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OP0157-HPR AGREEMENT BETWEEN JIA PATIENTS AND PARENTS ON DISEASE PERCEPTION ANALYSED BY THE NORWEGIAN VERSION OF THE JAMAR QUESTIONNAIRE

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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 outcome (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 circle VAS, 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 patients 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 JQLPsH 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 ($p=0.03$). 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 care. 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.

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OP0158-HPR EFFECTIVENESS OF AN E-HEALTH TAILORED SELF-MANAGEMENT PROGRAM FOR PATIENTS WITH RHEUMATOID ARTHRITIS: AN EXPLORATIVE RCT

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Background: E-health programs have potential to support RA patients in self-management. However, many of these programs are developed without involving patients. As a consequence, patient preferences for program use are not well

known and these programs may not well suit patient's needs for self-management support. We developed a tailored e-health self-management program for patients with RA with the help of a patient panel. While self-management interventions are complex interventions, it is informative to perform an explorative RCT before embarking on a larger trial.

Objectives: 1) Evaluate the potential effectiveness in patients with RA of a 12 month tailored e-health self-management program, versus 'usual care', on self-management behaviour, self-efficacy, general health status, focus on fatigue and the level of pain and fatigue; 2) exploration of floor and ceiling effects of the potential outcome measures at baseline and effect sizes at 6 and 12 months after baseline were used to identify outcome measures most likely to capture potential benefits

Methods: The RCT was performed in out-patients from two hospitals in the Netherlands. Inclusion criteria were RA patients 18 years or older, being able to speak and read Dutch and having access to internet. Patients were randomised to 'e-health' in addition to 'usual care' or to 'usual care' alone. The 'e-health' group received 12 months access to the online self-management program. Assessment of outcomes occurred at baseline, 6 and 12 months. Outcome measures included self-management behaviour (PAM-13, SMAS-S), self-efficacy (RASE, PEPP-5), general health status (RAND-36), focus on fatigue (MPCI-F), pain and fatigue (NRS scales). A linear mixed model for repeated measures, using the intention to treat principle was used to study differences between intervention and control groups. A sensitivity analysis was performed to study the influence of high and low compliance in the intervention group

Results: In total 157 patients ($n=78$ intervention group versus $n=79$ control group) were included in the study. A statistically significant ($p<0.05$) between-group difference was only shown for the RAND-36 vitality after 12 months, in favour of the 'e-health' group. Effect sizes were low. Compared with the patients with non or low compliance, patients with a high compliance to the intervention scored statistically significant better on RAND-36 perception after 12 months. Here also, effect sizes were low. Floor and ceiling effects were not apparent in the outcomes used.

Conclusions: Based on these results it is not possible to conclude on possible positive effects of the intervention: for all outcomes the effect sizes were low. Consequently, it is not possible to select outcome measures to be regarded as primary/main secondary outcomes for a larger trial. A process evaluation should be performed to give an explanation for the findings of this study.

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OP0159-HPR REUMANET BERNHOVEN: INTRODUCTION AND EVALUATION OF AN ONLINE SELF-MANAGEMENT TOOL AND PERSONAL HEALTH ENVIRONMENT FOR PATIENTS WITH RHEUMATOID ARTHRITIS(RA)

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Background: Over the past 15 years, there has been a huge shift in the management of RA: the armamentarium has increased but also the way antirheumatic drug are being used has changed, e.g. treat to target. This has implications for how the communication between professional and patient needs to occur: hence shared decision making part of most guidelines. Therefore, healthcare must be organised in a different way: patients should be more involved in their treatment and patient's self-management should play a very important role. The use of a personal health environment can be an effective tool to involve patients in their disease management and helps to optimise the communication between the patient and health professionals.

Objectives: The aim of this project was to create an online personal health environment with self-management tools for patients with rheumatoid arthritis (RA) and determine the factors limiting patients to use this environment.

Methods: Since April 2017 a new online personal health environment was developed in the Netherlands especially for patients with RA, called Reumanet Bernhoven. It includes: 1. an overview of the medication and comorbidities, 2. a graphic of disease-related values (e.g. DAS28, anti-ccp, SR, BMI, 36-Item Short Form Health Survey (SF-36), Health Assessment Questionnaire (HAQ) and RA Impact of Disease (RAID)), 3. a diary, 4. questionnaires such as the different VAS scales (pain, fatigue, general health), Health Assessment Questionnaire HAQ, SF-36 and RAID questionnaire to prepare the outpatient visit. 5. an application to send messages to the health professional. 6. a library with useful disease-specific information. 7. a graphic overview of the DAS28 in combination with the RAID questionnaire to self monitor disease activity. After six months those patients who did not use Reumanet yet were contacted to reveal the cause.