

Diagnostic delay in axial spondyloarthritis

Rebecca Parris (r.parris1@lancaster.ac.uk); Supervisors; Dawn Goodwin and Brigit McWade

Axial spondyloarthritis

- Axial spondyloarthritis (axSpA) is a form of arthritis characterised by inflammation of the entheses, where tendons and ligaments join to bone, in the spine and other joints. See fig. 1.
- Left untreated, it can lead to complete fusion of joints, especially in the spine.



Fig.1
Left: normal spine
Middle: early axSpA
Right: advanced axSpA

- The burden of the condition is variable, but it can be considerably reduced with early diagnosis and appropriate treatment.

The problem

- Mean diagnostic delay is reported to be between 8 and 10 years.
- Although more widespread use of MRI and the introduction of the NICE guideline in 2017 have led to some signs of improvement, significant diagnostic delays remain. (Barnett et al., 2020).
- Women, on average, experience both significantly greater delays in receiving a diagnosis (Rusman et al., 2018) and a greater symptom burden.
- Healthcare professionals often lack knowledge and awareness of axSpA.
- Misconceptions about the epidemiology of axSpA still prevail.
- These include that axSpA is a male disease, that it only occurs in people who have a specific genetic marker, and that inflammatory markers are always raised.

Research questions

- How is diagnostic delay experienced by people with axSpA?
- Are these experiences different for women and men?
- What do general practitioners think the diagnostic challenges are?
- What do rheumatologists think the diagnostic challenges are?

What is known about diagnostic delay in axial spondyloarthritis?

- Most studies have been quantitative only.
- Widespread concern has led to the formation of an All-Party Parliamentary Group (APPG) for axial spondyloarthritis.
- The APPG has concluded (Webb et al., 2020) that the causes of diagnostic delay come under four main headings. See fig. 2.

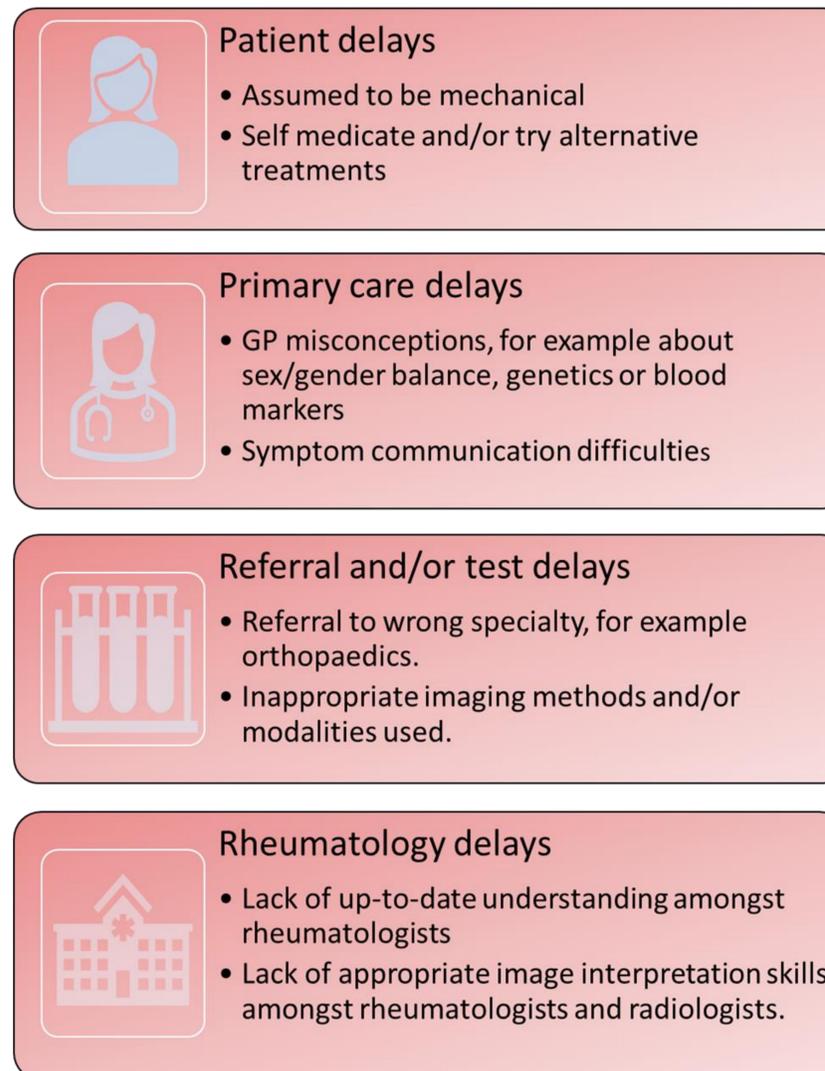


Fig.2
The main reasons for diagnostic delay identified by the All-Party Parliamentary Group for Axial Spondyloarthritis.

Method

- Qualitative thematic analysis.
- Semi-structured interviews with:
 - 20 – 25 people with axSpA who experienced diagnostic delay.
 - 5 –10 GPs.
 - 5 –10 Rheumatology specialists.

Aims

- I hope to uncover common themes in participants' experiences.
- I look particularly to highlight the experience of women with axSpA.
- I seek to identify diagnostic challenges from the perspective of medical practitioners.

References

- Webb, D., Zhao, S. S., Whalley, S., Hamilton, J., Sengupta, R. & Gaffney, K. (2020) A Gold Standard Time to Diagnosis in Axial Spondyloarthritis. London.
- Barnett, R., Ingram, T. & Sengupta, R. (2020) Axial spondyloarthritis 10 years on: still looking for the lost tribe. *Rheumatology*, 59 (Supplement_4), iv25-iv37.
- Rusman, T., Van Vollenhoven, R. & Van Der Horst-Bruinsma, I. (2018) Gender Differences in Axial Spondyloarthritis: Women Are Not So Lucky. *Current Rheumatology Reports*, 20(6), 1-12.