AB1414-HPR PATIENTS' EXPERIENCES OF FATIGUE IN AXIAL-SPONDYLOARTHRITIS

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Background: Axial spondyloarthritis (ax-SpA) is a chronic inflammatory arthritis that predominantly affects the spine and the sacroiliac joints. Fatigue is recognised as a central ax-SpA symptom. Ax-SpA fatigue is under-explored and often not addressed. Attention in clinical practice seems to be focused on pain and disease activity.

Objectives: The objectives of this study were to explore the meaning, contributing factors and the impact of fatigue on the ax-SpA patients. Self-management and the role of clinicians were also explored.

Methods: A qualitative phenomenological approach was used. A purposive sample of 10 patients with ax-SpA, who were experiencing fatigue (

and attending a specialist rheumatology clinic were selected. The participants completed a demographic questionnaire, the Bath ankylosing spondylitis disease activity index (BASDAI) and the Bath ankylosing spondylitis functional index (BASFI) outcome measures.

Semi-structured interviews using open-ended questions lasted 30-60 minutes. Interviews were tape-recorded and transcribed verbatim. Data was analysed using Colaizzi's framework. Two independent reviewers and 5 participants reviewed the data.

Results: Five males and five females were selected to participate in the study. The mean age was 46.6 years (29 - 69). Seven participants were working. The mean BASDAI was 5.4 and mean BASFI was 5. Most of the participants had disease duration of longer than 5 years.

The six themes that emerged from the data are:

- 1. The meaning of fatigue
- 2. Fatigue patterns
- 3. Factors that modulate fatigue
- 4. The impact of fatigue
- 5. Self-management of fatigue
- 6. Professional support.

Fatigue was defined as an unpredictable, extreme and persistent tiredness. Fatigue had a cognitive and physical component, which was not related to physical activity and did not resolve by rest or sleep. Fatigue was distinguished from tiredness. Tiredness was perceived as a normal feeling which occurred after physical activity and was resolved by rest or sleep.

The severity, duration and frequency of fatigue varied. Fatigue was described as having a multi-factorial aetiology. Fatigue had an overall negative impact upon participants lives affecting their quality of life, leading to psychological and emotional consequences. Participants struggled to self-manage fatigue, receiving no support from health care professionals.

Conclusion: This research has contributed to a better understanding of the patients experiences of ax-SpA fatigue. Fatigue was described as a huge burden and life-changing. Ax-SpA fatigue should be acknowledged in clinical practice. Ax-SpA patients should be asked about fatigue during their clinical consultation. Fatigue should be addressed in its own right and independently from pain and disease activity.

Disclosure of Interests: None declared

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AB1415-HPR PATIENTS PERSPECTIVES ON SELF-MANAGEMENT OF AXIAL SPONDYLOARTHRITIS FATIGUE

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Background: Axial spondyloarthritis (ax-SpA) is a chronic inflammatory arthritis that mainly affects the axial skeleton and can lead to bony ankyloses. Pain, stiffness and fatigue are the most frequently ax-SpA-reported symptoms. Ax-SpA fatigue is multidimensional incorporating physical, psychological and social components, implying that self-management strategies are crucial.

Objectives: This study aimed to explore the self-management of ax-SpA fatigue. Patients perceptions of whether clinicians give importance to ax-SpA fatigue were also explored.

Methods: A qualitative phenomenological approach was used. A purposive sample of 10 patients with ax-SpA, who were experiencing fatigue

(≥7cm on a 10cm VAS scale and attending a specialist rheumatology clinic were selected. The participants completed a demographic questionnaire, the Bath ankylosing spondylitis disease activity index (BASDAI) and the Bath ankylosing spondylitis functional index (BASFI) outcome measures.

Data was collected using semi-structured interviews that lasted about 30-60 minutes. Open-ended questions such as How do you manage fatigue?, How well do you think you are coping with fatigue?, What can be done to help address fatigue? and Is fatigue usually discussed when you attend clinic? were asked to the participants. Interviews were tape-recorded, transcribed verbatim and analysed using Colaizzi's framework. Two independent reviewers and five participants reviewed the data.

Results: Ten ax-SpA patients (5 males) with a mean age of 46.6 years (29 - 69) participated in the study. The mean BASDAI was 5.4 and mean BASFI was 5. Most of the participants had disease duration of longer than 5 years.

Learning to self-manage fatigue was clearly a difficult process for the participants. Only four participants felt that they had learnt to cope with fatigue. They described how they overcame the initial feelings of anger and denial to cope with the fatigue and being told fatigue was part of the condition was helping in accepting the fatigue.

There was consensus that fatigue was not addressed in the clinical setting. Participants felt that they were not guided and supported enough to manage fatigue. More information was needed from health care professionals (HCP) on fatigue management. There was a feeling that HCP focused on the management of pain rather than fatigue.

Conclusion: This research highlighted a clear lack of knowledge about self-management skills to manage ax-SpA fatigue. Lack of adjustments and coping with fatigue was prominent even in patients who had long disease duration. Furthermore, fatigue was not addressed in clinical practice.

Understanding patients beliefs is an important step towards guiding them to self-manage fatigue. Patients should be guided in implementing self-management plans that would fit their goals, priorities and lifestyle. Self-management is important in improving health outcomes and quality of life.

Disclosure of Interests: None declared

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AB1416-HPR A REVIEW OF PUBLIC PATIENT INVOLVEMENT AND ENGAGEMENT (PPI/E) AT THE ARTHRITIS RESEARCH UK CENTRE FOR ADOLESCENT RHEUMATOLOGY AT UCL, UCLH AND GOSH

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Background: The adolescent and young adult (AYA) rheumatology clinical service has a well established culture of involving our users in shaping how services are delivered. Since its inception in 2012 the Arthritis Research UK Centre for Adolescent Rheumatology has worked to offer every patient within the clinical service the opportunity to participate in research

Objectives: This was achieved by 2015 and from 2014 we renewed our focus on an active involvement programme to promote the role of young people in prioritising and designing our research agenda and work-streams. We are currently developing our strategy for the next five years and reviewing our experience to date.

Methods: PPI/E activity records were searched for the period October 2014 to April 2018. This included number of patients involved, their age and diagnosis, and the type of activity along with the number of times they have been involved.

Results: 19 PPI/E activities were organised. From a total of 1554 adolescent and young adult patients 150 patients having been involved in PPI/E, the age range was 11-27 and 118 were female.

The activities consisted of focus groups (79%) and support days (11%) all but two of which were disease specific groups.

The disease specific PPI/E activities have been focused on JIA, JSLE, and JDM. The number of patients involved in these activities were 24.62% (n=99), 24% (n=17) and 66% (n=25) respectively. The mean instances of involvement per disease were 2.09 for JIA, 2.53 for JSLE and 3.56 for JDM.

Conclusion: Our results show that many of our patients have taken part in PPI/E activities (11.19%) with over 65% of our JDM patients having taken part in either a focus group or support day. The focus on