A truly complementary approach: A qualitative exploration of complementary and alternative medicine practitioners' views of treating Ankylosing Spondylitis

Abstract

Objective: Ankylosing Spondylitis (AS) is a chronic inflammatory rheumatic disease in which individuals experience a lengthy delay to diagnosis. Prior to diagnosis, individuals report frequent use of complementary and alternative medicine (CAM) therapies. Whilst popularly used, there is a dearth of knowledge concerning the experiences of CAM practitioners in terms of treating individuals with AS. Addressing this knowledge gap, this study provides a detailed exploration of how UK based CAM practitioners treat individuals with AS.

Methods: Semi-structured telephone interviews were conducted with eight UK based CAM practitioners, (4 males), aged 45-69 years. CAM practitioners were recruited across a range of CAM therapies and years of CAM practice experience (8-46 years).

Results: Thematic analysis resulted in identification of three themes to characterise the data. Themes comprised: (1) the whole picture; (2) alarm bells, and (3) a common language. Themes highlighted CAM practitioner adoption of a holistic yet individualised approach to treating individuals with AS, despite a general sense of lack of knowledge concerning AS amongst CAM practitioners. Notably, results indicated a desire of CAM practitioners to work more collaboratively with mainstream health providers to provide more joined-up care for individuals with AS.

Conclusion: CAM practitioners emphasised the benefits of CAM to focus on providing effective symptom management when used in conjunction rather in opposition to mainstream health care. Adoption of a more holistic approach to AS management by CAM practitioners may empower clients to become more aware of symptoms, thus potentially reducing delays in receiving a formal diagnosis of AS.

Introduction

Ankylosing Spondylitis (AS) is a chronic, rheumatic condition causing inflammation of the spine and peripheral joints. Whilst the term Axial Spondyloarthritis has been more recently used to describe this type of Spondyloarthropathy (Akkoc & Khan, 2016; Sieper & van der Heijde, 2013) the term AS has been used throughout this paper as the most common and recognised term by individuals with AS and CAM practitioners.

Global figures estimate prevalence of AS to be 0.1-.2% (Dean et al., 2014) with average age of onset at 17-24 years old, a higher prevalence in men (Haroon, Paterson, Li, & Haroon, 2014) and an average age of 33-39 years at receipt of diagnosis (Feldtkeller, Khan, van der Heijde, van der Linden, & Braun, 2003). Delay in diagnosis is a particular issue in AS (Sykes, Doll, Sengupta, & Gaffney, 2015), with average delays of 9.8-10.4 years between symptom onset and diagnosis, although delays of 30 years have been reported (Feldtkeller & Erlendsson, 2008). Delay in receipt of an AS diagnosis is typically due to the difficulty that clinicians experience in identifying inflammatory back pain (Mansour et al., 2007), recognition of the main diagnostic criteria for AS (Dincer, Cakar, Kiralp, & Dursun, 2008), and an inability to differentiate this from mechanical back pain (Jois, Macgregor, & Gaffney, 2008).

During the period between symptom onset and receipt of diagnosis, individuals will typically attempt to self-manage their symptoms. The process by which individuals interpret and manage illness is usually conceptualised in terms of the self-regulatory model (Leventhal, Meyer, & Nerenz, 1980). This process starts with an interpretation of symptoms, whereby individuals develop illness cognitions (thoughts about cause, identity, timeline, consequences and curability of symptoms). This interpretation then influences the coping strategies chosen to manage their symptoms (Leventhal, Diefenbach, & Leventhal, 1992). When explanations or coping strategies are deemed inadequate, further assistance is typically sought from health professionals (Sheppard, Kumar, Buckley, Shaw, & Raza, 2008). Where no satisfactory explanation or symptom relief is experienced, individuals may then seek complementary and alternative medicines (CAM) (Bishop, Yardley, & Lewith, 2006) as an alternative coping strategy.

A UK survey of 276 AS patients found use of at least one type of CAM (osteopaths, chiropractors, acupuncturists or masseurs) by 40% of participants prior to diagnosis (Sengupta, Cook, & Gaffney, 2014). Defining CAM as any treatment outside prescription or recommendation from a mainstream practitioner, one Australian study identified CAM use in 94.7% of individuals with AS (Chatfield et al., 2009). In contrast, a UK population based study estimated that 32.1% of the adult population in England had used at least one of eight CAM therapies, demonstrating that individuals with AS make greater use of CAM compared with the general adult population.

Whilst evidence has demonstrated that individuals with AS use CAM therapies, research has focused on the experiences of individuals with AS rather than CAM practitioners. Only one study has explored the experiences of CAM practitioners with regard to treating individuals with AS (Sengupta et al., 2014). CAM therapists in this study reported lower confidence in managing inflammatory compared with mechanical, back pain. Consequently, little is known about CAM practitioners' knowledge and understanding of AS, their diagnosis and treatment of AS, how individuals with AS present symptoms to CAM practitioners and the possible benefits of CAM treatment for individuals with AS. This study addresses this knowledge gap, using qualitative methods to provide a detailed understanding of the experiences and knowledge of CAM practitioners towards diagnosing and treating individuals with AS.

Materials and Methods

This study adopted a relativist epistemology, seeking to gain a better understanding of what happens when people with AS visit CAM practitioners, through CAM practitioners accounts of their process and approaches to diagnosis. A phenomenological approach was also taken, analysing CAM practitioners accounts of their experiences of working with clients with AS, and what these experiences meant to them (Willig, 2013).

Semi-structured telephone interviews were conducted with eight CAM practitioners. Individuals were recruited to participate, either through an expression of interest at a public engagement event, completion of a previous online survey for CAM practitioners or via invitations

advertised by CAM regulatory bodies via social media, email or newsletter. Included participants were 18 years or above, UK based, fluent in English and currently practising at least one CAM therapy. For the purpose of this study, CAM therapy was defined as 'any health and wellbeing therapies or treatments that are not considered to be part of mainstream health care'. To ensure a range of views were captured, a specific effort was made to recruit male and female therapists who practised a wide range of CAM therapies. The minimum sample size was determined by the phenomenological focus of the study, for which a minimum sample of six participants is required (Morse, 1994). Recruitment continued until a range of CAM practitioners (as described above) were recruited, and data saturation had been reached (when no new information was being gained through additional interviews).

A topic guide (see Figure 1) was produced collaboratively by researchers with shared expertise in qualitative methods and AS, using a focus on the self-regulatory model and illness cognitions as a guide (Leventhal et al., 1992; Leventhal et al., 1980). Topic guide questions were developed following discussions with individuals with AS and CAM practitioners at a targeted public engagement event and later reviewed, amended and added to by two further individuals with AS, and two CAM practitioners independent to the study team. The topic guide addressed types of CAM practised, practitioner knowledge and experience of managing AS.

Following ethical approval from the Department of Psychology Research Ethics Committee at XXX University (31/05/2016), participants were recruited to the study. Eligible individuals provided informed written consent prior to participation and verbal consent at the start of each interview. Telephone interviews were audio recorded with a duration of 25-60 minutes. Participants received a debrief form and a £20 shopping voucher to thank them for their time after completing the interview.

Interviews were transcribed verbatim and anonymised. Data was analysed using Braun and Clarke's (Braun & Clarke, 2006) six phase thematic analysis. This involved the authors familiarising themselves with the data via audio files and transcripts, conducting semantic coding of data between authors across multiple time points, then searching for meaningful patterns and identifying similarity in the data codes to construct themes. Subsequent phrases included reviewing and refining of themes, creation of concise descriptions of named themes and report write up.

In order to establish quality, trustworthiness and credibility in the data (Morrow, 2005), all authors reviewed analyses at each stage of development and effort was made to include quotations from all participants when reporting results (O'Brien, Harris, Beckman, Reed, & Cook, 2014). Following guidance from Tong et al. (Tong, Sainsbury, & Craig, 2007), the authors used researcher triangulation to produce a greater and more accurate level of understanding of the client experiences.

1. Please tell us about how and when you became a CAM practitioner. *Prompts: qualifications, training bodies, length of practice, types of CAM practiced.*
2. Please tell us about your experiences of treating clients with back pain. *Prompts: symptoms clients present with, approach to treatment and diagnosis.*
3. Please tell us about any experiences you have had of treating clients with AS. *Prompts: How many clients? What is known about AS? When do AS clients present themselves? (before/after formal consultant diagnosis?)*
4. How did you learn about how to approach treating clients with AS? *Prompts: Academic journals? CAM professional bodies? Colleagues? National Ankylosing Spondylitis Society?*
5. What do you do when you suspect that a client has AS? *Prompts: How do you describe this condition/ explain their AS symptoms to patients. Timeline? Refer to other services? Own treatment approach? Tests (e.g. MRI/blood)?*
6. How do you support clients with AS over time? *Prompts: Follow up? How frequent/how many/time period? Who instigates follow up appointments? Collaboration with other HCPs/CAM practitioners? What would prompt finishing treatment? Lifestyle advice?*
7. How do you identify whether a client with AS is responding to treatment? *Prompts: Subjective accounts? Measure outcomes? How often? Which outcomes?*
8. What do you think are the main ways in which CAM therapies can help clients with AS?
9. Please tell us about any challenges which might arise when managing a client with AS.
10. How does your treatment of clients with AS fit with more traditional medical treatment for AS? *Prompts: Advise on meds? Advise about exercise? Similarities/differences?*
11. Is there anything else that you think we should know about the use of CAM in the management of AS symptoms?

Figure 1. Interview topic guide

Results

Eight CAM practitioners (four males, four females) aged 45-69 years who had practised a range of CAM therapies across the UK for 8-46 years took part in the interviews.

Insert Table 1 about here

Data were characterised by three themes: (1) The whole picture, (2) Alarm bells, and (3) A common language. Each theme is presented in turn with illustrative, verbatim quotes from participants' narratives (participant names are pseudonyms).

Theme 1: *The whole picture*

This theme concerns the therapeutic approach adopted by CAM practitioners in treating AS and the nature of the client-practitioner relationship. Prior to seeking CAM treatment, CAM practitioners reported that clients had typically experienced a journey characterized by multiple appointments with different healthcare professionals giving conflicting advice, leaving the individual confused about effective strategies for AS symptom management. As highlighted in the quote below, CAM practitioners sought to provide holistic individualised care that pieced together individual's physical, social and psychological symptoms.

> '*…helping people understand sometimes how to present the whole pattern of their symptoms…It's like you do look at the whole picture, otherwise you can miss out, and I think that seems to really delay the diagnosis of things.*' (Helen, Reflexologist, Shiatsu practitioner and Aromatherapist)

CAM practitioners described clients as experts of their own condition, placing them at the centre of their treatment by acknowledging the client's expertise about their own body.

> *'Because it's their body. So that's the first thing you've got to take into account, their diagnosis, because they're treating it I'm not. I'm not the expert.'* (Timothy, Sports therapist and Bowen therapist)

Taking a broad approach to treating AS enabled CAM practitioners to address a variety of symptoms and wellbeing issues reported by the client, ensuring that treatment addressed the client's individual concerns. This was achieved through listening to the client and empowering individuals to understand their symptoms; a luxury not often afforded to mainstream providers due to appointment time constraints.

> *'I think we can be supportive. We can certainly listen and we have the time to give people a listening ear. Often when that happens, when there's space and time, patients and clients come up with their own solutions…So we can do that. I think we have the luxury of more time than perhaps mainstream therapists like physiotherapists do.'*
> (Susan, Shiatsu and massage therapist)

Clients were at the very front of CAM therapy. In particular, CAM practitioners aimed to support clients to autonomously manage their symptoms through demonstrations of progress over time, symptom charting and engaging with self-care at home. Self-care advice might include re-affirming the strategies recommended by mainstream healthcare professionals in addition to relaxation techniques and CAM specific exercises. Treatments were flexibly timed, occurring when required by clients due to presentation of particular symptoms. This flexible approach to treatment timing also reflected a broader focus on placing individuals at the forefront of treatment.

> '*I will maybe see the patients and then I won't see them for a few months and then they'll have a flare-up and then I'll see them again' and 'if their response to the treatment has been successful, then what I would do is I would actually offer them an open appointment.'*
> (Adam, Acupuncturist)

Theme 2: *Alarm bells*

This theme captured practitioners' narratives concerning their experiences of working in CAM, their knowledge about AS and approach to treatment and diagnosis of AS.

Typically, CAM practitioners reported little everyday experience of working with individuals with AS. Practitioners most experienced in treating clients with AS were confident in distinguishing clients with AS from their other clients, reporting them to be younger, with reduced mobility and associated comorbidity.

'*Well, the first client I came across was some years ago, and the alarm bells rang early on, because it was a young man, he was 29 when he presented to me, but he'd had low back pain for some years.*' (Graham, Acupuncturist and Shiatsu practitioner)

Whilst placing client centred care at the core of their therapeutic approach, CAM practitioners often described a lack of AS knowledge and awareness among fellow practitioners.

'It's surprising, because when I spoke to other acupuncturists specifically, there was a very, very poor understanding of the difference between ankylosing spondylitis and other types of back pain.' (Adam, Acupuncturist)

Practitioners were aware of their knowledge gaps and keen to address these through self-directed research when presented with an individual with AS. Research included actively seeking out disease specific resources, discussing the condition with other healthcare professionals and referring to key teachings in CAM (e.g. Chinese Medicine).

'*I had to find a lot of extra time to research and make sure that I really knew enough to treat this person. And I was very honest with her* [individual with AS] *and said "I'm*

having to do this", and she was fine with that. But that was a challenge - a good challenge, but a challenge.' (Susan, Shiatsu and Massage therapist)

Further to identifying ways to manage AS symptoms, CAM practitioners were highly motivated to help clients obtain a diagnosis, recognising potential distress associated with a lack of diagnosis. In the search for a diagnosis, some CAM practitioners used multiple and sometimes conflicting therapeutic approaches (e.g. biomedical and traditional 5 element Chinese medicine theory). Often, practitioners combined use of these approaches, citing taking case histories, inspecting x-rays and conducting physical examinations. Practitioners would typically provide a diagnosis to clients that related to the particular pattern of disharmony identified (emotional, physical, habitual) for that individual with respect to Chinese medicine theory. With clients who presented with chronic back pain, but had not received a medical diagnosis, several practitioners advised that they would not offer a diagnosis until they felt more knowledgeable about the condition, suggesting a measured approach to diagnosis and treatment of AS amongst CAM practitioners.

'*Well, we don't diagnose, that's something we don't do as Bowen therapists. And we always refer to a GP or any professional health person if we feel that it's necessary* (Jenny, Bowen therapist)

CAM therapists discussed how a more holistic therapeutic approach avoided the pitfalls of mainstream healthcare which often overlooked symptoms due to their focused view of 'back pain'. This was important as overlooking symptoms was perceived to increase diagnostic delay and distress for clients.

Theme 3: *A Common Language*

This theme details the diversity in CAM practitioners' experiences of working with mainstream healthcare, how this supports referrals, and desire for further integration of services.

There was disparity between CAM practitioners with regard to their experiences of working alongside the National Health Service (NHS). Half of participants, either currently or had previously worked in a mainstream setting, demonstrating variety in experience concerning treatment of AS in mainstream care.

'Because I work in the National Health Service and work as part of a team with other medics, it's very important that we have a common language about what is happening for the patients.' (Adam, Acupuncturist)

Whilst some practitioners emphasised working together as part of a team in the NHS with clear communication, others described a sense of isolation and lack of acceptance of CAM from mainstream healthcare providers.

> *'But there are a couple of rheumatologists locally who are very open to chiropractic and there are two others who are totally against us and wouldn't even be in the same room as we are.'* (Geoffrey, Chiropractor)

When CAM practitioners felt isolated from mainstream healthcare professionals involved in their client's care, they adopted strategies to obtain information. These included encouraging clients to speak to healthcare professionals about CAM use and CAM practitioners asking clients details about mainstream healthcare treatments and medication. Practitioners acknowledged the pitfalls of relying on client recall and willingness to engage with this approach, recognising these as undesirable yet necessary strategies to support their client.

> '*When you're talking about such severe problems, the Doctor needs to know what you're doing, you need to be working together at some point.*' (Paula, Hypnotherapist and Yoga instructor)

CAM practitioners described the need for a common language to enable development and maintenance of a supportive relationship between CAM practitioners and healthcare providers, thus improving care for the individual with AS.

> '*From my point of view, yeah, what's difficult is it would be great if I could have more communication with their sort of GPs or specialists.'* (Helen, Reflexologist, Shiatsu practitioner and Aromatherapist)

Adopting an improved communicative strategy supports a CAM practitioner view that CAM is truly complementary to mainstream care, being able to work alongside rather than in opposition to mainstream care. Importantly, CAM practitioners perceived CAM to offer symptom relief rather than a cure, convergent with a focus on placing CAM therapy as a secondary rather than primary treatment for AS.

> '*My treatment is purely secondary and supportive, and is not frontline.'* (Geoffrey, Chiropractor)

CAM practitioners were keen to adopt an active role in supporting clients with mainstream care for AS. However, some participants described a perception of CAM being undervalued in mainstream care and considered as incompatible therapeutic approaches. These CAM practitioners argued for integrated CAM and mainstream services to enable a wider range of free to access NHS services for individuals with AS, and increased opportunities for CAM and mainstream healthcare professionals. There is a shared opinion among CAM practitioners that clients' needs may be best met with a multi-disciplinary approach.

> 'I *feel strongly that we should be working with doctors and all the other health professionals to give a full range of care for our patients.*' (Jenny, Bowen therapist)

Discussion

This study provides a unique and detailed understanding of CAM practitioners' experiences of treating individuals with inflammatory back pain, specifically in relation to the management of AS and a delay to receipt of diagnosis. Consistent with previous findings, CAM practitioners in this study reported that clients with AS experience a substantial delay between symptom onset and receipt of diagnosis (Feldtkeller & Erlendsson, 2008). Proposed explanations for this delay included the broad symptom specification and identification of 'back pain' in addition to clear knowledge gaps concerning the specific symptom manifestation of AS. In contrast to the assumption that clients with AS seek CAM therapies prior to diagnosis, CAM practitioners in this study reported that most clients presented to them post diagnosis of AS. There are a number of possible explanations for this phenomenon. Firstly, this may be an artefact of poor knowledge and awareness of AS amongst CAM practitioners, with some not having identified clients prior to diagnosis or reflective of use of a relatively small sample in this study. Nonetheless, it is notable that many of the CAM practitioners were knowledgeable about AS despite infrequently treating individuals prior to receipt of a diagnosis. Findings identified that CAM practitioners valued the importance of adopting an individualised holistic approach to managing AS. Importantly, practitioners perceived that such approach may support a reduction in the delay to diagnosis in some clients through recognition of a wider symptom pattern that may be missed by a more focused, mainstream approach. Nonetheless, there was an agreement that diagnosis through mainstream care was improving. This supports the view that an increase in knowledge and awareness of AS is important among CAM practitioners who are first consulted by individuals with AS, to guide a strategy for earlier referral to rheumatologists, who observe the shortest delay in diagnosing AS (Gerdan et al., 2012).

CAM practitioners claimed that CAM therapy provided effective AS symptom management and encouraged self-management, supporting the idea of a self-regulatory model (Leventhal et al., 1992). The holistic approach to consultations supported individuals with AS to interpret symptoms (illness cognitions) and provide an explanation for them, both in terms of traditional medical models and Chinese medicine. Practitioners emphasised the importance of actively listening to their clients as experts of AS, to help them autonomously manage

symptoms effectively and be in charge of their own CAM experience (e.g. appointment frequency). Consistent with this finding, research suggests that individuals using CAM perceive therapy as offering control over their illness (Klimenko & Julliard, 2007). Adoption of a holistic approach by CAM practitioners mean that in addition to addressing primary disease symptoms, suggested coping strategies also addressed secondary issues associated with living with AS (e.g. relaxation targeting psychological distress). This is an interesting contrast as mainstream treatments of AS are typically not afforded the time or resources to tackle these secondary symptoms.

CAM practitioners placed an emphasis on working together with mainstream healthcare providers and clients in a collaborative environment. Previous research has shown that encouraging the client to take an active role and adopt an internal locus of control, would be the most likely action taken by collaborating mainstream and CAM providers (Klimenko & Julliard, 2007). Therefore adoption of a 'team' approach to foster improved communication between mainstream and CAM practitioners could achieve this in AS care. Perhaps problematically, existing research supports our findings that clients do not discuss CAM use with their GP (Jong, van de Vijver, Busch, Fritsma, & Seldenrijk, 2012), despite CAM practitioners calling for a development of a common language to facilitate open communication with GPs and other healthcare professionals. Follow up with GPs in this context is a future area for investigation.

Taking a critical approach, this study contains a number of methodological limitations. Firstly, it is important to acknowledge that participants in this study were self-selecting. In the context of this study, this reflected the fact that the study attracted CAM practitioner participants who had experience of treating AS rather than those who did not. Notably, potential participants were reluctant to take part if they had no experience treating AS. Nonetheless, with efforts to address sampling issues, a good range of CAM practitioners were recruited; both male and female, across a variety of CAM therapies with a range of years of experience.

Secondly, participant interviews were conducted via the telephone rather than in person. Some studies suggest that telephone interviews provide lower quality data when compared with face to face interviews (Gillham, 2005; Novick, 2008) due to difficulties in establishing rapport with participants and following up on non-verbal cues during the interview

process. (Gillham, 2005) A body of research contests this and argues that telephone interviews provide rich data and can be a superior interview choice in particular circumstances (Stephens, 2007; Sweet, 2002).

A strength of this study was that all authors were involved in the coding, analysis and theming of the data. However, the analysis and findings were not peer reviewed by individuals with AS or CAM practitioners. This is a limitation as such reviews allow researchers to confirm the validity of their analyses.

With regard to extending research, future studies could usefully explore the views of other key stakeholder groups in the process of engaging with treatment for AS. Specifically, future studies could elicit the views of individuals with AS who seek CAM treatment and those who do not and additionally, the views of individuals who provide mainstream support for individuals with AS (e.g. rheumatologists, specialist nurses). In one study, over half of primary care workers reported that they were willing to take part in research investigating CAM (Van Haselen, Reiber, Nickel, Jakob, & Fisher, 2004). Eliciting a wider range of accounts would provide a more nuanced understanding of the role of CAM in mainstream AS treatment. Additionally, it would be interesting to adopt a longitudinal approach to studying how individuals and CAM practitioners negotiate the process of managing AS symptoms over time, from initial consultation to effective symptom management. This might include consideration of how CAM practitioners 'measure' reported outcomes in their treatment of AS to enable them to demonstrate effectiveness of treatment over time.

Findings highlight the desire of CAM practitioners for a more collaborative working relationship between CAM practitioners and mainstream health care providers with the shared aim of improved AS management. In some cases this already existed (e.g. one participant provided acupuncture as part of a management team in an NHS pain clinic). Whilst rare, a small number of specialist courses exist for individuals with AS hosted by rheumatology services which integrate mainstream and some CAM therapies. Further research with both mainstream practitioners and individuals with AS would help to investigate the usefulness of this more integrated approach to managing AS and reducing delay to diagnosis.

This study highlights the importance of providing a client-centred, holistic approach to treating AS and the importance of empowering individuals with AS to seek control of their treatment and self-manage symptoms through use of CAM and other therapies. Importantly, study findings identified the need for increased knowledge about AS amongst CAM practitioners, potentially resulting in earlier symptom detection, earlier referral to mainstream services and a reduction in delay to diagnosis for individuals with AS.

References

Akkoc, N., & Khan, M. A. (2016). ASAS classification criteria for axial spondyloarthritis: time to modify. *Clinical Rheumatology, 35*(6), 1415-1423. doi:10.1007/s10067-016-3261-6

Bishop, F. L., Yardley, L., & Lewith, G. T. (2006). Why do people use different forms of complementary medicine? Multivariate associations between treatment and illness beliefs and complementary medicine use. *Psychology & Health, 21*(5), 683-698. doi:10.1080/14768320500444216

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*: Sage.

Chatfield, S. M., Dharmage, S. C., Boers, A., Martin, B. J., Buchanan, R. R. C., Maksymowych, W. P., & Schachna, L. (2009). Complementary and alternative medicines in ankylosing spondylitis: a cross-sectional study. *Clinical Rheumatology, 28*(2), 213-217. doi:10.1007/s10067-008-1029-3

Dean, L. E., Jones, G. T., MacDonald, A. G., Downham, C., Sturrock, R. D., & Macfarlane, G. J. (2014). Global prevalence of ankylosing spondylitis. *Rheumatology (Oxford), 53*(4), 650-657. doi:10.1093/rheumatology/ket387

Dincer, U., Cakar, E., Kiralp, M. Z., & Dursun, H. (2008). Diagnosis delay in patients with ankylosing spondylitis: possible reasons and proposals for new diagnostic criteria. *Clinical Rheumatology, 27*(4), 457-462. doi:10.1007/s10067-007-0727-6

Feldtkeller, E., & Erlendsson, J. (2008). Definition of disease duration in ankylosing spondylitis. *Rheumatology International, 28*(7), 693-696. doi:10.1007/s00296-007-0499-y

Feldtkeller, E., Khan, M. A., van der Heijde, D., van der Linden, S., & Braun, J. (2003). Age at disease onset and diagnosis delay in HLA-B27 negative vs. positive patients with ankylosing spondylitis. *Rheumatology International, 23*(2), 61-66. doi:10.1007/s00296-002-0237-4

Gerdan, V., Akar, S., Solmaz, D., Pehlivan, Y., Onat, A. M., Kisacik, B., . . . Akkoc, N. (2012). Initial Diagnosis of Lumbar Disc Herniation Is Associated with a Delay in Diagnosis of Ankylosing Spondylitis. *Journal of Rheumatology, 39*(10), 1996-1999. doi:10.3899/jrheum.120106

Gillham, B. (2005). *Research Interviewing: The range of techniques: A practical guide*: McGraw-Hill Education (UK).

Haroon, N. N., Paterson, J. M., Li, P., & Haroon, N. (2014). Increasing proportion of female patients with ankylosing spondylitis: a population-based study of trends in the incidence and prevalence of AS. *Bmj Open, 4*(12). doi:10.1136/bmjopen-2014-006634

Jois, R. N., Macgregor, A. J., & Gaffney, K. (2008). Recognition of inflammatory back pain and ankylosing spondylitis in primary care. *Rheumatology (Oxford), 47*(9), 1364-1366. doi:10.1093/rheumatology/ken224

Jong, M. C., van de Vijver, L., Busch, M., Fritsma, J., & Seldenrijk, R. (2012). Integration of complementary and alternative medicine in primary care: what do patients want? *Patient Educ Couns, 89*(3), 417-422. doi:10.1016/j.pec.2012.08.013

Klimenko, E., & Julliard, K. (2007). Communication between CAM and mainstream medicine: Delphi panel perspectives. *Complementary therapies in clinical practice, 13*(1), 46-52.
Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research, 16*(2), 143-163. doi:10.1007/bf01173486
Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. *Contributions to medical psychology, 2*, 7-30.
Mansour, M., Cheema, G. S., Naguwa, S. M., Greenspan, A., Borchers, A. T., Keens, C. L., & Gershwin, M. E. (2007). Ankylosing spondylitis: A contemporary perspective on diagnosis and treatment. *Seminars in Arthritis and Rheumatism, 36*(4), 210-223. doi:10.1016/j.semarthrit.2006.08.003
Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of counseling psychology, 52*(2), 250.
Morse, J. M. (1994). Designing funded qualitative research. In N. K. a. L. Denizin, Y. S (Ed.), *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.
Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in nursing & health, 31*(4), 391-398.
O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine, 89*(9), 1245-1251.
Sengupta, R., Cook, D., & Gaffney, K. (2014). THE IMPORTANCE OF TARGETING EDUCATION STRATEGIES FOR COMPLEMENTARY THERAPISTS DEALING WITH POTENTIAL AXIAL SPONDYLOARTHRITIS PATIENTS. *Clinical and Experimental Rheumatology, 32*(5), 803-803.
Sheppard, J., Kumar, K., Buckley, C. D., Shaw, K. L., & Raza, K. (2008). 'I just thought it was normal aches and pains': a qualitative study of decision-making processes in patients with early rheumatoid arthritis. *Rheumatology (Oxford), 47*(10), 1577-1582. doi:10.1093/rheumatology/ken304
Sieper, J., & van der Heijde, D. (2013). Review: Nonradiographic axial spondyloarthritis: New definition of an old disease? *Arthritis & Rheumatism, 65*(3), 543-551. doi:10.1002/art.37803
Stephens, N. (2007). Collecting data from elites and ultra elites: telephone and face-to-face interviews with macroeconomists. *Qualitative Research, 7*(2), 203-216.
Sweet, L. (2002). Telephone interviewing: is it compatible with interpretive phenomenological research? *Contemp Nurse, 12*(1), 58-63.
Sykes, M. P., Doll, H., Sengupta, R., & Gaffney, K. (2015). Delay to diagnosis in axial spondyloarthritis: are we improving in the UK? *Rheumatology (Oxford), 54*(12), 2283-2284. doi:10.1093/rheumatology/kev288
Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care, 19*(6), 349-357.
Van Haselen, R., Reiber, U., Nickel, I., Jakob, A., & Fisher, P. (2004). Providing complementary and alternative medicine in primary care: the primary care workers' perspective. *Complement Ther Med, 12*(1), 6-16.
Willig, C. (2013). *Introducing qualitative research in psychology*: McGraw-Hill Education (UK).

Table 1

Details of CAM practitioner participants

Participant Identifier	**Primary CAM Speciality**	**Gender**	**Years in CAM Practice**	**Employment in mainstream healthcare**
Adam	Acupuncture	Male	30	Y
Graham	Acupuncture & Shiatsu	Male	23	N
Helen	Reflexology, Shiatsu & Aromatherapy	Female	20	N
Paula	Hypnotherapy & Yoga	Female	40	Y
Susan	Shiatsu & Massage	Male	23	Y
Jenny	Bowen Therapy	Female	8	Y
Timothy	Sports Therapy & Bowen Therapy	Female	18	N
Geoffrey	Chiropractic	Male	46	N

Note. Names are pseudonyms. Employment in mainstream healthcare refers to previous or current employment in any conventional medicine practice within the NHS. Y/N = Yes or No.