Disclosure baseline. The risk of major infections in juvenile SLE is significant and associated with worse in those who had an episode of major infection. Overall survival was 76.8-88.7 and 72.5% (95% CI 65-80.9) respectively. There were eight daily doses of corticosteroids (OR1.09, 95% CI 1.05-1.14) and predictors of a major infection. On multivariate analysis, only higher (16.1 vs 12.11-21) and a higher daily dose of prednisolone (2.5), use of cyclophosphamide (OR 7.63), higher baseline SLEDAI (zoster (2), Herpes simplex (1), MRSA (1), and Candida (1). Gastrointestinal involvement (OR 4.21), major organ involvement (OR zoster (2), Herpes simplex (1), MRSA (1), and Candida (1). Gastrointestinal involvement (OR 4.21), major organ involvement (OR 249), arthritis. In populations with axial spondyloarthritis (SpA), the risk of developing mental ill-health is high - for depression more than twice that of control populations. Positive emotions are protective against psychological distress and emotional wellbeing is favourably associated with physical illness prognosis. However, the emotional experiences of people who live with axial SpA are not well understood. This study aimed to explore and synthesise qualitative data about the emotional experience of living with axial SpA and identify barriers and facilitators to emotional wellbeing.

Methods First, a systematic review and thematic synthesis was conducted. Nine databases were searched from inception to December 2019. Qualitative and mixed methods studies were included if they reported qualitative participant level data about the lived emotional experiences of people with axial SpA and were published in English or German. The search was updated in March 2021. Study quality was assessed using a modified version of the CASP (Critical Appraisal Skills Programme) qualitative tool. Grey literature was appraised using the Authority, Accuracy, Coverage, Objectivity, Date, Significance (AACODS) checklist. Data were extracted, coded and categorised. Synthesis involved translation of concepts from one study into another and development of descriptive themes. Second, four axial SpA online forums were searched from inception to June 2020 for posts from UK-based individuals with axial SpA containing data about their emotional experiences of axial SpA. Thematic analysis was undertaken.

Results Of 10,824 database records screened, 27 studies, published between 1993 and 2020, went forward for synthesis. Study populations included people diagnosed with Ankylosing Spondylitis (n = 1143), axial SpA (n = 53) and non-radiographic axial SpA (n = 18). Two studies with mixed populations (n = 37) did not specify numbers diagnosed with axial SpA. Most participants were male and had established disease. No studies specifically focused on the psychological experiences of living with axial SpA. 537 posts were identified from online fora, 278 (52%) of which were from men. Seven descriptive themes were generated from the qualitative synthesis: delayed diagnosis: a barrier to emotional wellbeing; disruptive symptoms: a source of mood swings; work disability: a loss of self-esteem; obstacles in interpersonal relationships: a trigger of distress; taking up exercise: ‘personal pride’ or ‘unwelcomed reminders’; anti-TNF therapy: hope reignited despite concerns; journey of acceptance: worry mixed with hope. The findings from our review of online fora supported and validated these themes. One additional theme - COVID-19: uncertainty and anxiety during the pandemic - was developed from constructs identified from online posts.

Conclusion Our findings highlight substantial negative and mixed emotions experienced by people with axial SpA. However, data about the emotional experiences of women, people diagnosed with non-radiographic axial SpA, and those in the early stages of diagnosis, are limited.
Disclosure
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