

This is a repository copy of 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.

White Rose Research Online URL for this paper: <a href="https://eprints.whiterose.ac.uk/4993/">https://eprints.whiterose.ac.uk/4993/</a>

#### Article:

Astin, Felicity, Atkin, Karl orcid.org/0000-0003-1070-8670 and Darr, Aliya (2008) 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. European Journal of Cardiovascular Nursing. pp. 43-51. ISSN 1474-5151

https://doi.org/10.1016/j.ejcnurse.2007.06.002

#### Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

#### **Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



### promoting access to White Rose research papers



## Universities of Leeds, Sheffield and York http://eprints.whiterose.ac.uk/

This is an author produced version of a paper published in **European Journal of Cardiovascular Nursing**.

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/4993/

#### **Published paper**

Astin, F., Atkin, K. and Darr, A. (2008) 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. European Journal of Cardiovascular Nursing, 7 (1). pp. 43-51. http://dx.doi.org/10.1016/j.ejcnurse.2007.06.002

White Rose Research Online

# FAMILY SUPPORT AND CARDIAC REHABILITATION: A COMPARATIVE STUDY OF THE EXPERIENCES OF SOUTH ASIAN AND WHITE PATIENTS AND THEIR CARER'S

Felicity Astin PhD MSc BSc (Hons) RGN Research Fellow, School of Healthcare, Baines Wing, University of Leeds, Leeds LS2 9OT

Tel: 0113 4331373 Fax: 0113 3437560

F.Astin@leeds.ac.uk

Karl Atkin BA(Hons), DPhil Senior Lecturer in Ethnicity and Health, Department of Health Sciences, Seebohm Rowntree Building (Area Four) University of York, York YO10 5DD;

Tel: 01904 321355 Fax: 01904 321388

ka512@york.ac.uk

Aliya Darr BA(Hons), MA. PhD Senior Research Fellow Institute of Health Sciences and Public Health Hallas Wing 71-75 Clarendon Road University of Leeds Tel: 0113 343 4835 a.darr@leeds.ac.uk

# FAMILY SUPPORT AND CARDIAC REHABILITATION: A COMPARATIVE STUDY OF THE EXPERIENCES OF SOUTH ASIAN AND WHITE PATIENTS AND THEIR CARER'S

#### 1. Introduction

When an individual is discharged home from hospital after a cardiac event, such as myocardial infarction (MI), their recovery is characterised by a period of adjustment. Interactions between patients and their family influence the course of recovery and those individuals who live alone or who have poorly developed social networks are particularly vulnerable. 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<sup>1</sup>. Several reviews have reported a negative correlation between the level of social support and CHD mortality and morbidity even after controlling for conventional risk factors <sup>2,3</sup>

Family support is a significant mediating factor during recovery and readjustment after a cardiac event <sup>4,5</sup>, whether it be 'instrumental' (assistance with activities of daily living, such as food preparation, shopping and cleaning) or emotional (caring, understanding and empathy) <sup>6</sup>. The willingness of family members to support patients in making healthy lifestyle changes will be influenced by a range of factors such as 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 (for a more general discussion<sup>7</sup>). Levels of social support, however, vary. More generally, cultural and gendered expectations about care-giving mean there are differing levels of involvement from spouses, children and extended family members during the recovery process. 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 <sup>8,9,10,11</sup>.

There is, however, little published research about family support and cardiac rehabilitation experiences of South Asians. South Asians have poorer outcomes after myocardial infarction (MI)<sup>12</sup> than the general UK population, although the reasons for this are unclear <sup>13</sup>. Communication and language barriers, however, emerge as a significant problem in the provision of quality care for South Asians 14,15. Webster, Thompson & Mayou (2002) explored the experiences and needs of Gujarati Hindu patients one-month after MI and reported that patients and partners received limited information about their condition due to language barriers 16. This led to patients and carers displaying misconceptions about their condition which negatively influenced recovery. In particular, patients typically made few lifestyle changes and perceived their MI as an event that signified the end of their active life. 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 <sup>17,18,19,20,21,22</sup>. These difficulties often arise due to problems in accessing interpreters, resulting in family members being heavily relied on to function as interpreters<sup>20</sup>.

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 between socioeconomic factors, gender, culture, access to cardiac rehabilitation and social support; all of which are likely to influence recovery<sup>23</sup>. Little work, however,

explores this interplay. The aim of this exploratory, qualitative study was to examine participants' experiences of cardiac rehabilitation and the nature of family support across a sample of South Asian and white cardiac patients and their carers.

#### 2. Methods

#### 2.1 Setting

The study took place in West Yorkshire and recruited participants from one of three participating district general hospitals. The target area's population of people of South Asian origin is approximately ten per cent.

#### 2.2 Sample

The sample consisted of 'white' 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 guides 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 three interviews that required fluency in Sylheti and Gujerati. Prior to data collection, a series of meetings between interviewers were conducted to address issues around the translation of questions into South Asian languages. Efforts were made to ensure that words and phrases in the original topic guide, retained the same meaning when translated<sup>24</sup>.

Participants were given the choice of where their interview was conducted and the majority chose their homes. Interviews lasted between 60 and 90 minutes. 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. All interviews were fully transcribed 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<sup>23</sup>

#### 2.5 Data Analysis

Members of the research team read and reread transcripts and recurrent themes and concepts were 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<sup>25</sup>, 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<sup>26</sup>. This approach contributed toward establishing trustworthiness in our 'qualitative' inquiry as outlined by Guba & Lincoln (1989)<sup>27</sup>. 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<sup>28</sup>.

#### 3. Results

Of the 112 potential participants identified, 89 were identified as sufficiently fit by their General Practitioner to participate. Of these, 22 potential participants declined and 2 did not respond, 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 and (45) South Asian patients aged over 30 years who consented to participate in the study. Eligible participants had been admitted

to one of three district general hospitals in West Yorkshire during the preceding year 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<sup>29</sup>. This emphasises the value of selecting our South Asian sample, on the basis of both ethnic and religious identification<sup>24</sup>. On a more practical note, where we detected no differences among our South Asian sample, we use South Asian as a generic term. This, however, is not meant to undermine the heterogeneity of such populations and where differences within the South Asian sample occur, our analysis reflects this. A summary of participant's demographic characteristics is shown in Table 1. (Insert Table 1 here please).

The carer's sample consisted of 54 participants that patients had nominated as having influenced their views and behaviour, either positively or negatively. The relationship of carers to patients is shown in Table 2. (Insert Table 2 here please).

There were varying levels of fluency in English amongst the South Asian sample of patients and carers. The majority of Pakistani-Muslim patients preferred to be interviewed in Urdu or Punjabi; only one of the females in this group was an English speaker. In contrast, carers of these patients were more likely to be fluent in English (63%). Just over half the Indian Sikh patients, including all the females, could not speak English. However, a greater proportion of Indian Sikh carers were English speakers (62%). There were more English speakers within the Indian-Hindu sample (8), however only one of this group was female.

In presenting our findings we explore the generic experience of CHD and explore the influence of ethnicity and culture, when appropriate<sup>24</sup>. As well as drawing out similarities and differences between white and South Asian populations, we also draw out similarities and differences within our South Asian sample. This explains our terminology. Sometimes we are presenting a generic experience, typical of our South Asian sample. In other cases, we might want to reflect on differences. Pseudonyms are used to preserve anonymity.

#### 3.1 Household composition

Within the sample, there was considerable variation in household composition both across and within ethnic groups. White patients generally lived in smaller households than South Asian patients. Half of the white 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.

#### 3.2 Provision of advice and information

Within white 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. This degree of interaction was not always available for South Asian patients as many of the patients and their spouses could not speak English, particularly within the Pakistani-Muslim group. This meant that there was often very little communication between health care professionals and spouses. 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. They 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 CHD. In isolated cases, children opted not to tell their parents their diagnosis. More generally children tended to avoid conveying the negative aspects and seriousness of their condition.

On returning home families – irrespective of ethnicity - instituted a variety of care arrangement. 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 had been concerned about their need to provide them with 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 caused her family considerable anxiety as highlighted by Balvinder's daughter-in-law as she recalls her own and her husband's attitude towards the situation:

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 be 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?

Frequently, family members thought it important to minimise stress experienced by their relative and took practical steps to achieve this goal. Children rather than spouses were more likely to think about the impact of stress within South Asian families. In contrast,

within white families, spouses were equally as likely as their children to discuss stress reduction. Within both South Asian and white families, the most common approach to reduce stress within the household was for children to avoid disclosing information which they thought might be potentially upsetting to their parents (also see above).

Some younger patients had identified their own and their carer's employment as a potential source of stress. Carers reciprocated these concerns. In one case, a Pakistani-Muslim self employed accountant employed a business partner to reduce his workload at the request of his wife and eldest daughter who were convinced that his workload was excessive. Older white 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.

#### 3.3 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. White 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 patient 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 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 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 daughters-in-laws' role 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 highlights important gender differences visavis expectations that patients have in relation to family support.

Not all female patients were satisfied with their food preparation arrangements. 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 40s, 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.

Maintaining dietary modifications was a challenge for patients particularly when they were eating away from home. Even within the home, 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 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.

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.

#### 3.4 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 woman, Elsie, found that it was difficult for him to give her advice about exercise when he was unclear about the advice he had been given by the hospital.

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 families were more proactive than their South Asian counterparts in ensuring that patients incorporated some form of exercise into their lifestyle. Among the white 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, 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 cases illustrate the commonality of experience faced by South Asian and white 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 James, the 69 year old husband of a white patient, Alice, who was diabetic and had a history of CABG and MI. As in the previous case, James attended his wife's hospital appointments and was continually reminding 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.

#### 4. Discussion

A qualitative approach was used to examine the experiences of cardiac rehabilitation and the nature of family support across a large sample of South Asian and white cardiac patients and their carers. Findings showed that household structure varied both across and within ethnic groups. In general, white patients had smaller household than their South Asian counterparts and very few South Asian patients lived alone. The context of care, therefore, was different for white and South Asian samples, but the family remained a key provider of support, regardless of ethnicity. This finding is supported by others<sup>16</sup>. Differences across household, however, can lead to mistaken assumptions on the part of health professionals<sup>21</sup>. Since South Asian people typically lived in larger households, this might suggest that they might receive a greater level of social support than white 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 4,30. Moreover, there is evidence that such misconceptions are more common within South Asian and African Caribbean populations than the white population<sup>31</sup>. Recognising the importance of family involvement in the context of cardiac rehabilitation is not new<sup>32</sup>. 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 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

importance of family involvement in the rehabilitation process. It has been speculated that cultural differences are often incompatible with the couple centred model central to traditional cardiac rehabilitation programmes<sup>16</sup>.

patients provided health professionals with little opportunity to emphasise the

Linguistic barriers were evident in this study and these represented a significant obstacle to effective and comprehensive health information provision for patients. This, however, has been known for some time <sup>15,16,17,19,20,21,22</sup>. 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, which they considered too distressing. It seems likely that children adopting the role of 'interpreter' may experience tensions, not experienced by their white counterparts, as they try to reconcile multiple roles of health information provider, carer and child. Other authors have criticised the use of family members as interpreters <sup>15,33</sup> and have highlighted that non-English speaking patients are not always offered the option of using an interpreter <sup>20</sup>. 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.

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 may have had little or no contact with health professionals. This lack of information limited opportunities to adopt more healthy dietary habits. South Asian families placed less emphasis upon encouraging patients to participate in regular physical exercise compared to white 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.

This study has examined the experiences of cardiac rehabilitation and the nature of family support across a large sample of South Asian and white cardiac patients.

However, findings must be considered in the context of study limitations. 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 enabled the research to explore the extent to which similarities between the South Asian and white sample could be attributed to social class.

#### 5. Conclusion

There is considerable evidence suggesting services struggle to offer accessible and appropriate care to minority ethnic populations, without recourse to essentialised notions of difference (see<sup>23</sup> for a review). Various discriminatory practices - revealed in professional assumptions and organisational practices - reduce ethnic minority communities to monolithic, homogenous wholes defined by their ethnicity, religion or culture, with little reflection on differences within and similarities across ethnic groups, as marked by gender or socio-economic position<sup>34</sup>.

Our research identified several cultural and ethnic differences across our sample. Access to information, the context of support and the assumption of caring responsibilities within household, do reflect ethnic and cultural differences. Consequently, health care professionals need 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 <sup>35,36</sup>.

Our findings, however, also demonstrate similarities between patients and their families, irrespective of ethnicity. Ethnicity is not always a marker of difference. In presenting

our findings, patients and family members, articulate many similar concerns, worries

and needs alongside low uptake of cardiac rehabilitation, irrespective of ethnicity.

Family anxieties about what a person can or can not do and the negotiation of family

responsibilities, following CHD, reflect a generic experience. 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. 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.

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.

Table 1: Patient Characteristics n=65

21

Religious and	Gender		Age in years	
Ethnic origin	Male	Female	Mean and(Range)	
Pakistani Muslim	10	10	59 (46-72)	
Indian Sikh	7	5	63 (48-79)	
Indian Hindu	9	4	63 (40-82)	
'White'	10	10	66 (42-83)	
Total	36	29	63 (40-83)	

Table 2: Carers sample (n=54)

	Spouse	Children	Daughter- in-law	Sibling	Other	Total
Pakistani Muslim	7	9	2	-	1	19
Indian Sikh	2	3	3	-	-	8
Indian Hindu	9	-	1	-	-	10
White	10	6	-	1	-	17
Total	28	18	6	1	1	54

### **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.

#### References

- 1. Brink E, Karlson BW, Hallberg LRM. Readjustment 5-months after a first-time myocardial infarction: reorienting the active self. Journal of Advanced Nursing 2006; 53 (4): 403-411.
- 2. Bunker SJ, Colqohoun DM, Murray DE et al. Stress and coronary heart disease-psychosocial risk factors: National Heart Foundation of Australia Position Statement Update. Medical Journal of Australia 2003; 178:272-276.
- 3. Eriksen W. The role of social support in the pathogenesis of coronary heart disease: a literature review. Family Practice 1994; vol 11(2): 201-209.
- 4. Tennant C. Life stress, social support and coronary heart disease. Australian and New Zealand Journal of Psychiatry 1999; vol 33(5): 636-641.
- 5. Karner AM, Dahlgren MA, Bergdahl B. Rehbailitation after CHD: spouses' view of support. Journal of Advanced Nursing 2004; 46(2): 204-211.
- 6. Tapp DM. Dilemmas of family support during cardiac recovery, nagging as a gesture of support Western Journal of Nursing Research 2004; 26(5): 561-580.
- 7. Barry LC, Kasl SV, Lichtman J, Vaccarino V, Krumholz HM. Social support and change in health related quality of life 6 months after coronary artery bypass grafting Journal of Psychosomatic Research 2006; 60(2):185-93.
- 8. Twigg J, Atkin K. Carers Perceived, Buckingham: Open University Press 1994.
- 9. Kettunen S, Solovieva S, Laamanen R, Santavirta N. Myocardial infarction, spouses' reactions and their need of support. Journal of Advanced Nursing 1999; 30: 479-488.
- 10. O'Farrell P, Murray J, & Hotz SB. Psychologic distress among spouses of patients undergoing cardiac rehabilitation. Heart and Lung 2000; 29: 97-104.
- 11. Moser DK, Dracup KA, Marsden C. Needs of recovering cardiac patients and their spouses: compared views International Journal of Nursing Studies 1993; 30(2): 105-114.
- 12. Thompson DR, Ersser SJ, Webster RA. The experiences of patients and their partners 1 month after a heart attack Journal of Advanced Nursing 1995; 22: 707-714.
- 13. Bandolier, Evidence Based Medical Care accessed on 20 February 2007 at http://www.jr2.ox.ac.uk/bandolier/index.html

- 14. Peterson S, Peto V, Scarborough P, Rayner M. Coronary Heart disease Statistics. British Heart Foundation, London, 2005.
- 15. Kuppuswamy CV, Gupta S. Excess coronary heart disease in South Asians in the UK the. British Medical Journal 2005; 330: 1223-1224.
- 16. Robinson L. Race, communication and the caring profession. Open University Press, Buckingham, 1998.
- 17. Scouten BC, Meeuwesen L. Cultural differences in medical communication: a review of the literature, Patient Education and Counseling 2006; 64:21-34.
- 18. Webster RA, Thompson DR, Mayou RA. The experiences and needs of Gujarati Hindu patients and partners in the first month after a myocardial infarction. European Journal of Cardiovascular Nursing 2002; 1: 69-76.
- 19. Murphy K, Macleod-Clark J. Nurses' experiences of caring for ethnic minority clients. Journal of Advanced Nursing 1993; 18: 42-450.
- 20. Vydelingum V. South Asians patients' lived experience of acute care in an English hospital: a phenomenological study Journal of Advanced Nursing 2000; 32(1):100-107.
- 21. Anderson JM. Immigrant women speak of chronic illness: the social construction of the devalued self Journal of Advanced Nursing; 199116: 710-717.
- 22. Gerish K. The nature and effect of communication difficulties arising from interactions between district nurses and South Asian patients and their carers. Journal of Advanced Nursing; 2002 33(5): 566-574.
- 23. Katbamna S, Bhakta P, Ahmad W, Baker R, Parker G. Supporting South Asian carers and those they care for: the role of the primary health care team. British Journal of General Practice; 2002: 52; 3000-305.
- 24. Farooqi A, Nagra D, Edgar T, Khunti K. Attitudes to lifestyle risk factors for coronary heart disease amongst South Asians in Leicester: a focus group study. Family Practice; 2001 17: 293-297.
- 25. Atkin K. Primary health care and South Asian populations: institutional racism, policy and practice. In: Ali S, Atkin K, eds. South Asian Populations and Primary Health Care: Meeting the Challenges, Oxford: Radcliffe, 2004: 9-20.
- 26. Darr A, Astin F, Atkin K (In press) Causal attributions, lifestyle change and coronary heart disease: Illness beliefs of patients of South Asian and European origin living in the UK.

- 27. Richie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, eds. Analyzing qualitative data, Routledge, London, 1994: 173-194.
- 28. Silverman D. Doing qualitative research. Sage Publications, London, 2000.
- 29. Guba E, Lincoln Y. Fourth Generation Evaluation. California: Sage Publications, Newbury Park, 1989.
- 30. Karlsen S, Nazroo J. Defining and measuring ethnicity and 'race': theoretical and conceptual issues for health and social care research. In: Nazroo JY, eds. Health and social research in multiethnic societies, London: Routledge, 2006.
- 31. Modood T, Betthould R, Lakey J, Nazroo J, Smith J, Virdde S, Beishon S. Ethnic Minorities in Britain, London: Policy Studies Institute, 1997.
- 32. Astin F. Jones K. Heart disease attributions of patients prior to elective percutaneous transluminal coronary angioplasty. Journal of Cardiovascular Nursing 2004; 19(1): 41-7.
- 33. Lip GYH, Khan H, Bhatnagar A, Brahmabhatt N, Crook P, Davies MK. Ethnic differences in patients' perceptions of heart failure and treatment: the West Birmingham heart failure project. Heart 2004; 90:1016-1019.
- 34. Nolan M, Nolan J. Cardiac rehabilitation following myocardial infarction. British Journal of Nursing 1998; 7(4):219-25.
- 35. Chamba R, Ahmad WIU. Language, communication and information: the needs of parents caring for a severely disabled child. In: Ahmad, WIU, ed. Ethnicity, Disability and Chronic Illness, Open University Press, Buckingham, 2000: pp.85-102.
- 36. Gunratnam Y. Researching 'race' and ethnicity, Sage: London, 2003.
- 37. Dominelli L. Social work: Theory and practice for a changing profession, Cambridge: Polity Press, 2000.
- 38. Papadopoulos I, Tilkim M, Lees, S. Promoting cultural competence in health care through a research-based intervention in the UK. Diversity in Health and Social Care 2004; 1(2): 107-116.