

Original article

Patients with psychiatric diagnoses have lower quality of life than other patients with juvenile rheumatic disease: a prospective study

Silja Kosola ¹ and Heikki Relas ²

Abstract

Objectives. Transition of adolescents with chronic diseases from paediatric healthcare to adult care requires attention to maintain optimal treatment results. We examined changes in health-related quality of life (HRQoL) and disease activity among JIA patients with or without concomitant psychiatric diagnoses after transfer to an adult clinic.

Methods. We prospectively followed 106 consecutive patients who were transferred from the New Children's Hospital to the Helsinki University Hospital Rheumatology outpatient clinic between April 2015 and August 2019 and who had at least one follow-up visit. HRQoL was measured using 15D, a generic instrument.

Results. The patients' median age at transfer was 16 years and disease duration 4.0 years. Patients were followed for a median of 1.8 years. Disease activity and overall HRQoL remained stable, but distress (dimension 13 of 15D) increased during follow up ($P=0.03$). At baseline, patients with at least one psychiatric diagnosis had lower overall 15D scores [mean 0.89 (s.d. 0.14) vs 0.95 (s.d. 0.05), $P < 0.01$] and higher disease activity [DAS28mean 1.88 (s.d. 0.66) vs 1.61 (s.d. 0.31), $P = 0.01$] than patients without psychiatric diagnoses. The difference in overall 15D persisted over the study period.

Conclusion. Transition-phase JIA patients with psychiatric diagnoses had lower HRQoL than other JIA patients. Despite reduced disease activity and pain, HRQoL of patients with psychiatric diagnoses remained suboptimal at the end of follow-up. Our results highlight the necessity of comprehensive care and support for transition-phase JIA patients.

Key words: juvenile idiopathic arthritis, transition of care, health-related quality of life, distress, mental health

Rheumatology key messages

- An underlying psychiatric condition has a significant impact on HRQoL in patients with JIA.
- Ensuring the availability of psychiatric services for adolescents is highlighted.
- Disease activity and HRQoL were stable during the follow-up.

Introduction

JIA is a group of chronic arthritides that begin before the age of 16 years [1]. Disease activity often continues into adulthood [2, 3] and may cause permanent joint damage

[4]. For the best clinical and patient-reported outcomes, a crucial time is the transition of care from paediatric to adult healthcare settings.

Unsuccessful transfer from paediatric to adult healthcare is a significant problem [5, 6]. Special attention is required to maintain treatment adherence and low disease activity during this time. Disease-specific recommendations for transitional care of JIA patients have been published recently [7] but we found no studies reporting on how well these guidelines are followed.

Health-related quality of life (HRQoL) of JIA patients in adulthood is lower than in the general population [8]. In a previous study on patients from the Helsinki University

¹Pediatric Research Centre, Children's Hospital, Helsinki University Hospital and University of Helsinki, Helsinki, Finland and
²Department of Rheumatology, Helsinki University Hospital and University of Helsinki, Helsinki, Finland

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Correspondence to: Heikki Relas, Rheumatology, Helsinki University Hospital, PL 372, 00029 HUS, Finland. E-mail: heikki.relas@gmail.com

Hospital (HUH) transition clinic, we found that in general disease activity was low and HRQoL was good [9]. Unfortunately, follow-up studies covering the last phase of transition, that is after the transfer of care, are rare. The development of disease activity and changes in HRQoL, especially between ages 16 and 25 years, remain unknown.

Adult patients with rheumatoid arthritis have a high prevalence of comorbidities, the most common of which is depression [10]. Although most psychiatric conditions are first diagnosed during adolescence [11], we found no studies that combined information on JIA and psychiatric diagnoses during transition. The aims of the present study were to follow HRQoL and disease activity of JIA patients after the transfer of care and to explore the prevalence and associations of psychiatric diagnoses in this patient cohort.

Methods

Transition process

Essentially all JIA patients in Southern Finland who require follow-up after paediatric rheumatology care are referred to the HUH rheumatology outpatient clinic (background population 1.6 million). The transfer of care for rheumatology patients from the paediatric hospital to adult healthcare services occurs based on individual assessment at the age of 16–18 years [12]. More than half of all JIA patients are transferred to the adult rheumatology clinic, while ~40% of patients are transferred to primary healthcare because they have reached remission off medication [13]. In the HUH area, patients who still require medication first attend a transition clinic based within the adult rheumatological outpatient clinic until the age of 20 years and then integrate into the general adult clinic. Patients without DMARDs are usually transferred to primary healthcare after 1–2 years follow-up.

Patient cohort

The electronic patient registry of our hospital facilitated the identification of all JIA patients [International Classification of Diseases-10th Revision (ICD-10) codes M08.0-M08.9 and M09.0*L40.5] who were transferred from the HUH Children's Hospital to the HUH rheumatology outpatient transition clinic between April 2015 and August 2019 and who had at least one follow-up visit at the transition clinic. Data from the baseline and last visit of follow-up were analysed. All consecutive patients from this time period at the transition clinic were included in data collection and analyses.

Clinical data

Disease outcome was assessed using routine adult-oriented disease outcome measures. Patients estimated the intensity of their pain during the previous week on a 10-cm visual analogue scale (VAS), where higher scores indicated more intense pain [14]. Disease Activity Score

28 (DAS28)-CRP is a modification of DAS28 [15, 16]. The original DAS28 included the ESR, which was replaced by the serum CRP concentration in the DAS28-CRP. In this study, DAS28 refers to DAS28-CRP. DAS44 [17] could theoretically be a better measure for JIA patients with typical ankle manifestations. DAS44 is not routinely calculated in clinical practice, and outcomes calculated by DAS28 and DAS44 showed no difference in our previous transition study [12]. Thus, DAS28 was used in the analyses. Remission was defined as DAS28 < 2.6. The level of disease activity can be interpreted as low (DAS28 2.6–3.2), moderate (DAS28 3.3–5.1) and high (DAS28 > 5.1) [15]. The HAQ Disability Index (HAQ-DI) [18] includes eight categories that summarize the patient's ability to perform 20 activities of daily living on a four-point Likert scale (from 'without any difficulty' to 'not able to do'; respective scores ranging from 0 to 3). The highest score of any activity within the category is used as the category score. The total HAQ-DI score is the mean of the category scores. BASDAI [19] was used in patients with enthesitis-related arthritis (ICD-10 code M08.1). The BASDAI score ranges from 0 to 10. High values indicate active disease.

Health-related quality of life

Patients rated their HRQoL using the 15D, a generic instrument that can be used as a profile and a single score measurement [20]. The 15D consists of 15 dimensions: mobility, vision, hearing, breathing, sleeping, eating, speech, excretion, usual activities, mental function, discomfort and symptoms, depression, distress, vitality, and sexual activity. For each dimension, the patient chooses one of the five statements that best describes her/his situation at the moment (the optimal level is 1 and the worst level is 5). The final single index ranges between 0 (being dead) and 1 (no problems on any dimension) and it is calculated from the 15 responses using a set of population-based preference or utility weights as an application of the multiattribute utility theory (<http://www.15d-instrument.net/15d/>). The cross-sectional minimum important difference and the minimum important change over time in the 15D scores are ± 0.015 [21].

HAQ-DI, VAS, BASDAI and 15D are patient-reported outcomes, and DAS28 is rated by the practitioner. We also collected data on medication use. Data on psychiatric diagnoses was extracted from electronic medical records (ICD-10 diagnosis group Fx.x). We also recorded the dates of both rheumatic and psychiatric diagnoses to assess the sequence of diagnoses.

Ethics

We used prospectively collected data from patient files and the quality registry and patients were not contacted for this study. Thus, ethics approval was not required for this study at our institution.

Statistical methods

Data are presented as means (s.d.) for continuous variables and medians (with range) in case of skewed distribution. Percentages are reported for categorical variables. *t* tests were used to compare continuous, normally distributed variables. When distribution was skewed and for nominal values, non-parametric tests were used. Correlations were calculated by Spearman's correlation coefficient. A *P*-value <0.05 was considered statistically significant. Data analyses were performed using IBM SPSS Statistics 22 (IBM, Somers, NY).

Results

A total of 106 patients were identified and followed for a median of 1.8 years (Table 1). Four patients (4%) were lost to follow-up. Diagnoses of JIA were distributed as follows: 8% seropositive, 31% seronegative polyarthritis, 31% seronegative oligoarthritis, 23% enthesitis-related arthritis, 7% psoriatic arthritis and one unclassifiable arthritis. Disease activity (DAS28 and BASDAI) remained stable in the whole study group and the use of DMARDs diminished over the transition period (Table 1). Remission was the most common reason for tapering and cessation of medications. Patients who used no DMARDs at the last visit had higher DAS28 than patients on DMARDs [mean 1.93 (s.d. 0.87) vs 1.60 (s.d. 0.29), respectively, *P*= 0.013]. In general, HRQoL remained stable during the study period. Of the 15 dimensions of HRQoL measured, distress increased slightly [from mean 0.88 (s.d. 0.20) to 0.85 (s.d. 0.23), *P*= 0.003] during follow-up (Fig. 1). Increased distress was seen in women only (data not shown). Disease duration did not correlate with pain VAS (*r*=-0.11, *P*= 0.24), DAS28 (*r*=-0.081,

P= 0.46), HAQ (*r*=0.013, *P*= 0.91), overall 15D (*r*=0.015, *P*= 0.88) or distress (*r*=0.086, *P*= 0.39).

Seventeen patients had at least one psychiatric diagnosis (ICD-10 F diagnosis; namely depression, anxiety disorder or attention-deficit/hyperactivity disorder). Ages at psychiatric and rheumatic diagnoses are shown in Fig. 2. The median age for a psychiatric diagnosis was 15 years (5–18 years). All patients except for one received their psychiatric diagnoses after the diagnosis of the rheumatic condition. Among patients with both a JIA diagnosis and a psychiatric diagnosis, DAS28 and pain VAS remained essentially unchanged during follow-up (Table 2). DMARD use was similar in patient groups with and without psychiatric diagnoses.

Patients with psychiatric diagnoses had lower overall 15D scores than patients without psychiatric diagnoses [mean 0.87 (s.d. 0.12) vs 0.94 (s.d. 0.06), *P*= 0.001]. The dimensions of sleep, excretion, mental function and distress yielded lower scores at baseline among patients with psychiatric diagnoses than their peers (Fig. 3A), and among patients with psychiatric diagnoses, additional difficulties emerged during follow-up in dimensions of usual activities, vitality and sexual function (Fig. 3B). Distress increased during follow-up only among patients without psychiatric diagnoses (Table 2).

Discussion

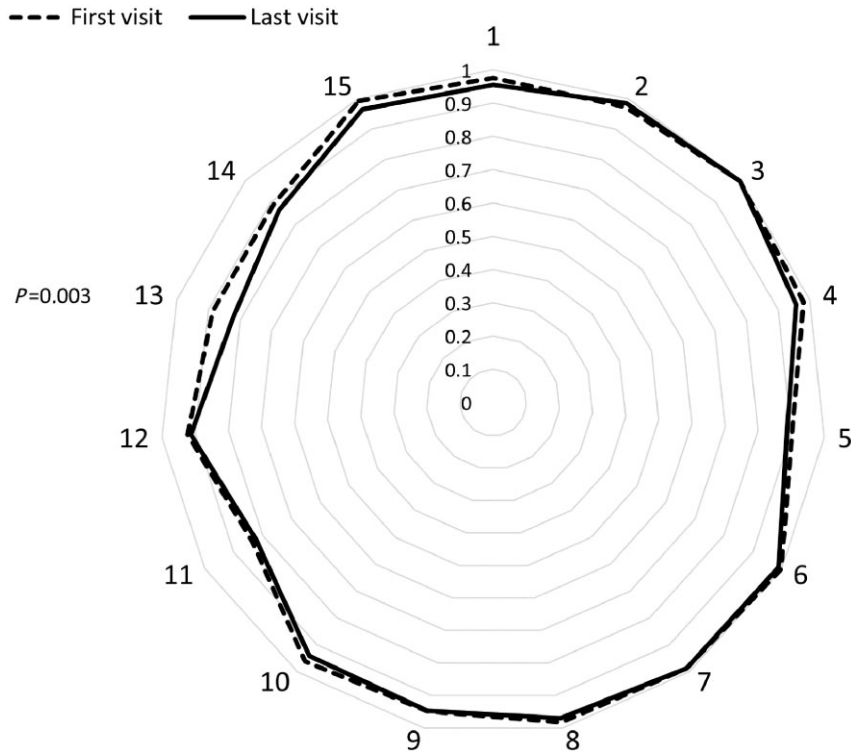
In the whole study cohort, disease activity and overall HRQoL remained stable, but distress increased slightly among women during follow-up. Seventeen patients (15%) had a psychiatric diagnosis, and their disease was more active at baseline. Patients with a psychiatric diagnosis had lower HRQoL and more distress both at

TABLE 1 Clinical characteristics, *n* = 106

	Descriptive statistics	Baseline	Last visit	<i>P</i>
Age, years	16 (16–20)			
Sex, female/male, %	64/36			
Disease duration, years	4.0 (1.0–16.5)			
Follow-up, years	1.8 (0.6–4.4)			
BMI, kg/m ²		21.2 (16.1–37.2)	22.3 (13.3–36.6)	<0.001
Smoker, %		5	7	0.414
CRP, mg/dl		1 (1–21)	1 (1–57)	0.261
Pain VAS, mm		10 (0–60)	5.0 (0–80)	0.759
DAS28		1.66 (0.40)	1.67 (0.48)	0.663
HAQ-DI		0 (0–0.4)	0 (0–1.0)	0.107
BASDAI		1.2 (0–7.5)	1.6 (0–5.9)	0.637
15D		0.94 (0.07)	0.93 (0.08)	0.103
sDMARD, %		84	61	<0.001
bDMARD, %		43	37	0.090
s+bDMARD, %		35	23	0.011
No DMARDs, %		6	24	0.896

The results for disease duration, follow-up, pain VAS, HAQ-DI and BASDAI are given as median (range) and the results for DAS28 and 15D scores as mean (s.d.). Age is presented as median (range) in years. bDMARD: biologic DMARD; HAQ-DI: HAQ Disability Index; sDMARD: synthetic DMARD; VAS: visual analogue scale.

Fig. 1 Health-related quality of life (15D scores) of 106 JIA patients during 1.8 years of follow-up



Numbers on the outer ring represent the 15 dimensions of HRQoL measured: 1, mobility; 2, vision; 3, hearing; 4, breathing; 5, sleeping; 6, eating; 7, speech; 8, excretion; 9, usual activities; 10, mental function; 11, discomfort and symptoms; 12, depression; 13, distress; 14, vitality; 15, sexual activity. Significant differences ($P < 0.05$) between groups in any dimension are accompanied by a P -value.

Fig. 2 Distribution of patient age at JIA diagnosis (solid bar) and at psychiatric diagnosis (open bar) of 17 patients with both a JIA diagnosis and a psychiatric diagnosis

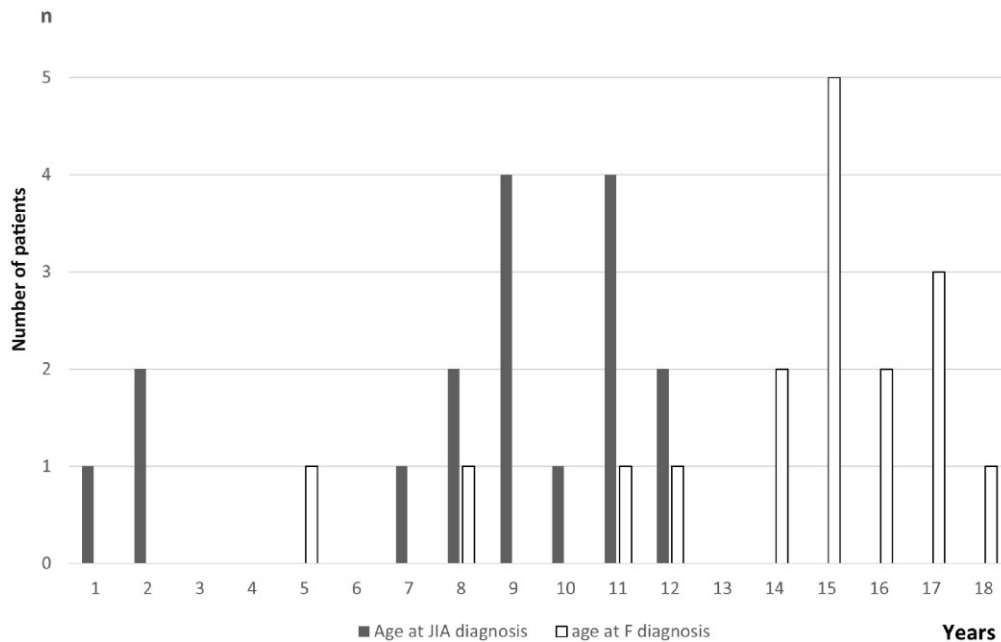
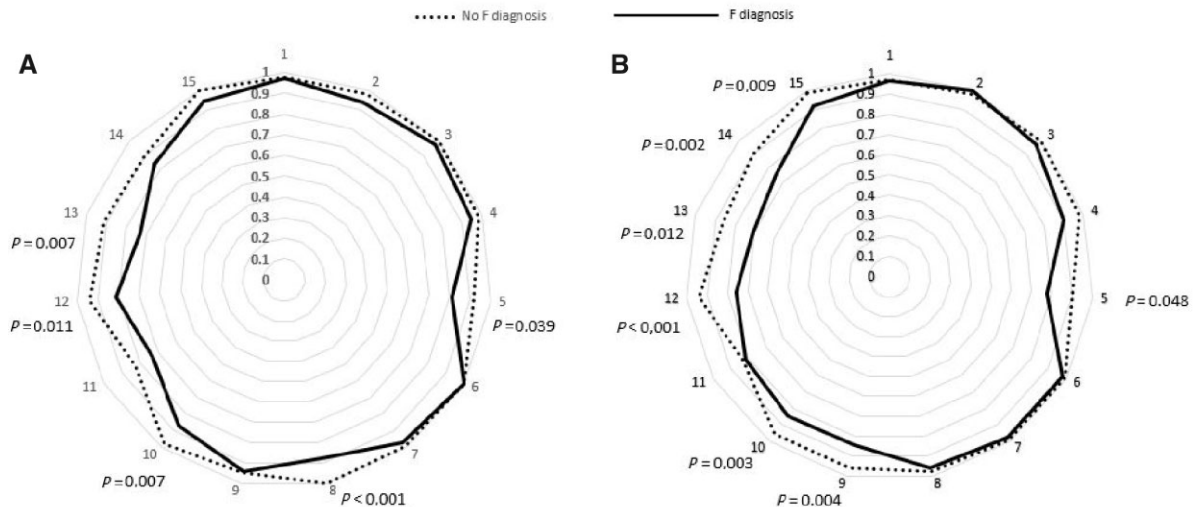


TABLE 2 Clinical characteristics of patients without psychiatric diagnosis (F diagnosis) and with at least one F diagnosis

	No F diagnosis (n = 89)	F diagnosis (n = 17)
Sex male, n (%)	31 (35)	7 (41)
Disease duration, years	4.0 (1.0–16.5)	5.0 (3.0–15.0)
Follow-up, years	1.9 (0.6–4.2)	1.5 (0.7–4.4)
Smokers, n (%)	4 (5)	3 (18)
BMI at baseline, kg/m ²	21.1 (16.1–37.2)	21.5 (16.4–32.3)
BMI at last visit, kg/m ²	22.3 (13.3–36.6) [#]	22.3 (14.8–31.6)
Pain VAS at baseline, mm	10 (0–60)	18 (0–60)**
Pain VAS at last visit, mm	5 (0–80)	10 (0–70)
DAS28 at baseline	1.61 (0.31)	1.88 (0.66)**
DAS28 at last visit	1.66 (0.51)	1.64 (0.34)
15D at baseline	0.95 (0.05)	0.89 (0.14)**
15D at last visit	0.94 (0.06)	0.87 (0.12)**
15D distress at baseline	0.91 (0.16)	0.73 (0.32)**
15D distress at last visit	0.86 (0.19) [#]	0.71 (0.32) [†]
No DMARDs at baseline, n (%)	6 (6.7)	0
No DMARDs at last visit, n (%)	20 (23)	4 (23)

The results for disease duration, follow-up, number of visits, BMI and pain visual analogue scale (VAS) are presented as median (range) and DAS28 and 15D scores as mean (s.d.). * $P < 0.05$, ** $P < 0.01$, for difference between patient groups. [#] $P < 0.05$, for difference between baseline vs last visit.

Fig. 3 Health-related quality of life (15D scores) of 17 JIA patients with psychiatric (F) diagnosis and 89 patients without F diagnosis during 1.8 years of follow-up



(A) HRQoL in patients with ($n=17$) or without ($n=89$) a psychiatric diagnosis at first visit. (B) HRQoL in patients with ($n=17$) or without ($n=89$) a psychiatric diagnosis at last follow-up visit. Numbers on the outer ring represent the 15 dimensions of HRQoL measured: 1, mobility; 2, vision; 3, hearing; 4, breathing; 5, sleeping; 6, eating; 7, speech; 8, excretion; 9, usual activities; 10, mental function; 11, discomfort and symptoms; 12, depression; 13, distress; 14, vitality; 15, sexual activity. Significant differences (minimum important difference, 0.015) between groups in any dimension are accompanied by a P -value.

baseline and at the end of the study than patients without a psychiatric diagnosis.

Disease activity, the proportion of patients on DMARDs and general HRQoL were similar to earlier studies at our centre [9, 12]. The proportion of patients

on synthetic DMARDs and combined synthetic and biologic DMARDs decreased over time. Luque Ramos *et al.* reported a similar decrease in DMARD treatment among patients in transition [22]. Unfortunately, we found that patients without any DMARDs had more

active disease, which may reflect a tendency of JIA to activate without treatments [23]. This finding highlights the need for close follow-up after the transfer of care.

The prospective data collection and relatively large sample size are strengths of this study. To the best of our knowledge, this is one of the first studies to report on disease activity and long-term HRQoL in JIA patients after the transfer of care. To the best of our knowledge, this is also the first study to explore the associations of psychiatric comorbidities in young rheumatology patients. Our study is limited because data was only collected at one centre. Although the median follow-up time of 1.8 years may be considered short in adult rheumatology, it is fairly long in transition literature.

The rates of psychiatric symptoms and disorders increase from adolescence to early adulthood, and as many as one adolescent in five may have a psychiatric disorder [11, 24]. In this study, 15% of JIA patients also had a psychiatric diagnosis. The age of onset for JIA is typically earlier than the onset of mental health problems [25, 26]. Chronic diseases increase anxiety in adolescents [27, 28], and during the 1.8-year follow-up, we also saw an increase in patient-reported distress among women. Pain is a common problem in young adults with JIA [29], and patients with accompanying psychiatric disorders may be especially prone to benefit from enhanced pain management. On the other hand, patients with a psychiatric diagnosis showed stable disease activity during the study period. This suggests that adherence to DMARD treatment was unaffected by the patients' psychiatric diagnosis.

An underlying psychiatric disorder may have a more significant role on HRQoL than JIA itself. In the long term, overlooked or poorly treated psychiatric conditions may undermine the clinical treatment results. Recently, the demand for psychiatric care has increased in developed countries and access to psychiatric care is limited, even for adolescents [30]. To truly reach the goal of patient-centred and individualized care, we need to collaborate to reduce the fragmentation of healthcare services and to obliterate the barriers between medical and psychiatric care.

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Data availability statement

The data underlying this article cannot be shared publicly due for the privacy of individuals that participated in the study. The data will be shared on reasonable request to the corresponding author.

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