

## Managing pain: A qualitative exploration of complementary and alternative medicine therapy use in individuals with Axial Spondyloarthritis

**Background:** Axial Spondyloarthritis (AxSpA) is a chronic inflammatory disease predominantly affecting the spine, causing back pain and stiffness. A significant issue for the treatment of AxSpA in the UK is the management of pain and stiffness before and after diagnosis. An often lengthy delay in diagnosis of AxSpA (Sykes et al., 2015) can lead to poor pain management. This delay is partly due to the difficulties that health care professionals experience in identifying inflammatory back pain (Mansour et al., 2007). Previous research has shown that up to 40% of 276 AxSpA patients attending a tertiary care rheumatology service had used at least one form of complementary and alternative medicine (CAM) therapy prior to diagnosis (Sengupta et al., 2014).

**Method:** The study used semi-structured telephone interviews to further understand CAM use by people with AxSpA. Participant details:

- Eight AxSpA individuals (5 female)
- Recruited via a public engagement event / previous online survey.

Interview data was transcribed verbatim and analysed using thematic analysis (Braun & Clarke, 2006) to identify initial codes and subsequent themes to represent participant experiences of using CAM to manage their pain. Ethical approval was granted by Bath Spa University.

**Results:** Participants reported using a range of CAM therapies (including hydrotherapy, reflexology, and acupuncture). Participants were given pseudonyms to maintain anonymity. Two themes were identified from participant's narratives:

(1) **'a pain in the neck'**; where participants' narratives highlighted that symptoms appear in painful bouts and flares, that diagnosis is prolonged and that they have become experts on their own bodies through management of their own symptoms.

'Big bouts' and 'bad flares'

*'And it's a bit like a horror movie, because you can't move, and the pain is there, but you've got to move because there's nowhere else to go... So I just somehow just have to get to where I can somehow squat or something, or sit down. And then usually it passes. But it is very, very acute pain.'* (Tracey)

'Finding the holy grail'

*'Yeah, and it was like finding the Holy Grail really, because it was like, right, now we know what we're dealing with and we can start to sort of treat it. So, yeah, it was like a eureka moment really.'* (Matthew)

'We know our own bodies'

*'I would still get flare-ups but now I've had the condition for such a long time I can usually spot the symptoms, so if I know it's coming then I can actually take anti-inflammatory medication on an as and when basis'* (Henry)

(2) **'suck it and see'**; that CAM is generally a positive experience, and is a valuable tool in relieving symptoms. Despite many difficulties and concerns that some therapies might make things worse, AxSpA individuals encourage others to try a variety of CAM therapies to find one that suits.

'it makes you feel good'

*'I think the Pilates undoubtedly, and the massage, yes. And the hydrotherapy definitely does. And the osteopathy... Yeah, that helps. I tend to only go and see him for one session, because his work is accurate and very helpful.'* (Amelia)

CAM Vs. Mainstream

*'I would say they contradict each other... I don't mean the hydrotherapy... it wouldn't be contradictory to do acupuncture and hydrotherapy, but I think it would be contradictory to use a chiropractor or an osteopath in our condition from what the healthcare professionals are telling us'* (Penelope)

'swings and roundabouts'

*'I don't use reflexology any more, mainly because it's quite expensive to use that on a regular basis. Even physio is expensive. I'm a firm believer that the NHS ought to provide better services'* (Kyle)

Participants made many distinctions between CAM and mainstream care, but suggested that an integrative approach may be best for pain management, particularly to enable them to access therapies that greatly reduced their pain and reliance on pain medication on the NHS. AxSpA symptoms vary greatly throughout the patients' journey and a client-led approach appears to be optimal for pain management, as without this, patients feel they are not being listened to.

**Conclusion:** This study explored the use of CAM therapies as symptom management in AxSpA individuals. CAM therapies provide useful pain relief for patients, which may be improved with greater accessibility to CAM therapies through the NHS. The usefulness of CAM in supporting AxSpA individuals should be better acknowledged and could be implemented into an integrative approach to empower patients to manage their pain in addition to mainstream care.

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