

THU0611 LONG-TERM FOLLOW-UP OF 269 CHILDREN BORN TO MOTHERS WITH SYSTEMIC AUTOIMMUNE DISEASES: A NATIONAL SURVEY FROM 24 RHEUMATOLOGY CENTERS

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Background: Rheumatic diseases (RD) affect women during reproductive age. Children's outcome is a major topic for counselling on family planning, but no large studies are available.

Objectives: We aimed at assessing the long-term health conditions of children born to mothers with RD through a self-reported questionnaire.

Methods: 24 Rheumatology Centers distributed the questionnaire (65 multiple choice and 12 open-answer questions) to consecutive women with RD attending their outpatient clinic during September 2015. Data were compared according to maternal diagnosis (MD) -chronic arthritis (CA) or connective tissue disease (CTD) - and to the timing of pregnancy (before or after MD of RD).

Results: The survey yielded data about 269 children born to 184 mothers (63 CA, 121 CTD). According to MD, children had a mean age of 17.1 (± 9.6 SD) and 14.4 (± 9.0 SD) years at the time of interview, and male children were 52/93 (56%) and 91/176 (52%), respectively. Twenty-nine children in the CA group (31.2%) and 64 in the CTDs group (36.4%) were born after MD of RD. Pre-term delivery (before 37 weeks) was observed in 48 cases (17.8%), mostly children born to mothers with CTD (37/48, 77%).

Regarding school performance, 12 children (4.5%) repeated one year of school, in 7 cases for indolence, in 3 for learning disabilities (LD)/health problems (HP), in 2 for family problems. Eleven of these children were born before MD. Overall, 9 children (3.3%) were diagnosed with a LD and 53 children were affected by HP requiring either hospitalization or evaluation by a Specialist (Table). Three children (1%) were affected by autoimmune disease.

269 children born to mothers with RDs	Children born to women with CA (n=93)	Children born to women with CTDs (n=176)
LEARNING DISABILITIES AND NEURODEVELOPMENTAL DISORDERS n=9/269 (3.3%)		
BEFORE maternal diagnosis	1/64 (1.6%) 1 "slow learner" (1 SGA female)	4/112 (3.6%) 2 LD; 1 ADHD; 1 Autism Spectrum Disorder
AFTER maternal diagnosis	0/29 (0%)	4/64 (6.3%) 3 LD; 1 ADHD
In utero exposure:		n=3 (3 low dose prednisone; 1 azathioprine)
- to drugs		n=4 (3 ANA, 2 anti-dsDNA, 2 anti-Ro/SSA, 2 aGc IgG)
- to maternal autoantibodies		
HEALTH PROBLEMS (ACUTE AND CHRONIC DISEASES) n=53/269 (19.7%)		
BEFORE maternal diagnosis	12/64 (18.8%) 1 Juvenile Rheumatoid Arthritis; 1 Diabetes Mellitus type 1; 8 AD; 2 Pneumonitis	23/112 (20.5%) 1 Chronic Autoimmune Thyroiditis; 1 Early infantile epileptic encephalopathy; 1 perinatal death (respiratory distress); 3 CD; 5 AD; 4 acute disease*; 4 chronic disease*; 4 surgery
AFTER maternal diagnosis	3/29 (10.3%) 1 Trisomy 21; 1 Enterovirus meningitis; 1 CD+AD	15/64 (23.4%) 1 FUO; 3 CD; 5 AD; 1 acute disease*; 2 chronic disease*; 3 surgery

aGc: anti-cardiolipin antibodies; AD: Atopic Dermatitis; ADHD: Attention Deficit and Hyperactivity Disorder; ANA: anti-nuclear antibodies; anti-dsDNA: anti-double stranded DNA antibodies; CD: Celiac Disease; FUO: Fever of Unknown Origin; LD: Learning Disabilities (dyslexia, dyscalculia, dyscalculia); SGA: small for gestational age; *non-neurological, non-immunological, non-infectious conditions.

Conclusions: The long-term follow-up of children born to women with RD is reassuring of an outcome similar to that of the general pediatric population (GPP). Autoimmune diseases are not frequent. Problems seem to cluster in children born to CTD, especially after MD, with a higher frequency of LD (6.3% vs 2.5–3.5% of GPP), but no particular pattern of exposure to maternal autoantibodies nor drugs was observed.

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THU0612 PROVIDING HEALTHCARE FOR THE POOREST IN EAST INDIA – A REPORT FROM A CHARITY INITIATIVE, SHAKUNTALA HOSPITAL

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Background: The region of Odisha in India has a population of over 40 million people and 45% are living in poverty. Approximately one percent of the population is affected by inflammatory rheumatoid diseases. In order to provide early diagnosis and adequate treatment initiation to prevent long term disability, patients require easily accessible basic health care and rheumatologists. Accessible and affordable health care for patients with inflammatory diseases may not only improve disease diagnosis and management, but also improve their quality of life significantly

Objectives: The aim of our abstract is:

1) To raise awareness of the need of support for common rheumatoid diseases in the developing world

2) To present Shakuntala Hospital as an example of a successful charity initiative
Methods: The Indo-Swedish Rheumatology Foundation (ISRF) is an association of physicians whose main aim is to raise awareness, fundraise and to provide health care for patients suffering from inflammatory arthropathies. In order to bridge the gap between our advanced level of knowledge and treatment options in the western world and patients suffering from rheumatologic diseases in the Indian state Odisha we have established this unique association. ISRF, including Shakuntala Hospital, was founded in 2013 and has so far not only provided health care through diagnostic and treatment support, but also ensured patient education and physiotherapy. Health camps are organized in the peripheral communities in order to screen, diagnose and initiate first line treatment and refer these patients for follow-up care to Shakuntala Hospital for further treatments with disease modifying antirheumatic drugs (DMARD), disease monitoring and physiotherapy. Shakuntala Hospital is an example of a non-profit hospital with the aim to provide health care amongst the poorest areas in India.

Results: We have so far registered over 2,000 patients under our care, which includes patients registered in Shakuntala Hospital and in our peripheral care health camps. So far we have established outpatient care for patients with inflammatory arthritis in the districts of Balasore, Maurbhanja, Bhdark, Keonjhar, Jajpur districts of Odisha and Mednapur district of West Bengal and raised more than 32,000 Euro by ISRF from fundraising initiatives.

Inspired by a Swedish model our osteoarthritis (OA) school was founded in October 2016 providing 6 week training courses with the main focusing on patients with knee OA.

Furthermore, ISRF has increased awareness of skeletal fluorosis and provide a comprehensive focus with cleaning of drink water in co-operation with the Royal Technical High School in Stockholm.



Conclusions: Shakuntala Hospital is an example of a successful charity initiative in order to provide healthcare for the poorest patients in East India. Awareness needs to be risen in order to further foster future support for Shakuntala Hospital.

References:

[1] <http://www.shakuntalahospital.com/>.

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THU0613 EXPLORING THE IMPACT OF HEALTH STATUS AND WELL-BEING OF PEOPLE WITH INFLAMMATORY ARTHRITIS ON PRESENTEEISM IN THE WORKPLACE: A QUALITATIVE STUDY

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Background: Presenteeism can be defined as the reduction in work performance due to ill-health at the workplace. Musculoskeletal conditions, including

inflammatory arthritis (IA), are one of the most common causes for presenteeism. There are no "gold standard" methods to identify, measure, or value the impact of presenteeism. Some evidence suggests the impact of presenteeism can be indirectly estimated using measures of health status and well-being.

Objectives: To explore whether selected measures of health status and well-being, commonly used in economic evaluations are conceptually useful to capture those aspects of IA that are associated with presenteeism.

Methods: A sample of individuals, aged 18 years and above, working in the UK with rheumatoid arthritis (RA), ankylosing spondylitis (AS), or psoriatic arthritis (PsA), was recruited via patient support groups. Semi-structured telephone interviews were designed to understand if, and how, RA, AS or PsA affects an individual's ability to work. Framework Analysis Methods were used and coding involved deductive and inductive approaches. A deductive approach was used to derive potential themes from measures of health status [EuroQoL-5 Dimension-5 level (EQ5D-5L) and Short Form 6 Dimension (SF6D)], and well-being (ICECAP-APability measure for Adults (ICECAP-A)). An inductive approach was used to generate other themes not captured by these measures.

Results: Twenty-two employed individuals with RA (n=10), AS (n=9) or PsA (n=3) were interviewed; 82% were female and, of the 22 patients, 23% had a manual job. The majority of interviewees explained that symptoms of the conditions increase levels of presenteeism, including: pain; stiffness; fatigue; emotional mental health; mental clarity. These symptoms make completing activities at work difficult, which, in turn, affects an individual's capability to maintain a successful career. The ICECAP-A was found to be a useful measure to capture the overall impact of presenteeism resulting from RA, AS or PsA. The SF6D and EQ5D were more specific measures capturing particular symptoms and activities that increase levels of presenteeism (see Table 1).

Table 1

Theme	Measure		
	ICECAP-A	SF6D	EQ5D
Achievement /Progress	x		
Decisions	x		
Energy	x	x	
Independence	x		
Mental Health	x	x	x
Mobility	x	x	x
Pain	x	x	x
Self-care	x	x	x
Settled /Secure	x		
Social Interaction	x		
Support	x		
Usual Activities	x	x	x
Vigorous Activities	x	x	

Two further themes were identified using inductive methods: mental clarity and feeling understood. The effect of mental clarity or feeling understood is not captured by any of the domains in EQ-5D-5l or SF6D. The ICECAP-A is potentially able to capture the impact of these themes in the respective domains ability to achieve and progress and ability to gain support.

Conclusions: This study suggests that three existing measures (EQ5D, SF6D, and ICECAP-A) were successful, in different degrees, to capture the impact of presenteeism that result from the aspects and symptoms of IA. Potentially, these measures may be used in economic evaluations to capture the impact of presenteeism.

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THU0614 FIDELITY OF AN INTERVENTION TO INCREASE PHYSICAL ACTIVITY IN OLDER ADULTS WITH CHRONIC PAIN: ANALYSIS OF AUDIO-RECORDED CONSULTATIONS FROM THE IPOPP PILOT TRIAL

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Background: Physical activity levels are low in people >65 years and those with chronic musculoskeletal pain, yet increased physical activity can lead to reduced pain. Walking is acceptable to older people with pain, but interventions to increase walking in this population are untested. The iPOPP pilot trial investigated feasibility and acceptability of a walking intervention delivered by trained Health Care Assistants (HCAs) in 4 general practices in an individually randomised three arm trial (usual primary care, pedometer only and iPOPP, n=50 each arm). The iPOPP intervention comprised two consultations (1 week apart) and 8 weekly follow-up prompts (postcard, email or text).

Objectives: To investigate fidelity of the iPOPP intervention to inform design of a full-scale randomised controlled trial.

Methods: HCAs were asked to record 6 consultations (3 participants, first and second consultation). A fidelity checklist was developed (aligned to HCA training) and included activities expected (pedometer, user guide, walking diary, pain toolkit

given; discussion of walking behaviour and barriers; action planning to develop walking goals; review of progress; positive feedback; revision of goals; relapse prevention strategies; and, preference for weekly prompts). Activities were scored as "Yes" (completed as intended), "partial" (some evidence), "No" (no evidence) or "NA" (not applicable). The checklist was applied to one recording (JP, CCG, CJ). Minor amendments clarified interpretation of checklist headings before application to 3 more recordings (JP, CCG). JP then scored remaining recordings (n=14).

Results: 3 HCAs recorded 18 consultations (9 first, 9 second). Most first consultations did not use the allocated 30 minutes (average 14 minutes). The pedometer, user guide, walking diary and pain toolkit were all given but there was a lack of explanation of the pain toolkit. Evidence of the benefits of walking on pain was well delivered (N=8), motivators to walk and goals were discussed in all 9, with goals set in 7. Barriers to walking were not always discussed (N=4) exploration of maintenance strategies lacking, especially with those patients who perceived themselves as already physically active. All HCAs arranged a second consultation within one week which were brief (average 6.5 minutes) and focused mainly on use of the pedometer. Patient goals were partially re-visited (N=7) and barriers to walking partially addressed (N=5). Maintenance strategies were not discussed (N=8).

Conclusions: Core iPOPP intervention components were well delivered. However we have identified areas to optimise ahead of a full-scale trial (how to discuss barriers to walking and maintenance strategies, development of motivational interviewing skills to support revision of goals, HCA knowledge of local activities). These findings will be triangulated with data from interviews with HCAs and participants to provide further evidence of the feasibility and acceptability of the iPOPP intervention.

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THU0615 PARTICIPANTS' EXPERIENCE OF THE MAKING IT WORK PROGRAM, AN ONLINE PROGRAM TO HELP PEOPLE WITH INFLAMMATORY ARTHRITIS REMAIN EMPLOYED

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Objectives: Health services addressing employment needs for people with arthritis are lacking. To address this need, we developed the Making it Work (MiW) program, an online self-management program aimed at helping people with inflammatory arthritis (IA) deal with employment issues. As part of a randomized controlled trial evaluating program effectiveness, this study reports on participants' experiences with various aspects of the program.

Methods: All participants in the MiW program between Jan20 and Dec7 2016 were included. Participants were recruited from rheumatologist practices, outpatient arthritis programs, a national consumer organization (Arthritis Consumer Experts), and community advertisements in BC, Alberta and Ontario. Eligibility criteria included: having IA; being currently employed; age 18–59 yrs; concern about their ability to work; and access to a computer. The program consisted of 5 online self-learning modules, 5 online group meetings facilitated by a vocational counsellor, an individual ergonomic assessment by an occupational therapist and an online session with a vocational counsellor. Feedback questionnaires were administered online after participants completed the program. Descriptive analyses were performed.

Results: The sample included 69 participants [80% female; mean (SD) age: 45.3 (10.5) yrs; 83% Caucasian; 91% with post-secondary education; 52% with RA, AS: 19%, SLE: 17%; PsA: 12%]. Overall, participants expressed satisfaction with the program with 94.2% agreeing (69.6% strongly and 24.6% somewhat) they would recommend this program to someone they know. When asked to rate program components on a scale of 0–10 where 0=not useful at all and 10=very useful, participants rated all components favourably: median [25Q;75Q] for online modules: 8 [7;10], with highest ratings for the fatigue module (rated 10 by 42%); online group meetings: 9 [7.5;10]; ergonomic and VRC assessments: 8 [7;10] each. Although participants had 2 weeks between meetings to complete the module, 55% did the module the week of, and 42% the day before, the group meeting. Median time to complete each module was 60 min. 81% enjoyed being able to listen to the information (somewhat or strongly agreed), although 35% stated they would have preferred to read the information than listen to a narrator. 74% expect to use the online modules again in the future. Participants were also satisfied with the online group meetings: 93% were very or somewhat satisfied with the group facilitation; 87% satisfied with the group dynamic; 84% comfortable with the online format. When asked to rate their online group meeting experience on a scale of 1 to 10, median [25Q;75Q] ratings for: ability to follow group discussion was 10 [9;10]; getting to know other participants: 7 [7;10]; feeling listened to and understood 9 [8;10]; feeling that group was supportive 9 [7;10]. 20% said it was difficult for them to attend group meetings.

Conclusions: In general, participants were highly satisfied with all aspects of the