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# Title: Exploring thoughts about pain and pain management: Interviews with South Asian community members in the UK

Abstract

Objective: This research sought to explore pain management beliefs of members of the South Asian community living in the UK. In particular, understandings regarding the key components of cognitive behavioural therapy (CBT) informed pain management programmes (PMPs) were explored.

Methods: Snowball sampling was used to recruit 10 participants of South Asian background for interview. Interviews were guided by a semi-structured interview schedule and explored pain history, specific pain experiences, community member expressions of and reactions to pain, treatment expectations, and perceptions of self-management. Interviews were transcribed verbatim and subjected to descriptive thematic analysis.

Results: Four themes were developed: impacts of chronic pain, within group variations in responses to chronic pain, personal responsibility vs paternalistic care, and the acceptability of pain management concepts (relaxation and meditation, exercise and physical activity, and thoughts and beliefs: the dangers of pain healers).

Conclusion: This work has highlights how discourses around the impacts of chronic pain, beliefs about and preferences for approaches to care, and the acceptability of pain management concepts fit with existing PMP content. Recommendations are made regarding opportunities for social prescribing, consideration of the incorporation of acceptable forms of physical activity including yoga and walking within PMPs, and the potential benefit of highlighting role models and creating social opportunities for these activities. Some beliefs and practices in this area are under researched and further work that explores gender and generational differences in pain perceptions, and the potential dangers of the use of pain healers is needed.

**Key Words**: Qualitative; South Asian; Pain; Self-management; Psychology; Patient perspective

# Main Text (5,278 words)

Ethnic minority groups in the UK experience health inequalities when compared to majority populations (Public Health England, 2017). Individuals from South Asian backgrounds, Indian subcontinent origin, are particularly disadvantaged (Evandrou, Falkingham, Feng, & Vlachantoni, 2016). While evidence suggests South Asian populations are more likely to attend general practitioner (GP) appointments, they are often less likely to take up the offer of outpatient services than white ethnic groups (Morris, Sutton, & Gravelle, 2005). One area with increased rates of GP consultation in this population is chronic pain (Gillam, Jarman, White, & Law, 1989; Njobvu, Hunt, Pope, & Macfarlane, 1999).

Chronic pain is a “common complex sensory, emotional, cognitive and behavioural long-term health condition which occurs when pain cannot be resolved by available medical or other treatments” (The British Pain Society, 2013 p.10). Experiencing chronic pain has been shown to negatively impact on a wide variety of factors including physical health, mental health, and the ability to work (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). There is strong evidence that multidisciplinary pain management programmes (PMPs), incorporating principles of cognitive behavioural therapy (CBT), can be effective for improving outcomes (Dysvik, Kvaløy, Stokkeland, & Natvig, 2010; Dysvik, Vinses, & Eikeland, 2004; Hoffman, Papas, Chatkoff, & Kerns, 2007). In line with this, the British Pain Society recommends these programmes for the management of chronic pain (The British Pain Society, 2013). However, PMPs are traditionally developed based on the experiences of and outcomes for white, western, English-speaking patients and little is known about suitability and effectiveness for other ethnic and cultural groups (Burton & Shaw, 2015).

One barrier to referral for secondary chronic pain services is the perception by GPs that pain reported by South Asian patients has an underlying psychological basis and that there is a lack of culturally appropriate physical therapy and community support (S. Patel, Peacock, McKinley, Clark-Carter, & Watson, 2009). Furthermore, individuals who deliver health education and self-management programmes to South Asian attendees have expressed uncertainty about the needs of this population; highlighting a need for cultural competence training (Hipwell, Turner, & Barlow, 2008).

Barriers to attendance at outpatient services (Morris et al., 2005), challenges with referral to secondary care (S. Patel et al., 2009), and uncertainty regarding the delivery of services to South Asian populations (Hipwell et al., 2008) illustrate a clear need to determine the suitability of PMP content in order to improve the development of these services. This research sought to explore pain management beliefs of members of the South Asian community living in the UK. In particular, understandings regarding the key components of CBT informed PMPs were explored in order to assess the applicability of key principles recommended by the British Pain Society (2013) which underly the majority of UK programmes.

# Method

## Recruitment

Project information was circulated to community-based groups and Mosques in Birmingham and placed as advertisements on social media, online discussion boards and mailing lists. Participants were asked to identify other community members who may be interested in taking part, using a snowball sampling technique (Atkinson & Flint, 2004). Snowball sampling is an effective strategy for recruiting these hard-to-reach groups who are underrepresented in health research (Sadler, Lee, Lim, & Fullerton, 2010). The study aimed to recruit 10-15 participants representing a small to medium project employing thematic analysis (Braun & Clarke, 2013). Sampling continued until no new themes or key issues were being identified in the interviews therefore achieving ‘theoretical saturation’ (Dallos & Vetere, 2005)

## Procedure

Interested individuals were sent a copy of the participant information sheet. Several days were given for consideration, then potential participants were contacted to answer any questions and arrange a time for interview. Participants were given the option of being interviewed by phone or face-to-face when geographically possible. Face-to-face interviews were completed in local community spaces chosen by the participants. Phone interviewees read a copy of the consent form, this was also read aloud by the interviewer and verbal consent was audio recorded. Face-to-face interviewees completed written consent in person. All declined the offer of an interpreter.

Interviews were guided by a semi-structured interview schedule (Table 1). The interview schedule was devised by the first and second authors and based on existing literature exploring health in South Asian communities, the second authors knowledge of PMPs and clinical practice experience, and the British Pain Society (2013) guidelines on the content of PMP programmes. The schedule was used flexibly to ensure participants were given the opportunity to voice the beliefs and ideas which were important to them. Questions explored demographic information, pain history, specific pain experiences (e.g. ‘What do you normally do when you experience pain?’), community member expressions of and reactions to pain (e.g. ‘How do you know when someone in your community is experiencing pain?’), treatment expectations (e.g. ‘How do you think chronic pain should be treated?’), and perceptions of self-management recommendations (e.g. ‘Health care professionals often advise to do regular physical activity to manage chronic pain - how easily could you fit this into your current day-to-day life?’). Interviews lasted between 30 minutes and 1 hour.

\*\*INSERT TABLE 1 ABOUT HERE\*\*

## Analysis

Interviews were transcribed verbatim and subjected to descriptive Thematic Analysis (Braun & Clarke, 2013) conducted by the first and third authors. A critical realist perspective was taken to data analysis, which acknowledges that contextual factors including culture, language and political interests, shape how reality is experienced and interpreted (Braun & Clarke, 2006, 2013). This approach recognises that we can only partially access a participants ‘reality’, but that we need to claim that an ‘authentic’ reality exists in order to create knowledge with practical applications (Stainton Rogers & Stainton Rogers, 1997). The coding strategy focused on the research aims to explore and describe understandings of concepts key to the delivery of CBT PMPS including thoughts, beliefs, knowledge, and self-care behaviours (e.g. physical activity). Themes were reviewed and confirmed by the second author. The first and third authors reviewed the themes and transcripts and agreed data saturation had been achieved.

# Ethical Approval

Ethical approval was granted by Staffordshire University faculty of Health Sciences ethics panel.

# Results

## Participants

Ten interviews (two in person, eight via telephone) were conducted with South Asian adults (Self-reported characteristics can be seen in table 2).

\*\*INSERT TABLE 2 ABOUT HERE\*\*

## Themes

Four themes were developed: impacts of chronic pain, within group variations in responses to chronic pain, personal responsibility vs paternalistic care, and the acceptability of pain management concepts (relaxation and meditation, exercise and physical activity, and thoughts and beliefs: the dangers of pain healers).

### Impacts of chronic pain

All participants reported that they had experienced some form of acute pain (headache, indigestion, muscular pain etc) and one participant reported an experience of chronic pain that lasted more than 6 weeks. Despite not necessarily having experienced it, when asked to consider the what chronic pain may be like, several commonly perceived impacts were suggested: low mood, reduced physical activity and challenges to sense of self. In addition, chronic pain was often perceived as a medical ‘emergency’.

Participants described the impact of chronic pain on mood as potentially *“debilitating” (participant 1)* highlighting a perceived risk of extreme low mood and depression: *“Psychologically dealing with pain it can be difficult, you can get depressed (participant 9)”.* These discourses highlight the perceived risk of psychological impacts of chronic pain within the sample.

There was also a common perception that pain onset leads to a reduction in physical activity. Most presented their own experience of acute or chronic pain as physically limiting: *“To some extent [pain] will affect what type of activities that I choose to do. (participant 1)”, “Recently I was… I had a bit of back pain. It was pretty stiff. It was quite bad. I couldn’t move for three or four days. It was quite bad (participant 10)”.* These accounts illustrate potentially unhelpful assumptions that pain should be associated with physical restriction and managed through rest.

Pain was also depicted as impacting on daily life though an influence on sense of self. One participant drew on her mother’s experience of chronic pain: *“[the medicines] seemed to hinder her more than help her. She really wasn’t herself. She wasn’t able to be as active as she should be (participant 1)”.* Another participant summarised the overarching impact of pain*: “I think that pain is so frightening that you don’t know how to manage […] it is frightening, isolating and it can take a great deal of your dignity away from you. (participant 7)”.* These examples show the potential for fear of chronic pain and the implications for altered sense of self and daily experience.

There was uncertainty about the best strategy to manage chronic pain with the experience often characterised as an emergency requiring immediate medical assistance: *“[if experiencing chronic pain] I would tell my doctor to transfer me to hospital and check it out”* (participant 5)*.* Some participants were critical of this highlighting a perception that some community members may abuse healthcare services:

I think people in this community go to the GP or to A&E even if it’s unnecessary as well. Like I said, people don’t want to be in pain and will do anything not to be in pain. Sometimes I think that it is unnecessary and it’s waste of the emergency services. Like they would go to A&E when they could have took some paracetamol for the pain (participant 9)

Most agreed that medication was an important element of the management of chronic pain and that healthcare professionals, particularly GPs, were the experts and should be consulted: *“I don’t normally take pain killers unless it’s sort of ongoing then by that time I will go and see somebody like a GP and been prescribed something. (participant 2)”.* However, some presented themselves as stoic and reluctant to seek medical assistance unless it was essential: *“I think because I am quite resilient, because I’d rather not take a pill. I’d rather try to hold out as long as I can before I have medication”* (participant 9). These participants drew on discourses of resilience and the need for self-care to illustrate a personal responsibility for managing pain.

### Within group variations in responses to chronic pain

Participants presented experience of and responses to pain as varying across different community members. Two key subgroups were highlighted: gender and generation. Females were presented as willing to discuss and share pain while males were presented as stoic and more likely to hide pain:

[When they experience pain, people in my community] will be vocal about it. They are not shy in coming forward with it. But it tends to be more from females than males. You never actually ever hear the males talking about it openly, that they are in some kind of pain. […] My dad has got pain in his knees he has arthritis and he has had the knee op on both of his knees but he does a lot of yoga and he tries not to complain about it. And you tend to see that generally in the males which means to me that the males tend to talk about it less. (participant 2)

The other key difference in terms of openly expressing pain was generational, with older people presented as more likely to discuss and share their pain experience than younger generations:

Particularly women of a certain age, it tends to be middle aged to elderly […] have noticed that in our community that it is something that is very socially acceptable to talk about it and it is something that seems to be expected. For example, there are two ladies and when they bump into each other in town they end up sharing stories about their pain very openly. (participant 3)

In addition, older generations were presented as more likely to manage pain though the use of home remedies (“*My parents, because they grew up in India, they would be more likely to take home remedies which have been passed down through the generations to them and things like ginger and turmeric, they probably take those more than I would.”*, participant 4); more likely to draw on religion to cope with pain experiences (“*I think especially the elderly. I think people who are very spiritual as well. People will turn to God. I think that the elderly are very religious and will turn to God for help or go to India and try to find something to help.”* , participant 9); and more mistrusting of healthcare professionals:

[My grandparents] would rather take advice from their friends than their GP. If the GP was to say take this medication or do that they may be a little more hesitant. Whereas if it was someone like their friend from their community or relative that gave them advice they are more likely to adhere to that. […] If their friend says they have had this medication and it might work why don’t you go and ask your GP to give you the same medication. So they are more likely to go to the GP and you know say so and so has this problem and their GP gave them that and it worked so give me that medication as well. (participant 4)

These examples illustrate the different responses to pain both within and between cultural groups. It is important for those delivering PMPs to be aware of and adjust content to reflect potential variation in responses to pain experience.

### Personal responsibility vs need for paternalistic care

Despite the common assumption that medication was a key element most talked about pain management as a personal responsibility. For some this was a responsibility to pro-actively seek medical support:

I would say that most people in my community are quite practical with regards to health and taking care of themselves. If the pain is extreme, I think most definitely yes that they would go to their GP almost immediately. I think that if it is less than extreme that they would just try to figure it out. (Participant 10)

There was also a broader awareness of potential activities that could contribute to self-management. These included discussions with medical professionals, changes to diet, engaging in exercise, relaxation, and other lifestyle changes. These activities were also presented as something requiring personal engagement and responsibility:

I think again that it’s about taking some proactive responsibility yourself. So, not just taking passively some prescribed medicines but having a full conversation with your medical professionals about how you are reacting to that prescribed medicine and thinking about probably how you can contribute to manage with the pain. (participant 1)

However, it was also evident that many participants felt these activities needed to be guided by healthcare professionals and founded on sound medical advice. One participant summed up the importance of Doctor’s advice for South Asian community members: “*I would say one thing that in Asian communities is that the doctors are […] people tend to take their word as gospel”* (participant 1). GPs were often viewed as playing a key role in chronic pain management with patients constructed as responsible for adhering to advice and guidance provided in order to manage their pain:

I think chronic pain, I think once it has been diagnosed the best thing is to go to your GP and see how they think you could manage it better. Whether that’s the medication you could take or lifestyle changes. I think there should be a discussion with the GP about the changes that may happen as a result of the chronic pain and how you can adjust to those changes and how you are going to manage over time. (participant 4)

These examples illustrate a common perception that South Asian individuals preferred a paternalistic style of care in which clear medical intervention was given and guidance was to be followed by the individual. However, this was juxtaposed against an acceptance of individual responsibility to manage pain and follow advice given.

### Acceptability of pain management concepts

#### Relaxation and meditation

One concept included in PMPs is that of enhanced acceptance. This is often promoted through development of skills in mindfulness and psychological flexibility (The British Pain Society, 2013). The British Pain Society highlight that these approaches are ‘designed to enhance participant openness and willingness to experience undesirable feelings, and to loosen the influence of judgemental, evaluative and analytic thought content’ (The British Pain Society, 2013 p.13).

Participants frequently discussed how relaxation, meditation and mindfulness were accepted concepts for both themselves and others in their communities:

I mean my dad reckons that meditation or mindfulness that you might want to call it tends to help him quite a bit [with his pain].[…] (participant 2)

Some participants highlighted how the acceptability of these concepts could be linked to core religious beliefs:

Sikhs they believe in the idea of relaxation and taking time. Sikhs just do a little less they get a little more excited and they can you know… They don’t have any problems with relaxation. […] I would say that the Hindu community is a lot more into yoga and relaxation music and all of that. (participant 10)

This element of pain management was acceptable to all participants. Given the close links to cultural practices and religion these comments illustrate how drawing on these practices may help facilitate these behaviours within PMPs.

#### Exercise and physical activity

Another key element of PMPs is physical activity (The British Pain Society, 2013). The promotion of exercise was presented as having the potential to be rejected by South Asian communities.

You probably already know that Asians and exercise don’t generally go. It just, yeah. There are no role models that I know of that in terms of sport or anything. It’s not even part of, it’s so alien to even think of doing it. (participant 2)

*I never see anyone from a South Asian background jogging or anything like that. (participant 4)*

Exercise was conceptualised as ‘*alien’* to South Asian individuals with participants highlighting the lack of role models or examples of others engaging in these behaviours. However, some types of exercise, such as Yoga, were more acceptable (*“My sister does yoga regularly at home” participant 5; “I think that people who are generally forty-five plus are. They generally do a lot of yoga”, participant 7*) and perceived as a useful way to manage pain experiences:

Yoga is something that is done correctly and done in the right way can actually take care of a lot of the pain over a period of time. […] In general, I think that most Indians do yoga and exercise. General lifestyle changes can certainly take care of pain often. (participant 10)

One reason for the popularity of Yoga, particularly in older generations, was the accessibility of role models through programmes on Asian television channels:

A yoga guy that comes on one of the Asian channels and he has done what the NHS as a whole has failed to do. Trying to get people from certain communities exercising and stuff. […] it’s like my dad will be telling me stuff that I have been telling him for years and he seems to not have listened when anybody else has been telling him but this guy has told him and it’s just great. (participant 2)

I know a lot of people in my community do yoga a lot. That’s because there is a lot of it on the TV like on the Asian channels. They have a lot of yoga shows and stuff so even the older generation they do participate in yoga a lot.[…] there is a programme that tells you how to do it step by step (participant 4)

The presence of role models for exercise behaviour seemed to be a strong motivating factor. Similarly, participants highlighted that engaging in exercise behaviour with others as part of a social activity was a potential motivator:

My mum said to me one day when I went to visit to come along we’ll go for a walk with one of her friends and walked all the way around this park. […] They are all from different communities and my parents are Indian, there are others Sikh, Muslim and there were women walking the other way. I said are they all walking? She said yes and I don’t know who it started or where started it but the women just go around walking and do a few laps. (participant 2)

I think that people, especially in the Punjabi culture where I am from are quite social beings. So if there was something going on like meditation in the park or something to do with lifestyle then people would be encouraged to do so (participant 7)

While exercise may be a challenging element of PMPs to deliver to South Asian individuals, approaches which include Yoga, role modelling and social support are all likely to encourage motivation for physical activity.

#### Thoughts and beliefs: The dangers of pain ‘healers’

No participants expressed that they had used pain ‘healers’ themselves, but they did perceive that they were used by others within their communities. Healers were discussed, particularly in relation to the Hindu community, as a dangerous option for the treatment of chronic pain:

For all sorts of ailments and if people are feeling unwell or have been unwell for a while they will go and see somebody else. It’s not necessarily in a temple, it can be, but it is usually somebody who they say is a… I don’t know how to describe it, not possessed, but had God enter them or something at some point […] . So you will go to some woman’s house and give her some money […] it can be quite a dangerous thing. (participant 2)

I think that people in my community take a lot of spiritual help and advice when it comes to pain and the majority of the time they take on the spiritual support and help which isn’t coming from a good place. […] some people go and see so called holy men […] This is particularly in the Hindu faith there is a lot of mystical, spiritual, so called spiritual people that say that they can help or get rid of any medical issues you have got. (participant 3)

One Sikh participant also discussed the risks of ‘con artists’ and ‘medicine men and women’:

I feel that the South Asian community can fall into traps with con artists […] Unfortunately, I have seen things growing in the Asian community and I do believe that there is a massive danger out there where people go to so called con artists and medicine men and women around. (participant 7)

These examples illustrate potential alternative sources of pain management that may be used by attendees at PMPs. Discussions around these beliefs and practices may be essential to ensure, where relevant, potentially dangerous beliefs and practices are challenged.

# Discussion

The present study contributes to the understanding of pain management perceptions of individuals of South Asian origin living within the UK. Findings demonstrate perceptions relating to the impacts of chronic pain, beliefs about and preferences for approaches to care, and the acceptability of pain management concepts. When considering the application of these findings it is important to remember that participants were from a range of faiths and cultures, and there are individual and group variations in beliefs and experiences. Traditional pain outcome research has illustrated differences between ethnic groups (Baker & Green, 2005; Bates & Edwards, 1993; Edwards, Fillingin, & Keefe, 2001); ignoring the potential variability within populations. However, there is evidence to show that interventions that are adapted to language, religious and cultural needs of particular South Asian groups can be effective (Shoiab, Sherlock, Ali, Suleman, & Arshad, 2016) and therefore understanding of these issues is essential for the development of pain services.

Participants discussed clear variations in the perception of and response to pain management. Rather than differences across religious or cultural groupings, the most common discourses highlighted generational and gender differences, indicating that stratifying PMPs by specific age and gender groups would help to ensure content is tailored to patient needs. Participant perceptions that older people are more likely to discuss their pain may relate to an increased prevalence of musculoskeletal pain, pain disability, and use of pain medication when compared to younger individuals (Soars, Sundin, & Grossi, 2004). Discussions indicated older adults may be more likely to engage with traditional medicine, and whilst this is unlikely to reduce engagement with Western health services (Surood & Lai, 2010) it should be discussed and acknowledged with South Asian older adults. In addition, for older adults, peer influence was suggested to be particularly important and potentially more influential than GP advice. Peer support has been shown to be a motivator for exercise in South Asian older adults (Horne, Emsley, Woodham, Wearden, & Skelton, 2018; Horne & Tierney, 2012) and should therefore be a central component in PMPs for this group.

Gender differences in perceptions, expressions and approaches to coping with chronic pain are common and embedded within gendered social norms (Samulowitz, Gremyr, Eriksson, & Hensing, 2018). Across ethnic groups women have been shown to be more receptive to and receive more benefit from multimodal pain treatment programmes than men (Pieh et al., 2012). South Asian women often experience barriers to self-care activities for health due to cultural expectations to spend time focussed on the family and performing domestic duties (Curry, Duda, & Thompson, 2015; Lawton, Hallowell, Ahmad, Hanna, & Douglas, 2005). It may be that, given the preference for paternalistic approaches to care illustrated by these participants, the structure of PMPs as a healthcare intervention legitimises engagement in self-care activities and facilitates cultural acceptance for South Asian women.

This research has been unique in that it has also captured perceptions of South Asian males and highlighted a discourse that men tend not to openly discuss pain experiences. In other areas of health self-management evidence indicates that South Asian men with diabetes often have poor health literacy levels (Estacio et al., 2015) and rely on female family members for activities like diet modification and medication support (N. R. Patel et al., 2015). This reduced health literacy and behavioural passivity may also apply to other chronic conditions and help to explain a lack of discussion of pain and pain management and engagement in secondary services. No other research has explored barriers and facilitators for engaging South Asian men in pain self-management and further work is needed in order to inform PMPs for this population.

Responsibility for self-care was highlighted within the accounts, however this was often associated with a need for actions to be grounded in GP provided medical guidance. This perceived importance of practitioner recommendations illustrates a potential avenue for developing motivation for chronic pain self-management. In particular, the practice of social prescribing may be a valuable addition to chronic pain service pathways for South Asian populations. Social prescribing is a model of care in which a GPs can provide non-medical referrals to existing voluntary and community sources of support (University of Westminster, 2016). The patient works with a link worker to co-design a non-clinical prescription to improve their health and wellbeing. This approach could help to address the potential for low mood, impact on sense of self and reduced physical activity associated with chronic pain within this study. Social prescribing enables link workers to connect patients to advice services, community activities, physical activities, befriending, enabling services and faith groups within their immediate community (University of Westminster, 2016). As a relatively new model in patient care there is currently mixed evidence about the effectiveness and cost effectiveness of social prescribing schemes and more evaluation is needed (Bickerdike, Booth, Wilson, Farley, & Wright, 2017; Kilgarriff-Foster & O’Cathain, 2015; Polley, Bertotti, Kimberlee, Pilkington, & Refsum, 2017; South, Higgins, Woodall, & White, 2008). However, given the expressed preference for GP recommended care, this could be a valuable approach to developing future chronic pain services for South Asian populations.

Engaging in physical activity may be particularly challenging, physical activity was not perceived to be a social norm and chronic pain was discussed as resulting in reduced physical activity. Fear-avoidance, leading to reduced activity participation, is a commonly associated with increased disability in chronic pain populations (Nicholas, Linton, Watson, & Main, 2011) and represents an unhelpful belief typically challenged in PMPs (The British Pain Society, 2013). An additional barrier for South Asian individuals appears to be a lack of cultural acceptance of physical activity (Horne & Tierney, 2012; Lucas, Murray, & Kinra, 2013) and may explain a lack of engagement with secondary care programmes of this type. Some pain management activities, including relaxation and meditation, were portrayed as acceptable practices due to their links with cultural and religious practices. This is encouraging as these are essential components of PMPs within the UK (The British Pain Society, 2013). There is therefore a need for culturally tailored physical activity programmes within pain management services whereby recommended exercise is integrated within the context of other meaningful activities which might include walking to the local mosque or spiritual stretching during prayer time. Two key forms of exercise, yoga and social walking, were discussed as acceptable and practiced by South Asian populations and should be considered as opportunities for development and education in PMPs and avenues for social prescribing.

Yoga has been shown to be an effective strategy for the management of chronic pain (Jacobs et al., 2004; Wellington, 2014; Williams et al., 2009), and may be a particularly effective form of physical activity for this population. In addition, by combining the practice of Yoga within PMPs with information about the availability of resources and role models for this activity, such as through signposting programmes available on Asian TV channels, it may be possible to maintain these behaviours beyond PMP delivery. This modelling opportunity is in line with Social Cognitive Theory which argues that vicarious experiences, in which we see others similar to ourselves succeeding in an activity, enhance our self-efficacy beliefs to enact new behaviours (Bandura, 1998).

Vicarious experiences (Bandura, 1998) can also be achieved through exercise with others. Group-based walking activities in local parks were presented as an appealing physical activity approach. Walking has been found to be an effective intervention for improving pain ratings in those with chronic musculoskeletal pain (O’Connor et al., 2015) and these findings support previous research in which walking has been identified as a potentially valuable physical activity for South Asian individuals (Cross-Bardell et al., 2015). Both professionally delivered and group-based walking interventions have been shown effective for increasing physical activity levels (Kassavou, Turner, & French, 2013) and would be a potentially useful addition to existing PMPs.

A discourse arose highlighting the potential financial, physical and psychological dangers of engaging with community pain ‘healers’. Within the UK there is an established network of community-based South Asian approaches to health care including: religious healing, faith healers (*gurus* or pirs) and *hakim* medicine (see Rhodes, Small, Ismail, & Wright, 2008 for a description of these traditional medicine approaches). While there is some evidence to suggest a preference for traditional over western medicine in some South Asian groups (Pieroni, Sheikh, Ali, & Torry, 2008) and reporting of use of faith healers in response to substance abuse, psychiatric illness (Rashid, Copello, & Birchwood, 2012) and epilepsy (Rhodes et al., 2008), to date there has no reported exploration of the use of traditional medicine and healing practices in relation to pain management within the UK. Given the perception of danger and concern regarding these practices, this is an important area for future research to inform development of PMPs for South Asian populations.

There are limitations to the research presented in this article. The recruitment of South Asian participants to health research studies can be challenging (Quay, Frimer, Janssen, & Lamers, 2017). Recruitment for this research was difficult, however while the sample size may be viewed as small, it is not unusual for qualitative research and saturation of themes was reached (Dallos & Vetere, 2005). Secondly, most participants were living in cities and discourses presented may represent elements of this social context and affect the transferability (Yarley, 2000) of these findings. Further exploration of the pain and pain management beliefs of individuals from South Asian backgrounds living in more rural locations would be of theoretical interest. It may be considered a limitation that only one participant had experienced chronic pain, however at the point of onset of chronic pain this will be a new experience and individuals will draw on their pre-existing knowledge and ideas about pain in order to make sense of their experience and decisions about pain-management. On this basis the sample is a suitable group with which to explore the acceptability of pain management concepts, however further research with South Asian community members currently experiencing chronic pain would be valuable to the development of PMPs.

# Conclusion

This study adds to the current understanding of pain and pain management beliefs within South Asian populations living in the UK. This work has highlighted how discourses around the impacts of chronic pain, beliefs about and preferences for approaches to care, and the acceptability of pain management concepts fit with PMP content. Several avenues for further development of chronic pain management for this population have been highlighted including, exploring opportunities for social prescribing, consideration of the incorporation of acceptable forms of physical activity including yoga and walking, and the potential benefit of highlighting role models and creating social opportunities for these activities. It is also evident that some potential beliefs and practices in this area are under researched and further work that explores gender and generational differences in pain perceptions, and the potential dangers of the use of pain healers is needed.

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Table 1: Interview schedule and rationale for questions asked

|  |  |  |
| --- | --- | --- |
| **Question** | **Rationale for asking for the question** | **Prompt** |
| **Pain History**  Have you ever experienced chronic pain (pain which has persisted for 6 weeks or more)?  If yes,  Have you ever attended a pain management programme? Or had any other treatment(s) for chronic pain? | Provide context about the participant | N/A |
| Can you describe the last time you were in pain? What was the situation?  What did the pain feel like?  Describe what chronic pain feels like (if relevant) | Ascertain the language used by participants to describe pain. | What does pain feel like? What does it look like? Sound like?  What does pain mean for your body? |
| What do you normally do when you experience pain?  Would you do the same if your pain lasted for more than 6 weeks ?  Would you continue doing the same if you were told that there was no cure for your pain?  Would other people in your community do the same? | Establish the participants own experiences of pain and what they do when they are in pain. Explore whether their own experiences fit with what they perceive other people in their community would do. | What are the biggest problems you experience when you are in pain?  Do you do anything to try and relieve the pain?  Do you talk to anyone about your pain?  If you were experiencing pain would you ask for help? |
| How do you know when someone in your community is experiencing pain?  Is there a certain way that people should act in your community when they are in pain? | Explore how culturally acceptable the expression of pain is. | When you experience pain what do you do?  Is it OK to show pain? Would you tell people that you were in pain?  How would you react to someone who was expressing their pain (verbally, in their body movements etc.)? – What about if a child is in pain? |
| How do you think chronic pain should be treated?  Do you think that chronic pain can be cured? How?  **Religion**  In your religion, does it say anything about pain and how it should be treated or managed?  Do people who live in your community seek any help from religious leaders for their pain? Who? Where?  **Self-management**  What do you understand about self-managing pain?  Is there anything you think the person with pain themselves can do to help manage it? | Explore the participants’ beliefs and attitudes about how pain should be treated/ managed. | What is effective when you are experiencing pain?  Should people take medications to treat their pain?  Is there anything people can do to manage chronic pain? |
| Health care professionals often advise to do regular physical activity to manage chronic pain - how easily could you fit this into your current day-to-day life?  What about for other people generally in your community? Would they be able to fit physical activity / exercise into their daily lifestyles? If no why not? | Establish whether physical activity is acceptable/ feasible to the participant and their perceptions of the feasibility for other members of the community. | What difficulties would you have?  How physically active are you?  How physically active are other people in your community? How about family members? |
| Another way that health care professionals advise to manage pain is to do regular relaxation - how easily could you fit this into your current day-to-day life?  What about for other people in your community? | Establish whether relaxation is acceptable/ feasible to the participant and their perceptions of the feasibility for other members of the community. | How do you relax?  How often are you able to relax?  How about other people in your community? Family? |
| What do you understand by the term ‘pacing yourself’?  How easy is it for you to pace your day-to-day activities?  What about for other people in your community? Would it be harder for certain members of your community? | Establish whether ‘pacing’ is understood and whether it is acceptable/ feasible to the participant and their perceptions of the feasibility for other members of the community. | Do you ever feel like you are doing too much?  What happens if you do too much?  Do other people in your community ever do too much?  If you needed to do less could you? Would your family understand? |

Table 2: Participant characteristics

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Number | Gender | Age | Position within the community | Location | Experienced Chronic pain? | Religion | Interview type |
| 1 | F | 45 | Not stated | Birmingham | No | Sikh | Telephone |
| 2 | F | 37 | Parent | London | No | Hindu | Telephone |
| 3 | F | 45 | Wife | Birmingham | No | Christian | Telephone |
| 4 | M | 24 | Support worker and a student | Walsall | No | Sikh | Telephone |
| 5 | M | 46 | Shop Owner | Stafford | No | Hindu | In person |
| 6 | M | 22 | Student | Stafford | No | Hindu | In person |
| 7 | F | 33 | Mature student | Buckingham  shire | No | Sikh | Telephone |
| 8 | F | 19 | Gap year Student | London | No | Sikh | Telephone |
| 9 | F | 27 | Medical Engineer | Birmingham | Yes  -Nerve pain | Sikh | Telephone |
| 10 | F | 32 | Software Developer | London | No | Sikh | Telephone |