

Complexities of patient choice in cardiac rehabilitation: qualitative findings

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Exploring the complexities of patient choice in cardiac rehabilitation

Abstract

Aims: To explore the complexities of patient choice in cardiac rehabilitation through an evaluation of a pilot home-based UK programme.

Background: Little is known about the patient experience of being offered a choice of cardiac rehabilitation programme or how patients make their cardiac rehabilitation choices.

Methods: Interviews conducted with 35 patients and 12 staff delivering the pilot programme during 2006-2008 and a questionnaire survey of all sites using the pilot programme. Data are also derived from an audit of the programme's uptake and outcomes compared with all of the other cardiac rehabilitation programmes taking part in the National Audit of Cardiac Rehabilitation

Findings: While staff surveyed said that all patients were given a clear choice between home and hospital or community based programme, this choice was less clear cut in the patient interviews. When choice was offered, the choice of a home-based programme was often based on constraints rather than being a positive choice. Obstacles to patient choice included: lack of information on which to base a choice; inadequate systems of referral; insufficient appropriately trained staff; restricted opening times; the location of services and restrictive socio-economic factors (inflexible working hours, access to transport).

Conclusion: Evidence-based cardiac rehabilitation interventions need to be offered to patients so that they can make informed choices, Nurses need an

awareness and commitment to finding out about and overcoming obstacles that impede patient participation. Only in this way will it be possible to fulfill the calls in national and international clinical guidelines for 'individualised' or 'menu-based' programmes tailored to specific patient needs

Keywords

Cardiac rehabilitation, qualitative research, patient choice, nursing, service evaluation.

Summary Statement

What is already known about this topic

- In many countries it has been noted that patients are not offered cardiac rehabilitation following an acute episode of a heart disease, despite recognition of it as a life saving service that should be available to the majority of cardiac patients.
- Providing patients with a choice between carrying out their rehabilitation programme at home instead of in hospital has been shown to increase patient uptake (Dalal et al 2007).
- Little is known about the patient experience of being offered a choice of cardiac rehabilitation programme or how they make those choices.

What this adds

- Based on the findings of an evaluation of a pilot home based cardiac rehabilitation, this paper tells us more about the context and contradictions experienced by patients when making choices about cardiac rehabilitation.

Implications for practice/policy

- Enabling patients to make informed choices about cardiac rehabilitation services starts with making evidence-based interventions available to them.

- An awareness and commitment among nurses to finding out about and overcoming obstacles that impede patient participation is required, in order to move away from pre-determined one-size-fits-all programmes towards the 'individualised' or 'menu-based' programmes tailored to specific patient needs stressed in national and international clinical guidelines.
- Obstacles to patient choice include: lack of information on which to base a choice; inadequate systems of referral; insufficient appropriately trained staff; restricted opening times; the location of services and restrictive socio-economic factors (inflexible working hours, access to transport).

Introduction

Coronary heart disease (CHD) is a leading cause of death and chronic illness in western post/industrialised nations and its incidence is predicted to rise internationally (WHO 2007). Cardiac rehabilitation (CR) is a life saving service (Taylor et al. 2004); yet in many western countries, referral and uptake to cardiac rehabilitation remains much less than optimal, with rates among eligible patients of less than 30% reported in the United States (Ayala et al. 2003). In the United Kingdom (UK) the majority of patients that could benefit are not offered the service (National Audit of Cardiac Rehabilitation [NACR] NACR 2007; 2008). When services are made available, the provision of choice between home and hospital based cardiac rehabilitation services has been shown to increase patient uptake (Dalal et al 2007). Using data from an evaluation of a new pilot home based CR service, this study examines the patient experience of being offered a choice of programme and how patients make their choices.

Background

Coronary heart disease (CHD) is a leading cause of death and chronic illness in the UK (Allender et al 2008). The most recent Cochrane Review (Taylor et al 2004) evidences the powerful effect that CR can have on survival. Patients who were randomised to attend CR had a 26% lower death rate over the next 2-5 years. The UK's National Service Framework for Coronary heart disease (DH 2000) recognised CR as a life saving service, saying that it should be available to the majority of cardiac patients.

A recent editorial summarised the two main models of Cardiac Rehabilitation in the UK (Bethell, Dalal, Lewin 2008: 3-4). Most common is a hospital based period of supervised, group, out-patient exercise-centred rehabilitation. The patient starts on the programme at around two weeks after angioplasty, four weeks after myocardial infarction (MI) or six weeks after heart surgery. A course of exercise training is supplemented by education about heart disease, risk factor monitoring and rectification, stress management and relaxation training. Some programmes are offered in community based settings rather than in hospital.

The other widely used model of CR is the Edinburgh Heart Manual. This uses written and audio-taped materials and is supervised by phone or through home visits with a specially trained “facilitator”, usually a nurse or physiotherapist. The Edinburgh Heart Manual has been evaluated on a number of occasions in randomised controlled trials and the evidence suggests that this home-based ‘self-management’ programme can deliver benefits equal to conventional hospital or group based rehabilitation programmes (Dalal et al 2007; Jolly et al 2006 & 2007).

A British Healthcare Commission survey (2005) on coronary heart disease estimated that fewer than 40% of the patients who could benefit were offered a CR programme; a figure confirmed by the National Audit of Cardiac Rehabilitation (NACR 2007; 2008). Although there is as yet no empirical data (Daly et al 2002). people from ethnic minorities, the elderly, women, smokers, the depressed and people in rural locations have all been suggested as

groups that are under-represented in cardiac rehabilitation programmes (Beswick et al 2004).

Tod et al (2002) carried out a qualitative study of the barriers to access for MI patient in South Yorkshire. This revealed limited service capacity and limited choice of venue and that information for patients about CR and its potential benefits was inadequate. The services that were available were subject to long waiting lists leaving patients feeling abandoned. CR was hospital based with exclusion criteria on the grounds of age, exercise tolerance, post infarct angina and heart failure. The provision did not meet the needs of those who did not want to travel, had problems with transport or found groups socially stressful, lacking in privacy or aimed at older, younger, or more or less ill patients. Those with childcare, paid work or other family responsibilities found it difficult to attend. A lack of adequate interpretation services also precluded choice and access.

A study by Dalal et al (2007) showed that one way to improve uptake is by offering patients a choice of a home-based or a hospital based programme; extending this choice improved uptake to more than 85% with a slight majority choosing home-based rehabilitation. The UK National Health Service (NHS) is currently engaged in a drive to expand patient choice with a view to making choice, "a core feature of a responsive NHS in the 21st century" (DH 2009). The NHS constitution gives patients the right to make choices about their NHS care and to information to support these choices. In 2008 a patients' prospectus was published detailing Government plans to, "extend to all

fifteen million patients with a chronic or long term condition access to a choice of 'active patient' or 'care at home' options - clinically appropriate to them and supported by the NHS" (DH 2009). The National Audit of Cardiac Rehabilitation (NACR) reveals that in 2007-2008 31.5% of patients who attended CR carried out some part of their rehabilitation at home. It is not known how many had an entirely home based programme (NACR 2009).

Little is yet known about the patient experience of being offered a choice of CR programme. Wingham et al (2006) conducted a small qualitative study to identify the factors influencing the choice patients made when given the option of hospital or home-based CR after MI. This study was linked to the Dalal et al (2007) research discussed above. Those patients who preferred hospital-based CR emphasised supervision during exercise and sought group support, they were willing to make travel arrangements and believed they lacked self-discipline. The home-based group were self-disciplined, disliked groups and preferred their CR to fit in with their lives.

Recently the British Heart Foundation carried out a pilot study of a home based exercise and education programme, The Road to Recovery Programme (R2R). The pilot commenced in 2006 and it was issued to any of the 36 programmes that were in receipt of a BHF / Big Lottery award. The R2R package consisted of an exercise programme on DVD or video, a patient-held information binder with diary pages and a relaxation tape or CD. After an introductory session which included a fitness assessment, patients exercised at home with weekly telephone support. The R2R programme

became part of the menu delivered by teams who were already providing CR services. As with all CR services in the UK it was provided free of charge to patients. This paper is based on the findings of an evaluation of the R2R pilot and what they tell us about the patient experience of being offered a choice.

Methods

Road to Recovery (R2R) evaluation

The R2R evaluation had two elements: a qualitative component to evaluate the R2R home-based programme and an additional multi-language resource from the patients' perspectives; and a quantitative component to audit the uptake and outcomes of the programme. The qualitative aspect of the evaluation focused on patients' views and recommendations about the programme gained from their experiences of participation. This information was derived from 35 in-depth interviews. A qualitative approach was chosen for its potential to provide powerful and detailed information about the context and contradictions that people with chronic clinical conditions experience (Dunderdale et al 2005; Campbell et al 2003). 12 health professionals who delivered the programme were also interviewed. Data were collected over a 24 month period in 2006-2008.

The investigation conforms with the principles outlined in the Declaration of Helsinki (Br Med J 1964;ii:177). Following the guidelines for NHS service evaluation (National Research Ethics Services NRES formerly COREC), the

field researcher negotiated ethical clearance with the Research and Development Department for each participating NHS site. The field researcher obtained an honorary contract with the participating PCT where necessary.

Sampling and profiling

The interviews took place at 5 BIG CR sites chosen to achieve a geographical spread of R2R sites in the North, Midlands and South of England.

CR population data were provided by the National Audit of Cardiac Rehabilitation (NACR) which is part of the Central Cardiac Audit Dataset (CCAD) programme run by the NHS Information Centre (NACR 2008). NACR data were analysed by the NACR statistician to profile the patients who attended R2R and other phase III CR programmes and to examine the outcomes achieved. Note that numbers returned to the NACR database may not represent all of the patients who actually attended CR in the UK (NACR 2008).

Numbers receiving the R2R programme peaked at 127 per quarter during 2006 and have steadily declined since then. The unexpectedly small number of patients accessing the pilot service meant that it was not feasible to pursue the original protocol objective of purposive sampling. Instead, a clinician from each local R2R team was asked to alert all patients to the evaluation and to refer anyone who gave permission to be contacted by the researcher. The

sample of 35 patients interviewed does not claim to be representative but is 4% of the R2R population during the life of the evaluation.

In keeping with the pattern for CR, R2R and other phase III, patients were mostly white British (84.2% vs. 81.3% in other CR programmes). Our interview sample was as likely to be White British (85% vs. 84% in all R2R programmes). 5/35 interviewees (14%) were not born in the UK. Two of these interviewees were Indian, one East African Asian, one Chinese and one was Spanish.

The interview sample was younger and comprised fewer women than the overall picture for R2R (Table 1). No such difference in age was observed in men.

Insert table 1 about here

R2R patients were more likely to be employed than other phase III CR patients (35% vs. 29% in other CR programmes). This correlates with the age profile of the R2R patient group. Our sample was still more likely to be employed; 20/35 (57%) were in full or part-time work (vs. 35% all RTR). 3/35 (9%) were unemployed and looking for work.

The mean age of the 12 health professionals interviewed was 40 (ranging from 26-61 years). 3/12 (25%) of interviewees were men. The mean length of NHS experience was 10 years (ranging from one year to 26 years). Six were cardiac specialist nurses; three were exercise instructors, one physiotherapist,

one physiologist and one clinical psychologist. 9/12 (75%) were White British of UK origin. One person was German, one Irish and one Middle Eastern.

Recruitment and interview conduct

The field researcher telephoned every patient initially referred to the study by the on-site clinician. All those who said that they might be willing to take part were sent a letter enclosing a leaflet about the project. The leaflet explained why the interviews were being conducted and what was involved in taking part. Each recipient was then telephoned again to arrange an interview time. Patients were informed that they could withdraw at any time without giving a reason. They were assured that the decision to withdraw or to not take part would not affect the standard of care they received. This process afforded each patient at least three opportunities to talk about the study before an interview was arranged. A consent form was completed before each interview which provided a fourth opportunity for patients to discuss the study and consider their participation.

Interviews with the patients were conducted at a time and place chosen by themselves, most frequently in their own home; in one case a patient preferred their place of work. Interviews with staff were conducted by telephone. All interviews were digitally recorded. 35 interviews were conducted by the same researcher using a topic guide. Follow-up interviews with patients were conducted by telephone 9-12 months later. A trained bilingual researcher was available where necessary. All interviews in English were transcribed in full from copies of the original digital recordings. The

transcription format focused on speech content rather than discourse construction. The bi-lingual researcher provided a recording of an oral translation into English which was then transcribed.

Interview analysis

Interviews yielded in-depth responses about patients' experiences, perceptions, opinions, feelings, and knowledge of heart disease and cardiac rehabilitation. Transcript data were analysed to produce readable narrative descriptions with major themes, categories, and illustrative examples extracted through content analysis (Braun & Clarke 2006; Sliverman 2004; Bryman & Burgess 1993; Miles & Huberman 1984; Ritchie & Spencer 1993). The Principal Investigator compared her own initial analysis of sample scripts with that of the main field researcher. No significant differences were identified. The final stage was deductive in testing and affirming the authenticity and appropriateness of the inductive analysis; this included carefully examining any unusual cases or data that did not fit the categories developed. The substantive significance of the findings was determined by:

- The solidity, coherence, and consistence of the evidence in support of the findings
- The extent to which the findings increased and deepened an understanding of the programme being evaluated
- The extent to which the findings were consistent with other knowledge

Survey

A self-administered 49 item survey instrument was designed and delivered to 30 sites who had conducted the R2R Programme. Questionnaires were completed and returned by 27/30 sites; a 90% response rate. Descriptive statistics were compiled using the Statistical Package for the Social Sciences.

Results

Offering a choice between home and hospital or community based programmes

Survey data collected from staff indicated that all currently running R2R sites gave patients a clear choice between home and hospital or community based programmes. The patient interviews revealed a somewhat different picture 21/35 patients interviewed (60%) said that they were given a choice between a home and hospital/community based programme (these included all interviewed patients at two of the five participating sites). One patient could not remember being offered a choice. 13/35 patients (37%) said they were not given a choice between a home and a hospital/community based programme. Seven of these patients had access to other programmes either during or after R2R; four undertook the R2R programme as an optional supplement to a hospital/community based programme and three were given the option of joining a community based programme alongside R2R once space was

available. Four of the remaining six patients (11%) who said that they had not been offered a choice said that they would have preferred a group based programme.

Informed consent

It is important to note that not all patients interviewed were aware that they had been taking part in a pilot cardiac rehabilitation programme. These patients may have been told and did not recall, or they had been offered R2R without being advised that they would be deciding to take part in a new (and therefore untested) intervention.

Gaps in individual treatment pathways

Gaps in individual treatment pathways created obstacles to patients receiving and/or completing CR (c.f. Tod et. al. 2002). Patient pathways were harder to negotiate for those who moved between hospitals for treatments. Three such patients were not initially offered a programme but took their own initiative to contact hospitals to try and find a rehabilitation programme.

C5 (man aged 45)

I weren't impressed that I had to chase them up for it. I think that's what's lost my motivation really. It took so long to get there; I just couldn't be bothered in the end.

The following patient was offered a choice of attending rehabilitation at a hospital nearer to home than the one in which he had his treatment. The implications that this choice might have for the type of programme available were not made clear:

C14 (man aged 59)

I could either do the [rehabilitation] programme at [name of hospital], or at [name of hospital], and I said, 'Can I do at both?' because I was determined to get fit and she said, 'Well, you can but it seems a bit silly.' So I said, 'OK then, I'll do [name of hospital] because it's right on my doorstep' ...

Did she say the programmes might be different that you'd get at [these hospitals]?

No she didn't, she said that I could choose a programme and I said I'd love to do this one. She said 'You can do it in your home or you can go to the hospital.' I said, 'I'd love to do it in my home.'... So, naturally, I assumed that one [hospital] was liaising with the other and they [the rehabilitation programmes] were of equal, and when they [R2R staff] came I was quite surprised that they weren't medical and was disappointed because I had some questions about some pain that was going on and some things that were happening to me bodily-wise that they didn't know the answer, said they hadn't heard that or and I felt a bit cast off at that point – adrift... I stopped asking in the end because I felt guilty and embarrassed for them, because they were clearly embarrassed that they didn't have medical answers for problems.

Reasons for the problem this patient encountered in getting answers to medical questions from R2R staff are:

1. The cardiac specialist nurse who was usually part of the R2R team at this centre was not replaced by another cardiac specialist nurse while she took maternity leave. Problems of staff retention, staff sickness, lack of like-for-like cover for maternity leave and a wide variety of local difficulties affected most of the sites during the life of the evaluation. The NHS reorganisation that came into effect in October 2006 coupled with the poor financial situation affecting many PCTs at this time created particularly significant challenges for those sites affected.
2. It is evident from the full interview that this patient missed out on a phase II cardiac rehabilitation programme which would have supported him in his physical and psychological recovery from bypass surgery.

The patient's interest in doing both programmes offered was dismissed as "silly" without full consideration. Some of the other patients interviewed had been given this opportunity and had done both home and hospital-based programmes simultaneously.

Positive choice vs. choice based on constraints

For some patients, the choice of a home-based programme was a positive one. For others it was a decision based on constraints. For example, nine patients gave work as the reason why they chose a home-based programme. Five of these said that without work constraints they might have preferred to join a group based programme.

C2 (man aged 57)

Yes it's work related. I don't get paid, unfortunately. I know it shouldn't matter really for my health, but unfortunately it's a factor. Being as I could do it at home, I mean if there wasn't a choice then obviously I would have had to do it – well I don't mean have to – I would have done it at the hospital...

If you hadn't had the pressures of work, do you think you would still prefer a home-based rather than a group based programme?

Me personally, probably a group based, because I sometimes have not done them, or find it hard to get up and do them, but if you was going to a group or you was going to the hospital, that would be better for me. I mean I haven't – I've done all right, but with the group it would be better.

Some interviews contradicted the idea that this home-based programme best suited workers. Two working patients said it was better for those who are at home and had time to do it rather than fitting it into a tiring work day. Two

more patients said that they had given the programme up once back at work because they were too tired to fit it in at the beginning or end of the working day.

After reasons related to work, the other most frequent reasons given for choosing a home-based programme were: avoiding problems with transport; not being tied to a fixed schedule; being able to exercise at their own convenience and not wanting to join a group. Some patients gave combinations of these reasons for choosing a home-based programme.

C3 (man aged 50)

There's a lot of different reasons. First of all I think because I didn't see myself as being in a bracket of an old fogey who's had a heart attack. That doesn't mean to say that's what everybody who has a heart attack is an old person, because they aren't, but I didn't want to be stuck sat in a circle doing, 'I'm an alcoholic', do you understand me? That's not me; I can't be doing that. I hate being on a bus when it's crowded, I hate being on a tube when it's crowded, it drives me bananas. I can't be going and doing it as a group. So it had to be as an individual, whether it be at home or going to the hospital in my time, to do whatever, that's fine. So that's the reason why I chose that particular way.

Two patients who had previous experience of hospital based rehabilitation chose a home-based programme in preference to that.

A4 (man aged 61)

I was bored [at the first rehabilitation group]. I mean, I'm sixty-one years of age, at that time I was fifty-eight, fifty-seven, whatever. There was a lot of old people there and the exercise they were asking me to do, I thought, 'This is pointless. It's doing nothing at all for me.' Walking about, picking a ball up, etcetera, etcetera. Standing up, sitting down. It was doing nothing at all for me. I thought, 'I can get more exercise walking my dog.' So I didn't complete the course [After a third heart attack] I was then offered the exercise at home and whatnot and I thought, 'What? I'll have a go' ...

Having done the home-based programme, two people thought that they might have been better off in a group where instructors could give them more guidance. Or, to be called into the hospital for more assessment during the home-based course:

C15 (man aged 54)

...perhaps it might be better to say for the first six weeks you'll be in a class and we will show you this, this, this, this... I said to her [wife], I said, 'I think I should have gone to the class.' She said, 'But you wouldn't have gone.' I said, 'But I think that's what should be drummed in to me, to go.'...I think it should be a part of the rehab thing. Should be if you don't go to the class then we'll assess you every three weeks or four weeks, or...You know it's, it's, you go to the class, the teachers can see how you're getting on, you don't go to the class, they can't. But they assess you more. You see what I'm saying?

One patient on the home-based programme who did not exercise to the DVD said that ideally he would have liked a hi-tech hospital programme.

B2 (man aged 54)

I believe that nowadays there should be more available to have more hi-tech equipment where somebody can understand how their heart is functioning during exercises...I think athletes do pay a lot of money to have such equipment in their special gyms but it may be made available for people who have heart conditions... to have a venue where they can meet maybe once every week...where people would feel more attracted to the venue because of enough space, enough equipment...

One patient started the R2R programme before she had a by-pass operation but decided that she preferred the group sessions after her procedure. The woman below was one of those not offered a choice of programmes and would have preferred to attend a hospital or community based group programme:

C4 (woman aged 53) interview translated from Punjabi.

I think the way that they designed this programme was not so good. Because they want you to...do the exercises at home. But me, like I said, I got really bored. I'm sure other people are out there as well who will get bored and they won't like to do this, and then leave it... I think

the thing that would help me more is that if they called me back to the programme and then I would go somewhere and they would give me an appointment in the hospital like they do for my kidney problems, like they do for diabetes clinic. I think that would be better for me. I would go there and I would be able to do things there and they would be able to show me how to do the exercises, I would meet other people ... I would go. Because I think I'm better with appointments. It's just when you're sat at home alone all day, you get depressed. You don't feel like doing this exercise.

Some of the staff interviewed were concerned that recruitment to and retention on the programme in their areas suffered because it was not presented as a positive choice for patients. Instead, it became a default option for those unwilling or unmotivated to do hospital or community based rehabilitation.

AP1 cardiac specialist nurse

... if patients didn't want the community, didn't want hospital, then we'd offer them Road to Recovery. And I think on reflection that made life very, very hard. Because you were getting the very, very unmotivated patients ... We did have patients who completed, but they were more the minority rather than the majority and I think it was because we said, do you want the Leisure Centre, no, do you want to come to hospital, no, then you can do Road to Recovery, and I think probably now, I would make sure that it was offered on an equal basis. ... – it sounds

dreadful but you're always left with the people who see it as an easy option.

Gate-keeping services

Part of the evaluation was concerned with the distribution alongside R2R materials of a resource for patients with little use of English (Madden et al 2009). Given the ethnic profile of the service (above) this resource did not reach the patient groups it might benefit. However, the evaluation produced some useful data about the (lack of) choice extended to patients who might benefit from the services of an interpreter. 22/27 sites answered a survey question about communicating with patients who had little use of English using the multi-language resource. Only 5/22 (20%) would request an interpreter. 15/22 (68%) would ask a family member to help.

CP2 cardiac specialist nurse

Usually we ask a family [member] who speaks English to translate for us and that usually works quite well, because the family is very supportive and the background they come from, there is an extensive family there and there's always somebody who can speak English and translate for us... it's not just the patient we're giving help and advice, it's the family.

Some staff members found it difficult managing communicating with patients through family members.

DP1 physiotherapist

Very difficult. Because although we'd arranged home visits and for him to come here and we'd say he'll need somebody with him, it just wouldn't happen. There'd be some other need to take the family away, or they'd just nipped out. I don't think for the family it was as high a priority as it was for us...

The survey asked how easy it was for R2R programmes to access interpreters. 25/27 R2R sites responded. 10/25 (40%) had never accessed an interpreter. 10/25 (40%) found it difficult or very difficult to access an interpreter. 5/25 (20%) found it easy or very easy.

Discussion

The complexity of service provision does not always easily cohere with a standard bioethics model of the autonomous patient, who is fully informed about service options, and then chooses from the menu without interference or medical paternalism. Patients in the study stated that they needed guidance from health professionals and their presence on a CR programme spoke of this willingness. From a staff perspective, the inherent difficulties of supporting patients in making changes to their behaviour were compounded when programmes were attended for negative rather than positive reasons.

It was clear from the interviews in this evaluation that people experiencing a cardiac event did not always have a pre-existing concept of what a CR service is and why it is important. Some patient interviews linked the question of choice with the (lack of) perceived status of the service, raising an interesting (and possibly gendered) question about whether CR services might be perceived differently if presented as part of a treatment programme *prescribed* by cardiologists rather than an optional lifestyle improver *suggested* by nurses. In the UK, CR programmes rarely have a cardiologist actively involved, in contrast to the experience in many European states.

The data on staff reliance on family members rather than interpreters has implications for patient choice. If CR staff are unaware of services they cannot make them available for patients and if staff are accepting the status quo of poor services rather than advocating for improved choice (Gerrish et al 2004). Routinely relying on family members rather than establishing the need for interpreters when working with people with little use of English does not comply with best practice guidelines (DH & BHF 2004). The assumption of a caring extended family rests on a cultural stereotype and family members may bring to bear their own misconceptions about heart disease (Robinson 2002; Chattoo & Ahmad 2004).

Conclusion

Enabling patients to make informed choices about CR services starts with making evidence-based interventions available to them. NACR data indicate that CR patient choice in the UK is currently impeded by a lack of good quality services from which to choose. There is more to consider if CR services are to move away from pre-determined one-size-fits-all programmes towards the 'individualised' or 'menu-based' CR programmes tailored to specific patient needs stressed in national and international clinical guidelines. In keeping with Tod et al (2002) and Wingham et al (2007), our study indicates that this will involve an awareness of and commitment to finding out about and overcoming obstacles that impede patient participation. These include lack of information on which to base a choice; inadequate systems of referral; insufficient appropriately trained staff; restricted opening times; the location of services and restrictive socio-economic factors (inflexible working hours, access to transport).

References

Allender S., Peto V., Scarborough P., Kaur A. & Rayner M. (2008) *Coronary heart disease statistics*. BHF: London.

Ayala C., Orenstein D., Neff L. J., Greenlund K. J., Croft J. B., Mensah G. A. Receipt of cardiac rehabilitation services among persons with heart attack—19 states and the District of Columbia, Behavioral Risk Factor Surveillance System, 2001. *MMWR-Morbidity and Mortality Weekly Reports*. 42:1072-1075, 2003.

- Beswick A.D., Rees K., Griebisch I., Taylor F.C., Burke M., West R.R., Victory J., Brown J., Taylor R.S., Ebrahim S. (2004) Provision, uptake and cost of cardiac rehabilitation programmes: improving services to under-represented groups, *Health Technology Assessment* 8 (41): 1-166.
- Bethell H., Dalal H., Lewin R. (2008) Cardiac rehabilitation: worth it? *Heart* published online 20 Jan 2008
<http://heart.bmj.com/cgi/content/abstract/hrt.2007.134338v1>
- BHF/NOF (2004) *New Opportunities for Health. The Cardiac Rehabilitation Programme: Guidance Notes*. London: BHF.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3(2), 77-101.
- British Medical Journal (1964) Human Experimentation Code of Ethics of the World Medical Association *Br Med J*; 2:195, doi: 10.1136/bmj.2.5402.195
- Bryman A., Burgess R. (eds.) (1993) *Analysing Qualitative Data*. London: Routledge.
- Campbell R., Quilty B. & Dieppe P. (2003) Discrepancies between patients' assessments of outcome: qualitative study nested within a randomised controlled trial. *Br Heart J*; 326, pp. 252–253.
- Chattoo S. & Ahmad W. (2004) The meaning of cancer: Illness, biography and social identity. In Kelleher D & Leavey G (eds.) *Identity and Health*. London: Routledge.

Dalal H.M., Evans P.H., Campbell J.L., Taylor R.S., Watt A., Read K.L.Q., Mourant A.J., Wingham J., Thompson D.R., Pereira Gray D.J. (2007) Home-based versus hospital based rehabilitation after myocardial infarction: A randomized trial with preference arms — Cornwall Heart Attack Rehabilitation Management Study (CHARMS). *International Journal of Cardiology* Volume 119, Issue 2, 10 July 2007, Pages 202-211.

Daly J., Sindone A.P., Thompson D.R., Hancock K., Chang E., Davidson P. (2002) Barriers to Participation in and Adherence to Cardiac Rehabilitation Programs: A Critical Literature Review. *Progress in Cardiovascular Nursing* 17 8-17.

Department of Health (2009) Patient choice: What's new? 21 January 2009
Retrieved from
<http://www.dh.gov.uk/en/Healthcare/PatientChoice/index.htm> on
19/05/2009.

Department of Health and British Heart Foundation (2004) *Heart Disease and South Asians: Delivering the National Service Framework for Coronary Heart Disease*. London: DOH.

Department of Health (2000) *National Service Frameworks. Coronary heart disease*. London: DOH.

Dunderdale K., Thompson D. R., Miles J. N.V., Beer S. F. and Furze G. (2005) Quality-of-life measurement in chronic heart failure: do we take account of the patient perspective? *The European Journal of Heart Failure* Volume 7, Issue 4, pp 572-582.

Gerrish K., Chau R., Sobowale A., Birks E. (2004) Bridging the language barrier: the use of interpreters in primary care nursing. *Health and Social Care in the Community* 12 (5): 407-413

Healthcare Commission (2005) *Coronary Heart Disease. Survey of Patients 2004*. London: Commission for Healthcare Audit and Inspection.

Retrieved from

http://www.cqc.org.uk/publications.cfm?search_string=coronary+heart+disease&widCall1=customDocManager.search_do_2&tcl_id=2&top_parent=4513&tax_child=4759&tax_grand_child= on 19/05/2009.

Jolly K., Taylor R.S., Lip G.Y.H., Stevens A. (2006) Home-based cardiac rehabilitation compared with centre-based rehabilitation and usual care: A systematic review and meta-analysis. *International Journal of Cardiology*, 111 (3), p.343-351.

Jolly K., Taylor R., Lip GYH, et al (2007) The Birmingham Rehabilitation Uptake Maximisation Study (BRUM). Home-based compared with hospital based cardiac rehabilitation in a multi-ethnic population: cost-effectiveness and patient adherence. *Health Technology Assessment* Sept. 11 (35): 1-118.

Miles M. & Huberman A. (1984) *Qualitative Data Analysis*. London: Sage.

The National Audit of Cardiac Rehabilitation (2008) *Annual Statistical Report*. London: BHF.

The National Audit of Cardiac Rehabilitation (2009) Personal communication with statistician 20/05/2009.

- Taylor R.S., Brown A., Ebrahim S., Jolliffe J., Noorani H., Rees K., Skidmore B., Stone J.A., Thompson D.R., Oldridge N. (2004) Exercise-based rehabilitation for patients with coronary heart disease: systematic review and meta-analysis of randomized controlled trials. *Am. J. Med* 116: 682-692.
- Ritchie J., Spencer L. (1993) Qualitative data analysis for applied policy research in Bryman A, Burgess R, (eds.) *Analysing Qualitative Data*. London: Routledge.
- Robinson M. (2002) *Communication and Health in a Multi-Ethnic Society*. Bristol: The Policy Press.
- Sliverman D (ed.) (2004) *Qualitative Research: Theory, Method and Practice*. London: Sage.
- Tod A, Lacey A, McNeil B (2002) 'I'm still waiting...': barriers to accessing cardiac rehabilitation services, *Journal of Advanced Nursing* Volume 40 Issue 4, Pages 421 – 431.
- World Health Statistics (2007) Geneva: World Health Organisation. Retrieved from www.who.int/whosis/whostat2007_10highlights.pdf on 19/05/2009.
- Wingham J, Dalal HM, Sweeney K & Evans P (2006) Listening to patients: Choice in cardiac rehabilitation, *European Journal of Cardiovascular Nursing* 5: 289-294

Table 1: Age and gender

	Other phase III patients (N=76401)		Road to Recovery patients (N=1178)		Road to Recovery interviewees (N=35)	
	Average Age	%	Average Age	%	Average Age	%
Male	64	73.4	63	74.8	59 (n=29)	83.0
Female	68	26.6	65	25.2	55 (n=6)	17.0