



Supporting Patients through Education & Research

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

The aim of this summer studentship was to explore the use (or not) of complementary and alternative therapies (e.g. reflexology, acupuncture) by people with ankylosing spondylitis. We also wanted to hear from complementary and alternative medicine therapists who had had clients who had ankylosing spondylitis and how they had supported them with their condition. We were interested in this as previous research carried out in Bath suggested that around 40% of people with ankylosing spondylitis used one or more complementary and alternative therapies, either prior to or after diagnosis. As some people used these therapies before diagnosis, we wanted to understand the patterns of use in order to consider ways to reduce delays to diagnosis in the future. To study this, we carried out a national survey of people with ankylosing spondylitis, and a similar survey of complementary and alternative medicine therapists. Following on from the survey we also carried out in-depth one-to-one interviews over the telephone with 8 people with ankylosing spondylitis and 8 complementary and alternative therapists.

We are still analyzing the data from the surveys and the interviews, but what we have learnt from the interviews with complementary and alternative therapists, is that they see a large number of patients with back pain, and one or two of these may have a diagnosis of ankylosing spondylitis. They felt that there were a range of practices and therapies available to people to support them with their symptoms of ankylosing spondylitis, particularly in managing pain and stiffness, but that these should be complementary and in addition to mainstream healthcare. The underlying approach of all these therapies, was a holistic consultation that helped people to piece together the pattern of their symptoms. The knowledge that complementary and alternative therapists had of ankylosing spondylitis varied with some practitioners having little knowledge, or misconceptions about the condition. Those who had the most knowledge, worked as part of NHS multidisciplinary teams in rheumatology services (e.g. acupuncturists). However, most were able to spot symptoms of concern that required follow up by a GP or Rheumatologist for possible ankylosing spondylitis. The complementary and alternative therapists felt there was sometimes good communication between them and mainstream healthcare, particularly those who worked as part of NHS services. Improving communication between mainstream and complementary healthcare as well as developing the knowledge base of complementary and alternative therapists about ankylosing spondylitis were seen as two key areas to help with delay to diagnosis. Analysis is on-going and our next task is to explore the views of people with ankylosing spondylitis and how this compares to the views of the complementary and alternative therapists in our study.

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 me 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.