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Access to cardiac rehabilitation among South Asian patients by referral method: A qualitative study

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Abstract

OBJECTIVES—South Asians (SA) suffer an increased prevalence of coronary artery disease. Although cardiac rehabilitation (CR) is effective, SA are among the least likely to participate. 'Automatic' referral increases CR utilization and may reduce access inequalities.

METHODS—This study qualitatively explored whether CR referral knowledge/access varied by referral method among SA patients. Participants were SA cardiac patients from Ontario hospitals. Each hospital refers to CR through one of four methods: automatically through paper or electronically; through discussion with allied health professionals (liaison referral); or through usual referral at physician discretion. Data was collected via interviews and analyzed using Interpretive-descriptive analysis.

RESULTS—Four themes emerged: 1) importance of pre-discharge CR discussions with health care providers; 2) limited knowledge of CR; 3) ease of referral process as facilitator of CR attendance; 4) participants' need for personal autonomy over decision to attend CR.

CONCLUSION—Liaison referral was perceived to be the most suitable method of referral for participants. It facilitated communication between patients and providers, ensuring improved CR understanding. Automatic referral may be less suited for this population, due to reduced patient-provider communication.

Keywords

Cardiac Rehabilitation; South Asian; Referral; Qualitative

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Introduction

Individuals of South Asian origin (i.e., from India, Pakistan, Sri Lanka and Bangladesh) have an increased risk of coronary artery disease (CAD) development and cardiovascular death (Anand et al., 2000; Bhopal, 2004; Gupta, Singh, & Verma, 2006; McKeigue, Miller, & Marmot, 1989). Although cardiac rehabilitation (CR) is effective in improving prognosis after a cardiac event, there is growing evidence that certain ethnic populations, including South Asians, are among the least likely to participate in such programs (Banerjee, Gupta, & Singh, 2007; Mochari, Lee, Kligfield, & Mosca, 2006; Oldridge, 1988; Tod, Wadsworth, Asif, & Gerrish, 2001; Yancey, 2004). This lower rate of participation is concerning, given the increased prevalence of CAD among South Asians (Wilkinson et al., 1996).

CR attendance is influenced by numerous factors, including referral practices. With usual methods of referral to CR, such as referral from a physician, there is generally low participation in CR - approximately 15–30% of eligible patients (Bunker & Goble, 2003; Cooper, Jackson, Weinman, & Horne, 2002; Grace et al., 2002). Following automatic referral, however, participation in CR has been shown to increase to approximately 50% (Grace, Evindar, Kung, Scholey, & Stewart, 2004b; Grace et al., 2007). Studies have suggested that automatic referral, whereby CR referral is a standard order for all eligible patients, not only increases the number of referrals made to CR but may reduce inequalities in access for ethnocultural minorities (Dafoe et al., 2006; Grace, Evindar, Kung, Scholey, & Stewart, 2004a; Smith & Harkness, 2006). However, there is a dearth of literature examining methods of referral as a means to increase CR access among ethnocultural minorities, let alone studies examining the poor CR attendance of South Asians (Jolly, Greenfield, & Hare, 2004; Tod et al., 2001; Yancey, 2004).

Through key informant interviews, three ways hospitals operationalize automatic referral have been identified (Krepostman, Scholey, Stewart, & Grace, 2005): universal electronic; universal paper; and liaison. Under universal electronic referral, all patients are referred to CR, unless ineligible based on clinical practice guidelines (Canadian Association of Cardiac Rehabilitation, 2004), via an electronically generated referral in their electronic health record. Referral data is printed out automatically in the CR program and there has been pre-approval by physicians for these referrals to be generated automatically where indicated. The universal paper referral category is similar in process, with the exception that the referral is paper-based. In the liaison referral category, an allied health professional discusses CR with individual cardiac patients. Referrals are not universal and require a physician signature; however, the opportunity for two-way communication between patients and providers increases and may be integral to encouraging CR enrollment. These three methods of referral, in addition to usual referral (at the discretion of the specialist or generalist), are examined in this study. The purpose of the present study was to qualitatively explore whether CR referral knowledge, access, and attendance vary among South Asian cardiac patients following different methods of referral.

Methods

Participants

This study employed qualitative research methods in exploring thoughts, opinions and ideas about CR and methods of referral to CR among South Asian cardiac patients. Participants were identified and recruited from a larger study evaluating referral methods to CR, the Cardiac Rehabilitation care Continuity through Automatic Referral Evaluation (CRCARE) study (Link et al., 2007). Consecutive inpatients with an underlying diagnosis of acute coronary syndrome (ACS) were recruited from eleven hospitals across Ontario, Canada. Each hospital operates under one of the four referral categories described above.

As part of a baseline survey for the CRCARE study, patients self-identified their ethnocultural background. Those who self-identified as South Asian and spoke English and/or Punjabi (as the first author is able to communicate in both English and Punjabi) were eligible for this study.

Design and Procedure

Ethics approval for the CRCARE study and this qualitative sub-study was obtained from each participating hospitals' ethics boards. Patients recruited and consenting to participate in the CRCARE study and who fit the selection criteria for this sub-study were contacted after discharge by telephone to determine interest in participating in the telephone interview. Participants were asked for consent to record the interviews to allow for later translation and transcription. Interviews were conducted in English or Punjabi depending on the participant's preference. Interviews followed a semi-structured interview guide with open-ended questions and probes to ensure relevant issues were examined such as participants' awareness and knowledge of their CR referral; beliefs of why they were or were not referred to CR; discussions with hospital staff about CR; and intentions to participate in CR (see table 1 for interview guide).

Data Analysis

Interviews were translated, if necessary, and transcribed verbatim to allow for analysis of content. Drawing upon Interpretive-descriptive analysis, interview transcripts were coded by the first author (KG) using NVIVO software (QSR International Pty Ltd, 2006) to identify major themes through the use of exploratory inductive reasoning. Themes were captured within a subjective perception and generated into an interpretive description capable of informing clinical understanding (Thorne, Kirkham, & McDonald-Emes, 1997). NVIVO software facilitated coding and analysis of interviews, searching and retrieving of related segments and sub-themes, and theorizing. Data transcription and analysis were concurrent with data collection, and involved inductively documenting emerging themes around differences in CR referral knowledge, awareness and intentions to participate; comparisons between referral methods; and opportunities for and barriers to CR access and participation. Concurrent data analysis (i.e. analysis of the previous transcript prior to the next interview) facilitated the generation of new questions for subsequent participants. Once overarching themes were developed, each theme was analyzed in regards to similarities and differences between referral methods.

To ensure the transparency of results, techniques of memo-ing to describe codes and transcripts was used, checks of the representativeness of the coding and categories were also implemented by discussing coding strategies and examples of quotes with other authors. To ensure the trustworthiness of analysis, processes such as extensive use of direct quotations from themes which they were derived from, and use of systematic coding were incorporated. In efforts to reduce bias, a second researcher (YWL) independently reviewed the coding tree and transcripts after the first iteration of coding for each transcript had occurred.

Results

Sixteen South Asian participants with a confirmed ACS diagnosis were interviewed. Fifteen (93.8%) participants were male, and the mean age of participants was 62.6 ± 7.9 years. The majority of participants (n=11, 68.8%) were born in India, with 2 (12.5%) born in Bangladesh, 2 (12.5%) born in Sri Lanka and 1 (6.3%) born in Uganda. Three participants (18.8%) had been in Canada for less than 10 years, 3 participants had been in Canada between 11–20 years, 2 participants had been in Canada between 21–30 years, and 7 participants had been in Canada for more than 31 years (this data for one participant was missing).

Four participants from each referral category were interviewed and theme saturation was achieved. Four central themes influencing patients' decision to attend CR emerged from analysis of interview data. Each theme and their relationship to referral method is described below.

1) Pre-discharge CR Discussions with Health Care Providers

Across all referral categories, participants noted that there was a general lack of discussion about CR with patients during their hospital stay. In the liaison referral category, however, some discussion about CR in the hospital was often evident although these discussions typically took place with health care professionals (i.e., nurses and/or physiotherapists) other than physicians. As liaison referral is not universal, one participant was not referred to CR and had not discussed CR with a health care provider.

As part of the automatic referral methods (universal paper and universal electronic), some study participants had been given information about CR from English language documents (i.e. letters/pamphlets) while in hospital, but had not discussed CR with health care providers in person. One participant referred through this method argued that:

> [Health-care providers] were not too emphatic about it… They do not, you know, emphasize on how important it is. It is just like any other instruction set that they give you… the only suggestion that I have is that they could make it kind of, you know, a little more emphatic and highlight the benefits of the program.

Another participant, referred through the universal electronic method, noted: “The only time I heard about [CR] was through the letter which I received, probably a week to ten days ago.” A few of the participants referred through usual methods had CR discussions with physicians or allied health professionals. However, similar to general cardiac populations, usual referral does not often result in CR utilization among South Asian patients, as many in this category were never initially referred to CR, as discussions about CR were non-existent. One participant noted, “I did not enroll, I did not go to any CR centre, nothing. I do not know anything about it.” Another participant initiated discussion about CR with his physician only after hearing about CR program benefits from friends and other patients.

Overall, participants from all referral categories stated that there was a lack of discussion with health care providers about CR while in the hospital. Furthermore, many study participants acknowledged that they desired to have CR discussions with physicians in particular. While liaison referral is not universal, some patients were not referred to CR; however, those who were referred were able to have in-hospital discussions regarding CR.

2) Patients’ Limited CR Knowledge

Many study participants who had not yet attended CR were unaware of the comprehensive nature of services offered by CR programs. Among those who were aware of CR, they often only spoke about the exercise component of CR programs. As one participant in the liaison referral category noted: “It involves walking and some exercises they give you and they monitor you while it is being done.” Some patients were altogether unsure of what CR programs offer, and this was especially evident in the two automatic referral categories (universal electronic and universal paper). One study participant, referred through universal electronic methods, hesitantly acknowledged that: “Well, I guess there are exercises and I have a first meeting on the 8th of May, and I don’t know, I guess they will be explaining it further.” For this participant, the first meeting is an important opportunity to gain information about CR; however, this in turn, highlights the lack of information received by the participant from health care providers during his hospital stay.

As noted above, patients in the usual referral category who were not referred to CR had not heard of CR while in the hospital or what it could offer and, oftentimes, obtained their knowledge of CR from other patients, family or friends who had undergone rehabilitation. One participant noted: “Well, I was told about it by the other patients who had the same bypass surgery, that you can go to rehab. So I asked my doctor and he recommended me to rehab.” For other study participants, the current cardiac hospitalization was not their first and, thus, they had an understanding of CR from previous attendance in CR. Both these situations highlight the haphazard level of awareness or knowledge about CR and CR programs among patients.

3) The Ease of Referral Process as a Facilitator of CR Attendance

The majority of participants in the universal electronic, universal paper and liaison categories believed the referral process was well facilitated. With liaison referral, patients had heard about CR while in the hospital, and then had follow up contact with the CR program upon discharge. Many of these patients were initially contacted by the CR program post-discharge to book an assessment appointment. One participant, referred through the liaison method stated:

> The process is already facilitated. They are proactive in terms of getting in touch with you. They already know that you have been to the hospital, have had a heart incident.

In some cases, when patients received a letter about CR, they were given instructions to call the CR program themselves to book the initial appointment. This was true for one patient in the liaison category and three of the four patients in the universal electronic category. One patient in the latter referral category pointed out that: “I called them to make an appointment. I got a letter, and the letter said ‘Contact them and make a date,’ so I called”. The major difference between referral categories was knowledge of CR prior to the referral, where most patients referred through liaison referral had a prior awareness of CR through in-hospital discussion.

4) The Need for Personal Autonomy over Decision to Attend CR

Where patients were referred to CR, the decision to enroll was deemed a personal choice. Patients who had enrolled in CR, or were intending on enrolling, did so because they believed it was a means of obtaining information and improving their health. Although there were external factors that influenced the patients’ decision to attend CR, such as medical advice, suggestions from friends, family or other patients, the underlying perception was that the final decision was largely the patient’s own choice. One individual argued:

> No, that’s solely my decision. I’m a conscious being and I understand the last time I could have done more. But this time, now that I’m off [work] for a good time, I should be able to make use of that program.

Participants who would not be attending CR believed it was not necessary. The majority of these patients said they could exercise at home or at a gym. One participant, referred through the usual method of referral, stated:

> Why I go? That’s the question. I talk to my doctor, he said, ‘Doesn’t need, up to you.’ So, I just control myself. I don’t eat much. I have good health. I do exercise, I join club here.

Furthermore, some patients who previously participated in CR thought they already had the necessary information and could exercise on their own.

Although many participants argued that the ultimate decision to participate in CR remained in their hands, many also identified barriers that made their decision to attend CR more complex. These barriers included the distance of the CR program from home, lack of transportation, the timing of the program with regard to work conflicts, and finally the wait time associated with commencing some CR programs. Interestingly, the concern over wait times only arose with those participants referred to CR via the universal electronic method. One such participant noted: “If they were to call me today, I would go. This is the proper time to do it, not after 4 months”. This theme highlights that the decision to attend CR among this population seems to be a largely personal choice. However, obtaining accurate information about CR programs could be beneficial to influence the patients’ decision to attend CR.

Discussion

Given higher rates of CAD and lower rates of CR participation found among South Asians in the literature (Banerjee, Gupta, & Singh, 2007; Mochari, Lee, Kligfield, & Mosca, 2006;

Oldridge, 1988; Tod, Wadsworth, Asif, & Gerrish, 2001; Yancey, 2004), this study qualitatively explored the effect of referral method on South Asian patients' awareness of and access to CR in Ontario. After analysis of themes and exploring differences in the themes based on referral category, results indicate that liaison referral may be the most suitable means of referral for South Asian cardiac patients and may result in the greatest positive perceptions/awareness of and access to CR. Specifically, this method of referral allows for greater two-way communication to occur between patients and providers. This may enable a better patient understanding of the comprehensiveness of CR and what it entails, while clarifying misconceptions about CR, and addressing barriers patients may perceive. However, such referrals should be universal in order to ensure all eligible patients are referred.

Liaison Referral

In the liaison category, patients had the opportunity to have one-on-one discussions with health care professionals, often nurses and physiotherapists, about CR. Hence, patients had an awareness of CR, even though this may have been limited to the exercise component. The opportunity to talk with a health care provider during a liaison referral may be related to greater intent to participate in CR. During a liaison referral, health care professionals have the opportunity to discuss the concept of CR, the benefits of participation in CR, and actual CR programs close to home (i.e. frequency of visits, duration, etc.). As such, this method of referral maybe particularly effective in increasing CR participation among South Asians. Furthermore, liaison referral offers an opportunity to address a potential obstacle to CR participation – language barriers. Health care providers fluent in the patient's first language may be able to communicate more effectively about CR with patients who experience barriers to communicating in English.

However, as noted above, South Asian patients may prefer to have these discussions about CR with physicians rather than allied health professionals. Indeed, previous research has shown that South Asian patients are receptive to physician advice (Muthu Kumar et al., 2004). Considering the strength of a physician's referral is one of the strongest predictors of CR attendance among cardiac patients generally (Daly et al., 2002), encouraging physicians to make referrals may be effective in increasing CR participation among South Asian cardiac patients. Given rates of physician referral under usual referral conditions, this however is unlikely to be universally practiced by physicians. Discussions with nurses involved in the patient's care may prove to be a useful alternative.

Automatic Referral

Among patients in the two automatic referral conditions, universal electronic and universal paper, similar issues often arose. For instance, few patients had the opportunity to discuss CR with allied health professionals while in the hospital. The majority of these patients either had little or no discussion about CR while in hospital or had obtained their information from pamphlets written in English. This latter point is concerning since, although patients in this study spoke and understood English, this could represent a barrier for non-English speaking South Asian (or other ethnocultural minority group) patients because they may be unable to fully understand CR information provided.

Some patients reported that they were unaware a referral for CR had been made until they received a letter in the mail at home after discharge. Pre-discharge discussions may increase CR awareness and the likelihood of attendance among patients (Arthur, 2006). At the same time, recall of in-hospital discussions may be difficult for patients due to the volume of information patients are given, anxiety, sedation, or other medication side effects. Thus, pamphlets patients can take home may represent a useful supplement to improve recall of these discussions. Development of multi-language pamphlets for dissemination in hospital along with outreach to and recruitment of ethnoculturally diverse and multilingual health care providers should be explored.

Patients in these two automatic referral categories also perceived the referral process as well facilitated. Some patients were initially called by the CR program to book an intake appointment. However, some received letters from the programs instructing them to call the program. The latter approach may reduce CR enrollment because initiation of booking an appointment is dependent on the patient. This approach is often used in programs with capacity issues, as discussed below.

Patients in the universal electronic condition reported wait times to access CR as barrier to attendance. In an article reviewing access to CR, Dafoe et al. (2006) recognized that through automatic referral “CR programs may exceed capacity, resulting in longer wait times” (Dafoe et al., 2006). Concern over wait times among patients in this study included: anxiety that delay in accessing care would negatively affect recovery or the effectiveness of CR after waiting, and worry that return to work would coincide with access to CR, thus, precluding their participation. As such, CR sites which institute universal automatic referrals need to consider the impact on service capacity and implement means to ensure patients have access to their services without lengthy delays. Dafoe et al. recommend seven to 60 days as an acceptable wait time for various diagnostic categories. Increases in funding for CR services would ensure timely access to this evidence-based care following universal referral.

Usual Methods of Referral (i.e. at physician discretion)

Finally, similar to the general cardiac population, this means of referral does not often result in CR utilization among South Asian patients. For example, it was within this referral category that some patients were never referred for CR, contrary to recommendations in clinical practice guidelines [23]. Compared to automatic referral, usual referral is at the discretion of the physician and, subsequently substantially fewer patients are actually referred to and enroll in CR when compared to automatic referral methods [16]. Though a few patients had heard of CR from health care professionals while in the hospital, discussions about CR with other patients, friends or family were a major source of information for patients in this condition.

Barriers to CR

Beyond the actual referral to CR, the decision to attend CR was perceived as a personal choice. As indicated in the results, patients would like discussions about CR while in the hospital. This information can be used to educate a patient’s decision to attend CR. As such, inhospital discussions can be tailored to overcome misconceptions about CR and address some of the barriers patients perceive when deciding to enroll in CR. For instance, two patients who decided not to attend CR said they believed it was not necessary to attend, as they engage in exercises independently at home or had already attended CR for a previous cardiac event. With one-on-one conversation about CR, there is an opportunity to clarify misconceptions, discuss the educational and other comprehensive components offered, the benefits of participation, and convey that exercise is undertaken in a medically-supervised environment.

Limitations

Caution is warranted when interpreting the results from this study. Results cannot be generalized to non-English or Punjabi speaking South Asians. Moreover, given the nature of the qualitative design and the lack of literature in this area, replication is warranted with a more heterogeneous population. Furthermore, because patients from other ethnocultural groups were not interviewed, it is unclear whether, or by how much, South Asian participants have differing perspectives on CR referral compared to other ethnic groups. Finally, the lack of women in this study warrants more exploration of CR participation among South Asian women.

Conclusion

While results from this first qualitative study on CR referral methods indicate that liaison referral may be optimal for referring South Asian cardiac patients, further investigation is needed. Clearly there are advantages to liaison referral including improved communication, however referrals are not universal and a provider fluent in the patient’s first language may not be available. After follow-up assessments, the larger CRCARE study will enable quantitative examination of the rates of CR referral, enrollment and participation by referral method.

In conclusion, results indicate that the opportunity for discussion with health care providers and the ease of the referral process may contribute to CR attendance among South Asian cardiac patients - all characteristics apparent in liaison referral. Overall, our preliminary findings highlight the importance of CR discussions pre-discharge between South Asian patients and healthcare providers, such as nurses. These conversations can increase the level of CR awareness among South Asian cardiac patients, and may also eliminate misconceptions about CR programs. Thus, nurses should be encouraged to engage patients in discussion about CR, as such opportunities for CR education are important for patients when making the personal decision to attend CR. Implementation of these methods, along with proactive facilitation of CR referrals at the health system level show promise in ensuring greater uptake of these life-saving services.

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Table 1

Semi-structured Interview Guide

1.	Where were you born?
2.	What religion do you practice?
3.	Have you heard of Cardiac Rehabilitation (CR)? • If yes, what have you heard about it, and how did you hear about it? • See if they have an accurate awareness of CR services
4.	Do you know whether you were referred to CR while you were in the hospital for your cardiac condition? • Description of the program, positive/negative tone, discussion of the benefits, barriers, facilitators, family / shared health care decision making, self-esteem/efficacy, health beliefs, attitudes towards health care system, support during/after decision, knowledge of CR – friends, relatives that participated
4a.	If YES, they were referred: • What type of discussions took place about CR with your health care providers? • Description of the referral process • Have you attended CR yet? Or did you sign up? Why or why not (barriers)? • What were the most important factors that influenced your decision? • Will you continue attending CR? Why or why not?
4b.	If NO, they were not referred or do not know whether they were referred • Did you ask your doctor/nurses about CR? – If so, tell me about the discussion. – Did you have ideas about what the program may be about? • Would you have gone if you knew about CR? Why? Why not? • What recommendations were made to you by doctors/nurses for ways to reduce your heart risk?
5.	What do you think were the barriers that made it hard for you to access heart services (i.e. CR) to help your recovery, or to follow through on recommendations to improve your heart health?
6.	Do you have any other thoughts or comments on the heart health care services you received, and/or how they can be improved? Do you have any thoughts on how being South Asian might affect your access to cardiac rehab?