# **Juvenile Chronic Arthritis**

# From Childhood to Adolescence and Adulthood

#### Akademisk avhandling

Som för avläggande av medicine doktorsexamen vid Göteborgs Universitet kommer att offentligen försvaras i föreläsningssalen (plan 3), Avdelningen för reumatologi och inflammationsforskning, Gulhedsgatan 10A, Göteborg

#### Tisdagen den 27 maj 2014, kl. 13.00

Av

Lennart Bertilsson

### Fakultetsopponent: Professor Berit Flatø Avd for Revmatologi Oslo Universitetssykehus, Rikshospitalet Oslo, Norge

Avhandlingen baseras på följande arbeten:

I. Bertilsson L, Andersson-Gäre B, Fasth A, Forsblad-d'Elia H. A 5-year prospective population-based study of juvenile chronic arthritis: onset, disease process, and outcome.

Scand J Rheumatol. 2012 Oct;41(5):379-82.

- II. Bertilsson L, Andersson-Gäre B, Fasth A, Petersson IF, Forsblad-D'elia H. Disease course, outcome, and predictors of outcome in a population-based juvenile chronic arthritis cohort followed for 17 years. J Rheumatol. 2013 May;40(5):715-24.
- III. Lennart Bertilsson, Boel Andersson G\u00e4re, Anders Fasth, Ingemar F Petersson, Helena Forsblad-d'Elia. Bone Mineral Density and Predictors Thereof in a Population Based Cohort of Individuals with Juvenile Chronic Arthritis 17 Years after Disease Onset. Submitted
- IV. Lennart Bertilsson, Boel Andersson G\u00e4re, Anders Fasth, Ingemar F Petersson, Helena Forsblad-d'Elia. Socioeconomic consequences of Juvenile Chronic Arthritis in a Population Based Cohort of Individuals 22 Years after Disease Onset. Manuscript

# Juvenile Chronic Arthritis

## From Childhood to Adolescence and Adulthood

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**ABSTRACT:** Juvenile chronic arthritis (JCA) is characterized by arthritis and onset before 16 years of age and of unknown etiology with an annual incidence between 7 and 23/100,000 in the Nordic countries. Several studies report different results concerning long-term outcomes. There are few population based longitudinal long-term follow-up studies of JCA.

We have conducted a longitudinal population based study of one cohort of incidence and one of prevalence cases of JCA. Out of 132 patients in the prevalence cohort, 128 were followed for 5 years with annual reports. At the 5-year follow-up the disease was active in 12%, stable in 28%, inactive in 25% and in remission in 34%. Thirty-four percent had changed subgroup, 8% had developed uveitis and the median Childhood Health Assessment Questionnaire (CHAQ) score was 0.13 (range 0.0–1.9). The number of involved joints at inclusion predicted active disease. Disease onset age, number of involved joints with arthritis at inclusion were positively correlated with continuous disease and the CHAQ score at the 5-year-follow-up.

After an average of 17 years from disease onset 86 individuals of the incidence cohort participated in a follow-up. Forty percent were in remission, 44% had changed subgroups, the median HAQ score was 0.0 (0.0–1.5) and Keitel functional test score 100 (54–100). Health related quality of life evaluated by the Short Form-36 was found significantly lower in JCA compared to a reference group. Thirty-nine percent of the individuals in remission at the 5-year follow-up were no longer in remission. Long-term outcome was predicted by characteristics at the 5-year follow-up rather than at the onset.

Calcanear bone mineral density (BMD) was measured with dual-energy absorptiometry and laser in 85 individuals of the incidence cohort at the 17-year follow-up. The BMD Z-scores were significantly lower in both sexes compared to the reference population, also in the individuals in remission. A BMD Z-score < -1SD was associated with the use of hormonal contraceptives in the women and the disease activity at the 17-year follow-up in the men.

To investigate long-term socioeconomic outcomes the prevalence cohort was examined at an average of 22 years after disease onset when the patients had reached 28–35 years of age. Ninety-five participants, 71% of the original cohort, were followed-up. The participants answered a questionnaire concerning education, income, disability benefits, marital/civil status and children. Among the women 14.9% had full or partial disability pension compared to 3.0% in the general population (p<0.001). The men had borderline lower education compared to the general population (p=0.051). No significant differences in income, marital/civil status and reproduction either for men or women were demonstrated; no predictors during the early disease course and socioeconomic outcomes were identified.

To conclude, in these two longitudinal long-term outcome studies, JCA was shown to be heterogeneous both concerning course of subgroup and disease activity and only 40% were in remission at the 17-year follow-up. The quality of life and the calcanear BMD were negatively affected. No large impact on socioeconomic outcomes was found on group level.

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