Work and rehabilitation

PARE0016 IMPACT OF AXIAL SPONDYLOARTHRITIS ON PATIENTS' PROFESSIONAL LIFE: RESULTS FROM THE ONLINE SURVEY EMAS OF 638 FRENCH PATIENTS

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Background: Axial spondyloarthritis (axSpA) can result in functional limitation and work disability. However, there are little data in the era of biologics.
Objectives: The aim of this analysis was to evaluate the impact of axSpA on professional life.
Methods: Between December 2017 and February 2018, patients followed for axSpA by their rheumatologists or affiliated to the French patients association AFLAR, and self-reporting axSpA, participated in the European Map of Axial Spondyloarthritis (EMAS) cross-sectional patient survey1. Socio-demographics (age, gender, relationship status, educational level, job status), disease activity (BASDAI) and the impact of axSpA on professional life (job choice, working hours, sick leave, unemployment and relationship with colleagues) were collected. The participants who were employed and working at the time of the survey were regrouped as "employed" and the ones employed or on temporary sick leave or students at the time of the survey as "active". No imputation of missing data was performed and the analyses were descriptive.
Results: In France, 638 persons (mean age 41.5 ± 11.1 years, 77% females, mean disease duration 6.9±8.2 years, mean BASDAI 5.9±1.7) participated to the survey. About half of them (51%) had a university degree. At the time of the survey, 54% were employed, 26% in temporary or permanent sick leave, 7% unemployed, 6% retired, 5% homemaker and 2% students. Overall, 176 (28%) received social compensation for handicap or disability due to their axSpA. Regarding the employed ones (n=331), 50% were unskilled workers, 15% had an intermediate profession and 23% a white-collar job. The majority (73%) reported working issues related to axSpA in the last 12 months, such as sick leave (60%), reducing or difficulties to fulfill working hours (62%) or missing working hours for health appointments (33%). Among patients on temporary sick leave (n=72), 92% reported that it was the consequence of their axSpA and the mean duration of their temporary sick leave in the last 12 months was 5.4±4.0 months. Considering active people (n=418), 39% declared that their relationships with their work colleagues were worse since their axSpA. AxSpA had also influenced 55% of them in their job choice and drove 44% to adapt their workplace and 34% to move to another job. Finally, 62% expressed their fear to lose their job because of axSpA.
Conclusion: In this survey of 638 young axSpA patients, 66% of participants were active; the impact of the disease on professional life was described as important and often had consequences including permanent sick leave or unemployment. These aspects of axSpA should be better assessed.

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Arthritis research

PARE0017 EXPLORING DIFFERENCES IN THE AGE ON ONSET OF JIA BETWEEN MALES AND FEMALES: A PARENT-LED SURVEY

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Background: The etiology of Juvenile Idiopathic Arthritis (JIA) remains unknown, despite a range of proposed mechanisms under investigation [1]. However, previous research has revealed biological differences depending on the age of onset of JIA, independent of the classification based on the number of joints involved [2].
Objectives: In this parent-led study, the age of onset of JIA by both disease subtype and sex of the child were explored, to identify whether there is a difference in age of onset of JIA between males and females.
Methods: An online survey was shared via social media, targeted at parents of children and young people (CYP) with JIA. Questions probed the age of symptom-onset and diagnosis (by single year of age), JIA subtype and Rheumatoid Factor (RF) status.
Results: Of the 409 CYP included, 296 had polyarticular (poly) or oligoarticular (oligo) JIA, including extended-oligo JIA (72% of all respondents). There were no differences between onset among these subtypes; therefore, they were grouped for further analysis, given comparable disease progression and genetic markers among these subtypes. There was no significant difference regarding age of symptom onset between RF-positive and RF-negative CYP. Amongst those with poly/oligo JIA, there was a clear peak of symptom-onset in the first few years of life, with over half experiencing symptoms before their third birthday, and 73% before the age of five years. Interestingly, the distribution of symptom-onset was significantly different in the poly/oligo JIA group between males and females (P=0.0093), with the onset of poly/oligo JIA appearing to occur earlier in females (Figure 1). Given that some CYP with older-onset JIA are sometimes reclassified as having enthesitis-related arthritis (ERA) when examined in adolescent services, the Mann-Whitney U Test was repeated with only those CYP with JIA onset before the age of seven years. In this case, there remained a significant difference in age of onset of poly/oligo JIA between males and females (P=0.0061).

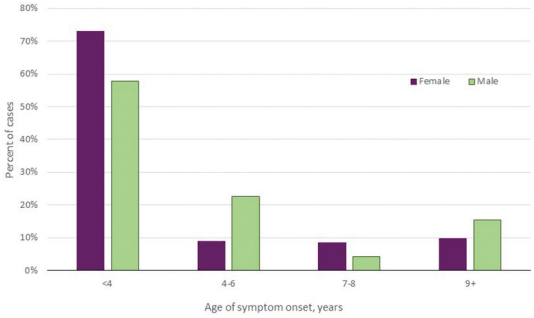

Figure 1. Grouped age of onset of polyarticular and oligoarticular JIA for females and males.

Conclusion: The age of symptom-onset among CYP with poly/oligo JIA differs between males and females, with females tending to exhibit symptoms earlier. This appears not to be attributable to misclassification of JIA subtype, and so this knowledge may assist future diagnoses of JIA. Further research is required to identify which temporal-associated factors may be critical in JIA onset and development.

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Building patient led organisations

PARE0018 ENABLING PATIENT-CENTRED CARE IN RHEUMATOID ARTHRITIS AND ASSOCIATED COMORBIDITIES

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Background: Patients with rheumatoid arthritis (RA) have an increased risk of comorbidities such as diabetes (IR of 8.6 per 1000 person-years[(1)]; 20% prevalence[(2)]), interstitial lung disease (7.7% incidence[(3)]; up to 60% (interstitial lung abnormalities in early RA)[(4)]), depression (up to 200%[(5)]; 16.8%[(6)]), and cardiovascular disease (40-70%[(7)]; 5-12.9%[(8)]) which contributes to increased long-term morbidity and mortality[(9)]. However, despite advances in treatment there are few established recommendations on the management of RA-related comorbidities.
Objectives: This study aimed to identify examples of good practice in the care of RA and associated comorbidities meeting standards of patient-centred care, and consider how these could be implemented in other European centres.
Methods: Following a literature review, multidisciplinary teams including specialists in rheumatology, cardiology and internal medicine, nurses, physiotherapists, psychologists, patient liaisons and care coordinators at 12 selected specialist centres across Europe (1 centre per country) were interviewed (approx. 180 interviews). The models identified were critically reviewed by a group of experts including a patient representative, and the degree to which the interventions impacted patient care and could be implemented in other centres was evaluated.
Results: Several care model interventions were identified which may improve quality and the patient's experience of care, e.g. fully integrated screening and diagnosis of comorbidities; coordination and sharing of care across different disciplines of comorbidity management; tailored individual education of patients and family members on lifestyle; enabling virtual engagement between patients on lifestyle management; and optimised convenience for patients having to attend multiple specialty appointments.
Conclusion: This study identified and evaluated interventions that may improve patient outcomes and quality of care in RA and associated comorbidities. The next steps will be to disseminate and implement these examples of good practices in a variety of European healthcare systems and settings.

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Patient information and education

PARE0019 LIVING WITH SYSTEMIC SCLEROSIS: EXPLORING ITS IMPACT ON CAREGIVERS: A QUALITATIVE STUDY

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Background: Systemic sclerosis (SSc) is a rare, chronic and heterogenous disease with many possible outcomes and an uncertain horizon which presents difficulties not only for patients, but also for caregivers.
Objectives: To gain more insight in the experiences and unmet needs of caregivers for people with SSc in the Netherlands.
Methods: The study had a qualitative design. Participants were recruited by the Dutch patient organization (NVLE) using social media. One focus group and two individual interviews with a semi structured approach were held. Participants were asked to note down their associations with the disease, which lead on to a group conversation moderated by two researchers (MRS, CHE). The focus group was audiotaped and transcribed. Individual telephone interviews were summarized. All participants verified and approved the reports afterwards.
Results: Eight caregivers (4 males, 4 females: 4 partners, 2 widowers, 1 parent and 1 friend) of patients with SSc participated. Six attended the focus group session, two were interviewed over the phone. Several challenges were reported by the participants. The first challenge is coping with the chronic disease course, unawareness of treatment options and lack of information about limitations in treatment modalities. Furthermore, the witness of patients' ailing, changing bodies, decreasing mobility and poor energy levels without being able to provide a cure, was experienced as a huge burden by caregivers. Alongside this distress, caregivers personal lives are also affected; future opportunities are cut off, such as starting a family or continuing an active life style.
Caregivers addressed invalidation and the decrease in support from others due to misjudgment and misconceptions about severity, duration