childhood, adolescence and adulthood (Peterson et al. 1997, Minden et al. 2002, Oen et al. 2002, Foster et al. 2003, Ravelli 2004). The long-term outcome of functioning in young adults with JIA is heterogeneous, depending on differences in the health care systems and various national care

and rehabilitation disciplines concerned, together with different recruitment protocols and the heterogeneity of age cohorts involved in different studies (Foster et al. 2003).

The main purpose of this study entity was to examine the outcomes of young adult patients with JIA in terms of effectiveness of their long-term treatment and rehabilitation. The examination of patients with JIA was performed from a multidimensional perspective in a life period where the long-term outcomes of active treatment and rehabilitation could be seen and measured. The International classification of functioning, disability and health, ICF (WHO 2001) offers one framework for a broad assessment of these long-term health outcomes. The ultimate success of treatment and rehabilitation in chronic diseases depends on the sustained initiative of the patient (Fuhrer 1997); therefore examination of the patient's perspective in terms of quality of life is equally valid and merits equal attention (Whiteneck et al. 1997). The other purpose of present study was to evaluate psychometric properties of two multidimensional questionnaires which were decided to use in the health evaluation studies. Good questionnaires used in health research studies need to be assessed and proved to be reliable and valid (Coolican 2004, Bowling 2005).

2   JUVENILE IDIOPATHIC ARTHRITIS

2.1 Nomenclature and classification of juvenile arthritis

The first description of chronic arthritis in children in the literature was published by G.F. Still in 1897 (Still 1897, 1978). Since then classifications for childhood chronic arthritis of unknown cause have varied. During the past 30 years two main classifications of childhood arthritides have been used. On the one hand in the United States the American Rheumatism Association (ARA) published its criteria for juvenile rheumatoid arthritis (JRA) in 1973 (JRA subcommittee 1972) and the same nomenclature was used in the revised criteria published in 1977 (Brewer et al. 1977). This classification included subgroups comprising systemic arthritis, pauciarticular arthritis with four joints or fewer affected, and polyarticular arthritis with five or more joints affected. In 1978 the European League Against Rheumatism (EULAR) published an agreed proposition for criteria in juvenile chronic arthritis (JCA) (Wood 1978). The subgroups of JCA were defined as systemic, polyarthritis, and pauciarticular onset arthritis. The classification also introduced juvenile ankylosing spondylitis (JAS), psoriatic arthropathy (JPA), and arthropathies associated with inflammatory bowel disease (IBD). In both JRA and JCA the age at onset is under 16 years, but the duration of joint symptoms necessary for the diagnosis is 6 weeks in the former and 3 months in the latter.

An important step forward in improving the comparability of international clinical work and research in paediatric rheumatology was taken when the Paediatric Standing Committee of the International League of Associations for Rheumatology (ILAR) proposed a new set of criteria using the term juvenile idiopathic arthritis (JIA) in 1995 (Fink 1995). According to the revised criteria published in 1998 (Petty et al. 1998) JIA is divided into seven subgroups: systemic arthritis, oligoarthritis, polyarthritis [rheumatoid factor (RF) -negative], polyarthritis (RF-positive), psoriatic arthritis, enthesitis-related arthritis, and other arthritis. A summary of the three sets of criteria for childhood arthritis is given in table 1.

TABLE 1 Summary of the three sets of criteria for childhood arthritis of unknown cause.

	ILAR	EULAR	ARA
Nomenclature	JIA	JCA	JRA
Disease duration for diagnosis	6 weeks	3 months	6 weeks
Age of patients at onset	0-15	0-15	0-15
JAS, JPA, IBD[†]	included	included	excluded
Definition of subtypes at 6 months' disease duration (course type)	yes	yes	yes

[†] JAS= juvenile ankylosing spondylitis, JPA=psoriatic arthropathy,
IBD=arthropathies associated with inflammatory bowel disease

According to the ILAR criteria JIA subgroups are defined (Petty et al. 1998) as follows:

1. *Systemic arthritis*: arthritis with or preceded by daily fever of at least 2 weeks' duration, documented to be quotidian for at least 3 days, and accompanied by one or more of the following:
   1. Evanescent, non-fixed, erythematous rash
   2. Generalized lymph node enlargement
   3. Hepatomegaly or splenomegaly
   4. Serositis

2. *Oligoarthritis*: Arthritis affecting 1-4 joints during the first 6 months of disease. Two subcategories are recognized:
   1. Persistent oligoarthritis: affects no more than 4 joints throughout the disease course.
   2. Extended oligoarthritis: affects a cumulative total of 5 joints or more after the first months of disease

3. *Polyarthritis (RF-negative):* Arthritis affecting 5 or more joints during the first 6 months of disease; test for RF is negative.

4. *Polyarthritis (RF-positive):* Arthritis affecting 5 or more joints during the first 6 months of disease, associated with positive RF tests on 2 occasions at least 3 months apart.

5. *Psoriatic arthritis:*
   1. Arthritis and psoriasis, or
   2. Arthritis and at least 2 of:
      a) Dactylitis
      b) Nail abnormalities (pitting or onycholysis)
      c) Family history of psoriasis confirmed by a dermatologist in at least first degree relative

6. *Enthesitis related arthritis:* Arthritis and enthesitis, or arthritis or enthesitis with at least 2 of:
    a) Sacroiliac joint tenderness and/or inflammatory spinal pain
    b) Presence of HLA-B27
    a. Family history in at least one first- or second-degree relative of medically confirmed HLA-B27-associated disease
    c) Anterior uveitis usually associated with pain, redness or photophobia
    d) Onset of arthritis in a boy after the age of 8 years

7. *Other arthritis:* Children with arthritis of unknown cause which persists for at least 6 weeks but which either
    1. Does not fulfil the criteria for any of the other categories, or
    2. Fulfils the criteria for more than one of the other categories

2.2 Epidemiology

The first study in Finland in which the incidence of chronic juvenile arthritis was examined was that of Laaksonen (1966), who reported an incidence rate of 3.5 in 100 000 children. Two decades later Kunnamo (1986) found a higher rate, 19.6 per 100 000 children. The results in the 1990s have shown the incidence of chronic juvenile rheumatic diseases in Finland to be 14/100 000 in the population 16 years of age or under (Kaipiainen-Seppänen and Savolainen 1996). This finding is in accord with the latest incidence figures in the Nordic countries as a whole, reported by Berntson and co-workers (2003) applying the ILAR criteria. In the light of that study, however, Finnish regional results in the Helsinki district showed a somewhat higher incidence rate, with 21/100 000. A similar rate, 22.7/100 000, was found by Kaipiainen-Seppänen and Savolainen (2001).

According to review of large group of epidemiological studies (Andersson Gäre 1998), the sex distribution in juvenile arthritis in the Western countries has shown to have an overall predominance of girls over boys, 2-3:1. Girls are shown to predominate in oligo- and polyarticular arthritis and JPA patients, while sex distribution is more even in the systemic arthritis patients. Age distribution at onset in this review was found to have a bimodal pattern. Girls with oligoarticular arthritis constitute the main part of the early peak, while the second peak is constituted of girls with polyarticular arthritis or JPA and boys and girls with JAS (Andersson Gäre 1998). However, the latest incidence study performed in the Nordic countries (Berntson et al. 2003) could not prove the assumption of the bimodal pattern to be true in that study population.

According to mentioned review (Andersson Gäre 1998) the oligoarticular onset patients constitute the largest group of all cases, with more than half of the cases in the subtype distribution of juvenile arthritis. Twenty-five per cent of the cases have polyarticular onset and 10 % systemic onset. In the study of

Berntson and co-workers (2003), the proportion of patients with oligoarticular disease varied from 45% to 76%, where the latter was the Finnish percentage of cases. In the whole population of this study using ILAR classification criteria of JIA, the proportion of oligoarticular onset patients was 46%, polyarticular onset patients 21% and systemic onset patients 4%. The differences in these figures between studies could be explained by the different classification criteria used and differences in the width of the geographical area observed.

Finnish estimates of the prevalence of JCA are from the 1980s (Mäkelä 1981, Lantto and von Wendt 1985), with 80/100 000 and 79/100 000 respectively. According to Manners and Bower (2002) the prevalence estimates studied in different countries reveal considerable variance, from 7 to 401 per 100 000 children. Major factors in the variation in estimates of both the incidence and the prevalence in epidemiological studies of juvenile arthritis in general may be found in methodological difficulties such as case definition, study designs, criteria used for inclusion and also case ascertainment and definition of the study population. Secondly, geographical, ethnic and temporal differences may vary between studies (Anderson Gäre 1998, 1999, Manners and Bower 2002).

Asymptomatic uveitis is an important manifestation of JIA. It occurs in about 20% of patients with oligoarthritis and less frequently (5-10%) in those with RF-negative polyarthritis. It is rare in systemic disease and uncommon in RF-positive polyarthritis (Kotaniemi et al. 2001, Rosenberg 2002, Zulian et al. 2002, Kotaniemi et al. 2003). In some patients uveitis is acute, with redness and pain of the eye, and typically affects boys at the age of 10-13, who often carry the HLA- B27 antigen and may later develop spondyloarthritis.

2.3   Clinical characteristics, treatment and rehabilitation

JIA is an inflammatory joint disease which can affect the health of a young person in several ways. Clinical manifestations such as pain, morning stiffness, fatigue, lack of energy and loss of function are among the most common clinical features of joint inflammation (Davidson 2000, Cassidy and Petty 2001). Extra-articular manifestations such as general and local growth disturbances, delayed puberty (Milojevic and Ilowite 2002), and several features of organ-specific extra-articular symptoms, e.g. chronic uveitis, can also occur (Kotaniemi et al. 2001). Chronic anterior uveitis, as a most common form of uveitis, involves predominantly the iris and ciliary body, but effects can also occur in all parts of the uvea (Kotaniemi 2001).

Regarding the multiple effects of the disease on the patient, the objectives in the treatment and rehabilitation of patients with JIA in different age groups are extensive (Ansell and Chamberlain 1998, Davidson 2000, Cassidy and Petty 2001, Duffy 2005). The aim in the immediate time period is to relieve discomfort, preserve function, prevent deformities and control inflammation. In

the long-term the side-effects of disease and treatment should be minimized and normal growth and development should be promoted. In minimizing disability the patient's need for rehabilitation and education are essential (Davidson 2000, Cassidy and Petty 2001).

Since at the onset prediction of the development of chronic and progressive disease at the individual level is not possible, the initial drug treatment must be vigorous in all children (Davidson 2000, Cassidy and Petty 2001). The standard drug therapy of juvenile rheumatic diseases includes a wide range of disease-modifying antirheumatic drugs (DMARDs); e.g. methotrexate, sulfasalazine, hydroxychloroquine, gold, and penicillamine have been used actively during the last decades. Corticosteroids are used as systemic medication and as intra-articular injections (Ilowite 2002, Milojevic and Ilowite 2002, Murray and Lovell 2002). Immunosuppressive and cytotoxic drugs have proved useful for children with life-threatening complications. Research into and wider use of newer drug therapy based on the tumour necrosis factor (TNF) inhibition will extend the possibilities to control disease activity in affected children more effectively (Cassidy and Petty 2001). Beside drug therapy the management of JIA includes the work of expert multidisciplinary team including paediatric rheumatologists and rheumatology nurses, physio- and occupational therapists together with social workers, psychologists, ophthalmologists, orthopaedists and vocational guidance who cooperate closely with patient and family (Davidson 2000). The general approach in the multidisciplinary teamwork with the JIA child or adolescent and family includes child- and family-centred, coordinated care and rehabilitation within and between different health care levels. Special consideration in the management of JIA subjects is needed in the matter of education, school attendance and the role of siblings and the adolescent's successful preparation for transition to adult, independent life (Davidson 2000, Athreya 2001, White 2002).

3 EXTERNAL AND INTERNAL EVALUATION PERSPECTIVES OF HEALTH

3.1 Classification of Functioning, Disability and Health

The International classification of functioning, disability and health, ICF was endorsed by the World Health Assembly in May 2001. It provides a standard language for the description of health and health-related states (WHO 2001). The WHO classification could be seen as a stage of ongoing development which commenced for forty years ago especially in the field of rehabilitation.

The process of disablement according to Nagi (1965) basically comprises the sequence: active pathology → impairment → functional limitation → disability. This model was not widely known before the late 1980s, but gradually gained acceptance among the disability researchers (Verbrugge and Jette 1994). *Impairment* was defined as anatomical, physiological, mental or emotional abnormalities or loss. *Functional limitation* was seen in this model as a limitation in the individual's ability to perform tasks and obligations of the usual roles and daily activities. *Disability* was seen as a pattern of behaviour which evolves in situations of long-term or continued impairments associated with functional limitations and as a condition which has an impact on the performance of normal social roles (Nagi 1965).

In the year 1980 the WHO published taxonomy of the consequences of disease entitled the International classification of impairments, disabilities and handicaps (ICIDH). The ICIDH presented a sequence of different dimensions of disease: disease → impairment → disability → handicap. *Impairment* referred to loss or abnormality of psychological, physiological or anatomical structure or function; in principle, impairments represented disturbances at the organic level. *Disability* was seen as restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; disability thus represented disturbances at the level of the person. *Handicap* was seen to involve a disadvantage for a given individual, resulting from an impairment or a disability, which limits or

prevents the fulfilment of a role which is normal (depending on age, sex, and social and cultural factors) for that individual; handicap thus reflects interaction with and adaptation to the individual's surroundings (WHO 1980).

In 1994 Verbrugge and Jette published their sociomedical model of disability and the disablement process which was derived from the previous models of Nagi and ICIDH (Verbugge and Jette 1994). The main pathway in this process was pathology → impairment → functional limitation → disability. The writers defined *impairment* as dysfunctions and significant structural abnormalities in specific body systems, *functional limitation* as restrictions in performing fundamental physical and mental actions pertaining to the daily life by one's age-sex group, and *disability* as experienced difficulty in activities in any domain of life due to health or physical problem. The novelty of this model was that Verbrugge and Jette (1994) took to consideration risk factors and extra- and intra-individual factors as interventions and exacerbations contributing to the main pathway. The authors also described the possibility of feedback loops where the latter stage of the disablement process affects the former stages.

The new classification ICF, a result of a revision process initiated in 1993 has moved away from being "consequences of disease" as was the case in the ICIDH to "components of health". These components were divided into two parts: **1)** functioning and disability including two components: a) body functions and structures b) activities and participation and **2)** contextual factors including the components: c) environmental factors and d) personal factors. As seen in figure 1, the interactions in the ICF framework are bidirectional (WHO 2001).

In ICF *impairments* were seen as problems in body function or structure such as a significant deviation or loss. *Activity limitations* included difficulties an individual may have in executing activities; *participation restrictions* referred to the problems an individual may experience in involvement in life situations; *environmental factors* constituted the physical, social and attitudinal environment in which people live and conduct their lives. In this model the concept of *disability* serves as an umbrella term for impairments, activity limitations and participation restrictions and for three perspectives of body, individual and societal. Each component of health can be expressed in both positive/neutral and negative terms. Thus, a neutral form of the term disability is *functioning*, an umbrella term for body functions and structures, activity and participation. Each component consists of various domains and, within each domain, of categories which constitute the units of the classification (WHO 2001).

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                    Health condition
                   (disorder / disease)



Body functions and          Activity              Participation
structures



           Environmental              Personal
             factors                   factors
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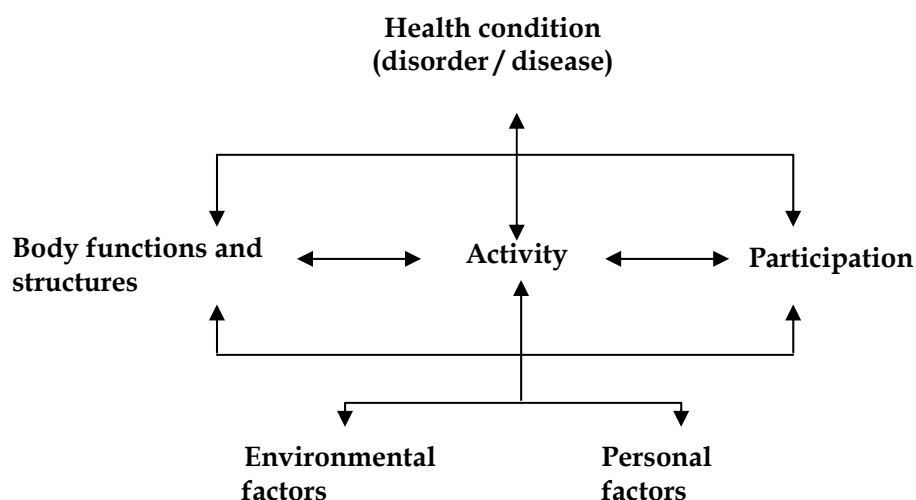
FIGURE 1   The ICF model and interactions between its components (WHO 2001).

The aim of the ICF was to provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants. Also the establishment of a common language for describing health was intended to improve communication between health care workers, researchers, policy-makers and the public. By means of ICF comparisons of data across countries, health care disciplines, services and time would also be possible (WHO 2001).

3.2   Quality of life

The concept of quality of life (QoL) is controversial. Despite the lack of an international consensus on the definition of QoL or health-related quality of life (HRQoL), interest in studying it as an outcome measurement increased considerably in the 1990s (Gill and Feinstein 1994, Carr et al. 1996, Wade 2003). Although there is no consensus on the definition of these concepts (Bowling 1995, Andresen and Meyers 2000, Carr et al. 2001), QoL is nevertheless an important aspect of the outcome of the rheumatic patient (Wilson and Cleary 1995, Higginson and Carr 2001).

        Post and colleagues (1999) have reviewed the literature concerning the different approaches to the concept of QoL. They note that QoL has been considered firstly as synonymous with health or HRQoL or health status; secondly it has been considered the same as well-being as a subjective evaluation of one's functioning; and thirdly it has been seen as a superordinate and inclusive construct for both health and well-being. However, in all approaches QoL was considered as a subjective dimension of health or well-being. The writers also proposed a new framework to describe outcomes of rehabilitation. In this proposal they enlarged the ICIDH model with QoL to integrate objective and subjective elements in rehabilitation outcomes.

According to different levels of ICIDH (organ, person and social levels), a sequence of subjective elements were labelled. The subjective part of the organ level was labelled 'somatic sensation', the subjective part of the person level 'perceived health' and the subjective part of the social level as 'life satisfaction' (Post et al. 1999). QoL was seen in this framework as an overall term incorporating happiness, health and other aspects beyond actual health. Also Whiteneck and colleagues (1997) have elaborated the ICIDH model to QoL. They propose that QoL might be considered as, but not limited to the subjective perceptions of health, activity limitations and role limitations. Ueda and Okawa (2003) have also provided a framework for the subjective dimension of functioning, called subjective experience, besides the ICF model presented as an objective dimension. Peters (1996) expanded the perspectives of disablement from the bipartite objective-subjective perspective to a three-part perspective. The 'outsider's perspective' was considered as observed disablement, the 'interventionist's perspective' as addressed disablement and the 'insider's perspective' as disablement experienced. The outsider's perspective was characterized by descriptions found in diagnostic reports, professional journals and so forth, interventionist's perspective by concrete applications of the individual's goals to be achieved, while the insider's perspective was naturally characterized by the context of people living the reality of disablement. All perspectives were organized across the three planes of ICIDH, impairment, disability and handicap.

The ICF (WHO 2001) unifies different health domains and other domains of well-being under the concept of a "universe of well-being". Well-being is defined "to encompass the total universe of human life domains, including physical, mental and social aspects, which make up what can be called 'a good life'. Health domains are a subset of domains constituting the total universe of human life." QoL is mentioned in the ICF manual in a footnote on challenges for future work in terms of gaining conceptual compatibility between QoL and disability constructs (WHO 2001, footnote 24). To date there are no clear presentations or publications adopting such a conception. Post and colleagues (1999) and Whiteneck and co-workers (1997) have proposed the frameworks of integrated models of ICIDH and QoL. After the publication of the ICF, this question has been brought up in the WHO's inner developmental discussions (Talo, personal communication 2005). Unlike the former investigators Talo from the WHO's ICF Nordic Center emphasizes that the content of the evaluation of QoL and expert evaluations (ICF) could be the same or distinct depending on the categories or items of functioning chosen for the internal (QoL) and external (ICF) evaluations. There is thus no stable content by which to measure QoL, it depends on which ICF items QoL is defined by (Talo, personal communication 2005).

4 HEALTH OUTCOMES OF PATIENTS WITH JIA IN EARLY ADULTHOOD

There is no consensus as to defining outcomes. In general, outcomes are results of treatment, care or rehabilitation such as change in the patient's condition following intervention, and the effect of intervention on the patient's functions (Keith 1995, Maloney and Chaiken 1999). Thus, all modes of intervention – treatment, care and rehabilitation constitute active measures to diminish the impact of disease and disablement on the components of the subject's health.

Outcome assessment in juvenile rheumatic diseases has historically focused on impairments such as organ system damage and disease activity (Duffy 2004) and also on physical function (Oen 2002). During recent years the need for a multidimensional aspect of long-term outcomes, for example psychosocial and socioeconomic and quality of life has increased (Duffy and Watanabe 1997, Maloney and Chaiken 1999, Oen 2002).

During the past fifteen years a growing number of long-term follow-up studies conducted among adult patients with JIA have been reported. In table 2 these long-term outcome studies are depicted with a follow-up time of 10 years or over, a figure (mean or median) for the age of patients of 20 years or over during the study and functional measures applied for adult patients.

TABLE 2 Literature review of outcome studies in JIA patients.

Author, year	Country	No of patients	Follow-up, years	Age, years	Measure†	Study population	Active disease	HAQ score	No disability‡
David et al. 1994	Great Britain	43	20 (mean)	27 (mean)	Steinbrocker, BDI,GHQ, MAA	Hospital-based	48%	ND	26%
Peterson et al. 1997	USA	44	25 (mean)	34 (mean)	HAQ, SF-36	Population-based	66%	ND	ND
Ruperto et al. 1997	Italy USA	227 (118 adults)	15 (mean)	21 (mean)	CHAQ/HAQ, QOLS	Hospital-based	ND	0; 58% >1.5; 4%	ND
Zak and Pedersen 2000	Denmark	65	26 (median)	32 (median)	HAQ, Steinbrocker,	Hospital-based	37%	0; 53%	68%
Packham and Hall 2002a	Great Britain	246	28 (mean)	35 (mean)	HAQ	Hospital-based	43%	0-1.5; 57%	ND
Minden et al. 2002	Germany	215	17 (median)	23 (median)	HAQ, RAQoL, Depression scale	Hospital- and population-based	55%	0; 61% ≥1; 6%	55%
Foster et al. 2003	Great Britain	82	21 (median)	30 (median)	HAQ, SF-36	Hospital-based	39%	<1; 45% >1; 43%	ND
Flatø et al. 2003	Norway	268 (204 adults)	15 (median)	22 (median)	HAQ, SF-36	Hospital-based	50%	>0; 36%	ND

† Steinbrocker=Steinbrocker Functional Class, BDI=Beck Depression Inventory, GHQ=General Health Questionnaire, MAA=Mental Adjustment to Arthritis, HAQ=Health Assessment Questionnaire, SF-36=Health status questionnaire, 36-item, Short Form, QOLS=Quality of Life Scales, RAQoL=Rheumatoid Arthritis Quality of Life Questionnaire, Depression Scale=Center for Epidemiologic Studies Depression Scale, AIMS2=Arthritis Impact Measurement Scales.

‡ Steinbrocker or ARA functional classification.

ND=no data available.

4.1 Functioning as long-term outcome in young adult patients with JIA

Reviewing the studies shown in table 2 regarding disease activity, 37-66% of the young adult patients have been reported to have active disease (David et al. 1994, Peterson et al. 1997, Zak and Pedersen 2000, Minden et a. 2002, Packham and Hall 2002a, Flatø et al. 2003, Foster et al. 2003). Patients with JIA have also been reported to experience more bodily pain than controls (Flatø et al. 2003, Foster et al. 2003), but there are also reports where 15-46% of the patients have been reported to experience no pain (Ruperto et al. 1997, Zak and Pedersen 2000, Minden et al. 2002). Long-term outcome is reviewed to be best in persistent oligoarthritis and worst in RF-positive polyarthritis (Ravelli 2004). According to a recent study among adult patients with JIA, function (measured with Health Assessment Questionnaire, HAQ) and coping strategies predicted 31% of variance in pain (Packham et al. 2002).

The most widely used evaluation instrument for function in the studies of young adult patients with JIA is the HAQ (Fries 1980) (Peterson et al. 1997, Ruperto et al. 1997, Zak and Pedersen 2000, Minden et al 2002, Packham and Hall 2002a, Flatø et al. 2003, Foster et al. 2003). Steinbrocker's functional class (1949) (classes I-IV, where I is complete functional capacity and IV is a largely incapacited person) was used in 4 studies (David et al. 1994, Zak and Pedersen 2000, Minden et al. 2002, Packham and Hall 2002a). Steinbrocker's or also the so-called ARA functional class I (no disability) was found in 26 to 68 per cent of juvenile arthritis patients in the reports of David and co-workers (1994), Zak and Pedersen (2000) and Minden and co-workers (2002). No disability (HAQ=0) was found in 53-64% of patients with JIA by Ruperto and co-workers (1997), Zak and Pedersen (2000), Minden and colleagues (2002) and Flatø's group (2003). Functional disability (HAQ score) was found to deteriorate as the duration of disease (Minden et al. 2002, Packham and Hall 2002a) and age (Foster et al. 2003) increased.

No published studies have considered fatigue and sleep among the psychological symptoms as long-term outcomes among young adult JIA patients. Findings with a broader psychological aspect have shown that severity of disease has no association with adjustment (Ungerer et al. 1988, Baildam et al. 1995) or psychosocial functioning (Aasland et al. 1997) among young adult juvenile arthritis patients.

Although the outcome of JIA has interested many researchers during the past three decades (Savolainen et al. 1998, Minden et al. 2002, Fantini et al. 2003, Foster et al. 2003, Oen et al. 2003), only limited information is available on the prognosis of uveitis in JIA patients reaching adulthood. In a recent Danish 25-year-long retrospective study, uveitis had occurred in 10 out of 65 adult patients with juvenile arthritis up to the follow-up; the eye inflammation was persistent or chronic in 3 of them (Zak et al. 2003). The association of uveitis activity in relation to the activity of arthritis remains unclear, although there is some

evidence that uveitis could be associated with active arthritis (Kotaniemi et al. 2002).

Although the early adulthood has been noted as an important life period in paediatric rheumatology clinics (Ansell and Chamberlain 1998, Leak 2000, McDonagh et al. 2000), the amount of research in the area of education and employment during the past 15 years is surprisingly small. Earlier findings regarding juvenile arthritis patients' educational achievement reported during the preceding decade run mainly parallel with each other, with comparable or higher education level compared to controls (Wirrell et al 1995, Peterson et al. 1997, Minden et al. 2002, Packham et al. 2002b, Flatø et al. 2003, Foster et al. 2003). A lower level of education has also been found in young adults with arthritis starting in early adulthood (Archenholtz et al. 2001). The level of unemployment has deviated between reports: higher in juvenile arthritis patients than in controls in four studies (Peterson et al. 1997, Packham et al. 2002, Flatø et al. 2003, Foster et al. 2003) and lower than or similar to controls in two (Andersson Gäre and Fasth 1995, Minden et al. 2002).

4.2 Quality of life as long-term outcome in young adult patients with JIA

Only few of the studies shown in table 2 used measures of QoL and were conducted with healthy controls included in the study designs (Peterson et al. 1997, Flatø et al. 2003, Foster et al. 2003). All research groups mentioned have found lower levels of the physical component of QoL in juvenile arthritis patients compared to controls. Peterson and colleagues (1997) reported similar levels of QoL in the mental component in patients and controls. Foster and colleagues (2003) and Flatø's research group (2003) found differences in some subdomains of the QoL mental component between patients and controls. QOLS (Quality of Life Scale) – an instrument to measure QoL without healthy controls was used in one study (Ruperto et al. 1997) with findings of 77% of juvenile arthritis patients experienced their QoL "delighted" or "pleased". Follow-up times varied within all studies mentioned from 15 to 25 years. Foster's group (2003) found a trend, although not significant, suggesting that with longer follow-up time the QoL valuation decreases.

5 SOME CHARACTERISTICS OF PSYCHOMETRIC EVALUATION

Scientific and technical measuring of questionnaires which gather structural information from various human behaviours can be called psychometric evaluation or testing (Coolican 2004). In evaluating a test or questionnaire two main characteristics of a measurement are its reliability and validity. These terms are conceptually distinct but interdependent constructs (Thorndike 1982, Rothstein 1985).

Reliability is considered as extent to which findings or measures can be repeated with similar results. Assessment of reliability indicates the external or internal consistency of the measure. Common measures of external reliability are measures of stability across time, such as test-retest reliability. Test-retest reliability can be measured by calculating intraclass correlation coefficient or coefficient of repeatability or reproducibility. As an indication of internal reliability Chronbach's alpha depicts the internal consistency of a measure. Alpha is equivalent to the average of all possible split-half reliability values that could be calculated on the data set. Good consistency is represented with alpha values from .75 up to 1. (Coolican 2004).

Validity can be defined as extent to which instruments measure what they were intended to measure. There are number of different measures of validity. One of them is construct validity, which can be tested by calculating the extent to which operational measures of variables match the intended theoretical construct. This can be formalized through the procedures of factor analysis in which measures designed to appraise the same attribute should load on a common factor. (Thordike 1982, Coolican 2004). Convergent and divergent validity are two forms of construct validity. Convergent validity measures whether the measures of the same concept correlate with each other. Divergent validity measures whether a measure fails to correlate with measures that are intended to be different (Katz 2003).

6   PURPOSE OF THE STUDY

The main goals in the present work were to evaluate levels of functioning in the framework of ICF and quality of life among JIA patients in early adulthood and to compare these results to age-, sex- and domicile-matched controls.

In detail, the study was conducted to provide answers to the following questions:

1.   What are the psychometric characteristics of the Finnish version of the Arthritis impact measurement scales 2 (AIMS2) instrument?

2.   What are the psychometric characteristics of the Finnish version of the Multidimensional health assessment questionnaire (MDHAQ)?

3.   What is the level of functioning of JIA patients in early adulthood?

4.   What are the prevalence and characteristics of uveitis in patients with JIA in early adulthood?

5.   What is the level of quality of life of patients with JIA in early adulthood?

7 SUBJECTS AND STUDY DESIGNS

There were two separate adult rheumatoid arthritis (RA) patient groups and study designs in the psychometric evaluation studies (I, II) and one young adult JIA patient group in the health evaluations studies (III, IV, V). All study designs were approved by the Ethical Committee of the Central Hospital of Päijät-Häme, Lahti, Finland.

7.1 Psychometric evaluation studies (I, II) in patients with RA

For the evaluation studies of the AIMS2 (Meenan et. al. 1992) and the MDHAQ (Pincus et al. 1999) participants were recruited in separate processes from three different institutions treating rheumatic patients. The institutions in study I were Helsinki University Hospital (outpatient department), the Rheumatism Foundation Hospital (RFH), Heinola (inpatient department) and the Rheumatism Association Rehabilitation Centre, Kangasala. The institutions in study II were the Central Hospitals of Lapland, Rovaniemi and South Ostrobothnia, Seinäjoki, (outpatient departments) and the RFH (inpatient department). As inclusion criteria, all participants fulfilled the 1987 ARA criteria (Arnett et al. 1988) for rheumatoid arthritis. Patients with a definite and stable diagnosis, with their arthritis diagnosed ≥ 3 years previously, were included. Participants were ≥ 16 years old at diagnosis, and had had no changes in their disease-modifying antirheumatic medication for the previous 2 months. The translations of the English questionnaires of AIMS2 and MDHAQ into Finnish were undertaken following the standardized guidelines for the process of cross-cultural adaptation of self-report measures (Guillemin et al. 1993, Beaton et al. 2000). The characteristics of the Finnish versions of the AIMS2 and MDHAQ questionnaires were studied by testing psychometric values in construct and convergent validity, reproducibility and internal consistency.

7.2 Health evaluation studies (III,IV,V) in patients with JIA

The RFH provides specialized services in the treatment and rehabilitation of subjects with musculoskeletal diseases. Multidisciplinary treatment and rehabilitation practice has been an important part of the treatment protocol for many decades at the RFH department for children, adolescents and families. From the files of juvenile patients (aged <16 years) treated at the RFH, children born between 1976 and 1980 were identified, altogether 587. The data of the patients who had been diagnosed as suffering from juvenile arthritis were collected; thus 189 patients were excluded as having some other diagnosis than juvenile arthritis. From among the remaining 398 patients those in whom juvenile arthritis disease was diagnosed in the RFH were collected. This led to the exclusion of a further 211 patients because their treatment had been initiated elsewhere. Finally, there were thus 187 patients with early untreated patients with JIA whose diagnosis was made at the RFH and treatment was initiated there (Figure 3). All these patients were reclassified using JIA (Petty et al. 1998) criteria.

The medical records of the patients in the RFH were reviewed to obtain clinical characteristics: onset of disease, subtype (course type) of JIA, sex, age at onset and time of the first visit to RFH. There were no differences in sex or mean age at onset of disease between the early, untreated JIA patient group (untreated group) and those whose treatment was initiated elsewhere than RFH (treated group). However, there were more oligoarticular patients and fewer polyarticular patients with JIA in the untreated group than in the treated group. Compared with the untreated study group, in whom therapy was started during the first visit to RFH, therapy in the treated group was initiated at a mean of 2.0 (range 0.1-13.6) years earlier, before their first visit to RFH.

Four of the 187 untreated patients had Down's syndrome. These were excluded because their social and educational problems would be difficult to distinguish from a possible rheumatic component. In addition, two of the patients had died (in both cases of accidental causes). Thus 181 patients were invited by mail to take part in the study.

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                        ┌──────────────────────────┐
                        │  Patients born 1976-1980  │
                        │          n=587            │
                        └──────────────────────────┘
                                    │
   ┌──────────────────────┐         │
   │ Patients with no JIA │ ◄───────┤
   │        n=189         │         │
   └──────────────────────┘         ▼
                        ┌──────────────────────────┐
                        │    Patients with JIA      │
                        │          n=398            │
                        └──────────────────────────┘
                                    │
   ┌──────────────────────┐         │
   │ JIA patients with     │ ◄──────┤
   │ treatment             │        │
   │ initiated elsewhere,  │        │
   │ n= 211                │        ▼
   └──────────────────────┘
                        ┌──────────────────────────┐
                        │  JIA patients with        │
                        │  treatment                │
                        │  initiated in RFH         │
                        │         n=187             │
                        └──────────────────────────┘
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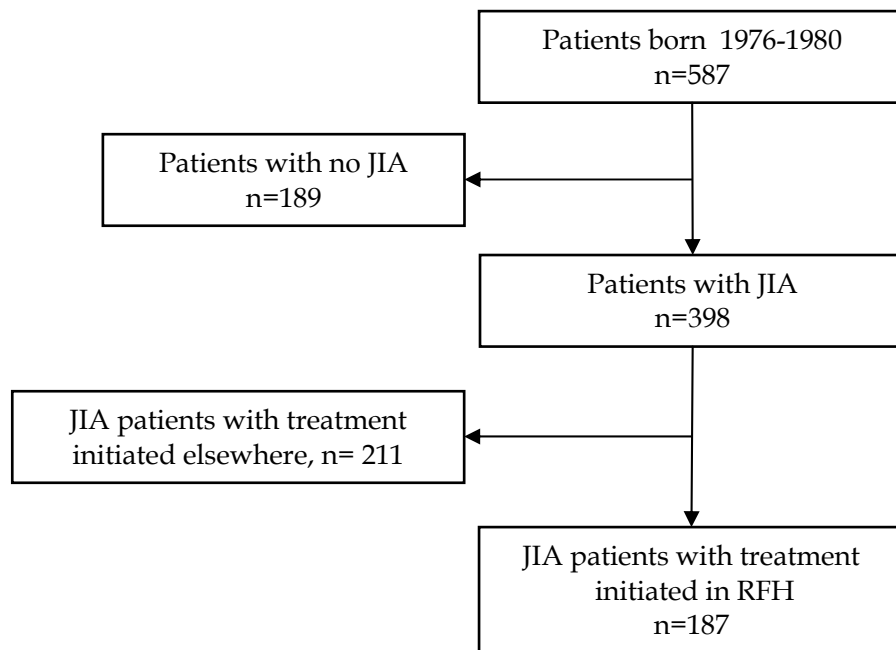
FIGURE 3   Flow chart of patient recruitment.

In all, 123 patients (68%) participated. The comparability of the study group and the withdrawal group was analyzed and no difference between the groups in the distribution of diagnosis and clinical characteristics was found. The only difference between the groups was in the distribution of men, 28% in the study group and 43% in the remainder. Population controls were identified in the Finnish population registry matching the participating patients for age, sex and domicile.

8   METHODS

8.1   Evaluation study of AIMS2 (I)

AIMS2 (Meenan et al. 1992) is a multidimensional, disease-specific, self-administered questionnaire designed to measure improvements in health status produced by therapeutic interventions in arthritis patients. The Finnish version of the AIMS2 questionnaire (Finn-AIMS2) consists of 75 items. The first 57 items are divided into 12 health area scales, namely mobility level, walking and bending, hand and finger function, arm function, self-care tasks, household tasks, social activities, support from family and friends, arthritis pain, work, level of tension, and mood. In addition, the questionnaire includes sections measuring levels of satisfaction, self-designation of priority areas for improvement, perceived current and future health, and demographic data. Three questions from the English version, concerning the racial background, education and the amount of family income were omitted from the Finnish version for cultural reasons.

In addition to Finn-AIMS2, the patients were also asked to complete the HAQ (Fries et al. 1980, Hakala et al. 1993), and two visual analogue scales (VAS), one for the patient's global assessment of disease activity and the other for pain. The physician completed the physician's global assessment of disease activity on a 100-mm analogue scale (VAS) and ARA functional class (Steinbrocker et al. 1949). Disease activity was measured by erythrocyte sedimentation rate (ESR, mm/h) and by physician's assessment of the number of patient's swollen and tender joints. The test-retest reliability of the questionnaire was assessed on outpatients who received no intra-articular injections with glucocorticosteroids during the visit and in whom no change in therapy was made. These patients were further asked to complete a new Finn-AIMS2 questionnaire two weeks later and return it by mail.

8.2 Evaluation study of MDHAQ (II)

The MDHAQ is derived from the HAQ (Fries et al. 1980) and its modified version, MHAQ (Pincus et al. 1983). The HAQ was published in 1980 and has been translated or culturally adapted into over 60 different languages (Bruce and Fries 2003) and has also been part of the core set of physical function measures for clinical care of patients with RA from 1993 (Felson et al. 1993). The MHAQ was further modified to MDHAQ with an eye to overcoming the phenomenon of floor effect and assessing besides the physical status also the psychological aspects of patient outcomes (Pincus et al. 1999). The internet version of the MDHAQ questionnaire (International questionnaire resource, Inquire 2004) used in the present study is an abridged version from the original one (Pincus et al. 1999), consists of 8 items from the MHAQ (Pincus et al. 1983) with questions on activities of daily living (ADL) and two new items concerning advanced function (hereafter referred to as the Function scale, FN), and 3 items on Psychological stress (hereafter Psychological scale, PS). Patients completed the Finn-MDHAQ questionnaire and were also asked to complete the Finnish HAQ (Hakala et al. 1993, Häkkinen et al. 2005) and the Finn-AIMS2. A physician clinically evaluated the patient by completing the physician's global assessment (VAS) and ARA functional classification (Steinbrocker et al. 1949). Disease activity was measured by ESR (mm h^{-1}), and assessing the number of patient's swollen and tender joints. The reproducibility of the questionnaire was tested on patients who had no change in therapy and received no intra-articular injections with glucocorticoids during the visit concerned. These patients were also asked to complete a new Finn-MDHAQ questionnaire 2 weeks later and return it by mail.

8.3 Health evaluation studies (III,IV,V)

The health evaluation studies were conducted so that the health status of the participants was evaluated as an external perspective of their health (Studies III,IV,V), including physical, mental and social determinants. The ICF (WHO 2001) was used here as a framework to give a structure and a means of organizing the information on functioning and disability as elements of health. Second, the QoL was evaluated by the participants as their internal perspective of health (Study V).

8.3.1 Functioning in patients with JIA (III)

The patients visited the RFH and were examined by a paediatric rheumatologist and laboratory tests were also performed. The examination included recording the number of patient's swollen and tender joints and the physician's global

assessment of disease activity (VAS). Laboratory tests were performed to assess disease activity. A patient was considered to be in remission at follow-up if the ESR was ≤ 20 mm/h, morning stiffness ≤ 15 minutes, there were no tender and no swollen joints and the patient had been off DMARDs or glucocorticoids for at least the past two years (Zak and Pedersen 2000). During the one-day visit to the RFH the patients completed the Finn-MDHAQ instrument based on the publication of Pincus and co-workers (1999). The items concerning ADL, sleep, psychological stress and global assessments of pain and fatigue (VAS) were linked to the categories of the ICF (WHO 2001) and divided into three components of functioning; body functions, activities and participation (Table 3). The linking rules reported by Cieza and co-workers (2002) were applied. The partial overlap between components of activities and participation was chosen so that mobility was the common domain in both components, but single item under the mobility domain was entered only into one component (WHO 2001).

Patients completed the Finn-AIMS2 questionnaire. Only item 60 was used in this part of the study. This item deals with the patient's preferences to see improvement in the areas of health. These areas were: mobility, walking and bending, hand and finger function, arm function, self-care, household tasks, social activity, support from the family and friends, arthritis pain, work, level of tension and mood. In item 60 the respondent is asked to report 3 out of 12 areas of health in which he or she would like to see improvement. These health areas were also linked to the ICF categories (WHO 2001) according to the practical example of the area concerned given in parentheses (Table 4).

The control subjects identified from the Finnish population registry were interviewed by mail. They completed the Finn-MDHAQ questionnaire and demographic data.

8.3.2   Uveitis in patients with JIA (IV)

Measurement of the eye-related structure and seeing-related functions, as expressed with ICF constructs, was performed as an example of extra-articular manifestation of JIA and in view of the importance of visual acuity for global functioning. ESR, C-reactive protein, the level of RF, and HLA-B27 status (if not previously determined) were established. Besides the examination by a paediatric rheumatologist during the RFH visit, patients were also examined by an ophthalmologist. The ophthalmic examination included the best corrected visual acuity, careful biomicroscopy and examination of the posterior part of the eye by Volk lens, applanation tonometry, Schirmer's test and an interview recording the presence of dry eyes. Uveitis was regarded as active in cases where 3 or more cells were found in the anterior chamber and/or if the patient was receiving topical corticosteroids for uveitis. Asymptomatic uveitis was mostly chronic anterior uveitis which had lasted for months or even years with minimal or no symptoms. Acute anterior uveitis was defined as uveitis with redness, photophobia and pain which usually healed in 4-6 weeks using topical treatment.

TABLE 3   Finn-MDHAQ items in the components and domains of ICF with individual codes.

Item	Component of ICF	ICF domain	ICF code
a) Dress yourself, including tying shoelaces and doing buttons?	Activity	Self-care	a540
b) Get in or out of bed?	Activity	Mobility	a4100
c) Lift a full cup or glass to your mouth?	Activity	Mobility	a4450
d) Walk outdoors on flat ground?	Activity	Mobility	a450
e) Wash and dry your entire body?	Activity	Self-care	a5101
f) Bend down to pick up clothing from the floor?	Activity	Mobility	a4105
g) Turn regular faucets on and off?	Activity	Mobility	a4402
h) Get in or out of a car, bus, train or airplane?	Participation	Mobility	p410
i) Run errands and shop?	Participation	Domestic life	p6200
j) Climb up a flight of stairs?	Activity	Mobility	a4551
k) Walk two miles?	Participation	Mobility	p4501
l) Run or jog two miles?	Activity	Mobility	a4552
m) Drive a car 5 miles from your home	Participation	Mobility	p4751
n) Participate in sports and games as you would like?	Participation	Community, social and civic life	p9201
o) Get a good night's sleep?	Body structure and functions	Mental functions	b134
p) Deal with the usual stresses of your life?	Activity	General tasks and demands	a2401
q) Deal with the feelings of anxiety or being nervous?	Activity	General tasks and demands	a2401
r) Deal with the feelings of depression or feeling blue?	Activity	General tasks and demands	a2401
VAS Pain	Body structure and functions	Sensory functions and pain	b280
VAS Fatigue	Body structure and functions	Mental functions	b130

TABLE 4   Areas of health (Finn-AIMS2 item 60) as priorities for improvement in the components and domains of ICF with individual codes

Areas of health	Component of ICF	ICF domain	ICF code
1. Mobility level (e.g. do errands)	Participation	Domestic life	p620
2. Walking and bending (e.g. climb stairs)	Activity	Mobility	a450
3. Hand and finger function (e.g. tie a bow)	Activity	Mobility	a440
4. Arm function (e.g. comb hair)	Activity	Self-care	a5202
5. Self-care (e.g. take a bath)	Activity	Self-care	a5101
6. Household tasks (e.g. housework)	Participation	Domestic life	p640
7. Social activity (e.g. visit friends)	Participation	Interpersonal interactions and relationships	p750
8. Support from family (e.g. help with problems)	Environmental factors	Support and relationships	e310
9. Pain (e.g. joint pain)	Body structure and functions	Sensory functions and pain	b280
10.Work (e.g. reduce hours)	Participation	Major life areas	p840
11. Level of tension (e.g. felt tension)	Body structure and functions	Mental functions	b152
12. Mood (e.g. down in dumps)	Body structure and functions	Mental functions	b152

8.3.3 Social functioning and quality of life in patients with JIA (V)

During the visit to the RFH patients completed a Finnish version of the RAND 36-Item Health Survey 1.0 (RAND-36) questionnaire (Aalto et al. 1999) and the Finn-AIMS2 questionnaire, from which the work scale (items 43-47) was used in this part of the study.

The RAND-36 (Hays et al. 1993) is a quality of life measure containing 36 items on eight scales: physical functioning, bodily pain, role limitations due to physical health problems (hereafter called role functioning /physical), general health, energy, role limitation due to personal emotional problems (hereafter called role functioning/emotional), emotional well-being, social functioning. The work scale from Finn-AIMS2 is a 5-item scale covering the respondent's ability to work during the past month. Patients also completed the global assessment of disease activity and pain in VAS form. Social and educational data were collected by questionnaire.

The control subjects identified from the Finnish population registry completed the RAND-36 questionnaire (Aalto et al. 1999) and questions of the work scale in the Finn-AIMS2 questionnaire and social and educational data.

A summary of the measurements in the health evaluation studies (III, IV, V) depicted in the ICF framework as the external perspective of health and study V as the internal perspective of health is given in figure 4. The health status evaluation (external perspective of health) has more stable form of evaluation than the internal one (QoL), which can be influenced and re-determined within a short time period according to individual's experiences. From the standpoint of the dynamic character of the QoL evaluation, this measurement is depicted in figure 4 as an arrow. For clarity to the reader the arrow is drawn below the ICF model. It could also be drawn overlapping with ICF because in this study the QoL instrument included partly the same domains as those of health status from different components of health.
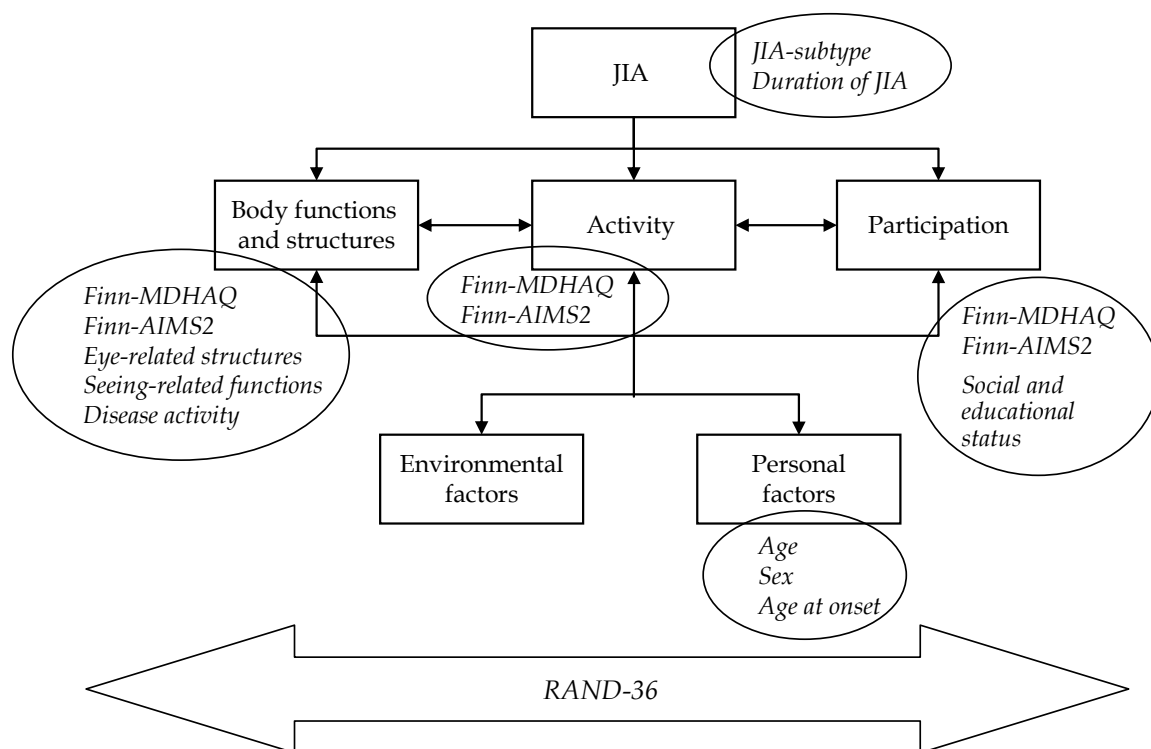
FIGURE 4   Summary of the measurements used in the health evaluation studies III, IV, V (depicted inside the circles) within the ICF framework (WHO 2001) and study V, QoL as internal perspective of health (depicted in an arrow).

8.4 Statistical methods

8.4.1 Evaluation study of AIMS2 (I)

Results are expressed as mean or median, standard deviation (SD) or interquartile range (IQR), with 95% confidence intervals (95% CI). The test-retest reliability of the 12 scales of the instrument was evaluated by calculating the intraclass correlation coefficient (ICC) with 95% CI for ordinal measures. Internal consistency was estimated by calculating Cronbach's alpha internal consistency coefficients with 95% one-sided confidence interval. This implies a 95% chance that Cronbach's alpha will be higher than this value. Convergent validity was studied by calculating the relationship of the Finn-AIMS2 scales and ESR, number of swollen joints, patient's global assessment and assessment of pain, ARA functional class, and HAQ. Construct validity was assessed by maximum likelihood factor analysis and the varimax rotation method with Kaiser normalization for the 12 Finn-AIMS2 item scales. Correlation coefficients were calculated by the Spearman method using Sidak-adusted probabilities.

8.4.2 Evaluation study of MDHAQ (II)

Results are expressed as mean or median, standard deviation or interquartile range, with 95% confidence intervals. The 'floor value' is defined in this study as the poorest possible value for the item or as the minimum total value of the scale, and the 'ceiling value' is the best possible value for the item or the maximum total value of the scale. The test-retest reliability of the two scales in the questionnaire was evaluated by calculating the intraclass correlation coefficient and coefficient of repeatability, with bias-corrected and accelerated bootstrapping (5000 replications) confidence intervals. Internal consistency was estimated by calculating Cronbach's alpha for internal consistency with 95% one-sided CI. Convergent validity was assessed by calculating the relationship of the Finn-MDHAQ scales and HAQ and the Finn-AIMS2 scales and construct validity was studied by MINRES factor analysis with promax-rotation for the Finn-MDHAQ items matrix of polychoric correlations. Item analysis of the Finn-MDHAQ scales was performed by analyzing item discriminating power (corrected item correlation) and item difficulty (item mean) depicted by explanatory data analysis. Corrected item correlation was estimated using polychoric or polyserial correlations, and correlation coefficients were calculated by the Spearman method, using Sidak-adjusted probabilities.

8.4.3 Study of functioning in patients with JIA (III)

The mean with standard deviation was used as measure of location. Confidence intervals for the means were obtained by bias-corrected and accelerated bootstrapping (5000 replications). Differences between JIA patients and their matched controls were compared using the permutation test and multivariate Hotelling-type permutation test for related samples. Data analysis was performed with the statistical software package R 2.0.1 (R Foundation for Statistical Computing 2005).

8.4.4 Study of uveitis in patients with JIA (IV)

Results are expressed as mean or median, standard deviation or interquartile range. Statistical comparison between groups was made by t-test, Mann-Whitney test with exact p-values or Chi-square test. Kaplan-Meier curves were used to illustrate findings pertaining to the cumulative proportions of uveitis. The most important descriptive values were expressed with 95% CI. The α-level was set at 0.05 in all tests.

8.4.5 Study of social functioning and quality of life in patients with JIA (V)

Results are expressed as mean or median, standard deviation or interquartile range with 95% confidence intervals. Maximum likelihood factor analysis with varimax rotation was applied to construct the physical and mental components and their summary scales. Differences between JIA patients and their healthy

matched controls were compared using McNemar's and Marginal Homogeneity test for categorical variables, paired t-test and Hotelling's T-squared generalized means test for continuous variables. Statistical comparison between subgroups was made by unpaired t-test or Mann-Whitney U test, analysis of variance (ANOVA) and multivariate analysis of variance (MANOVA) with Pillai's trace statistics. When assuming unequal variances, analysis of variance with general scores or Welch's test was used. We used Hommel's adjustments to correct significance levels for multiple testing. To determine the best predictors of RAND-36 dimensions, forward stepwise ordered logistic regression analysis was applied. The normality of variables was evaluated by the Shapiro-Wilk test.

9 RESULTS

9.1 Psychometric results

9.1.1 Evaluation of AIMS2 (Study I)

In all, 107 patients, 93 female (87%), mean (SD) age 54 (11), range 36-68 years, completed the Finn-AIMS2 questionnaire. Internal consistency values ranged from 0.79 to 0.89 in the Finn-AIMS2 health area scales except the Work scale; there were only 42 patients working at the time responding. The means of the heath status scores were 1.0 – 5.1 (0 representing best values and 10 poorest).

TABLE 5   Test-retest reliability of Finn-AIMS2 health status scores.

Scale	1st measurements	Difference from 1st to 2nd measurements	ICC[†] (95% CI)
	Mean (SD)	Mean (95% CI)	
Mobility level	0.84 (1.41)	0.11 (-0.13 to 0.34)	.94 (.86 to .98)
Walking and bending	3.92 (2.38)	0.63 (0.23 to 1.03)	.90 (.77 to .96)
Hand and finger function	2.37 (2.16)	0.13 (-0.47 to 0.74)	.82 (.60 to .93)
Arm function	1.45 (1.85)	0.03 (-0.62 to 0.68)	.75 (.47 to .90)
Self-care	0.79 (1.66)	-0.03 (-0.25 to 0.18)	.97 (.92 to .99)
Household task	1.02 (2.54)	0.36 (-0.20 to 0.92)	.84 (.64 to .94)
Social activities	4.93 (1.66)	0.30 (-0.23 to 0.83)	.72 (.42 to .88)
Support from family and friends	2.24 (1.86)	-0.30 (-0.62 to 0.03)	.92 (.81 to .97)
Arthritis pain	3.62 (1.98)	-0.12 (-0.76 to 0.53)	.88 (.65 to .96)
Work	2.15 (3.32)	-0.07 (-1.04 to 0.90)	.94 (.76 to .98)
Level of tension	3.71 (1.43)	-0.24 (-0.66 to 0.19)	.82 (.60 to .93)
Mood	2.61 (1.23)	0.08 (-0.15 to 0.31)	.94 (.85 to .98)

[†] Intraclass correlation coefficient.

The test-retest reliability was examined in 22 cases. ICC varied from 0.72 to 0.97 (Table 5).

Factor analysis within each scale showed all Finn-AIMS2 scales to be loaded on three factors: physical, psychosocial and pain, thus explaining 71 % of the total variance. This indicates support to the initial AIMS2 construct structure (Table 6).

TABLE 6   Factor analysis of the Finn-AIMS2 scales.

Scale[†]	Factor 1 [‡] Physical	Factor 2 [‡] Psychosocial	Factor 3 [‡] Pain
Mobility level	.73		
Walking and bending	.65		
Hand and finger function	.70		
Arm function	.77		
Self-care	.83		
Household task	.82		
Social activities		.55	
Support from family and friends		.52	
Arthritis pain			.67
Level of tension		.78	
Mood		.57	

[†] Work scale was excluded as the number of patients working was low.
[‡] Coefficients with value below 0.5 not shown.

With the exception of social activities, all health area scales in Finn-AIMS2 correlated significantly with HAQ. There were significant correlations between physically related Finn-AIMS2 scales and patient's assessment of pain, patient's and physician's global assessments of disease activity and ARA functional class. There were no significant correlations between Finn-AIMS2 scales and duration of disease or number of swollen joints. The Finn-AIMS2 arthritis pain scale correlated with ESR, patient's global assessment and physician's global assessment, patient's assessment of pain and HAQ (Table 7).

TABLE 7   Correlations and statistical significances between Finn-AIMS2 health status scores and measures of disease activity and functional status.

Scale	Duration of disease	ESR	Number of swollen joints	Physician's global assessment	Patient's global assessment	Patient's assessment of pain	Functional class	HAQ
Mobility level	.12	.22	.17	.35**	.53***	.48***	.49***	.66***
Walking and bending	.21	.19	.13	.51***	.52***	.49***	.49***	.63***
Hand and finger function	.25	.20	.17	.38***	.54***	.49***	.60***	.79***
Arm function	.14	.25	.23	.40***	.54***	.51***	.59***	.71***
Self-care	.13	.10	-.02	.34**	.48***	.42***	.50***	.59***
Household tasks	.01	.23	.08	.34**	.50***	.36**	.52***	.56***
Social activities	-.09	-.11	-.01	.06	.00	-.06	.17	.09
Support from family and friends	.09	.13	.10	.10	.09	.05	.35**	.31*
Arthritis pain	-.01	.39**	.25	.49***	.70***	.72***	.23	.44***
Work	.05	.45*	.24	.29	.36	.37	.44*	.42*
Level of tension	.17	-.04	-.07	.35**	.29*	.30*	.28*	.40***
Mood	.09	.13	-.03	.23	.36**	.30*	.14	.31*

Abbreviations: *p<0.05, **p<0.01, ***p<0.001; statistical significance calculated using Sidak-adjusted probabilities.

9.1.2 Evaluation of MDHAQ (Study II)

One hundred and twenty-three patients, (103, 84% female) completed the questionnaire. The mean age of the patients was 56 years, mean duration of disease 20 years. The response rate on the Finn-MDHAQ scales varied from 95% to 100%. The mean (SD) score on Function scale (FN) was 1.03 (0.63) and on Psychological scale (PS) 0.80 (0.52). Floor and ceiling values on FN were 4 and 1 per cent, and on PS 13 and 1 per cent respectively. In the HAQ, which was also completed by the respondents, the floor and ceiling values were 4 and 2 per cent, respectively. We found a correlation of 0.37 (95% CI 0.20 to 0.51) between FN and PS scales in the Finn-MDHAQ.

Internal consistency values (95% CI lower limit) were 0.92 and 0.66 on FN and on PS, respectively. Thirty-two patients completed the Finn-MDHAQ retest questionnaire. The reproducibility of the Finn-MDHAQ was on FN 0.93 and on PS 0.84 (Table 8).

TABLE 8   Reproducibility of MDHAQ scores.

Score	N	1st measurements	Difference from 1st to 2nd measurements	Reproducibility	
		Mean (SD)	Mean (95% CI)	ICC[†] (95 % CI)	CR[‡] (95% CI)
Function (FN)	32	0.96 (0.74)	0.11 (0.02 to 0.21)	0.93 (0.82 to 0.97)	0.53 (0.42 to 0.70)
Psychological (PS)	32	0.77 (0.56)	0.01 (-0.09 to 0.12)	0.84 (0.70 to 0.92)	0.62 (0.50 to 0.83)

[†] Intraclass correlation coefficient.
[‡] Coefficient of repeatability. Expresses the expected maximum size of 95% of the absolute differences between paired observations. The 95 per cent confidence intervals (CI) were obtained by bias-corrected and accelerated bootstrapping.

Factor analysis carried out for construct validity showed the FN scale to be loaded on two factors: mobility of upper extremities and trunk and mobility of lower extremities, these explaining 61 per cent of the total variance (Table 9).

TABLE 9   Explanatory factor analysis with promax-rotated factor loadings in the Finn-MDHAQ function items.

Item	Factor 1 ‡	Factor 2 ‡
a) Dressing yourself, including tying shoelaces and doing buttons?	0.88	
b) Get in or out of bed?	0.60	
c) Lift a full cup or glass to your mouth?	0.62	
d) Walk outdoors on flat ground?		0.61
e) Wash and dry your entire body?	0.82	
f) Bend down to pick up clothing from the floor?	0.82	
g) Turn regular faucets on and off?	0.81	
h) Get in or out of a car, bus, train or airplane?		0.66
i) Walk two miles?		0.99
j) Participate in sports and games as you would like?		0.67

‡ Coefficients with value below 0.5 not shown.

Item analysis of the FN scale showed that all items had a high corrected item correlation, but one ("Participate in sports and games as you would like") had a higher item mean than the others. Item analysis of PS showed two items to have a high corrected item correlation and one ("Get a good night's sleep") had low (Figure 5).
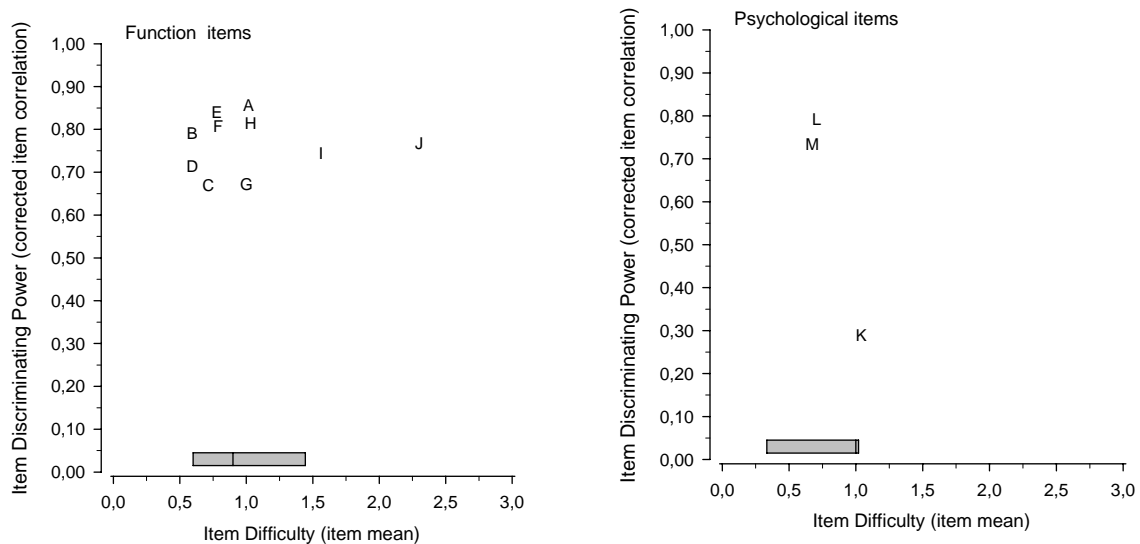

FIGURE 5   Item analysis for Function and Psychological items. The bar denotes median and interquartile of total scores. The capital letters indicate corresponding items in Function (see Table 9) and Psychological scales (K= Get a good night sleep, L= Deal with the feelings of anxiety or being nervous, M= Deal with the feelings of depression or feeling blue).

For convergent validity statistically significant correlations were found between the FN scale and HAQ and between FN and all the subscales of Finn-AIMS2

except two social subscales. In view of the moderate internal consistency in the PS scale and clear differences in the item analysis between PS items we studied the relationship of PS and HAQ, Finn-AIMS2 and clinical characteristics in two different approaches, first for the initial 3-item scale and second for the 2-item scale and separately for the sleep-item. In both approaches the PS scale showed no underlying significant correlation with HAQ. The two-item PS scale showed statistically significant correlations with two physical subscales of Finn-AIMS2 (mobility level and household tasks) and two psychological subscales. The sleep item had statistically significant correlations with some physical subscales of Finn-AIMS2 and the subscale of arthritis pain (Table 10).

TABLE 10   Correlations and statistical significances between Finn-MDHAQ scores and HAQ and Finn-AIMS2 subscales.

| | Multidimensional Health Assessment Questionnaire | | | |
| | Function | Psychological | | |
	FN score	PS score	PS score 2-item[†]	PS score Sleep[‡]
HAQ	.91***	.25	.18	.28
AIMS2:				
Mobility level	.74***	.43***	.38***	.32**
Walking and bending	.73***	.29*	.17	.31**
Hand and finger function	.57***	.26*	.29*	.14
Arm function	.60***	.32**	.20	.35**
Self-care	.61***	.29*	.22	.27*
Household tasks	.57***	.33**	.37***	.20
Social activities	.19	.21	.23	.10
Support from family and friends	.06	.21	.26*	.08
Arthritis pain	.35**	.40***	.23	.43***
Level of tension	.33**	.67***	.69***	.25
Mood	.33**	.59***	.66***	.19

[†] Only items "Deal with the feelings of anxiety or being nervous?" and "Deal with the feelings of depression or feeling blue?"
[‡] Only item "Get a good night's sleep?"
 Abbreviation: *p<0.05, **p<0.01, ***p<0.001; Sidak-adjusted probabilities.

As shown in Table 11, FN had statistically significant correlations with almost all clinical characteristics studied. In both PS scale relationship approaches there were significant correlations with physician's and patient's global assessment of disease activity. The sleep item had a significant correlation with the patient's assessment of pain, but the two-item PS scale did not evidence this relationship.

TABLE 11   Correlations and statistical significances between Finn-MDHAQ scores and demographic and clinical characteristics.

| | Multidimensional Health Assessment Questionnaire | | | |
| | Function | Psychological | | |
	FN score	PS score	PS score 2-item[†]	PS score Sleep[‡]
Age	.32**	.14	.09	.18
Duration of disease	.21	.15	.05	.21
ESR	.18	.01	.02	.01
Number of swollen joints	.08	.17	.24	-.04
Number of tender joints	.31**	.24	.29*	.09
Physician's global assessment	.39***	.35***	.26*	.30**
Patient's global assessment	.48***	.40***	.32**	.30**
Patient's assessment of pain	.40***	.30**	.20	.28**
DAS28	.28*	.19	.20	.06
Functional class	.49***	.22	.20	.14

[†] Only items "Deal with the feelings of anxiety or being nervous?" and "Deal with the feelings of depression or feeling blue?"
[‡] Only item "Get a good night's sleep?"
 Abbreviation: *p<0.05, **p<0.01, ***p<0.001; Sidak-adjusted probabilities.

9.2   Results in health evaluation studies (III, IV, V)

9.2.1   General clinical characteristics of young adults with JIA (Studies III, IV, V)

One hundred and twenty-three patients (89 female and 34 male, mean age 23 years) participated in the study. The median (IQR) time from first symptoms to first visit to RFH and diagnosis of the disease was 3 (1 , 5) months. The mean (SD) age at onset of disease was 7.8 (4.4) years, the mean time from diagnosis to follow-up 16.2 (range 6.0 – 23.8) years. At follow-up 28 (31%) of the female and

18 (53%) of the male patients were in remission (including those three patients who had had no disease activity for the past two years but were on DMARDs). The difference between groups was 21% (95% CI, —40 to —2), p = 0.028. Demographics and main clinical characteristics of the patients are set out in table 12.

TABLE 12   Demographic and general clinical characteristics of patients.

Variables	Male (N=34)	Female (N=89)	All (N=123)
Age at onset, mean (SD), years	9.4 (4.0)	7.2 (4.5)	7.8 (4.4)
Diagnosis (course type), no (%):			
Oligoarthritis	26 (76)	52 (58)	78 (63)
Extended oligoarthritis	3 (9)	12 (13)	15 (12)
Polyarthritis RF-negative	4 (12)	19 (21)	23 (19)
Polyarthritis RF-positive	0 (0)	4 (4)	4 (3)
Systemic arthritis	0 (0)	2 (2)	2 (2)
Psoriatic arthritis	1 (3)	0 (0)	1 (1)
Disease activity at follow-up, no (%)			
Remission, no DMARDs	17 (50)	26 (29)	43 (35)
No activity, on DMARDs	1 (3)	2 (2)	3 (2)
Active disease	16 (47)	61 (69)	77 (63)
Time from diagnosis to follow-up, mean (range), years	14.7(6.7 – 22.6)	16.7(6.0 – 23.8)	16.2(6.0 – 23.8)
Age at follow-up, mean (range), years	23.2 (21 – 26)	23.4 (21 – 26)	23.3 (21 – 26)

DMARD= disease modifying antirheumatic drug.

9.2.2   Functioning including uveitis in young adults with JIA (Studies III, IV)

In the multivariate analysis there were significant differences between patients and controls in all three ICF components of functioning; body functions, activity and participation. The MDHAQ items and visual analogue scales in the components, domains and codes of ICF are shown in table 13. In the univariate analysis in the component of body functions there was a higher level of pain among JIA patients compared to controls. Further, in the activity component JIA patients had lower levels of mobility compared to controls and in the component of participation a lower level of functioning in the domains of mobility and social life was found in JIA patients compared to controls (Table 14).

TABLE 13   MDHAQ items and visual analogue scales in the components and domains of ICF with individual ICF codes.

Item	Component of ICF	ICF domain	ICF code
a) Dress yourself, including tying shoelaces and doing buttons?	Activity	Self-care	a540
b) Get in or out of bed?	Activity	Mobility	a4100
c) Lift a full cup or glass to your mouth?	Activity	Mobility	a4450
d) Walk outdoors on flat ground?	Activity	Mobility	a450
e) Wash and dry your entire body?	Activity	Self-care	a5101
f) Bend down to pick up clothing from the floor?	Activity	Mobility	a4105
g) Turn regular faucets on and off?	Activity	Mobility	a4402
h) Get in or out of a car, bus, train or airplane?	Participation	Mobility	p410
i) Run errands and shop?	Participation	Domestic life	p6200
j) Climb up a flight of stairs?	Activity	Mobility	a4551
k) Walk two miles?	Participation	Mobility	p4501
l) Run or jog two miles?	Activity	Mobility	a4552
m) Drive a car 5 miles from your home	Participation	Mobility	p4751
n) Participate in sports and games as you would like?	Participation	Community, social and civic life	p9201
o) Get a good night's sleep?	Body structure and functions	Mental functions	b134
p) Deal with the usual stresses of your life?	Activity	General tasks and demands	a2401
q) Deal with the feelings of anxiety or being nervous?	Activity	General tasks and demands	a2401
r) Deal with the feelings of depression or feeling blue?	Activity	General tasks and demands	a2401
VAS Pain	Body structure and functions	Sensory functions and pain	b280
VAS Fatigue	Body structure and functions	Mental functions	b130

TABLE 14   Components and domains of functioning in patients and controls (capitals in parenthesis indicate MDHAQ items, see table 13).

ICF components (MDHAQ item*)	Patients	Controls	P-value	
	Mean (SD)	Mean (SD)	Univariate‡	Multivariate‡
Body structure and functions				0.045
Mental functions (o)	0.23 (0.44)	0.26 (0.49)	0.68	
Sensory functions and pain (Pain, VAS)	15 (21)	10 (14)	0.036	
Mental functions (Fatigue, VAS)	23 (27)	23 (24)	0.82	
Activity				0.0021
General tasks and demands (p, q, r)	0.29 (0.49)	0.34 (0.49)	0.47	
Mobility (b, c, d, f, g, j, l)	0.20 (0.26)	0.12 (0.15)	0.0034	
Self-care (a, e)	0.06 (0.21)	0.03 (0.15)	0.32	
Participation				<0.001
Mobility (h, k, m)	0.15 (0.32)	0.05 (0.19)	0.0046	
Domestic life (i)	0.08 (0.30)	0.02 (0.13)	0.053	
Community, social and civic life (n)	0.64 (0.88)	0.14 (0.35)	<0.001	

* Letters in parenthesis refer to the MDHAQ items in table 13.
† Permutation test for related samples.
‡ Hotelling-type permutation test for related samples.

JIA patients were divided into two separate groups in the context of disease activity to compare their functioning with that of controls. In the group of patients with active disease versus controls significantly lower levels of functioning were found in JIA patients in every ICF component concerned in the multivariate analysis; body functions $p = 0.0015$, activity $p < 0.001$, participation $p < 0.001$. JIA patients with active disease had higher levels of pain ($p = 0.0011$), lower levels of mobility ($p < 0.001$) and self-care ($p = 0.027$) and lower levels of participation in all domains concerned (mobility $p < 0.001$, domestic life $p = 0.0039$, community, social life $p < 0.001$) (Figure 6). There were no significant differences in any components of functioning between JIA patients in remission and controls in the multivariate analysis; body functions $p = 0.051$, activity $p = 0.50$, participation $p = 0.46$ (Figure 7).
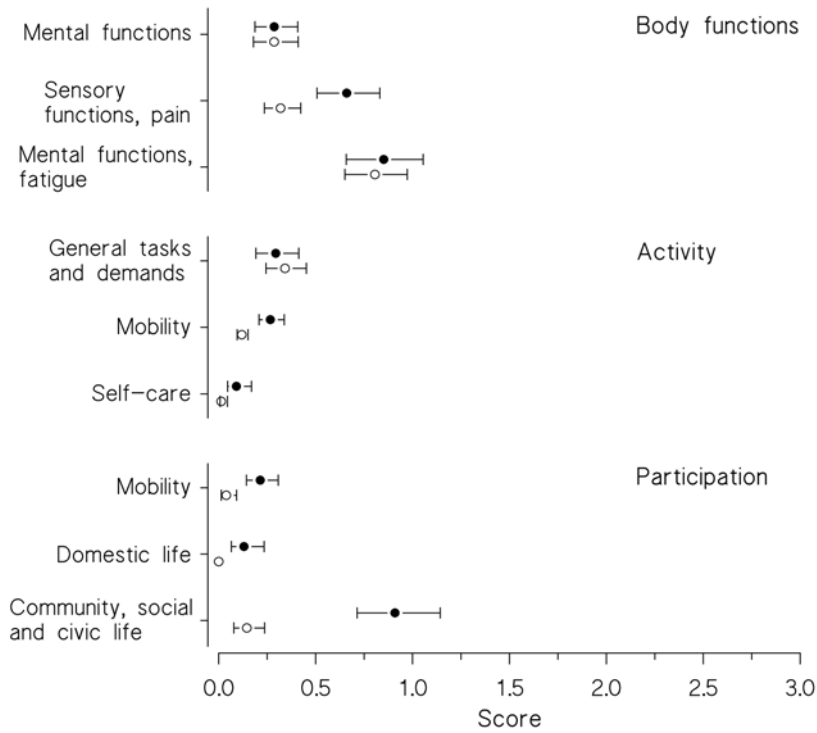
FIGURE 6   Level of functioning in JIA patients with active disease (= filled circles ●) and age-, sex- and domicile-matched controls (= empty circles ○). Pain and fatigue VAS are standardized from 0 to 3. Confidence interval obtained by bias-corrected and accelerated bootstrapping.
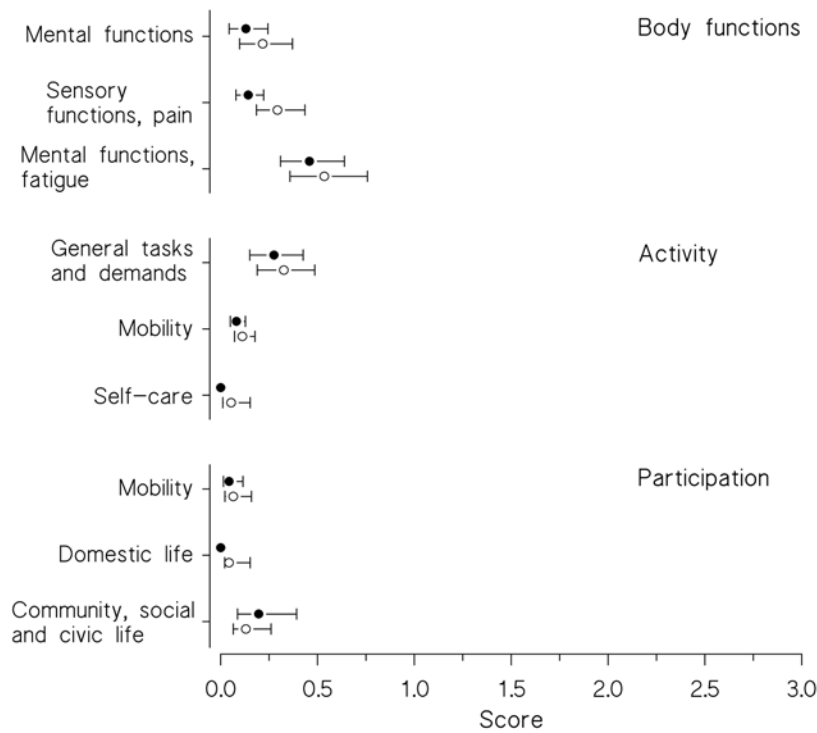

FIGURE 7   Level of functioning in JIA patients in remission (= filled circles ●) and age-, sex- and domicile-matched controls (= empty circles ○). Pain and fatigue VAS are standardized from 0 to 3. Confidence interval obtained by bias-corrected and accelerated bootstrapping.

The patients with JIA were asked in which 3 areas of health out of the 12 in Finn-AIMS2 they would prefer to experience improvement. Those areas of health the patients with active disease and those in remission differed from each other were analyzed. The groups differed only in arthritis pain and in social activity. The Patients with active disease wished to see improvement in arthritis pain and patients in remission in their social activity.

The main demographic and clinical characteristics of the study population regarding history of asymptomatic or acute uveitis are presented in table 15.

TABLE 15   Demographic and clinical characteristics of young adults with juvenile idiopathic arthritis with asymptomatic or acute uveitis or without it.

Characteristics	History of asymptomatic uveitis			History of acute uveitis
	Present	None	*P*	
Number of patients	19	98		6
Female, number (%)	16 (84)	71 (72)	*0.39*	2 (33)
Age at onset of arthritis, mean (SD), years	4.3 (3.4)	7.7 (4.4)	*0.002*	10 (4.1)
Diagnosis (course type), number (%)			*0.33*	
Oligoarthritis	10 (53)	63 (64)		5 (83)
Extended oligoarthritis	5 (26)	9 (9)		1 (17)
Polyarthritis RF-negative	2 (11)	21 (21)		0 (0)
Polyarthritis RF-positive	2 (11)	2 (2)		0 (0)
Psoriatic arthritis	0 (0)	1 (1)		0 (0)
Enthesitis related arthritis	0 (0)	0 (0)		0 (0)
Systemic onset arthritis	0 (0)	2 (2)		0 (0)
HLA-B27 positive, number (%)	7 (37)	28 (27)	*0.47*	6 (100)
ANA-positive, number (%)	7 (37)	20 (20)	*0.14*	0 (0)
Interval from diagnosis of arthritis to re-evaluation, mean, years	19.3	15.5	*<0.001*	15.3
Age at re-evaluation, mean years	23.7	23.6	*0.31*	23.2

As a part of the outcome in body structures and functions assessment, uveitis had been detected in 25 (20%) of the 123 patients. Out of these 25 patients, 19 were affected by asymptomatic anterior uveitis with minimal or no ocular symptoms. At the onset of arthritis their mean age was 4.3 years (range 1.5-16.8) and at the diagnosis of asymptomatic uveitis 10 years (range 2.6-23.5). The mean interval from the diagnosis of juvenile arthritis to the diagnosis of uveitis was 4.8 years (range 0-20.2). Antinuclear antibody (ANA) positivity was found in 7/19 (37%) patients. Only 3 out of 19 patients had had one short episode of asymptomatic uveitis (duration <3 months) and 16 out of 19 had chronic asymptomatic uveitis (duration >3 months). Five out of these 16 patients with chronic asymptomatic uveitis had inflammation in both eyes and in 11 cases the affliction was unilateral. At the time of the clinical evaluation uveitis was still

active in 8 cases (mean duration of uveitis 15 years) and arthritis was ongoing in all but one of them. Uveitis was detected in 3 of the 19 cases after the age of 16.

Uveitis was acute anterior symptomatic (pain, photophobia and redness) in 6 cases out of 25. All 6 were HLA B27-positive and ANA-negative. The mean age at the diagnosis of acute uveitis was 20 years (range 14.5-22); in 5 cases uveitis appeared after the age of 16. The mean interval from the diagnosis of JIA to the diagnosis of uveitis was 9.1 years (range 1.9-18).

9.2.3 Social functioning and quality of life of young adults with JIA (Study V)

Social functioning contained spousal relationship, education and employment, all items of the participation component. At follow-up spousal relationship was similar between patients with JIA and controls (Table 16). There was no statistically significant difference between the educational levels of these two groups, nor was there any difference between them in the frequencies of employment, unemployment and disability pension (Table 16). In both groups, patients with JIA and controls, those who were working (paid or home work) or students, there was no statistically significant difference in ability to work (data not shown).

TABLE 16 Spousal relationship, educational and employment status of JIA patients and controls.

	Patients (N=123)	Controls (N=123)	P value
Marriage or common-law marriage, n (%)	62 (50)	75 (61)	0.12
Educational status at follow-up, n (%)			0.67
Basic education only	8 (7)	8 (7)	
Vocational education	39 (32)	43 (35)	
Upper secondary school (USS)	47 (38)	30 (24)	
USS and vocational education	12 (10)	25 (20)	
Higher education	17 (14)	17 (14)	
Employment status, n (%):			0.30
Employed	51 (41)	55 (45)	
Unemployed	12 (10)	19 (15)	
Student	58 (47)	48 (39)	
Disability pension	2 (2)	1 (1)	

Results of self evaluation of health (RAND-36) data on the patients and age-, sex- and municipally matched controls are shown in Table 17 (data missing in one patient). In the univariate analysis of the Physical component scales (PCS) (including physical functioning, role functioning/physical, pain and general health) the physical functioning score in the patient group was statistically lower (poorer) than in the control group. In the Mental component scales (MCS) (including energy, role functioning/emotional, emotional well-being and social functioning) univariate analysis brought out no difference between the groups.

In multivariate analysis of the PCS a statistically significant difference (Hotelling T^2: p=0.0017) was found between patients and controls. In multivariate analysis of the MCS no statistically significant difference emerged between the groups (Hotelling T^2: p=0.15).

TABLE 17   Quality of life (QoL) as measured by the RAND-36 in 122 young adults with JIA and controls.

Domain	Patients	Controls	P value[*]
	Mean (SD)	Mean (SD)	
Physical component scales[†]			
Physical functioning	89. 6 (16.3)	96.8 (6.8)	<0.001
Role functioning/physical	84.4 (28.6)	87.5 (26.1)	0.37
Pain	81.6 (19.9)	83.7 (16.1)	0.36
General health	71.1 (19.4)	75.6 (18.2)	0.18
Mental component scales[‡]			
Energy	74.2 (15.9)	69.5 (18.4)	0.08
Role functioning/emotional	87.2 (22.2)	84.2 (29.1)	0.45
Emotional well-being	81.9 (14.1)	78.0 (14.7)	0.086
Social functioning	93.4 (13.1)	88.8 (16.1)	0.057

[*] P value adjusted using Hommel's method.
[†] Hotelling's T-squared generalized means test for 4 scales: p=0.0017
[‡] Hotelling's T-squared generalized means test for 4 scales: p=0.15

When comparing QoL between patients in remission (including the three in remission with no disease activity for the last two years but on DMARDs), those with active disease and controls, differences were found in all scales of PCS (p<0.01) but none in MCS between controls in univariate analysis. There was, however, a difference in PCS (MANOVA Pillai's trace: p<0.001) in the multivariate analysis but none in the MCS between these three groups (MANOVA Pillai's trace: p=0.74). On all scales of PCS there were localized signficant differences (post hoc: α=0.05) in controls and in patients in remission compared to patients with active disease. There was no difference between controls and patients in remission on the PCS scales (Figure 8).

QoL was compared in patients with oligoarthritis, extended oligoarthritis and polyarthritis, and in univariate analysis in PCS differences between the groups emerged on the scales of physical functioning and role limitations due to physical health problems. Further, in univariate analysis the only difference between the respective JIA subgroups in MCS emerged on the social functioning scale. In multivariate analysis we found a difference between the groups in PCS (MANOVA Pillai's trace: p=0.030) but not in MCS (MANOVA Pillai's trace: p=0.071). The extended oligoarthritis group had the lowest value for QoL on all scales of PCS and MCS. The mean (SD) physical health summary score was 51.1 (7.5) in oligoarthritis patients, 42.2 (8.4) in extended oligoarthritis patients and 50.5 (9.2) in polyarthritis patients (p<0.001), and the mean mental health summary scores respectively 50.9 (8.1), 44.6 (10.3) and 49.6 (8.5) (p=0.041).
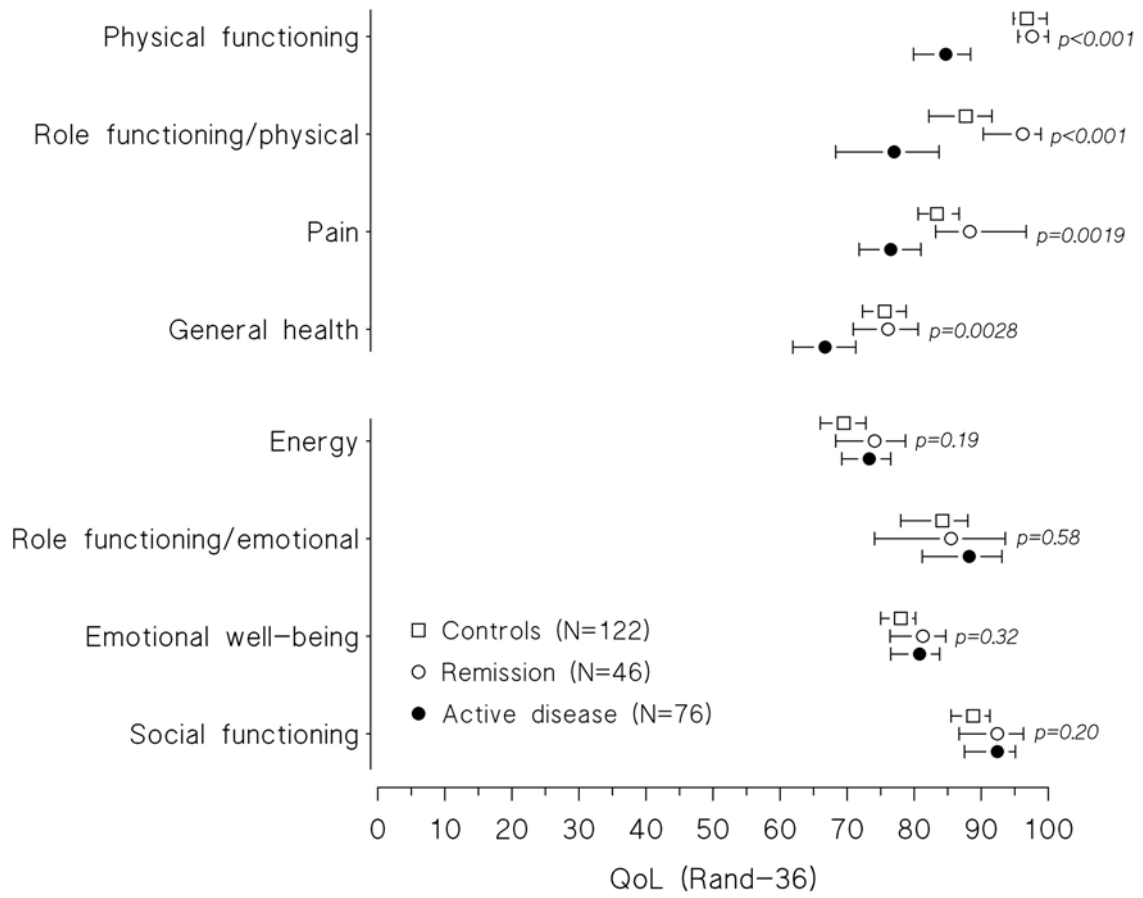
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FIGURE 8   Mean QoL with 95% confidence intervals of patients with JIA in remission
and with active disease. P values adjusted using Hommel's method.
Confidence interval obtained by bias corrected and accelerated
bootstrapping.

Patients' global assessments (VAS) of <20 mm and remission at follow-up were
entered into the forward ordered logistic regression model as an explanatory
variable for high (better) QoL in the physical health summary scales. In the
mental health summary scales likewise a patients' global assessments (VAS) of
<20 mm were entered as an explanatory variable for better QoL.

10 DISCUSSION

10.1 Subjects, study design and methods

10.1.1 Psychometric evaluation studies (I, II) in patients with RA

Evaluation of the properties of AIMS2 in Finnish patients with RA revealed that the demographic features of this study tallied with those in evaluation studies previously reported for RA patients (Meenan et al. 1992, Pouchot et al. 1996, Riemsma et al. 1996, Archeholtz and Bjelle 1997). The present results concern middle-aged rheumatic patients; the youngest patient here was 36 years old. However, since one section of patients in rheumatic clinics comprises young adults, longitudinal outcome studies would require a measurement instrument which has been validated for all adult age groups. In the evaluation studies of the Swedish (Archeholtz and Belle 1997) and the French (Pouchot et al. 1996) versions of AIMS2 an age group of young adults (from 23-26 years) was also included. Although juvenile and adult arthritis are separate diseases the character of disability is quite similar in both groups. However, the applicability of Finn-AIMS2 in young adult age groups needs to be confirmed in further research. RA patients with a definite and stable diagnosis were recruited to cover a wide range of these patients. Translation of the questionnaire calls for special attention to cultural differences affecting measurement and assessment (González-Calvo et al. 1997). The Finnish population is culturally still relatively homogeneous, which may explain why cultural differences presented no serious difficulty in the translation of Finn-AIMS2. Three questions of racial, educational and financial issues were omitted from the final version and other minor modifications were made to preserve semantic equivalence to the original questionnaire.

The same patient inclusion criteria were applied in the study of MDHAQ (II) as in the evaluation of Finn-AIMS2. The process of evaluating MDHAQ was carried out on patients with a stable diagnosis of RA but who, however, represented a wide range of disease and age groups of RA patients. Twenty (3-

53 range) years as a mean duration of the disease may indicate that recruitment succeeded in the case of diverse disease duration but not in respect of the age spectrum. The mean (SD) age of the patients was 56 (11) years, which leaves out the young adult age groups. Data on the age range of the patients in the initial MDHAQ report (Pincus et al. 1999) were not available. Cultural differences again presented no serious difficulty in the translation process of the instrument in this evaluation study.

One limitation of the present study is that there were two different versions of MDHAQ instruments applied in psychometric and health evaluation studies. The initial version of the instrument (Pincus et al. 1999) was translated into Finnish and tested in RA patients but the statistical analysis was made from the shortened version. The initial version was used in one health evaluation study (III). However, the item groups were the same in both, Function scale (ADL, advanced function), and Psychological scale. The majority of the items were also in the shortened version, e.g. in the ADL items, the amount of question was reduced from 10 to 8. Also the same scoring method was applied in both versions.

10.1.2 Health evaluation studies (III, IV, V) in patients with JIA

The study entity in health evaluations (III, IV, V) included one 5-year age cohort in a hospital population. The RFH is a hospital which provided third- and second-level and centralized services for juvenile arthritis children and adolescents from all over the country during the years (1976-1995) when the patients visited the hospital for the first time. The regional distribution of the patients was in accord with the distribution of the population in Finland. It may be however concluded that despite recruitment as a hospital population-based cohort, the sample can be considered to be representative in general and regarding different areas of the country.

The strength of the study design was that the whole spectrum of JIA patients was included in the study population. Bias to the severe spectrum of disease was avoided by excluding patients whose treatment was started elsewhere than the RFH, as these patients often visited the RFH for specialist consultation due to unstable disease. In the analysis of the exclusion group this view was strengthened by results on the different distribution of diagnostic subgroups among these patients. The excluded patient group was biased in having a more severe disease with more polyarticular form. The wide spectrum of the population may also involve the possibility to one limitation to the study. The study population included few patients with severe disability in early adulthood. These patients nonetheless constitute challenging group from the viewpoint of the health care system as an important client group. According to a recent German study (Minden et al. 2004), one of the three factors increasing the annual costs of illness in young adult patients with JIA is functional disability, which can increase costs tenfold compared to patients who have no functional disability. However, two other factors influencing costs were

according to Minden and co-workers (2004) disease activity and quality of life, on which we now have more information as a result of the present study.

One of the strengths of the study design was the case-control arrangement. The outcome of patients with JIA has improved, with a decline in frequency of cases with severe disability over the years (Ravelli 2004). One objective of the treatment of patients with JIA is to gain remission of disease, normal activity and equal social participation. One mean of establishing the extent to which multidimensional objectives have been reached comprises sex- and age-stratified controlled outcome studies (Oen 2002).

One obvious limitation in this study is that one subgroup of patients, enthesitis related arthritis, was missing from the study population. Also the fact that the number of participants recruited was 68% of the whole study population can weaken the representativeness of the study. The only difference between the study population and remainder was, however, the number of men in both groups. Regarding other clinical characteristics the groups were similar.

Several researchers have argued the need to examine the subjective as well as the objective dimension of patients' health (Peters 1996, Ruggeri et al. 2001, Ueda and Okawa 2003). The internal aspect of health is semantically a more neutral mode to express patients' experience over their health. The internal perspective should be placed on an equal footing with the external evaluation of health (Whiteneck et al. 1997), which has been said to be privileged by modern medicine (Peters 1996). The subjective view has been said to have important role in integrating both subjective and objective dimensions into a coherent whole of human functioning (Ueda and Okawa 2003). This is true not only from the standpoint of health professionals but also as seen from the patients' point of view. Patients can benefit from the results of a thorough evaluation made by health professionals and expressed in understandable terms to formulate a coherent picture of their own health besides their own internal experience. For developmental work on QoL and ICF constructs, the potential content of QoL as an open composite of the patient's internal evaluations in the domains of well-being would be fruitful instead of trying to define and score QoL as if it were one distinct construct, as Post with co-workers (1999) have expressed the matter.

Since the approval of the ICF classification by the World Health Assembly in May 2001 a growing number of papers have been published on the application of the ICF classification to rheumatology and rehabilitation (Dahl 2002, Stucki and Cieza 2004a, 2004b, Stucki et al. 1995, 2002, 2004, Cieza and Stucki 2005). Use of the classification presents a challenge among other things by reason of the wide range of applicable categories and also for the lack of experience in using the classification as a research tool. Linkage of the 18 items and 2 visual analogue scales of MDHAQ to ICF categories produced 3 categories to each component of functioning. As the emphasis of the MDHAQ instrument lies in physical function, it was expected that the largest part of the items (12 out of 20) would be directed to the component of activity. Three and five items were directed into the components body functions and participation respectively. The items concerning mental functions – anxiety, depression and

handling stress – were directed to the activity component by reason of the character of the questions, including the ability to deal with these feelings. The importance of MDHAQ is to include mental functioning with the physical in the same instrument, but from the ICF point of view the fact that three different mental aspects are depicted with one general ICF code could oversimplify mental functions. The overlapping of mobility between the categories of activity and participation was one of the 4 options given in the ICF manual (WHO 2001, Annex 3) to code items into these categories. We chose to use partial overlap for the wide range of mobility items used in the MDHAQ and for the social context connected with some items. However, there has been criticism concerning the confusion between the definitions of activity and participation and the lack of theoretical coherence (Nordenfelt 2003) in this part of the ICF. Future developmental work on ICF may clarify these definitions and the use of the categories.

The RAND-36 questionnaire (Hays et al. 1993) was applied to measure QoL. This instrument has the same items as the SF-36 (Ware and Sherbourne 1992) questionnaire but a slightly different scoring method. The results are nonetheless amenable to comparison (Hays et al. 1993).

10.2 Results

10.2.1 Reliability and validity of Finn-AIMS2 and Finn-MDHAQ instruments in adult RA patients (Studies I, II)

The internal consistency of all Finn-AIMS2 health status scales showed high values (with the exception of the work scale) indicating good internal reliability. The small number of patients who were working at the time of responding was not surprising in view of the long mean duration of the disease and the mean age of the patients.

The test-retest reliability of the health status scores exceeded moderate or high levels in every score and for 6 of the 12 scales in the ICC values exceeded 0.90 indicating good external reliability. These findings are in accord with those reported for the original version of AIMS2 by Meenan and associates (1992).

In the case of construct validity using factor analysis physical, psychosocial and pain factors were identified when the work scale was excluded. In the evaluation of the Swedish version of AIMS2, Archenholtz and Bjelle (1997), likewise excluding the work scale, physical, psychological and social factors were identified. In the present study the social and the psychological dimensions were found not to load to separate factors in these data. The size of the body of data could explain these differences. According to the Swedish report (Archenholtz and Bjelle 1997) the arthritis pain scale did not emerge as a single factor even when a 4- or a 5-factor analysis was added. However, in three-factor analysis their arthritis pain scale was markedly loaded in the physical factor. According to the AIMS2 User's Guide (ProQolid.org

2003), in three-component factor analysis arthritis pain has appeared as a single factor.

Of all the patient and physician oriented, clinical and laboratory measures, HAQ showed strongest correlations with the Finn-AIMS2 health status scales, as also shown by Brandão and colleagues (1998) in the Brazilian AIMS2 study. However, no correlation between social activities scale and HAQ was observed, which could be expected in view of the physical character of the HAQ questionnaire. No statistically significant correlations were found between two social scales and the measures of disease activity (duration of disease, number of swollen joints, ESR, physician's and patient's global assessment, and patient's assessment of pain). The poor correlation can be explained by the fact that patients with RA receive active treatment with fairly good suppression of inflammation and good function.

The evaluation of MDHAQ is the first translation and cross-cultural adaptation research to be made on the questionnaire mentioned. This instrument is not yet in widespread use but it unifies three important characters of a rheumatologic assessment instrument: the physical and mental aspects of the patient's functioning (Pioro and Kwoh 1996), a patient-oriented perspective (Kwoh and Ibrahim 2001) and a brief, patient-friendly format (Katz et al. 1992).

High response rates were found on all items in both Finn-MDHAQ scales, from which it may be concluded that the instrument was easy to complete. Previously, in the case of MHAQ (Stucki et al. 1995, Serrano et al. 1996) and the initial MDHAQ (Pincus et al. 1999), the floor and ceiling effect was discussed, but no signs of this effect of clustering were found here in Finn-MDHAQ, as the floor and ceiling values of the two total scales were low. The results indicate that the Finn-MDHAQ can detect the whole spectrum of physical and psychological aspects of RA patients' outcome. However, as in the PS scale two or three items can only provide a useful screening tool for psychological distress, as previously stated (Pincus et al. 1999). The reproducibility of Finn-MDHAQ can be considered good on both FN and PS scales with ICC values 0.93 and 0.84, respectively.

Internal consistency was good in the FN scale and moderate in PS indicating good internal reliability. This finding was supported by the results of item analysis. In the three-item PS scale the corrected item correlation of the sleep question was clearly lower than the others. To ask the patient about his/her quality of sleeping is clinically very important, but it does not here support the item structure in the PS scale and does not measure the same attribute as the other items in that scale. For future use of MDHAQ it would be appropriate to consider leaving the sleep item as a separate element, as was done in another version of HAQ, CLINHAQ (Wolfe 1989). Perhaps also altering the form of the question from the Likert scale to VAS form would give patients more freedom to rate their quality of sleep. In the item analysis of the FN scale there was one item with high item difficulty ("Participating in sports and games as you would like"). As this item does not indicate the games and sports the respondents would participate in, the question leaves the respondent a wide range of activities to

choose from and for example the wish to play darts or to play badminton imply very different standards of mobility (see figure 5 page 44).

Two factors in Finn-MDHAQ – mobility of upper extremities and trunk, and mobility of lower extremities – detected on the FN scale were to be expected by reason of the physical character of the initial HAQ questionnaire from which this scale is derived. Thus the FN scale covers a wide spectrum of mobility in the subject.

The Finn-MDHAQ was compared to another multidimensional questionnaire, Finn-AIMS2: the strongest correlations were between the FN scale and Finn-AIMS2 physical subscales and between the PS and Finn-AIMS2 psychological subscales, this indicating convergent validity. As seen in tables 10 and 11, sleep is correlated with measures of pain. This result is in line with the finding of Houssien and co-workers (1997). A subject of consideration was the lack of correlation between FN score and number of swollen joints, for which no explanation was found. However, it can be stated that low correlation between these two measures is a sign of divergent validity and thereby a strength of the measure. Contrary to this result Pincus and co-workers (1989) have found a strong correlation between total joint count (including joint swelling, joint tenderness and joint limited scores) and MHAQ score.

10.2.2 Functioning and quality of life in young adult patients with JIA (Studies III, IV, V)

Outcome research requires a multiplicity of perspectives by reason of the multiple interest groups involved (Maloney and Chaiken 1999). Research on the effectiveness of treatment and rehabilitation is a good example of this kind of activity. The present study entity involves several different research perspectives. Besides the methodological (psychometric) and outcome interests, the internal and external aspects of health have been examined. The internal perspective has included examination of personal outlook on the health (QoL) in patients with JIA and controls, while external (ICF) has included body, individual, societal levels. These perspectives have included physical, psychological and social determinants. The significance of different perspectives varies according to evaluator. For example the education, employment and other social integration of young adults are important aspects when policy-makers evaluate the effectiveness of the health care system in juvenile diseases. Unlimited functioning, equal participation and favourable QoL are important factors for every young individual and his/her family. Management teams in paediatric rheumatic and rehabilitation clinics are also interested in outcomes in diversity of perspectives. In this study entity the environmental components of functioning were not examined. This would have brought important information on the physical, social and attitudinal factors which can operate as facilitators or barriers to the different components of functioning. The investigation of environmental factors and their significance is one subject for future research work recommended in young adult patients with JIA. Another missing approach is economic outcome evaluation as an

important part of effectiveness research in general. Economic evaluation is one of the first objectives in further research work planned with this and other allied data.

The age group examined in this study entity (Studies III,IV,V) represents those patients with JIA who have just passed the most important transition in a young person's life up to that day. By reason of the variance of the problems experienced by patients with JIA in different life periods from early childhood to young adulthood, a developmental approach to understanding the effects of chronic illness on the adjustment of children and young adults has been advocated (Ungerer et al. 1988, Quirk and Young 1990). The importance of researching the young adult life period of patients with JIA is also supported here by the fact that as many as 63% of patients in this age group have persistent disease in adulthood. The number of patients with active disease in the present study is in line with figures in other studies depicted in table 2, although within the limit of its upper range.

The novelty of the present health evaluation studies is that these results offer a new kind of perspective on the long-term outcomes of patients with JIA based on a new kind of information entity and information structure. The measures of functioning, the MDHAQ and partly also AIMS2, were set for the first time in the framework of ICF in an outcome study. It is clear that these measures were not designed with an eye to the structure of ICF. The usefulness of the ICF framework will be reinforced or abrogated by time and further research.

One further purpose of this study entity was to examine uveitis as an extra-articular manifestation of JIA. Uveitis can be considered as a part of ICF's component of body functions and structures. In 20% of patients uveitis was found to continue into adulthood and was frequently associated with the activity of joint inflammation. This study also showed clearly that patients with acute symptomatic uveitis had the first attack of uveitis later in their life than those with asymptomatic uveitis. Moreover, they were all HLA-B27-positive and 4 out of 5 of them were boys. This is fully in accord with a previous Finnish study (Kotaniemi 2001). The overall frequency of HLA-B27 in the Finnish population is as high as 14.5% and among patients with JIA about 30% (Savolainen et al. 1998). Among patients with asymptomatic uveitis, arthritis began earlier. Also positive HLA-B27 was found more frequently in this group. The relationship between the activity of arthritis and uveitis in JIA has often been poorly documented. According to some earlier findings, the activity of arthritis in patients with JIA-associated uveitis tended to be greater than in those without, but results did not reach statistical significance (Rosenberg and Oen 1986, Hertzberger-ten Cate et al. 1992, Cimaz and Fink 1996). The above-mentioned Finnish prospective study of 372 recently diagnosed patients with JIA with oligo- or RF-negative polyarthritis suggested that the occurrence of uveitis was associated with active arthritis (Kotaniemi et al. 2002).

According to the criteria for remission of JIA used in this study, the number of patients with some evidence of ongoing joint inflammation was significantly greater in the group of patients with asymptomatic uveitis than in

the non-uveitis group. Eight patients had active longstanding uveitis at clinical evaluation and arthritis was in remission in only one of them. Also the occurrence of dry eyes was slightly more common among uveitis patients, possible associated with the inflammatory activity in these patients. The cumulative rate of the development of uveitis shows that uveitis was mostly diagnosed shortly after the diagnosis of arthritis. Especially those with extended oligoarthritis developed uveitis quite early. However, in some cases uveitis can begin after the age of 16, as was noted in 3 cases among the patients with asymptomatic uveitis and even in 5 of the 6 cases with acute uveitis in this study. While the first attack of uveitis in adulthood was usually acute and symptomatic, and was typically similar to the acute anterior uveitis occurring in HLA-B27 positive diseases, the need for ophthalmic investigation should be kept in mind when treating adult patients with JIA.

There is one recent British study report concerning the long-term follow-up of 246 adults with JIA where also eye changes were taken into account. Uveitis was found in 22% of the patients, mostly within the oligoarthritis or extended oligoarthritis patient groups. The most common complications of uveitis were cataract and glaucoma (Packham and Hall 2002a), which is in line with our findings.

A lower level of mobility was found in patients with JIA compared to controls, whereas in the mental dimension the results did not differ. The difference between patients and controls was revealed in JIA patients with active disease vs. controls. Patients with active disease had lower levels of mobility and self-care compared with controls. Peterson and colleagues (1997) studied the health status of JRA patients and controls and also found lower levels of functional status in patients compared with controls using the HAQ. Flatø and colleagues (2003) found 36% of JRA patients to have impaired physical function. Ruperto's research group (1997) found a large proportion of patients to have little or no residual functional long-term disability as measured by HAQ in an age group more or less similar to that in the present study.

The results on fatigue, sleep and the ability to handle stress show that patients with JIA have levels of mental adjustment similar to their controls irrespective of the level of disease activity. Our findings are in line with those studies which have shown that among young adult juvenile arthritis patients severity of disease has no association with mental functioning (Ungerer et al. 1988, Baildam et al. 1995, Aasland et al. 1997).

The level of functioning was decreased in the patient group compared with controls when proceeding in a sequence of ICF from the component of body functions to the component of participation. The differences within the participation even increased when comparing patients with active disease and controls. Patients in remission vs. controls did not evince this trend. The present study, with the use of multidimensional instruments of functioning and ICF classification, may indicate that more attention should be paid to the different aspects of functioning from the patients' point of view, especially to the level of participation in patients with JIA. The patients had restrictions in mobility, in running errands and participating in sports and games. This result should

remind treatment and rehabilitation teams to operate on all the relevant objectives of the patients. By operating on the traditional targets of clinical work, i.e. level of impairment and activity, the objectives of participation level cannot be automatically achieved. Therapy goals in functioning at the participation level require different kinds of arrangements in therapy settings compared to operating with the goals of reducing disability at the impairment and activity level. The similar results in all components of functioning between patients in remission and controls, contrary to those with active disease, indicate that reduction of disease activity, gaining remission and preventing disability in patients with JIA have to be a high priority in management. The amount of treatment and rehabilitation patients have received are not known at this point of the study, but examination of the content and the character of services in the course of the disease will be included in the economic evaluation in further research work.

The patient group with active disease and those in remission differed from each other in their wishes of health area where they would like to see improvement. Patients with active disease wished improvement in their arthritis pain status as noted also in three previous studies conducted with RA and adult JIA patients (Heiberg and Kvien 2002, Bruinooge et al. 2003, Heiberg et al. 2005). Patients in remission wished to visit their friends more often.

From both society's and the patient's point of view favourable social functioning, i.e. comparable spousal relationship, education and employment, was found in JIA patients as in healthy controls. Two Finnish studies among juvenile arthritis patients from previous decades found after 15-16 years of follow-up higher educational levels in juvenile arthritis patients than in the general population in Finland (Laaksonen 1966, Ylijoki 1998) and lower levels of unemployment in patients than in general population (Ylijoki 1998).

The term quality of life is used here, but it is obvious that a study such as this can examine only a minor composite of the overall quality of life of the young adult. The present results on QoL in patients with JIA are comparable with those reported by Foster and colleagues (2003) and Peterson and co-workers (1997), although with two slightly differing instruments. Both research groups found differences in almost all physical scales of QoL, while the only difference in our analysis was one lower scale (physical functioning). Lower QoL was found in all physical components in patients with active disease compared to those in remission and controls. In the mental component of QoL no differences emerged between the groups. In the different JIA subgroups there was a clear difference in the physical component of QoL, but only minor in the mental. The results underline the importance of effective suppression of the patient's disease activity, and also of paying attention to differences in the outcome in different subgroups of JIA. Contrary to the results of one recent study (Foster et al. 2003) we found the lowest QoL in the extended oligoarthritis group.

The patient's global assessment explained both the physical and the mental component of QoL (see page 54). The importance of the patient's own evaluation in the assessment of QoL is thus supported by this study. Hence the

finding that patients with JIA in early adulthood broadly evaluate their mental component of QoL similarly to healthy controls is worthy of note – multidisciplinary team has reached one very important goal of treatment and rehabilitation. There is, however, much to be done in reducing the negative components of JIA in the health of young patients.

11 CONCLUSIONS AND PRACTICAL IMPLICATIONS

The novelty of the present health evaluation studies is that the long-term outcomes of patients with JIA are expressed on the ICF, a new kind of information entity and information structure within functioning and health. More consideration than in earlier studies should be paid to the various components of functioning, especially to the participation and its restrictions. Also the patient's own perspective in outcome research should be placed on a more equal footing with the health professionals'. In the future, in designing and modifying multidimensional instruments, more attention should be paid to a balanced structure between different components of functioning and different aspects of health among rheumatic diseases.

The results of the present study indicate that patients with JIA experienced more pain and had lower levels of mobility and social life in early adulthood than controls. In patients with active disease versus controls these differences became even clearer. In all, 20% of the patients had uveitis diagnosed during the course of disease. However, levels of education and employment in JIA patients were similar to controls. From the patients' own standpoint the QoL was lower concerning one sub area of physical health but similar concerning mental health compared to controls. Those patients who had active disease had lower QoL in all areas of physical health compared to those who were in remission and to controls, while in the areas of mental health no differences were found. The lowest QoL was found in the subgroup of extended oligoarthritis patients. The JIA patients with active disease wished to see improvement in pain caused by arthritis. Patients in remission wished to see improvement in their social activity.

The tradition of measuring outcomes in rheumatic diseases involves for the most part a physical dimension. With good reason AIMS2 and MDHAQ has brought applicable multidimensional instruments into use in research on rheumatic diseases. The use of AIMS2 in clinical practice is limited by reason of the length of the questionnaire. As Meenan and co-workers state (1992), AIMS2 was developed primarily as a tool for clinical research. AIMS2 has been translated into several languages, MDHAQ to our knowledge to date only into

Finnish. The Finn-AIMS2 was found to be a reliable and valid instrument, providing an excellent tool for the assessment of middle-aged patients' health outcomes in RA. However, two European studies have found AIMS2 to be applicable also in young adult age groups. The validity and the reliability of the Finnish version also support the usefulness of AIMS2 internationally. The Finnish version of the MDHAQ has proved to be applicable, reliable and also valid for the part of the FN scale measuring the functional ability of Finnish rheumatic patients. However, the incongruity in the Psychological scale structure produced only moderate internal consistency in this scale. With minor modifications of item form this weakness can be overcome and the instrument tendered appropriate for rheumatic patients' outcome research. Future outcome studies with Finn-MDHAQ are still needed to reinforce the usefulness of the instrument.

Summary of the practical implications:

1) Multidisciplinary outcome studies of young adult patients with JIA should be encouraged.

2) Gaining remission should remain a high priority in clinical practice in patients with JIA.

3) Young adult patients with JIA, especially those with active disease need active treatment and rehabilitation interventions designed to maintain functioning and to decrease pain.

4) The importance of patients' subjective view of their health as a part of clinical evaluation should be noted.

5) In the evaluation studies of the measurement instruments for adult rheumatic patients, the young adult age groups should be included in study groups to ensure the applicability of the instrument in all adult age groups.

6) The application of multidimensional outcome measurement tools should be increased in clinical practice and a broad approach to health evaluation practice in patients with JIA should be adopted. ICF can offer a promising model to operate in this direction.

7) In designing and modifying new multidimensional instruments in research on rheumatic diseases more attention should be paid to a balanced structure between and within the different components of health and functioning.

TIIVISTELMÄ

Toimintakyky ja elämänlaatu terveyden näkökulmina lastenreumaa sairasta-neilla nuorilla aikuisilla. Mittaaminen ja pitkäaikaistulokset.

Tämän viidestä osajulkaisusta koostuvan tutkimuskokonaisuuden tarkoituk-sena oli tutkia lapsuudessaan lastenreumaan sairastuneiden henkilöiden toi-mintakykyä ja elämänlaatua nuorena aikuisena samanikäisiin ja samaa suku-puolta oleviin terveisiin vertailuhenkilöihin tarkasteltuna. Lisäksi selvitettiin kahden tutkimuksessa käytetyn laaja-alaisen toimintakykymittarin pätevyyttä ja luotettavuutta suomalaisessa reumaa sairastavassa aikuisväestössä.

Lastenreumatutkimukseen halutut nuoret aikuiset, jotka olivat syntyneet vuosina 1976–1980 ja jotka olivat sairastuneet lastenreumaan vuosina 1976–1995, kerättiin Heinolassa toimivan Reumasäätiön sairaalan potilastiedostoista. Tutkittavien terveyden ja toimintakyvyn osa-alueita arvioitiin yhden päivän sairaalakäynnin aikana Heinolassa ja tutkimus koostui lasten reumatologin ja silmälääkärin tutkimuksista sekä laboratoriotutkimuksista. Lisäksi tutkittavat täyttivät päivän aikana toimintakyvyn (AIMS2, MDHAQ) ja elämänlaadun (RAND-36) kyselylomakkeita. Iän-, sukupuolen- ja asuinpaikan mukaan kal-taistetut vertailuhenkilöt kerättiin väestörekisteristä. Tutkimustuloksia tarkasteltiin WHO:n toimintakyvyn, toimintarajoitteiden ja terveyden käsitteel-lisen mallin (ICF) avulla. Tutkimuksen näkökulmina olivat terveysammat-tilaisten tekemä arvio lastenreumaa sairastaneiden nuorten aikuisten terveydestä ja toimintakyvystä sekä sairastuneiden nuorten aikuisten oma arvio elämänlaadustaan terveyden ja toimintakyvyn näkökulmasta. Nivelsairauden vaikutusten mittarin (AIMS2) ja laaja-alaisen toimintakyky- ja terveydentila-lomakkeen (MDHAQ) suomenkielisten versioiden pätevyyttä ja luotettavuutta tutkittiin kahdessa suomalaisessa reumaa sairastavassa aikuisväestön otoksessa.

Nuorten aikuisten toimintakyky- ja terveydentilatutkimuksiin osallistui yhteensä 123 lastenreumaan sairastunutta henkilöä. Tutkimushetkellä he olivat keskimäärin 23-vuotiaita ja heidän keskimääräinen seuranta-aikansa oli 16 vuotta. Heistä 63 %:lla lastenreuma oli edelleen aktiivinen, hoitoa ja kuntou-tusta vaativa sairaus. Kaikki tutkimusryhmään kuuluneet, lastenreumaa sai-rastaneet henkilöt (potilaat) kokivat enemmän kipua sekä heillä oli toiminta-rajoitteita liikkumisessa ja sosiaalisessa toiminnassa harrastustoiminnan osalta vertailuhenkilöihin tarkasteltuna. Niillä potilailla, joiden sairaus oli edelleen aktiivinen, mainitut toimintarajoitteiden erot vertailuhenkilöihin edelleen korostuivat. Koko tutkimusryhmästä 20 %:lla oli todettu silmän keskikalvon tulehdus (uveiitti) sairastamisaikana. Potilaat olivat kouluttautuneet saman-asteisesti kuin vertailuryhmä ja he olivat myös työllistyneet yhdenvertaisesti vertailuhenkilöiden kanssa. Koko potilasryhmän arvio elämänlaadustaan oli samanlainen kuin vertailuryhmällä lukuun ottamatta yhtä matalampaa fyysistä osa-aluetta. Sitä vastoin elämänlaadun koko psyykkisessä osa-alueessa tulokset

potilailla ja vertailuhenkilöillä olivat yhteneväiset. Aktiivia tautia sairastaneilla elämänlaadun fyysisen osa-alue oli selvästi heikompi kuin vertailuhenkilöillä ja niillä, joilla sairaus oli tutkimushetkellä oireeton.

AIMS2 ja MDHAQ osoittautuivat päteviksi, luotettaviksi ja käyttökelpoisiksi tulosmittareiksi käytettäväksi aikuisilla reumapotilailla. MDHAQ:iin ehdotetuilla vähäisillä muutoksilla mittarin käyttökelpoisuutta voidaan tulevissa tutkimuksissa parantaa. Tulevien tutkimusten avulla voidaan vielä saada lisätietoa molempien mittareiden soveltuvuudesta nuorten aikuisten ikäryhmien tutkimuksissa.

Tutkimustulosten perusteella voidaan päätellä, että tärkeä tavoite arkipäivän hoitokäytännöissä tulisi edelleen olla pyrkimys lastenreuman aktiviteetin sammumiseen. Nuorena aikuisena aktiivista lastenreumaa sairastavat henkilöt tarvitsevat aktiivisia hoito- ja kuntoutustoimia, joiden avulla voidaan välttää toimintarajoitteiden kehittyminen sekä taata suotuisa elämänlaatu varhaisessa aikuisiässä. Pitkäaikaissairauden onnistuneessa hoidossa potilaan omatoimisen hoidon osuus on merkittävä. Sen vuoksi elämänlaadun tutkimusta ja potilaan omaa näkemystä tilanteestaan osana terveyden tuloksellisuustutkimusta tulisi vahvistaa. ICF tarjoaa lupaavan mallin tutkia terveyttä ja sen osa-alueita laaja-alaisen näkökulman avulla ja se auttaa vertailemaan eri terveystutkimuksia ja niiden tuloksia kansallisesti ja kansainvälisesti yhdenmukaisen ja yhteisen käsitteistön avulla.

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APPENDIX 1

Tutkimuksen nimi: _____

Päivämäärä: _____

Vastaava lääkäri: _____

Arthritis Impact Measurement Scales (AIMS2)

Suomenkielinen versio 03.06.2003

Nivelsairauden vaikutusten mittari 2

Koodi: ☐ ☐ ☐ ☐ ☐

Pvm: ☐☐.☐☐.☐☐

NIVELSAIRAUDEN VAIKUTUSTEN MITTARI 2 (AIMS2)

Ohjeet: Olkaa hyvä ja vastatkaa seuraaviin kysymyksiin, jotka koskevat terveydentilaanne. Suurimmaksi osaksi kysymyksissä tiedustellaan terveydentilaanne **viimeksi kuluneen kuukauden aikana**. Kysymyksiin ei ole oikeita tai vääriä vastauksia, ja useimpiin voi vastata pelkästään rastimalla. Olkaa hyvä ja vastatkaa jokaiseen kysymykseen.

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

Nämä kysymykset koskevat **LIIKKUMISTA**.

Viimeksi kuluneen kuukauden aikana…	Joka päivä (1)	Useimpina päivinä (2)	Joinakin päivinä (3)	Harvoin (4)	En lainkaan (5)
1. Kuinka usein kykenitte ajamaan autoa tai käyttämään yleisiä kulkuneuvoja?	☐	☐	☐	☐	☐
2. Kuinka usein olitte kodin ulkopuolella ainakin osan päivää?	☐	☐	☐	☐	☐
3. Kuinka usein kykenitte hoitamaan asioitanne kotinne lähistöllä?	☐	☐	☐	☐	☐
4. Kuinka usein tarvitsitte jonkun apua kodin ulkopuolella liikkumiseen?	☐	☐	☐	☐	☐
5. Kuinka usein vietitte suurimman osan päivästä tai koko päivän vuoteessa tai tuolissa?	☐	☐	☐	☐	☐

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

Nämä kysymykset koskevat **KÄVELEMISTÄ JA KUMARTUMISTA**.

Viimeksi kuluneen kuukauden aikana…	Joka päivä	Useimpina päivinä	Joinakin päivinä	Harvoin	Ei lainkaan
	(1)	(2)	(3)	(4)	(5)
6. Oliko teillä vaikeuksia raskaissa toimissa kuten juoksemisessa, painavien esineiden nostamisessa tai rasittavissa urheilu- lajeissa?	☐	☐	☐	☐	☐
7. Oliko teillä vaikeuksia kun kävelitte useita kadunvälejä tai kun nousitte muutamia kerrosvälejä portaita?	☐	☐	☐	☐	☐
8. Oliko teillä vaikeuksia kyykistyä, suoristautua tai kumartua?	☐	☐	☐	☐	☐
9. Oliko teillä vaikeuksia **yhden** kadunvälin kävelemisessä tai **yhden** kerrosvälin portaiden nousemisessa?	☐	☐	☐	☐	☐
10. Oliko teidän mahdoton kävellä ilman toisen ihmisen apua tai kävelykeppiä, kainalosauvoja tai kävelytukea?	☐	☐	☐	☐	☐

Nämä kysymykset koskevat **KÄSIEN JA SORMIEN TOIMINTAA**.

Viimeksi kuluneen kuukauden aikana…	Joka päivä	Useimpina päivinä	Joinakin päivinä	Harvoin	En lainkaan
	(1)	(2)	(3)	(4)	(5)
11. Pystyittekö vaivatta kirjoittamaan kynällä?	☐	☐	☐	☐	☐
12. Pystyittekö vaivatta napittamaan paidan tai puseron?	☐	☐	☐	☐	☐
13. Pystyittekö vaivatta kiertämään avainta lukossa?	☐	☐	☐	☐	☐
14. Pystyittekö vaivatta solmimaan solmun tai rusetin?	☐	☐	☐	☐	☐
15. Pystyittekö vaivatta avaamaan aikaisemmin avaamattoman purkin?	☐	☐	☐	☐	☐

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

Nämä kysymykset koskevat **YLÄRAAJOJEN TOIMINTAA.**

Viimeksi kuluneen kuukauden aikana…	Joka päivä	Useimpina päivinä	Joinakin päivinä	Harvoin	En lainkaan
	(1)	(2)	(3)	(4)	(5)
16. Pystyittekö vaivatta pyyhkimään suunne lautasliinaan?	☐	☐	☐	☐	☐
17. Pystyittekö vaivatta pukemaan yllenne villapaidan?	☐	☐	☐	☐	☐
18. Pystyittekö vaivatta kampaamaan tai harjaamaan hiuksenne?	☐	☐	☐	☐	☐
19. Pystyittekö vaivatta rapsuttamaan alaselkäänne kädellänne?	☐	☐	☐	☐	☐
20. Yletyittekö vaivatta hyllyille, jotka olivat päänne tason yläpuolella?	☐	☐	☐	☐	☐

Nämä kysymykset koskevat **OMATOIMISUUTTA.**

Viimeksi kuluneen kuukauden aikana…	Aina	Hyvin usein	Joskus	Hyvin harvoin	En koskaan
	(1)	(2)	(3)	(4)	(5)
21. Tarvitsitteko apua kylvyssä tai suihkussa käyntiin?	☐	☐	☐	☐	☐
22. Tarvitsitteko apua pukeutumiseen?	☐	☐	☐	☐	☐
23. Tarvitsitteko apua WC:ssä käyntiin?	☐	☐	☐	☐	☐
24. Tarvitsitteko apua vuoteeseen ja vuoteesta pois pääsemiseen?	☐	☐	☐	☐	☐

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

Nämä kysymykset koskevat **KOTITÖITÄ.**

Viimeksi kuluneen kuukauden aikana…	Aina	Hyvin usein	Joskus	Hyvin harvoin	En koskaan
	(1)	(2)	(3)	(4)	(5)
25. Mikäli teillä oli tarvittava kuljetus, pystyittekö käymään ruokaostoksilla ilman apua?	☐	☐	☐	☐	☐
26. Mikäli käytössänne oli keittiö, pystyittekö valmistamaan omat ateriannne ilman apua?	☐	☐	☐	☐	☐
27. Mikäli käytössänne oli kodinkoneita, pystyittekö tekemään taloustyöt ilman apua?	☐	☐	☐	☐	☐
28. Mikäli teillä oli pyykinpesukone tai pesulamahdollisuus, pystyittekö pesemään pyykkinne ilman apua?	☐	☐	☐	☐	☐

Nämä kysymykset koskevat **SOSIAALISTA AKTIIVISUUTTA.**

Viimeksi kuluneen kuukauden aikana…	Joka päivä	Useimpina päivinä	Joinakin päivinä	Harvoin	En lainkaan
	(1)	(2)	(3)	(4)	(5)
29. Kuinka usein vietitte aikaa yhdessä ystävien tai sukulaisten kanssa?	☐	☐	☐	☐	☐
30. Kuinka usein ystävät tai sukulaiset kyläilivät luonanne?	☐	☐	☐	☐	☐
31. Kuinka usein kyläilitte ystävien tai sukulaisten luona?	☐	☐	☐	☐	☐
32. Kuinka usein keskustelitte puhelimessa hyvien ystävien tai sukulaisten kanssa?	☐	☐	☐	☐	☐
33. Kuinka usein kävitte kerhon, joukkueen, kirkon tai muun ryhmän tapaamisessa?	☐	☐	☐	☐	☐

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

Nämä kysymykset koskevat **PERHEEN JA YSTÄVIEN TUKEA**

Viimeksi kuluneen kuukauden aikana…	Aina	Hyvin usein	Joskus	Hyvin harvoin	Ei koskaan
	(1)	(2)	(3)	(4)	(5)
34. Tuntuiko teistä siltä, että perheenne tai ystävänne olivat saatavilla, jos tarvitsitte apua?	☐	☐	☐	☐	☐
35. Tuntuiko teistä siltä, että perheenne tai ystävänne tajusivat henkilökohtaiset tarpeenne?	☐	☐	☐	☐	☐
36. Tuntuiko teistä siltä, että perheenne ja ystävänne olivat kiinnostuneita auttamaan ongelmienne ratkaisemisessa?	☐	☐	☐	☐	☐
37. Tuntuiko teistä siltä, että perheenne ja ystävänne ymmärsivät nivelsairautenne vaikutukset?	☐	☐	☐	☐	☐

Nämä kysymykset koskevat **NIVELSAIRAUTEEN LIITTYVÄÄ KIPUA**.

38. Millaiseksi kuvailisitte viimeksi kuluneen kuukauden aikana nivelsairauteenne tavallisesti liittynyttä kipua?
      ① Ankara
      ② Kohtalainen
      ③ Lievä
      ④ Hyvin lievä
      ⑤ Ei lainkaan kipua

Viimeksi kuluneen kuukauden aikana…	Joka päivä	Useimpina päivinä	Joinakin päivinä	Harvoin	Ei lainkaan
	(1)	(2)	(3)	(4)	(5)
39. Kuinka usein teillä oli nivelsairaudesta johtuvaa ankaraa kipua?	☐	☐	☐	☐	☐
40. Kuinka usein teillä oli kipua kahdessa tai useammassa nivelessä samanaikaisesti?	☐	☐	☐	☐	☐
41. Kuinka usein aamujäykkyys kesti pitempään kuin tunnin heräämisestä?	☐	☐	☐	☐	☐
42. Kuinka usein kipu vaikeutti nukkumistanne?	☐	☐	☐	☐	☐

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

Nämä kysymykset koskevat **TYÖTÄ.**

43. Mikä on ollut pääasiallinen työnne viimeksi kuluneen kuukauden aikana?

     ① Palkkatyö
     ② Kotityö
     ③ Opiskelu
     ④ Työtön
     ⑤ Työkyvytön
     ⑥ Eläkeläinen

Jos vastasitte työtön, työkyvytön tai eläkeläinen, hypätkää neljän seuraavan kysymyksen yli kysymykseen numero 48.

Viimeksi kuluneen kuukauden aikana…	Joka päivä (1)	Useimpina päivinä (2)	Joinakin päivinä (3)	Harvoin (4)	En lainkaan (5)
44. Kuinka usein olitte kykenemätön palkkatyöhön, kotitöihin tai opiskeluun?	☐	☐	☐	☐	☐
45. Niinä päivinä, joina teitte työtä, kuinka usein teidän oli tehtävä tavallista lyhyempi päivä?	☐	☐	☐	☐	☐
46. Niinä päivinä, joina teitte työtä, kuinka usein olitte kykenemätön tekemään työnne niin huolellisesti ja täsmällisesti kuin olisitte halunnut?	☐	☐	☐	☐	☐
47. Niinä päivinä, joina teitte työtä, kuinka usein jouduitte muuttamaan tapaa, jolla palkkatyönne, kotityönne tai opiskelunne yleensä tehdään?	☐	☐	☐	☐	☐

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

Nämä kysymykset koskevat **HERMOSTUNEISUUTTA**.

Viimeksi kuluneen kuukauden aikana…	Aina (1)	Hyvin usein (2)	Joskus (3)	Hyvin harvoin (4)	Ei koskaan (5)
48. Kuinka usein olette tuntenut olonne kireäksi tai hermostuneeksi?	☐	☐	☐	☐	☐
49. Kuinka usein hermostuneisuutenne tai kireät hermonne ovat häirinneet teitä?	☐	☐	☐	☐	☐
50. Kuinka usein pystyitte rentoutumaan helposti?	☐	☐	☐	☐	☐
51. Kuinka usein olette tuntenut olonne rentoutuneeksi ja huolettomaksi?	☐	☐	☐	☐	☐
52. Kuinka usein olette tuntenut olonne levolliseksi ja rauhalliseksi?	☐	☐	☐	☐	☐

Nämä kysymykset koskevat **MIELIALAA**.

Viimeksi kuluneen kuukauden aikana…	Aina (1)	Hyvin usein (2)	Joskus (3)	Hyvin harvoin (4)	Ei koskaan (5)
53. Kuinka usein olette nauttinut tekemästänne?	☐	☐	☐	☐	☐
54. Kuinka usein olette ollut allapäin tai hyvin allapäin?	☐	☐	☐	☐	☐
55. Kuinka usein teistä on tuntunut siltä, että mikään ei ole mennyt haluamallanne tavalla?	☐	☐	☐	☐	☐
56. Kuinka usein teistä on tuntunut siltä, että muille olisi parempi, jos olisitte kuollut?	☐	☐	☐	☐	☐
57. Kuinka usein olette ollut mieli niin maassa, ettei mikään ole saanut teitä piristymään?	☐	☐	☐	☐	☐

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

Nämä kysymykset koskevat **TYYTYVÄISYYTTÄ KUHUNKIN TERVEYDENTILAN OSA-ALUEESEEN.**

58. Kuinka tyytyväinen olette ollut kuhunkin alla mainituista terveydentilanne osa-alueista?

Viimeksi kuluneen kuukauden aikana…	Erittäin tyytyväinen	Melko tyytyväinen	En tyytyväinen enkä tyytymätön	Melko tyytymätön	Erittäin tyytymätön
	(1)	(2)	(3)	(4)	(5)
LIIKKUMINEN (esim: asioiden toimittaminen)	☐	☐	☐	☐	☐
KÄVELEMINEN JA KUMARTUMINEN (esim: portaiden nouseminen)	☐	☐	☐	☐	☐
KÄSIEN JA SORMIEN TOIMINTA (esim: rusetin solmiminen)	☐	☐	☐	☐	☐
YLÄRAAJOJEN TOIMINTA (esim: hiusten kampaaminen)	☐	☐	☐	☐	☐
OMATOIMISUUS (esim: peseytyminen)	☐	☐	☐	☐	☐
KOTITYÖT (esim: taloustyöt)	☐	☐	☐	☐	☐
SOSIAALINEN AKTIIVISUUS (esim: ystävien luona vierailu)	☐	☐	☐	☐	☐
PERHEEN TUKI (esim: apua ongelmissa)	☐	☐	☐	☐	☐
NIVELSAIRAUTEEN LIITTYVÄ KIPU (esim: nivelkipu)	☐	☐	☐	☐	☐
TYÖ (esim: työajan vähentäminen)	☐	☐	☐	☐	☐
HERMOSTUNEISUUS (esim: kireyden tunne)	☐	☐	☐	☐	☐
MIELIALA (esim: mieli maassa)	☐	☐	☐	☐	☐

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

Nämä kysymykset koskevat **NIVELSAIRAUDEN VAIKUTUSTA KUHUNKIN TERVEYDENTILAN OSA-ALUEESEEN**.

59. Kuinka suurelta osin kunkin terveydentilan osa-alueen ongelmat johtuivat nivelsairaudesta?

Viimeksi kuluneen kuukauden aikana…	Ei ollut ongelma minulle	Johtui pelkästään muista syistä	Johtui suurelta osin muista syistä	Johtui osaksi nivelsairau-desta ja osaksi muista syistä	Johtui suurelta osin nivelsairau-desta	Johtui pelkästään nivelsairau-desta
	(0)	(1)	(2)	(3)	(4)	(5)
LIIKKUMINEN (esim: asioiden toimittaminen)	☐	☐	☐	☐	☐	☐
KÄVELEMINEN JA KUMARTUMINEN (esim: portaiden nouseminen)	☐	☐	☐	☐	☐	☐
KÄSIEN JA SORMIEN TOIMINTA (esim: rusetin solmiminen)	☐	☐	☐	☐	☐	☐
YLÄRAAJOJEN TOIMINTA (esim: hiusten kampaaminen)	☐	☐	☐	☐	☐	☐
OMATOIMISUUS (esim: peseytyminen)	☐	☐	☐	☐	☐	☐
KOTITYÖT (esim: taloustyöt)	☐	☐	☐	☐	☐	☐
SOSIAALINEN AKTIIVISUUS (esim: ystävien luona vierailu)	☐	☐	☐	☐	☐	☐
PERHEEN TUKI (esim: apua ongelmissa)	☐	☐	☐	☐	☐	☐
NIVELSAIRAUTEEN LIITTYVÄ KIPU (esim: nivelkipu)	☐	☐	☐	☐	☐	☐
TYÖ (esim: työajan vähentäminen)	☐	☐	☐	☐	☐	☐
HERMOSTUNEISUUS (esim: kireyden tunne)	☐	☐	☐	☐	☐	☐
MIELIALA (esim: mieli maassa)	☐	☐	☐	☐	☐	☐

Nyt olette vastannut kysymyksiin, jotka koskivat TERVEYDENTILANNE ERI OSA-ALUEITA. Nämä osa-alueet on lueteltu seuraavassa. Rastittakaa (X) ENINTÄÄN KOLME OSA-ALUETTA, jossa **HALUAISIT-TE MIELUITEN TAPAHTUVAN PARANNUSTA.** Lukekaa kaikki 12 vaihtoehtoa ennen kuin valitsette:

60. Terveydentilan osa-alueet	Kolme parannettavaa osa-aluetta
LIIKKUMINEN (esim: asioiden toimittaminen)	☐
KÄVELEMINEN JA KUMARUMINEN (esim: portaiden nouseminen)	☐
KÄSIEN JA SORMIEN TOIMINTA (esim: rusetin solmiminen)	☐
YLÄRAAJOJEN TOIMINTA (esim: hiusten kampaaminen)	☐
OMATOIMISUUS (esim: peseytyminen)	☐
KOTITYÖT (esim: taloustyöt)	☐
SOSIAALINEN AKTIIVISUUS (esim: ystävien luona vierailu)	☐
PERHEEN TUKI (esim: apua ongelmissa)	☐
NIVELSAIRAUTEEN LIITTYVÄ KIPU (esim: nivelkipu)	☐
TYÖ (esim: työajan vähentäminen)	☐
HERMOSTUNEISUUS (esim: kireyden tunne)	☐
MIELIALA (esim: mieli maassa)	☐

Varmistakaa, että rastititte vain KOLME parannettavaa OSA-ALUETTA edellisestä kysymyksestä.

Seuraavat kysymykset koskevat **TÄMÄNHETKISTÄ ja TULEVAA TERVEYDENTILAA**.
Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

61. Onko **TERVEYDENTILANNE NYT** kokonaisuutena erinomainen, hyvä, kohtalainen vai huono?

① Erinomainen

② Hyvä

③ Kohtalainen

④ Huono

62. Kuinka tyytyväinen olette **TERVEYDENTILAANNE NYT**?

① Erittäin tyytyväinen

② Melko tyytyväinen

③ En tyytyväinen enkä tyytymätön

④ Melko tyytymätön

⑤ Erittäin tyytymätön

63. Kuinka suuri osa **TÄMÄNHETKISEN TERVEYDENTILANNE** ongelmista johtuu nivelsairaudesta?

⓪ Ei ole ongelma minulle

① Johtuu pelkästään muista syistä

② Johtuu suurelta osin muista syistä

③ Johtuu osaksi nivelsairaudesta ja osaksi muista syistä

④ Johtuu suurelta osin nivelsairaudesta

⑤ Johtuu pelkästään nivelsairaudesta

64. Uskotteko, että **TERVEYDENTILANNE** on kokonaisuutena **10 VUODEN KULUTTUA** erinomainen,
hyvä, kohtalainen vai huono?

① Erinomainen

② Hyvä

③ Kohtalainen

④ Huono

65. Kuinka suuren ongelman arvioitte nivelsairautenne olevan **10 VUODEN KULUTTUA**?

① Ei lainkaan ongelma

② Vähäinen ongelma

③ Kohtalainen ongelma

④ Suuri ongelma

Nämä kysymykset koskevat **NIVELSAIRAUDEN KOKONAISVAIKUTUSTA.**

66. KUN OTTAA HUOMIOON KAIKKI TAVAT, JOILLA NIVELSAIRAUS VAIKUTTAA TEIHIN,
kuinka hyvin tulette toimeen muihin ikäisiinne verrattuna?

① Erinomaisesti

② Hyvin

③ Kohtalaisesti

④ Huonosti

⑤ Erittäin huonosti

67. Minkälainen nivelsairaus teillä on ensisijaisesti?

Nivelreuma ☐

Lastenreuma ☐

Selkärankareuma ☐

Artroosi / nivelrikko ☐

LED ☐

Fibromyalgia ☐

Skleroderma ☐

Nivelpsoriaasi ☐

Reiterin tauti / reaktiivinen ☐
niveltulehdus

Kihti ☐

Alaselän kivut ☐

Jännetulehdus / limapussi- ☐
tulehdus

Osteoporoosi ☐

Muu ☐

68. Kuinka monta vuotta teillä on ollut edellä mainittu nivelsairaus? _____ vuotta

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

69. Kuinka usein teidän on täytynyt ottaa **LÄÄKKEITÄ** nivelsairauteenne viimeksi kuluneen kuukauden aikana?

    ① Joka päivä
    ② Useimpina päivinä
    ③ Joinakin päivinä
    ④ Harvoin
    ⑤ Ei lainkaan

70. Vaikuttaako jokin seuraavista vaivoista terveydentilaanne tällä hetkellä? Rastittakaa (X) kyllä tai ei vastuksena kuhunkin kysymykseen.

	Kyllä (1)	Ei (2)
Korkea verenpaine	☐	☐
Sepelvaltimotauti	☐	☐
Psyykkinen sairaus	☐	☐
Diabetes	☐	☐
Syöpä	☐	☐
Alkoholin tai huumeiden käyttö	☐	☐
Keuhkosairaus	☐	☐
Munuaissairaus	☐	☐
Maksasairaus	☐	☐
Mahahaava tai muu mahan sairaus	☐	☐
Anemia tai muu veritauti	☐	☐

Rastittakaa (X) kuhunkin kysymykseen sopivin vastaus.

71. Onko teillä päivittäinen lääkitys johonkin muuhun kuin nivelsairauteen?
       ① Kyllä
       ② Ei

72. Kävittekö lääkärissä useammin kuin kolmesti viime vuonna jonkin muun kuin nivelsairauden vuoksi?
       ① Kyllä
       ② Ei

73. Ikänne tällä hetkellä?   _____ vuotta

74. Sukupuoli
       ① Mies
       ② Nainen

75. Siviilisääty
       ① Avio- tai avoliitossa
       ② Asumuserossa
       ③ Eronnut
       ④ Leski
       ⑤ Naimaton

Kiitos, että täytitte tämän kyselylomakkeen!

APPENDIX 2

Tutkimuksen nimi: _____

Päivämäärä: _____

Vastaava lääkäri: _____

Laaja-alainen toimintakyky- ja terveydentilakartoitus

Multidimensional Health Assessment Questionnaire
(MDHAQ)
Suomenkielinen versio 11.05.2005

94

Numero: _____

LAAJA-ALAINEN TOIMINTAKYKY- JA TERVEYDENTILAKARTOITUS

Tämän kyselykaavakkeen tarkoituksena on selvittää tämänhetkistä terveyden-
tilaasi. Vastaa jokaiseen kysymykseen. Jos Sinun on vaikeaa löytää juuri omaa
tilannettasi kuvaava vaihtoehto, valitse se, joka kuvaa parhaiten tilannettasi.
Rastita yksi vaihtoehto kultakin riviltä.

1. Kykenetkö tällä hetkellä

	Kyllä, vaikeuksitta	Pienin vaikeuksin	Suurin vaikeuksin	En kykene lainkaan
a) pukeutumaan itse, kengän- nauhojen solmimista ja napittamista myöten.	①	②	③	④
b) menemään vuoteeseen ja nousemaan sieltä.	①	②	③	④
c) kohottamaan täyden kupin tai lasin huulillesi	①	②	③	④
d) kävelemään ulkona tasaisella maalla.	①	②	③	④
e) pesemään ja kuivaamaan koko kehosi.	①	②	③	④
f) kumartuen ottamaan vaatteita lattialta.	①	②	③	④
g) avaamaan ja sulkemaan kierrettävän vesihanan.	①	②	③	④
h) menemään sisään ja ulos henkilöautosta, linja-autosta, junasta tai lentokoneesta.	①	②	③	④
i) suorittamaan ostoksia ja toimittamaan asioitasi.	①	②	③	④
j) nousemaan yhden kerrosvälin portaita.	①	②	③	④
k) kävelemään 3 kilometriä.	①	②	③	④
l) juoksemaan tai hölkkäämään 3 kilometriä.	①	②	③	④
m) ajamaan autoa alle 10 kilometriä kotoasi.	①	②	③	④

n) osallistumaan haluamiisi urheilu- tai pelisuorituksiin.	①	②	③	④
o) nukkumaan yösi hyvin.	①	②	③	④
p) tulemaan toimeen okapäiväisen elämän stressitilanteiden kanssa.	①	②	③	④
q) tulemaan toimeen ahdistuksen tai hermostunei- suuden tunteiden kanssa.	①	②	③	④
r) tulemaan toimeen masen- nuksen ja alakuloisuuden tunteiden kanssa	①	②	③	④

2. Kuinka paljon kipua Sinulla on ollut EDELTÄVÄN VIIKON AIKANA? Merkitse poikkiviiva alla olevalle suoralle siihen kohtaan, joka ilmaisee kokemasi kivun määrää?

Ei lainkaan

Sietämätön

kipua   ├──────────────────────────────────┤ kipu
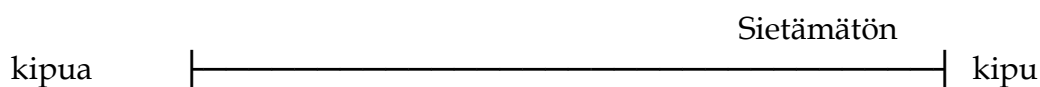
3. Kuinka paljon epätavallista väsymystä tai uupumusta Sinulla on ollut EDELTÄVÄN VIIKON AIKANA? Merkitse alla olevalle suoralle poikkiviiva siihen kohtaan, joka kuvaa väsymyksesi määrää:

En ole ollut lainkaan uupunut.   ├──────────────────────────────────┤ Olen ollut äärettömän uupunut.