



CARDIAC REHABILITATION: PATIENT SURVEY REPORT

Introduction

Evidence has shown that participation in a program of cardiac rehabilitation improves outcomes and quality of life for cardiac patients. The evidence suggests that when cardiac rehabilitation services are being provided to an optimum level, mortality can be reduced by as much as 20-25% over a three year period¹.

Physical activity is a recognised risk factor for coronary heart disease and approximately 36% of deaths from CHD in men and 38% of deaths in women are due to lack of physical exercise¹. A cardiac rehabilitation program needs to consist not only of exercise, but also psychological interventions and education about lifestyle and risk factors. The key elements are skilled support and supervision that is tailored to individual patients can provide the following:

- help people understand their illness and its treatment
- provide psychological and emotional support
- improve people's success in making beneficial lifestyle changes
- help people make the transition back to a full and as normal a life as possible

Traditionally, cardiac rehabilitation is set up in four phases as follows:

Phase I	Phase II	Phase III	Phase IV
Inpatient phase – explanation/ education and support	Primary care based – period between discharge and first follow-up	Formal exercise and education programme – often hospital based	Long term maintenance and risk factor modification

The content of each phase may vary within programmes in terms of content, support, personnel involved and the amount of behavioural/lifestyle management incorporated. The introduction of the 'Heart Manual', 'Angina Plan', menu-driven programmes and the shift to have more access to cardiac rehabilitation in the community has changed the traditional approach by providing more focus on tailoring programmes to individual patient needs.

Addressing cardiac rehabilitation along the whole of the patient's pathway including beyond phase IV provides a comprehensive and inclusive programme. In particular, Patients are often at their most vulnerable straight after discharge when the visible support of the hospital team has disappeared and contact from the cardiac rehabilitation team is vital in providing follow-up and access to phases II and III. The same applies to patients who have completed phase III and require a long term maintenance plan to support their continued lifestyle changes. This is provided in phase IV but requires professional support in order for patients to sustain their lifestyle changes in the long-term.

This report outlines the findings from the patient satisfaction questionnaires developed by the patient and public information sub-group of the Cardiac Network, the Heart 2 Heart (H2H) User Forum. The H2H User Forum were keen to gauge patient's views on the various aspects of cardiac services across NW London and decided to undertake a series of patient satisfaction surveys as part of their work-plan to assist in determining how to improve services from the patients' perspective.

Analysis of the survey provides an evaluation process for cardiac rehabilitation teams and their programmes, enabling them to initiate service improvements where needed and highlighting areas of good practice.

Background

Within NW London there are 15 cardiac rehabilitation programmes, 11 within a hospital setting (3 providing phases I-II/III only) and 4 within the community (phases II/III-IV). All the cardiac rehabilitation teams provide varying programmes, with the main themes based on exercise and education.

All information given to patients is based upon generic literature, compiled from different sources, the main source being the British Heart Foundation. Other information sources are used, predominantly through contact with other professionals working with the cardiac rehabilitation teams including dieticians, physiotherapists, pharmacists, psychotherapists and smoking cessation teams. Visual aids including videos and DVD's are also used within some of the programmes. The education component of the programme provides patients with the necessary information on specific areas relating to their condition. The following list is an example of information generally provided and frequently delivered through a series of workshops:

- Exercise advice
- Healthy eating
- Weight management
- Medicines management
- Managing anxiety and stress
- Smoking

This list provides the most common topics addressed but is not exclusive and some programmes include other topics which expand the education remit eg lifestyle changes, risk factors, physiology, first aid etc.

The exercise component is delivered differently by each Trust often dependent upon whether the programme is run within a hospital or community setting and the resources available. Exercise programmes can consist of gym (using equipment) or class (gentle aerobics or dance) and home (individual assessment) based exercises, with class sizes ranging from 6 to 10 (the BACR/BCS recommend a ratio of staff to patients of 1:10, with a minimum of two staff supervising). All exercises are conducted by a qualified exercise instructor and these are tailored to fit around access and available resources.

Methodology

Good practice indicates that all patients who complete a phase III programme should be audited so that the long term effectiveness of their programme can be monitored. This provided the basis for the H2H User Forum in deciding where along the cardiac rehabilitation pathway they should target the questionnaire. The questionnaires were therefore developed to capture information from patients who have completed phase III of their rehabilitation programme.

The questionnaire was reviewed by the H2H User Forum several times and the framework for the survey was developed to highlight key areas pertinent to standard 12 of the NSF and as an indicator for service improvement. The NW London cardiac rehabilitation network group was asked to provide their expertise and support for the survey. The cardiac rehabilitation teams assisted in identifying patients for this project and a cohort of 100 patients details were requested from each cardiac rehabilitation programme.

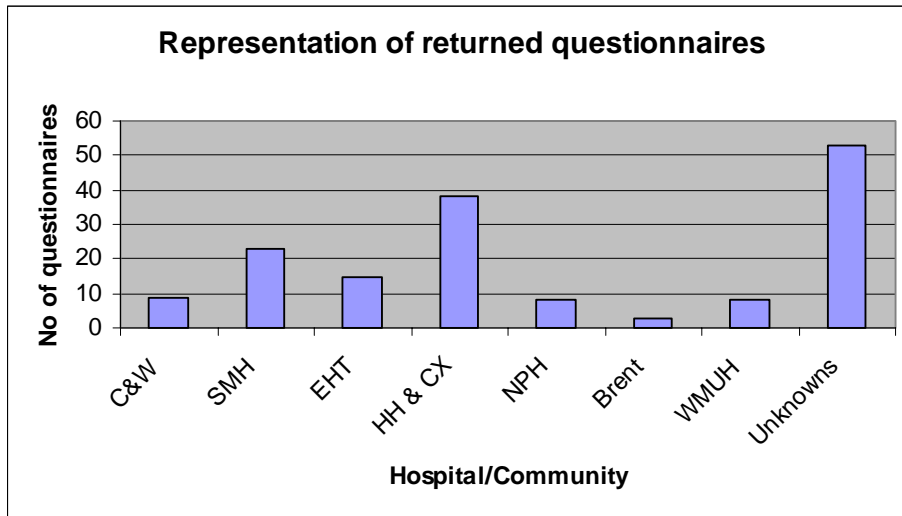
An explanatory letter was attached to the questionnaire giving information on the purpose and expected outcomes of the survey. Seven programmes took part in the survey out of a possible eleven. All questionnaires were anonymised but patients were asked to specify the name of the hospital they were offered cardiac rehabilitation whilst an inpatient in order that centre specific results could be fed back to individual rehabilitation teams.

The questionnaire asked 11 questions significant to patients who had completed phase III of their cardiac rehabilitation programme. Question 12 required patients to remark on what improvements to the programme they would recommend and any further comments they would like to add.

Where possible, the analysis of the questionnaires was apportioned to each hospital or community cardiac rehabilitation programme that had responded. This was not relevant to all questions and five questions have been used to provide a snapshot within each site of those questions answered.

An issue identified which affected the analysis was that no identity reference was appended on each questionnaire. Therefore, in the event that a patient omitted writing the name of the hospital, the form had to be assigned to unknown.

Not all cardiac rehabilitation programmes took part in the survey and only one Trust supplied a cohort of 100 patients. The remaining cardiac rehabilitation programmes supplied patients' details ranging from 33 to 68; the response for each cardiac rehabilitation programme was low, with the unknowns making up the bulk of the returns. This is represented in the graph below and provides a reference for the analysis:



Findings

Approximately 400 questionnaires were sent out to patients with 157 returns. 53 responses were from unknown cardiac rehabilitation programmes.

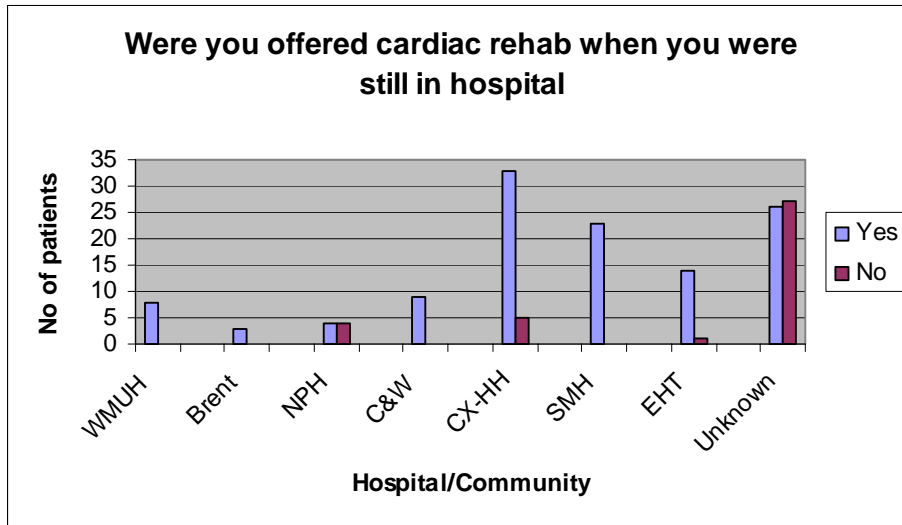
Findings were categorised into:

- Hospital representation which asked patients when and where they were offered cardiac rehabilitation, what they were offered and the support they received and how long they were waiting.
- Patient representation illustrated what the patients received in terms of their cardiac rehabilitation programme, how they felt about participating before and after, the benefits to them and to their families and if there was any other information they would like to contribute in regards to the service that was provided.

Not all questions were answered and this is reflected in some of the graphs.

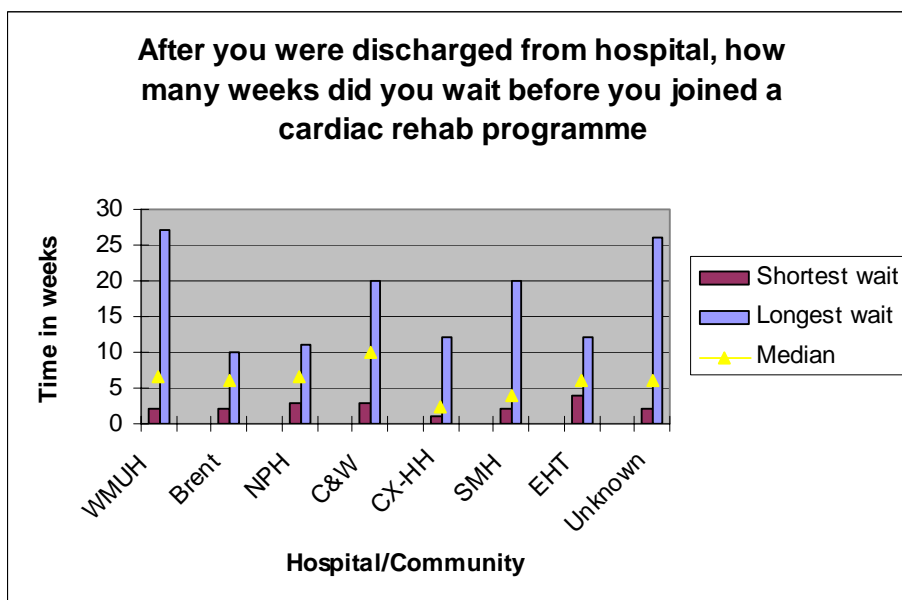
Additional information provided by patients as further comments, were included within the sections most relevant to the statement made. These comments were also included within the recommendations to assist in the delivery of service improvements.

This section provides a graphic representation of the responses.



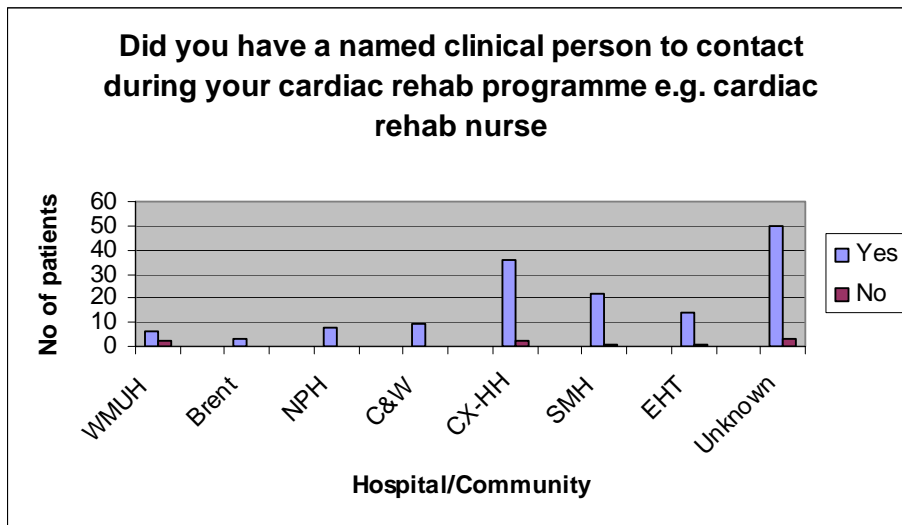
The National Service Framework⁵ (NSF) states that all patients after an acute myocardial infarction or post-coronary intervention should be offered cardiac rehabilitation. In relation to the responses returned, the results are almost 100%. Where there has been a negative response, this could relate to patients being discharged early, in particular with patients who have had a primary angioplasty.

Other issues to factor in relating to the negative responses are low workforce levels where cardiac rehabilitation nurses cannot visit wards to capture patients suitable for cardiac rehabilitation and where there are limited resources available for the ward nurses to refer patients onto a cardiac rehabilitation programme.



The NSF states that; four weeks after an acute cardiac event, patients should attend a formal cardiac rehabilitation programme that includes exercise and education modules. Within NW London most Trusts invite patients to attend a cardiac rehabilitation programme between four and six weeks and this is evident on the above graph as shown by the median wait.

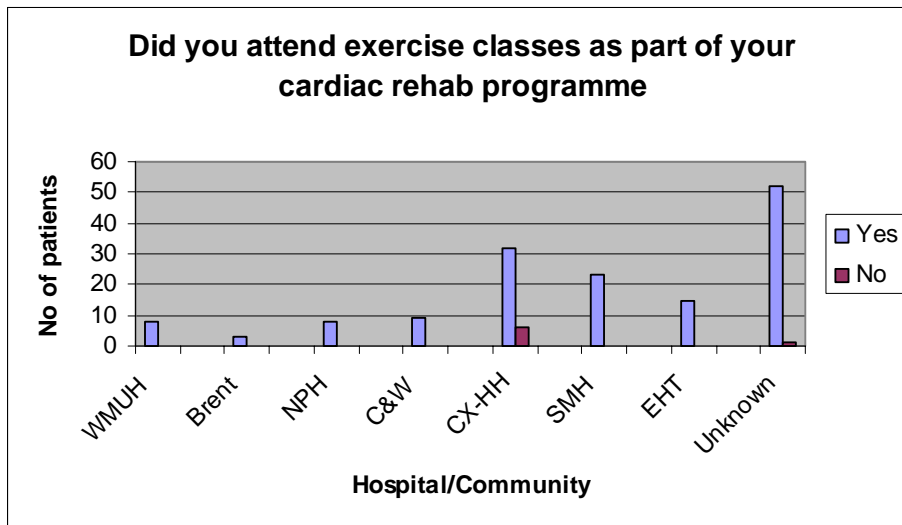
Anomalies shown here relate to a very small number of patients. Patients can defer attendance to a cardiac rehabilitation programme for different reasons, often which are beyond their control. These can relate to being clinically unfit to attend, although this would not necessarily prohibit them from attending the education modules. Other possible reasons for long waits could be reduced workforce impacting on a reduced service. Further investigation may be necessary to understand the exact reasons within each cardiac rehabilitation programme.



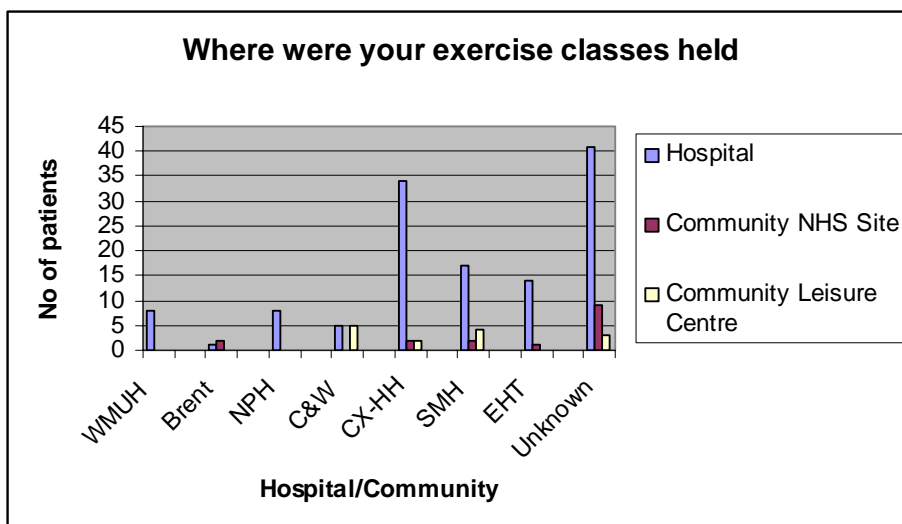
The provision of skilled help, support and supervision is vital in providing help to patients to understand their illness and its treatment, and in particular to regain their confidence. Contact from the cardiac rehabilitation team to provide follow-up and access to information provides patients with information to assist in sustaining their lifestyle changes and a return to as normal a life as their condition will allow.

Support included not just the details of the cardiac rehabilitation teams but patient information leaflets which inform not just patients and carers but their family and friends as well.

This graph illustrates that the majority of responses was positive and that patients are given that vital contact for support.

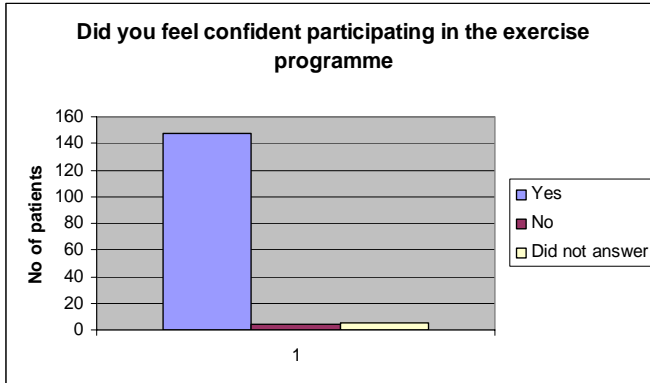


Structured exercise as a beneficial intervention is central to cardiac rehabilitation and is a core component within all cardiac rehabilitation programmes. This is illustrated in the above graph, as the majority of patients replied that they had attended an exercise class as part of their cardiac rehabilitation programme. The small minority who answered no had taken up the education component and provided the following reasons for not attending the exercise training: attended exercise classes elsewhere (private gym/instructor), administered their own exercise regime (mostly walking), unable to attend classes due to hearing problems or co-morbidities (eg arthritis).



This graph provides information on where patients had their exercise classes and it shows that the majority of classes are being held at the hospital where they were admitted. The assumption is that this is a safe and comfortable environment for them to come back to and illustrates the limitations of provision within the community to provide exercise classes for these patients.

Specific issues that were raised within the survey mentioned timings of classes and travelling to venues which did not have access to public transport close by. Day classes did not suit patients who had gone back to work and some classes held at night were of particular distress due to safety concerns.



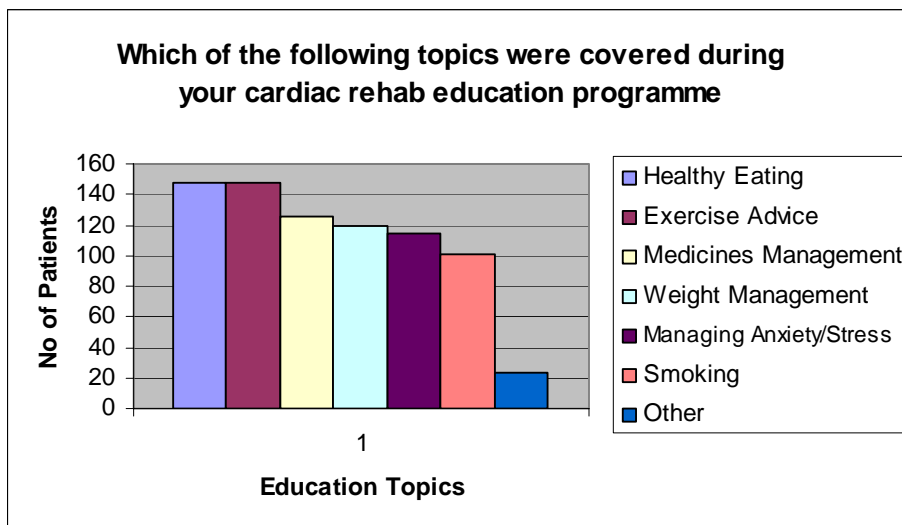
These two questions were to provide information on how patients felt before and after attending their exercise programme. The first question illustrates how patients felt before they attended their exercise class, particularly in relation to cardiac misconceptions and the second to demonstrate if there was any significant difference. The graphs illustrate that the majority of patients are happy to participate in the exercise programme and reflects that patients are well informed prior to attending; have attainable access; retain or gain confidence and benefit from attending.



This graph illustrates the benefits for patients in helping them to sustain what they have gained from attending the exercise programme. The provision of a comprehensive cardiac rehabilitation programme that encourages patients to maintain their healthy lifestyle, particularly by evaluating their progress from start to finish, offers measurable success.



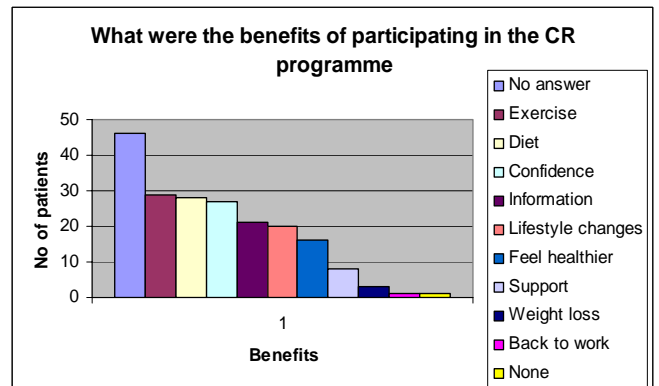
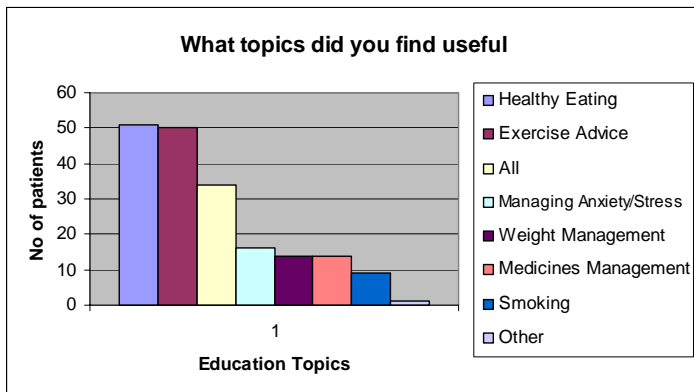
When discussing exercise with patients, walking is recommended as a safe and practical mode of exercise, this is also stated in the Network's patient booklet: 'Summary of Advice on Healthy Living'⁷. As illustrated in the graph walking is the most popular mode of exercise. It provides relatively unrestricted access and is cost effective compared to joining a gym or leisure centre. Being able to afford lifestyle changes such as joining a gym to keep active was an additional comment by patients who felt they were restricted by their low incomes.



In NW London, cardiac rehabilitation programmes are provided using a flexible approach, offering menu-based cardiac rehabilitation programmes where patients are offered cardiac rehabilitation to suit their needs. Many education workshops offer the flexibility for patients to select the education component which they feel they would benefit from most or they find most relevant to them.

The education element provides an intrinsic component of the cardiac rehabilitation programme and is particularly effective when combined with exercise training. The requirement is to provide patients and carers with increased knowledge on the effects and benefits of a healthy lifestyle in relation to their disease. The two top topics being healthy eating and exercise advice, as illustrated in the above graph.

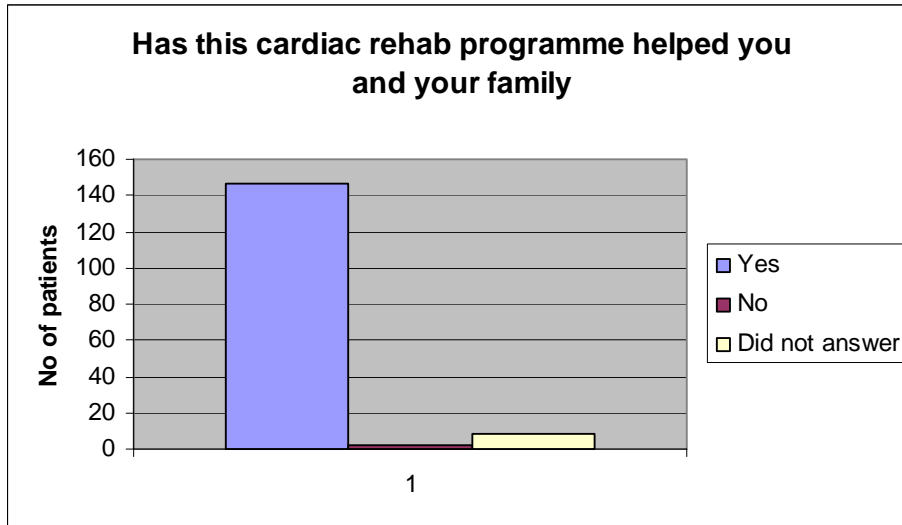
Other education topics relevant to the patient's condition reflect what is most appropriate such as medicine management, weight management, managing anxiety/stress and smoking. Other topics outside of these areas included specialist education such as first aid and social, cultural and vocational needs. Although education topics covered a wide remit their content was not as comprehensive as some of the patients would have wanted.



The education component is illustrated as a popular module within the cardiac rehabilitation programme and provides patients with the information they require to assist in their recovery and sustainability of a healthy lifestyle to prevent relapse and possibly readmission to hospital. Although patients did not find the other topics as useful as the healthy eating and exercise advice, a significant number felt that the education component as a 'whole', which is illustrated by the 'all' column, was useful and constructive.

In comparison, what patients found beneficial echoed the topics they found useful, resulting in the two top topics being exercise and diet. Confidence was also rated highly and this reflects the benefits of being able to participate in a programme which produces measurable results.

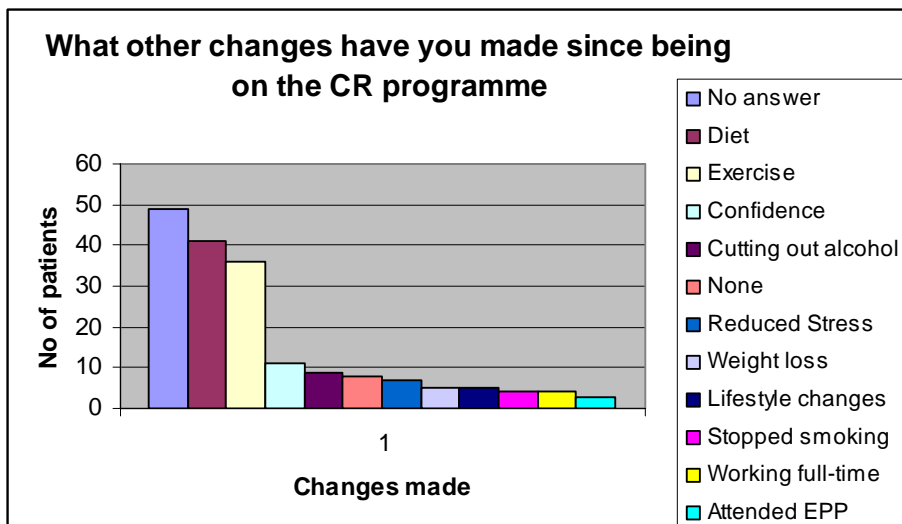
The only restriction noted was where patients wanted more information than was available to them, in particular where all education topics were included in a one day workshop, limiting the content of each topic.



To be able to include the patients' carers and their family's in their cardiac rehabilitation extended the understanding of cardiac rehabilitation and its benefits, allowing the supporting role to broaden.

The graph illustrates the enormous benefit of involvement and how cardiac rehabilitation programmes encourage the participation of carers and family members to participate at all levels.

An additional comment made by patients was the need for specific carer/family information on the changes that affect patients after their CHD episode and how this can affect the people around them.



This graph illustrated the changes made by patients since being on a cardiac rehabilitation programme. With diet and exercise being the top two, it highlights the significant benefits for patients who attend a cardiac rehabilitation programme and provides an insight into the fact that many patients were not previously aware of the connection between their disease and its causes.

The provision of a comprehensive cardiac rehabilitation programme provides the support required to make these changes. The other changes, although relatively small, provide a snapshot of what patients feel made a difference.

Recommendations

Overall, this survey has provided considerable information, from the patient's perspective, on the benefits of providing CHD patients with a comprehensive cardiac rehabilitation programme. Also emphasised are the areas where significant service improvements can be made to provide more choice, access and information to relieve pressure on already impacted services.

The following points address areas that provide beneficial support for CHD patients:

- Patients who are discharged from hospital can miss out on cardiac rehabilitation due to not being captured at the early post discharge period. During this period is often when many patients feel isolated and insecure and support at this stage is a vital ingredient to encourage recovery.

Provision of a cardiac rehabilitation contact during hospital admission can improve both the patients and the partners' knowledge of heart disease and reduce anxiety and depression. This can be particularly beneficial if patients have to wait outside the recommended time to attend their cardiac rehabilitation programme.

- With the majority of patients attending cardiac rehabilitation programmes within the hospital, there appeared to be little choice for patients to attend programmes elsewhere. The implications for this could be reduced attendance, although reasons for non-attendance could include other factors, such as cultural and religious differences, co-morbidities as well as demographics and transport.

Expanding a cardiac rehabilitation service to provide access and choice, in particular to include community and home provision, could assist in patient's accessing a cardiac rehabilitation programme convenient to them. Provision could include simple additions and changes such as written information in different languages, visual information – DVD's/Video's, access to subsidised gyms or other therapeutic resources.

- The requirement to provide exactly what patients feel they require is not always possible considering the demand being made to reduce services as a cost-cutting benefit. With exercise a core component of cardiac rehabilitation programmes, the implications do not fit in with what patients have said about wanting the exercise component extended beyond the recommended eight week period.

With many cardiac rehabilitation programmes having to rethink about the way they provide their services, the fact that walking was identified as the most popular form of exercise for patients, may offer a solution.

Previously, the Network has provided walking pedometers to cardiac rehabilitation teams which were used in conjunction with some of the cardiac rehabilitation programmes or given out to patients to encourage exercise. They proved to be extremely popular amongst the patients and some programmes still use them.

Many 'Countryside Agencies' developed walking programmes working alongside cardiac rehabilitation teams to provide walking initiatives with CHD patients, although some of these have now ceased, they were popular with patients, many of whom were walk leaders.

A 'walking pedometers' programme is currently being piloted at a NW London Trust and aims to address the needs of patients who do not follow the 'normal' exercise pathway in cardiac rehabilitation. Findings from this pilot will be fed back to inform cardiac rehabilitation teams within NW London of their results.

- Information and access to information appears to be a main area of need identified by the survey. Although information is available, its how patients are receiving it and when. Within the education topics the amount of time spent to inform patients was limited and patients wanted more time allocated to topics they felt required more explanation. Other areas within the education module was information for carers and family members, patients felt there was no provision of information that specifically identified their needs for support.

The 'Expert Patient' programme is a self-management course giving people the confidence, skills and knowledge to manage their condition better and be more in control of their lives. This programme could fill some of the gap, in particular to inform patients, carers and family members what to expect before, during and after their treatment and provide an invaluable and much needed network of support.

In summary, patients want cardiac rehabilitation information whilst they are still in hospital or at the very least during their first week at home. Information and communication were key factors in the provision of assisting patients, carers and family members to understand their illness, how to cope and where to get support.

Exercise was the most popular module and noted as the most beneficial and linked to education, provided a greater understanding in making the necessary changes. Some of those changes included the benefits that would be gained such as confidence, healthy food/diet and healthy lifestyles as well as specific changes linked to risk.

In understanding what patients want in order to help them attain their optimum return to leading as normal a life as possible after their CHD experience, will provide the basis for a comprehensive cardiac rehabilitation programme.

Many patients have found cardiac rehabilitation extremely beneficial and are grateful for the opportunity to be able to assist in their recovery through the guidance of attending a cardiac rehabilitation programme. The following quotes are some of the comments provided by patients at the end of the questionnaire:

'I thought the staff were very supportive and encouraging. It was and is needed – cardiac rehab, I am only too glad to have come and joined and happy to have the choice and to look to a better life'.

'To know you were not alone, other people in same situation'.

'The service provided was excellent. All the staff were very kind and helpful. I wish to thank you all'.

'Every one of you have been brilliant, thank you very much. This has been invaluable and very helpful'.

'Its one thing to have a cardiac problem but most importantly the rehabilitation programme helps a lot – keep it up – thank you'.

References

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6. Scottish Intercollegiate Guidelines Network (2002) Guideline 57: Cardiac rehabilitation. Glasgow.
7. Summary of Healthy Living Brochure (2006). North West London Cardiac Network. London.

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