A qualitative study of complementary and alternative therapy use by people with ankylosing spondylitis, prior to their diagnosis.

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Lay Summary

Ankylosing spondylitis (AS) is a chronic inflammatory disease affecting the back, causing ongoing pain and stiffness in individuals affected by this condition. People with symptoms of AS may experience symptoms for five years or longer before they receive a diagnosis. It is thought this is due to the difficulties that clinicians have in recognising the difference between AS symptoms and other types of back pain. Research has found that people with AS feel they have to fight for a diagnosis and to be believed about their symptoms. For this reason, they may be accessing complementary and alternative therapies (CAM) as a way to help them to manage their symptoms. In line with this, it has been found that approximately 40% of people with AS used one or more form of CAM before receiving their diagnosis.

The aim of this study will be to further explore AS patients’ CAM use prior to diagnosis. A survey, will be conducted with AS patients to ask them about their use of CAM, and CAM practitioners about their experiences of treating people with possible AS. Understanding patterns of CAM use prior to diagnosis may help identify opportunities to reduce delays in diagnosis through CAM settings.

Scientific Summary

Delay to diagnosis remains a significant issue in the treatment of Ankylosing Spondylitis (AS) in the UK [i]. The delay is in part due to the difficulty that general practitioners and other clinicians experience in identifying inflammatory back pain [ii] and low public awareness of the condition. AS patients report needing to fight for a diagnosis and to be believed about their symptoms [iii]. Difficulties gaining a diagnosis and treatment may lead to the use of complementary and alternative therapies (CAM). A survey of 276 AS patients attending the RNHRD found that 40% had used at least one form of CAM prior to diagnosis. This study also found that CAM practitioners were less confident in managing inflammatory compared to mechanical back pain [iv].

The aim of this study will be to further explore AS patients’ CAM use prior to diagnosis with the objectives of understanding the factors that influence individuals’ decisions to (or not to) access CAM services, and the advice that CAM practitioners provided about symptoms. A qualitative survey, involving free text responses will be conducted with both AS patients and CAM practitioners to explore these objectives and consider opportunities to reduce delays in diagnosis through CAM settings.

References


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