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Onset of Axial Spondyloarthritis Repercussions on Patients' Social and Family Life: Results from the European Map of Axial Spondyloarthritis (EMAS)

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on behalf of EMAS working group

Background:

Axial Spondyloarthritis (axSpA) is associated with a high degree of functional limitation in daily life activities. However, few studies have evaluated the social and family burden from the patient's perspective.

Objectives:

To describe the impact of axSpA on social and family life since disease onset, and the associated PROs.

Methods:

Data from 2,846 unselected patients of the European Map of Axial Spondyloarthritis (EMAS) study through an online survey (2017-2018) across 13 European countries were analysed. The impact of axSpA on social and family life were assessed through four PROs: i) Impact on relationships with the spouse, family, friends, neighbours, and work colleagues since disease onset (5 point Likert scale; 1 "much better" – 5 "much worse"; ii) Frequency of social activities including outings to bars/restaurants, cinema/theatre/museums, practising sports, travel/excursions, and intimate relations since disease onset (5 point Likert scale; 1 "much more" – 5 "much less"); iii) Adaptations made to cope with axSpA since disease onset (yes/no question); iv) The degree of functional limitation in 18 daily activities (3 point Likert scale). Self-reported BASDAI (0-10), spinal stiffness (3-12), functional limitation (0-54), and psychological distress (GHQ-12) were analysed using Pearson's correlation comparing the impact on relationships and frequency of social activities since disease onset.

Results:

Among 2,846 participants, mean age was 43.9 years, 61.3% were female, 48.1% had a university degree. The greatest impact on relationships (sum of 'worse' and 'much worse') since disease onset were those with work-colleagues (44.5%), friends (35.6%), and spouse (30.4%). Sport was the activity they reduced the most since disease onset (64.2%), followed by travel/excursions (57.3%) and intimate relationships (56.4%) (Fig. 1). 55.5% had purchased comfortable shoes (N = 2748) and 43.9% had made adaptations to their

workplace (N = 2651). For those who reported their level of functional limitation in daily activities, the greatest limitations were in physical exercise (85.5%), cleaning the house (84.4%) and using stairs (79.2%) (Fig. 2). In the correlation analysis, BASDAI, spinal stiffness, functional limitation, GHQ-12 were associated with a worsening in all of relationships and social activities (p < 0.001) (Table 1).

Conclusion:

For most participants the onset of axSpA marked the worsening of personal relationships in different areas, as well as the reduction of social, leisure, and entertainment activities.

References:

Figure 1. Reported social and family life changes since disease onset

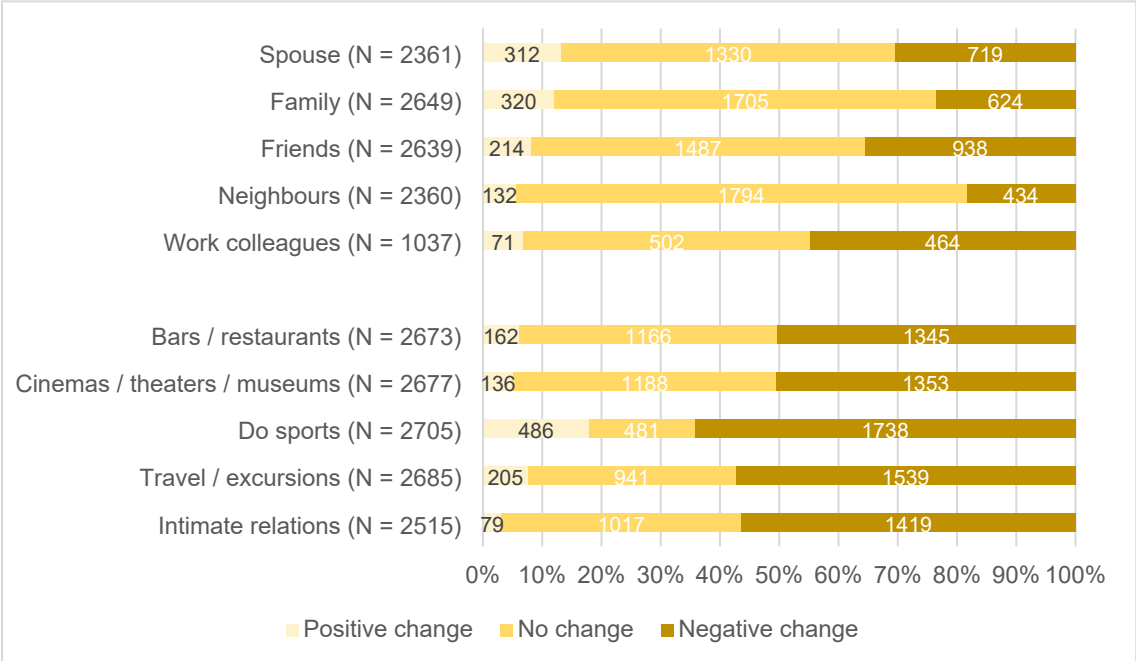


Figure 2. Reported level of functional limitation in daily life activities

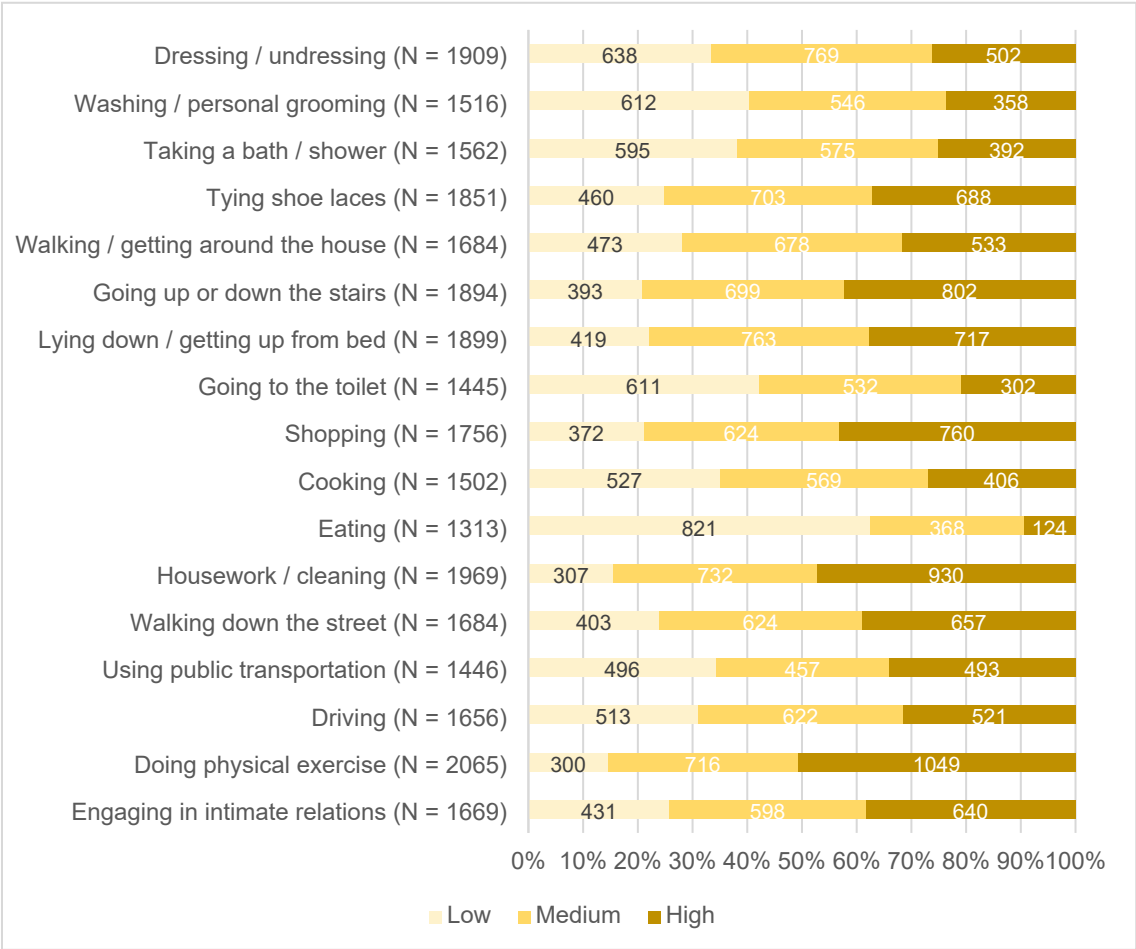


Table 1. Pearson's correlation between social and family life changes and PROs

Relationships: 1 much better – 5 much worse	BASDAI	Spinal Stiffness	Functional Limitation	GHQ-12
Spouse	0.157*	0.130*	0.167*	0.258*
Family	0.162*	0.133*	0.138*	0.206*
Friends	0.211*	0.173*	0.180*	0.282*
Neighbours	0.210*	0.165*	0.112*	0.229*
Work colleagues	0.229*	0.153*	0.213*	0.334*
Frequency activities: 1 much more – 5 much less				
Bars / restaurants	0.261*	0.246*	0.314*	0.316*
Cinemas / theatres / museums	0.291*	0.243*	0.299*	0.338*
Do sports	0.271*	0.213*	0.240*	0.242*
Travel / excursions	0.308*	0.218*	0.307*	0.362*
Intimate relations	0.284*	0.254*	0.288*	0.321*

*p <0.001

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