Joint Bone Spine 83 (2016) 69–74

Available online at ScienceDirect www.sciencedirect.com

Elsevier Masson France EM|consulte www.em-consulte.com/en

Original article

Impact of juvenile idiopathic arthritis on quality of life during transition period at the era of biotherapies

Julien Wipff[a,1], Laetitia Sparsa[b,c,*,1], Anne Lohse[d], Pierre Quartier[e], Andre Kahan[a], Chantal Job Deslandre[a]

[a] Paris Descartes University, Rheumatology A department, Cochin Hospital, 75014 Paris, France
[b] Paris Descartes University, Rheumatology B department, Cochin Hospital, 75014 Paris, France
[c] Rheumatology department, Émile-Muller Hospital, 20, avenue du Docteur-Laennec, 68100 Mulhouse, France
[d] Rheumatology department, Hospital center of Belfort-Montbeliard, 90016 Belfort, France
[e] Paris Descartes University, Pediatric department, Necker Hospital, 75015 Paris, France

ARTICLE INFO

Article history:
Accepted 4 March 2015
Available online 29 July 2015

Keywords:
Health-related quality of life
Juvenile idiopathic arthritis
Transition period

ABSTRACT

Objective: Few studies have assessed Health-Related Quality of Life (HR-QoL) in adults following juvenile idiopathic arthritis, and none since the advent of biotherapies. The aim of our study is to assess the impact of juvenile idiopathic arthritis on quality of life in a large transitional cohort, evaluate which factors influence quality of life in juvenile idiopathic arthritis, and determine which questionnaire should be used in practice.

Methods: All consecutive juvenile idiopathic arthritis patients followed during adulthood in a transitional care program were included. Demographical, clinical and biological data were collected. The following quality of life questionnaires were administered: SF36 and EuroQoL. Age- and sex-matched controls (without rheumatic disease) were included.

Results: One hundred and sixty-one juvenile idiopathic arthritis (120 women and 41 men) and 76 (51/25) controls were included. Out of 161, sixty-five (40%) were considered to be in remission. Juvenile idiopathic arthritis had a large impact on the physical scales of quality of life. Pain seemed to be the most important factor affecting quality of life in cases of juvenile idiopathic arthritis. No significant difference was found between sub-types of juvenile idiopathic arthritis.

Conclusion: In this large transitional cohort of patients at the era of biotherapies, juvenile idiopathic arthritis has a larger effect on physical than mental scale of quality of life measures. Pain was the main factor influencing quality of life. Sub-types of juvenile idiopathic arthritis do not seem to influence quality of life.

1. Introduction

Young people with JIA still experience active disease with significant morbidities in adulthood [1]. If healthcare professionals know what the lived experiences of young people with JIA are, they can provide better transitional care and they can help patients make the transfer from paediatric to adult care [2–4]. Transitional care is a multidimensional, multidisciplinary and active process that addresses the medical, psychosocial and educational/vocational needs of adolescents with JIA [5–7]. Previous studies report that the impact of JIA on the quality of life (QOL) of children [8] does not decline when they become adult; however, these studies were conducted before the era of biologic therapy [9–11].

Over the last 10 years, there has been a great deal of effort to develop measures of outcomes in children with JIA. Many instruments are used to assess severity of disease, disability, and health-related quality of life (HR-QoL) in JIA [12]. The Child Health Assessment Questionnaire (CHAQ), derived from the Health Assessment Questionnaire (HAQ) used in adults, is the questionnaire most widely used to assess physical function of children with JIA; it has good internal reliability and test-retest reliability [13,14]. CHAQ seems to be the best questionnaire for the assessment of incapacity in JIA but its results correlate poorly with disease activity and responsiveness [14].

Health-related-QoL (HR-QoL) in JIA has been less extensively evaluated than disease activity and functional impairment. Two

* Corresponding author. Rheumatology department, Hôpital Émile-Muller, 20, avenue du Docteur-Laennec, 68100 Mulhouse, France.
E-mail address: sparsal@ch-mulhouse.fr (L. Sparsa).
[1] J. Wipff and L. Sparsa equally contributed to this work.

http://dx.doi.org/10.1016/j.jbspin.2015.03.005
1297-319X/

specific questionnaires (CHQ, Peds-QL) have been used, but their psychometric measurement appears to be weak and too few patients have been tested with Peds-QL for robust conclusions to be drawn [15]. Recently, Haverman et al. evaluated 152 JIA patients with a web-based survey and showed that HR-QOL is severely affected in children and adolescents with JIA [16].

HAQ is widely used in clinical practice and for studies of patient's adult rheumatic diseases and in particular in rheumatoid arthritis (RA) [17]. HAQ is the best predictor of functional ability in terms of mortality, work disability, joint replacement and medical costs [17,18]. The questionnaire most widely used for the evaluation of adult QOL is SF36 [18].

Indeed, adult HR-QOL can be influenced by sociological, economic, philosophical and ethical factors, such that results for a transitional cohort may not be the same as those for a childhood cohort. For patients in transition from paediatric into adult, healthcare validated instruments are still required to measure the adolescents' QOL.

The aim of our present study was to determine the consequences of JIA for QOL in a large transitional JIA cohort at the era of biotherapies, and to determine which questionnaire should be used in practice to assess HR-QOL.

2. Methods

All unselected consecutive JIA patients, seen between December 2010 and January 2012, in a transition program in a single tertiary referral center were included. Diagnoses were based on the International League of Associations for Rheumatology criteria [19]. We decided to gather under the name of "juvenile spondyloarthritis" the two sub-types (enthesitis-related arthritis and psoriatic arthritis) of JIA that were considered belonging to spondyloarthropathies. This has been done because of the size of the psoriatic arthritis sub-group that not allowed relevant statistics. Healthy subjects, i.e. without any personal or familial history of rheumatic disease, matched for age and sex, were included as a control group. This control group included for one-hand sisters and brothers of JIA patients and in other hand young students from urban area. Because the use of questionnaires, which measure QOL, is part of routine medical care, no ethics committee approval was needed.

A cross-sectional study design including patient and control groups was used. Demographic and clinical data were collected as follows: age, sex, onset of symptoms of disease, date of JIA diagnosis, disease duration, tender and swelling joints (TJC, SJC, respectively), limitation of joint mobility (LOM), and core outcome variables including physician's global assessment of overall disease activity, erythrocyte sedimentation rate (ESR), and C-reactive protein value (CRP). Pain and overall well-being were measured using a Visual Analog Scale (VAS). Functional ability was assessed with CHAQ (Child Health Assessment Questionnaire), HAQ (Health Assessment Questionnaire) and clinical functional Steinbrocker classification. Low, moderate and high disease activities were defined using the American College of Rheumatology criteria according the sub-type of JIA [20]. The criterion "remission yes/no" was left to the appreciation of the attending rheumatologist (CJD, JW) without using Wallace's criteria because there was no longitudinal follow-up [21].

The results of immunological tests for Rheumatoid Factor (RF), anti-cyclic citrullinated peptide (CCP) and anti-nuclear antibodies (ANA) were collected. Data on current therapies were collected: non-steroid anti-inflammatory drugs, corticosteroid, methotrexate, leflunomide, hydroxychloroquine, azathioprine, and biotherapy [IL-1 RA, anti TNF-α (etanercept, adalimumab), abatacept and tocilizumab]. The history of surgery was also recorded: we considered only JIA-related replacement procedures.

Health-related quality of life of JIA patients and controls were measured using:

- EuroQOL (EQ), a descriptive system of health-related quality of life states consisting of five dimensions (http://www.euroQoL.org) described in supplementary data (text S1; See the supplementary material associated with this article online). In this study, patients without problems were compared to those with any (moderate or extreme) problems.
- Short-Form-36 (SF36) is a multi-purpose, short-form health survey with only 36 questions (http://www.sf-36.com). Description of SF36 questionnaire and how to calculate sub-scales and composite scores is described in the text S1. Basic and norm-based scoring are used in this study. There is no consensus cut-off for PCS (Physical Component Score) and MCS (Mental Component Score) SF36 allowing the classification of patients into good or bad physical and/or mental QOL. To overcome this problem, we subdivided PCS and MCS into quartiles: JIA patients were considered to have "bad quality of life" when PCS for physical or MCS for mental scale was in the first quartile (Q1) and "good quality of life" when these composite scores were in the fourth quartile (Q4).

All patients were asked to fill in CHAQ, HAQ, SF36 and EuroQOL questionnaires.

3. Statistical analysis

All data analyses were performed using MedCalc® version 12.3.0.0. Data are presented as mean ± standard deviation (SD) for continuous variables and numbers (percentages) for categorical variables. Data were analyzed using Chi^2 tests for differences in frequency and the Student's *t*-test for comparison between two normally distributed continuous variables. A probability value $P < 0.05$ was considered statistically significant. A multivariate stepwise logistic regression analysis was also performed for all variables identified with $P \leq 0.05$ in univariate analysis, with calculation of odds ratio (OR) estimates and 95% confidence intervals (95% CI). ANOVA tests were used for assessments of sub-types of JIA. The correlation between the two questionnaires was determined using the intra-class correlation coefficient for consistency (ICC), in accordance with the two-way mixed model.

4. Results

A total of 161 JIA patients, 120 women and 41 men, and 76 age- and sex-matched controls were included. The mean age was similar in the JIA and control groups (21 ± 3.7 years and 20.2 ± 2.5, respectively; $P = 0.09$). The mean age at diagnosis was 8.6 ± 5 years. Oligoarticular forms ($n = 57$), including 29 extended-oligoarticular forms, were the largest sub-group of JIA (Table 1). The disease activity level could be determined for 109 of the 161 patients: only 6/109 had high disease activity and 36/109 had low disease activity, as previously defined; 67/109 were considered to be in remission. Respectively, the remission was on and off medication in 49/67 (73%) and 16/67 (24%). DMARDs were being taken by 42/161 (26%) patients and biotherapies were used in 80/161 (50%).

There were some demographic and disease differences between the groups with different JIA sub-types: the SpAj sub-group was significantly taller (172 ± 7.7 cm) than the others, the persistant oligoarticular form sub-group was significantly lighter (54.1 ± 10 kg). LOM was more prevalent in polyarticular RF+ and systemic sub-type patients, and corticosteroids were more widely used in systemic, polyarticular RF+ and extended oligoarthritis forms (Table S1).