BACKGROUND: Juvenile Idiopathic Arthritis (JIA) has a broad impact on the child and family life. There is an increasing interest in the importance and recognition of the value of parent/patient reported outcomes (PRO). Juvenile Arthritis Multidimensional Assessment Report (JAMAR) assesses essential aspects of the child’s disease perception and Health Related Quality of Life (HRQoL). The intention is to enhance adequate medical decisions and to improve patient care in routine clinical setting.

OBJECTIVES: To determine the level of agreement between patients with JIA and their parents on the quantitative items of the Norwegian version of JAMAR, the direction of potential differences and if sex, age, disease activity and duration influence the level of agreement.

METHODS: 129 patient/parent dyads participated in the study. The patients, aged 12 to 18 years, were included consecutively at Oslo University Hospital, St. Olavs Hospital in Trondheim, and the University Hospital of Northern Norway in Tromsø during 2012-2013. Both patients and parents completed the JAMAR questionnaire. Demographic and disease specific data were recorded. The study examined the level of agreement for the seven quantitative items in JAMAR. Pain, disease activity (DA) and wellbeing (WB) were measured by a 21-numbered circleVAS, physical function with Juvenile Arthritis Functional Score (JAFS) and HRQoL with Paediatric Rheumatology Quality of Life Scale (JQL) total score including the sub-dimensions Physical Health (JQLPhH) and Psychosocial Health (JQLPsH). Both the direction of the differences in scores and whether sex, age, disease activity (MDGlobal), and duration influenced the degree of agreement were investigated. Intraclass correlation coefficient ICC was used for analysis together with paired and independent t-test.

RESULTS: Median age for patients were 15 years, 66% were girls, 37% had oligoarticular JIA, 25% had polyarticular RF negative JIA, 4% had systemic JIA, 34% belonged to other categories, and median MDGlobal was 1 (range 0-7). As a group, patients and parents median scores were similar, except for JQLPhH, where parents scored better than parents (p=0.002). Correlations between answers from patients and parents were significant for all items (p<0.001), strength varying from ICC 0.70 for JQLPhH to strongest correlation for pain with ICC 0.93. Individual dyads agreement was low showing discordance (>1 in at least one item in up to 70% of the pairs). Male patients scored better and female patients scored worse for WB than their parents (p=0.003). Patients with MDGlobal ≤1 scored less pain and patients with MDGlobal >1 scored more pain than their parents (p=0.01).

CONCLUSIONS: The Norwegian version of JAMAR is a PRO- and HRQoL tool suitable for standard clinical use. The study shows high level of agreement between patients and parents as groups, but the strength of the agreement varies between the items. Comparing dyads showed substantial differences on all items. Thus it is important that both adolescent patients and parents complete the questionnaire, and that both reports are used to support adequate clinical assessment and care.

REFERENCES:

Disclosure of Interest: None declared