

PARE Poster Tour

POS0057-PARE SUMMARY OF PATIENT/PARENT ORGANISATION SERVICES PROMOTING SELF- AND SHARED-MANAGEMENT OF JIA IN THE UK AND IRELAND

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Background: Various patient/parent organisations provide information, education, and support services to children and young people with JIA and their families. Some organisations are JIA/uveitis focused, while others are umbrella rheumatic and musculoskeletal disease (RMD) organisations or have a broader remit to long-term conditions (LTCs). However, there are no summaries of such collective services offered in the UK and Ireland, which can add to confusion for children, young people, and families, while contributing to inconsistent signposting to services from healthcare professionals.

Objectives: To summarise current and recent services promoting self- and shared-management of JIA by patient/parent organisations in the UK and Ireland.

Methods: An electronic search of known patient/parent organisation platforms (website and/or social networking sites) was performed between August 2020 and January 2021. Materials provided at conference exhibitions since October 2016 were also reviewed. Services were identified, including their aims and further details, if available. These were then mapped by format (e.g., educational, telemedicine, art therapy) and element (e.g., informational videos, monitoring through self-report diaries, discussing art and related feelings), according to their mode of delivery (individual or group), adapted from Sattoe et al. (2015) [1].

Results: Twelve patient/parent organisations in the UK and Ireland were identified (11 of which had some form of charity/company registration): seven were JIA-specific, one was uveitis-specific, two were RMD-focused, and two were LTC-focused. In total, 48 services were identified across the twelve organisations. Generally, group mode of delivery was more popular than individual mode of delivery. Of group-based services, educational and/or support sessions and residential/excursion programmes were the most frequently observed. Of individual-based services, educational sessions including written and visual information were predominant. No one organisation provided services across all formats and elements identified. There appeared to be a limited focus on goal setting, individual level skills training, and explicitly improving self-and/or shared-management capacity. Gamification techniques were notably absent, as was the use of psychotherapeutic approaches, such as cognitive behavioural therapy and motivational interviewing.

Conclusion: Various services are offered by multiple patient/parent organisations with an interest in JIA across the UK and Ireland to promote self- and shared-management. However, no single organisation provides a comprehensive package of services to address the entire information, education, and support needs of children and young people with JIA, or their families. Furthermore, clarity of services offered across the sector is poor. Enhanced collaboration between organisations, together with a clearer focus on enhancing self- and shared-management of JIA across the lifecourse, may help to improve the offering to children, young people, and their families, so that they can more competently manage JIA.

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POS0058-PARE INCREASING PREECLAMPSIA KNOWLEDGE IN SLE WITH A SPECIFIC EDUCATIONAL TOOL: PRELIMINARY RESULTS

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Background: Pregnant women with systemic lupus erythematosus (SLE) are at high risk of preeclampsia, leading to substantial maternal and fetal morbidity. Aspirin reduces preeclampsia risk but recent studies suggest aspirin is used only

in a minority of SLE pregnancies. There is an urgent need to improve preeclampsia counselling and management in this vulnerable population.

Objectives: We are conducting the PREPARE (PREeclampsia knowledge & Aspirin adheRence in lupus prEgnancies) trial, a randomized controlled trial (RCT) evaluating an educational tool on preeclampsia knowledge and aspirin adherence among pregnant women with SLE. We present preliminary analyses of the effect of this tool on preeclampsia knowledge.

Methods: Consecutive pregnant SLE women are recruited until the 16th gestational week at 5

Canadian Systemic Lupus International Collaborating Clinics centres (i.e. Montreal, Halifax, Quebec, Winnipeg, and Calgary) since 05/2018. Subjects are randomly assigned to receive either the specifically-designed educational tool (intervention group) or standard of care (control group). At baseline (i.e. first trimester) and second trimester visits, the participants complete self-administered preeclampsia knowledge questionnaires (scored out of 30 by the research team blinded to the intervention). We restricted the current analysis to participants enrolled in Montreal (accounting for nearly half of the total planned sample size). We performed a univariate linear regression analysis to assess the effect of the educational tool on preeclampsia knowledge (i.e. mean score difference between the two groups from baseline to second trimester visit).

Results: Thirty-three pregnant SLE women were included in the study, among which 16 were exposed to the intervention and 17 were unexposed. Baseline characteristics were well balanced between the two groups with similar mean maternal age between intervention group (32.2 years, standard deviation, SD, 4.6) and control group (34.1 years, SD 4.2) and identical proportion of subjects with post-secondary education (i.e. 80%). The difference in mean preeclampsia knowledge scores between second trimester and baseline visits in the intervention group was 4.4 points (95% CI -0.1, 9.0) and in the control group was 1.5 points (95% CI -2.7, 5.7). The mean difference in knowledge scores (from baseline to second trimester) for those receiving the educational tool was 2.7 points higher (95% CI -1.5, 6.9) than those receiving standard of care.

Conclusion: Approximately midway into the PREPARE trial, we observed a trend for improvement in preeclampsia knowledge from the baseline to the second trimester visit in pregnant women with SLE who received a specifically-designed educational tool compared to the control group, although the CIs included the null. Our RCT is well-poised to provide a new evidence-based approach to improve preeclampsia knowledge in pregnant women with SLE, which could help to optimize aspirin use and outcomes in this vulnerable population.

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POS0059-PARE DELAY TO DIAGNOSIS IN AXIAL SPONDYLOARTHRITIS – TIME FOR A GOLD STANDARD APPROACH

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Background: In the UK, the average time to diagnosis of axial SpA is 8.5 years (1). There is little evidence this has improved, despite the acceptance of MRI use in diagnosis (2). A recent review identified significant clinical, economic and humanistic burden from delayed diagnosis (3). Urgent action is needed to ensure delayed diagnosis is not normalized.