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# 'Causal attributions, lifestyle change and coronary heart disease: Illness beliefs of patients of South Asian and European origin living in the UK

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#### **Abstract**

Objective: To examine and compare the illness beliefs of South Asian and European patients with coronary heart disease about causal attributions and lifestyle change.

Methods: A qualitative study that used framework analysis to examine in-depth interviews.

Sample: Sixty five subjects (20 Pakistani-Muslim, 13 Indian-Hindu, 12 Indian-Sikh, and 20 Europeans) admitted to one of three UK sites within the previous year with unstable angina, myocardial infarction or for coronary artery bypass surgery.

Results: Beliefs about CHD cause varied considerably. Pakistani-Muslim participants were the least to report that they knew what had caused their CHD. Stress and lifestyle factors were the most frequently cited causes for CHD irrespective of ethnic grouping, although family history was frequently cited by older European participants. South Asian patients were more likely to stop smoking than their European counterparts but less likely to use audio tape stress relaxation techniques. South Asian patients found it particularly difficult to make dietary changes. Some female South Asians developed innovative indoor exercise regimens to overcome obstacles to regular exercise.

Conclusion: Misconceptions about the cause of CHD and a lack of understanding about appropriate lifestyle changes were evident across ethnic groups in this study. The provision of information and advice relating to cardiac rehabilitation must be better tailored to the context of CHD patient's specific needs, beliefs and circumstances regardless of their ethnicity.

#### Introduction

Overall mortality rates from coronary heart disease (CHD) have decreased over recent years in developed countries. This trend, however, is not uniform and health inequities exist across some ethnic populations such as African Americans, Australian Aboriginals and people of South Asian origin resident in the United Kingdom (UK).

People of South Asian descent living in the UK represent the largest ethnic minority and have a mortality rate from CHD approximately 40% greater than the general population <sup>1, 2</sup>. The reason for this is unclear but it has been suggested that primary and secondary prevention messages aimed at encouraging healthy lifestyle change to reduce coronary risk are failing to make an impact <sup>3</sup>. This remains, however, speculation as research rarely addresses South Asian people's understanding of CHD and "few social and behavioural scientists would dispute that an individuals understanding of events is a primary determinant of their response to those events" <sup>4</sup> (p2).

When an individual is faced with the diagnosis of a life threatening illness such as CHD they must 'make sense' of the threat to their health. Part of this cognitive process involves the generation of a unique model or representation of their illness which is influenced by sociodemographic, biological, cultural and psychological factors <sup>5</sup>. Such representations guide coping responses that may in turn influence recovery.

Illness representations have been shown to influence a range of outcomes such as dietary change <sup>6</sup>, help seeking behaviour <sup>7</sup>, in-hospital recovery <sup>8</sup> functional status and return to work <sup>9</sup> in patients diagnosed with CHD. In light of this, effective education and counselling of patients recovering from a cardiac event should include the exploration

and understanding of patients' illness representations and how these may influence lifestyle modification choices.

## Background

#### **Causal Attribution**

One facet of illness representation is belief about cause (causal attribution); the factors that individual's typically attribute to the development of their illness. The majority of studies on patients with CHD have focused almost exclusively upon males recovering from acute myocardial infarction (AMI) in Western countries. Findings indicate that patients most commonly believed that stress, worry, tension and overwork caused their CHD. A systematic review identified that 41% of studies found stress listed by participants as the most important cause of their CHD whilst lifestyle behaviours were cited in 31% of studies <sup>10</sup>.

Few studies have looked at cultural differences in beliefs about cause in individuals with established CHD. Two qualitative studies conducted in the same geographical region of the UK found that South Asian people identified stress as the most commonly cited cause of their CHD <sup>11, 12</sup>. In the latter study, participants frequently related their self-reported stress to their ethnic minority status. A descriptive study conducted in Japan reported that participants most commonly cited smoking, stress and diet as causing their CHD <sup>13.</sup> The scant research available about causal attributions for CHD reported by those from different ethnic groupings points to some similarities in beliefs irrespective of ethnicity. In addition, there was little concordance found between Japanese patients' actual coronary risk factor profile and their beliefs about cause <sup>11</sup>. This mismatch between patients' coronary risk factor profiles and their beliefs about cause has been found amongst populations of European descent in other studies <sup>14, 15, 16</sup>.

## **Lifestyle Change**

Secondary prevention is acknowledged as an effective intervention to reduce levels of CHD <sup>17</sup>. A key component of this approach requires patients to adopt healthy lifestyle habits and cease harmful ones to reduce coronary risk. This approach confers benefits both as a preventive measure for healthy individuals and as a strategy to reduce the risk of a further cardiac event in those with established disease.

Recent studies have shown that there is considerable room for improvement in secondary prevention efforts <sup>18</sup>. Changing lifestyle habits that have been developed and reinforced over a number of years is notoriously difficult. Non-adherence by patients to recommended health behaviours is not a new phenomenon. It is estimated that only one third of patients with CHD implement lifestyle changes and even then only in the short term <sup>19</sup>.

In addition lifestyle factors such as a high fat diet and lack of physical exercise have been identified as specific factors contributing to the excess risk of CHD that many UK South Asian people currently experience <sup>1</sup>. An individual's understanding of their illness may influence their inclination to adopt, or reject lifestyle modification to reduce future coronary risk.

Few studies have explored the experiences of people of South Asian origin recovering from a cardiac event. Key findings from two UK studies <sup>11, 12</sup> show that there is a lack of accessible information for South Asian people with CHD and that language is a key barrier to accessing services. Although experiences and health care needs may differ between South Asian and European peoples it is suggested that there is a need to

avoid the unnecessary stereotyping of patients by their ethnic grouping i.e. presuming that all patients from the same ethnic groups are alike <sup>12</sup>.

The current study was undertaken to examine and compare the beliefs of UK South
Asian and European individuals with CHD about causal attributions and lifestyle change
one year after admission to hospital.

#### Methods

We defined 'South Asian' people as those individuals originating from the Indian subcontinent and 'European' people as all those of white European descent. This definition is consistent with other studies <sup>20</sup>. A qualitative methodology was chosen as this research topic has been largely unexplored. Such a method is especially useful in understanding how people make sense of what is happening to them, within a social context <sup>21</sup>

## Sample

The UK South Asian population is a heterogeneous group. Increasingly, factors such as ethnicity, religion, language, gender and class serve to highlight differences as well as commonalities amongst members <sup>22</sup>. The subdivision of the sample by ethnic group into people of Pakistani, Bangladeshi and Indian descent was one potential approach to understanding such differences. However the use of religious belief as a grouping, when used in conjunction with a person's ethnic identity has been shown to be a more effective approach with which to explore diversity <sup>23</sup>.

Accordingly, our sample of people of South Asian origin was drawn on the basis of a person's ethnic and religious background and the sample divided by religious belief

(Pakistani-Muslim, Indian-Sikh and Indian-Hindu). Other studies support this sampling approach <sup>24</sup>. A comparative group of European patients was recruited to enable our analysis to explore similarities and differences among a range of ethnic groups.

Eligible participants were patients over 30 years of age admitted to one of three district general hospitals in West Yorkshire, UK during the previous year with a diagnosis of unstable angina (32%), myocardial infarction (42%) or for coronary artery bypass surgery (26%). In most cases, patients were interviewed within the first year after being discharged from hospital as it was thought that this would be the most appropriate period in which to capture people's experience of rehabilitation. We were also aware that the passage of time could impede patients' ability to recall important details about the advice and information provided to them by health professionals, as well as their own previous behavioural patterns. Patients diagnosed with terminal illness, severe mental illness and a drug or alcohol addiction were excluded.

#### **Procedure**

Ethical approval was obtained from the three participating hospitals prior to study commencement. Cardiac rehabilitation nurses from participating centres were informed of the study and asked to identify eligible participants. Following this, letters were sent to patients' General Practitioners to establish as to whether those identified might be well enough to participate. Of the 112 potential participants identified by cardiac rehabilitation nurses, 89 were considered fit enough to participate by their General Practitioner and letters of invitation were forwarded. Of these, 22 potential participants declined and 2 did not respond, leaving 65 participants in the final sample (a response rate of 83%). Almost half of the participants had been admitted to hospital after AMI

(42%), 26% for Coronary Artery Bypass Surgery and 32% with Unstable Angina. Approximately one third of these participants had attended cardiac rehabilitation classes within the previous year, with no major differences in uptake between ethnic groups. A summary of participant's demographic characteristics is shown in Table 1.

## Table 1 here please

Semi-structured interviews with 65 individuals were conducted in participants' language of choice (Urdu, Hindi, Punjabi, Sylheti, Gujarati or English) by an experienced interviewer fluent in most of the languages of the participants. Sylheti and Gujerati speaking colleagues were contacted to conduct interviews with the remaining patients. The use of topic guides provided structure to the interview process and ensured similar issues were covered across participants. The development of the topic guide was informed first, by the available research literature and second, from the input of an advisory group consisting of both South Asian and European individuals diagnosed with CHD. Patients were asked a range of questions about their experiences and beliefs including; their understanding of their condition, their experience of information provision after diagnosis, lifestyle modification and the role of family members in the provision of Interviews were transcribed, or back translated and transcribed where support. appropriate. When translating, 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>21</sup>. Pseudonyms were used in all presented data to conserve participant confidentiality.

#### **Data Analysis**

The framework approach used in this study was devised by Ritchie and Spencer (1994) and is commonly used in health policy research <sup>25</sup>. Data analysis is informed by the nature of the questions posed during interview and resultant responses are compared across the sample by generating data maps and grids. In this way data analysis is systematic, transparent and amenable to audit.

In the early stages of the analysis members of the research team read and re-read transcripts to facilitate an initial understanding of the data. The preliminary identification of emerging concepts led on from this and a coding frame was developed and refined based upon the common themes and sub-themes running across interviews.

The coding frame was then applied to each transcript and relevant text indexed in the transcript whenever a particular theme appeared. Following this, indexed data was transferred onto a grid that enabled researchers to focus upon the experiences and views of each individual and relate them to the identified themes across interviews. This assisted the comparison of both cases and groupings. Moreover, using this approach facilitated the identification of commonalities in experiences across ethnic groups and helped highlight when ethnicity made a difference to people's understanding.

Using this method of analysis, 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>.

#### Results

This section presents data across ethnic groupings to illustrate participants' beliefs about causal attributions and their experiences of lifestyle change. Excerpts are labelled and are coded according to the ethnicity, gender, hospital site and heart condition of the patient. In this way, WMDC08 relates to an interview conducted with a European male who was admitted to a hospital in to undergo a coronary artery bypass surgery and was the eighth member of this particular sub-sample.

Generally there was considerable variation in the manner in which patients were diagnosed with heart disease and the explanations provided by health professionals about the cause of their illness. Across all ethnic groups only a small number of individuals said that that they had been told with any degree of certainty about the cause of their heart condition. Although, most patients had been informed about a number of factors that may have contributed to the onset of their illness.

Individuals decision making processes about the adoption of particular lifestyle changes are linked to their own underlying health beliefs, including those about cause. As these are related, sub-themes of family history, the role of fate, stress, tobacco smoking, physical activity and exercise, dietary intake and stress management are presented under the broad theme of Causal Attribution and Lifestyle Change.

## **Causal Attributions and Lifestyle Change**

When asked to explain the cause of their illness, individuals forwarded a variety of explanations. On the whole Pakistani-Muslim participants were least likely to report that they knew what had caused their CHD. This group contained the largest proportion of individuals who did not speak English well, which might provide some explanation for this finding.

#### Family History

Family history was mentioned as a possible cause of heart disease by participants from all ethnic groups in the sample. However, generally European participants were much more likely than their South Asian counterparts to consider family history as having a bearing upon the onset of their CHD. Furthermore some of these individuals felt that because they were genetically more prone to CHD there was nothing that they could have done to avoid the onset of the condition.

This was evident in an extract from John's interview, a 61 year European male who had suffered two AMI's. He was convinced that heart 'trouble' ran in his family and therefore believed that lifestyle modification would not make any difference to his heart condition. As a result he did not comply with advice from health care professionals to modify his diet and alcohol intake:

Well, I don't think you can do owt. I mean ... if it's in your genes, it's in your genes. Now this is true because my brother had been in the army, well me oldest brother, he smoked, drunk, everything and had heart attack, and then me other brother, our Albert had been in the army, was a vegetarian and he didn't drink, he didn't smoke, he was a State Registered Nurse and he had a heart attack and died and then me other brother, our Richard, he didn't drink a lot, he didn't smoke a lot and so you can't go on that ... (WMDC08)

Pankaj, an Indian-Hindu patient who was equally frustrated by the perceived illogical way in which CHD had struck himself and his friends, expressed similar views:

As far as I can see, if it's going to happen, it is going to happen no matter how careful you are. Quite a few of my friends never drink, never smoke and

they don't eat meat. They have had cancer, blood pressure or heart trouble. Another friend starts drinking at 6am or 7am each day. When he drinks, he smokes one after another like a chain ... There is nothing wrong with him. He drinks and smokes too much. I don't smoke or eat red meat. I go for a walk and look at me. (HMSC05)

Others who felt that they had been at a higher risk of developing CHD found it difficult to identify specific aspects of their lifestyle that could have contributed to causing their CHD. Not knowing the cause made it difficult for these individuals to assess how they needed to change their lifestyle. For example Elsie, an elderly European widow who was in her seventies could not comprehend how she could have avoided her AMI:

I don't really know why I had mine, I just don't know. As I say a lot of it is to do with your family history. My father used to say, what has to be will be. If your name's on it I shall get it ... I am like my father. What happens is your destiny. (WMSMI01)

Elsie had smoked tobacco heavily from an early age but did not acknowledge the link between smoking and CHD. She found it difficult to quit and reported that this made her feel miserable. Despite this she did state that she had reduced the number of cigarettes she smoked and also reduced her sugar and fat intake.

One of the younger Indian-Hindu participants, Akshay, who was a 49-year-old shopkeeper also found it difficult to come to terms with having an AMI at such a young age. Although he was diabetic and a tobacco smoker, Akshay still reported that he was too young to be suffering from heart trouble. He explained:

My dad were old he were seventy odd ... when he died, but if that happened to me if I was in my sixties or sixty five then I could have understood, but not at this age when I'm on the go all the time so I personally can't explain why it happened to me. (HMDC11)

Nevertheless, Akshay had made some lifestyle modifications. Since discharge from hospital he was exercising daily and had reduced his consumption of cigarettes and alcohol. Despite being advised to lose weight he had not altered his diet as he considered it to be healthy and low in fat.

#### The Role of Fate

For many participants there was a strong belief that they had been fated to suffer from CHD, irrespective of ethnicity. These participants felt that there was nothing that they could have done to prevent their CHD from happening and found it difficult to identify any cause. Such beliefs were particularly prevalent amongst older participants. Take the example of Baljinder, an elderly Indian-Sikh man who had suffered an AMI and was told that his attack had occurred because his blood was too thick. After being reassured by his dietician that his diet had not been at fault, Baljinder resigned himself to the fact that there was nothing he could have done to avoid developing CHD:

I am now 80 years old and it is up to God what he does to us, first he makes your hair white, then he gives you eye problems then knee problems. These are all warning signs from Him above, it is like God telling us what is to come ... I think [thick blood] is my main problem because my diet is OK so I believe

it was in my fate as well. This is just an excuse, we have all got to go. (SMSMI03)

On the whole, South Asian participants were more likely than their European counterparts to contextualise their heart disease in relation to their religious beliefs. Within the South Asian sample, the idea that it was God, and not the individual who was responsible for the condition, was discussed by some of these participants. This response was especially common among Pakistani-Muslim people. This, however, should not be confused with fatalism; the belief that life events are destined and that individuals are therefore are powerless against fate. Findings showed that although some individuals felt that they had no personal control over the onset of their illness, they were still willing to make changes to their lifestyles in order to improve their health and safeguard against further problems. This was because for these individuals, developing an illness was an indication from God that they had not looked after their health and a sign that they needed to make changes to their lifestyle. As a elderly Pakistani-Muslim woman Sakina, explained:

It [illness] comes from Allah (God) ... whatever's going to happen, but then you should still be careful shouldn't you ... Allah will do whatever he wants to do ... but Allah also says that you can do things for yourself so you should be aware of the cause of it. (MFDC21)

Similarly, Hanif, a Pakistani-Muslim male patient, stressed that although he felt that there was little he could do to change the timing of his death, there was a lot that he could do in terms of lifestyle modification to ensure that he maintained good health before he died:

You're going to die when you are going to die, no one can stop that. When a person becomes ill and sits around he becomes helpless, he is dependent ... But if you get up and walk around, you get out and about, you are not dependent on anyone, that's the only difference there's nothing else, you're going to go when it's your time. The rest of the time will pass, whether you exercise or not, whatever you do ... if you listen to the doctor and you reduce your diet, you still have to die according to your time. (MMSMI06)

## **Stress**

Almost half of the participants reported stress as contributing to the development of their CHD. Both South Asian and European participants described events in their families' lives that they felt had caused them considerable worry and tension. Some of the patients thought that their CHD had developed as a result of the stress they experienced due to a particular life incident, for example the sudden death of a family member. Participants recalled such incidents bringing on feelings of extreme remorse and grief, which they had found difficult to control. One of the Pakistani-Muslim females talked about the stress brought about by losing her son at a young age:

I used to have a twelve year old son, this was in Pakistan, and I took him to the doctor. We lived in a village at the time. My husband and my cousin, they went with him to the doctor, and he said he had really bad pain in his stomach. At that time, he was my only child. They went to the doctor with him, at about twelve o'clock, and by one o'clock, there he'd died....I was depressed. I used to cry, and beat myself, and think, 'I won't survive this.' He was such a handsome boy, and he died in a second. So, that grief is still in my heart. I think that's why now I've got the heart problem. If I talk about it

too much even now, it affects my heart, and my head starts throbbing. Then I can't talk too much. This is what's happened to me. (MFSA19)

Other participants reported that they had been living under stressful circumstances for a prolonged period and that as a result stress had accumulated over time. Individuals who had been caring for family members with ill health for a prolonged period, those experiencing work-related problems and those dealing with stressful family situations felt that this had had a negative impact upon their health. As one Indian-Sikh female explained:

Sometimes you think you're worrying on top but you don't know ... you don't know if you're worrying inside ... you don't know yourself if you are worried. I think it's the pressure, the worry, because at the end of the day, you've got to think about everybody ... obviously the mother and the father ... you've got to see to your kids ... and your kid's kids. You don't know what they're doing ... and when they grow up you don't know what they're going to do at the end and if they do something wrong, that hits you straightaway. (SFSA10C)

As part of cardiac rehabilitation patients had adopted a variety of coping strategies to manage stress, although relaxation techniques were seldom used. Very few participants used the relaxation tapes that they had been provided with once they returned home. Notably, European participants were more likely to use the tapes than South Asians. Some younger participants had reduced their workload to improve their work leisure balance thereby avoiding the replication of their prior work patterns. This was particularly prevalent amongst those who were self-employed. Others had reported making a conscious effort to reduce patterns of worrying thoughts. This was sometimes difficult as patients were returning home to manage the same stressful situations that they had left.

## Tobacco Smoking

Tobacco smoking behaviour appeared to vary by ethnic group. Far more individuals in the European sample reported being current and ex-tobacco smokers compared to their South Asian counterparts and there was little difference by gender. Generally tobacco smoking was less common amongst the South Asian sample. In particular South Asian women were the least likely to report that they had ever smoked.

The Pakistani-Muslim participants in the sample were most successful in terms of changing their smoking habits. All had quit and in most cases this was precipitated by their diagnosis of CHD. In some instances however concerns expressed by other family members had also influenced peoples' decision to give up smoking as in the case of Yusuf, a patient suffering from angina:

I used to have about 20 to 25 a day, and a year and a half before I'd stopped... [my] youngest son said, "Dad, you get ill, sometimes you get this, sometimes you get that pain so give up your cigarettes. who else will I have if I don't have you?" because I do not have a real brother of my own, I am the only one. (MMDA16)

Participants from other groups however, had varying levels of success at smoking cessation. Beliefs about smoking as a causal factor for CHD varied considerably amongst the European sample. Most recognised the damage of smoking upon their heart and many had quit, whilst a few did not attribute smoking as causing their CHD.

With the exception of the Pakistani-Muslim sample, it was common for participant's to continue smoking despite being aware of the detrimental effect to their health. Most of these individuals had considerably reduced the number of cigarettes they smoked but found complete cessation difficult. Rakesh, a 54 year old Indian-Hindu patient had

modified his diet considerably after suffering from his heart attack and was trying hard to reduce his intake of tobacco despite encouragement from his friends to continue:

When I am in the pub I might have one if my friends are with me. So now I just go to the pub once a week and I will have one cigarette there that's all...I don't take any cigarettes myself, I don't buy them, but other people offer them to me so I take (HMDMI09)

Some participants who had quit smoking whilst in-patients were unsuccessful in maintaining abstinence once home. This was the case for two European individuals who reported that having spouses who smoked made it difficult for them to quit. However, even those not cohabiting with current tobacco smokers found it difficult to quit. Both Indian-Sikh male participants in the sample lived alone and were finding it hard to follow the advice given to them by health professionals and family members. One of these was Virinder, a 51 year old patient diagnosed with angina who started smoking heavily whilst as a youth whilst in the navy. He reported smoking 60 cigarettes a day prior to his most recent angina attack. Having been advised by his GP to lose weight and stop smoking, he had managed to reduce his intake to 20 cigarettes daily but was having difficulty decreasing this further whilst simultaneously modifying his diet and alcohol consumption. He talked about the difficulties of breaking a habit which had been with him for most of his life:

I've tried patches and all, didn't work...wish I could give up honest to God doctors told me you must give these up because otherwise they'll kill you they will but I can't help it got used to it haven't I? First thing when I get up in morning first thing I want is a cup of tea and a cigarette which is not very good is it?No breakfast nothing, cup of tea and cigarette... (SMSA04)...

It was not uncommon, particularly for European participants in the sample to disagree with advice imparted to them about tobacco smoking. Rather they preferred to believe that smoking did not affect their condition. Such was the view of Betty, an elderly European woman diagnosed with multiple sclerosis. She had her first AMI aged 65 years of age and reported that the prospect of quitting smoking to prolong her life as unappealing. She was prepared to continue eating a healthy diet but was adamant that she would not forego smoking, which was one of the few pleasures left in her life. She explained her reasoning on this subject:

They [doctors] don't nag, you know, like they used to do cause all I say to them ... as I have right from beginning I'm 66 I'm knocking up 70. I says, "I've only smoked 50 odd a year so what has it done to me?" That's all a load of bull is what smoking does for you. Why hasn't it done it to me? (WFDMI21)

The fact that some participants knew non-smokers who were suffering from CHD made them question the association between tobacco smoking and CHD. It also led them to consider other possible causes for their condition. Furthermore, for some, tobacco smoking was seen as an effective approach to stress relief and therefore a valued activity which they were unwilling to sacrifice.

#### Physical Activity and Exercise

A lack of time and the presence of other co-morbidities prevented some individuals from participating in what they considered an appropriate amount of physical exercise. Others perceived that vigorous exercise was unnecessary in the context of their advancing age and that keeping mobile and active was preferable. An elderly Indian-

Sikh woman, Sukhvinder, who attempted a daily walk explained her views on this subject:

I'm nearing on 80 and my husband, he's passed 80 so what can you expect at this age? We're not going to be jumping around are we? I mean I'm not worried about anything now, I mean .... I'm not even scared about death. I think the best thing is to keep you yourself active, that's the best thing. Being sat down all the time is not good for you. (SFSA11)

The majority of participants, irrespective of ethnicity, reported walking as their preferred form of physical exercise, but few were successful in walking regularly. Participants identified a number of barriers to walking outdoors. The greatest problem was the variability in weather conditions which made it difficult to plan walks as part of one's daily routine. Some individuals also complained of physical symptoms which discouraged them from walking such as; breathlessness, swollen feet, dizziness and excessive tiredness. Moreover, cold weather precipitated symptoms in those with angina make them understandably reluctant to take walks during the winter months. There were also participants living with other co-morbidities and sensory impairments which limited their physical functioning.

A number of participants raised concerns about the distance they had been recommended to cover whilst walking. This was more of an obstacle for South Asian participants who were less likely to walk as an outdoor pursuit and subsequently found it more difficult to think of places where they could exercise. Salma, an active 72-year Pakistani-Muslim widow who lived alone and had undergone coronary artery bypass

surgery, highlighted this issue. As an inner city resident, she found it difficult to access open spaces that would enable her to walk uninterrupted without having to stop for traffic. In addition, Salma reported that she did not walk outdoors because she felt uncomfortable doing this unaccompanied. Inevitably this resulted in her being taken to places by car rather than on foot. She explained her situation:

They [nurses] say, "When you feel like it go ... walk for a mile, two miles". I said, "Where can you go for so many miles?" You can go to town if you have some job to do there. But the children come and take me in the car ... I sometimes go around and about here, to my daughters and even there I go in the car. (MFDC21)

As an alternative to walking outdoors, some of the Pakistani-Muslim females who lived in larger homes had established a regular indoor walking routine. This obviated their concerns about local weather conditions and the need for family members to accompany them. In addition to walking a small number of individuals across ethnic groups had joined a gym or started to use exercise machines within their own homes. European females were just as likely as their male counterparts to use exercise bikes to improve their physical fitness. However, none of the South Asian female participants had ever used exercise machines or joined a gym, although some had started regular swimming.

Within each ethnic group there were a number of individuals who were physically inactive. This included those with co-morbidities and physical limitations that reduced their mobility. Some individuals who had resumed employment reported that they had

insufficient time to engage in physical exercise. Vijay, a 47-year-old Indian-Hindu patient diagnosed with angina was advised to lose weight. Having resumed work, he was finding it difficult to incorporate exercise into his daily routine and was struggling with the demands of occupying three different jobs. In addition, he felt that he was getting enough exercise through his employment despite this being sedentary in nature.

#### **Dietary Intake**

Amongst the sample, few participants appeared to recognise the link between poor diet and the development of CHD. Despite this, a considerable number of participants across groups admitted that they were overweight and needed to modify their diet. Amongst the South Asian groups, males were more aware than their female counterparts of the need to lose weight, while the reverse was true within the European group. However many of these overweight individuals did not know how to lose weight and faced major obstacles in their attempts to modify their dietary intake.

South Asian participants, in particular Pakistani-Muslims and Indian-Sikhs, were most likely to feel that their dietary habits caused their CHD and that the traditional South Asian diet had been detrimental to their health. However, the South Asian sample consumed an extremely varied diet and not all individuals complied with a strictly traditional South Asian diet. Nevertheless, most participants consumed a South Asian meal at least once daily.

Individuals preparing South Asian meals used a variety of fats. In many households sunflower oil was used routinely, whilst olive oil was seldom used. Very few participants were consuming dishes cooked in 'ghee', a clarified butter that is traditionally used in

South Asian cooking. Only one patient, an elderly Pakistani-Muslim female participant, was required to continue consuming food cooked in ghee after being diagnosed with CHD. This was due to the fact that she regularly visited her son's household in which it was the norm to cook using ghee.

Some participants reported that since being diagnosed with CHD they were eating dishes that were cooked in less fat, but not everyone was willing to compromise the taste of their meals in order to improve their health. Two male participants in the Pakistani-Muslim sample diagnosed with angina admitted that they did not enjoy eating South Asian meals cooked in minimal oil and would therefore instruct their wives to continue preparing meals using large amounts of oil in the usual way. This resistance to modifying food preparation was a significant obstacle for some. Charanjit, whose wife was diagnosed with angina, had modified the way in which they cooked curries by using less fat. However, they did not feel that other people were willing to follow their example:

We talk to a lot of people who say, "No, the taste of oil is not very good" and I say, "Well are you going to look at the taste of it or what's good for your health?" You have to look after your health, taste is secondary ... Before we had an interest in the taste of ghee, tastes nice, yes that is true, but if it's not good for your health, then that's no good. (SMDA13C)

A number of participants had reduced their intake of fried foods. Grilling foods rather than frying them was seen as one approach to reducing dietary fat intake. Some South Asian individuals reported however that it was not always possible to modify their fat intake, especially on social occasions or when visiting others. For this reason, some

older participants in the sample reported that they avoided visiting people if they knew that they would be expected to eat meals that they considered unhealthy.

Few South Asian patients mentioned the substitution of some of their dietary components with lower fat alternatives. Only one Pakistani-Muslim patient talked about introducing low fat yoghurts into her diet. Furthermore whilst a few patients mentioned that they had switched to using semi-skimmed milk, others admitted that they still preferred to drink full fat milk. On the whole, European participants were more likely than South Asians to discuss the introduction of low fat products into their diet. In addition, South Asians were less likely than their European counterparts to cut down on their intake of sweet foods.

#### Stress Management

As part of cardiac rehabilitation, patients had adopted a variety of coping strategies to manage stress, although relaxation techniques were seldom used. Very few participants used the relaxation tapes that they had been provided with once they returned home. and notably, European patients were more likely to use tapes compared to their South Asian counterparts. One of the older European female patients listened to story tapes with her husband as away of relaxing as he explained:

Well yeah. We do a bit of that every afternoon, as soon as we put us tape on. There's many a time we, we've to, you know we've put the story tape on and before you know, we have to wait while next time before you catch up. It's great for relaxing... listening to somebody else reading you a story and we do, that's how we relax, you know (WFSC12C).

Notably, European participants were more likely than their South Asian counterparts to use tapes as a means to unwind.

Some of the younger participants in the sample had chosen to reduce their workload to improve their work leisure balance thereby avoiding the replication of their prior work patterns. This was particularly prevalent amongst those who were self-employed as illustrated by the case of Younis, a 53 year old accountant of Pakistani-Muslim background whose second AMI had prompted his grown up children and wife to help him cut out unnecessary pressures from his life. His daughter explained how this was achieved:

His work is quite stressful but...the stressful thing is...talking to the clients because they just don't co-operate so...we have changed [this] job to the manager, he has to do that. We ourselves have made it happen, we've all sat down and we sold half the business...and the buildings that we used to have, like for students we've sold those too..so we've done quite a lot so that he doesn't get stressed (MMDA13C)

Other patients had reported making a conscious effort to reduce patterns of worrying thoughts. This was sometimes difficult though as patients were returning home to manage the same stressful situations that they had left. The daughter of an elderly female Pakistani-Muslim patient, Zohra, had decided that it would be less stressful if her mother moved out of her brother's house and came to live with her after she had been discharged from hospital. A member of the European sample, Caroline, had been advised by her GP to undertake counselling to help her cope with the stresses of living with an alcoholic husband and a teenage daughter with serious health problems. She talked in detail about the difference that counselling had made to her life:

I'd never have gone for counselling, I talked about it and talked about it, and then in the end I thought "I'm gonna go." Best thing I ever did. I should have done it ages ago. Now I know where to go. I wouldn't be frightened of going for it again. I mean, it's quite .. it's quite .. in-depth, cos there's other things that it sort of brings up as well...sort of like stresses and strains of your past, and stuff like that, but .. I mean, he did say to me "What do you do for yourself?" and at that time I wasn't doing anything for me. You know, even if I was doing, like knitting, it was for somebody else. It wasn't because I enjoyed doing it it were, well, it was, I do enjoy doing it, but there was always "Oh, well, can you do me this and can you do me that." So you've got a pressure behind it again. (WFDA19)

#### **Discussion**

There was considerable variation in patients' understanding about CHD, both within and across ethnic groups. Knowing what caused their CHD influenced the way in which participants managed their condition and helped them to make decisions about lifestyle modification. Whilst some patients were equipped with relevant information and advice in order to make such changes, others lacked motivation and the appropriate support to improve their lifestyle.

In particular South Asian patients, particularly Pakistani-Muslim patients were least likely to report that they knew the cause of their CHD which may be explained in part by language barriers. A language barrier has been reported as an obstacle to information provision for South Asian cardiac patients in other studies <sup>11, 12</sup>. It has been suggested that cardiac patients of South Asian origin might be disadvantaged in terms of knowledge and awareness about their condition; first by not always having the choice to

access trained interpreters whilst in hospital and second, by the reliance on written information that incorrectly assumes that the whole population is able to read <sup>27</sup>.

Almost half of the sample reported stress as contributing to their CHD, irrespective of ethnicity. Other studies have reported stress as one of the most frequently reported causal attributions for CHD <sup>10</sup>. However, South Asian patients were more likely than their European counterparts to attribute their CHD to unhealthy eating habits. These findings concur with other studies that have reported South Asian participants to be cognisant about the link between poor diet and the development of CHD <sup>11, 12</sup>.

Some confusion existed within the sample about the significance of coronary risk factors. This finding is supported by other studies that have found a lack of concordance between patient's actual coronary risk factors and their beliefs about cause <sup>14, 15, 16</sup>. In particular, uncertainty existed about the significance of family history; making it particularly difficult for some individuals to act upon the advice they had been given. For many of the older patients there was a strong belief that they had been fated to suffer from CHD, irrespective of ethnicity. These participants felt that there was nothing that they could have done to prevent their CHD from happening and found it difficult to identify any cause.

In some ways this belief has the potential to shift the locus of control away from the sufferer. This may be a significant factor at a time when there is considerable emphasis on patient's successfully self-managing chronic conditions <sup>28</sup> which requires considerable motivation. It could be that causal attributions may influence patient's uptake of such initiatives. Despite this, many participants acknowledged the

manifestation of their CHD as signalling the need for them to adopt a healthier lifestyle, but it is not clear to what degree these intentions were translated into lifestyle change.

The results also highlighted some differences in the way in which ethnic groups responded to their heart condition. South Asian patients were more successful in smoking cessation than their European counterparts but were less likely to use relaxation techniques as a coping strategy to manage stress. South Asians experienced considerable difficulties in trying to lose weight. This may be because they were less likely than their European counterparts to cut down on their consumption of sweet foods and substitute foods they normally bought with low-fat alternatives.

Practical problems often limited patient's ability to succeed in making healthy lifestyle changes. For example concomitant co-morbidity, a lack of available time and the absence of sustained support all influenced participants ability to lead a healthier lifestyle.

Engaging in regular physical exercise was a challenge across all ethnic groups. However, South Asian patients, particularly females, found it difficult to identify suitable and safe routes for walking in inner city areas. The lack of available family members meant that they were also reluctant to take a walk on their own. South Asian females were the least likely patient group to visit a gym or attend cardiac rehabilitation classes. These findings are similar to others that have identified that South Asian Pakistani-Muslim women report several barriers to participating in physical exercise such as a lack of access to appropriate facilities <sup>11, 29</sup>.

#### Limitations

This study has a number of limitations amongst these its retrospective design and the lack of information about participant's coronary risk factor profiles. The latter would have been valuable in enhancing the interpretation of participants' health beliefs and behaviours. The small sample size of each individual group also represented a limitation. The findings, although not generalizable, offer important insights which have implications for both the in-hospital care and cardiac rehabilitation of patients from different ethnic groups and the study addressed a topic area that is largely unexplored.

#### **Conclusion & Implications for Practice**

The findings from this comparative study suggest that South Asian and European patients with CHD articulate many similar concerns, worries and needs. The challenge for those involved in providing cardiac rehabilitation services to these patients is to offer information and advice that is tailored to their particular circumstances and to bear in mind that not every problem or difficulty a person encounters can be attributed to his or her ethnic background. The key to progression in this arena is for health care professionals to know when ethnicity makes a difference and mediates a person's relationship with service support and when it does not. One example of this is the shortage of appropriate translation and interpreting facilities in the context of healthcare provision that has been identified as a problem <sup>11, 12, 27</sup>.

More importantly, there is increasing evidence that socio-economic status, age and gender are as important as ethnicity in making sense of a person's health and social care needs. In the development of policy and practice guidelines there is a need to recognise this and understand how ethnicity relates to other aspects of an individual's

identity. Otherwise it will offer solutions on the basis of misguided and mistaken premises.

Having said this, however, we do need to acknowledge that heath care providers struggles to offer accessible and appropriate care to ethnic minority populations. These struggles occur against a backdrop of socio-economic disadvantage and social exclusion, in which the needs of ethnic minority communities are either ignored or misrepresented <sup>31</sup>. Within the field of CHD, the low participation in cardiac rehabilitation classes amongst South Asian females could be interpreted as women with a lack of interest in regaining good health. However, it could also highlight the lack of provision of appropriate services such as single sex exercise facilities and the shortage of information that is culturally relevant.

Health care professionals, therefore, need to develop a cultural repertoire to engage with diversity and difference. The need for more advanced training to improve health care professional's levels of knowledge and cultural awareness has previously been identified <sup>32</sup>. This includes an awareness of clients' 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>33</sup>. This finds resonance in current debates about culturally competent practice in health care, which emphasises the importance of getting practitioners to challenge their own values, develop understanding and sensitivity and apply their awareness and knowledge to appropriate practice <sup>34</sup>.

Additional research is required in order to promote culturally sensitive care. Developing support for those with CHD in multi-cultural societies needs to include accounts such as

ours, in order to provide a better understanding of the experience of people from a range of ethnic backgrounds.

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Table 1 Sample characteristics (n=65)

Religion/ethnicity	Males	Female	Age
			(Mean) Range
Pakistani-Muslim	10	10	59 (46-72)
Indian-Sikh	7	5	63 (48-79)
Indian-Hindu	9	4	63 (40-82)
European	10	10	66 (42-83)

#### **Abridged Version of the Topic Guide for Patients**

## 1) UNDERSTANDING OF CONDITION

I'd like to start off by asking you a few questions about your health.

- First of all can you describe what your general state of health was like before you had this heart problem?
- Did you think that you were healthy? Probe Why?
- Did you do anything specific to stay healthy?
   Probe Exercise, diet, other e.g. avoiding things deemed harmful, doing things deemed health enhancing
- Could you briefly tell me about other medical problems that you have Probe Obesity, diabetes, other conditions that limit mobility/ create dependence/necessitate special diet, high blood pressure, breathing problems, mental health problems

Importance compared to heart condition

- Did you ever think that you would have a problem with your heart?
- What do you think caused your heart condition?
   Probe Diet, smoking, lack of exercise, overweight, stress, family history, other
- Do you know anybody else with a similar condition? Probe Who? How similar/different from own experience? Known before/after own heart condition?

## 2) JOURNEY THROUGH THE HEALTH CARE SYSTEM

Now I am going to talk to you about your experience of health services and the kind of advice that you may have been given by doctors and nurses to help you get better

- Can you just tell me a bit about your heart condition?
   Probe What happened? How did you find out? Other heart problems in the past
- Who explained what was wrong with you [most recent event]?
   Probe Understanding of terms used, presence of other family members, use of interpreters
- Did you ask questions?
   Probe Opportunity, emotional appropriateness, knowledge of what to say

[Add this sentence for Asian patients]

Sometimes when people use family members as interpreters, they are not always able to talk about everything openly with the doctor.

Did you feel that you were able to discuss all the issues you were concerned about?

[Only ask this question to those people who have had previous heart problems]

- How does this compare to previous episodes?
- Did anyone invite family members to the hospital to discuss your condition?
   Probe Which health professional? When? Who came? Why? Usefulness
- Did you have contact with any other health professionals whilst you were in hospital?
   Probe Physiotherapist, psychologist, dietitian, social worker, other
- Were you advised to make changes to your life? Probe By whom?
- What kind of advice have you been given?
   Probe Exercise, diet, relaxation, sex, support groups
   Verbal/written/audio/combination, one off sessions/series of meetings
   Level of agreement/perceived usefulness
- Were you happy with the way in which you were provided with this information?
   Probe Appropriateness of advice/person giving advice, use of interpreters, understanding of terms used, coverage of subjects, appropriateness to own needs/lifestyles
- Are there any other subjects about which you needed more information? Probe Which? Why were these subjects not discussed?
- Were you invited to attend rehabilitation programme?
   Probe Perceived usefulness, cultural appropriateness, improvements/alternatives
- Have you been given a Heart Manual?
   Probe Usefulness
- Since you came out of hospital have you had any concerns about your heart? Probe What about?
- Have you spoken to anyone about this?
   Probe Cardiac liaison/community nurse, consultant, GP,other
- Who would you contact if you experienced any problems now?

Probe GP, nurse, consultant

Do you know about the telephone help line to contact the cardiac nurse?
 Probe Usage

- 3) EFFORTS TO REGAIN GOOD HEALTH/PREVENT FURTHER PROBLEMS Now I want to ask you some questions about the kinds of things which you and your family are doing to help you get better.
- For people with your condition can you tell me what you think you need to do in order to regain good health?
   Probe Medication-prescribed/other, smoking, alcohol, diet, exercise, stress, other
- What have you done in order to regain good health?
   Probe Medication-prescribed/other, smoking, alcohol, diet, exercise, stress, other
- Do you think you are doing enough?
   Probe Smoking, alcohol, diet, exercise, stress, other.
- What do you find most difficult?
- Are there any things which you continue to do even though you feel you should not be doing them?
- In making decisions about how to regain health, whose advice would you most value?
   Probe Doctors/specialists/nurses, a particular family member, friends, other

Probe Doctors/specialists/nurses, a particular family member, friends, other patients, other sources of information

- Has your family done anything to help you regain good health?
   [Ask them to identify who does what and why]
   Probe Medication-prescribed/other, smoking, alcohol, diet, exercise, stress, other
- Are you satisfied with the level of support provided by your family?
- Are there any areas in which you feel your family could provide you with more support?

Probe Which areas?

- Why aren't they providing this support?
   Probe Information, time, material resources, other
- 4) IMPACT OF HEART DISEASE ON LIFESTYLE AND RELATIONSHIPS Now I want to talk to you about how you are coping with your heart condition and how it has affected your daily life.
- How is your health now [in relation to heart]?

[If person has other illnesses, then explore their feelings towards these in relation to concerns about CHD]

- Which medicines are you taking for your heart?
   Probe Compliance, perceived benefits, side effects
- Do you think that your life has changed since you had a heart attack? Probe In what ways?
- What are the good/bad changes?
- What would make it easy/easier for you to cope with your condition?
   Probe More family support, material resources, health professionals, religion.
- Do you think that your relationship with other family members has changed since you became ill?

Probe Spouse, children, siblings, extended family.

Does heart disease prevent you from doing any other things you think you ought to be able to do?

Probe Work, domestic responsibilities, hobbies, religious activities, other

- Do you talk about your illness with other family members?
   Probe Perceived causes
- Do family members ever do things which upset you?
   Probe Over protectiveness, monitoring, not supporting you, undue criticism

Some people who have heart problems say that their relationship with their partner changes.

Do you think that having heart disease has affected you relationship with your spouse?

Probe In what ways? Any concerns?

Some people report that they feel low/anxious/depressed after their heart attack.

- Are there any times when you feel low? Probe When? Why? How often?
- Do you think that feeling low has affected your recovery?
- If you are feeling low, what makes things better?

Probe Things you can do, Things others can do

How has your heart problem affected your work?
 Probe Sick leave, intentions to resume work, social implications, longer term job/career ambitions

## **Looking Ahead**

- How do you feel about the changes you are making to your life?
- Do you feel that you are getting better?
- Which things do you think will help you to get better? Probe Compliance with medication, reduction of risk factors, improved health, care services, family support, material resources, better living circumstances, prayer.
- What are your plans for the future?
- Do you think you may suffer from further heart problems?
- If there was one thing you could say to someone about avoiding your condition, what would you say

[Thank interviewee and ask them about the possibility of interviewing another family member ]

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