

Research Paper

"There are several different castes, you know?" South Asian tutors' experiences of delivering a self-management programme to Punjabi Sikhs

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What Is Known:

- Chronic Disease Self-Management Programmes (CDSMPs) are cost-effective interventions that help people with a long-term health condition to take control of their daily lives.
- Attendance levels are low amongst Black and Minority Ethnic (BME) groups, which could contribute to social inequalities in health.
- Little attention has been paid to the experiences of the tutors who deliver SMPs to BME populations and therefore the insight that they could contribute is largely unrecognised.

What This Paper Adds:

- Whilst provision of Punjabi courses was appreciated, cultural sensitivity to the context of delivery was lacking on a number of levels.
- Attendance barriers included lack of awareness about the intervention, and the social influence of the highly refined Sikh caste system, whilst comprehension barriers related to the language of the course manual, medical terminology and conceptual content.
- Facilitators included the provision of single-language and single-religion courses, pictorial content in the course manual, and culturally competent recruitment strategies.
- Policy-makers, providers and commissioners can consider introducing a number of these changes to SMPs in BME communities, developed in close consultation with target communities, to improve access and understanding.

ABSTRACT

Structured, group-based, psycho-educational self-management interventions, such as the Chronic Disease Self-Management Programme (CDSMP), are designed to help people living with a long-term condition to better manage their daily lives. However, in the UK, the uptake of these interventions among South Asian people is low.

Internationally, cultural and structural adaptations of CDSMPs for members of Black and Minority Ethnic (BME) communities show encouraging outcomes. However, scant attention has been paid to the experiences of tutors delivering CDSMPs to these populations and the insight that they could contribute is largely unrecognised. By examining the experiences and understandings of these tutors, more refined cultural and structural modifications may be identified. The aim of this study was, from the perspectives of South Asian tutors, to describe their experiences of delivering CDSMPs that had included South Asian attendees. Richly informative interview data were analysed using Interpretative Phenomenological Analysis. Findings revealed substantial barriers to South Asian people attending, engaging and understanding elements of the intervention. We provide experiential examples to support tutors' arguments for highly tailored courses, targeted at specific sub-groups of particular communities, and offer insight into practical steps to achieve this. Attendance barriers included lack of awareness about the intervention, and the social influence of the highly refined Sikh caste system, whilst comprehension barriers related to the language of the course manual, medical terminology and concepts. Tutors' identified pragmatic facilitators to South Asian people's participation in, and understanding of, the intervention. These included having single-language and single-religion courses, pictorial content in the course manual, and culturally competent recruitment strategies. Further research with South Asian SMP attendees may reveal additional insights into South Asian people's attendance and performance of self-management behaviours. Policy-makers, providers and commissioners should work with BME communities to adapt SMPs, in order to improve access and understanding, and reduce health inequalities.

Keywords: Ethnicity, Long term conditions, Self-management, South Asian, Interpretative Phenomenological Analysis

Introduction

The global burden of disease is growing, and long-term conditions (LTCs) such as cardiovascular disease and diabetes are increasing as leading causes of mortality worldwide (World Health Organisation, 2014). In England, 15 million people have LTCs with this figure predicted to climb in the next decade, particularly for those with three or more conditions; 70% of the NHS budget is spent on treating LTCs (DH, 2013). Yet people with LTCs typically spend less than 1% of their time in contact with health professionals; the remainder of the time they, their carers and families, manage by themselves (NHS England, 2014a). Specialised services for LTCs are commissioned directly by NHS England, including personalised services to support and enable the active self-management of LTCs (Parliamentary Select Committee review, 2014), such as self-management interventions. These empower people to choose positive health and lifestyles, enabling them to live as independently as possible, with enhanced quality of life and nominal recourse to formal health services (NHS England, 2014b).

Structured, group-based, psycho-educational self-management interventions are designed to help people living with LTCs to manage their daily lives. The Stanford Model Chronic Disease Self-Management Programme (CDSMP) (Lorig and Holman, 2003), known as the Expert Patients Programme (see http://selfmanagementuk.org/) in the UK, is theoretically grounded within the Biopsychosocial Model and self-efficacy, social learning, cognitive behaviour theory (Bandura, 1977, 1999). The Biopsychosocial Model of health and illness expands the biomedical view by adding psychological and social factors to biological factors. This model proposes that ˙all three factors affect and are affected by the person's health' (Sarafino and Smith, 2014; page 13).

The UK's Expert Patient Programme comprises six, weekly sessions, each lasting approximately 2.5hours, led either by pairs of trained lay-tutors, who themselves live with a LTC, or co-delivered by a trained lay-tutor and a health professional. Sessions cover diet and lifestyle choices, medication usage, working in partnership with health professionals, communication skills, relaxation tools, action planning and problem solving, all of which increase self-confidence and motivation.

Self-management interventions have been shown to reduce healthcare utilisation in the USA and UK (Lorig et al., 1999; Richardson et al., 2008). Successive reviews confirm effectiveness data across different domains. For example, Barlow et al. (2002) concluded that SMPs increased knowledge, symptom management, use of self-management behaviours, self-efficacy, and promoted beneficial medical outcomes. Similarly, Newman et al. (2004) found that arthritis interventions led to some improvement in self-reported symptoms and disability measures and identified behaviour-change as the most successful outcome in relation to managing arthritis, asthma and diabetes disease. Warsi et al. (2004) and Chodosh et al. (2005) found improvements in the management of diabetes in terms of haemoglobin levels and systolic blood pressure levels; people with asthma had fewer attacks, and pain and function improved amongst people with osteoarthritis. Both Newbould et al. (2006), and Foster et al.'s (2007) systematic review and meta-analysis involving nearly 7,500 LTC patients, concluded that SMPs led to small improvements in self-efficacy, depression, pain, disability, fatigue, self-rated health, aerobic exercise and cognitive symptom management. The largest UK randomized controlled trial of the EPP showed improvements in energy, self-efficacy and other psychosocial outcomes, and confirmed its cost-effectiveness (Kennedy et al., 2007). Brady et al.'s (2013) meta-analysis reported small improvements in cognitive and health status, from SMPs delivered to different populations and

varied community settings. Together these provide evidence that SMPs improve various psychological and physiological outcomes; however, study populations are typically White females.

SMPs have been culturally and structurally adapted for certain minority ethnic populations, who have disproportionate levels of morbidity and mortality compared with White European-origin populations (Liu et al., 2013). Black and Minority Ethnic (BME) groups experience difficulties self-managing LTCs and worse outcomes, whilst typically living in socioeconomically deprived locations (Nolte and McKee, 2008). Sidhu et al.'s (2014) systematic review identified interventions in the US with Mexican-Americans, Hispanic/Latinos, Black Americans and Native Hawaiians, Filipino, and Pacific Islander populations. In the UK, an adapted SMP was delivered to Bangladeshis (Griffiths et al., 2005) and in Australia to Vietnamese, Chinese, Italian and Greek communities (Swerrisson et al., 2006). In their systematic review, Sidhu et al. (2014) concluded that lay-led self-management interventions designed for minority ethnic populations led to significant short- to medium-term improvements in self-efficacy, self-rated health distress, pain and fatigue. Modest statistical improvements in blood pressure and Body Mass Index were found; these outcomes are similar to SMPs designed for the general population (Sidhu et al., 2014). The necessity to improve accessibility and adaptations to behaviour-change interventions for people from BME backgrounds has repeatedly been recognised (Kennedy et al., 2004, Netto et al., 2010; Wilson et al, 2012; Davidson et al., 2013a; Sidhu et al., 2014).

Several of our previous studies have shown the importance of tutors in delivering lay-led SMPs. Tutors experienced increased confidence, gained a renewed sense of purpose in life, felt useful and valued members of society, enjoyed sharing their own learning through helping others and found that delivering the intervention reminded them of techniques to self-manage their own condition (Barlow and Hainsworth, 2001; Hainsworth and Barlow 2001, 2003; Barlow et al., 2004; Barlow et al., 2006a). Attendees perceived tutors as sympathetic and insightful, by virtue of their own experiences (Barlow, Edwards, Turner, 2008), and appreciated both the informational and emotional support that tutors gave (Barlow et al., 2006b). Tutors provided important role modelling opportunities, offering mastery experiences, persuasion techniques and reinterpretation of physiological and affective states, which assisted attendees in making changes (Barlow et al., 2009).

However, few studies have harnessed the experiences of tutors delivering SMPs to BME populations and therefore the insight that they could contribute is largely unrecognised. One recent exception to this is Sidhu et al. (2015), who found that culturally diverse lay-educators perceived themselves as knowledgeable and able to help attendees to differentiate between evidence-based and folk health beliefs. SMP attendees valued trust, rapport and empathy in the tutors above ethnic concordance, although the ability to speak a South Asian language was highly valued. We have previously described issues around White tutors delivering the EPP to English-speaking South Asian attendees, identifying their perceptions of South Asian attendees' needs, and highlighting tutors' need for cultural competence training (Hipwell et al., 2008). Additionally, the White tutors' understandings of the complexity of cross-cultural intervention delivery were illustrated.

By examining the experiences and understandings of South Asian tutors, more refined cultural and structural modifications may be identified. In the present study, we conducted interviews with South Asian EPP tutors to further illuminate these issues. The aim of this study was to describe the experiences of delivering EPP courses that included South Asian attendees from the perspectives of South Asian tutors.

Methods

Design

Adopting an Interpretative Phenomenological Analysis (IPA) methodological approach, our exploratory qualitative design used in-depth, semi-structured interviews. With an epistemological focus on experience (Langdridge, 2007), our phenomenological approach focused on participants' socially constructed perceptions of the world, and what these meant to them (Ashworth, 2003). Ethical approval was obtained from Coventry University.

Participants

The EPP co-ordinator in Coventry, UK, had identified that South Asian communities were particularly poorly represented on previous EPP courses, confirming Kennedy et al.'s (2004; 2007) assertions that particular attention needed to be paid to such groups. We therefore decided to interview South Asian tutors who had delivered this SMP to South Asian attendees, about their experiences, to identify any potential issues that they had encountered and which might present a barrier for South Asian people attending the intervention. At the end of each EPP course, attendees are given the opportunity to undertake structured training to become a tutor. Upon completion, basic demographic and course delivery details are held for every accredited tutor. Participants were purposively sampled, as is usual for IPA, for their experience of delivering an EPP course that had included a South Asian attendee, in any language (Reid, Flowers and Larkin, 2005; Osborn, 2005; Smith et al., 2009). The entire available population of tutors who had delivered an appropriate course was three people; funding requirements determined the location of the study. AH telephoned the tutors, gave an overview of the study's aims, and sent an information pack containing an outline of the study, informed consent sheet, and demographic data-collection form. All three agreed to participate. Participants were Punjabi Sikh Indian women aged 43–68; their LTCs included cancer, rheumatoid arthritis and Type II diabetes.

Addressing misunderstandings about small sample sizes, Reitmanova (2008) asserted that the socio-cultural meanings of health and illness experiences, not simply their frequency, are hugely important in social science research. Importantly, in phenomenological research such as the present study, the use of small samples (<10) are specifically advocated (Smith, 2004; Smith and Eatough, 2007). This allows for detailed analysis of participants' accounts of a particular experience, without losing the texture of their experiences. Flowers' (2005) review of

studies using IPA identified that sample small sizes allow for the detailed analysis (Smith, 2008) that IPA studies exact.

Data collection

Qualitative data were collected in face-to-face, in-depth, interviews with each participant, in English. The semi-structured interview schedule was constructed with reference to the literature and the local BME Lead (JS), who checked and confirmed the likely appropriateness of the interview schedule for use with the identified participants. Questions explored participants' motivations to become a tutor, what they enjoyed most/least about delivery to South Asian attendees, their communication strategies with attendees from different ethnic backgrounds and suggestions to improve this SMP for South Asian people.

Interviews were conducted in the location of each participant's preference; one took place at the University Research Centre, one at the participant's workplace, and one in the participant's home. Interviews were conducted in English and digitally recorded with each participant's express permission, transcribed verbatim and line-numbered prior to analysis.

Data analysis

IPA is considered particularly useful in novel, under-researched, complex or ambiguous areas (Osborn, 2005), and Todorova (2011) calls for increased focus on the social context in which the experiences take place. IPA is concerned with the detailed examination of personal, lived experiences, the meaning of the experiences to participants, and how they make sense of them. Unlike purely descriptive approaches, IPA encompasses different levels of analysis and, whilst there is no single prescriptive method, this typically comprises detailed phenomenology, insightful hermeneutics, and nuanced analysis (Smith, 2008). Descriptive analysis started with AH identifying examples of 'what it is like' from the participants' accounts (Larkin, Watts and Clifton, 2006). Next, during interpretative analysis, she attempted to understand participants' 'sense-making' (Larkin et al., 2006) of their experiences. This second order analysis allowed their data and her interpretations to be critically examined for alternative meanings or understandings (Smith et al., 1999). Caution was exercised to ensure that the hermeneutic nature of this process did not lose sight of participants' own words. Finally, connections were identified between the data and the interpretations. These were clustered collated into themes (Eatough and Smith, 2006; Smith et al., 1999). This cyclical process was undertaken on each transcript, with newly emergent themes tested against previous transcripts and current themes.

Results

To protect participants' identities, pseudonyms are used throughout.

Barriers to South Asians' attendance, engagement and self-management

Participants' experiences of delivering the intervention to South Asian attendees revealed several barriers with regard to attending, engaging and understanding parts of the course's concepts, content and its delivery mode, and also in performing self-management behaviours.

Attendance Barriers

These included the lack of recognition of EPP amongst BME groups, and the need for ethnicity-specific courses, which considered the Sikh caste system. The most significant barrier to BME attendance was a lack of awareness of EPP:

'I think EPP still needs a lot of awareness in the ethnic minority, EPP, not many people know' (Sukhpreet).

However, Sukhpreet dismissed the notion raised in a previous study (Hipwell et al., 2008) that ethnicity-specific courses could be perceived as segregational. She felt that offering single-ethnicity courses was important, to avoid attendees feeling isolated as she had, as the only South Asian attendee on her course:

'But I think people do feel comfortable when they're in their own group. … I'm pretty easy-going person, I can adapt in any situation. But then when you go, if you're only on your own and you're placed in a group of other people, you feel lost, don't you? … I feel, I don't feel comfortable at all' (Sukhpreet).

She highlighted the fine-textured complexity and hierarchical social structure of the Sikh caste system, which she evidently perceived as a significant barrier to South Asian people's attendance:

Sukhpreet: 'In my own Sikh community ... there are several different castes, you know, upper class and lower class, and it's the job they have been doing back home and then they come here, and 'Oh, I'm higher than that person and I'm higher than this person'.

AH: 'And that's still active in Coventry?'

Sukhpreet: 'Oh yes!'

AH: 'I see, so even within say, a Punjabi Sikhs' course?'

Sukhpreet: 'Yes'.

AH: 'Would then, would the NHS people – how would they find out who to put on what course?'

Sukhpreet: 'They won't at all! ...in Asian people, especially in Sikh religion, we have people who sweep the road, who does carpentry, joinery, blacksmiths, farmers... You were not allowed to marry people like that, but nowadays people don't care!'

This shows that caste might present an attendance barrier for some Sikhs, if they perceived the course to be attended by Punjabi Sikh people from a different caste to their own. In addition to the usual demands of the intervention, Sukhpreet perceived that Sikhs who DID attend, would also potentially have to contend with the discomfort arising from their being from differing castes. She did not consider the potential impact of caste differences between a Sikh tutor and attendees, but it seems plausible that the same effect may occur. However, Sukhpreet understood that although this matter appears imperceptible to those outside the community, it does not present an entirely intractable barrier, given her own social mobility, and her suggestion that the caste system appears to be increasingly flexible.

Comprehension and Engagement Barriers

Other potential barriers included understanding manuals, their translation and terminology, and the intervention's content.

a. The tutor manual was translated into Punjabi, but attendees on Punjabi-language courses were given English-language manuals, as no Punjabi translation was available. Jangjeet considered this to lack cost-effectiveness:

˙So I mean that was a total waste of time... They shouldn't have bothered really. I think that's just such a waste of resources, giving them a Manual that's not going to be any good for them to use' (Jangjeet).

Her annoyance is clear; attendees would not have enough information to self-manage effectively without the manual. Karamdeep argued that attendees were then forced to depend on their children to translate the manual, in order to understand an intervention intended to increase their self-efficacy:

˙They say 'I'm not going to understand it', some of them don't take it; some of them take it, they say, 'oh my child can help me' (Karamdeep).

b. The use of medical terminology also affected comprehension:

˙And some of the …types of illnesses and the words … that were used, they didn't know what it meant! … They make references to your liver, your heart, your lungs, and they're all very medical terms, and a lot of the old people, when I did that Punjabi course, they didn't know what we were talking about' (Jangjeet).

This important finding indicates that the course would benefit from clear lay explanations to ensure that attendees with low levels of health literacy can follow its content. Alternatively, it may be that the cultural norms of health management are so different in South Asian cultures from the assumptions underpinning EPP that these terms were simply not recognised by attendees as relevant.

C. A central construct of the intervention, action planning, caused particular concern. This section of the course required each attendee to set a small, achievable, goal, to be completed by the following week. Attendees then reported back to the group, highlighting any difficulties encountered, and how they did/did not overcome them. Attaining these small goals was intended to foster a sense of personal achievement that enhances their self-efficacy. However, Punjabi attendees did not, generally, grasp this concept:

˙Their perception of Action Planning, they just didn't have an understanding of it. And really what the meaning of the 'Action Plan', what we wanted them to get out of it. Because they still did what they [did] every day' (Jangjeet).

Jangjeet's experience suggests that attendees' lacked understanding of the concept of action planning. One explanation is that they were unfamiliar with setting their own health-related goals, perhaps used to paternalistic healthcare professionals doing this for them. Alternatively, this issue may have arisen as the Punjabi-language course used the English words action plan, which would, presumably, have been meaningless to the non-English speakers.

Facilitators

Participants' also identified attendee characteristics and access factors that they considered would enhance South Asian people's attendance on, and understanding of, the intervention. The following experiential examples support tutors' arguments for highly tailored courses to be targeted at specific sub-groups of particular communities, and offer insight into practical steps that might achieve this.

Characteristics

Language: All participants perceived language as a major determinant of the likely success (or otherwise) of EPP with any group. Sukhpreet highlighted the complexity of delivering multi-lingual courses to South Asian attendees:

Sukhpreet: ˙…the 2nd set [of attendees] I had was Gujarati and then I had to speak Hindi and some Gujarati'.

AH: ˙In that same session'?

Sukhpreet: ˙In the same session, and English! Because most of the course was delivered in English, it was only if people didn't understand you know, and we ...we will try and explain. So people would just put their hand up and we would explain in Gujarati or Hindi or Punjabi'.

These English-speaking South Asian attendees may have been more educated than those on South Asian language courses. However, their need for explanations underscores the earlier point that the assumed level of Western health literacy inherent within the intervention, may be inappropriate for South Asian attendees.

Another participant did not encounter this difficulty when delivering a Punjabi-language course, enjoying her experience:

˙I really enjoyed doing it in Punjabi, because I could, being a Punjabi myself, I could relate to their problems at home, medical problems, social problems, because it was my culture. I could see where they were coming from' (Jangjeet).

Jangjeet appeared able to fully embrace Punjabi cultural norms when delivering in Punjabi, perhaps feeling culturally attuned to her attendees. Single-language delivery may represent a more effective delivery-mode for tutor and attendees than the experience Sukhpreet described above. This suggests that interventions tailored around language and ethnicity may be preferential to generic South Asian/language courses.

Literacy: One participant identified the usefulness of the pictorial content in the (English) course manual, for attendees with low literacy:

Karamdeep: ˙But some of the exercises, like neck exercises, feet, they find that useful'.

AH: ˙Are there pictures of those'?

Karamdeep: ˙There are some pictures there. So for exercises, and stuff'.

It is encouraging that some attendees recognised the exercise diagrams as useful, and highlights a potential approach to overcome language barriers through pictorial content, where possible.

Religion: Sukhpreet asserted that recruiting South Asian attendees from the same religious background would facilitate both their participation in EPP and her own delivery experience:

Sukhpreet: ´it would have been better if the Muslim people's group was separate from the Hindus. Because if there was any religious issue and the people could not speak up openly...there were certain issues that you have to think 'Oh I shouldn't be saying that' you know. And ...sometimes, you would probably say the Muslims don't do this, the Sikhs don't do that and the Hindus don't! But then you can't, you can't say that'.

AH: ´Because it might offend'?

Sukhpreet: ´Yes, yes, yes'.

This quote reveals the highly refined subtleties of South Asian inter-cultural relations, which are overlooked when courses are organised around language alone. The quote conveys a near-tangible sense of discomfort, even tension, for Sukhpreet herself, and between the different attendees. It is implicit that the cultural-specificity of EPP was lacking. It was Sukhpreet, above, who identified the need to consider attendees' caste; together, these findings reveal the sensitive adaptations that might ensure EPP's cultural competence.

Gender: Jangjeet advocated recruiting Punjabis as couples, at the Gurdwara, to overcome the issue of South Asian men purportedly misunderstanding their wives' attempts at healthy eating:

Jangjeet: ´Women aren't allowed to be flexible enough to change the diet, if they want to experiment. So that's why you catch them at the Temple, they're there together and then there's an understanding – the husband doesn't think the wife's trying to do something to him!! [Both laugh] When the food doesn't taste as nice! Or he thinks she's just being mean'!

AH: ´So you could get the men at the Temple as well, to educate them as well'?

Jangjeet: ´Yes, they're there'!

Jangjeet understood Punjabi gender-roles and the pivotal importance of Punjabi men's acquiescence if the nutrition section is to be effective. She identified that recruiting husbands and wives together at the Gurdwara and involving men in EPP would achieve this.

Access facilitators

Having indentified that South Asian groups lack of awareness of EPP, one participant suggested practical guidance to overcome this:

´I think there should be more sort of awareness in the temples, in the mosques, in the mundirs, the other places when there are big functions going on. …because they have get together evenings and somebody can put a stall up there and put a little bit about it' (Sukhpreet).

She argued that placing an information stand at in religious or community-centres, would raise EPP's profile. This resonates strongly with Jangjeet's earlier suggestion to recruit couples at places of worship. All participants' understood that older Punjabi Sikhs learned from each other, in their informal social groups at the Gurdwara:

´I think from the Punjabi point of view, the biggest learning place for them is in their social groups, and I would say that 90% of all the 60+ Punjabi people go to the Temple. They have like, erm, they have these morning functions, where all the ladies go off for this religious thing and then afterwards, we all sit and have a natter! ...Cos that's the time they're all talking to each other 'I've been on this course' and 'I've been doing this' and 'this is the medicine I'm taking for my bad back' and that's where you're learning a lot of stuff as well' (Jangjeet).

This suggests that Punjabi culture embraces the concepts of social learning and peer support, which is encouraging as both are integral to the EPP. Jangjeet understood that this might not only address issues of awareness and potential recruitment opportunities, but also offer an informal learning environment between people who have attended EPP, and those who have not. This confirms the previous findings that awareness-raising sessions and recruitment could be undertaken at places of worship.

Discussion

This study revealed a range of possible barriers to South Asian people's attendance, engagement in EPP and self-management behaviours, from the perspectives of Punjabi Sikh tutors. It also identified a number of facilitators that may promote EPP amongst South Asian communities, including attention to attendees' characteristics and access factors.

Tutors' perceptions of a fundamental lack of awareness about EPP amongst South Asian people is clearly important, given that these groups require particular attention to avoid exacerbating health inequalities (Department of Health, 2010; Scottish Government, 2010). It suggests that the need to improve accessibility to and adaptation of SMPs for people from BME backgrounds (Kennedy et al., 2004, Wilson et al, 2012, Sidhu et al., 2014) could be addressed by commissioners identifying and addressing access and participation barriers (Netto et al., 2010) and providing targeted and visible awareness-raising (Liu et al., 2015) in faith-based locations.

Revelations about the impact of the Sikh caste system on attendance and participation are particularly noteworthy. Culturally-tailored, linguistically-appropriate SMPs are associated with improved cognitive outcomes amongst BME attendees (Lorig et al., 1999, 2003, 2005; Griffiths et al., 2005; Sidhu et al., 2014), yet little attention has been paid to caste. Not only are ethnicity-specific courses a pre-requisite to some Sikhs' attendance, but our findings suggest that attendees may still face further barriers to engagement, depending on the perceived caste of other attendees. The reported increasing flexibility of the Sikh caste system suggests that a cultural transition is in progress, so that this issue may become less relevant in time. The Sikh caste system in the context of healthcare and behaviour-change interventions therefore requires further exploration. Attention

to the influence of religious sensitivities on SMP attendance and effecting behaviour-change cannot be under-estimated, given that the performance of religious behaviours is prioritised over self-management among South Asians including Sikhs (Greenhalgh et al. 2011). Clinical Commissioning Groups (CCGs) may consider highly sensitive recruitment strategies that address diversity within Sikh culture, in order to ensure equality for example, by recruiting attendees from the same Gurdwara, which is typically attended by Sikhs from the same caste. Alternatively, recruiting attendees from existing social groups e.g. community-centres where such barriers have already been broken down, or are considered less relevant by group-members, could prove effective. This resonates with Liu et al.'s (2012) call to consider attendees' social environment and group heterogeneity, and that shared ethnic background and ancestral ties can operate as a source of tension and limit participation in interventions.

The absence of a manual in Punjabi was a barrier. The effectiveness of different delivery-modes - with or without a manual - has not been evaluated, so its role in attendees' understanding is not known. Nevertheless, the fact that attendees did not receive the same basic materials constitutes a clear inequity but, as many attendees were illiterate in any language, it is questionable whether a Punjabi-language manual would help them. The action planning element was considered inappropriate; tutors found it challenging to deliver. Commissioning bodies could avoid such issues in future, by involving community-members in the planning stage of any adaptation (Adebajo et al., 2004; Greenhalgh et al., 2005, 2011; Samanta et al., 2009; Liu et al., 2012; Davidson et al., 2013b),) to ensure that the needs of attendees are met (Netto et al., 2012, Davidson et al., 2013b).

The need for tailored behaviour-change interventions for low health literacy attendees is confirmed by the present study. This finding is unsurprising given the descriptions that participants gave of many attendees' demographic profile: ´low health literacy is more common in low income and minority ethnic groups, immigrants, people without full citizenship, those with fewer years of education, and older people; it is especially common in people who fall into several of these risk groups' (Greenhalgh 2015). Pictorial representations helped some attendees which accords with previous studies in low-literacy and low health-literacy groups that found non-text-dependant education to be appropriate in South Asian groups; literacy is a major issue for many patients, who might benefit from materials using culturally-sensitive pictorial representations (Adebajo, et al., 2004; Davidson et al., 2013b**,** Greenhalgh et al., 2005). Commissioning collaborative work with target communities should develop cultural adaptations of the design of the intervention and its education materials, along with regular evaluations and thus more effective health promotion (Adebajo et al., 2004; Greenhalgh et al., 2005, 2011; Samanta et al., 2009).

This finding has potential implications beyond the Punjabi Sikh community: Weinman et al. (2009) investigated levels of anatomical knowledge, finding that, generally, people lacked rudimentary knowledge of the location of organs, including the heart, liver and lungs. In Australia, limited health literacy was found in up to 26% of the population (Barbour et al., 2009). Given the descriptions provided by the present study's participants, it therefore appears entirely plausible that their concerns around older, illiterate, Punjabi Sikh attendees' lack of comprehension are entirely warranted. It is further possible, based on Weinman et al. (2009)'s findings, that the inherent assumptions of health literacy within the SMP's content could also be challenging for non-Punjabi Sikh attendees: this requires further investigation.

One participant's understanding of Punjabi Sikh traditional gender-roles in relation to managing dietary aspects of LTCs is note-worthy, with male concordance apparently pre-requisite to Punjabi Sikh women effecting dietary changes. Liu et al. (2012) identified women as both targets and agents of behavioural change and highlighted the cultural complexity of mobilizing health-driven changes to food practices (Liu et al. 2015). In their systematic review of behaviour-change interventions for BME groups in high income countries, Nierkins et al.(2013) proposed research incorporating family-level adaptations.

The findings about the Sikh caste system and the absence of a Punjabi manual, combined with assumptions about attendees' literacy and health literacy, offer strong confirmation from our previous study, with White EPP tutors that ´...we're not fully aware of their cultural needs' (Hipwell et al., 2008). It seems that not only White tutors but the intervention itself lack cultural competence. Community involvement in redesigning the intervention may start to address some of the issues raised in the current study.

Participants' experiences of delivering the intervention to South Asian groups allowed them to identify features that, if present, could improve the SMP, both from their own perspectives as tutors, and in how they perceived that attendees would receive it.

One participant had encountered difficulties when delivering the intervention to attendees from different religious and linguistic backgrounds, which she believed negatively impacted upon their engagement. This led her to advocate that courses require tailoring around religious beliefs and that attendees should be recruited by religion and language; this appears to have been successful for another participant. There is considerable evidence to support this (Netto et al., 2010; Liu et al., 2012; Davidson et al., 2013), including Griffiths et al.'s (2005) RCT of Bangladeshis, who were recruited onto a specifically adapted intervention that reflected attendees' local dialect and Islamic culture. This confirms our previous findings with White tutors and our observation that EPP delivery in a multi-cultural society is highly complex (Hipwell et al., 2008).

Participants' experiences provided insight into access facilitators that could promote BME attendance on behaviour-change interventions. The use of faith-based and faith-placed health education interventions to help address health disparities in underserved communities is widespread in the USA (e.g. Rodriguez et al., 2009). Such interventions are perceived as socially, culturally, and spiritually acceptable to members (Auslander et al, 2002; Wilcox et al., 2006 Williams et al, 2006). Faith-based and faith-placed programmes can produce positive outcomes, including increased disease knowledge, improved screening behaviours and reduced disease symptoms (DeHaven

et al. (2004). Cultural and structural changes that sensitively consider the target group's needs can enhance the planning and community engagement stages of behaviour-change interventions (Netto et al. 2010, Liu et al. 2012).

A noteworthy observation of the current study is the stark contrast it provides in comparison with our previous study with White tutors whose experience of delivering EPP to South Asian attendees was largely unproblematic (Hipwell et al., 2008). It may be that the English-speaking South Asian attendees encountered by the White tutors were acculturated and therefore better understood the course. The current study unequivocally confirms the need for involvement of the target community when developing any targeted intervention.

Limitations

The low attendance rates amongst South Asian people meant that the three tutors interviewed had limited experience of delivering to South Asian attendees. Clearly, this will have influenced participants' views and experiences. However, the breadth of results presented here indicates that neither small sample size nor limited experience appears to have unduly restricted our findings. All three Punjabi Sikh tutors agreed to be interviewed, representing 100% of the available population. In comparison, at the time, there were only two Somalian tutors in the whole of England. Another potential limitation is that of socially desirable answering, particularly as the interviewer's (AH) ethnicity differed from participants', and the sensitive nature of the topic. However, the right to anonymity was stressed prior to, and during interviews as necessary, to assure participants that they could speak freely. Given the diversity of answers, and participants' open criticism of some aspects of the intervention, response bias does not appear to have compromised this study. Another consideration is that many of the suggested recommendations arising from participants' experiences, may be difficult to operationalise, given budgetary constraints. For example, recruiting sufficient numbers of highly homogeneous attendees might improve attendance amongst this group, but compromise the course's cost-effectiveness. Should any of the suggestions be used, then efficacy/effectiveness studies would be required.

Strengths

This study also has a number of strengths. The results may provide informative strategies for those developing and implementing similar health interventions for South Asian groups. Findings about transitions in Sikh culture may represent a useful reference point for the future. The highly detailed descriptions have provided thought-provoking insights into these Punjabi Sikh participants' experiences of delivering courses to South Asian attendees, afforded by the study's qualitative design. Whilst not intended to be generalisable, our findings may, however, represent a useful starting point for future research in this area. It was evident that whilst some similarities exist, South Asian community-members may have very different experiences of attending the intervention than has been previously understood in mainstream studies. Further research exploring these experiences may reveal further insights into South Asian people's attendance and performance of self-management behaviours.

Summary

This small-scale, in-depth, study has identified a number of ways in which commissioners can culturally adapt behaviour-change interventions, for example, by raising awareness about the intervention and clarifying its purpose and content, recruiting attendees, and delivering courses in faith-placed locations. Commissioning highly refined interventions, comprising attendees who speak the same language, are from the same religion and caste may help with South Asian recruitment, engagement and delivery. The need for non-text-dependent innovations in intervention materials, incorporating culturally-specific self-management guidance, developed in partnership with community-members who have low literacy and health literacy, would address the substantial barriers that were recognised by participants. In conclusion, policy-makers, providers and commissioners should work with BME communities to tailor SMPs, in order to improve access and understanding and reduce health inequalities.

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CONFLICT OF INTEREST

None

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