PATIENT VOICE IN GOUT – A EUROPEAN PATIENT SURVEY TO UNDERSTAND THE NEEDS OF PEOPLE LIVING WITH GOUT

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Background: Gout is one of the most common forms of inflammatory arthritis in Europe, but awareness of it is relatively low. There is limited information available about the impact of gout on patients, and more generally on society.

Objectives: To give gout patients a voice to better understand the impact that the disease has on their lives.

Methods: From June to September 2018, gout patients from 14 European countries were invited to complete a 15 minutes online survey. Adult (18+) patients diagnosed with gout who met the criteria and finished the survey were included in the analysis. The design and content of the survey has been developed together with several patient and clinical experts to ensure that the most relevant aspects of the disease were covered. The questionnaire was translated into 11 different languages and checked that patient-friendly language was used. Patients were recruited via patient associations, leaflets provided to doctors and consumer online market research panels to reach the targeted number of patients.

Results: 1,100 gout patients completed the survey, 78% of respondents were male and 22% female. The mean age of participating patients was 55 years, 56% were employed or studying. The mean age of patients at diagnosis was 45 years and 38% were diagnosed during their first flare. The patients had on average 2.9 flares per year and the length of their last flare was 5 days on average. 84% of patients experienced moderate to severe pain with their most recent flare, 63% had severe pain with their worst flare ever. Patients reported that gout has a significant impact on their daily activities: on their ability to walk (59%), changes in mood and mental well-being (43%) and difficulties relating to their partner (28%). 27% of patients reported that their self-esteem has dropped.

Conclusion: The results of this survey demonstrate that gout has a significant impact not only on patients, but also on their families and society. Gout seems to lead to stigma and many patients may feel guilty about their lifestyle choices. Actions need to be taken to manage dissatisfaction of patients and to encourage them to speak up to request better management of the disease. There seems to be an urgent need to educate both patients and the general public about the seriousness of gout and the burden on patients and their families. The results of this survey will be used for communication with healthcare professionals to better address patients’ unmet needs.

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Psychosocial support

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Background: The most common co-morbidities amongst people with RA are mental health conditions, such as depression and anxiety, as evidenced by previous surveys and reports by the NRAS. NRAS also understands, through interaction with its membership across the UK, that mental health and well-being are important issues for people living with RA and JIA. NRAS therefore partnered with City University to undertake a survey exploring the impact of RA and adult JIA on mental health.

Objectives: To explore the psychological impact of Rheumatoid Arthritis (RA) and Juvenile Idiopathic Arthritis (JIA), along with any psychological support people may have received or would like to have access to, to help manage the anxiety, emotions and stresses that come with being diagnosed with and living with RA or JIA and its treatment.

Methods: Following a focus group held in Central London in early 2018 with a dozen NRAS members, NRAS and City University designed a survey to look at a range of aspects relating to emotional health and well-being, including validated questionnaires to compare data to existing research. The survey was open between May and July 2018, with participants recruited via NRAS newsletters, social media platforms, the NRAS HealthUnlocked forum and via healthcare professionals at rheumatology units. A total of 1,999 people participated in the survey and a final sample of 1,650 was used for analysis.

Results: The survey found that people with RA and adult JIA were less satisfied with their life, believed the things in their life were less worthwhile, and were less happy. The proportion of people who scored poorly on life satisfaction and life worth was over 7 times greater in those with RA and adult JIA than the national average. Despite this, the survey found that 2 in 5 people had never been asked by a health professional about their emotional and psychological well-being, and 1 in 3 people who had requested or been offered support had never received it. Positive experiences that respondents shared included a psychological support, such as GPs and rheumatologists being very supportive, the importance of family, and services offered by NRAS, demonstrate the benefits of good and appropriate support being available. Negative experiences, such as lack of health professional understanding about mental health, lack of understanding of RA by counsellors, and lack of personalised care demonstrate the future work that must be done to help adequately support people with RA and adult JIA.

Conclusion: The survey has demonstrated the need to provide more effective self-management techniques of emotional as well as physical well-being, ultimately leading to overall improved health outcomes. In line with NICE guidelines, other additional support is needed, such as the availability of cognitive behavioural therapy and the implementation of mental health and well-being assessments at annual review. Further research is needed into specific areas, such as health inequalities and why people with severe mental health issues experience poorer disease activity, understanding why adults with JIA have poorer life quality than people with RA, and understanding the impact of psychological interventions for people with adult JIA.

REFERENCES

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Work and rehabilitation

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 limitations 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% 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.

REFERENCE

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Arthritis research

EXPLORING DIFFERENCES IN THE AGE 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 (polo) 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 cases at 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=0.0061).

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.

REFERENCES

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

Figure 2. Grouped age of onset of polyarticular and oligoarticular JIA for males and females.