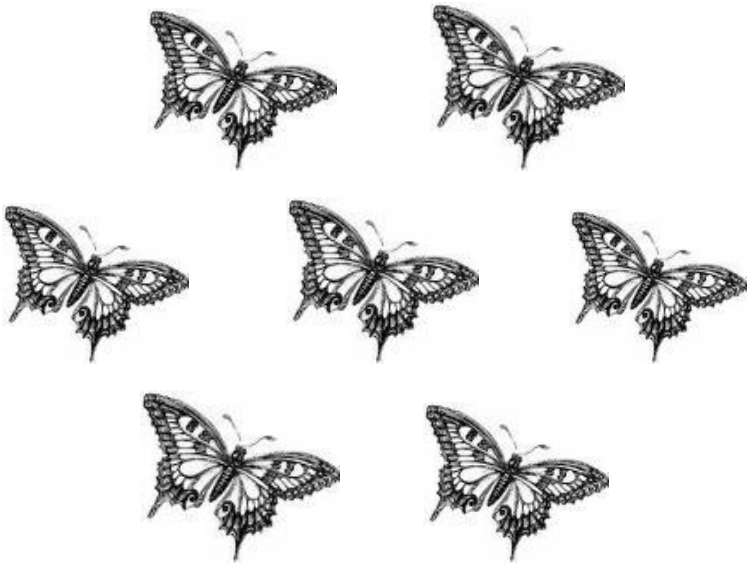
Living with Juvenile Idiopathic Arthritis from childhood to adult life

An 18 year follow-up study from the perspective of young adults



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Abstract

Background and aim: As an experienced paediatric nurse I have recognised that adolescents with persistent chronic childhood diseases fall between two chairs. International studies support this recognition. Norwegian adolescents with juvenile idiopathic arthritis are no exception. Chronic arthritis from childhood might have far-reaching consequences for the growth and development of the child, and for the family and community. The fact that a considerable proportion of children with JIA continue to have active disease and disease residua through adolescence into adulthood underlines the importance of illuminating the situation in a public-health perspective. Through this study I aim at exploring physical and psychosocial health among young adults with JIA in a life-span perspective from childhood and adolescence into adult life.

Methods: The thesis has a qualitative and a quantitative approach. Study I had an abductive explorative design. The experiences and perceptions of health-care transition were explored by focus-group interviews with young people with JIA and related health professionals respectively. Qualitative content analysis was utilised. Study II had an abductive explorative design with qualitative interviews to explore young adults' experiences of living with JIA in a life-span perspective. Qualitative content analysis was utilised. Study III had a longitudinal deductive design. The standardised questionnaires of Health Assessment Questionnaire, General Health Questionnaire version 30, and Visual Analogue Scales of pain, fatigue, and illness were utilised to explore physical ability, psychosocial health, pain, fatigue, and illness in a cohort of patients with JIA 18.3 years after symptom-onset. Comparisons with baseline and first follow-up were performed. Data were analysed by descriptive statistics and non parametric tests. Study IV had a cross-sectional deductive design. In addition to the questionnaires utilised in study III, the questionnaire of SF-36 Health Survey and data on education, employment, need of assistive equipment at work, and use of health services the previous year were employed. Comparisons with Norwegian population- based data were performed. Data were analysed by descriptive statistics, and parametric and non parametric tests.

Findings: In study I, ability to live a meaningful and responsible adult life seemed to be a common goal. Obstacles for the young people were the nature of the disease, a lack of focus on transition processes, and overprotective parents and health professionals. Obstacles for the health professionals were lack of inter-professional and inter-institutional formal co-

operation and agreed practice, and lack of competence on adolescent development and health. Study II demonstrates that living with JIA implies a constant oscillation between struggle and adjustment to an insecure everyday life and an unpredictable life course. This was expressed as bodily experiences of limitation and freedom, interpersonal experiences of being included or set on the sidelines, and intrapersonal perceptions of insecurity and confidence. Of the 55 young adults with JIA in study III, 21 reported physical disability, and 12 reported psychiatric distress within the clinical range. Furthermore, 26 patients reported illness, 27 pain, and 33 fatigue above 10 on the VAS scale (0-100). Significant correlations were found between physical disability, pain, illness and fatigue, and between psychiatric distress, pain, and fatigue. Comparisons from first to second follow-up of the cohort showed no significant changes in physical or psychosocial functioning, pain, or fatigue. In study IV, physical ability and pain were significant predictors of the average variation of physical health while psychiatric distress and female gender were significant predictors of the average variation of mental health. Impaired physical health was associated with low rates of psychiatric distress. As compared to the general Norwegian population, impaired HRQL in the physical domain was found, but not in the mental domain, and a higher level of education, but similar employment rate.

Conclusion: The four studies demonstrate complementary findings. Discrepancies between interviews and inquiries indicate that the interviews illuminate a depth and breadth of life with JIA in a life-span perspective that not is possible to unveil solely by standardised inquiries. Although persistent favourable outcomes are found physically and psychosocially from first to second follow-up, young adults with JIA reveal that life with JIA encompasses struggle and adjustment to an insecure life situation physically, psychologically, and socially.

Keywords: Juvenile idiopathic arthritis, adolescence, transition, life-span, self-rated health, public health

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Sammenfatning

Bakgrunn og mål: Mange års erfaring som pediatrisk sykepleier har vist meg at unge mennesker med kroniske barnesykdommer faller mellom to stoler i overgangen til voksent liv. Internasjonale studier støtter denne erfaringen, og norske ungdommer med juvenil idiopatisk artritt er ikke noe unntak. Kronisk barneleddgikt kan ha vidtrekkende konsekvenser for barnets vekst og utvikling, for familien og samfunnet for øvrig. Det faktum at mange barn fortsetter å ha aktiv sykdom og senvirkninger av sykdommen gjennom ungdomsårene og inn i voksent liv, understreker betydningen av å belyse de unges helse og livssituasjon i et folkehelseperspektiv. Gjennom denne avhandlingen ønsker jeg å undersøke fysisk, psykisk og sosial helse blant unge voksne med barneleddgikt i et livsløpsperspektiv.
Metode: Avhandlingen har en kvantitativ og en kvalitativ tilnærming. Studie I hadde en abduktiv eksplorerende design. Gjennom fokusgruppeintervjuer med respektivt unge mennesker med barneleddgikt og helsepersonell innen revmatologi ble opplevelser og erfaringer med overgangen til voksenhelsetjenesten undersøkt. Kvalitativ innholdsanalyse ble benyttet. Studie II hadde også en abduktiv eksplorerende design med kvalitative intervjuer for å utforske livet med barneleddgikt blant unge voksne i et livsløpsperspektiv. Kvalitativ innholdsanalyse ble benyttet også her. Studie III hadde en longitudinell deduktiv design. Standardiserte spørreskjemaer om fysisk funksjon (Health Assessment Questionnaire), psykososial helse (General Health Questionnaire versjon 30), og sykdomsfølelse, smerte og trøtthet (Visual Analogue Scales) ble anvendt for å undersøke selvvurdert helse blant kohorten 18.3 år etter symptomdebut. Sammenligning med baselinestudien og første oppfølging ble gjort. Deskriptiv statistikk og non parametriske tester ble benyttet i dataanalysen. Studie IV var en deduktiv tverrsnittsstudie. I tillegg til spørreskjemaene som ble benyttet i studie III, ble spørreskjemaet SF-36 Health Survey benyttet for å undersøke selvvurdert helserelatert livskvalitet. Data fra telefonintervjuet om utdanning, yrkesaktivitet, behov for hjelpemidler på jobb, og behov for helsetjenester siste året ble inkludert. Sammenligninger ble gjort med norske normdata. Deskriptiv statistikk, parametriske og non parametriske tester ble benyttet i dataanalysen.
Funn: Studie I viste at det å være i stand til å leve et meningsfylt og ansvarsbevisst voksenliv var et felles mål. Hindringer for de unge viste seg å være sykdommens natur, manglende fokus på overgangsprosessen, og overbeskyttende foreldre og helsepersonell. Hindringer blant helsepersonell var mangel på formelt samarbeid og omforent praksis på tvers av

profesjoner og institusjoner, og mangel på kompetanse om ungdoms helse og utvikling. Studie II viste at livet med barneleddgikt innebærer en konstant veksling mellom kamp og tilpasning til et usikkert dagligliv og et uforutsigbart livsløp. Dette kom til uttrykk i erfaringer om kroppslige begrensninger eller frihet, interpersonlige opplevelser av å bli inkludert eller satt til side, og intrapersonlige opplevelser av usikkerhet eller trygghet. Blant de 55 unge voksne med barneleddgikt i studie III rapporterte 21 fysiske funksjonshemninger og 12 psykiatrisk distress. Videre rapporterte 26 pasienter sykdomsfølelse, 27 smerter, og 33 trøtthet med en skåring på 10 eller mer på VAS-skalaene (0-100). Signifikante korrelasjoner ble funnet mellom fysisk funksjonshemning, smerter, sykdomsfølelse og trøtthet, og mellom psykiatrisk distress, smerter og trøtthet. Sammenligninger fra første til andre oppfølging av kohorten viste ingen signifikante endringer i fysisk eller psykisk funksjonsevne, smerter eller trøtthet. Studie IV viste at fysisk funksjons-hemning og smerter var signifikante prediktorer for den gjennomsnittlige variasjonen i fysisk helse, mens psykiatrisk distress og kvinnelig kjønn var signifikante prediktorer for den gjennomsnittlige variasjonen i mental helse. Sviktende fysisk helse var ikke assosiert med psykiatrisk distress. Sammenlignet med norske normdata fant vi sviktende helserelatert livskvalitet i det fysiske domene, men ikke i det mentale domene, og høyere utdanningsnivå, men ingen forskjell i yrkesaktivitet.
Konklusjon: Funnene fra de fire delstudiene kompletterer hverandre. Diskrepansen mellom funnene fra intervjuene og spørreskjemaene belyser en bredde og dybde i opplevelsene av livet med barneleddgikt som det ikke er mulig å avdekke bare gjennom bruk av standardiserte spørreskjemaer. Selv om funnene viser vedvarende positive utfall av sykdommen både fysisk og psykososialt fra første til andre oppfølging, viser unge mennesker med barneleddgikt at livet innebærer kamp og tilpasning til en usikker livssituasjon fysisk, psykisk og sosialt.

Nøkkelord: Juvenil idiopatisk artritt, ungdom, overgang, livsløp, selvvurdert helse, folkehelse

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Papers

This thesis is based on the following original papers, which are referred to in the text by their Roman numerals:

I. Östlie, I.L., Dale Ö. and Möller, A. (2007). From childhood to adult life with juvenile idiopathic artritis (JIA) – A pilot study. Disability and Rehabilitation. Vol 29 (6) pp. 445-452.

II. Östlie, I.L., Johansson I. and Möller, A. (2009). Struggle and adjustment to an insecure everyday life and an unpredictable life course
Living with juvenile idiopathic arthritis (JIA) from childhood to adult life – An interview study. Disability and Rehabilitation. Vol 31 (8) pp. 666-674.

III. Östlie, I.L., Aasland A, Johansson I, Flatö B. and Möller, A. (2009). A longitudinal follow-up study of physical and psychosocial health in young adults with chronic childhood arthritis. Clinical and Experimental Rheumatology. (Accepted 21st May 2009)

IV. Östlie, I.L., Johansson I, Aasland A, Flatö B. and Möller, A. (2009). Self-rated physical and psychosocial health in a cohort of young adults with juvenile idiopathic arthritis. (Submitted, July 2009)

Abbreviations

ACR	American College of Rheumatism
BURG	Norwegian Organisation for Children and Young People with Rheumatism
CBCL	Child Behaviour Checklist
CGAS/GAS	Children's or Adults' Global Assessment Scale
CHAQ	Childhood Health Assessment Questionnaire
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorders, 3rd ed., revised
EULAR	European League Against Rheumatism
GHQ-30	General Health Questionnaire version 30
HAQ	Health Assessment Questionnaire
HAQ-DI	Health Assessment Questionnaire Disability Index
HRQL	Health Related Quality of Life
HSCL	Hopkins Symptom Checklist
ILAR	International League Against Rheumatism
JIA	Juvenile Idiopathic Arthritis
MCS	Mental Component Summary scale
NRRK	Norwegian Competence Centre of Rheumatology and Rehabilitation
NSD	Norwegian Social Science Data Services
PCS	Physical Component Summary scale
PGA	Physician's Global Assessment of Disease Activity
RA	Rheumatoid Arthritis
RF	Rheumatoid Factor
SD	Standard Deviation
SF-36	The Medical Outcome Study Short Form – SF-36 Health Survey
SSB	Statistics Norway
VAS	Visual Analogue Scale
WHO	World Health Organisation
YSR	Youth Self Report

CONTENT

1 Introduction

Through my career as the Head of nursing in the Children's Department in a Norwegian hospital for many years, I have met young people suffering from a variety of chronic diseases causing impairments and disabilities in varying degrees visibly, physically, mentally and socially. What worried us as health professionals working with these children was their future as adolescents and young adults, and how they would manage life with their special needs. Through the past few decades health professionals have become more aware of the challenges these young people face on the road to adult life. In a period of life with great demands on developmental processes and milestones, these young people also face major demands on how to manage life with the accompanying effects of chronic diseases. How they succeed through adolescent years may have considerable consequences relating to their health, well-being and functional abilities in adult life.

As a result of developments within medical technology and therapy more children reach adult life with chronic conditions (Boice, 1998; White, 1999). In the Nordic countries there was an increase in the total number of chronic conditions among children and adolescents aged 2-17 years from 8.3% in 1984 to 15.7% in 1996 (Köhler, 2000). This is in line with American and European estimations, although there are differences dependent on the diversity of methodology and definitions used. American estimations show a prevalence of 18% of children under 18 years of age in 1994 who had a chronic physical, developmental, behavioural, or emotional condition and required health and related services of a type or amount beyond that required by children generally (Newacheck, et al., 1998). European estimations show a prevalence of 10% to 15% for in-school adolescents (Suris, et al., 2004). Many personal and familial histories are hidden in these numbers. The increasing prevalence of chronic conditions in this age group should be of major concern to the community, both with regard to family functioning and the individual child's present and future life.

Through my engagement period at the Norwegian Competence Centre of Rheumatology and Rehabilitation (NRRK) at Diakonhjemmet Hospital, Oslo, Norway, I realised that young people with juvenile idiopathic arthritis (JIA) were no better off than young people with

other chronic conditions regarding transitional planning and care. At NRRK I had the opportunity to do a search on transitional care for young people with JIA (paper I). This was my entrance into research in this field.

The major part of the thesis (paper II-IV) is based on a second follow-up in 2004/-06 of a Norwegian cohort of patients with JIA first admitted in 1985/-86 to the Centre for Rheumatic Diseases at Oslo University Hospital, Rikshospitalet, Norway which has the only paediatric rheumatology clinic in Norway and serves the whole country (4.5 mill inhabitants). The baseline study was done by Vandvik (1991) in 1985/-86. In 1994/-95 a first follow-up study was carried out by Aasland (1998) and Flatö (1999).

Only a few longitudinal follow-up studies on physical and psychosocial consequences of JIA for more than 18 years are reported. Even fewer studies describe young adults' own experiences with JIA in a life-span perspective from childhood through adolescence into adult life. Furthermore, studies on how young people with JIA and related health professionals describe the care in the transition process from child-centred to adult-centred health services have not been reported in Norway before.

Although there seems to be a decline in the frequency of severe physical disability among young people with JIA over the years, the proportion of young people who enter adulthood with active disease does not seem to decrease (Ravelli, 2004). This fact has consequences for the transitional care that should be provided for these young people. Studies on user perspectives of transitional care among young people with JIA (Shaw, et al., 2004) and congenital heart disease (Moons, et al., 2009) have illuminated a need for improved care including individual assessment of the adolescent's holistic needs and increased transfer preparation, although generally the adolescents have a positive attitude toward transferring to adult care programs.

The focus of this thesis is the life-span perspective on living with JIA from childhood through adolescence into adult life. Young adults' assessment of their health and life situation and their experiences of growing up with JIA are investigated. Furthermore, in focus-group interviews young people with JIA and related health professionals reflect upon health

services provided to this group of patients. Moreover, public health and the health-promotion perspective are focused, as normal growth and development into adult life with good health and well-being should be the aim also for young people with JIA.

2 Background

2.1 Juvenile idiopathic arthritis

JIA is a heterogeneous group of inflammatory arthritides of unknown aetiology that begins before the 16th birthday with persistent objective arthritis in one or more joints for at least six weeks, and where other conditions are excluded (Klippel, 2008; Petty, et al., 2004). According to the International League of Associations for Rheumatology (ILAR) Classification of Juvenile Idiopathic Arthritis, JIA is classified in seven categories: Systemic arthritis, persistent oligoarthritis, extended oligoarthritis, polyarthritis RF negative, polyarthritis RF positive, enthesitis-related arthritis, psoriatic arthritis, and undifferentiated arthritis. These subtypes present different clinical symptoms, immunogenic associations, and disease courses (Klippel, 2008; Petty, et al., 2004). Diagnosis and division into subtypes are based on clinical examination, and no diagnostic tests are available. The ILAR classification has replaced the former American (ACR) and European (EULAR) classification systems (Andersson, 1999).

The disease course might be variable with unpredictable remissions and exacerbations. Children and adolescents experience acute and chronic pain, limited joint motility, fatigue, functional limitations, prolonged pubertal development, and changes in physical appearance. The aim of the treatment is pain control, improved joint motility and muscle strength, and optimal growth and development (Cassidy, et al., 2005).

JIA is a relatively common chronic childhood-onset disease, affecting approximately the same number of children as juvenile diabetes, at least four times as many children as cystic fibrosis, and at least 10 times as many as haemophilia, acute lymphatic leukaemia, chronic renal failure, or muscular dystrophy (Klippel, 2008). Geographical and ethnic differences can be found as well as differences in age-onset, subgroup distribution, and immunological markers (Klippel, 2008). Seasonal variations and variations in incidence over time have also been observed, indicating environmental influences on disease frequency, while familial aggregations indicate the influence of genetic factors (Andersson, 1999).

The heterogeneity of the disease and, until recently, lack of uniform classification criteria internationally, differences in methodology for case identification, and inadequate definition of study populations have complicated the interpretation of epidemiological studies on JIA. European and North American studies with similar methodology show an annual incidence of 10 to 19.2 per 100,000 children under 16 years of age (Andersson, 1999). A recent Nordic study reports an annual incidence rate of 15 per 100,000 (95% CI 13, 17) children under 16 years of age (Andersson, 1999). The prevalence shows great geographical variations, from 8 to 400 per 100,000 children under 16 years of age (Andersson, 1999). In a meta-analysis study by Oen and Cheang (1996) a prevalence of 132 per 100,000 (95% CI 119, 145) children under 16 years of age was reported.

The sex ratio differs by disease subtype. For polyarthritis RF negative and positive, and persistent and extended oligoarthritis the female:male ratio is 3:1 and 4:1 respectively. For enthesitis-related arthritis the female:male ratio is 1:7. For the other subtypes the female:male ratio is 1:1 (Klippel, 2008). In a Nordic study oligoarticular disease represented 66% of the childhood arthritis on average corresponding with the overall predominance of girls over boys, with a ratio of 2-3:1 (Andersson, 1998, 1999).

The prognosis of JIA varies according to the disease subtype. Patients with extended oligoarthritis (arthritis in five or more joints after six months) and systemic arthritis (arthritis associated with fever and symptoms from other organs) have symptoms associated with persistent moderate to severe physical impairment. Patients with persistent oligoarthritis (arthritis in four or fewer joints) are at less risk of persistent joint damage. However, these patients are at high risk of uveitis and consequently eye damage (Klippel, 2008). The prognosis among patients with enthesitis-related arthritis is variable, and psoriatic arthritis may deteriorate from oligoarthritis to polyarthritis (Cassidy, et al., 2005).

Due to the diversity of methodology, differences in diagnostic criteria and remission definitions, and the major therapeutic advances in the treatment through recent decades, studies on long-term outcomes of JIA are difficult to compare and interpret. However, in an analysis of outcome studies published from 1994 to 2004, Ravelli (2004) found remission or inactive disease ranging from 40% to 60%, and severe functional impairment at their last

observation in 10% on average. This is in line with other studies reporting that 30% to 55% of young people with JIA will enter adulthood with persistently active disease with considerable pain and severe physical disability (Davidson, 2000; Flatø, 1999; Flatø, et al., 1998; Gäre & Fasth, 1995; McDonagh, et al., 2000; Packham & Hall, 2002; Zak & Pedersen, 2000). Approximately 60% of the patients will have persistent problems with everyday life activities. Regarding ocular complications, a recent study reports that still 15% of patients with eye disease had significant visual loss 9.4 years after eye-disease onset (Cassidy, et al., 2005). Furthermore, less obvious consequences of prolonged systemic inflammation and the treatment may be cardiovascular disease, osteopenia, and decreased fertility (Sullivan, 2005).

In spite of major therapeutic advances the last decades, the patients experience pain, fatigue, and limitations in daily activities and participation physically, socially and in society. Although the different studies are hard to compare and interpret, the findings indicate that the disease is a considerable burden to many young people into adult life (Bruinooge, et al., 2003; LeBovidge, et al., 2003; Packham & Hall, 2002; Schanberg, et al., 2003; Sällfors, et al., 2004; Vandvik, et al., 1989; Wilkinson, 1981; Zak & Pedersen, 2000; Aasland, et al., 1997).

2.2 Developmental transition from childhood to adult life

The term “transition” can have several meanings and can be seen as a result of, or it can result in, changes in life, health, relationships, and environments (Meleis, et al., 2000). Meleis (2005) maintains that transitions are developmental, situational and health/illness events. Developmental transitions (both bio-physiologic and psychosocial) may include transition from childhood to adolescence and young adulthood and from adulthood to mature adulthood. Situational transitions require a definition or redefinition of the roles that the client is involved in, such as transition from child-centred to adult-centred health-care systems, transition from a student role to an occupation role, or transition from a non-parental role to a parental one. Health/illness transitions include sudden role changes related to changes from wellness to acute or chronic illness and changes or fluctuations in chronic illness. Young people with chronic diseases may experience multidimensional transitions as they move from childhood and adolescence to young adult life and

simultaneously shift from child health-care to adult services, from education to employment, and from single life to family life. People in transition tend to be more vulnerable to risks that may in turn affect developmental processes, health and relationships (Meleis 2000).

Adolescence is a time of developmental transition with rapid physical, psychological, and social developmental changes, and implies unique challenges of communication and health management. Challenges through adolescent years include the achievement of biological and sexual maturation, forming of personal identity, emerging independence and autonomy, establishment of lasting personal relationships outside the family and intimate sexual relationship, decisions on education and vocation, and obtaining a meaningful and responsible adult life in the context of the socio-cultural environment (Boice, 1998; Christie & Viner, 2005; White, 1997).

Developmental tasks in the physical domain include puberty, the pubertal growth spurt, changes in body shape, and simultaneously maturational changes in other organ systems (Christie & Viner, 2005; Dahl & Hariri, 2005; Dahl & Spear, 2004; Patton & Viner, 2007). In the psychological domain young people improve in verbal abilities and develop from concrete to complex abstract thinking, enabling the adolescents to think hypothetically about the future and assess various outcomes. Forming of personal identity, recognition of morality and law, and impulse control, gradually increase. The vulnerability of being different from peers in physical appearance may have a major impact on body image and self-esteem. At the same time a concept of self as not vulnerable to the normal rules of life is characteristic in the early adolescence displayed as exploratory and risk-taking behaviours (Boice, 1998; Christie & Viner, 2005). Socially, adolescence is a time of changing the balance of independence and dependence in relation to parents, peers, and community. The process of forming individual identity may impact on how adolescents define other people in relation to themselves and may influence the adolescent's way of thinking of other people, such as devaluation of adults' knowledge and advice, beliefs about adults' lack of ability to understand the adolescents, and how other people may react to and be affected by the adolescent's behaviour (Boice, 1998; Christie & Viner, 2005).

Chronic childhood disease and adolescent development may have reciprocal effects. Psychological and biological maturation may be delayed by illness and/or medical treatment, and lack of an intact body image may affect the forming of a personal identity and thus affect the adolescents' acquiring social skills needed to negotiate in the adult environment. On the contrary, the physiological and psychological development and psychosocial adjustment can have an impact on the disease and the disease course (Suris, et al., 2004; White, 1997). In JIA chronic inflammation frequently causes delayed growth and puberty, often with later catch-up growth, although permanent growth loss may occur. Furthermore, joint damage may alter the adolescent's physical appearance, and pain and fatigue may limit the ability to participate with peers physically and socially. Biological, psychological, and social development are highly inter-related, and thus delayed growth and puberty may affect identity forming, body image, and the establishment of independence and autonomy. Furthermore, this may have consequences on the separation process from parents and on how the adolescent is treated by peers and adults, and consequently have an impact on his/her self-concept and relations to family and peers (Gortmaker, et al., 1990; Möller & Nyman, 2003). Moreover, future expectations might be affected (Sällfors, et al., 2002).

In addition to their physical condition, adolescents with JIA have to cope with their own emotional reactions to their illness and its care as well as to the reactions of family members, peers, teachers, and others. Findings on the epidemiology of behaviour problems in a nationally representative sample of 11699 children and adolescents aged 4 to 17 years in the United States confirmed that chronic physical conditions were a significant risk factor for behaviour problems, independent of socio-demographic variables (Gortmaker, et al., 1990). A meta-analytic review of psychological adjustment of children and adolescents with chronic arthritis reported that young people with arthritis displayed increased risk for overall adjustment problems and internalising symptoms, but not for externalising symptoms or poor self-concept (LeBovidge, et al., 2003).

The family constitutes the arena of close relationships, socialisation, nutrition and care, where the child grows and develops within the context of the family system and values and parental roles and functioning (Möller & Nyman, 2003). When a child is stricken by a chronic disease the whole family will be affected. The parents will be responsible for the provision of

everyday care including the integration of therapeutic activities. Consequently, the parents are tied in double roles as both parents and therapists (Haug, 1998). This situation may be demanding on the parent-child relationship. In the first follow-up of the current cohort the adolescents reported more overprotection from parents than adolescents in the general population (Aasland, 1998). Furthermore, increased closeness in the families of rheumatic children was found at first follow-up and this may have had positive consequences on the family functioning, as reported by the majority of the parents (Aasland, 1998). However, the family closeness may have developed at the expense of the transition and separation processes of the adolescents and, accordingly, at the expense of the development of mutual relationships with parents and peers.

2.3 Transition from child-centred to adult-centred health care

During recent decades more attention has been paid to the health care provided to adolescents with chronic diseases in the transition process (Shaw, et al., 2005; White, 1997). Transition in health care should not only be confined to the administrative event of transfer to adult care, but rather to the much longer process which should start in early adolescence and reflect adolescent development (McDonagh, et al., 2007; Sawyer, et al., 2007). Transition in health care can be defined as a multidimensional, active process that is age and developmentally appropriate and attends to the medical, psychosocial, and educational-vocational needs of adolescents as they move from child- to adult-centred lifestyles and systems (American Academy of Pediatrics, et al., 2002; McDonagh, 2008; White, 1997). Differences in culture, knowledge and clinical practice between child care and adult health services appear as a gap in the health-care system. Bridging this gap requires recognition of the situation, interdisciplinary co-operation, and planning (Robertson, et al., 2006; Viner, 1999). Challenges for the adolescents are not only the achievement of normal developmental tasks; they face demands on acquisition of self-management skills pertaining to their chronic condition as well. From a parental perspective, the challenge implies how to maintain a supervisory role and involvement while supporting the adolescent's growing ability to independently manage their health (Haug, 1998; Sawyer & Aroni, 2005).

For the health professionals the concept of transition in health-care challenges the provision of services necessary to prepare the adolescents for successful transition to adulthood, including skills in self-management of health, educational and vocational planning, and independent living (Michaud, et al., 2004; Sawyer & Aroni, 2005; Shaw, et al., 2006b; Viner, 1999; White, 1997). Also, it might be necessary to support the parents in gradually relinquishing control and responsibility and promote the adolescent's independence and autonomy (Sawyer & Aroni, 2005; Sawyer, et al., 2007). These challenges are demanding on both the individual health professional and the health-care system. Knowledge on adolescent development, the nature of chronic childhood diseases, and communication skills are required as well as the establishment of adequate transitional care programmes (McDonagh, 2008; Michaud, et al., 2004; Sawyer, et al., 2007).

The Norwegian law of patients' rights (Norwegian Ministry of Health, 1999b) and the law of health professionals (Norwegian Ministry of Health, 1999a) emphasise the patients' right to information and autonomy, and the health professionals' obligations to provide practices and arenas enabling the patients in this respect. The laws include the rights of the child and adolescent in accordance with their developmental transition processes.

Several medical associations, such as American Academy of Paediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine, and the Society for Adolescent Medicine, have developed consensus statements on health care transitions for young adults with special health care needs. The purpose has been to bridge the differences in approaches between child- and adult-centred health services confirming the important role of health professionals in the transition process (American Academy of Pediatrics, et al., 2002; Blum, et al., 1993; Rosen, et al., 2003).

The efforts of these associations aim to ease the developmental processes through adolescence and help young people to achieve expected milestones and move on to an autonomous and meaningful adult life of good health and well-being in spite of their chronic condition (McDonagh, et al., 2007; Meleis, et al., 2000; Shaw, et al., 2006a).

2.4 Public health perspectives on health care and transition of adolescents with chronic childhood diseases

Public health can be defined as "the art and science dealing with the protection and improvement of community health by organized community effort and including preventive medicine and sanitary and social science" (Acheson & Britain, 1988; Merriam-Webster, 2003). This definition involves a commitment to promote health and well-being also among young people with inherent or acquired chronic childhood diseases. The field of public health was primarily concerned with the prevention and control of infectious diseases locally, nationally and globally. However, prevention and control of chronic conditions have been of increased concern since the mid-20th century as the recognition of relations between chronic conditions and life-styles has evoked and the number of elderly people is increasing (Klippel, 2008). Subsequently, the emerging concerns about adolescent health during recent decades has led to a particular health promotion focus on young people, addressing healthy adolescents as well as the increasing number of adolescents and young adults with chronic childhood diseases (Christie & Viner, 2005; Patton & Viner, 2007; Sawyer, et al., 2007; Viner & Macfarlane, 2005). Although there are issues that are specific to each chronic condition, there are more things in common than differences with regard to age and developmental processes in adolescence (McDonagh, 2008; Suris, et al., 2004). Therefore, it is important to focus on adolescent issues such as biological, mental and social developmental changes and how young people interact with the environment during these processes of change.

Young people's health can be put at risk by their tendency to keep a here-and-now focus on life, their immature ability to control impulses and imagine future consequences, and the importance of peer conformity. Adherence to treatment regimes may be impaired or even neglected for the same reasons. In addition, the developmental needs to explore adult behaviour and possibilities of life in an extended perspective can lead to risky behaviour among young people, such as tobacco smoking, harmful alcohol drinking, drug misuse, risky sexual behaviour, injury and violence (Gortmaker, et al., 1990).

Young people with chronic conditions or disabilities are no less likely than their peers to be sexually active, and substance use-rates seem to be similar or even higher than among healthy controls (Gortmaker, et al., 1990; Suris, et al., 2004). The continuity into adulthood of health behaviour acquired in adolescence will have immediate as well as long-term influence on health, morbidity and quality of life (Toumbourou, et al., 2000; Viner & Macfarlane, 2005).

The Ottawa Charter for Health Promotion defines health promotion as "the process of enabling people to increase control over, and to improve, their health" (WHO, 1986). Health is not the objective for living, but a resource for everyday life including social and personal resources, as well as physical capacities. The aim of health promotion goes beyond healthy life-styles to equity in living conditions and well-being as proposed by the New global Health for All targets: "to reach and maintain the highest attainable level of health throughout their lives" (WHO, 1998). The European health policy program target 7 commits to giving children and young people the opportunity to grow and develop to their full physical, mental and social potential (WHO, 1991).

In childhood and early adolescence health attitudes and behaviour are dominated by parental health behaviour and shared family values. In adolescence socialising with peers and youth-cultures are increasingly influencing young people's health attitudes and behaviour (Viner & Macfarlane, 2005). Therefore, specific interventions targeted for the adolescent and his/her family are urgent, addressing general adolescent issues as well as disease specific concerns. The development of personal skills in self-management is an imperative in this respect. There is growing evidence that a transitional care program can potentially improve adolescents' health-related quality of life (HRQL) (McDonagh, et al., 2007).

Health and its maintenance involve the individual as well as the whole of society, and not merely the health sector. Rootman et al. (2001) describe seven basic principles of health promotion including empowerment, participation, equity, holism, sustainability, inter-sector cooperation among relevant sectors in society, and the use of multi-strategy approaches. Potential relations between chronic conditions and life-styles and the tendencies of risky

behaviour among adolescents are emerging concerns in society. In order to promote longstanding health and well-being among young people with JIA and other chronic childhood conditions, Rootman's perspective of health promotion seems reasonable and is what the present thesis leans at.

2.5 Health and health-related quality of life

Since the World Health Organisation (WHO) introduced an expanded definition of health after the Second World War, a shift away from the traditional medical model of health has evoked. The bio-medical model is based on the assumption that disease is generated by specific etiological agents which lead to changes in body structure and function. Health is described in terms of the absence of disease while illness is seen as the subjective experience of dysfunction (Bowling, 2002; Tranöy, 2000).

The traditional medical model has been challenged by health philosophers and scientists who advocate broader perspectives on health and ill-health as being influenced by a combination of biological, social and psychological factors and predispositions (Bowling, 2002). Pörn (2000) maintains the theory of action as the frame of a holistic health model. This approach emphasises the human being as an active subject in a surrounding environment. The holistic approach involves the person, his/her goals, and circumstances in the environment in which the person acts. Pörn (2000) advocates health as the person's ability to function according to his/her life goals. Nordenfelt (2000) criticises this concept of health as it may be identified with the concept of adjustment. He develops the holistic health model further, and conceptualises health as realisation of vital goals in standard circumstances. Nordenfelt (2000) proposes that the standard situation should be established through consensus. As opposite to the bio-medical model which is based on the concepts of disease and illness, the holistic approach is based on the concept of health.

Antonovsky (1979, 1987) describes health as a continuum between states of complete health or "ease" and un-health or "dis-ease". Mechanisms that make people move towards the healthier or positive end of the continuum are called salutogenic as opposed to pathogenic mechanisms. Salutogenic factors supposedly contribute directly to health and

predict favourable health outcomes. People can experience health in spite of a diagnosed disease and, thus, the definition of health is relative compared to the first WHO definition (Antonovsky, 1979, 1987).

The WHO definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity” has later been criticized for its utopian and static formulation, and WHO has later adapted the health concept for use in an interdisciplinary context also considering its positive implications (Bowling, 2002; Lindström, 1994; WHO, 1991, 1998). The emerging usage of the term “health status” implies a multifaceted concept and overlaps with the broader concept of HRQL. Both concepts might include conditions pertaining to physical health, physical functioning, social functioning and social health, psychological well-being, emotional well-being, and perceptions (Bowling, 2002).

In a project undertaken to develop an instrument for measuring quality of life, WHO has defined the concept of quality of life as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL-Group, 1993). This is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment. In this term HRQL is considered the impact of the illness condition and its treatment on the individual’s quality of life (Bjorner, et al., 1996).

The concept of HRQL may include health status defined as self-rated health and functional ability (Bjorner, et al., 1996). Self-rated health includes perception of symptoms, well-being, general health, and vulnerability, while functional ability represents a social definition of health described as the performance of tasks and roles within a social context (Bjorner, et al., 1996). Consequently, HRQL might be seen as both a relative and a subjective concept since the assessment might be influenced of the immediate life situation and the frame of reference of the individual. Carr (2001) proposes that HRQL is the gap between our expectations and our experiences of health, and that the perception of HRQL varies between

individuals and is dynamic within them. This underpins the concept of HRQL as relative and subjective.

Thus, other conditions than physical or mental health, i.e. good social relationships and achievement of personal goals, may be of greater value and, consequently, the individual's assessment of HRQL remains unchanged in spite of deterioration in physical or mental health (Bowling, 2002). This is in line with Carr et al. (2001) who propose that people with different expectations will report different quality of life although they have the same clinical condition. Furthermore, in spite of deterioration in health condition, patients may report the same level of quality of life when measures are repeated (Carr, et al., 2001).

In the perspective of HRQL as both a relative and a subjective concept, HRQL in adolescence and early adulthood may or may not change over time dependent on personal goals and expectations and the experience of goal achievement, irrespective of the disease course.

In the current thesis the point of departure is the broader concept of health including conditions pertaining to physical and social health, physical and social functioning, psychological and emotional well-being, and individual perceptions.

2.6 Adjustment processes

Children and adolescents with JIA are confronted with disease-related stress on the top of everyday stresses (Boekaerts & Röder, 1999). Disease-related stress may include being confronted with pain and fatigue, taking medication every day, living with restrictions, and having to visit health professionals regularly. In addition, the adolescents are confronted with stresses regarding social consequences of the disease, such as limited participation in social and physical activities and absenteeism. Moreover, the variability of the disease may increase the experience of stress and pose heavy demands on the adolescents with regard to coping resources mediating adjustment processes (Boekaerts & Röder, 1999).

Complicated emotional responses may accompany the disease and a complex set of processes is involved in adjustment to chronic illness (Sharpe & Curran, 2005). Sharpe and

Curran (2005, p. 1161) view adjustment to illness "as a process to maintain a positive view of the self and the world in the face of a health problem". The process implies considerations and re-considerations of the individual's views of the illness and its impact on the entire life, physically, emotionally, and socially to regain equilibrium. The first step in this process may be the attempts to develop more adaptive views of the manifestations and course of the illness. If these efforts do not bring emotional balance, the next step may be to question the coping strategies assessed as successful. Further on, views about the world may be altered by re-evaluation of priorities and goals through response shift. In order to minimise the impact of the illness on everyday life, the individual may attempt to re-define the way he/she evaluates success in life. If all these efforts are unsuccessful, the individual may attempt to reconsider his/her view of the self including personal beliefs and values of life (Sharpe & Curran, 2005; Sprangers & Schwartz, 1999).

Although children and adolescents are in a state of developmental transition and JIA is an unpredictable and variable disease, this concept of adjustment seems applicable. Ability to maintain the adjustment processes in order to develop more helpful views of the illness, their world, or themselves may improve the adolescents' emotional balance and thus their psychosocial functioning. On the contrary, poor psychosocial functioning may occur (Sharpe & Curran, 2005).

2.7 Rationale for the study

As a specialist in paediatric nursing with management and leadership competence I worked as a head nurse in a children's department in a Norwegian hospital for many years. I recognised that adolescents with persistent chronic childhood diseases fall between two chairs. As I switched to rehabilitation in adult rheumatology my experience was reinforced. In Norway the care for young people with JIA in the transition period from childhood to adult life was scarcely formalised in child health care and nor in adult health care. Chronic arthritis from childhood might have far-reaching consequences for the growth and development of the child, and for the family and community. The fact that a considerable proportion of children with JIA continue to have active disease and disease residua through adolescence

into adulthood underlines the importance to illuminate the situation in a public health perspective.

3 Overall and specific aims

3.1 Overall aim

The aim of this thesis is to add to the body of knowledge of physical and psychosocial health among young adults with JIA in a life-span perspective from childhood and adolescence into adult life.

The study explores how young people with JIA and health professionals experience care provided in the transition process from a child-centred to an adult-oriented health-care system, how young people have experienced life with JIA through childhood and adolescence into adulthood, and how they assess their health and health-related quality of life as young adults.

The longitudinal perspective of the cohort study will bring unique insight into the life span of young people with JIA and illuminate factors that might impact on physical and psychosocial health into adult life.

3.2 Specific aims were to illuminate

- Health-care service provided for children and young people with JIA in the transition to adulthood from the perspective of young people themselves and related health professionals (I)
- Young adults' own experiences of life with JIA through childhood and adolescence into adult life (II)
- Long-term self-rated outcome of physical and psychosocial health from baseline and first follow-up to second follow-up of the cohort (III)
- Self-rated physical and psychosocial health at second follow-up of the cohort and comparison to a matched Norwegian population (IV)

4 Methods

The thesis is an investigation of chronic childhood arthritis in a life-span perspective from childhood through adolescence to adult life based on the perspective of health professional sciences (Nortvedt & Grimen, 2004) and the public health science (Laverack, 2005).

In a pilot study in 2001 health-care transition from the perspective of young people with JIA and related health professionals was investigated (paper I). Additionally, a cohort of patients with JIA was investigated in 2004/-06 in a second follow-up study 18.3 (17.0-28.9) years after baseline to explore the course of life with JIA and the current health status physically and psychosocially (paper II, III and IV). The baseline study of the cohort was conducted by Vandvik in 1985/-86 (1991) and the first follow-up by Aasland (1997) and Flatö (1998) in 1994/-95.

Recognition of the human being in a humanistic and holistic perspective is fundamental in this field of science (Nortvedt & Grimen, 2004). The life-span perspective from childhood through adolescence to adult life involving changes and development in all aspects of life underpins the significance of this perspective.

4.1 Methodical considerations

The complexity in studies on human beings involves variations in time and culture and the human's ability to create his own world and history by means of individual concepts and comprehensiveness (Martinsen, 2005; Nortvedt & Grimen, 2004). Furthermore, scientists can never separate themselves from the social, cultural and political context of their work, and thus their role can never be defined as objective and value-free (Bowling, 2002; Malterud, 2001). Previous personal and professional experiences, pre-study beliefs about how things are and what is to be investigated, motivation and qualifications for an exploration of the field, and perspectives and theoretical basics related to education and interest are preconceptions present in our assumptions of the world (Bowling, 2002; Malterud, 2001). Thus it is important, as far as possible, to make the assumptions explicit and to maintain reflection on our preconceptions. This will contribute to appropriate

decisions on research methods and data analysis in accordance with the research question under study.

The complexity of the questions under study in this thesis involves a variety of unknown elements pertaining to the life-span perspective including the developmental transition of adolescence and the transitional health-care provision as well as the fluctuating nature of the disease, and a tendency of relativism may complicate the generalizability of findings and inferences (Bowling, 2002; Foss & Ellefsen, 2002; Malterud, 2001). A broad approach may contribute to increasing comprehensiveness of the complexity of the questions by obtaining both breadth and depth in the data and thus extend the illumination of the questions under study. Accordingly, a combination of qualitative and quantitative methods with data collection from diverse sources and different analysis approaches was considered advantageous. This triangulation might strengthen the validity of the study, presupposing that each method utilised is valid (Bowling, 2002; Malterud, 2001).

With regard to the pilot study (paper I) a thorough preparation was done to make clear the aim of the study and to decide on the target group. We wanted to explore the adolescents' perceptions and experiences of the health-care transition. Furthermore, we wanted to investigate the health professionals' perceptions of adolescents' needs and the provision of appropriate care for these patients. Accordingly, adolescents with JIA and health professionals working with patients with JIA in a child- or adult ward respectively were included. We decided not to include parents as we regarded the adolescents themselves as competent partakers in focus-groups and we were interested in the adolescents' perceptions of the question under study. In order to obtain discussions on the topic in groups, the method of focus-groups was assumed applicable (Krueger, 1994; Ramirez & Shepperd, 1988). Consequently, an illumination of diversities in perceptions and experiences could be obtained. An interview guide was developed in order to keep the group discussion on track.

The aim of the qualitative interview study of the cohort (paper II) was to explore the experiences of life with JIA through childhood and adolescence into adult life as described by the young adults themselves. We wanted to get a deeper understanding of the experiences

of the individuals reported in their own words (Bowling, 2002; Kvale, 1997). As mentioned above, the human creates his own world and history by means of individual concepts and comprehensiveness. Accordingly, an abundance of variation in personal experiences may result and thus provides rich variations in the data collected. This allows for a deeper understanding of what it means to live with JIA through childhood and adolescence into adult life.

The longitudinal study of the cohort (paper III) was performed to explore the long-term outcome and possible changes in physical and psychosocial health from baseline and first follow-up to second follow-up (Bowling, 2002; Field, 2005). The cross-sectional study of the cohort (paper IV) was carried out to explore current self-rated physical and psychosocial health at second follow-up and to make comparison to the general Norwegian population (Bowling, 2002; Field, 2005). In order to make comparisons the employment of comparable measurements was critical (table 2). The selection of measurements was based on the following criteria:

1. Similar or comparable to instruments used at first follow-up to allow for assessment of changes at second follow-up.
2. Internationally acknowledged and well-known instruments previously used for self-assessment in the general population and in young people with chronic diseases to allow for comparisons within the cohort over time and with matched groups.
3. Documented validity and reliability to provide satisfactory psychometric properties.

The age span in the cohort constituted a challenge with regard to decision on measurements. At first follow-up, the CHAQ (Singh, et al., 1994) was employed for patients under 18 years of age. This measure is adapted to children by adding questions to the HAQ so that at least one question in each area is relevant to children in all ages (Singh, et al., 1994). The rating and scoring of HAQ and CHAQ are equal. At second follow-up, only HAQ was employed as all responders were over 18 years of age. At first follow-up VAS pain and VAS fatigue were employed. At second follow-up VAS illness was added (Wewers & Lowe, 1990). Three standardised questionnaires, each adapted for a certain age group, measuring mental health were utilised at first follow-up while at second follow-up only the GHQ-30 was

chosen since this questionnaire was more recognised at the time (Bekkelund, et al., 1995; Malt, et al., 1997). In the psychosocial domain comparisons could only be utilised by means of scores defining psychiatric distress within a clinical range. In the physical domain scores by HAQ, VAS pain and VAS fatigue were suited for comparisons from first to second follow-up.

4.2 Design

This thesis has a qualitative and a quantitative approach. The pilot study (paper I) had an abductive explorative design with focus-group interviews to identify the perceptions as they were illuminated in the groups. Also, the second study (paper II) had an abductive explorative design with qualitative interviews to explore the variation of experiences described by the individual informant. A longitudinal deductive design was employed in the third, and a cross-sectional deductive design in the fourth study (paper III and IV). An overview of study design, data collection, participants, and data analysis of the studies is outlined in table 1.

An abductive approach indicates recognition of the preconceptions that are present in our assumptions of the world. The role of the scientist can never be objective and value-free. Thus, commuting between inductive and deductive approaches, conceptualised as an abductive approach (Peirce, 1955), is a more comprehensive description of the research design of the first two studies.

Table 1. Design, data collection, participants, and data analysis in study 1–4.

	Design	Data collection	Participants, recruited from	Data analysis
Study 1	Abductive explorative qualitative	Focus-group interviews 4 groups, one time each, á 1 hour	Group1: 6 females, 15-26 yrs, BURG[a)] Group 2: 6 females, 1 male, 16-27 yrs, BURG[a)] Group 3: 6 HP[b)], paediatric rheumatology clinic Group 4: 7 HP[b)], adult rheumatology clinic	Qualitative content analysis
Study 2	Abductive explorative qualitative	Individual qualitative interviews, one time each, á 1 hour	From the cohort: 15 participants 9 females, 6 males, 22-38 yrs	Qualitative content analysis
Study 3	Deductive analytical quantitative Longitudinal follow-up	Postal self-administered questionnaires	From the cohort: 55 participants 33 females, 22 males, 19-35 yrs	Descriptive and inferential statistical analyses
Study 4	Deductive analytical quantitative Cross-sectional	Postal self-administered questionnaires and telephone interview Norm-data	From the cohort: 55/51 participants Questionnaires: 33 females, 22 males, 19-35 yrs Telephone interviews: 30 females, 21 males, 19-35 yrs Population based: 1196 persons, female 60.5%, male 39.5%, 19-35 yrs	Descriptive and inferential statistical analyses

a) The Norwegian Association for Children and Young People with Rheumatism

b) Health Professionals: nurses, occupational therapist, physiotherapist, rheumatologist, school teacher, and social worker

4.3 Participants – recruitment and drop-outs

4.3.1 Study I

In the first study (paper I) young patients with JIA and relevant health professionals were interviewed in focus-groups. The patients were recruited via the Norwegian Association for Children and Young People with Rheumatism (BURG) and the health professionals were recruited via the professor of one paediatric and one adult rheumatology clinic respectively.

Inclusion criteria for the patients were: age 15 – 27 years, active disease present at least since fourteen years of age, still in medical therapy and consulting a rheumatologist in either paediatric or adult setting. Inclusion criteria for the health professionals were employment in a paediatric or an adult rheumatology clinic. Ability to express themselves verbally in Norwegian was an inclusion criterion for all the participants for technical reasons since the group conversations were tape-recorded.

The investigators gave written information about the study including participation and inclusion criteria, which was mailed via BURG to members aged 15 – 27 years. Those who received the inquiry replied directly to the investigators.

Two males and 14 females responded. They all met the inclusion criteria and were included in the study. However, the selection procedure had some limitations: we were not able to select the participants; we only used what we got. If more members had responded we would have been able to make a purposive selection of participants in order to obtain variation in the data collected and to obtain an appropriate sex distribution (female:male ratio=3:1) (Andersson, 1998). In that case we would have had to inform all respondents whether they had been selected to participate or not.

One male and two female patients dropped out on the day of the interview or the day before for personal reasons. As a result, one male and 12 females participated.

With regard to the health professionals, they were contacted personally by the investigators after getting the consent of the respective professors. To catch the variation in perceptions on the topic under study health professionals from the following disciplines were purposely selected: nurses, occupational therapists, physiotherapists, rheumatologists, social workers, and one school teacher from the children's unit. They all received written information about the study before the focus-group interviews took place.

In recognition of youth-cultures and young people's dependence on peer relationships, the composition of separate youth- and health-professional groups respectively was intended

allowing the participants to speak more freely. The division within the youth group was done by convenience in order to ease the travelling for the participants.

4.3.2 Study II-IV

The cohort study (paper II, III, and IV) was based on patients with suspect or definite arthritis first admitted to the Centre for Rheumatic Diseases at Oslo University Hospital, Rikshospitalet, Norway from September 1985 to September 1986 (Vandvik, et al., 1991). Of the patients admitted, 84 had JIA. At first follow-up median (min-max) 8.7 (7.2-19.9) years after symptom-onset, 72 (85.7%) patients were re-assessed (Flatø, et al., 1998; Aasland, et al., 1997) of whom 70 patients were willing to participate in the psychosocial study (Aasland, 1998). In the present study, the second follow-up, median (min-max) 18.3 (17.0-28.9) years after symptom-onset, only the 70 (83.3%) patients who were willing to participate in the psychosocial study at first follow-up were included (figure 1). Also, these patients were willing to have their identifiable personal data stored at Norwegian Social Science Data Services (NSD) in case of future studies, confirmed by an inquiry in October 1999 by the researchers from the baseline and first follow-up studies. The inclusion criterion for participating in the second follow-up study was belonging to the first follow-up cohort (Flatø, et al., 1998).

In the longitudinal follow-up and the cross sectional study 55 (78.6%) of the 70 patients responded to postal questionnaires on self-rated health (paper III and IV). One patient had died, four were lost to follow-up, and 10 refused to participate. These 15 patients were comparable to the participants with regard to sex, age, disease duration, number of active joints, and physician's global assessment at first follow-up (Flatø, et al., 1998).

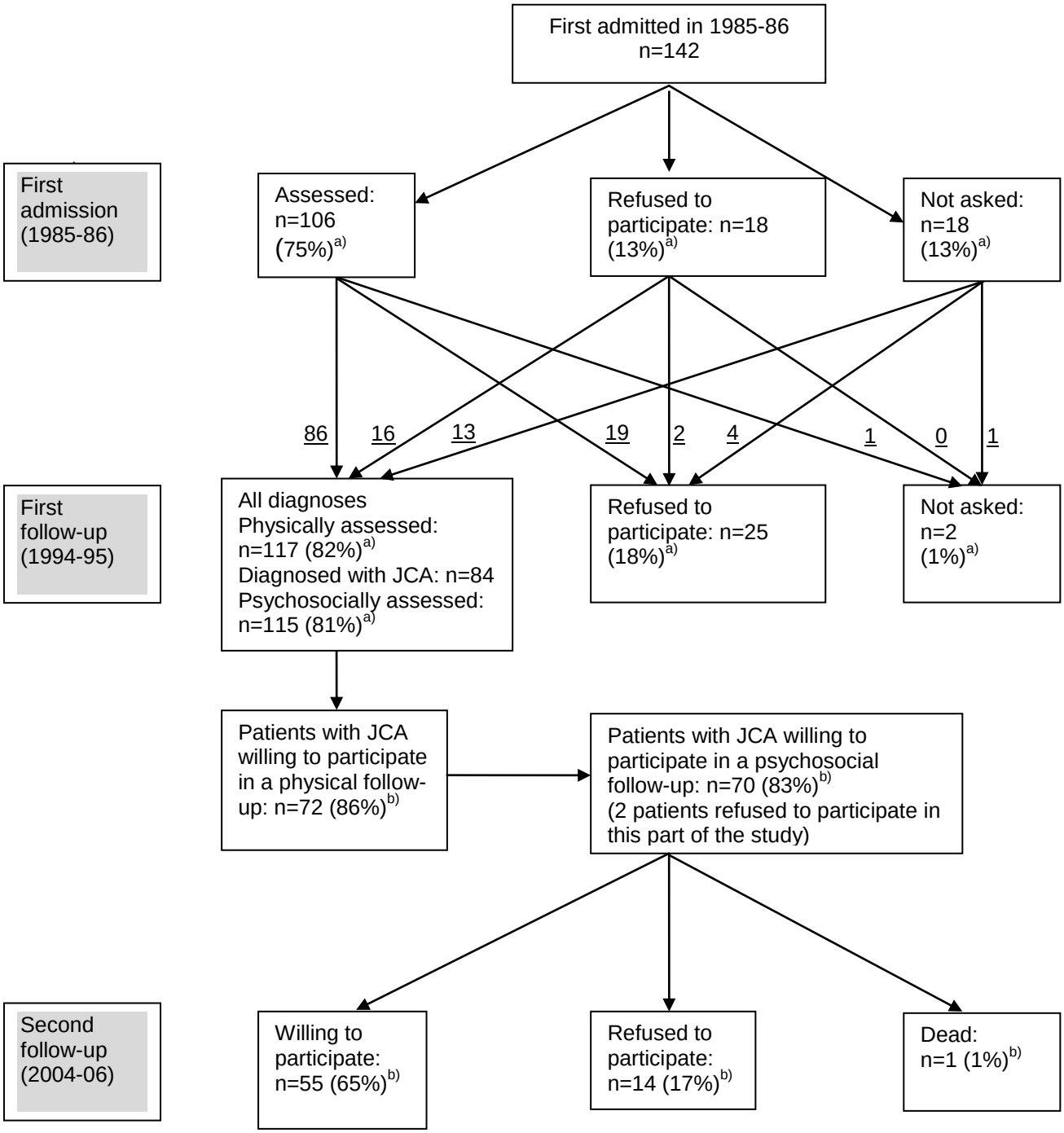
Telephone interviews were carried out after the respondents had returned the postal questionnaires (paper IV). Those who were willing to participate in a telephone interview had written down their telephone number on the sheet containing background data in the postal questionnaires. Fifty-one of the fifty-five patients were willing to participate.

In the qualitative interview study of the cohort (paper II), all the 45/55 patients who were willing to participate were informed about whether they were selected or not, and that they might be contacted in case of replacement if anyone withdrew. Three participants withdrew before the interview was to take place, and thus three matched informants were selected from the group of 45. The three who withdrew were too busy at work or felt it was too far to travel.

The cohort is considered representative for the population of people with JIA in Norway since all patients referred to the only paediatric rheumatology clinic in Norway during one year were included in the baseline study (Vandvik & Eckblad, 1991; Aasland, et al., 1997). The respondent rate at second follow-up was 65.5% of the 84 patients diagnosed with JIA at baseline, and 78.6% of the 70 patients who were inquired at second follow-up.

Together with the statistical tests performed the facts above indicate that the findings from the longitudinal and cross-sectional studies are generalisable to the Norwegian population of persons with JIA.

Figure 1. Participants at the first admission to hospital (1985/-86), at first follow-up (1994/-95), and at second follow-up (2004/-06).



a) In per cent of all patients admitted through the year 1984/-85
b) In per cent of the patients diagnosed with JIA

4.4 Data collection

4.4.1 Study 1

With regard to the focus group interviews, an interview-guide was utilised. Four main themes were discussed including: preparation for the transfer from a child-centred to an adult-centred health care system, experiences from hospitalisation in a children's ward compared to an adult ward, the transition process and care, suggestions related to the transition process, and other comments. Additional questions were asked in order to clarify the statements and get a deeper understanding of the questions explored.

The two investigators (ILØ and ØD) conducted the focus-group interviews. One investigator took the main responsibility for the interview process, while the other assisted. The focus-group discussions were all tape-recorded, and notes were made during the interviews. Immediately after each interview the investigators had a debriefing of the interview situation and made summary notes. The focus-group interviews had a different context for each interview whereas the adolescents were split into two groups by region, one group met in a hospital meeting-room in Oslo, the capital of Norway, while the other group met in a hotel meeting-room in a city in the western part of Norway. The two health professional groups met in a meeting-room in two different hospitals.

4.4.2 Study 2

One investigator (ILØ) conducted all the 15 interviews. An interview-guide was used to help the informants to remember events that had happened during the life-span under study. The main question asked the informants to tell how they had experienced life from JIA-onset and up till today. Additional questions were asked about special events at different age periods, the transition process from childhood to adolescence into adult life, education and vocation aspects, possibilities and limitations in daily life, body image, social and societal relations, changes during life, and additional comments. In order to clarify the statements and get a deeper understanding of the questions explored additional questions were asked.

The interviews were all tape-recorded while notes were made during and immediately after each interview. The qualitative interviews were conducted at Oslo University Hospital,

Rikshospitalet, Norway (for the long-distance informants), or in a neutral place close to their homes, or in their homes (if the informants preferred).

4.4.3 Study 3

Postal questionnaires for self-administration were employed. The questionnaires included the Health Assessment Questionnaire (HAQ) assessing physical ability (Fries, et al., 1982), Visual Analogue Scales (VAS) assessing pain, fatigue, and illness (Fries, et al., 1982; Wewers & Lowe, 1990), and General Health Questionnaire version 30 (GHQ-30) assessing psychosocial health (Goldberg & Williams, 1988). For comparison relevant data from the first follow-up study of the same cohort were obtained from Norwegian Social Science Data Services (NSD).

4.4.4 Study 4

In addition to the questionnaires employed in study 3, the questionnaire for self-administration SF-36 Health Survey was used to assess HRQL in the physical and psychosocial domain (Ware, 2000). Selected questions from the telephone interview including education, employment, use of health services during the previous year, and need of assistive equipment at work were employed. For comparison relevant norm-data from the general Norwegian population were obtained from Statistics Norway (SSB).

The Norwegian survey of living conditions is carried out on a regular basis by SSB in co-operation with leading Norwegian research- and administration-institutions (Statistics Norway, 2002). The survey is theme-rotating over time and covers the fields of employment, housing, environment and leisure, and health. Data from the employment and health modules of the Norwegian survey of living conditions in 2002 (Statistics Norway, 2002) were used for comparison with the SF-36 scores and the education and employment scores in study 4. From the survey sample of 6827 persons, 1196 sex- (female 60.5%) and age- (19-35 years) matched persons were randomly selected.

4.5 Measurements used

Assessment measures utilised at first (1994/-95) and second (2004/-06) follow-up used for comparisons at second follow-up are outlined in table 2. Study 1 and 2 had a qualitative design as they aimed at exploring experiences of certain phenomena. Thus, an interview-guide was developed for each study respectively to guide the interview process. The interview-guides were developed based on the investigator's clinical experiences from the field and referred studies. Drafts were discussed with colleagues and revised before interviewing the informants. The interview-guides had a few major themes based on the phenomenon under study, and some sub-themes to keep the interviewees on track during the interview process. The investigator asked additional questions to get a deeper understanding of the questions explored during the interview process.

Study 3 and 4 had a quantitative design, and postal questionnaires for self-administration were employed. Instruments used at baseline and first follow-up are described elsewhere (Flatø, et al., 1998; Vandvik, et al., 1989; Aasland, et al., 1997).

To measure physical ability the Health Assessment Questionnaire (HAQ) was used (Fries, et al., 1982). The patient's level of functional ability in eight areas is measured over the past week: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and common daily activities. For each item, there is a four-level difficulty scale that is scored from 0 to 3, representing no difficulty (0), some difficulty (1), much difficulty (2), and unable to do (3). Dependence on equipment or physical assistance increases a lower score to the level of 2 to more accurately represent underlying disability (Fries, et al., 1982). The validity and reliability of the questionnaire is proved acceptable in numerous translations and cultural adaptations (Bruce & Fries, 2003a, 2003b; Felson, et al., 1993; Flatø, et al., 1998; Wolfe & Pincus, 1999). At first follow-up, the HAQ was used for patients 18 years and older while the HAQ adapted for children (CHAQ) (Singh, et al., 1994), with scoring similar to the HAQ-DI, was used for patients under 18 years of age (Flatø, et al., 1998).

Pain, fatigue, and illness were measured by visual analogue scales (VAS) (Wewers & Lowe, 1990). The scale consists of a 100 mm doubly anchored, horizontal line, rated from the left

("no pain", "no fatigue" and "no illness" respectively) to the right end ("the worst pain", "severe fatigue" and "severe illness" respectively). The patient rates his/her assessment of the particular phenomenon over the past week on the scale. The VAS has been widely used in clinical everyday and in different research settings (Bruce & Fries, 2003a; Wewers & Lowe, 1990). At first follow-up, only the VAS scales for pain and fatigue were used (Flatø, et al., 1998).

To assess psychosocial health the General Health Questionnaire version 30 (GHQ-30) (Goldberg & Williams, 1988) was used. The instrument includes 30 items covering symptoms considered to reflect distress and psychopathology in five factor-analysed dimensions corresponding to anxiety, feelings of incompetence, depression, difficulty in coping, and social dysfunction over the past two weeks (Huppert, et al., 1989). The measurement can be used both as a screening test (Likert score) and to detect cases of psychiatric distress (Case score) (Goldberg & Williams, 1988). The validity and reliability of the instrument is proved acceptable in numerous translations and cultural adaptations (Goldberg & Williams, 1988; Malt, et al., 1997; Vandvik & Eckblad, 1991). At first follow-up, the Child Behaviour Checklist (CBCL) (Achenbach, 1991), Youth Self-Report (YSR) (Achenbach & Edelbrock, 1987), and the Hopkins Symptom Checklist (HSCL) 25-item version (Derogatis, et al., 1974; Nettelbladt, et al., 1993) were used (Aasland, et al., 1997). For all the tests general emotional state is measured and there have been estimated case cut-off scores indicating psychiatric distress in the clinical range (Achenbach, 1991; Achenbach & Edelbrock, 1987; Derogatis, et al., 1974; Goldberg & Williams, 1988). The GHQ-30 is considered more suitable and valid in samples of adult patients with physical illness since physical symptoms as indicators of distress are avoided (Goldberg & Williams, 1988). Therefore GHQ-30 was preferred in the second follow-up. To make comparisons of psychiatric distress possible we used the cut-off scores.

To get a view of HRQL, the SF-36 Health Survey was used (Ware, 2000). The questionnaire is not specific to any age, disease or treatment group and is extensively used internationally in measuring HRQL (Ware, 2003; Aaronson, et al., 1992). Two distinct components of health are measured over the past four weeks: the physical component summary scale (PCS) comprising the dimensions of physical functioning, role limitations due to physical health problems, bodily pain, and general health perceptions, and the mental component summary

scale (MCS) comprising the dimensions of vitality (energy and fatigue), social functioning, role limitations due to emotional problems, and general mental health (psychological distress and psychological well-being). The validity and reliability of the questionnaire are proved acceptable also in a Norwegian translation and cultural adaptation (Loge & Kaasa, 1998; Aaronson, et al., 1992). No comparable measure was employed at first follow-up of the cohort.

A questionnaire was developed for use in telephone interviews. The questionnaire included open-ended questions and alternative answers covering dimensions concerning physical and psychosocial health, and educational and socioeconomic status. The questionnaire was tested on three colleagues and revised before interviewing the patients by telephone. Data analysed for use in study 4 were confined to structured questions related to the level of education, socioeconomic status, use of assistive equipment at work, and use of health services the previous year.

Table 2. Assessment measures utilised at first (1994/-95) and second (2004/-06) follow-up used for comparisons at second follow-up

	Measures at first follow-up		Measures at second follow-up
Age/number	<18 years n=31	≥18 years n=41	>18 years n=55
Physical variables			
Disease activity	PGA	PGA	-
Physical disability	CHAQ	HAQ	HAQ
Pain	100 mm VAS	100 mm VAS	100 mm VAS
Fatigue	100 mm VAS	100 mm VAS	100 mm VAS
Illness	-	-	100 mm VAS
Mental and psychosocial variables			
Mental health	CBCL/YSR	HSCL-25	GHQ-30
	DSM-III-R	DSM-III-R	-
	CGAS	GAS	-
Life-span experiences	-	-	Patient interview
Family variables			
Chronic family difficulties	Parent interview	Patient interview	-

PGA=Physician's Global Assessment of Disease Activity, CHAQ/HAQ=Childhood or Adult Health Assessment Questionnaire, VAS=Visual Analogue Scale, CBCL=Child Behaviour Checklist, YSR=Youth Self Report, HSCL=Hopkins Symptom Checklist, DSM-III-R=the Diagnostic and Statistical Manual of Mental Disorders, 3rd ed., revised, CGAS/GAS=Children's or Adults' Global Assessment Scale, GHQ-30=General Health Questionnaire 30-item version

4.6 Data analysis

4.6.1 Study 1

The process of qualitative analysis was applied inspired by the transcript-based analysis outlined by Krueger (Krueger, 1994). The analysis includes 4 steps; 1) the first transcription from tape to text, 2) reading the entire transcribed text and writing down the main impressions from each interview, 3) systematising the data from each interview in emerging codes in a third transcription, and 4) coding and categorising the data. The two investigators (ILØ and ØD) analysed the text separately and then came together and tested the codes, and then the categories, always in close conjunction with the interview text to ensure consistency and concordance.

In steps 1 and 2, we used the interview guide systematically to organise the statements of the informants. In step 3, data in each transcript were coded crosswise of the interview guide themes, and lastly, in step 4, the coded data in each transcript were tested against the coded data in the other transcripts before being finally organised into unified codes. These codes were tested against each other and against the statements of the informants back and forth until the subcategories and the core category emerged. These categories are the expression of what the text tells, and the result of the study.

4.6.2 Study 2

In this study the process of qualitative content analysis was applied. Content analysis can be useful to identify core consistencies and meanings in qualitative data, and according to Graneheim and Lundman (2004) creating categories is the core feature of content analysis. Hsieh and Shannon (2005) define content analysis as “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (p.1278).

The process of analysis might be described as inductive category development and starts with a reading of all data to achieve immersion and get a sense of the whole and then write down the immediate impression (Hsieh & Shannon, 2005). Then, read each interview

transcript word by word to derive meaning units, codes, subcategories, and finally categories and themes (Graneheim & Lundman, 2004). Categories refer mainly to a descriptive level of content and represent the manifest content of the text, while themes represent the underlying meaning of the text on an interpretative level and might thus be an expression of the latent content of the text (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). The investigator analysed the text. Through the entire process the research team was involved by testing codes, categories and interview text against each other back and forth to ensure consistency, internal homogeneity and external heterogeneity (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005).

4.6.3 Study 3

Patients with JIA demonstrate great variations in disease manifestations individually and over time. Consequently the distribution of data might become asymmetric. For the asymmetric-distributed variables, central tendencies and dispersion were calculated as medians (min-max). Otherwise descriptive data were calculated as frequencies, proportions and means with standard deviations (SD). To describe the health status of the cohort at second follow-up, frequencies, means (SD), and medians (min-max) were employed. Correlations between variables at second follow-up and between first and second follow-up variables were tested by Spearman Correlation Rank Test. For comparisons of variables between first and second follow-up, differences between two unrelated groups were tested by Chi-Square Test for categorical variables, by Mann-Whitney U-Test for non-normal distributed variables, and by an independent sample t-test for the means. Differences within two related groups were tested by Wilcoxon Signed-Rank Test for non-normal distributed variables, and by McNemar Test for categorical variables. In all the analyses, limit values for significance were set at $p < 0.05$ (Field, 2005). The Statistical Package SPSS version 16 was used for all calculations.

4.6.4 Study 4

With a cross sectional approach the study focus was on the health status at the time of the second follow-up. The same challenges with asymmetric distributions were present. For

unrelated groups, the non-parametric tests of Kruskal-Wallis Test and Mann-Whitney Test were employed to test variations between age groups and variations between disease subtypes respectively. Categorical variables of unrelated groups were tested by Pearson Chi-Square Test. To test correlations between cohort variables, Pearson Correlation Coefficient Test was employed, and multiple linear regression forward analysis was used to assess predictors of HRQL. To compare variables of the cohort with variables of the general Norwegian population, Mann-Whitney U-Test was employed for non-normal distributed variables and Pearson Chi-Square Test for categorical variables. Limit value for significance were set at $p < 0.05$ in all of the analyses (Field, 2005). The Statistical Package SPSS version 16 was used for all calculations.

4.7 Ethical considerations

Ethical principles in science involve ethical conduct in the performance of research as well as ethical considerations with regard to the participants (Resnik, 1998; World Medical Association, 2000). Standards of ethical conduct in science include honesty, truthfulness and carefulness in all aspects of the research process, and openness and freedom should be warranted. Respect for the participants in the research process involves respect for the inherent moral dignity and basic rights of the individual (Resnik, 1998). The ethical principles of beneficence and non-malificence including voluntariness, confidentiality and integrity were applied.

Written informed consent was obtained from the participants in each study. The participants were informed that participation was voluntary; they could withdraw whenever they wished and have their contribution deleted without consequences for their need of health-care. Also, they were informed that all material is treated confidentially.

All the four studies are conducted in accordance with the Helsinki Declaration (World Medical Association, 2000) and approved by the Regional Committee for Medical Research Ethics in Norway. For the first study (paper I) no data registers were established: thus no approval by the Norwegian Data Inspectorate was required. However, the cohort studies (paper II, III, and IV) were approved by the Norwegian Data Inspectorate, and the Norwegian

Social Science Data Services (NSD) gave access to data from the first follow-up of the cohort to allow for comparisons at second follow-up.

In the interview situation there might be an imbalance between the interviewer and the interviewee with regard to position and power. The principles of autonomy and self-determination should be observed by the investigator in order to secure the rights of the participants. Furthermore, during the interview process as well as during the answering of the questionnaires, the participants might be confronted with their own limits and the sense of being a burden to their family (Kvale, 1997). In the postal questionnaire study it was not possible to discover any reactions of the respondents unless they made some notes on the document returned to the investigator. No such notes were made. In the interview situation, however, both in face-to-face and telephone interviews some had problems with talking about difficulties in life. Nevertheless, they insisted on continuing the interview, and felt it was good to be open about feelings and experiences. This is in line with Kvale's (1997) proposal that an interview can be regarded as a positive experience by the interviewee as the interviewer openly and interested is listening to what the person has to say for an extended period of time.

Ethical considerations should also include questions about compensation of the inconvenience the informants may experience. In the qualitative interview study, the participants were invited to an appointment with a rheumatologist, and they all received economic compensation for the visit to the hospital. A summary of the reported findings of the studies will be distributed to all the participants as indicated in the initial written information.

In the publication of the studies, confidentiality is of utmost importance in order to protect the participants from harm. It is the investigator's responsibility to observe the integrity and anonymity of the informants in the presentation of research findings. Furthermore, the investigator is responsible for keeping the person-identifiable data properly. Presented quotations may be recognised as identifiable to the individual informant; however, this might strengthen the trustworthiness of the data.

4.8 Validity and trustworthiness

In all scientific research, the presumptions of the investigator are put at stake. However, investigating established knowledge and truth is the nature and the commitment of all science. Within philosophy, three classical criteria of truth are outlined (Kvale, 1997). The correspondence criterion refers to whether a knowledge statement corresponds to the objective world. The coherence criterion is concerned with the consistency and internal logic of a knowledge statement. With regard to the pragmatic criterion the truth of the knowledge statement is related to its practical consequences.

In science, verification of knowledge is fundamental since it is supposed to serve as the basis for practice and for further development of knowledge. In both quantitative and qualitative scientific research approaches the concepts of validity, reliability, and generalizability are commonly used when discussing the trustworthiness of research findings (Kvale, 1997). The quality of the craftsmanship of research should be emphasised in all scientific work and should be addressed through the entire research process from the research question till publication of the research findings (Kvale, 1997).

In quantitative research approaches, the concept of validity refers to whether the instrument is actually measuring what is intended to measure, while reliability is concerned with whether an instrument will produce the same results when administered repeatedly to an individual in the same setting (Campbell & Machin, 1993). In qualitative research approaches, validity refers to the quality control through all the stages of the research process, while reliability is concerned with the consistency of the research findings, but also consistency through all the stages of the research process. With regard to generalizability, Kvale (1997) outlines three classic forms; naturalistic, statistical and analytic generalisation. Naturalistic generalisation is based on personal experience and tacit knowledge of how things are, statistical generalisation is formal and explicit, based on subjects selected at random from a population, and the analytic generalisation is based on an analysis of the similarities and differences in comparable situations.

In qualitative research other concepts have also been used to verify the trustworthiness of the research study; credibility, dependability and transferability (Graneheim & Lundman, 2004). Credibility refers to how well data and processes of analysis address the intended research focus. Dependability refers to the evolving process of new insight during the process of analysis and the degree to which follow-up questions and data change over time. Transferability refers to "the extent to which the findings can be transferred to other settings or groups" (Polit & Hungler, 1999, p. 177) .

The strength of qualitative research approaches pertains to the depth of data, namely the experiences as they are stated by the individual. This strengthens the content validity and, thus, the naturalistic and analytic generalizability of the research findings. The strength of quantitative research approaches is the quantity of data and the formal and explicit data analysis and statistical tests which strengthens the reliability and statistical generalizability of the research findings (Kvale, 1997).

In the present thesis the research team, including the doctoral student and the two mentors, were involved in the design and carrying out of the research process of all the four studies to ensure quality through all the stages of the work. The researchers from baseline and first follow-up add to the validity and reliability of the second follow-up study. Vandvik (1991), Aasland (1998) and Flatø (1999) were all involved in the design of the second follow-up study, and the latter two have been co-authors in the longitudinal and the cross sectional studies (paper III and IV).

The presumptions of the investigator were discussed at different stages and the accuracy through the processes of analyses was related to the original interviews back and forth to ensure consistency (paper I and II). The questionnaires employed (paper III and IV) are internationally acknowledged and well-known instruments used for self-assessment in the general population as well as in young people with chronic diseases (Fries, et al., 1982; Goldberg & Williams, 1988; Ware, 2000; Wewers & Lowe, 1990). Reliability and validity are proved acceptable and Norwegian translations of the instruments have been used in several studies (Loge & Kaasa, 1998; Malt, et al., 1997; Uhlig, et al., 2006). Fifty-five patients (65.5% of the original 84) responded to postal questionnaires on self rated health. The non-

responders both at first and second follow-up were comparable to the participants at second follow-up with regard to sex, age, disease duration, number of active joints, and physician's global assessment at first follow-up (Flatø, et al., 1998). Thus the cohort under study is regarded representative to the Norwegian JIA population.

5 Summary of results

5.1 Study 1

Transition and transfer processes in adolescents with JIA were focused in the first study, which was regarded as a pilot study to investigate whether these issues represented any challenge in Norwegian health care. The method of focus-group interviews was chosen to obtain perceptions on transition in health care from participants who had this issue in common, although from different points of view; two groups of youths suffering from JIA and two groups of health professionals providing care for JIA patients in a child- and an adult ward respectively (Krueger, 1994).

The findings indicate that although the participants had common goals, they did not have common plans for reaching their goals. The emerging subcategories 'being enabled' from the adolescent's point of view, and 'enabling the young patients' from the health professionals' perspective constituted the core category 'capability to lead a meaningful adult life'. The core category might be seen as a goal on the road to becoming autonomous and responsible adult citizens.

From the adolescents' point of view, reaching developmental tasks and milestones like their peers was critical, as well as belonging to the peer group. The adolescents claimed that knowledge and competence are prerequisites for social autonomy, and that having a job is vital for social belonging in adulthood. They stated that they experienced support from parents and health professionals in order to develop autonomy and responsibility with regard to their health and future life. However, obstacles on the road were the fluctuating disease and the therapeutic needs limiting activity and participation, but also over-protecting parents and health professionals and a lack of transition-focused care.

From the health professionals' perspective, disease-caring responsibilities were central, while developmental milestones and psychosocial consequences of the disease were less emphasised, even less in adult health care. The health professionals stated that each health worker discussed relevant transition issues more informally, although in adult ward they stated that the transitional care was scarce. Both in child- and adult ward the health

professionals had the intension to provide care relevant to the adolescents. However, there seemed to be a common experience that the care provided suffered from a here-and-now focus, a random follow-up of adolescent developmental needs, and an inadequate formal preparation for the transition process and the transfer to adult health care. Obstacles to the health professionals' efforts were the lack of formal collaboration or unified practice, inadequate cross-professional and cross-institutional communication and documentation, and lack of competence on adolescent developmental issues.

Several gaps were identified. The health professionals and the adolescents had divergent experiences of the care provided and received. Also, the cultures in child- and adult health-care systems appeared divergent; the child health care had a holistic and familial approach while the adult health care appeared more impersonal and organ-focused.

5.2 Study 2

The purpose of this study was to get a deeper understanding of the meaning of living with JIA in a life-span perspective. The study is part of a second follow-up of a cohort of patients with JIA 18.3 years after symptom onset. The time span investigated included the time from symptom onset until the time of the interview, ranging from 17-29 years. Overall, there were obvious individual variations in the informants' experiences and perceptions. Furthermore, within the individual the experiences varied according to developmental processes, disease fluctuations, and time course.

The meaning of living with JIA was found to be struggle and adjustment to an insecure everyday life and an unpredictable life course. Three categories including the body, relationships and the self, illuminated the paradoxical meaning of living in constant struggle and adjustment. The bodily experiences of limitations or freedom were consequences of a suffering or well-functioning body and an unpredictable or stable course of the disease. Being acknowledged or set aside in interpersonal relationships were consequences of the experiences of being devoted or abandoned, being believed or mistrusted, and the feeling of loneliness or closeness. Intrapersonal experiences of insecurity or confidence were

consequences of perceiving the disease as a loss or a value, struggling against or along with the disease, and perceiving low self-esteem or a positive self-image.

The informants were struggling to overcome the impact of the fluctuating disease in order to achieve a normal life on the same conditions as their peers. Simultaneously, they were struggling to adjust to the everyday insecurity and the consequences of the disease in order to obtain emotional balance. Additionally, they had to cope with the ambivalence of being in the liberation process and at the same time being dependent on personal assistance to a varying extent. The complexity of these processes appeared demanding on the individual over time, and challenged the individual's self image.

Experiences of loss and changes in functions and relationships caused a great deal of resistance and struggle in childhood and early adolescence. The findings indicated a change to greater acceptance and adjustment over time. However, the perception of being inadequate and different seemed to persist. Insecurity about the future course of the disease seemed more prominent in adult years.

5.3 Study 3

The focus in this study was the longitudinal perspective on physical and psychosocial health in the cohort from first to second follow-up. At second follow-up the cohort, including 55 (65.5%) of the 84 patients diagnosed with JIA persistently showed favourable physical and psychosocial outcomes as reported at first follow-up (Flatø, et al., 1998; Aasland, et al., 1997).

At second follow-up, 21 of the participants (38%) reported HAQ-DI >0 indicating physical disability to a certain extent, 12 (22%) reported GHQ-30 case score of 5 or more indicating psychiatric distress within the clinical range, and on the VAS scales scores of 10 or more were reported by 26 (47%) of the participants on illness, 27 (49%) on pain, and 33 (60%) on fatigue respectively indicating an experience of illness, pain, and fatigue to certain extents. The correlations between physical disability by HAQ-DI, and pain, illness and fatigue by VAS, showed significant values indicating a close relation between physical disability, pain,

fatigue, and illness. Furthermore, VAS pain and fatigue were significant correlates of psychiatric distress by GHQ-30 case score indicating a close relation between psychiatric distress, pain and fatigue.

When comparing variables from first to second follow-up, no significant change in physical disability, pain or fatigue was found. However, individually eight participants (14.5%) improved while six participants (11%) deteriorated as reported by HAQ-DI, of whom five and four were females respectively. VAS fatigue score tended to be higher at both times compared to VAS pain. Although the descriptive statistics showed tendencies of differences when comparing disease subtypes or sex from first to second follow-up, no significant differences were found.

When comparing psychiatric distress at first and second follow-up, no significant changes were found, neither when comparing psychiatric distress at second follow-up with physical and psychosocial functioning at first follow-up nor number of chronic family difficulties at baseline and first follow-up respectively.

Although favourable physical and psychosocial outcomes persist, arthritis related ill-health is still evident in a considerable proportion of the participants, and fluctuations and residua contribute to consequences that might have considerable impact on the individual, and thus of major importance to unveil in clinical practice.

5.4 Study 4

The focus of the last study was self-rated physical and psychosocial health at second follow-up of the cohort. Correlations were performed to explore associations between physical and psychosocial variables and to determine self-rated HRQL within the cohort. Comparisons to Norwegian norm-data were employed with regard to HRQL by the physical and mental component summary scales of SF-36, level of education, and employment status.

Significantly impaired physical health was found in the cohort as compared to the general Norwegian population, while no difference in psychosocial health was found. The

educational level was significantly higher in the cohort, with a significant contribution by cohort females compared to females in the norm-data. No difference was found in employment status.

Physical disability and pain were the independent variables of significant influence on the average variation of physical impairment, while the independent variables of psychiatric distress and female sex significantly influenced the average variation of impairment in the mental domain of HRQL. Increase in physical disability was associated with decrease in psychiatric distress.

6 General discussion

This thesis is a study on living with juvenile idiopathic arthritis in a life-span perspective. We investigated a group of young people with JIA and related health professionals working in a child and an adult hospital setting respectively, and a cohort of patients with JIA, 18.3 (17.0-28.9) years after symptom-onset. Our main findings in the cohort were the patients' perceptions of life over time as a constant oscillation between struggle and adjustment to the consequences of the disease and its fluctuating nature, and persistent favourable physical and psychosocial outcomes from first to second follow-up. Furthermore, inadequacies in the care provided for young patients with JIA in the transition process from child- to adult-centred health services were identified.

In the following, the findings will be discussed with special reference to the patients' perceptions of life with JIA over time and the persistent favourable physical and psychosocial outcomes. Subsequently, persistent chronic childhood disease into adulthood will be discussed in a public health perspective.

6.1 Juvenile idiopathic arthritis in a life span perspective

6.1.1 The patients' perceptions of life with JIA over time

The patients experienced a complexity of challenges pertaining to the physical body, interpersonal relationships, and intrapersonal perceptions. The dynamics in life experiences emerged as dichotomies on a continuum individually and over time.

Möller and Nyman (2003) propose that four complex aspects form the human's development over time, namely individual, relational, structural, and life events. The individual factors, such as physical and psychological dimensions include the anatomy and functioning of the body, constitution, and personality. The relational factors include the individual's interplay with parents, siblings, relatives, and subsequently, significant others. The structural factors constitute society, including educational institutions and health and social services. Finally, life events are conditions and incidents of vital importance for life and developmental processes. The experiences of the young people investigated are memories

with historical aspects of this complexity, also influenced by present life and future expectations (Good, 1994). Moreover, life with JIA is a constant reflection of this complexity.

Acquiring JIA may entail a dramatic change in the entire life of the child and the family. For the child the disease implies experiences of pain, fatigue, and illness that may limit participation and activities physically and socially in various situations. From the parents' perspective their roles and obligations within and outside the family may be influenced. Also, the environment may be affected as considerations must be taken with regard to school, job, leisure, and social activities. According to Möller and Nyman (2003), this major life event and the interplay within the social context has a vital impact on the development of the child and adolescent over time.

In the cohort the disease occurred during childhood, between 1-16 years of age. High rates of physical and psychosocial distress including chronic family difficulties were demonstrated in the baseline study. However, improvement in the family situation was found at first follow-up as well as an increase in family closeness and a high level of co-operation between parents (Aasland, et al., 1998). This is in line with findings at the second follow-up where the informants experienced the parents as seriously concerned and involved in the disease follow-up even into adulthood (paper I and II). This closeness may have had positive consequences for the patients' self-value during childhood and early adolescence. However, in later adolescence family closeness may endure at the expense of the independence of the adolescent, and thus impair the adolescent's competence to manage life and health.

In childhood, relations outside the family with peers and friends gradually develop, and participation in physical and social activities becomes increasingly important. Physical limitations due to the disease limited the young persons' ability to participate and obstructed the development of peer relations. This may explain the experiences of loneliness and loss and the insecurity of being believed or mistrusted as described in study II. Also, this may have influenced the self-image as weak and inadequate that persisted into adulthood to a various extent.

School and regular contact with the health-care system were central issues in the everyday life of the child and adolescent. A closer co-operation between the health-care system, home, and school may have lead to better solutions with regard to participation in school gymnastics and leisure activities and thus limited the experience of being placed on the sidelines. Various fellow-patient gatherings seemed to be of great importance for most of the informants and should be encouraged. The prospects of experiencing closeness and similarity, feeling safe, and learning life and health management skills together with equals may improve the individual's self-perception and coping abilities.

From a transitional point of view, the young people were exposed to developmental processes involving changes and demands pertaining to body appearance and health status, physical and mental capacity, role relationships, expectations, and abilities (Meleis, 2005; Meleis, et al., 2000). Simultaneously the adolescents had to cope with an unpredictable and fluctuating disease of remissions and exacerbations, often with invisible burdens such as pain, fatigue and vision impairments, and the anticipation of an insecure future. In this state of transition decisions had to be made on education and vocation. Consultation was not always available or appropriate, and for several informants absenteeism was a prominent problem with regard to education and work situation. Competent education counsellors should be provided in order to assist the individual's decisions, and openness with regard to absenteeism should be encouraged.

As they grew older, the young adults realised that they were not as different and abnormal as they experienced during childhood and early adolescence. In spite of limitations pertaining to activity and participation they seemed to develop maturation in acceptance and adjustment. Protest and denial declined and a sense of self-value improved. The less severe course of the disease may also have had a positive impact on the young adults' perceptions of life. This seems to be in line with Folkman (2001) who highlights the importance of positive affect in coping processes. Also, the mental and cognitive maturation through adolescence may help the young adults to adjust to their life situation (Christie & Viner, 2005).

To a certain extent the young adults considered life as satisfactory and meaningful beyond pain and struggle. They experienced fewer struggles against the disease, they had enlarged their activity register, established lasting relationships outside the childhood family, established intimate relationship, and several had their own family. Moreover, they were studying or had completed their education and most of them were in paid work. Accordingly, they were not socially different although the disease still had an impact on everyday life.

Throughout life attachment, interplay, and experiences of activity and participation physically and socially are fundamental to human life in accordance with the developmental stage of the individual (Carlsson, et al., 2000). The model of adjustment to chronic illness proposed by Sharp and Curran (2005), may be a reasonable frame to understand the processes that have resulted in satisfaction with life to a certain degree among the informants. Considerations and reconsiderations about the disease and its impact on everyday life, re-definition of what are successful coping strategies, and reconsiderations of the self and the world are aspects in the process that according to Sharp and Curran (2005) may result in adjustment to the chronic illness.

The adjustment model proposed by Sharp and Curran (2005) is in line with the holistic concept of health proposed by Pörn (2000) who describes health as the constitution of the individual's goals of life, repertoire of actions, and the surrounding environment and circumstances. Nordenfelt (2000) criticises this concept as a concept of health as adjustment. Nordenfelt (2000) rather conceptualises health as the realisation of all the individual's vital goals, given standard circumstances. Thus, satisfaction with life may depend on whether there is concordance between the individual's goals and expectations and his/her experiences of life.

This holistic perspective on health may be mirrored in the self-administered health questionnaires representing an immediate view of the informants' self-assessment. The findings indicate that although their physical health was impaired, the informants reported mental well-being similar to that of the Norwegian population (paper III and IV).

6.1.2 Physical and psychosocial outcomes at second follow-up

At baseline, the first admission to hospital with suspected or definite disease, high rates of physical and psychosocial distress were reported (Vandvik, 1990; Vandvik & Eckblad, 1991). However, at first follow-up significant improvements were reported in physical as well as mental health and psychosocial functioning (Flatø, et al., 1998; Aasland, et al., 1997). The understanding of the persistent favourable outcomes at second follow-up may be based on the explanations at first follow-up. The authors of the first follow-up study concluded that a cohort sample less skewed towards severely diseased patients and the use of more aggressive treatment regimes were probable explanations of the favourable physical outcome (Flatø, et al., 1998). This is in line with Ravelli (2004) who claims that selection bias towards more severe cases is a major problem when comparing different JIA-studies. Furthermore, Ravelli (2004) proposes that the therapeutic advances have markedly improved the prognosis of the disease . In a comparison of studies before and after 1991 Ravelli (2004) demonstrates a decline in the frequency of patients with severe physical disability, although the proportion of patients who enter adulthood with active disease seems to persist. Most remissions occur within 5 years after disease onset, and the probability of remission decreases progressively after that time (Oen, 2002). A few studies have applied a recently developed set of criteria for clinical remission in JIA (Wallace, et al., 2004), and demonstrate that only a few patients with JIA will remain in long-term remission status without medication (Ravelli & Martini, 2006).

The improvement in disease severity due to therapeutic advances may be an explanation of the persistent favourable physical outcome at second follow-up, although we did not investigate the therapeutic regimes of the cohort patients. Nevertheless, our findings indicate persistently active disease or disease residua in a considerable proportion of the patients since we found significant impairment in the physical domain of HRQL by SF-36 compared to the general Norwegian population and physical disability by HAQ among 21 (38%) of the patients. Furthermore, a considerable proportion of the patients reported pain, illness and fatigue above 10 on the VAS scales (1-100). Physical disability by HAQ and pain by VAS were significant predictors of impaired physical functioning.

The unpredictable nature of the disease is of great concern: in whom or when exacerbations occur, and the severity of the exacerbations. Also, the less obvious consequences of prolonged systemic inflammation and the treatment: cardiovascular diseases, osteopenia, and decreased fertility may occur (Sullivan, 2005). This is not investigated in the current study; yet, such consequences may have influenced the patients' health perceptions.

Also, the psychosocial outcome seemed to be persistently favourable from first to second follow-up. The high rates of psychopathology and chronic family difficulties early after disease onset had improved significantly at first follow-up (Aasland & Diseth, 1999; Aasland, et al., 1997), and the association between psychosocial functioning and chronic family difficulties observed at first follow-up was not evident at second follow-up. Moreover, no association was found between psychosocial functioning and disease severity as assessed by the physician at first follow-up or by self-assessment of physical disability at second follow-up.

However, at second follow-up there seemed to be an association between psychosocial functioning, pain and fatigue. This may reflect the longstanding chronicity of the disease, although the disease seemed to be less severe. Studies among patients with rheumatoid arthritis (RA) show high rates of fatigue, and one of the strongest independent predictors of fatigue was pain (Wolfe, et al., 1996). Furthermore, fatigue seems to be the most disturbing symptom besides pain among patients with RA (Repping-Wuts, et al., 2008). Loge et al. (1998) found that disabled people and people with health problems reported more fatigue as compared to people who were working or in good health. Sällfors et al. (2004) found that pain is a robust predictor of well-being in young people with JIA, and that pain controls the children's lives and restricts participation in social life (Sällfors, et al., 2002).

As pain and fatigue are persistently evident in the young adults, it may be an association with psychiatric distress. Zautra et al. (2007) have found dynamic relationships between depression, stress, and pain among patients with RA. Strand et al. (2006) found that positive affect is most influential in reducing negative affect during weeks of higher pain among patients with RA and may be a factor of resilience, helping patients experiencing pain fluctuations as less distressful than at lower levels of positive affect. This is in line with

Folkman (2001) who highlights the importance of positive affect in coping processes, as mentioned above.

Nevertheless, at second follow-up, mental health and psychosocial functioning seemed to be similar to the general Norwegian population (paper IV). Some informants stated that it might be easier to adjust to a chronic condition acquired in childhood compared to chronic conditions acquired in adult life (paper I and II). Changes in developmental stages and increased ability to cope with the disease may have influenced the persistent favourable psychosocial outcomes at second follow-up. Also, during childhood young people are more dependent on their families, and thus they are more vulnerable to family difficulties. As they grow up, the family becomes less important in young people's lives, and thus the young people might be less influenced by family difficulties. However, overprotected adolescents may experience difficulties in developing independence from family, and thus be more vulnerable to the challenges and demands they are facing as young adults.

The cohort is aged 19 to 36 years: thus they are in the establishing or settled phases of life occupied with education and employment, social and intimate relations, and children and family obligations. For the females with JIA, pregnancy and child birth may be of great concern due to necessary changes in medication in advance of conception and the fact that the disease course may change for the better or worse during pregnancy and the time after delivery.

The educational level was significantly higher, and there is no difference in employment status as compared to the general Norwegian population. This may demonstrate the attitudes of the young people who claimed that knowledge and competence are prerequisites for social autonomy, and that having a job is vital for social belonging in adulthood (paper I).

Other studies show conflicting results in mental health, psychosocial functioning, level of education, and employment rates. This might be due to methodical and cultural differences, advances in treatment regimes, and variations in groups investigated owing to the nature of the disease.

In spite of a chronic disease accompanied by pain, fatigue and unpredictability, and a significantly lower physical functioning, the young people in the cohort demonstrate a rate of psychiatric distress similar to the general Norwegian population. In addition to the model of adjustment to chronic illness proposed by Sharp and Curran (2005), the concept of response shift may illuminate this fact. Response shift denotes a "re-calibration" of the person's perception of his/her situation with regard to what has value and meaning in life inherent to the process of adjustment to the chronic condition (Schwartz, et al., 2004; Sprangers & Schwartz, 1999). Such changes in internal standards, values, and the conceptualisation of life quality may be an explanation as well as comparisons to others who are more severely diseased. Indeed, as they grew older and became more aware of other people, some participants stated that no one passes through life without adversities or problems.

6.2 Persistent chronic childhood disease into adulthood in a public health perspective

The public health perspective includes both an individual level and a group and society level. Chronic childhood disease through adolescence into adult life implies these perspectives.

Generally, chronic childhood diseases affect the whole family and the environment, such as school and leisure activities, and health- and social services. The demands on the parents and siblings may be major and cause strains on the relationships (Möller & Nyman, 2003). Chronic childhood conditions, either congenital or acquired, may have many issues in common. Recognition of the fact that children and adolescents are just children and adolescents is imperative. Young patients face the same challenges of developmental transition and achievement of developmental milestones while simultaneously struggling with consequences of a chronic disease. Variations in the disease course, due to the nature of the disease and/or developmental changes, seem to accompany many of the diseases (Boekaerts & Röder, 1999; Boice, 1998; Stam, et al., 2006). This unpredictability may entail problems pertaining to participation in everyday life and social relations as well as

absenteeism related to school and work with consequences for educational achievements and job-keeping.

Irrespective of the chronic disease and its consequences, patient information and education are central rights for the patient and the parents (Norwegian Ministry of Health, 1999b), but also central responsibilities for the health professionals, according to Norwegian law (Norwegian Ministry of Health, 1999a). In the beginning mostly the parents might be informed, dependent on the child's condition and developmental stage. However, gradually the child should be involved in order to develop skills needed to maintain health and manage life with a chronic disease (Ansell & Chamberlain, 1998). Information appropriate to the child's developmental stage should be provided.

Transition through adolescence combined with an unpredictable chronic childhood disease is considered a tumultuous and demanding period of life and a unique challenge of communication and health management (Suris, et al., 2004). Adolescent development involves all domains of the life-course. Achieving developmental milestones is considered critical to the identity-forming and socialising processes (Erikson, 1992; Harter, 1990). For many young patients the meaning of fellowship with fellow patients should not be underestimated as well as relationships with healthy peers, since peers are critical in socialising processes during adolescence.

Differences in culture, knowledge and clinical practice between child and adult health-care services are well known and represent challenges for both patients, families, health professionals, and health-care managers (Viner, 1999). Recognition of these challenges among health-care managers is required to convey interdisciplinary education, co-operation and planning. In view of the need to develop and maintain organisational structures and professional competence on adolescence and adolescent needs professional education and health transition programmes should be emphasised. Preparation for the transition in health care should be of great concern to provide comprehensive processes for the young patients with regard to health care and disease management. This should also include educational and vocational counselling, arrangement of assistive equipment and time schedule modifications as well as counselling with regard to absenteeism at school and work.

Adolescent health is a focused issue in public health in order to prevent life-style diseases and injuries and promote health in a tumultuous period of life and thus avoid the risk of illness later in life (Patton & Viner, 2007; Viner & Macfarlane, 2005). Adolescents with chronic conditions should be included as a target group of health-promotion efforts, and special attention should be paid to the special needs for the individual adolescent to promote continuity in life, well-being physically and psychologically, and in socioeconomic matters, and thus promote good quality of life for the individual.

6.3 Methodical considerations

The most prominent strengths of this study are the length of the follow-up, the multidimensional measures employed, the patients' self-assessment of health, and the availability of comparable measures utilised at first and second follow-up. Also, the prospects of individual and group interviews enabling the interviewees to in-depth reflections contribute to shed light on the questions under study.

The data were collected by focus-group interviews in the first study (paper I), qualitative interviews in the second study (paper II), self-administered questionnaires and comparison of the cohort over time in the third study (paper III), and finally, self-administered questionnaires and comparison between the cohort and Norwegian norm-data in the fourth study (paper IV).

This combination of qualitative and quantitative approaches may be controversial, but rather it is a question of attitudes and decision on a scientific philosophical level. With a pragmatic utilitarian attitude toward methods as research tools, application of methods should be according to the research question and thus provide an illumination of the phenomenon from a wider perspective. This might strengthen or weaken associations and contribute to the wholeness of the phenomenon under study, thereby strengthening the validity of the research findings (Malterud, 2001; Mays & Pope, 2000).

Interestingly, there seemed to be discrepancies between the inquiries and the interviews. The favourable outcomes physically and psychosocially found in the inquiry-studies (paper III and IV) did not convincingly reflect the experiences and perceptions of struggle and adjustment that emerged from the interviews (paper I and II), and yet the interview-findings were supported by the health professionals (paper I). The triangulated understanding of the findings involves a deeper and wider perspective on what it means to live with JIA in a life-span perspective. The interviews illuminate what the processes of struggle and adjustment are about, while the inquiries demonstrate the immediate assessment of the physical and psychosocial health status. Overall, the findings may indicate a search for emotional balance in the individual's life through adjustment processes.

At the time of the interview, in the pilot study (paper I) as well as in the cohort study (paper II), the informants were at different stages of developmental transition. Recall bias could constitute a problem. However, through the dialogue the memories could be clearer to the person concerned. Moreover, memories in individual life stories are central in a life perspective inasmuch as memories both influence how people manage life at present, and are also formative for the present life. Moreover, memories are in dynamic relations to people's expectations about future life, especially when life is experienced as unpredictable (Good, 1994; Kvale, 1997).

The data collected in the pilot study (paper I) and among the cohort (paper II-IV) involves a dispersion of age, life situation, and social situation, and thus includes a varying self-concept among the participants. This might contribute to variations in the data collected. Also, the fact that only one male participated in the pilot study (paper I), may have influenced the findings and the inference, as current knowledge indicates that males value physical ability and functioning while females value psychosocial functioning and well-being in life (Helman, 1994; Östlin, 1996). However, findings from the pilot study (paper I) seem to be in concordance with findings in the interview study (paper II). Furthermore, the disease is variable and fluctuations may have influenced the perceptions and self-assessment of the individual. Moreover, the patients may have acquired methods and techniques enabling self-sufficiency to a great extent in spite of physical impairment. Whether the patients have adjusted to their impairments or the impairments have become more distinctive compared

to healthy peers and thus have influenced their self-perception, may have had an impact on the patients' self-assessment. These facts may also have influenced the comparison of health status of the cohort over time.

The sensitivity and responsiveness of the questionnaires utilised in the cohort study might be questioned since the majority of the patients were in the healthy part of the scales. This may be due to the general improvement in disease severity. However, the skewed scoring might be an effect of response shift and adjustment to the life situation and thus allow the patients to maintain homeostasis in self-rated health despite physical deterioration (Schwartz, et al., 2004; Sprangers & Schwartz, 1999).

The validity and reliability of the questionnaires employed were proved acceptable in numerous translations and cultural adaptations, also the Norwegian. In order to make comparisons over time, the researchers were to a certain extent bound to the questionnaires employed at first follow-up. The involvement of the researchers from baseline and first follow-up add to the validity and reliability of the second follow-up study. Vandvik (1991), Aasland (1998) and Flatø (1999) were all involved in the design of the second follow-up study, and the latter two have been co-authors in the longitudinal and the cross sectional studies (paper III and IV).

With regard to the findings in the qualitative studies (paper I and II) the concept of transferability might be more suitable and replace the concept of generalizability (Graneheim & Lundman, 2004; Polit & Hungler, 1999). In this thesis it might be reasonable to consider adolescent development and health transition processes as overarching the nature of JIA (McDonagh, 2008). Thus the findings may be transferable to adolescents suffering from other chronic childhood conditions.

7 Conclusions, clinical implications and further research

7.1 Conclusions

The focus of this thesis has been the life-span perspective on living with JIA from childhood through adolescence into adult life. Through analysis-triangulation the research question is illuminated in a width and breadth that provides a triangulated understanding of the findings, i.e., what it means to live with JIA physically, psychologically and socially in the perspective of developmental transition into adulthood.

1. The adolescents experienced support from parents and health professionals in order to develop autonomy and responsibility with regard to their health and future life. However, provision of transitional care for the adolescents very much depended on the individual health workers' interest and involvement in the adolescents' multidimensional transition.
2. Through childhood and early adolescence pain and illness obstructed physical activities and participation with peers. The children reacted to the limitations with protest and denial as they wanted to be like their peers. The experience of being on the sidelines caused a sense of loneliness and loss of self-esteem.
3. In later adolescence and young adulthood, the informants obtained a broader spectrum of activities and social relations and they experienced social belonging to a greater degree. At the same time there seems to be a decrease in struggle while adjustment to the persistent limitations in physical functioning is increasing. However, the self-image as weak and inadequate seems to persist into adulthood to a various extent.
4. The fluctuating course and often invisible symptoms complicated the interpretation of the disease and caused insecurity pertaining to everyday life planning and being believed and also pertaining to future expectations.
5. Family closeness may have had a positive effect on the young persons' self-image through childhood and early adolescence, but may have obstructed the development of autonomy and independence in later adolescence and early adulthood.
6. From first to second follow-up the cohort demonstrated persistent favourable outcomes in physical and psychosocial functioning.

7. Cross-sectionally the cohort demonstrated that physical disability and pain were significant predictors of HRQL in the physical domain, while psychosocial functioning and female sex were significant predictors of HRQL in the mental domain. Psychosocial distress may be associated with disease marginality and invisibility, but not with manifest physical disability.
8. As compared to the general Norwegian population, the cohort reported significantly lower rates of HRQL in the physical domain, but not in the mental domain, and a significantly higher level of education, while the employment status was similar.

7.2 Clinical implications

The persistent experience of an insecure everyday life and an unpredictable life course remind us that although the disease severity has declined the disease is still present to a various extent and impacts the individual's health and quality of life. Moreover, the individual may have obtained emotional balance through adjustment processes and thus demonstrate favourable psychosocial functioning. However, the implications of the disease on everyday life and the persistent unpredictable course of the disease should always be kept in mind in the clinical practice.

With regard to the first study, the findings contributed to the development of a transition-focused program at the Centre of Child Rheumatology, Department of Rheumatology, Oslo University Hospital, Rikshospitalet, Norway during 2004/-05. Moreover, in 2005 a cross-professional group developed guidelines regarding the transfer from child care to adult rheumatology clinics. These guidelines were distributed to participants from general children's wards and adult rheumatology clinics on a national conference for health professionals arranged by the Department of Rheumatology, Rikshospitalet in the spring 2006.

However, in order to develop and maintain transitional care for adolescents with JIA and other chronic childhood conditions it seems urgent to focus on organisational systems and professional competence. The increasing proportion of young people with chronic conditions surviving childhood requires the establishment of systems and competence to provide

services that enable the adolescents to manage life as adults. Recognition of the needs of adolescents with chronic childhood conditions is urgent in order to maintain normal growth and development and promote health according to the aims of the World Health Organisation (1998).

7.3 Further research

Over the past 40 years an increasing number of long-term outcome studies on JIA have been reported. Mostly the studies have focused on traditional disease-centred outcomes including physical disability, clinical remission, and radiographic damage (Ravelli, 2004). However, increasing attention has been paid to how the patients experience and manage life with JIA in a broader perspective (LeBovidge, et al., 2003; McDonagh, 2008; Stinson, et al., 2008; Sällfors, et al., 2004; White, 2008), adolescent health generally and related to the variety of persistent chronic childhood conditions (Betz, 2004; Boekaerts & Röder, 1999; Geenen, et al., 2003; Healy & Rigby, 1999; Michaud, et al., 2007; Yeo & Sawyer, 2003).

Nevertheless, many questions about growing up with JIA and other chronic childhood conditions still remain unsolved, and continual improvements with regard to therapy regimes early in the disease course lead to the need of regular repetition of investigations in long-term outcomes from multidimensional perspectives.

It would be of great interest to investigate health professionals' role with regard to health promotion among adolescents with chronic childhood diseases, in hospital as well as in primary health-care settings, and whether interventions of supportive programmes for parents of chronic diseased children are beneficial.

Research on comparable chronic childhood conditions with regard to coping and adjustment processes would be of great interest. Moreover, how the course of chronic childhood diseases impacts on physical and psychosocial health and quality of life in later adulthood.

In a rehabilitation perspective, barriers in society are of great interest; do people with JIA have access to the facilities of the society with regard to educational institutions, health care

systems, public transport, internet technology, and public buildings? Furthermore, possible barriers with regard to employment should be investigated. Also, effective solutions on the problem of absenteeism in education and employment settings should be a target of research. In this respect attention to the experiences and knowledge of the patients is imperative.

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1983

1983:1 Hälsa för alla i Norden år 2000. Föredrag presenterade på en konferens vid Nordiska hälsovårdshögskolan 7–10 september 1982.

1983:2 Methods and Experience in Planning for Family Health – Report from a seminar. Harald Heijbel & Lennart Köhler (eds).

1983:3 Accident Prevention – Report from a seminar. Ragnar Berfenstam & Lennart Köhler (eds).

1983:4 Självmord i Stockholm – en epidemiologisk studie av 686 konsekutiva fall. Thomas Hjortsjö. Avhandling.

1984

1984:1 Långvarigt sjuka barn – sjukvårdens effekter på barn och familj. Andersson, Harwe, Hellberg & Syréhn. (FoU-rapport/shstf:14). Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.

1984:2 Intersectoral Action for Health – Report from an International Workshop. Lennart Köhler & John Martin (eds).

1984:3 Barns hälsotillstånd i Norden. Gunborg Jakobsson & Lennart Köhler. Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.

1985

1985:1 Hälsa för äldre i Norden år 2000. Mårten Lagergren (red).

1985:2 Socialt stöd åt handikappade barn i Norden. Mats Eriksson & Lennart Köhler. Distribueras av Allmänna Barnhuset, Box 26006, SE-100 41 Stockholm.

1985:3 Promotion of Mental Health. Per-Olof Brogren.

1985:4 Training Health Workers for Primary Health Care. John Martin (ed).

1985:5 Inequalities in Health and Health Care. Lennart Köhler & John Martin (eds).

1986

1986:1 Prevention i primärvården. Rapport från konferens. Harald Siem & Hans Wedel (red). Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.

1986:2 Management of Primary Health Care. John Martin (ed).

1986:3 Health Implications of Family Breakdown. Lennart Köhler, Bengt Lindström, Keith Barnard & Houda Itani.

1986:4 Epidemiologi i tandvården. Dorthe Holst & Jostein Rise (red). Distribueras av Tandläkarförlaget, Box 5843, SE-102 48 Stockholm.

1986:5 Training Course in Social Pediatrics. Part I. Lennart Köhler & Nick Spencer (eds).

Förteckning över NHV-rapporter

1987

1987:1 Children's Health and Well-being in the Nordic Countries. Lennart Köhler & Gunborg Jakobsson. Ingår i serien Clinics in Developmental Medicine, No 98 och distribueras av Blackwell Scientific Publications Ltd, Oxford. ISBN (UK) 0 632 01797X.

1987:2 Traffic and Children's Health. Lennart Köhler & Hugh Jackson (eds).

1987:3 Methods and Experience in Planning for Health. Essential Drugs. Frants Staugård (ed).

1987:4 Traditional midwives. Sandra Anderson & Frants Staugård.

1987:5 Nordiska hälsovårdshögskolan. En historik inför invigningen av lokalerna på Nya Varvet i Göteborg den 29 augusti 1987. Lennart Köhler (red).

1987:6 Equity and Intersectoral Action for Health. Keith Barnard, Anna Ritsatakis & Per-Gunnar Svensson.

1987:7 In the Right Direction. Health Promotion Learning Programmes. Keith Barnard (ed).

1988

1988:1 Infant Mortality – the Swedish Experience. Lennart Köhler.

1988:2 Familjen i välfärdsstaten. En undersökning av levnadsförhållanden och deras fördelning bland barnfamiljer i Finland och övriga nordiska länder. Gunborg Jakobsson. Avhandling.

1988:3 Aids i Norden. Birgit Westphal Christensen, Allan Krasnik, Jakob Bjørner & Bo Eriksson.

1988:4 Methods and Experience in Planning for Health – the Role of Health Systems Research. Frants Staugård (ed).

1988:5 Training Course in Social Pediatrics. Part II. Perinatal and neonatal period. Bengt Lindström & Nick Spencer (eds).

1988:6 Äldretandvård. Jostein Rise & Dorthe Holst (red). Distribueras av Tandläkarförlaget, Box 5843, SE-102 48 Stockholm.

1989

1989:1 Rights, Roles and Responsibilities. A view on Youth and Health from the Nordic countries. Keith Barnard.

1989:2 Folkhälsovetenskap. Ett nordiskt perspektiv. Lennart Köhler (red).

1989:3 Training Course in Social Pediatrics. Part III. Pre-School Period. Bengt Lindström & Nick Spencer (eds).

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1989:4 Traditional Medicine in Botswana. Traditional Medicinal Plants. Inga Hedberg & Frants Staugård.

1989:5 Forsknings- och utvecklingsverksamhet vid Nordiska hälsovårdshögskolan. Rapport till Nordiska Socialpolitiska kommittén.

1989:6 Omstridda mödrar. En studie av mödrar som förtecknats som förståndshandikappade. Evy Kollberg. Avhandling.

1989:7 Traditional Medicine in a transitional society. Botswana moving towards the year 2000. Frants Staugård.

1989:8 Rapport fra Den 2. Nordiske Konferanse om Helseopplysning. Bergen 4–7 juni 1989. Svein Hindal, Kjell Haug, Leif Edvard Aarø & Carl-Gunnar Eriksson.

1990

1990:1 Barn och barnfamiljer i Norden. En studie av välfärd, hälsa och livskvalitet. Lennart Köhler (red). Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.

1990:2 Barn och barnfamiljer i Norden. Teknisk del. Lennart Köhler (red).

1990:3 Methods and Experience in Planning for Health. The Role of Women in Health Development. Frants Staugård (ed).

1990:4 Coffee and Coronary Heart Disease, Special Emphasis on the Coffee – Blood Lipids Relationship. Dag S. Thelle & Gerrit van der Stegen (eds).

1991

1991:1 Barns hälsa i Sverige. Kunskapsunderlag till 1991 års Folkhälsorapport. Gunborg Jakobsson & Lennart Köhler. Distribueras av Fritzes, Box 16356, SE-103 27 Stockholm (Allmänna Förlaget).

1991:2 Health Policy Assessment – Proceedings of an International Workshop in Göteborg, Sweden, February 26 – March 1, 1990. Carl-Gunnar Eriksson (ed). Distributed by Almqvist & Wiksell International, Box 638, SE-101 28 Stockholm.

1991:3 Children's health in Sweden. Lennart Köhler & Gunborg Jakobsson. Distributed by Fritzes, Box 16356, SE-103 27 Stockholm (Allmänna Förlaget).

1991:4 Poliklinikker og dagkururgi. Virksomhetsbeskrivelse for ambulent helsetjeneste. Monrad Aas.

1991:5 Growth and Social Conditions. Height and weight of Stockholm schoolchildren in a public health context. Lars Cernerud. Avhandling.

1991:6 Aids in a caring society – practice and policy. Birgit Westphal Victor. Avhandling

1991:7 Resultat, kvalitet, valfrihet. Nordisk hälsopolitik på 90-talet. Mats Brommels (red). Distribueras av nomesko, Sejrøgade 11, DK-2100 København.

Förteckning över NHV-rapporter

1992

1992:1 Forskning om psykiatrisk vårdorganisation – ett nordiskt komparativt perspektiv. Mats Brommels, Lars-Olof Ljungberg & Claes-Göran Westin (red). sou 1992:4. Distribueras av Fritzes, Box 16356, SE-103 27 Stockholm (Allmänna förlaget).

1992:2 Hepatitis virus and human immunodeficiency virus infection in dental care: occupational risk versus patient care. Flemming Scheutz. Avhandling.

1992:3 Att leda vård – utveckling i nordiskt perspektiv. Inga-Maja Rydholm. Distribueras av shstf-material, Box 49023, SE-100 28 Stockholm.

1992:4 Aktion mot alkohol och narkotika 1989–1991. Utvärderingsrapport. Athena. Ulla Marklund.

1992:5 Abortion from cultural, social and individual aspects. A comparative study, Italy – Sweden. Marianne Bengtsson Agostino. Avhandling.

1993

1993:1 Kronisk syke og funksjonshemmede barn. Mot en bedre fremtid? Arvid Heiberg (red). Distribueras av Tano Forlag, Stortorget 10, NO-0155 Oslo.

1993:2 3 Nordiske Konference om Sundhedsfremme i Aalborg 13 – 16 september 1992. Carl-Gunnar Eriksson (red).

1993:3 Reumatikernas situation i Norden. Kartläggning och rapport från en konferens på Nordiska hälsovårdshögskolan 9 – 10 november 1992. Bjarne Jansson & Dag S. Thelle (red).

1993:4 Peace, Health and Development. A Nobel seminar held in Göteborg, Sweden, December 5, 1991. Jointly organized by the Nordic School of Public Health and the University of Göteborg with financial support from SAREC. Lennart Köhler & Lars-Åke Hansson (eds).

1993:5 Hälsopolitiska jämlikhetsmål. Diskussionsunderlag utarbetat av WHOs regionkontor för Europa i Köpenhamn. Göran Dahlgren & Margret Whitehead. Distribueras gratis.

1994

1994:1 Innovation in Primary Health Care of Elderly People in Denmark. – Two Action Research Projects. Lis Wagner. Avhandling.

1994:2 Psychological stress and coping in hospitalized chronically ill elderly. Mary Kalfoss. Avhandling.

1994:3 The Essence of Existence. On the Quality of Life of Children in the Nordic countries. Theory and Pracitice. Bengt Lindström. Avhandling.

Förteckning över NHV-rapporter

1995

1995:1 Psykiatrisk sykepleie i et folkehelseperspektiv. En studie av hvordan en holistisk-eksistensiell psykiatrisk sykepleiemodell bidrar til folkehelsearbeid. Jan Kåre Hummelvoll. Avhandling.

1995:2 Child Health in a Swedish City – Mortality and birth weight as indicators of health and social inequality. Håkan Elmén. Avhandling.

1995:3 Forebyggende arbeid for eldre – om screening, funn, kostnader og opplevd verdi. Grethe Johansen. Avhandling.

1995:4 Clinical Nursing Supervision in Health Care. Elisabeth Severinsson. Avhandling.

1995:5 Prioriteringsarbete inom hälso- och sjukvården i Sverige och i andra länder. Stefan Holmström & Johan Calltorp. Spri 1995. Distribueras av Spris förlag, Box 70487, SE-107 26 Stockholm.

1996

1996:1 Socialt stöd, livskontroll och hälsa. Raili Peltonen. Socialpolitiska institutionen, Åbo Akademi, Åbo, 1996.

1996:2 Recurrent Pains – A Public Health Concern in School – Age Children. An Investigation of Headache, Stomach Pain and Back Pain. Gudrún Kristjánsdóttir. Avhandling.

1996:3 AIDS and the Grassroots. Frants Staugård, David Pitt & Claudia Cabrera (red).

1996:4 Postgraduate public health training in the Nordic countries. Proceedings of seminar held at The Nordic School of Public Health, Göteborg, January 11 – 12, 1996.

1997

1997:1 Victims of Crime in a Public Health Perspective – some typologies and tentative explanatory models (Brottsoffer i ett folkhälsoperspektiv – några typologier och förklaringsmodeller). Barbro Renck. Avhandling. (Utges både på engelska och svenska.)

1997:2 Kön och ohälsa. Rapport från seminarium på Nordiska hälsovårdshögskolan den 30 januari 1997. Gunilla Krantz (red).

1997:3 Edgar Borgenhammar – 65 år. Bengt Rosengren & Hans Wedel (red).

1998

1998:1 Protection and Promotion of Children's Health – experiences from the East and the West. Yimin Wang & Lennart Köhler (eds).

1998:2 EU and Public Health. Future effects on policy, teaching and research. Lennart Köhler & Keith Barnard (eds) 1998:3 Gender and Tuberculosis.
Vinod K. Diwan, Anna Thorson, Anna Winkvist (eds)

Förteckning över NHV-rapporter

Report from the workshop at the Nordic School of Public Health, May 24-26, 1998.

1999

1999:1 Tipping the Balance Towards Primary Healthcare Network. Proceedings of the 10th Anniversary Conference, 13-16 November 1997. Editor: Chris Buttanshaw.

1999:2 Health and Human Rights. Report from the European Conference held in Strasbourg 15-16 mars 1999. Editor: Dr. med. Stefan Winter.

1999:3 Learning about health: The pupils' and the school health nurses' assessment of the health dialogue. Ina Borup. DrPH-avhandling.

1999:4 The value of screening as an approach to cervical cancer control. A study based on the Icelandic and Nordic experience through 1995. Kristjan Sigurdsson. DrPH-avhandling.

2000

2000:1 Konsekvenser av urininkontinens sett i et folkehelsevitenskapelig perspektiv. En studie om livskvalitet hos kvinner og helsepersonells holdninger. Anne G Vinsnes. DrPH-avhandling.

2000:2 A new public health in an old country. An EU-China conference in Wuhan, China, October 25-29, 1998. Proceedings from the conference. Lennart Köhler (ed)

2000:3 Med gemenskap som grund - psykisk hälsa och ohälsa hos äldre människor och psykiatrisjuksköterskans hälsofrämjande arbete. Birgitta Hedelin. DrPH-avhandling.

2000:4 ASPHER Peer Review 1999. Review Team: Jacques Bury, ASPHER, Franco Cavallo, Torino and Charles Normand, London.

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Living with Juvenile Idiopathic Arthritis from childhood to adult life

Adolescence is a time of developmental transition with rapid physical, psychological, and social developmental changes. Young people's health can be put at risk by their tendency to keep a here-and-now focus on life, their immature ability to control impulses and imagine future consequences, and the importance of peer conformity. The fact that young people with persistent chronic childhood diseases tend to fall between two chairs in the health care system may complicate the unique challenges of communication and health management involved in the adolescence.

Chronic arthritis from childhood might have far-reaching consequences for the growth and development of the child, and for the family and community. A considerable proportion of children with juvenile idiopathic arthritis (JIA) continue to have active disease and disease residua through adolescence into adulthood. The persistent experience of an insecure everyday life and an unpredictable life course remind us that although the disease severity has declined the disease is still present to a various extent and impacts the individual's health and quality of life.

In order to develop and maintain transitional care for adolescents with JIA and other chronic childhood conditions it seems urgent to focus on organisational systems and professional competence in adolescent health care. This thesis is an attempt to contribute to the development of knowledge and understanding of young adults' experiences of life with juvenile idiopathic arthritis in a life-span perspective. It is my hope that the findings will contribute to the development of a high quality care for adolescents with persistent chronic childhood diseases in order to maintain normal growth and development and promote health in a short- as well as a long-term perspective.

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