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Supporting Patients through Education & Research

Scientific Summary - A qualitative study of complementary and alternative therapy use by people with ankylosing spondylitis, prior to their diagnosis - Kelly Blaxhall

Introduction - Delay to diagnosis remains a significant issue in the treatment of Ankylosing Spondylitis (AS) in the UK [1]. The delay is in part due to the difficulty that general practitioners and other clinicians experience in identifying inflammatory back pain [2] and poor public awareness of the condition. AS patients report needing to fight for a diagnosis and to be believed about their symptoms [3]. 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 surveyed osteopaths, chiropractors, acupuncturists and massage therapists who reported they were less confident in managing inflammatory compared to mechanical back pain [4]. Similar results have been found in US based research with a sample of 241 AS patients attending rheumatology services, 48% had visited a chiropractor in the year following their diagnosis, 35% had visited another practitioner (to include CAM practitioners) [5]. Whilst in Austria, more than 50% of people with AS reported using CAM [6].

Research into the effectiveness of specific CAM therapies for treatment of AS symptoms has produced mixed results. For example, a Chinese study, where 32 patients with AS were treated with combined acupuncture and cupping therapy for 40 days had a clinical remission rate of 62.5% whereas a control group (n=30) treated with just acupuncture for 40 days had a 33.3% clinical remission rate [7]. Other studies have claimed that CAM is superior to western medicines when treating AS [8]. In this study individuals with AS (n=58) randomised to the treatment arm of the study were given 3 courses of acu-injection and moxibustion. The control group of individuals with AS (n=58) received oral medication (sulfasalazine (titrated from 0.25g up to 1g three times a day over 30 days) and diclofenac sodium sustained release (75mg once a day for 30days). This study reported that in the treatment group, 38.9% reported symptoms had gone and joint function was substantially restored, compared to 11.9% of the control group. Acupuncture is one of the CAM therapies with a growing evidence base that is often available through NHS settings and practiced by physiotherapists and other healthcare professionals [9]. Whilst, Ayurveda has been suggested to lack reasonable foundation for use in AS [10].

What the current evidence does not tell us, is why people with AS are accessing CAM, the broader range of CAM therapies people with AS are accessing, what benefits or symptom relief these therapies can provide people with AS, any negative experiences people with AS have of CAM therapies and the role that their CAM practitioners play in the diagnosis and management of their AS. Furthermore, little is known about the range of knowledge or training that CAM practitioners have in AS, recognising the presentation of AS compared to other forms of back pain, and treatments that would be beneficial or contraindicated in this condition.

Methods - Two separate qualitative studies were undertaken, and these ran between June and September 2016.

Qualitative Surveys - Two online qualitative surveys were conducted, one with people with AS, and the other with CAM practitioners. The aim of these surveys was to further explore AS patients' CAM use prior to and after 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. The qualitative surveys, involved free text responses, and were conducted with both individuals with AS and CAM practitioners to explore these objectives and consider opportunities to reduce delays in diagnosis through CAM settings. The survey was advertised to people with AS through the National Ankylosing Society for Spondylitis through their online networks and their newsletter. This survey was also posted on other relevant forums for people with AS. We contacted a large range of CAM practitioner organisations, societies and voluntary regulatory bodies, and many of these advertised the CAM practitioner survey to their members. Ethical approval for the survey study was received from the Research Ethics Approval Committee for Health at the University of Bath prior to starting the research.

In-depth Interviews - The survey provided us with important detail about a good sized sample but not about the idiographic experience of AS patients and CAM practitioners. Whilst the surveys were collecting data, in-depth interviews were also conducted with people with AS, and CAM practitioners. Individuals who participated in the surveys were invited to leave their name at the end of the survey if they would be interested in taking part in an interview. We also gave individuals the option of just participating in the interview. In addition to recruiting through the survey, we also attended the NASS members day in June, where we met with both CAM practitioners and people with AS, and we received a number of expressions of interest to take part in the study from this event. Ethical approval for the interview study was received from the Department of Psychology Research Ethics Committee at Bath Spa University prior to starting the research.

Analysis - A thematic, qualitative analysis [11] was carried out on the interview data. A similar approach will be undertaken (using thematic matrices) [12] to organise and analyse the qualitative survey data. The four sets of data (interviews and surveys with people with AS and interviews and surveys with CAM practitioners) then need to be brought together (triangulated) to consider the overlapping themes and differences in the data.

Results - In total, 30 responses to the surveys were received from people with AS and 52 from CAM practitioners. Although these are relatively small numbers for a survey they are large numbers for a qualitative survey which produces a large amount of rich textual data to analyse and interpret. A total of 8 in-depth interviews were conducted with AS individuals, and 8 in-depth interviews with CAM practitioners.

At the time of writing, a large amount of the analysis is still to be done. The analysis of the interviews with people with AS is on-going (almost complete at time of writing) and the analysis of the survey data from the individuals with AS and CAM practitioners will be started on completion of the analysis of the AS individual's interview data.

Below we present results from the completed analysis of the CAM practitioner interviews, which is the analysis that has been completed to date. Three themes were identified in the data (See Table 2), and below a narrative and summary of the themes is presented, along with their sub-themes and verbatim quotes from participants. Table 1 gives an overview of each participant's background and CAM speciality.

Table 1: *CAM practitioner Interviews Participant demographics*

Participant Identifier	Primary CAM Speciality	Number of Years in Practice
CAM1	Acupuncture	30
CAM2	Acupuncture & Shiatsu	21
CAM3	Reflexology, Shiatsu & Aromatherapy	20
CAM4	Hypnotherapy & Yoga	40
CAM5	Shiatsu & Massage	23
CAM6	Bowen Therapy	8
CAM7	Sports Therapy & Bowen Therapy	18
CAM8	Chiropractor	46

Table 2: *Main themes and subthemes of CAM practitioners' experiences of AS.*

1.	A Therapeutic Practice
1.1	*'CAM is a very broad church'*
1.2	Effective symptom management is *'an important part of their treatment'*
2.	CAM Practice life
2.1	Journey into CAM
2.2	Knowledge and awareness
2.3	A 'Typical' patient
3.	Working together
3.1	A truly complementary therapy
3.2	Communication and referral
3.3	Integration of multiple services

1. **A Therapeutic Practice -** Complementary and Alternative Medicine (CAM) therapies appear to take a therapeutic view. The approach is holistic and with the client's individualistic needs at the forefront of care. When discussing with CAM practitioners their therapeutic practice, three sub-themes emerged, the importance of symptom management, the breadth of CAM practice and the focus on client-led treatment which are described in turn below.

1.1 Effective symptom management is *'an important part of their treatment'* - CAM practitioners *"I very much work off the patient's subjective account"…*and '*I would use not just the criteria of pain, but also the criteria of mobility.*" (CAM1). Therapies are used to '*to support, move and warm'* and some e.g. Acupuncture "*in combination with Moxa…it's like a heating stick you use over joints - relieved the pain tremendously and was really, really very effective"* (CAM2). *"*[reflexology] *can be a really useful tool for just increasing mobility and sort of management of chronic pain."*(CAM 3)

Practitioners are able to assess whether the treatment is affective through *"reduction in pain and increased mobility, and an ability for her to live her life more fully"* (CAM5) *and "so those are the tests - how flexible are you and what moves can you make that you perhaps couldn't make before?"* (CAM7)

1.2 '*CAM is a broad church*' - CAM therapies are client-centred and take an individualistic and holistic approach. "*That's one thing that's great in CAMs is the kind of holistic consultation. 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."* (CAM3). The client is considered the expert of their own AS *"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."* (CAM7). Therapy appears to be centred around *"helping people understand sometimes how to present the whole pattern of their symptoms"* and "*taking time to kind of piece those things together for them."* (CAM 3). Most CAM practitioners related the view that clients could often feel pushed from pillar to post in the search for a diagnosis or resolution to their symptoms.

1.3 Client-led Treatment - Treatment is usually client-led and occurs little and often; '*It's a bit like spinning a plate, you have to just keep spinning it'.* (CAM4). Practitioners *"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."* (CAM1)

2. **CAM practice life -** CAM practitioners work in a range of settings, the majority of our participants had been practising for many years. This theme captures four sub-themes which relates their journey into becoming a CAM practitioner, the knowledge they have developed about back pain symptoms, and particularly those specific to AS, what symptoms would make them consider referring a client for a diagnosis of AS, and their approach to diagnosis.

2.1 Journey into CAM - It was common for CAM practitioners to feel they have *"been very fortunate to make my hobby and my passion into my work… a lot of people go into these things because they've been helped by something."* (CAM4). There is a sense of empathy and care for the clients, sometimes due to their own introduction into CAM *'as a result of sort of traumatic effects in my life'.* (CAM7). A pattern appeared that practitioners may have retrained into their CAM profession due to a personal interest or journey into it.

2.2 **Knowledge and awareness -** A common topic of conversation when discussing AS is the apparent lack of knowledge and awareness around it, practitioners suggest "*knowledge of AS is appalling*." (CAM2). Although practitioners appear to be keen to learn and proactively research the disease when clients present with symptoms or a diagnosis. Back pain is a broad symptom and a difficulty in treating it is *"there's so many different aspects that it could be."* (CAM3). Two quotes represent both the lack of knowledge about AS amongst CAM practitioners, but also that there is a strong desire to learn more:

"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." (CAM1).

"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 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." (CAM5).

2.3 A 'Typical' patient - AS clients show a wide array of symptoms, from back pain to aching joints. CAM practitioners were also aware that this was a rare condition amongst the clients they saw: *"I found that ankylosing spondylitis patients are not largely represented in the back pain patients that I've seen. I would say probably I have at any one time only 1 or 2 patients a year who are referred specifically with ankylosing spondylitis. So if I'm seeing 600 patients a year, then that's a very small percentage."* (CAM1). For most practitioners, their experience was that their clients who had AS, already had a diagnosis of AS at the time they came to see them. There was a general acknowledgement amongst most of the practitioners, that people with AS tended to be young and their mobility and pain issues did not fit with the overall picture of that person's health and day to day activities and this would be a trigger for concern.

2.4 Approach to diagnosis - Delay to diagnosis is an important topic when discussing AS, as it has been found that clients are waiting a considerable amount of time to receive a diagnosis. Practitioners agree that *"diagnosis is really, really useful and great"* (CAM3) and *'diagnosis is extremely important because diagnosis gives us a much clearer idea of what we can expect to happen with the patient, but also so that we can say to the patient what we would hope their prognosis would be."* (CAM2). Practitioners have advised that some say '*we don't diagnose"* (CAM6) themselves, some "*will act quite cautiously until we realise what that is"* (CAM3), and others will diagnose from a Traditional Chinese Medicine perspective (CAM2); Also, "*the NHS or, shall we say, the conventional medical side, is getting a lot more astute at actually diagnosing these people now."* (CAM8)

3. **Working together -** CAM practitioners vary in their work setting and therefore their level of working with mainstream or conventional healthcare practitioners and also with other CAM practitioners. There were three sub-themes that related to working together, the view that CAM was a truly complementary therapy, the communication and referral pathways between mainstream and CAM treatment and the integration of CAM into mainstream care.

3.1 A truly complementary therapy - CAM is considered "*a supportive treatment, you see, it's not a primary treatment"* (CAM8). Practitioners '*work alongside as a complementary* therapist' (CAM2) to mainstream healthcare. "*So it's not a panacea for all things, it usually gives people some relief."* (CAM7)

3.2 Communication and referral - Communication is an important part of any multi-disciplinary team. Referral is an ongoing and improving service, most practitioners agree that "*the patients that I see have been referred by their GPs or by hospital specialists"* (CAM1) already with a diagnosis. Where there isn't a diagnosis CAM practitioners often refer clients to mainstream healthcare for diagnosis and treatment and "w*hen you start mentioning AS to a GP, the GP will do what's necessary"* (CAM8) and also to other CAM practices that may be better suited to the client, although they would "avoid a physio or an osteopath or a chiropractor, I think that could cause more damage, personally" (CAM4). Practitioners feel *"it's very important that we have a common language about what is happening for the patients"* (CAM1) and *'it would be great if I could have more communication with their sort of GPs or specialists"* (CAM3).

3.3 Integration - Practitioners feel that maybe "*there's a bit of a juxtaposition between complementary therapies sometimes and that side of things. Which would be nice if there wasn't, because they could kind of somehow overlap more*." (CAM 3) It is common to "*feel like sometimes it's underestimated and it shouldn't be an either/or situation, but actually it can work very well together.*" (CAM3). A number of practitioners already practice integration and work together with other practitioners: *"I would be working very closely with the rheumatologist to maybe be looking at whether their disease modifying medication needed to be changed or not."* (CAM1). And feel this is positive as '*if they actually go and get those structural issues sorted it's going to move forward much quicker than if I just worked on my own, and so it saves people time and money.'* (CAM3). It was also felt that great integration would allow more services to be available through the NHS, and offer a wider range of opportunities for both CAM practitioners and for patient benefit: "*I've spent most of my life working in the NHS and I just think I wish I could have done some of this when I was working with patients who I couldn't really offer a lot, apart from just nursing care."* (CAM6).

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Impact of the BIRD studentship on Kelly's future career (written by Kelly)

The BIRD summer studentship has had a positive impact on my current and future career plans. It has helped my gain relevant research experience in order to pursue my goal of postgraduate training in Psychology. The studentship has opened doors into the health psychology field and opened my eyes to the experience of individuals living with ankylosing spondylitis. I have developed both personally and professionally and have met some wonderful people and hopefully future colleagues on the way.