
Referral to and discharge from cardiac rehabilitation: key informant views on continuity of care

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Abstract

Objectives To assess the system-level barriers and facilitators of continuity of care from acute care to cardiac rehabilitation (CR), and from CR discharge to follow-up with primary health care providers. **Method** Semi-structured individual interviews with 24 key informants including CR staff, research scientists, policy makers, cardiologists and other doctors from a regional to international level were conducted regarding the processes of referral to and discharge from cardiac rehabilitation. Key informant interviews were audio taped, transcribed, and imported into QSR N6 software for Grounded analysis. **Results** Themes that emerged related to communication, referral and discharge processes, health care provider practices, inter- and intra-institutional relationships, and alternative models of delivery to improve continuity. **Conclusions** Ramifications for enhancing referral of patients to beneficial CR services and follow-up by primary care providers to ensure maintenance of functional and health-related gains are discussed.

Introduction

Substantial health risks continue following coronary events and procedures (Kannel *et al.* 1979; Law *et al.* 2002), and cardiac rehabilitation (CR) improves subsequent prognosis (Oldridge *et al.* 1988; Jolliffe *et al.* 2001). However, most research demonstrates low enrolment and inequality in access to CR (Barber *et al.* 2001; Grace *et al.* 2002). While the literature copiously presents patient factors related to low utilization (Daly *et al.* 2002), there are also health system and doctor factors at play (Suter *et al.* 1992;

Pashkow & Dafoe 1998; Grace *et al.* 2004a). For instance, because of the increasing use of day revascularization surgery, shorter hospital stays, and frequent movement of cardiac patients from one system of care to another (Anderson & Helms 2000), the continuity between hospital care and CR programmes can be disjointed. Moreover, doctor encouragement (Ades *et al.* 1992a) has been shown to be a strong motivating factor in patients' decisions to participate in CR, but questions remain with regard to reasons for low rates of doctor referral (Grace *et al.* 2004a).

Even more disconcerting is the lack of concentration on post-CR care. Clinical attention should be paid to, for example, preserving functional gains achieved during CR, and maintaining positive health behaviour changes such as physical activity and smoking cessation (Jolly *et al.* 1998). Primary health care providers may benefit from constructive discharge summaries regarding care provided during CR to ensure appropriate long-term follow-up. Taken together, these health system issues can lead to discontinuity (Reid *et al.* 2002) of cardiac care, which may ultimately affect patient health outcomes. The objective of this study was to assess the system-level barriers and facilitators of continuity of care from acute care to CR, and from CR discharge to follow-up with primary health care providers.

Methods

The key informant method of inquiry guiding this study was qualitative and descriptive. Following informed consent, semi-structured interviews (see Table 1) were conducted by the first author in person (where possible) or by telephone. Interviews were approximately 40 minutes in length. Each interview began with a broad question to focus the interview, facilitate establishment of rapport, and encourage participants to speak openly. Each participant was asked to describe the CR referral process at the CR site where they worked, or with which they were most familiar. Then broader questions related to our key focus concerning health system factors related to continuity between acute care, CR and primary care were posed.

Table 1 Semi-structured interview guide

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1. What are the barriers and facilitators to referral from acute care to cardiac rehabilitation?
 2. What are the barriers and facilitators to continuity in discharge from cardiac rehab to primary care follow-up?
 3. How do you think continuity of care could be improved within your organization?
 4. How do you think the continuity of care could be improved regionally?
 5. Based on our discussion, what would be the main actionable message that you would like to convey regarding continuity of cardiac care and rehabilitation?
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Key informant interviews were audio taped, transcribed verbatim (except to preserve anonymity), and imported into QSR N6 (QSR International Pty Ltd 2003) software. This software was used to facilitate coding and analysis of the 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. Concurrent data analysis facilitated generation of new questions for subsequent key informants. Themes were coded and analysed using Grounded analyses (Glaser & Strauss 1967; Strauss & Corbin 1990; Bartlett & Payne 1997). When all interviews were complete, the first two authors re-indexed the data by code. To ensure the transparency and validity of the results, an audit trail was used, incorporating the techniques of memo and overall checks of the representativeness of the coding and categories. In addition, participants who agreed received a summary of overall results in order to validate our findings.

Participants

Key informants were sought to represent a broad spectrum of the cardiac health system from a regional to international level, and were identified by co-authors through a review of authors of salient journal articles, and discussion with experts in the field. Following approval from the University Health Network Research Ethics Board, the purposive sample of key informants including CR professionals, research scientists, doctors and policy makers were contacted by email and invited to participate in an interview about continuity of cardiac care. Key informants provide an expert source of information and insight regarding a given issue owing to their position in work or community, their knowledge and their communicability (Marshall 2003). Twenty-four informants consented to participate: 12 were in key roles at a CR programme, 3 were policy-makers, 4 were research-scientists, and 5 were doctors also engaged in clinical research (1 family doctor, 2 cardiologists, and 2 internists). Saturation was achieved.

Results

Qualitative analysis of interviews resulted in the emergence of a core category, namely vertical and

horizontal pathways to continuity of cardiac care, with five main themes: communication, referral and discharge processes, health care provider factors, inter- and intra-institutional relations, and alternative models of service delivery.

Theme 1: communication

Communication was identified as an integral factor in continuity of care and referral to CR. Three main parties form the essential communication pathways: the patient, the health care providers (from both the acute care and primary care settings), and the CR programmes.

Communication between health care providers and patients

It became apparent that good communication between patients and health care providers ensures that patients are aware of the options available to them for the management of their care following a cardiac event or procedure. Key informants perceived that patients often would not attend CR programmes if they were not encouraged to do so by their health care providers. This, coupled with a lack of awareness of the existence and benefits of such programmes, results in low enrolment rates.

... I think if people are made more aware of it I think a lot of patients would be interested. Not all obviously – some no matter what you do they're not going to change their lifestyle and they won't be interested, but I think a lot of patients would be. (doctor)

... Clearly one of the things that's happening is that the health staff puts that [referral] in the computer and never tells the patient about it, and so, during the three or four day hospitalization where they get shuttled to catheterization labs, nuclear, and echo and G-d knows what – Somewhere along the way they see some poor little rehab nurse who comes and gives them a pamphlet saying, 'exercise will be good for you,' and you know, 'we'll try and call you once you get home', kind of type thing, and they can't tell that from the ... menu that they get from the dietician every day ... and then when the rehab staff calls them afterwards they have absolutely no recollection that they were seen in the

hospital ... and they don't tend to enrol because their doctor didn't tell them that they were supposed to go ... (doctor)

Communication among CR programmes and health care providers

In general, good communication must be clear, open and multidirectional. All parties should be able to navigate their way through the health care system while being aware of the services available to them along with their benefits. As was described during the interviews, when CR programmes and doctors do not have a solid, trusting relationship with open lines of communication, the patient ultimately suffers.

I think part of the problem is that we're just not made aware of where we can get good access to it [CR] and I think we all know it exists but you know there's a low level of awareness of CR facilities that serves the ... community. (doctor) ... we do regular mailings to family physicians and specialist physicians about our program ... so we get referrals from them as well. (CR)

So I would say in the last couple of years we've been getting a lot of referrals from community physicians and I think that's all about communication. The patients go back looking better, feeling better, telling the doctor that they like it there, and him referring more and more patients to the rehab ... I think that marketing is a big key ... if you have someone to speak for your program in the bigger meetings, in bigger executive meetings, then you have a fighting chance. (CR)

Communication between a patient's various specialty providers is also key. For example, the family doctor reported that CR referral had been discussed with an eligible patient, and that the patient had subsequently been directed to their cardiologist who generally makes the referrals. However, the informant noted that the cardiologist was not as 'interested' in making the referral, and inferred that the patient did not want to make the effort, and ultimately did not attend CR.

Theme 2: referral and discharge processes

Managing continuity of cardiac care involves the processes of referral to and discharge from CR

programmes. These entry and exit points represent critical moments in the flow of a patient's care, which are dependent upon actions by the health care provider, CR programme and patient.

Referral

Enrolment in CR programmes is highly dependent on the mechanics and timing of the referral as well as patient preferences. As demonstrated by key informant statements below, there was wide variability in referral processes between sites.

I think for us within the hospital setting it works quite well, but what happens is then you know, people are discharged...getting information...from primary healthcare practitioners or family physicians or their cardiologists' offices can be a bit of a pain. (CR)

...all that has to happen is that the physician has to sign a referral form. So, we have a standardized form that is distributed – we hope widely – and we just simply receive it by fax. (CR)

in terms of how a referral is generated...It's variable depending upon the service. If you look at the surgery side, every patient is approached about the program by the inpatient physiotherapy team... (CR)

Timing of the referral was also viewed as key to enlisting patient interest in participating.

...the referral is only generated if the patient agrees to participate at that point in time [while in hospital]... There are certainly drawbacks to that because they might not be in that frame of mind at that point in time to make that decision. (CR)

Discharge

The discharge process should promote the maintenance of CR gains in health behaviours, functional capacity, and risk reduction through self-management and a supportive relationship with a long-term health care provider. However, this can be a challenge in rural and remote communities (Canadian Institutes of Health Information 2003).

30% of our population don't have a primary care provider...one of the problems we had

was that people were very dependent on the program. People got into the program and stayed there for years. (CR)

It is essential for a patient's various health care providers to be aware of their patient's progress through the CR programme and recommendations for continuing risk reduction. When discharge summaries (i) do not contain necessary information for providers, (ii) are not utilized by providers, or (iii) are not sent at all, the potential for appropriate follow-up of the cardiac patient is diminished.

... years ago you know, we used to have a discharge report that went to the family physician and we tried to get some feedback on that and typically just, it wasn't read... and we haven't had a massive call for this... we'll be happy to put something together but typically at discharge there's nothing sent to the family physician. (CR)

Theme 3: health care provider factors

Health care providers are an essential link between patients and CR programmes. When a CR programme can gain the trust of local and regional health care providers, the resulting promotion of and referral to CR can positively affect patient enrolment.

Facilitators to referral

Patients put trust in their health care providers and rely on them for advice, information and education regarding all aspects of their health. As such, cardiologists, internists, family doctors, nurses and allied health professionals have a strong influence on whether or not patients will attend a CR programme following hospitalization.

We have an advanced practice nurse liaison... and she contacts our clinic directly and gives us names... (CR)

If you look at the surgery side every patient is approached about the program by the inpatient physiotherapy team, which are part of our team – so the inpatient physios, social workers, and dieticians are part of our rehab program... So they on behalf of the program do tell every patient... (CR)

We have a full-time cardiac educator on the floor, so that's advantageous for us because basi-

cally she says to them, 'you've been referred to the Cardiac Wellness Centre, this is what it's all about ... if you want I can take you down there for a tour and see it ...' You know, it's very convenient for our nurse educator to do that and because she also is a part of our multidisciplinary team ... she's very gung ho about the program just as much as everyone else is so she makes sure that ... people get on board ... (CR)

Barriers to referral

The absence of a CR endorsement can be associated with a patient's disinclination to attend a CR programme. Many doctors are aware of CR and its benefits and do refer eligible patients to nearby programmes; however, there are some practitioners who generally do not refer their patients.

... actually I must confess that I rarely if ever refer patients to CR ... I don't think I've ever referred anyone, I must confess, even though I do see patients with heart failure ... and heart attacks. (doctor)

... like I said, even though right now it's automatic referral, we do have physicians telling the clerks not to send that referral. (CR)

Theme 4: inter- and intra-institutional relations

Funding/policy and territoriality issues came to light as factors integral to the existence and sustainability of CR services. Funding/policy refers to basic financial and legislative issues facing CR programmes and referral to CR. Territoriality refers to struggle between health care providers and CR programmes over the management of patient care.

Funding/policy

The provision of secondary preventive services to cardiac patients requires stable resources. Currently, most health systems do not directly fund CR programmes, and therefore these programmes strain to cover their basic costs each year. Many CR programmes rely on funding from hospital budgets, which continually suffer from cutbacks and shortages. Others must find additional alternative sources of income in order to survive and remain viable.

The funding has always been catch-as-catch-can. (CR)

... we realized that you know, that was a great start but we wanted to build a real program and there were some cardiologists in the area who were also interested in that so they managed to get some funding from ... [non-profit organization] and we were able to get this program off the ground ... so fundraising is the way to go ... and we're just starting up a - what we call a pre-CR program ... that's being heavily subsidized by a pharmaceutical company who is trying to do some initiatives, you know, good will. (CR) ... even though we're not meeting our target numbers, but we're spending money, we're running at a deficit because we're having to return money to the [government] Ministry ... because we have an inefficient model. (CR)

Governments have reviewed the state of the evidence supporting CR, but have further questions before developing policy to support the full cardiac care continuum.

We kind of look at what are we going to do to collect some further evidence. We would like to look at it from a health system perspective because first reaction is CR costs a lot and we have to go beyond that to be able to justify the costs ... (policy)

... I think we want to be very careful [about] what gets funded with public dollars, that we don't inadvertently assume responsibility for what should be a personal decision around lifestyle. (policy)

Territoriality

Some CR informants perceived that health care providers held certain attitudes toward CR, such as scepticism of the benefits of CR or fear that they will lose their patients.

... there's some doctors who don't want to refer to our program because they're afraid that our doctors in our program are going to steal their patients away ... Well we know that can't happen, but ... those patients don't end up getting referred. (CR)

... the doctors like to see that. They like to see how ... their patients are doing and that's why they will continue to refer if they know that we're not stealing their patients and also knowing that it's done something for them. (CR)

Theme 5: alternative models of service delivery

Access to CR can be hindered by many factors including distance and transportation barriers, inconvenient programme hours for participants who work during the day, and in the case of rural or remote patients, lack of a doctor to make the referral. To reach a wider range of patients and potentially reduce costs, some programmes have developed innovative models of service delivery.

Automatic referral

Automatic referral can be described as the systematic non-manual enrolment of all eligible cardiac patients from acute care to CR. This has been proposed to ensure that all patients receive guideline-based care.

We're actually thinking of implementing a system where when the physician fills out the prescription and discharge note, that they will actually have a box 'rehab' and they will tick if they want a referral, right on that box. (CR)

So every patient that comes in and receives surgery – has surgery at this site – an order is generated to go to CR. (CR)

Although automatic referral has increased referrals where instituted, it has not necessarily increased the number of enrolments.

... you know, people don't like being automatically referred to nothing. So our secretary spends considerable amount of time when she calls them [patients] to come to the program. They don't even know that they were referred! (CR)

... this automatic referral thing has been a real, you know, mixed blessing ... it has worked to a degree and we have gotten a whole lot more referrals ... but then if we look at the number of people who actually enrol, it didn't go up very much. ... clearly one of the things that's happening is that the health staff puts that in the computer and never tells the patient about it ... and so it's been basically from that end not a terribly successful program ... (doctor)

Health informatics and CR

In response to funding and geographic constraints, some sites have instituted home-based pro-

grammes to ensure continuity of care. Some CR programmes are also experimenting with telephone and Internet-based monitoring of these home-based patients.

... the home exercise program is a program for people that feel they're motivated and that really are back at work and cannot come to a supervised – structured or supervised – program during the day ... (CR)

... we've also been trying to set up – although we're just in the initial stages of this – for folks that are farther away we're trying to establish a shorter stay coming directly to the program and trying to support them with home programs in their community a bit more. (CR)

... we have had some discussion you know, about setting up some kind of either Internet-based or telephone monitoring for those individuals ... I would love to do it because I think there's a need out there, but I don't have the resources to do it. (CR)

... the new thing that we're – actually I've just gotten some money to do – is more Internet-based. So these programs are actually run through the Internet, which provides, I think, much better access and patients like it better. (research scientist)

Discussion

This study identified a complex web of factors affecting continuity of cardiac care. By examining this continuum from the lens of the health system rather than the patient, some novel factors have been raised. Clearly, CR programmes have implemented highly variable CR referral and discharge processes that are locally viable. It was evident that innovative models of service delivery have been created to address gaps in referral, but unfortunately relatively less attention has been paid to discharge and maintenance.

Similar to findings from previous qualitative work with a sample of 15 CR staff in the UK (Tod *et al.* 2002), the principal theme is communication. Interesting to note were the gaps in communication between specialty doctors providing care to a given cardiac patient. Research demonstrates that improving communication between these providers can

result in improved outcomes such as lowered re-admission rates, increased use of evidence-based medications, and improved left ventricular function when compared to solo care (Ahmed *et al.* 2003). Improving communication between CR programmes and governments, among CR programmes (through regional, national and international organizations), between CR programme, specialty providers, and family doctors involved in patient care, and finally promoting two-way communication between providers and patients will require continued efforts to ensure continuity in the primary and secondary care interface.

Many key informants raised the issue of systematizing the referral process or ensuring it is non-manual to increase utilization and promote equity in access. While automating processes of referral is assumed to be a panacea, sites that had instituted such processes described it as a 'mixed blessing'. First, CR staff may become overloaded with referrals to process. Then, despite this labour, patients may neglect to attend their intake appointment. Second, the significant increase in referrals may lengthen the wait list for CR, so that patients cannot access services in a timely fashion. Third, automatic referral supersedes personal doctor-to-patient endorsement of CR, yet this doctor encouragement has been shown to be integral to patient willingness to attend CR (Ades *et al.* 1992b; Grace *et al.* 2002). Fourth, the significant increase in referrals holds important financial ramifications for these CR programmes. Automatic referral does ensure ample referrals, but meeting the service needs of these patients requires adequate funding. Most CR programmes have finite financial resources and may not be able to meet the demand for service from all eligible CR patients [particularly if we are currently serving less than 20% of those eligible (Cardiac Care Network of Ontario 2002)]. Finally, automatic referral requires 'buy-in' from cardiologists, cardiovascular surgeons, internists and family doctors in a given region. Although this is a worthy goal, it can be quite difficult to achieve. While preliminary empirical results support automatic referral as a means to increase utilization and equitable access (Grace *et al.* 2004b,c), future research is required to empirically compare referral processes and their effect on patient uptake of CR.

Structurally, many of the obstacles related to service capacity and demand. While many key informants identified alternative models of service delivery to address problems of utilization and sustainability, it is clear that our resource-scarce health systems cannot meet demand for the growing number of cardiac patients (Dafoe 2000; Cardiac Care Network of Ontario 2002). Moreover, in most health regions there is no dedicated funding for CR services by governments or private payers, and many policy makers expressed hesitation toward funding population-wide preventive interventions. Within this state of affairs, a means to stratify cardiac risk, ensure all eligible high-risk patients are referred to CR equitably, and that low-risk patients are offered lower cost services [e.g. home-based CR (Miller *et al.* 1996)] is warranted in future research endeavours.

The limitations of the current study relate to the generalizability of results. Our purposive sample of key informants is unlikely to represent all views. However, informants demonstrated a willingness to express opinions that were not always politically sensitive, and the quality of ideas expressed and richness of information varied between informants.

Key informants identified modifiable barriers to the CR referral process are as follows: (i) improving communication among doctors and CR programmes, (ii) automating processes to reduce reliance on haphazard referral, (iii) minimizing territoriality, and (iv) increasing doctor awareness of CR sites. It is imperative that we communicate across service providers and health systems to address these barriers. In conclusion, multifactorial interventions are required to address the patient, doctor and health system barriers to referral to CR. More attention should be paid to linking CR discharge and follow-up to ensure patients maintain their functional gains, quality of life, and risk reduction behaviours.

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