Family support and cardiac rehabilitation: A comparative study of the experiences of South Asian and White-European patients and their carer’s living in the United Kingdom

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Received 11 January 2007; received in revised form 19 June 2007; accepted 20 June 2007
Available online 24 October 2007

Abstract

Background: Effective lifestyle modification facilitated by cardiac rehabilitation is known to reduce the occurrence of adverse coronary events and mortality. South Asians have poorer outcomes after a myocardial infarction than the general UK population, but little is known about their experiences of family support, cardiac rehabilitation and lifestyle change.

Aims: To explore the nature of family support available to a sample of South Asian and White-European cardiac patients and to highlight similarities and differences between these groups with regard to cardiac rehabilitation and lifestyle modification.

Methods: Using a qualitative approach, semi-structured interviews (in 1 of 6 languages) were conducted by researchers with; 45 South Asian patients and 37 carers and 20 White-European patients and 17 carers. Interviews were conducted in a home setting, up to eighteen months after discharge from hospital following myocardial infarction, coronary artery bypass surgery or unstable angina.

Results: The main themes that emerged related to the provision of advice and information, family support and burden, dietary change and exercise regimes.

Conclusions: Several cultural and ethnic differences were identified between patients and their families alongside similarities, irrespective of ethnicity. These may represent generic characteristics of recovery after a cardiac event. Health professionals should develop a cultural repertoire to engage with diversity and difference. Not every difficulty a person encounters as they try to access appropriate service delivery can be attributed to ethnic background. By improving services generally, support for South Asian populations can be improved. The challenge is to know when ethnicity makes a difference and mediates a person’s relationship with service support and when it does not.

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Keywords: South Asians; Coronary heart disease; Qualitative research; Cardiac rehabilitation; Health behaviours; Family support

1. Introduction

When an individual is discharged home from hospital after a cardiac event, such as myocardial infarction (MI), their recovery is characterised by adjustment [1]. Those individuals who live alone or who have poorly developed social networks are vulnerable because interactions between patients and their family influence the course of recovery from MI. Accordingly, social isolation or a lack of social support is recognised as a risk factor for both the development of coronary heart disease (CHD) and as a negative prognostic factor for those with established CHD [2]. Reviews conducted in 1994 and 1999 have reported a negative correlation between the level of social support and CHD mortality and morbidity even after controlling for conventional risk factors [3,4].

Family support is a significant factor that can influence recovery and readjustment after a cardiac event [5,6], whether it be ‘instrumental’ (assistance with activities of
daily living, such as food preparation, shopping, cleaning) or emotional (caring, understanding and empathy) [7]. Levels of social support vary and the willingness of family members to support patients in making healthy lifestyle changes can be influenced by a range of factors [8]. Some of these are their own beliefs and attitudes towards CHD, their motivation to adopt a healthier lifestyle themselves as well as contextual factors, which include their relationship to the patient, support available to themselves and their relationship to service delivery. More generally, levels of involvement of spouses, children and extended family members during recovery are different because of differences in cultural and gendered expectations about care-giving. Studies show that this period is particularly challenging for family members as they may experience a range of negative emotions such as anxiety, depression, uncertainty, fatigue, irritability, poor concentration and insomnia [9–12].

Cardiac rehabilitation is an important adjunct to recovery and aims to improve short-term recovery and promote long-term changes in lifestyle which help to reduce coronary risk [13]. There is, however, little published research about family support and cardiac rehabilitation experiences of South Asians living in the United Kingdom (UK). It is known that South Asians have poorer outcomes after MI [14] than the general UK population, although the reasons for this are unclear [15]. Communication and language barriers, however, emerge as a significant problem in the provision of quality care for South Asians [16,17]. Webster, Thompson and Mayou (2002) explored the experiences and needs of Gujarati Hindu patients’ 1 month after MI and reported that patients and partners received limited information about their condition due to language barriers [18]. This led to patients and carers displaying misconceptions about their condition which negatively influenced recovery [18]. In particular, patients typically made few lifestyle changes and perceived their MI as an event that signified the end of their active life [18]. Other studies have identified similar communication and language difficulties experienced by South Asian patients, being treated for a range of chronic diseases, leading to a lack of information for patients and their families about diagnosis, medication and advice about their care [19–24]. These communication and language issues often arise due to problems in finding appropriate interpreters, resulting in using family members as interpreters [23].

A lack of health information is likely to influence individuals in their efforts to effectively self-manage their chronic condition. Language, however, is not the only problem facing South Asian populations; and the literature suggests that there is a complex interplay among socioeconomic factors, gender, culture, access to cardiac rehabilitation and social support; all of which are likely to influence recovery [25]. Little work, however, explores this interplay. The aim of this exploratory qualitative study was to explore the nature of family support available to a sample of UK South Asian and White-European cardiac patients and to highlight similarities and differences between these groups with regard to cardiac rehabilitation and lifestyle modification.

2. Methods

2.1. Setting

The study took place in West Yorkshire, UK and participants were recruited from one of three participating district general hospitals. Approximately 10% of the population which was sampled comprised of people of South Asian origin.

2.2. Sample

The sample consisted of ‘White’ European and ‘South Asian’ patients, aged over 30 years old, who consented to participate. Eligible patient participants had been admitted to hospital within the preceding year with a diagnosis of unstable angina, MI or for coronary artery bypass graft surgery (CABG). Consenting patient participants were asked to identify a family carer they felt had influenced their views and behaviour, either positively or negatively. All carers willing to participate were included.

2.3. Data collection

Semi-structured interviews were conducted using thematic topic guides to explore key issues. Published literature and views expressed by professional and patient advisory groups influenced their development. The topic guide, which is published elsewhere [26], explored people’s understanding of CHD; the impact of CHD on their lives; the influence of social networks on how they make sense of CHD; their relationship with service delivery; and their specific experience of rehabilitation. We used a similar topic guide for interviews with patients and carers, to allow for comparison. The majority of interviews were conducted by a female researcher (fluent in Urdu, Hindi and Punjabi) or a male researcher (fluent in Urdu and Hindi). Two other researchers conducted interviews that required fluency in Sylheti and Gujarati. Prior to data collection, a series of meetings were conducted which enabled interviewers to discuss issues that arose concerning the translation of questions from English into South Asian languages. Efforts were made to ensure that words and phrases in the original topic guide, retained the same meaning when translated.

Participants were given the choice of where their interview was conducted and the majority chose their homes. Audio taped interviews lasted between 60 and 90 min. Given the potentially sensitive nature of some of the questions, participants were offered the option of a same sex interviewer. The majority of patients and carers took this option although this arrangement was not always possible (such as when patient and carers wanted to be interviewed together, which occurred in 29 cases).
2.4. Procedure

After gaining local ethics committee approval, potential participants were identified by cardiac rehabilitation nurses from participating centres. General Practitioners were then contacted and asked about their patients’ fitness to participate. Great care was taken to ensure that interviews remained confidential. When patients and carers were interviewed separately, each participant was assured that material would be confidential. Participants were also assured that the information they provided would not be discussed with their health care professionals. Members of the research team fully transcribed all interviews and when necessary, translated. During translation, our concern was to capture conceptual equivalence – which preserved the use of local metaphor and the meaning intended by the person – rather than present a literal translation [25].

2.5. Data analysis

Transcripts were read and reread by members of the research team and recurrent themes and concepts identified. This guided the development and refinement of a coding frame based upon the emergent themes and sub-themes, which was then applied to each transcript. Relevant text was indexed in the transcript whenever a particular theme appeared and organised into a grid. Using this method of Framework analysis [27], we were able to explore concepts; establish linkages between concepts; and offer explanations for patterns or ranges of responses or observations from different sources. This involved constant cross-referencing between part and whole, as we generated an understanding of the meaning of actions, beliefs, attitudes and relationships, from the range and frequency of participants’ views [28]. This approach contributed toward establishing trustworthiness in ‘qualitative’ inquiry as outlined by Guba and Lincoln [29]. Researchers were able to focus upon the experiences and views of individual cases and relate these to themes. This approach facilitated the comparison of both cases and groupings and the identification of commonalities and differences in experiences across ethnic groups including within the South Asian group [30].

3. Results

3.1. Sample characteristics

Of the 112 potential participants identified, 89 were identified as sufficiently fit by their General Practitioner leaving 65 participants in the final sample. Approximately one third of these participants had attended cardiac rehabilitation classes within the previous year, with no major differences in uptake between ethnic groups.

The patient sample consisted of 20 White-European and 45 South Asian patients aged over 30 years, with a diagnosis of unstable angina (32%), MI (42%) or for CABG surgery (26%). In selecting our South Asian sample, we recognised the heterogeneity of this group. A person’s ethnic identify, as defined by their country of origin, is an important starting point, although for many South Asian people living in the UK, religion and ethnicity often reinforce each other [31]. This emphasises the value of selecting our South Asian sample, on the basis of both ethnic and religious identification [27]. A summary of participant’s demographic characteristics is shown in Table 1.

On the whole, white patients tended to live in smaller households than South Asian patients. Half of the White-European participants lived with their spouse and had grown up children living in separate households. A quarter lived alone, either widowed or divorced. Roughly half the patients within each South Asian group were sharing their household with their spouse and children. However Indian-Hindu patients were much more likely than their Indian-Sikh and Pakistani-Muslim counterparts to live in smaller households. Half of the Indian-Hindu households consisted of married couples, compared to only one Pakistani-Muslim and one Indian-Sikh household. A smaller number of patients within each ethnic minority group lived in extended families, usually consisting of a spouse, son, daughter-in-law and grandchildren. In contrast to the white sample, very few South Asian patients lived alone.

A similar proportion of carers (75%) were recruited to the study from each ethnic group and in some cases we interviewed a number of family members who were looking after the same patient. In cases where carers were not interviewed, patients either felt that it was unnecessary or difficult to interview their carer or could not identify anyone

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<th>Religion/ethnicity</th>
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<th>Carers (n=54)</th>
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<td>Male Female Total Age (years) mean (range)</td>
<td>Spouse Children Daughter-in-law Sibling Other Total</td>
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<td>Pakistani-Muslim</td>
<td>10 10 20 59 (46–72)</td>
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<td>Indian-Sikh</td>
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<td>Indian-Hindu</td>
<td>9 4 13 63 (40–82)</td>
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<td>White-European</td>
<td>10 10 20 66 (42–83)</td>
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<td>Total</td>
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who performed the role of a carer. A few of these patients were living alone but most lived in household with other family members. The relationship of carers to patients taking part in the study is shown in Table 1.

There were varying levels of use of English among patients and carers of South Asian origin. The majority of Pakistani-Muslim patients preferred to be interviewed in Urdu, Hindi or Punjabi as only 5% of this patient group spoke English. Within the other patient and carers subsamples 58–70% spoke English.

The next section presents four key themes that resulted from the data analysis with supporting excerpts. Pseudonyms are used to preserve anonymity.

3.2. Provision of advice and information

Within White-European families, spouses typically accompanied their partners to hospital appointments. Accordingly, couples were able to discuss the advice they had received concerning rehabilitation and could interact jointly with health professionals to identify potential problems. In this way spouses were able to provide considerable emotional support for their partners both during the initial stages of their diagnosis and as a ‘sounding board’ for patients to discuss health concerns that arose following interactions with health professionals.

In contrast, for some of the South Asian patients, such a high level of interaction was not always possible due to language barriers. As a result, three way communications between health care professionals, patients and spouses was limited as in the case of Aziza, Pakistani-Muslim patient who had recently suffered her second heart attack and was totally dependent upon her children to provide her with information about her condition. She explained:

People go with me [to the hospital] who can speak English and they tell me when I have an appointment... I don’t go on my own. Whenever I go, I take someone with me. I don’t know anything on my own... if nobody is with me then I can’t do anything. (MFSMI01).

Non-English speaking wives were not always able to understand the information given by health professionals to their husbands and were often dependent upon their spouses or their children to advise them as to what changes needed to be made within the home. In such cases children were expected to act as interpreters and pass on relevant information to their parents. English speaking children were therefore an important source of information for patients within these families. The wife of Jehangir, a Pakistani-Muslim who had recently suffered a heart attack at the age of 61, talked about the support provided to both parents by their youngest daughter

My daughter keeps books with her, I think she keeps all of the books with her, she reads them regularly, she says to me mum if I’m not here...she doesn’t live here, she lives in another house, she tells me if anything happens to daddy then...it tells you in the book what to do and she explains to me what to do and she says do this, I’ll explain it to you... she’s always explaining things to us... (MMDMI07C).

Children were also an important channel through which patients could direct questions of health care professionals about their condition. This, however, generated some inherent difficulties as children and patients were not always satisfied with this arrangement, feeling it breached expectations of family life. In isolated cases families withheld information from patients in a bid to prevent them from becoming alarmed and distressed about their heart disease and occasionally children opted not to tell parents about their diagnosis.

More generally children tended to avoid conveying the negative aspects and seriousness of their condition, as reflected in the comments made by an 18 year old daughter of a Pakistani-Muslim angina patient:

We don’t talk a lot about it she gets upset and sometimes she says oh I don’t know what’s happened to me she starts crying so we try not to mention any of it in front of her or something... if there’s like something that’s gonna make her better I read something and I tell her that oh that’s gonna make you better, you better try doing that and stuff but then if its like something bad that can happen I don’t tell her I think she’s going to start thinking and then she’ll get worse so we don’t tell her (MFDAI4C).

3.3. Family support and burden

On returning home from hospital families – irrespective of ethnicity – instituted a variety of care arrangements. Female patients who lived alone reported that they needed support during early recovery and tended to stay with children or siblings. Elsie, a 72 year old widow, who had suffered her first MI explained why she couldn’t face going back to her own home in the first few weeks: ‘Well you are frightened at first. You think I have had a heart attack. If there is somebody with you it helps. If I was on my own 24 hours a day, it would drive me around the bend’.

Other patients – again irrespective of ethnicity – found that spouses or children took time off work to care for them. Some patients recalled that their families wanted to provide a lot of physical support in the early stages of recovery, while they themselves were eager to regain their independence as soon as possible. This caused occasional tensions. Balvinder, who had been admitted to hospital for unstable angina was keen to resume her normal activities soon after she was discharged from hospital. This however caused her daughter-in-law considerable anxiety:

At the beginning we thought that she can’t go on the bus, she can’t walk up here, she can’t go here and my husband would take her ... in the car he used to take her here and
there, even if she had to get the shopping we had to take her because we used to think we had to do with her, she can't go by herself ... She was like 'thinking'... I'm getting locked up inside and are they always going to treat me like that? (SFSA10C).

Frequently, family members thought it important to minimise stress experienced by their relative and took practical steps to achieve this goal. Within South Asian families, stress was more of a concern to children rather than spouses whilst within White-European families, spouses were equally as likely as their children to discuss stress reduction. The most common approach to reduce stress within the household was for children to delay or avoid disclosing information which they thought might be potentially upsetting to their parents.

Some younger patients had identified their and their carer’s employment as a potential source of stress. Carers reciprocated these concerns. In one case, a Pakistani-Muslim self-employed accountant took on a manager to reduce his workload at the request of his wife and eldest daughter who were convinced that his workload was excessive. Older White-European patients were encouraged by their spouses to rest more but only one couple used the opportunity to relax together; this was achieved by listening to story tapes on a regular basis in the afternoons which both of them enjoyed.

Generally, family members – irrespective of ethnicity – felt they needed additional support from health professionals to perform their role as carers more effectively. Some individuals had been shocked and frightened by the experience and needed someone with whom to share their anxieties and negative thoughts. Others felt they had not been adequately prepared for their relatives’ discharge home and felt unable to cope.

There was confusion within some families about the amount of help that they should be providing. Some family members, who had given up work to care for their relative, wanted advice about their eligibility for financial support as carers.

3.4. Dietary change

There were several ways in which families supported patients in adopting healthier dietary habits. This included providing information about the nutritional composition of foods and showing patients how to prepare healthier meals. On the whole, White-European families seemed to be better equipped to share information and were more likely to adopt healthier eating habits.

The nature of the meals prepared within households was obviously determined by the food purchased. For all families, provisions were not always purchased by the patients themselves. In some cases, couples shopped together; in others, older children who lived within close proximity to their parents assumed responsibility for buying food. The latter was particularly common amongst White-European families. In contrast, it was generally the male spouse in South Asian households who shopped for food items, either alone or with their offspring.

Responsibility for food preparation varied within and across ethnic groups. In white families, this responsibility was sometimes shared, which meant that husbands were just as likely to prepare meals for female patients as wives were for male patients. Consequently, White-European spouses could play an important role in helping their partners modify their diet. Daughters also tended to advise parents about healthier ways of preparing food. South Asian households were different. Food preparation was not generally undertaken by male members of the family. Within South Asian nuclear families, this role was the responsibility of the eldest female in the family, usually the mother. Some patients who were mothers found this role difficult as they suffered from pains in their chest and legs which made it difficult for them to stand for long periods in the kitchen. As a result, mothers tended to delegate the responsibility to their daughters. Within extended families, the patient tended to have less involvement in food preparation, as it was usually the role of the daughters-in-law to prepare meals for the whole family. Within South Asian families, wives who were responsible for food preparation typically reduced the amount of salt and fat used in their cooking to improve their husbands’ diet. Some wives, however, were unable to adopt this approach as their husbands were not willing to compromise on the taste of their food. In such cases, male patients opted to eat less rather than compromise on preferred taste.

There was an expectation within South Asian families that if the patient was male, that the rest of the family would adopt his dietary modifications. This was less likely to happen for female patients. Indeed many South Asian female patients were preparing a different main course for themselves as they did not consider it appropriate for the whole family to consume dishes perceived as less enjoyable or to exclude specific foods from their diet, such as red meat. This was not an ideal situation for some of the female patients. Some women reported that preparing separate dishes was time consuming and created unnecessary work. This led many to adopt the same unmodified dietary habits as their family. Rubina, a Pakistani-Muslim woman in her 40’s, felt that it was more practical to prepare one dish for the whole family despite her husband being keen for her to eat a modified diet. She explained her dilemma:

I just tend to cook for the whole of the family and then just eat from that. I mean I could separate some for myself but I don't think there's any point ... My husband's always saying "Oh ... when you're cooking take a bit out for yourself. You know, if there's chicken and vegetables, separate it and you have it before ... we add the oil to it". But it's me myself. I think, "Oh what's the point? I'll just eat whatever everyone else is eating". I just decide to eat less of what they're eating. (MFDC12).

Maintaining dietary modifications was a challenge for patients particularly when they were eating away from home. Even within the home though, some family members reported difficulties in encouraging patients to maintain
dietary changes. For example, Bharti, the wife of Sanjeev, was keen to help her husband modify his diet and had reduced the amount of oil she used in her food preparation, even though she attributed stress rather than diet as the cause of his CHD. She found it was especially difficult to control her husband’s craving for sweet foods and was unsure about ways in which she could encourage him to reduce his sugar intake. She described a strategy, used to reduce his sugar intake in tea:

*I told him because I don’t take sugar he can stop and my daughter she doesn’t take sugar as well and I said, “If she can stop, I can stop, you can as well”. First I just put half a spoon, he said it wasn’t nice you know, I said, “OK a few days you try, if you don’t like it then you can start”. Now if he is not in a good mood, then he wants sugar and I give him a little bit on the side and I say if you want to put it in, you can. Otherwise he leaves it.* (HMSM107C)

Patients’ resistance to dietary modification was a cause of concern for many family members, particularly adult children. Some children felt that though their parents had been told about the health risks associated with eating certain foods, it was extremely difficult to change eating habits among the older generation.

3.5. Exercise regimes

Family members gave their relatives varying levels of encouragement regarding physical exercise. About half the families in the sample had identified the need for their relative with CHD to exercise. Those family members who were most supportive in this way, tended to be those who exercised regularly themselves. However, the son of an elderly White-European woman, Elsie, found that it was difficult for him to give her advice about exercise as he was unclear himself about the advice that he had been given by health professionals.

*If somebody sits you down face-to-face and has a little chat with you about it because unlike these information packs they give you, it’s not exactly interactive. I mean if you’ve got a question say well you know the information pack was designed for anybody and it was talking about 200 yards on one day then half a mile in several weeks. I mean there’s no way [my mothers] going to walk half a mile ever again… so you need to tailor it to the individual person involved so it would have been more useful if they could have sat you down just for five minutes.*

On the whole White-European families were more proactive than their South Asian counterparts in ensuring that patients incorporated some form of exercise into their lifestyle. Among the White-European sample, spouses and children encouraged patients to exercise, whereas within the South Asian sample, children were most likely to emphasise the importance of exercise. Walking was the favoured form of exercise for most individuals. Some female patients in the sample, many of whom were White-European, were encouraged by their husbands to go out walking with them. While some patients participated in this way, others lacked motivation despite having the full support of another family member. This caused tension for those family members, usually spouses, who were desperate for patients to take more control of their recovery, although for some South Asian families, women walking on their own, undermined cultural values. Some families also commented on the dangers of women walking on their own.

The following two cases illustrate the commonality of experience faced by South Asian and White-European families in trying to provide support to someone with CHD. Rajesh, a 60 year old Hindu businessman was particularly concerned about his wife, Priya, who was diabetic and had suffered her first MI. Being diabetic himself he was conscious of the need to follow a low-fat diet and exercise regularly. Given that his wife was not a fluent English speaker, Rajesh had obtained a lot of information about rehabilitation on her behalf from the cardiac rehabilitation nurses. Once Priya returned home, he took every opportunity to educate her about the need for her to adopt a healthier lifestyle and reduce the amount of time she spent sleeping. Having made sure that Priya joined the rehabilitation programme, Rajesh assumed that she would modify her dietary habits and start exercising on a regular basis. He was, however, disappointed when she refused to accompany him on his daily walks and felt that there was a need for someone external to the family who could provide information about the importance of lifestyle modification in her own language. He reflected upon his wife’s attitude:

*For some it all depends on the taste and if they don’t like the taste they won’t eat it. But it shouldn’t be whether it tastes nice or not, but more on what is good for your health… I am always telling her but whether she understands is another matter and it is of benefit to her. If her health is good then I will benefit also. For her it is a matter of understanding. If I keep on about it, then she sees it as a bad thing.*

The second case involved a White-European married couple. Alice suffered from diabetes and a history of CABG and MI. As in the previous case, she was supported by her spouse James, who accompanied her to hospital appointments and continually reminded her of the lifestyle changes she needed to make. In particular, he was keen for her to start walking as he felt this would assist her in losing weight and she had previously enjoyed this activity. Alice, however, was not keen to resume any form of exercise and instead felt the need to relax more which was a cause of increasing concern for James. He explained what he considered to be the main problem in terms of her rehabilitation:

*She doesn’t exercise… that’s the biggest thing and we talk a lot and I encourage her as far as I can but she’s obviously getting bigger and bigger and the bigger she is, the more she’s sleeping. I don’t mean there’s a*
relationship necessarily between those things. It's probably her condition but somehow, somewhere, even if she was just exercising...she really has to get to grips with that I think.

In this instance both South Asian and White-European families faced similar challenges in trying to provide support to their relative with CHD regardless of ethnicity.

4. Discussion

A qualitative approach was used to examine the nature of family support and the experiences of cardiac rehabilitation across a large sample of South Asian and White-European cardiac patients and their carers. Findings showed that household structure varied both across and within ethnic groups. In general, White-European patients had smaller households than their South Asian counterparts and very few South Asian patients lived alone. The context of care, therefore, was different for White-European and South Asian samples, but the family remained a key provider of support, regardless of ethnicity. This finding is supported by others [18]. Differences across household, however, can lead to mistaken assumptions on the part of health professionals [23]. Since South Asian people typically lived in larger households, this might suggest that they might receive a greater level of social support than White-European patients. Closer examination showed that on the contrary, the larger size of some South Asian families could make it difficult for families to prioritise the practical needs of patients.

The provision of education and health information for patients and their carers is a key component of cardiac rehabilitation, particularly since patients with cardiac conditions and their carers often develop misconceptions about their condition and its treatment [5,32]. Moreover, there is evidence that such misconceptions are more common within South Asian and African Caribbean populations than the White-European population [33].

Recognising the importance of family involvement in the context of cardiac rehabilitation is not new [34]. While findings from this study showed that most families were able to offer emotional support to patients, their ability to give patients practical help and advice varied considerably. For the majority of White-European families, spouses were most likely to have contact with health professionals and subsequently played a major role in supporting and encouraging patients in to adopt healthy lifestyle modification. By contrast, for a large proportion of South Asian families, linguistic barriers meant that children, rather than spouses, were more likely to interact with health professionals and provide their parents with health information. The lack of direct communication with South Asian patients provided health professionals with little opportunity to emphasise the importance of family involvement in the rehabilitation process. It has also been suggested that the couple centred model central to traditional cardiac rehabilitation programmes is not necessarily the most appropriate approach to use with cardiac patients from different cultural backgrounds [18].

Linguistic barriers were evident in this study and these represented a significant obstacle to effective and comprehensive health information provision for patients. This has been known for some time [17,19–24]. It is disappointing that, at least in the cases we examined, limited progress appears to have been made in addressing this problem. Accordingly, South Asian children were often required to interpret for their parent. In some cases, this led to children withholding health information from their parents, they considered too distressing. It seems likely that children adopting the role of ‘interpreter’ may experience tensions, not experienced by their White-European counterparts, as they try to reconcile multiple roles of health information provider, carer and child. Other authors have criticised the inappropriate use of family members as interpreters [17,35] and highlighted that non-English speaking patients are not always offered a choice of interpreter [22]. The experience of our South Asian sample confirms this and although interpreters might, theoretically at least, be available, they were often difficult to access in practice. Ensuring that a well-resourced and sufficiently flexible interpreting service exists within hospitals is therefore crucial so that non-English speaking patients and their carers are provided with detailed information and advice relating to CHD and rehabilitation services.

With regard to lifestyle changes, such as dietary modification and physical exercise, differences across ethnic groups emerged. Within South Asian households, food preparation was normally undertaken by female members of the family, who in some cases had little or no contact with health professionals. This meant that they were not always equipped with the required information to help cardiac patients to adopt more healthy dietary habits. In addition, South Asian families placed less emphasis upon encouraging patients to participate in regular physical exercise compared to White-European families. There also appeared to be some gender differences within South Asian families. Male patients appeared to get more family support during their recovery, while females attempted to modify their lifestyle with limited help.

A potential limitation of the study was the sample. A larger sample structured according to ethnic origin, religious values and social class would have enabled the research to explore further the differences and similarities within South Asian populations. It would also have allowed an exploration of the extent to which similarities between the South Asian and White-European sample could be attributed to social class.

5. Conclusion and recommendations

There were similarities between patients and their families, irrespective of ethnicity. Patients and family members often
articulated many similar concerns, worries and needs, irrespective of ethnicity. Family anxieties about physical limitations after a cardiac event and the negotiation of family responsibilities during convalescence reflected a generic experience. However access to information, the context of support and the assumption of caring responsibilities within households, did reflect ethnic and cultural differences. For South Asian household language barriers meant that access to health information was often inadequate and discussions between patients, health professionals and family members limited in a way that was not experienced by White-European counterparts. South Asian children were often required to interpret information. Differences in household responsibilities meant that South Asian females were more likely than White-European counterparts to take responsibility for the way in which meals were prepared. South Asian households needed additional support to enable them to adopt healthier eating habits and engage with physical exercise as part of recovery. Stress was more likely to be discussed by spouses of White-Europeans than their South Asians counterparts.

There is a need for health professionals to develop a cultural repertoire to engage with diversity and difference. This includes an awareness of a person’s cultural and religious beliefs and ability to respond to them in an appropriate way, while valuing clients as both an individual and a member of particular community [36]. From a practice perspective, health professionals must address linguistic barriers which potentially lead to misinformation for patients and carers combined with unnecessary tension for adult children required to interpret. Expert consultation should be sought from culturally appropriate advisory groups to develop interventions to support South Asians with dietary modification and physical exercise. The testing of these interventions should be the subject of future research. These interventions also need to take account of the diversity within the South Asian population as well as the similarities such populations have within the general population.

Although not every problem or difficulty a person encounters as they attempt to gain access to appropriate service delivery can be attributed to his or her ethnic background cardiac rehabilitation services need to be more closely tailored to the needs of users. By improving services generally we can often improve support for South Asian populations. The challenge is to know when ethnicity makes a difference and mediates a person’s relationship with service support and when it does not.

Acknowledgements

The study was funded by The Community Fund and the British Heart Foundation (Grant Number RB217616). The authors would like to thank the participants for their contribution and also the advisory group for their invaluable guidance.

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