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### Article

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# **‘I don’t do it for myself, I do it for them’. A grounded theory study of South Asians’ experiences of making lifestyle change after myocardial infarction.**

## **Abstract**

**Aims and objectives:** To explore South Asians’ experience of choosing and prioritising lifestyle changes during their recovery from first myocardial infarction.

**Background** Coronary heart disease continues to be a leading cause of premature death globally. South Asians’ suffer increased risk of coronary heart disease and have poorer outcomes following myocardial infarction compared to other ethnic groups. Lifestyle modification slows atherosclerosis and models of behaviour change have been proposed to support such changes. However, little is known about the experiences of South Asians’ when attempting to modify their lifestyle.

**Design** Constructivist grounded theory design, using longitudinal, face-to-face, semi-structured in-depth interviews. The consolidated criteria for reporting qualitative research checklist was used to report the study.

**Method** A series of in-depth interviews with a purposive sample of South Asian patients were conducted at 3 and 16 weeks following hospital discharge. Transcripts were analysed line by line with focused and theoretical coding using the constant comparative method and memo writing. Data collection and analysis occurred simultaneously.

**Results** Three categories characterised the findings. First, patronage of the family, referring to the role that family played in supporting recovery. Conflict often existed between the needs of the family and the individual with the family needs taking priority resulting in lifestyle modifications being abandoned. Second, conforming to beliefs, which explains how religious and health beliefs influenced decisions. Third, affinity towards one’s group which refers to the conflictual nature afforded by social norms. The need for ‘harmony’ was identified as the substantive theory. Decisions about choosing and prioritising lifestyle changes were based on what helped participants to maintain harmony in their life rather than meeting individual health needs.

**Conclusion:** South Asians’ choose and prioritise lifestyle changes after first myocardial infarction against a backdrop of competing religious, cultural and family beliefs.

## **Relevance to Clinical Practice**

This paper illustrates that South Asians attempt to balance their individual needs with their family goals, cultural priorities and their religious beliefs when attempting to adopt a healthy lifestyle post myocardial infarction. We propose a model of shared priority setting as a means of promoting behaviour change with South Asians

**Keywords:** Myocardial infarction, Cardiac rehabilitation, South Asians, Grounded theory, Shared-priorities

## **1. Introduction**

Diseases of the heart and circulation lead to 17.7 million deaths each year and account for one third of global mortality (Benjamin et al., 2018). The main forms of cardiovascular disease (CVD) are coronary heart disease (CHD) and stroke. CHD is the leading single cause of mortality in Europe, responsible for 862,000 deaths a year (Wilkins et al., 2017). However, the disease burden shows no egalitarian pattern and standardised comparisons among different ethnicities show that South Asian people have a disproportionately higher CVD prevalence (Scarborough, Bhatnagar, Wickramasinghe, Mitchell & Smolina, 2010), higher risk of atherosclerotic events (Joshi et al., 2007; Yusuf et al., 2004; Zahid et al., 2011; Anand et al., 2000; Gupta & Brister, 2006; Gupta et al., 2002), higher rates of hospital admissions (Ahmed and El-Menyar, 2015) and earlier disease onset (Volgman et al., 2018). Such disparity is not limited to British South Asians but is also evident in worldwide migrant South Asians (Fischbacher, Bhopal & Povey, 2007).

These disparities exist despite the diversity of origins, culture, customs, socioeconomic status, differing adaptation and assimilation to host countries (Joshi et al., 2007). Contributing risk factors are thought to be both physiological and socioeconomic in nature, compared to the general populations of those countries (Meadows et al., 2011; Nair and Prabhakaran, 2012). Physiological risks include, differences in pro-thrombotic (Anand et al., 2000; Hoogeveen et al., 2001) and pro-inflammatory (Anand et al., 2004) responses, a greater incidence and prevalence of impaired glucose tolerance (Gujral, Pradeepa, Weber, Narayan & Mohan, 2013), diabetes (Kanaya et al., 2013), higher levels of visceral fat (Rana et al., 2014; Shah et al., 2016), hypertriglyceridaemia (Kalhan, Puthawala, Agarwal, Amini & Kalha, 2001), low HDL cholesterol (Akeroyd, Chan, Kamal, Palaniappan & Viranni, 2015), and increased prevalence of hypertension (Chiu, Austin, Manuel & Tu, 2010; Rana, de Souza, Kandasamy, Lear & Anand, 2014; Patel et al., 2006). Socioeconomic risks include diets rich in carbohydrate and saturated fat (Misra, Khurana, Isharwal & Bhardwaj, 2009), low levels of physical activity (Brodersen, Steptoe, Boniface & Wardle, 2007; Fischbacher, Hunt & Alexander, 2004; Hayes et al., 2002; Williams et al., 2011) and increased prevalence of adverse psychosocial factors (Joshi et al., 2007). Whilst CHD has no known cure, adopting a healthy lifestyle, including regular physical activity, a healthy diet and smoking cessation, slows disease progression and reduces the risk of future adverse cardiac events, crystallising its importance as a cost-effective health strategy (Challis et al., 2010; De Gucht, Dusseldorp, Janssen & Maes, 2013). Recognising the need to support behaviour change, the National Institute for Health and Care Excellence in England, advocate that all patients who have suffered a myocardial infarction should be referred to a cardiac rehabilitation programme prior to hospital discharge (National Institute for Health and Care Excellence, 2015). Cardiac rehabilitation is an evidence based intervention that provides attendees with access to a coordinated and structured programme designed to optimise physical, mental and social conditions so that people can, by their own efforts, continue to play a full part in their community (Ibanez et al., 2017; National Institute for Health and Care Excellence, 2015). Exercise-based cardiac rehabilitation (CR), when compared to usual care, is shown to reduce cardiovascular mortality and the risk of hospital readmission with some evidence of a positive effect on healthcare costs and exercise capacity (Anderson et al., 2016). Other reviews have reported improvements in quality of life and psychological well-being associated with attendance at CR (Whalley et al., 2011; Wong et al., 2012; Rauch et al., 2016). However most trials

testing the effectiveness of exercise-based cardiac rehabilitation have focused upon white Caucasian male populations.

There are clear recommendations about the potential benefits of making healthy lifestyle changes after acute myocardial infarction (AMI), but these are not consistently translated into improved clinical outcomes (Piepoli et al., 2010). Contemporary data from large European studies such as EuroAspire IV (Kotseva et al., 2019) highlight that many patients are unable to modify and maintain healthy lifestyles in the long term. These limitations raise questions about the merit of current cardiac rehabilitation programmes advocated by key organisations. (National Institute for Health and Care Excellence, 2013).

South Asians are a diverse people with cultures and communities originating from seven countries in the Indian subcontinent (Waisundara and Shiomi, 2017). Historically South Asians tend to have had low referral rates, uptake and adherence to cardiac rehabilitation (Banerjee, Gupta & Singh, 2007; Beswick et al., 2004; Jolly, Greenfield & Hare, 2004; Galdas and Kang, 2008; Scott, Gravely, Sexton, Brzostek & Brown, 2013); although uptake may vary by country (Rana et al., 2013). A Canadian study (Grewal et al., 2010) exploring South Asian patients' barriers to CR identified a number of factors that might help explain such poor uptake; the importance of in-hospital communication with care providers, providing knowledge of the comprehensive nature of cardiac rehabilitation and the importance of post discharge follow-up and the need to support personal autonomy were identified as important factors. Chauhan, Baker, Lester & Edwards (2010) in a British study with 20 South Asian participants reported that patients had limited understanding of their condition, had negative experiences of healthcare, valued social networks, held fatalistic health beliefs, and identified religious, cultural and practical barriers.

Lifestyle change after a cardiac event is a challenge as patients are experiencing both physical and psychological sequelae. A qualitative synthesis of primary research that reported how people make lifestyle changes after a cardiac event gave insight into the hidden complexity that many patients experience (Astin, Horrocks & Closs, 2014). Findings synthesised from over 500 participants showed that all participants had to negotiate a changed self-identity. As part of this they 'lost' their 'familiar' self-identity which triggered a process which was likened to stages in the grief cycle. Many participants experienced a strong drive to get back to a new 'normal', but making lifestyle changes was just one element of a much wider 'life change' (Astin et al., 2014). Most of the included studies recruited Caucasian study participants with much less comparable data available about how South Asian people make lifestyle changes illustrating a gap in the current research literature.

Understanding how people make lifestyle changes is important as the process does not occur in isolation but is influenced by a multitude of factors, including ethnic, religious and cultural norms. To be successful health services designed to support coronary risk factor modification need to focus upon the context within which behaviour change and maintenance takes place (Astin et al., 2014; Murray, Honey, Hill, Craigs & House, 2012).

Reviews focusing on ethnic minority groups have reported a range of barriers and facilitators to lifestyle change. Patel et al (2017) studied diabetic patients and noted that social norms and values in the South

Asian community influenced peoples' health behaviours. They also reported the existence of gender norms with men often prioritising financial security, and women prioritising caring responsibilities over exercise. Furthermore, there was a general resistance to any activity that involved the participant becoming breathless and sweating. Instead, they considered physical activity to correlate with being busy in their lives, but often cited such busyness as the cause of ill health suggesting that exercise was detrimental. Other norms impeding behaviour change included cooking practices. Reducing the volume of Ghee (clarified butter) or salt in food was considered to render the food tasteless and thus shameful, emphasising the need to adhere to traditional practices. Another potential obstacle to lifestyle change concerned the concepts and terminology underpinning the Western view of self-management such as empowerment and self-efficacy. Findings from a qualitative synthesis reported that such concepts were unlikely to be relevant to South Asian (Lucas, Murray & Kinra, 2012). Cardiac rehabilitation programmes for South Asian people are more likely to be successful if they are tailored to reflect the relevant cultural beliefs and social support networks (Kandula et al., 2013).

Health care organisations and staff need support to enable them to provide culturally competent care; defined as the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviours, and needs presented by consumers and their communities (Cross, Bazron, Dennis & Isaacs, 1989). However, to design cardiac rehabilitation programmes in a culturally and linguistically meaningful way we need to understand how South Asians choose and prioritise lifestyle changes after an acute myocardial infarction which was the objective of this study.

### **Design and methods**

A descriptive qualitative design was appropriate to explore and explain how South Asians engage with lifestyle changes after first myocardial infarction. There are several approaches in which grounded theory can be undertaken drawing on the ideas of its creators (Glaser and Strauss, 1967). The research team have conducted grounded theory studies using approaches described by both Charmaz (2006) and Corbin and Strauss (2008). A constructivist grounded theory approach was chosen because this view acknowledges the researcher as an influential actor in the process; a view that aligned with the views of the lead researcher (Charmaz, 2006). (The lead researcher is herself South Asian and completed training in grounded theory procedures and analysis which included seminars presented by Charmaz).

The ontology and epistemology of Charmaz's (2006) grounded theory assumes that knowledge is not static, nor is it waiting to be discovered, but is always emerging and transforming, co-constructed by both observer and participant. This inductive approach focuses upon the development of a theoretical understanding of the context in which the phenomenon takes place (Charmaz, 2014).

A series of interviews with participants provided detailed accounts of individual experiences to explore 'how' and 'why' South Asians make lifestyle changes as they do to generate a substantive theory based on participant perspectives. Face-to-face interview methods are particularly useful because meaning is constructed through participant-researcher interactions in order to generate new knowledge (Charmaz, 2006). For Charmaz, (2006) emotions speak louder than words for the meaning of incidents which is shown *in the emotions* participants *express* when they '*retell the story*' more than the words they choose

to tell the story (Charmaz 2006: 34). Interviews make such '*emotions visible*'. Moreover, it allows collection of data from participants unable or unlikely to complete questionnaires (Burns and Grove, 2003), such as those whose reading, writing or ability to express themselves is marginal. The consolidated criteria for reporting qualitative research (COREQ) checklist was used to report the study (Supplementary File 1).

### **Setting and recruitment of participants**

Participants were recruited from three U.K. hospitals between June 2015 and December 2016. All three hospitals provide care for South Asians diagnosed with acute myocardial infarction and provide cardiac rehabilitation programmes. A member of the local cardiac rehabilitation team contacted potential participants within three days of hospital discharge to invite them to participate in the study. Those who provided consent were contacted by a researcher and invited to participate in two in-depth interviews that were scheduled for 3 and 16-weeks post discharge to coincide with the time immediately pre and post phase 3 cardiac rehabilitation. The interview timeline was chosen for two reasons. Firstly because patients recovering from AMI often find the early recovery period particularly challenging (Astin et al., 2014). Secondly because lifestyle behaviour changes become established as habits over an average period of 2 months (Lally et al., 2010). The interviews took place at a time and place convenient to the participants. During the telephone conversation, the researcher explained the purpose of the study and answered any additional questions. This process was seen as an important step in attempting to form a reciprocal relationship with participants; a key part of constructivist grounded theory.

Participants were recruited over a one-year period between June 2015 and December 2016. As Corbin and Strauss (2008) make clear, theoretical sampling in grounded theory is 'concept driven', rather than by a specified number of sampled respondents. The recruitment period was not predefined but once repetition in the categories from interviews became apparent recruitment was ceased. Indeed, here we depart from Corbin and Strauss' notion of 'theoretical saturation' as such, since no matter how many people are in the sample it may be that there could always be contrary cases or new concepts. However, our 14 participants, interviewed twice, led us to a very rich conceptual framework from which to derive our theory and we believe lent credibility.

### **Sample**

A purposive sample of participants was recruited based on whether they self-identified as Punjabi Sikh, Indian Hindu, Gujarati Hindu or Indian-Christian, Pakistani Muslim or Kashmiri Muslim. Participants were included in the study if they were over the age of 18 years, had recently suffered a first myocardial infarction and were of South Asian origin. All patients were contacted within 10 days of hospital discharge (0-10 days). Patients who had suffered a repeat heart attack were excluded as their needs may be different from those facing the crisis for the first time.

### **Data Collection**

To align with the principles of grounded theory only a brief scoping review was undertaken to identify the sensitising concepts prior to data collection. Data were collected using in-depth, face-to-face, semi-structured interviews with fourteen participants. The development of the topic guide was informed by

a scoping review of the literature that had been reviewed prior to data collection (Astin, Atkin & Darr, 2008; Darr, Astin & Atkin, 2008) and with input from an advisory group consisting of South Asian service users and professionals. The interview questions used terms such as ‘how or why’ to allow participants to express their views without constraints as recommended by Charmaz (Charmaz, 2006). Topics that were covered included participants understanding of their condition, anticipated lifestyle modifications and perceived challenges, sources of support and experiences of cardiac rehabilitation.

All of the interviews were conducted (by DD) in the patients’ home lasting between 45-140 minutes. On entering the participant’s home, the interviewer, who is a South Asian woman, was dressed in traditional South Indian dress. Instead of the traditional Namaste (folded hands), she slightly bowed her head and smiled, indicating respect. She removed her shoes on entering the house. However, she did not touch the feet of the elders choosing to embrace the lady (as a mark of respect). She thanked participants for inviting her into their home and when offered a drink she took her lead from her hosts. During the month of Ramadan, her hosts were fasting and on these occasions she politely refused. The practical aspects of the research were explained in a cordial atmosphere so that the interviewees felt secure and have the confidence to speak freely. The interviews were conducted in a conversational style being both open and approachable so that the participants remained in control and felt that they had the right to share what they wanted, in the way they wanted.

Participants were asked to describe their experiences of the cardiac event, to make sense of individual experiences within the context of their lives and personal perspectives (Attfield, Adams & Blandford, 2006; Julien and Michels, 2004), to develop a greater understanding of their perspective. This enabled the researchers to develop an understanding of the phenomenon grounded in the participants’ world-views (Bryant and Charmaz, 2010), which in turn can be used to develop or extend theories about how they chose and prioritised the lifestyle changes. Interviews were audio-recorded and fully transcribed verbatim one day after each interview.

Field notes were not taken during the interview but were made immediately following the interviews. These notes recorded recollections of the pauses, the facial expressions and any disruptions that occurred to support the development of early memos. At the end of each interview each participant and family member was thanked for their time and willingness to share their stories.

## **2.4 Data Analysis**

Data collection and analysis were performed simultaneously using a process of constant comparison. Transcripts were independently coded by DD. However, other researchers (MH;MJ;IJ) provided alternative interpretations of the data and independent feedback on codes and the coding process to support a robust analytical process. The codes, concepts and emerging categories, and the substantive theory were discussed amongst the research team. Where there was disagreement amongst the researchers the transcribed data was revisited and scrutinised to reach consensus. Though the primary researcher was trained in NVIVO, it was not used in this research to assist data analysis, as the researchers felt that such software did not fully help the scaffolding and ‘immersion experience’ required in developing the substantive theory.

The interviewer used excerpts of her reflective journal and memos to illustrate the path of theory construction and to consider the practical implications at an early stage. Memos written after each interview to capture ideas, continued as a simultaneous activity through the analysis and thereby facilitated reflection on data collection methods, interpreting the interview accounts, clarifying the relationships among codes and categories, developing final categories and introduce wider academic literature into the analysis.

***Coding & formation of categories:*** The data analysis process was carried out according to Charmaz' Constructivist Grounded Theory (2014), including line by line, focused, and theoretical coding. Through the iterative constant comparative method and theoretical sampling, line-by-line codes were developed into focused codes. These focused codes, identified as coherent patterns, were extracted and analysed. Theoretical coding was used to conceptualise how categories may affect each other and ideas developed to inform substantive theory. The data were constantly compared and contrasted throughout the data collection and analysis process. The categories were analysed thoroughly, and the relationships between the categories and connections between the other categories were determined. Data was collected until theoretical saturation was assumed, meaning that data collection continued until new data did not add any new information. A comprehensive and substantial literature review was deferred until the data analysis was undertaken. The literature added to the theoretical sensitivity and helped to situate the emerging theory.

### **Methodological rigour**

As this research was conducted using a constructivist grounded theory approach, the concepts of credibility, originality, resonance and usefulness (Charmaz, 2006) were used to appraise the quality of this study. Credibility refers to the degree to which the development of codes, concepts and categories are informed by the empirical data (Charmaz, 2006). The lead researcher's position as a South Asian probably enabled a greater degree of entrée with respondents from this community, irrespective of their particular religion and she worked closely with the team of researchers to ensure that there was robust discussion around the development of codes, concepts and categories. The narrative of the participants was made explicit throughout comparative analysis, whilst simultaneously ascertaining, as an aspect of reflexivity, that the researcher's presence was maintained. We have also specified how and why the participants in the study were selected to ensure fittingness and delineated the scope of the research as well as contextualised the setting for the theory that was generated.

The criterion of resonance refers to 'making sense' of the narrative and providing insight into the co-construction of meaning (Charmaz, 2014). Following presentation of the findings of the study at international research conferences, clinical experts and practitioners in the field confirmed that both the narrative, and the process, resonated with their clinical experiences of supporting South Asian patients. They voiced their support for a more culturally appropriate cardiac rehabilitation model for this vulnerable patient group demonstrating the value of the findings to clinical practice.

### **Ethical considerations**



Ethical approval for the study was obtained from the institutional review boards and ethical committees. To ensure the confidentiality of the information, all participants were allocated a pseudonym.

## **Findings**

The final sample consisted of 14 participants, 13 of whom were attending a cardiac rehabilitation programme. Table 1 shows the socio-demographic characteristics. 11 The final analysis consisted of three categories: patronage of the family, affinity towards one's group and conforming to religious and health beliefs. Table 2 shows the categories and supporting quotes.

Table 2: Codes that lead to the substantive theory

The participants' heart attack represented a significant life event – for some it was expected for others unexpected. The new diagnosis and with it the requirement for a 'lifestyle change' caused disruption in their family, cultural and religious spheres, such as domestic considerations, each of which had an impact on their decisions to choose and prioritise lifestyle changes. When therapeutic lifestyle advice was offered by healthcare professionals, participants prioritised the lifestyle changes that caused minimal disruption in the established family patterns social norms and codes. This meant that participants' choices were selected to avoid conflict with cultural norms. Where there was a potential clash or conflict of priorities then personal priorities gave way to cultural norms.

### ***Patronage of the family***

This category illustrates the significance of the family in South Asian communities and the ways in which they provided influential support in the early stages of recovery after myocardial infarction. Participants relied on the support from their family and friends to make and maintain lifestyle changes. The support that participants received did not always align with health professional recommendations. For example the type of food that was provided varied across different 'homes' even when prepared by the same person;

*My mother who lives in Sheffield comes and makes sure I take rest and eat the right food (88-year-old mother travelling to see her twice-married son who is 67 years old). When she (his mother) comes to my house there will be fruits but when I go to my mom's house she gives me samosas (fried snack) (laugh). – Mohammed.*

According to the participants, family and friends were their primary source of support. Family networks provided emotional support and encouragement to participants.

*My sisters and brothers all encourage each other that you have really got to look after your diet and lose your weight. In myself I cannot say I have enough strength to go through the changes, but if it was my daughters, they said –amma you need to do start looking after yourself now. It's easy to talk to them (sisters and brothers) you know they have been there, they know what you go through. - Padma*

One participant considered the presence of her mother as a support that strengthens her whilst experiencing the hardships of the heart attack. She believed that her challenges could be overcome through collaborative family support and so she insisted her mother join her from Pakistan. Praising her family for the support she received, Fatima said:

*...when in crisis we would first rely on our family first because Asians are family oriented. - Fatima*

Similar views were shared by other participants who explained that it was natural to turn to family for support.

*The help is natural, they are family members. We're a close-knit family in the sense that we're always there. He (brother) knows that I'd do the same for him, if he was in this situation. We are used to receiving help from family; it's our duty to help. - Raju*

Participants made the distinction between 'individual' and 'family' priorities. Typically, domestic duties were prioritised over individual health priorities such as healthy lifestyle changes. For example taking the grandchildren to school was seen as more important than exercising. The family routine was seen as the main priority.

*I think of them (his children) you know. After all they come first. At the end of the day they are only there for us. - Philip*

*Yes, this is a terrible disease, but it cannot interfere with our family pattern, the routine is set, they (family) come first. – Sayed*

However, in contrast the 'family approach' also helped some participants to adopt healthy lifestyle behaviours.

*If it wasn't for my family I wouldn't be able to say no to what I was drinking and eating. In the programme I attended they said it's your goal this is the target, and I come home sit down with others, even my deaf mom, bless her soul, she will come and sit around and I will go through what I learned and we make it our target. Then it's easy. I don't do it for myself I do it for them (family). – Philip*

Family input was also an important source of emotional support. For some women it was important that they maintained a strong outward facing persona for the sake of their husband and children, but relied on their mother to enable them to share their emotions;

*It does make a difference to have a family here because if your family is with you then you can support each other; otherwise, you will be depressed. It was an extremely painful experience which kept me depressed most of the time. It was difficult because I wanted to be upset, but I couldn't be more upset, because this will only upset my husband and my sons. But when my mother came from Pakistan it was like I could behave like my son (laughs). - Fatima*

The notion of "change" for oneself appeared to be given little priority by participants as family goals and needs were prioritised and the notion of 'family first' was a key influence on lifestyle choices and priorities.

### **Conforming to religious and health beliefs**

This category explains how participants' religious and health beliefs influenced the way a diagnosis of heart attack was perceived and the subsequent lifestyle changes that were initiated. Faith was perceived as an important adjunct to medical therapy. Religious expressions were often used in conversations about their recent heart attack and the road to recovery. This demonstrated the close links between participants' health and religious beliefs. For participants, religious practices such as praying and trusting in God ran in parallel, and more often than not, seemed more important than the advice and guidance provided by the health care professionals.

*Sometimes I think.... I take the medicine but who decides it should work, Allah? Isn't? If I prayer and prayer I can become better, that is also going in my mind... after all who knows what is there in the medicines? All is polluted, God only has the power to make clean my soul and body..... Usman*

For Muslim participants 5 Niskars\* per day, the Sikh participant following the teachings of the Gurbani\*, the 2 Christians going to mass and reading the bible and the Hindu participants, conducting pujas and reciting shlokas were seen to be just as vital as prescribed cardio-protective medication for their recovery.

*Of course, you need to take the medicines, but the praying to your God is also important. Yes it is important. You take 5 pills a day, you pray 5 times a day. - Fatima*

Although participants held strong belief in God's involvement and a predetermined destiny, they still took responsibility for their own actions and outcome of their decisions citing 'my decisions are my fate'. They recognised that the mixture of fate and a strong family history of heart disease was an important coronary risk factor. This belief led some participants to go for health checks with their GP and make lifestyle changes.

*My brothers all had heart attack, I was waiting for it. But I cannot sit here thinking oh I was born in heart attack family it's my fate, so I went to my GP and said please check me up. - Raju*

As part of a process of accepting their diagnosis there seemed to be a perception of a dual accountability in which both God, and the individual, contributed to the development of the myocardial infarction;

*You cannot say it is God who has done, so I do not have to do anything. No it is daivam pathi than pathi, we too have responsibility. You know when you born you were clean – there is nothing dangerous to your health. God gave you good health. But I did not look after it. I ate what was not good for me and made it like this. But it must be written in my fate. But it's my responsibility! - Satti*

Some participants described examples of religious considerations prevailing over dietary ones. The way medications or food could clash with their religious activity, in particular mosque attendance and Niskars (ritual prayers). Negotiating these competing and conflicting demands often led to one activity being ignored or avoided. Here, one participant makes a link between increased flatulence and her new diet.

*...it makes my wind (flatus) problem worse... I just don't eat it. Fatima*

Subsequently, she explains how adopting this diet could potentially affect her ability to attend mosque, indicating how she has prioritised her religious beliefs over her health needs.

*Because we pray regularly, we need to be constantly in ablution. Making wind makes us not so. So I did not do what they asked me to do. No, I did not tell the doctors. They wouldn't understand. See.. What do they know? Being in the state of purification for prayer? No. first they do not have time, second they will not understand.....Fatima*

Another participant explains how her need to follow religious convention limits her ability to participate in mixed gender exercise classes despite acknowledging the benefits of such activity.

*You know ..... if there are religious restrictions for example you ask me to go an exercise class where there is the mix (of men and women), then I would not go, even if I really need to go. Religion comes even before myself. - Miriam*

Thus, religious beliefs, practice and lifestyle were interlinked and this influenced participant's decision-making and choices. More often than not, the religious duties and priorities took precedence over lifestyle change and health professional advice.

### ***Affinity towards one's group***

This category explains the strong culture and social norms of hospitality, which were both obligatory and pivotal in day-to-day life. For example, during an interview with a participant at their home, there was a constant flow of neighbours and community members bringing food.

*It would have been very rude to refuse them (neighbours) and even though I know I should not eat these kind of food, it's not health (healthy). Mohammed*

Moreover, the food was prepared in a way that the 'patient would have liked to eat, most often this would mean traditional South Indian food 'fried fish, oil rich curry'.

*This happens all the time, you know. Sometimes I eat, sometimes she (mother) says, no you cannot. And then I don't. But the thing is more than my body getting upset with the bad food, I don't want to upset them (those who bring in the food)... we know how difficult it is to cook food and bring it. How can I throw them away like that? - Philip*

Yet, despite recognising that the food was unhealthy, they accepted the gift rather than cause upset. It was accepted as not to 'hurt their feelings'.

*...It would have been very rude to refuse them (neighbours) and even though I know I should not eat these kind of food, it's not healthy. Das*

The conflictual nature afforded by social and religious norms added to the complexities of negotiating dietary changes. Lifestyle modification may not be a priority for South Asian people whilst protecting valued societal roles maybe vital and take precedence over personal norms. To avoid conflict, their decisions were based on what helped them to be in 'harmony'. Their choices reflected the need to harmonise the lifestyle changes within a family, religious and cultural sphere. With an aim to maintain harmony, the familial, faith and folk beliefs and norms influenced their choices and often

took precedence over the advice and information given by health professionals, despite acknowledged health implications. And yet, lifestyle changes that were in harmony with the family routines were welcomed and chosen.

Based on these findings, an inherent ‘conflict of priorities and the need for harmony’ was identified as the substantive theory (as Charmaz’s approach advocates multiple realities, we have used the term substantive theory as a corollary of the analysis instead of core category) Table 2 illustrates the development from the initial quotes and codes. We propose the “Harmony Model” (Figure 1) as a means of illuminating how South Asians’ choose and prioritise lifestyle changes during their recovery from a myocardial infarction. The model illustrates how participants consider potential lifestyle changes against a background of competing demands. The needs of family members, religion and cultural and social norms are factored into a complex decision making process that we have termed shared priorities. The participants subsequently only adopt those lifestyle changes that do not conflict with these shared priorities as their ultimate goal is to maintain harmony.

#### **4 Discussion**

Much of the evidence that supports the delivery of cardiac rehabilitation is underpinned by social and behavioural science theories, including the trans-theoretical model (Prochaska & DiClemente, 1983), self-regulatory model (Leventhal, Meyer & Nerenz, 1980) and the health belief model (Rosenstock, Strecher & Becker, et al., 1988), all of which consider an individual’s decision making in isolation, failing to recognise the social context in which the change occurs. Astin and colleagues’ (2014) qualitative synthesis goes some way to highlight the role that family and healthcare staff play in this process. The authors describe how patients reassess their past, present and future lives following a cardiac event. They suggest that patients initially review their self-identity and contend with a range of emotions prior to accessing, interpreting and integrating advice. Patients subsequently seek support from others to aid their recovery before reaching a “new normal”. Whilst the recognition of external forces is a step forward, these findings and their proposed model of recovery largely represents a Caucasian viewpoint, which differs from the experience described by South Asian participants.

The participants in this study describe how they attempt to balance a multitude of health, social, religious and cultural factors. They explain how their desire to make lifestyle changes were weighed against these additional needs and whilst they reference a desire to adhere to health advice, they provide examples of where this was not possible and where other needs were prioritised. Whilst health professionals perhaps viewed the participants in isolation, the participants themselves adopted a more holistic approach, considering an array of competing needs. The research team viewed this process of contestant evaluation and prioritisation as an attempt to maintain harmony in the participants’ lives, attempting to juggle the numerous factors that affected theirs and their families’ lives and reaching a decision that maintained these relationships even when this decision conflicted with the health advice provided.

Consequently, we propose a “Harmony model” (Fig 1) that recognises the importance of faith/religion, a collective identity and patronage of the family be adopted to support lifestyle change in South Asian patients. Only when healthcare professionals gain a deeper understanding of the influence of these

factors and the conflict that ensues when South Asians attempt to maintain harmony within their lives will long term behaviour change be possible.

Some of what was previously known should be reconsidered in light of this deeper understanding of this journey. Webster, Thompson & Mayou (2002) reported that South Asians' held a fatalistic attitude towards recovery from myocardial infarction relating to the 'will of God'. Patel, Phillips-Caesar & Boutin-Foster (2012), in a qualitative synthesis reported that within the complexities of the South Asian belief structure, patients tended to gravitate towards supernatural factors or humoral imbalances rather than considering environmental or personal lifestyle as causal factors. Contrary to these findings, in this study, beliefs about fate were tempered by an individual responsibility, challenging simplistic notions of fate. South Asians' concept of fate is better understood as a confluence of inner and external forces, which directs individual outcome. Understanding how and why they choose as they do, helps to contextualise their behaviour as they attempt to make lifestyle changes.

The influence of family members and cultural or religious identification upon an individual's ability to initiate and maintain lifestyle changes has long been recognised (Stolley and Fitzgibbon, 1997; Greenhalgh, Collard & Begum, 2005; Netto, Bhopal, Lederle, Khatoon & Jackson, 2010; Kennedy, Rogers & Bower, 2007). Astin et al (2014) and Darr et al (2008) noted that family and friends can enable or constrain lifestyle changes. These findings are supported here where we found that family members and the cultural and causal belief systems provided an important value based framework upon which the participants based their decisions, superseding advice provided by healthcare professionals. Though the participants recognised the changes as an integral approach to prevent the recurrence and progression of the disease their decision making was rooted within a larger and more intertwined, encompassing milieu.

Walters and Simoni (2002) identified cultural practices and the inclusion of family and community as protective factors that can buffer, or mediate, negative mental and emotional outcomes in the face of stress and trauma. Numerous cultural factors including but not limited to, involvement in cultural activities, and spirituality have been linked previously to positive mental and behavioural health outcomes (Carlson and González-Prendes, 2016; Schiefer and Krahé, 2014). Furthermore, Guo and Harris (2016) reported that the experience of making adjustments and adopting lifestyle changes following acute coronary syndrome were influenced by subjective life experiences in conjunction with individual, sociocultural and environmental contexts. Nunes et al (2016) showed that this is important even with native as well as immigrant populations. However, this literature focusses on the South Asian's journey towards the desired behaviour, failing to provide the context within which the behaviour change took place and why such choices are made in the face of personal health risk.

Therefore, whilst much is known about the role of family, religion and cultural influences, this current study provides a substantive theorisation of how these multiple influences interact to produce 'shared priorities'. In cultures that are, predominately individualistic, the self is characterised by self-defining attributes such as self-reliance, independence, autonomy, and self-efficacy, which serve to fulfil personal goals. They hold 'self' apart from the group and are responsible for their own decisions and actions. However, within South Asian communities with collective orientations, the interdependent construal is the norm where the self is part of a community – defined relative to others and is concerned

with dependency and reciprocity. Against such a background, it is easy to understand how South Asians may place the well-being of their family/community, over the attainment of individual health goals and wellbeing. We therefore question the merit of models of behaviour change that privileges individual action without giving due consideration to the wider milieu in which the behaviour changes occur.

If we are to improve clinical outcomes a paradigm shift is needed for a profound ontological understanding of a person as a 'node in a network' - where the person is not a whole, only a part, and becomes whole only in connection with others. What can be inferred is that in the South Asian community, it is not the lack of motivation or 'self-efficacy' that inhibits them making lifestyle changes, but the inability to make it a reality lies in the intricacies and complexities provided by the web of family and community. If that is the case, then we may have to reconsider some of the primary tenets of behaviour change interventions, for example – self-efficacy.

The notion of self-efficacy (Bandura 1977) sits within the western paradigm, which presents the decision making as a highly individualised autonomous act. However, for South Asians, decision-making and the outcomes are seen as intimately connected, for them decision-making is a collective act. Thus individual lifestyle changes may compromise their family and communal relationships. When 'self-efficacy' conflicts with the group norms, family-centric activities are prioritised, and it is less possible to be 'compliant' (with structured programs such as cardiac rehabilitation). Mol (2008) argues that such conflicts are alien to healthcare professionals who have been schooled in the Western individualistic philosophy resulting in tensions within the therapeutic relationship. For South Asians, the choice is not a matter of defining and asserting their 'self' or 'individuality' but to maintain the harmony and create community, deferring to the choices of people that are familiar and trusted. Consequently, possessing an understanding of sociocultural and religious values, coupled with family dynamics and an acknowledgement that these concepts are valuable assets, will support South Asian people with coronary heart disease to initiate and maintain lifestyle changes.

## **5 Conclusion**

Research into South Asian health behaviours has mainly been driven by the increased rates of lifestyle related diseases in the older South Asian population. Yet, how they manage lifestyle change and the processes of negotiation or concessions made to cultural values and beliefs remains unexplored. Findings from this study provide a novel insight into the complexities that surround South Asian participants' lifestyle choices after myocardial infarction and highlight that South Asian perceptions and sociocultural attributes may conflict with individualist motivations and current models of self-management. These findings show that peoples' experiences of health and illness are underpinned, not just by biographical issues, but by wider social and cultural complexities and affiliation. Without a working knowledge of the finer 'motors' that drive lifestyle choices and the conceptual structures within which they find meaning it seems unlikely that current interventions will be successful across all ethnic groups. There is therefore considerable scope to adapt current interventions and evaluate a new model of care which considers the context in which the lifestyle changes occurs as a means of improving the uptake of services and behaviour change. The originality and usefulness of this grounded theory lies in revealing the underpinning rationale for lifestyle modification among South Asians – showcasing the

complex web of socio-cultural and familial milieu in which the individual choices take place – highlighting the choice as a shared, rather than individual act.

### **Limitations of the study**

Whilst this study addresses an important gap in the current literature, it has some limitations. Patients' ethnicity and religion data were frequently omitted from the healthcare records meaning that some eligible patients may not have had the opportunity to participate in the study. Another limitation is the relative homogeneity of the sample in marital and educational status. This means that the views of participants who lived alone or were from a lower socio-economic group may not have been represented. In addition, the study is based upon a retrospective self-reporting method of data collection and is therefore reliant upon recall. Future research that was designed to recruit participants immediately post myocardial infarction would enable a series of interviews to be undertaken at the very time when participants were navigating their way through their new life and would provide an interesting comparison. That said this study addresses an important gap in the research literature as little is known about how South Asian people choose and prioritise the lifestyle changes after an acute myocardial infarction.

### **What is already known about the topic?**

- South Asian patients are at increased risk of coronary heart disease but tend not to engage in cardiac rehabilitation
- Behaviour change models emphasise the importance of empowering the individual to facilitate change
- Previous studies have suggested that cardiac patients explore their individual identity whilst moving towards a new normal

### **What this paper adds**

- The way that South Asians' choose and prioritise lifestyle changes during their recovery from first myocardial infarction is influenced by family, individual beliefs and the need to conform to social and religious norms.
- This concept of 'self-efficacy' that underpins behavioural theory and informs the structure and content of cardiac rehabilitation should be re-considered for the South Asian community, as the 'self' is perceived as relational.
- A new model of 'shared priorities' should be applied to ensure that cardiac rehabilitation programmes for South Asian people are culturally competent.
- Advice to facilitate lifestyle changes must be aligned with the family goals, cultural priorities and their causal and religious beliefs.



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