An Exploration of the Experiences of South Asian Patients as they Navigate the Cardiac Rehabilitation Journey.

Abstract

Background/Aims: South Asian individuals are at a greater risk of developing Coronary Heart Disease. Cardiac Rehabilitation reduces the risk of future cardiac events, yet uptake is low from South Asian populations. This study explored South Asian patients' understanding and experiences of cardiac rehabilitation.

Methods: This qualitaitve semi-structured study sought to recruit a purposeful sample of 36 eligible patients, of which 6 participated in an interview that explored their experiences and perceptions of cardiac rehabilitation.Data were analysed using inductive analysis.

Results: Three themes are presented: Starting the Conversation; Expectation versus Reality; and Meeting Our Needs. Patients perceived cardiac rehabilitation as additional support rather than a fundamental part of care, resulting from a lack of information during the in-hospital phase. Moreover, they considered the content of CR programmes to lack cultural sensitivity, influencing both attendance and perceived relevance.

Conclusions: Nurses must promote cardiac rehabilitation during the acute phase of recovery whilst considering the South Asian patient's beliefs, perceptions, knowledge, and cultural acceptance of cardiac rehabilitation. Invitations to attend, and cardiac rehabilitation delivery must be personalised, accounting for cultural influences on lifestyle.

Keywords

Cardiac rehabilitation, Coronary heart disease, Cardiovascular disease, Patient experience, Qualitative, South Asian patients

Key Points

- South Asian patients did not view cardiac rehabilitation as an important aspect of cardiac care.
- Patient's expectation of cardiac rehabilitation differed from reality and as such was not prioritised.
- Promotion and delivery of cardiac rehabilitation must account for cultural influences.

Reflective Questions

- Reflect on your experiences of sharing information with patients in a culturally flexile manner.
- What Motivations should be addressed in order to promote uptake in, and adherance to, cardiac rehabilitation programmes in ethnic minority populations?
- What strategies are implemented in practise to allow for cardiac rehabiliation content to be more culturally sensitive?

Introduction

Coronary heart disease (CHD) accounts for 8.9 million deaths each year[1]. However, there is evidence[2-10] that South Asian people, whose ethnicity originates from the Indian subcontinent, are at greater risk of developing CHD, suffer earlier disease onset[11,12], and experience higher rates of death[13] compared with white people. Moreover, when presenting with symptoms, South Asians experience treatment delays at both the pre and post-hospital stages[14], are less likely to call for an ambulance when experiencing chest pain[15] and access angiography and revascularisation[16,17] less often during hospitalisation.

The causes of this disparity are considered both biological and non-biological. Studies have reported a higher prevalence of traditional CHD risk factors that are attributed to the typical South Asian lifestyle. They are often reported to engage in low levels of physical activity[18-22] and consume a high saturated fat diet,[23] which is prevalent regardless of acculturation[24]. In addition, South Asians are at greater risk of psychosocial maladaptation[2,25] with depression and stress playing a role in their increased risk of acute myocardial infarction[2] and possibly influencing their ability to manage a healthy lifestyle post-event.

In an attempt to reduce the risk of future cardiac events, patients are invited to attend a cardiac rehabilitation programme[26,27]. European Guidelines recommend that this be a "multi-factorial and comprehensive secondary prevention intervention, designed to limit the physiological and psychological effects of cardiovascular disease, manage symptoms, and reduce the risk of future cardiovascular events"[28] The British Association for Cardiovascular Prevention and Rehabilitation recommends that programmes adopt a biopsychosocial approach, which is culturally appropriate and sensitive to individual needs and preferences. The efficacy of such programmes has been demonstrated in a plethora of studies reporting

reductions in mortality, hospital readmissions and healthcare costs, with improved exercise capacity[29], quality of life and psychological well-being[30-32]. However, South Asians experience low referral rates, and subsequent low uptake and adherence[33-38]. Several factors attempt to explain this[39], however, these data collection periods pre-date the wholesale use of Primary Percutaneous Coronary Interventions (PPCI)[40]. The increased availability of PPCI at high volume centres improve clinical outcomes[41] and reduce length of stay[42-44], but additionally reduce the time available to deliver in-hospital cardiac rehabilitation, potentially limiting the opportunity for patients to be invited and discuss their understanding of the programme.

It is, therefore, imperative that we gain a contemporary understanding of the experiences of South Asian patients as they navigate their cardiac rehabilitation journey.

Methods

Participants

This study was granted ethical approval by London-Stanmore ethics committee. Eligible patients were identified through three cardiac rehabilitation services across the North West of England. Cardiac nurses screened for a purposive sample of South Asian patients reporting a potential study sample of n36. Those who refused to participate did so on the basis of a lack of time or interest. The patients who expressed interest in participating (n12), were subsequently contacted by telephone by a female South Asian post-doctoral researcher able to communicate in several languages, and the purpose of the study was explained.

Five eligible patients declined interview participation (not wishing to discuss cardiac rehabilitation/participate in research), and one was uncontactable, resulting in a final sample of six (Table 1). In line with ethical standards, we have not disclosed individual participant characteristics to protect anonymity.

Data Collection

Semi-structured telephone interviews were undertaken with each participant between April-July 2018. Written consent was obtained prior to the commencement of each interview and all interviews were digitally recorded. The interview topics explored patients:

- experiences of hospital stay
- invitation to attend cardiac rehabilitation
- the programme itself
- any changes they felt would improve the programme

Based on our previous research with this population[45], we additionally explored their family's involvement (see interview schedule: supplementary files). Interviews were undertaken by author TP, two of which were conducted in Gujrati, and lasted an average of 24.65 minutes (range 17.50-34.05). Recordings were transcribed verbatim and where required, translated into English.

Analysis

An inductive analysis was adopted using a constant comparative-based approach[46] with continuous reference to original transcripts. Each interview was read for understanding and individually coded. The analytical coding process was thorough, inclusive, comprehensive, and informed by Grounded Theory methods[46] using NVivo software[47]. Coding outputs were compared and discussed for context and meaning, then merged to create concepts, identify connections and finally, construct categories.

Findings

Three categories were developed through an iterative process and reflect South Asian participants' engagement, or lack thereof, in cardiac rehabilitation.

Category 1: Starting the conversation

Starting the conversation explored the variation in participants' recollection of the mechanisms through which the option of attending cardiac rehabilitation was raised and the subsequent impact of these experiences on their decision to attend.

The timing of the offer of cardiac rehabilitation was crucial to subsequent uptake. If introduced too early while patients were psychologically navigating competing clinical information, the message was often lost. Participants had a vague recollection of being invited prior to discharge:

> *"I think I was asked… about attendance." (P2).*

Additionally, patients often rejected the offer when contacted post-discharge, demonstrating no recollection of discussing the programme while in hospital. The 'out of the blue' invitation phonecall from an unknown healthcare professional was perceived negatively from the patients, subsequently diminishing the importance of rehabilitation:

> *"I didn't get told anything else, so I said no and put the phone down as … I was not interested.".*

For all those who participated, the invitation was provided by a health professional in person, pre-discharge, and was perceived as an instruction, reinforcing the importance of attending:

> *"…she said that this cardiac rehabilitation programme will really help, so she was the person that gave me … she made me go to … for this…".*

Whilst participants may have acknowledged cardiac rehabilitation existed, they were unable to explain why they were advised to attend. In some instances, no information was forthcoming despite direct requests:

> *"When I asked they didn't give any detail at all…" (P2).*

Some appeared confused about what cardiac rehabilitation was and assumed that details relating to medical needs, such as the guidance offered surrounding medication routines, was part of it:

> *"…they advised me and gave me booklets and guide books, something like that … they gave me medicine and explained how to take it, making the spray…"*.

This lack of mutual understanding caused confusion when patients attended classes. An example of this was a patient who had experienced complications arising from dehiscence of their leg wound. When recalling the conversation regarding the importance of attending, they assumed that this would provide support for his most pressing concern, namely his leg wound. This led to frustration on the part of the patient upon attendance:

> *"…how the wound is healing, you know, they never monitor properly. No support … nothing from support. I don't know who to complain really…".*

Lack of information during the acute admission period resulted in perceived disjointed care, where rehabilitation was not considered as an integral part of recovery, but rather a voluntary 'add-on'.

Language and communication challenges, mainly when the patient's English was limited, also interfered with the process of inviting an individual to cardiac rehabilitation. Patients were often reliant on friends or family to interpret key messages. Translation of key clinical information was prioritised, such as informing patients about their clinical diagnoses:

> *"My brother, he can speak and understand English. The doctor spoke to him … translated it to Gujrati to me that I had an heart attack and this is why it has happened…".*

The importance placed on imparting clinical information and assessing understanding was further highlighted when discussing preparation for discharge:

> *"…they gave me medicine and explained how to take it, making the spray and …. She explained and she asked me again twice...".*

The same rigour, however, was not applied when informing patients about the importance of subsequent care and the relevance of cardiac rehabilitation. When questioned about the information provided, a participant stumbled before eventually suggesting that rehabilitation entailed being informed about good exercises:

> *"They explained to me that you get all kinds of … there are …. they gave me information … what exercises are good…".*

This reflects the experience of all the participants; no one was able to recall any information provided about the content of the programme:

> *"They didn't talk very much about it…. When I asked they didn't give any detail at all...".*

Category 2: Expectation versus reality

The second category provides some insight into participants' understanding of the cardiac rehabilitation process. Universally, the participants expectations differed significantly from reality. This may have been a consequence of the lack of information provided and/or retained as described in category 1. For some, this translated to low expectations, with little consideration to the content or benefit they may receive:

> *"No, I didn't expect it at all actually…".*

All participants initially assumed it would consist of basic health promotion advice, but little else:

> *"I was initially thinking that it was just exercising and maybe some food advice or something, but there were many more other things…"*.

For some, attendance did not meet expectations:

> *"Its just a waste of time. They tell you to do this and do that, go home, thank you very much. Nothing much.".*

Furthermore, misapprehension of the concept of cardiac rehabilitaion meant that patients who received basic health promotion messages on the ward saw no benefit in participating:

> *"It was easy because they told me what to eat and what to drink (on the ward) so it was okay for me (I didn't need to attend)".*

For those who attended, perceived benefits often didn't relate to content, rather to aspects such as confidence building:

"The benefits… I get confidence … so I really improved".

Whilst the sessions were generally perceived as informative, the participants expressed concern that content was too generic and some felt as though the diversity of the group meant a personalised programme was undeliverable:

"…they explained all these things in a general way, but South Asian food is very oily and stuff, so they're not talking especially…".

Language barriers were again identified where classes were offered in English:

"I went to cardiac exercise it was good, if you know English…".

Some participants were able to take a family member to translate:

"My daughter recorded everything on her phone … they explained everything to my daughter really well…".

However, this wasn't always feasible.

Difficulties in maintaining the changes taught at classes were highlighted by all attendees:

"But the thing is when you come home you cannot do the same as what you did in the classes you get lazy. That is where the problem is.";

"That's the only problem, we don't listen. We agree with everything but we don't do it.".

Whilst behavioural change is complex, a number of specific practical issues were identified, making application more difficult. Referring to food preparation, one participant suggested,

"The way you do it in programme you cannot do it at home…".

Suggested changes also resulted in difficulties engaging in social activities:

"I still go to weddings, but I eat from home, a bit tasteless but I don't go for food. I found it really hard.".

Therefore, maintaining changes was difficult.

Category 3: Meeting our specific needs

Category 3 provides an insight into the barriers that patients experienced and the perceived requirements for cardiac rehabilitation by this population.

A number of practical difficulties were identified. Language was highlighted by many as problematic:

"…they should have more interpreters for people … like, Asian people".

And written information was perceived as a poor substitute:

"Yeah, if you read them. Most of the people don't read them".

In addition, participants felt that there were cultural barriers in place that were impeding their ability to modify their lifestyle, and reported feelings of being targeted, when group facilitators who were catering for a mix of patients highlighted the ills of South Asian lifestyles:

"…because maybe some people think that they are targeting South Asian people.".

Despite being made aware of these risks, they were not provided with relevant alternatives:

"I just went along and you know what, he told me, told me off…".

Lack of relevance was explicitly highlighted in areas that culturally diverge, in particular, food preparation "They are generally on the food, but not specific to the South Asian people…";

and gender-specific activities:

"Separate for women and separate for men…".

The community culture of food accentuated the difficulties in making dietary changes:

"…he was cooking everything for me, like my diet had more salt and other things … it was a big help for me.".

Many participants relied heavily on family or community members for support:

"My wife has been doing everything for me, I am lucky, she's a good woman…";

"My sister-in-law came and did the housework for me and she helps me..

And whilst this support was welcomed, it highlights that the patient is attempting to navigate individual behaviour change with an inter-dependent family network:

"What choice do I have? If you want to eat, what choice do you have?".

When asked what participants felt should be included in cardiac rehabilitation programmes, they sought advice that would enable them to modify their behaviour while respecting their traditional lifestyles:

> *"…advice from a south Asian point of view and explain to people that you can enjoy the same thing by cooking another way…".*

Dietary advice, specific to the South Asian population also featured highly:

> *"I'd like to see these person go there to tell us more information tell us more healthy eating lifestyle".*

Whilst the influence of family support has been highlighted, some participants also noted the role of community education:

> *"And they've been telling it in mosques, everybody…".*

Discussion

The categories developed reflect participants' experiences of engaging with cardiac rehabilitation. Timing the offer of cardiac rehabilitation and greater explanation of the benefits was important, with a need to embed and anchor these discussions within discharge planning. A mismatch between participants' understanding of the role of cardiac rehabilitation, and reality was apparent, suggesting a lack of preparation or understanding of the concept, and several barriers to engagement were identified. In particular, a perceived lack of culturally sensitive content and delivery prohibited engagement.

A Cochrane review and meta-analysis assessed 26 randomised controlled trials evaluating interventions to increase enrolment, adherence, and completion of cardiac rehabilitation[48]. A sample of the included trials applied strategies to increase enrolment in under-represented groups of women and older people. However, ethnicity has not been a focus of such interventions (and for most of the studies, patient ethnicity was not reported), highlighting a dearth of evidence to support the care of this population. This study provides insight into the

cardiac rehabilitation experiences of South Asian patients and should inform future enrolment and adherence interventions within this cohort.

Our findings can be interpreted and are discussed below with reference to the Capability, Opportunity and Motivation Behaviour (COM-B) model[49] which is used to identify behaviour foci in which to intervene. The model would suggest that for a patient to participate in a particular Behaviour (B), in this case cardiac rehabilitation, both physical and psychological Capabilities (C) are required to use social and physical Opportunities (O) via Motivators (M) that are reflective or automatic. The latter three components are interactive and offer a feedback loop between these and the target Behaviour.

Participants in this study who recalled being spoken to by a health professional during their acute stay were more likely to enrol in cardiac rehabilitation. Those who received a follow-up call post-discharge, or did not recall being invited, perceived it as voluntary, with limited reference to any benefits to health outcomes or quality of life. This finding is in line with that of Santiago de Araújo Po et al.'s review[48], which reported an increased likelihood of cardiac rehabilitation enrolment when messages were delivered directly by a health professional face-to-face. Grace et al.[50] also reported that in-patient advice increased subsequent enrolment and adherence, hence, two-way communications may enable exploration of the benefits-costs and processes associated with the referral. However, this study reports that invitations to enrol during the acute stay did not guarantee subsequent uptake. Capable patients should possess sufficient knowledge surrounding the programme, but our findings suggested this to be limited, with participants alluding to a disconnection with any invitation to attend.Therefore, patients may have been deterred due to low levels of appreciation or health literacy. This was quantified in a previous audit of cardiac rehabilitation uptake, where although 91% of the study population received information (either written or verbal), only 6% reported any subsequent understanding.[51] In a systematic review involving CHD patients, Lima de Melo Gisa and colleagues[52] concluded that those possessing low levels of health

literacy were more likely to be older, male and from a non-white ethnic group. These data highlight the importance of reinforcing health messages and stresses that patients be supported in processing imparted information.

South Asian patients' health beliefs, perceptions of cardiac rehabilitation and alignment of rehabilitation to specific cultural and lifestyle practices appeared to influence their engagement. Psychological interpretation and cultural beliefs presented as being the biggest influences, subsequently impacting healthcare decisions. The acute cardiac nurse has an important role to play in providing patients and their families with information that is culturally meaningful, enabling them to make an informed decision about their future health. Whilst traditionally the first phase of cardiac rehabilitation commenced during the hospital phase of recovery, thus enabling the nurse to provide such explanations[53], the most recent British guidelines[54] fail to highlight the importance of this first stage. Moreover, the European guidelines[55] suggest that the core components of rehabilitation should be delivered in the outpatient setting, except where the patient is deemed high risk. Whilst community cardiac rehabilitation is essential to long-term behaviour change, our findings demonstrate that a lack of culturally meaningful input at the earlier stages of the journey devalues the message, and in doing so reduces the likelihood that patients will attend.

Moreover, perceptions of social support are also relevant to patients' Motivations. Those who attended rehabilitation reported feelings of being 'judged' and 'singled out' as high risk in lifestyle factors, but were provided limited management support. This aligns to previous work which highlights the challenges South Asian patients experience balancing rehabilitation recommendations against the reality of acknowledging specific cultural, religious and family needs[45]. Where social Opportunity dictated that individual needs were not informing their care, cardiac rehabilitation was not deemed appropriate lifestyle support. Hence, Motivation to enrol and adhere was driven by both Capability and Opportunity.

The role of cultural adaptation in delivery of health messages is of utmost importance where behaviour change advice is culturally and individually patient-centred. This was not the participants reported experience. They described a sense of detachment in that attendence was not relevant or tailored to their needs and expressed no real acknowledgement of the value of cardiac rehabilitation in the management and future prognoses related to their health. Therefore, the way information is communicated about rehabilitation should be sensitive to psychological interpretations; where South Asian patients do not ‘feel’ the healthcare services are personal, relevant and culturally acceptable, then uptake and attendance will be low. They may have misconceptions about cardiac rehabilitation, and their expectations, previous experiences of healthcare, and cultural beliefs may all contribute to their openness to accept a referral.

Limitations

We acknowledge that the participant sample size is small. It is particularly noteworthy that of a potential 36 eligible patients who were contacted by the healthcare team, only 12 initially agreed to discuss the study and subsequently only 6 consented to complete a recorded interview. Rather than considering these patients a 'hard to research group'[56], this recruitment challenge may add to our insight of South Asian patient experiences. Given the findings of this study, we suggest that declining to participate may be an extension of unaddressed Capabilities, Opportunity and Motivation to engage with, and discuss cardiac rehabilitation.

We are not claiming data saturation; nevertheless, the data offers valuable insight into the experiences of South Asian patients relative to cardiac rehabilitation, which has not recently been explored. We present a conceptual schema[57] providing insight grounded to a specific cohort, in a specific situation, influenced by specific social processes. For theoretical development, further investigations exploring the system process of invitation and referral, and the health professionals experiences of enrolling and providing cardiac rehabilitation to South Asian patients is warranted.

Conclusion

The evidence that is available on enrolment, adherence and completion of cardiac rehabilitation is scant and of low quality. Hence, further exploration is warranted. Cardiac rehabilitation should consider population needs, including those of ethnic minority groups such as South Asian patients who form a significant cohort of the UK population. To encourage attendance and completion, invitations and content need to target patients' psychological Capability to challenge myths and consider the relevance of the programme to both their cardiac condition and their culture. Interventions should address patients' Capabilities including their knowledge, confidence and cognitions regarding their health, their Opportunity, investigating the cultural milieu affecting rehabilitation perceptions, and finally, their Motivations, exploring the groups beliefs regarding cardiac conditions and seeking treatment as well as emotional perceptions such as any associated anxiety or fear to attend.

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