PARE Poster Tour

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

S. Stones¹, V. Swallow², L. Milnes¹. ¹University of Leeds, School of Healthcare, Leeds, United Kingdom; ²Sheffield Hallam University, Department of Nursing & Midwifery, Sheffield, United Kingdom

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.

REFERENCES:

- [1] Sattoe et al. Self-management interventions for young people with chronic conditions: A systematic overview. *Patient Education and Counseling* 2015; 98(6): 704-715.

Acknowledgements: This work formed part of a PhD study funded by the University of Leeds.

Disclosure of Interests: Simon Stones Speakers bureau: Janssen., Consultant of: Envision Pharma Group., Veronica Swallow: None declared, Linda Milnes: None declared.

DOI: 10.1136/annrheumdis-2021-eular.1153

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

J.Y.E. Lee¹, A. Mendel², I. Malhamé³, S. Bernatsky², E. Vinet². ¹McGill University, Experimental Medicine, Montréal, Canada; ²McGill University Health Centre, Department of Medicine, Division of Rheumatology, Montreal, Canada; ³McGill University Health Centre, Department of Medicine, Division of General Internal Medicine, Montreal, Canada

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.

REFERENCES:

- [1] Schramm AM, Clowse ME. Aspirin for prevention of preeclampsia in lupus pregnancy. *Autoimmune Dis.* 2014;2014:920467. doi:10.1155/2014/920467
- [2] Bujold E, Roberge S, Lacasse Y, et al. Prevention of preeclampsia and intrauterine growth restriction with aspirin started in early pregnancy: a meta-analysis. *Obstet Gynecol.* 2010;116(2 Pt 1):402-414. doi:10.1097/AOG.0b013e3181e9322a
- [3] Andreoli L, Bertsias GK, Agmon-Levin N, et al. EULAR recommendations for women's health and the management of family planning, assisted reproduction, pregnancy and menopause in patients with systemic lupus erythematosus and/or antiphospholipid syndrome. *Ann Rheum Dis.* 2017 Mar;76(3):476-85. doi: 10.1136/annrheumdis-2016-209770.
- [4] Mendel A, Bernatsky SB, Hanly JG, et al. Low aspirin use and high prevalence of preeclampsia risk factors among pregnant women in a multinational SLE inception cohort. *Ann Rheum Dis.* 2019;78(7):1010-1012. doi:10.1136/annrheumdis-2018-214434

Disclosure of Interests: None declared.

DOI: 10.1136/annrheumdis-2021-eular.1480

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

D. Webb¹, K. Gaffney², R. Sengupta³, S. S. Zhao⁴, L. Swinger⁵. ¹National Axial Spondyloarthritis Society, CEO, London, United Kingdom; ²Norfolk & Norwich NHS Foundation Trust, Rheumatology, Norwich, United Kingdom; ³Royal National Hospital for Rheumatic Disease, Rheumatology, Bath, United Kingdom; ⁴University of Liverpool, Rheumatology, Liverpool, United Kingdom; ⁵National Axial Spondyloarthritis Society, Service Improvement, London, United Kingdom

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.

Objectives: We created a proposal for a Gold Standard time to diagnosis for axial SpA and a national implementation plan (4) through consensus development with patients, healthcare professionals and professional bodies.

Methods: A.A scoping literature review identifying where delays occur, from first symptom onset to diagnosis by a rheumatologist, and potential solutions. From this, a summary report / draft plan was produced for consultation

B.A national consultation survey to elicit views on the proposals from clinicians, healthcare professionals, professional societies and patients

C.Structured feedback to written proposals via e-consultation with clinicians and patients

D.A consensus development workshop to finalise the Gold Standard and implementation plan.

Results: The literature review identified four delays:

1. People do not know axial SpA may be a cause of their chronic back pain
2. Primary care practitioners may not recognise features of axial SpA
3. People may be referred to non-rheumatologists who may not recognise axial SpA promptly
4. Rheumatology and radiology teams may not optimally request or interpret investigations.

202 participants responded to the summary report (74% patients, 21% healthcare professionals, 5% professional societies). All supported the principles behind the gold standard time to diagnosis. Qualitative analysis confirmed agreement with the proposed solutions, underscoring the importance of education and visibility for axial SpA within primary care and increased public awareness. Additional proposals were suggested, including a tool in primary care to run audits on IT systems.

40 clinicians contributed to the e-consultation and 55 clinicians, policy makers, social marketing experts, health journalists and patients attended the consensus workshop. Consensus was reached on a gold standard time to diagnosis of one year, and the principles, key components and phasing of the implementation plan. This included: public awareness about axial SpA symptoms; a primary care clinical champions programme; creating a referral pathway from primary care direct to rheumatology; a secondary care service educational programme.

Conclusion: There is consensus from UK axial SpA clinicians, patients and professional societies on the need for a Gold Standard time to diagnosis of axial SpA of one year, so that patients can live happy, healthy and productive lives.

REFERENCES:

- [1] Hamilton L, Gilbert A, Skerrett J, et al. Services for people with ankylosing spondylitis in the UK - a survey of rheumatologists and patients. *Rheumatology* 2011;50:1991
- [2] Sykes MP, Doll H, R Sengupta, Gaffney, K. Delay to diagnosis in axial spondyloarthritis: are we improving in the UK? *Rheumatology*, July 2015
- [3] Yi E, Ahuja A, Rajput T, et al. Clinical, Economic, and Humanistic Burden Associated With Delayed Diagnosis of Axial Spondyloarthritis: A Systematic Review. *Rheumatol Ther*. 2020 Mar;7(1):65–87.
- [4] Webb D, Zhao S, Whalley S, et al. Gold Standard Time to Diagnosis in axial Spondyloarthritis: Consultation Document. 2020, NASS.

Disclosure of Interests: Dale Webb Speakers bureau: Janssen, Novartis, Grant/research support from: NASS receives grants from AbbVie, Biogen, Eli Lilly, Novartis and UCB, Karl Gaffney Speakers bureau: Abbvie, Lilly, Novartis, UCB, Consultant of: Abbvie, Celltrion, Lilly, Grant/research support from: Abbvie, Pfizer, Lilly, UCB, Raj Sengupta Speakers bureau: Abbvie, Biogen, Celgene, Novartis, Roche, UCB, Consultant of: Advisory boards for Abbvie, Biogen, Novartis, UCB, Grant/research support from: Abbvie, Celgene, Novartis, Sisheng Steven Zhao: None declared, Lisa Swingle Grant/research support from: NASS receives grants from AbbVie, Biogen, Eli Lilly, Novartis and UCB.

DOI: 10.1136/annrheumdis-2021-eular.846

POS0060-PARE RHEUMATOID ARTHRITIS IN NORWAY: A SURVEY-BASED PATIENT EXPERIENCE

C. P. Fjellstad¹, M. Hägg², M. Kautonen³, R. Mandla⁴. ¹Norsk Revmatikerforbund, PAG, Oslo, Norway; ²Nordic Healthcare Group Oy, Research, Helsinki, Finland; ³Nordic Healthcare Group Oy, Service Design, Helsinki, Finland; ⁴Pfizer, Medical Affairs, Oslo, Norway

Background: The Norwegian Association of Rheumatologists has established a national procedure for management of rheumatoid arthritis (RA) in Norway.¹ The

purpose of the procedure is to support equal and evidence-based diagnosis, care and follow-up of RA patients¹. It serves as guidance to all responsible of RA patient health care. The procedure includes recognized themes in rheumatic care.^{2,3} The impact of the procedure on RA care in Norway is, however, unknown.

Objectives: To understand the patient experience through evaluating how the national procedure for RA is being followed from the patient viewpoint. To identify gaps and areas of improvement to align the national procedure and patient experience.

Methods: Members of patient organization Norwegian Rheumatism Association were invited to answer a survey on demographic and disease-specific variables, perceived health and quality of care. The survey was supported by service design patient interviews (N=14). The invitations for interviews were sent through many initiatives for a representative population.

Results: The observational RA cohort constituted of N=374. The patients were on average satisfied with shared decision-making, care and follow-ups: 71 % felt their illness was under control. Patients in centralized areas were more satisfied with well-being. Diagnosis times have shortened from on average 1.7 to 1.5 year in 10 years. Patients, especially those working, were dissatisfied with rehab support. 30 % of patients felt cooperation of primary and secondary care was not satisfactory and 32 % were worried for future treatment.

Table 1 shows the differences in awareness of comorbidities and regular vaccination need. Where applicable, the table also shows the percentage of patients screened. The results show that patients are aware of risks, but are not being screened for the conditions. Younger patients (< 50 years) with symptoms for less than five years were generally less aware.

Table 1. Awareness of comorbidity and regular vaccination need

	Comorbidities						Regular vaccine need
	Heart disease	Lung disease	Osteoporosis				
	Awareness	Screened	Awareness	Screened	Awareness	Screened	Awareness
Overall (# of patients)	70 % (239/342)	34 % (115/342)	37 % (127/342)	25 % (87/342)	58 % (201/344)	41 % (141/343)	56 % (191/344)
Age							
Under 50 yrs	67 % (42/63)	24 % (15/63)	39 % (24/62)	27 % (17/63)	46 % (29/63)	19 % (12/63)	51 % (32/63)
Over 50 yrs	71 % (197/279)	36 % (100/279)	37 % (103/280)	25 % (70/279)	61 % (172/281)	46 % (129/280)	57 % (159/281)
Disease onset							
Under 5 yrs	56 % (27/48)	19 % (9/48)	29 % (14/48)	20 % (10/49)	51 % (25/49)	21 % (10/48)	59 % (29/49)
Over 5 yrs	72 % (212/294)	36 % (106/294)	38 % (113/294)	26 % (77/293)	59 % (176/295)	44 % (131/295)	55 % (162/295)

The education of patients about regular vaccines (e.g. influenza and pneumonia) could be improved. Only 56 % were aware of the need for these vaccines due to RA. When asked specifically, 73 % of patients had received an influenza vaccine and 48 % pneumonia vaccine.

Conclusion: This survey examines quality of care, shared decision-making, disease awareness and planning and provides a gap analysis of patient experience and national procedure. The results show that national procedure in RA is being followed from the patient viewpoint. Patients are satisfied with care, but information on preventive care (e.g. vaccination and comorbidity awareness and screenings) could be strengthened. This could improve planning of care and the outlook, particularly for young patients.

REFERENCES:

- [1] Aga AB, Haavardsholm EA. Revmatoid artritt. Nasjonal veileder i revmatologi. 2020
- [2] Barber CEH, Lacaille D, Hall M, Bohm V, Li LC, Barnabe C, Hazlewood GS, Marshall DA, Rankin JA, Tsui K, English K, MacMullan P, Homik J, Mosher D, Then KL. Priorities for High Quality Care in Rheumatoid Arthritis: Results of Patient, Health Professional, and Policymaker Perspectives. *J Rheumatol*. 2020
- [3] Brekke M, Hjortdahl P, Kvien TK. Involvement and satisfaction: a Norwegian study of health care among 1,024 patients with rheumatoid arthritis and 1,509 patients with chronic noninflammatory musculoskeletal pain. *Arthritis Rheum*. 2001 Feb;45(1):8-

Disclosure of Interests: Christian Pollock Fjellstad: None declared, Milla Hägg Consultant of: Pfizer, Moona Kautonen Consultant of: Pfizer, Randeep Mandla Shareholder of: Pfizer, Consultant of: Pfizer, Employee of: Pfizer.

DOI: 10.1136/annrheumdis-2021-eular.966