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Occasional Paper No. 4 - April 2002 **Coronary Heart Disease National Service Framework: Cardiac Rehabilitation - Meeting the Information Needs**

Background

An effective programme of cardiac rehabilitation is an essential component of the National Service Framework for Coronary Heart Disease¹. This Occasional Paper is the report of a project which is intended to act as a resource to assist those who are responsible for putting the NSF in to action.

Summary

- Cardiac rehabilitation patients should be offered treatments based on an assessment of their individual needs;
- There is a need to improve services by auditing outcomes;
- Methodologies for gathering clinical outcomes data already exist;
- A package of assessment and outcome measures for cardiac rehabilitation and minimum data set has been produced which includes behavioural, health-related and psychosocial measures;
- There is currently no suitable measure of dietary habit and further work should be undertaken to develop one;
- Only by collecting data can the benefits of cardiac rehabilitation and the need for further resources be demonstrated.

Introduction

Cardiac rehabilitation aims to restore an individual with heart disease to their optimal level of physical, psychological, social and vocational well-being.

Both the National Service Framework (NSF) for Coronary Heart Disease¹ and the national clinical guidelines for cardiac rehabilitation² state that cardiac rehabilitation should be multidisciplinary and "menu driven". That is, the patient should be offered treatments based on an assessment of his or her individual needs rather than being asked to attend a predetermined programme in which all patients take part in all elements. Both documents stress the need to improve services by auditing outcomes.

The most commonly used outcomes measures have been survival and functional status as measured by treadmill performance. Neither reflects the holistic nature and aims of cardiac rehabilitation.

A telephone survey of cardiac rehabilitation programmes in the UK, conducted in 1997, established that few cardiac rehabilitation programmes used valid or reliable measures to either direct the provision of care, or to assess the outcome of treatment³.

Aims and objectives of this project

- To construct a package of valid, reliable and sensitive assessment and outcome measures appropriate to the aims of cardiac rehabilitation;
- To develop a minimum data set for cardiac rehabilitation.

Any such package must:

- Consist of measures that have been validated with cardiac patients;
- Reflect the diverse aims of cardiac rehabilitation;
- Be acceptable to patients and staff;
- Be suitable for use in busy clinics; and
- Provide clinically useful information.

Such a package could be used to:

- Aid the planning of individualised care;
- Assess the effectiveness of care;
- Establish benchmarks for cardiac rehabilitation;
- Allow "process benchmarking" to compare different methods of delivering cardiac rehabilitation.

The domains to be measured in cardiac rehabilitation

The American Association of Cardiovascular and Pulmonary Rehabilitation has suggested the following domains⁴:

- *Clinical* (e.g. heart rate, blood pressure, lipids);
- *Behavioural* (e.g. smoking, activity levels);
- *Health* (e.g. mortality, health-related quality of life).

The UK guidelines² broadly concur with these distinctions but add *psychological assessment*. In view of the overwhelming evidence that a significant proportion of cardiac patients are clinically anxious or depressed we have added this domain.

Well-established methodologies for gathering the clinical outcomes already exist and have not been considered here.

Measuring health-related quality of life and psychosocial domains presents a greater challenge and the first three stages of the project were designed to establish robust methods for measuring the most important *psychosocial*, *behavioural* and *health-related quality of life* domains.

Methods

The project had four stages:

1. Identifying potential measures through:
 - a) Searching electronic databases;
 - b) Searching for similar work in other English speaking countries; and
 - c) Consulting national and international experts in the area in question.
2. Screening the search results to identify those measures that were valid, reliable and usable in clinical settings.
3. Assessing the acceptability and user friendliness of the identified measures through focus groups and field testing with patients and staff.
4. Compiling a draft minimum data set and establishing its acceptability through:
 - a) Determining minimum data sets used in other countries;
 - b) Focus group discussion with a panel of clinicians; and
 - c) Written expert review.

Results

Stage 1: Identifying potential measures

a) Searching electronic databases

We searched the following databases to identify suitable measures:

- MEDLINE;
- CINAHL;
- PsycInfo; and
- EMBASE.

This identified 201 articles. A researcher filtered "obviously irrelevant" articles from this list and the remainder were screened to ensure that they were one of the following:

- A report of the development and validation of an outcome measure;
- A systematic review of the outcome measure; or
- A report of a trial in which the measure was compared.

This resulted in 22 articles, the reference lists of which were screened by hand. This resulted in an additional three articles being identified.

b) Searching for existing assessment packages

Guidelines produced by the European Association of Cardiovascular Rehabilitation⁵, the American Association of Cardiovascular and Pulmonary Rehabilitation^{4,6}, the Canadian Association of Cardiac Rehabilitation⁷ and the National Heart Foundation of Australia (Victoria)⁸ have all stated the need for accurate and relevant evaluation of practice, but none have, as yet, defined a national assessment package or minimum data set. The Scottish Intercollegiate Guidelines Network has recently launched its guidelines and minimum data set⁹.

c) Consulting national and international experts

The names of experts in the assessment of the domains under consideration were established from the literature and from the personal recommendation of others. These experts were contacted to ask if they knew of any measures we had not already identified.

Stage 2: Screening the potential measures for validity, reliability and usability

The measures identified in Stage 1 were scrutinised to identify those that satisfied the following criteria:

- Satisfactory *psychometric properties* (validity, reliability, sensitivity);
- *Applicability* (i.e. suitable for all of the sub groups of cardiac patients who might be referred to cardiac rehabilitation);
- *Practicability* (i.e. capable of self-completion, reasonable length).

The following measures remained as potential candidates:

- *Psychosocial distress*: the Hospital Anxiety and Depression Scale¹⁰, the Beck Depression Inventory¹¹;
- *Health-related quality of life*: the Sickness Impact Profile¹², the Dartmouth COOP Charts¹³, the Medical Outcomes Study Short Form Health Survey (SF-36)¹⁴;
- *Physical inactivity/functional status*: the Physical Activity Questionnaire¹⁵, the Duke Activity Status Index¹⁶;
- *Dietary habits*: the Dietary Instrument for Nutritional Assessment¹⁷, the Health Education Authority's Food Portions Questionnaires¹⁸.

Stage 3: Assessing the acceptability and user friendliness

We recruited a multi-disciplinary panel of health practitioners from 10 cardiac rehabilitation programmes selected to reflect geographical and social diversity.

a) First meeting of the focus group

The members of the panel took part in a focus group to discuss the utility and applicability of the selected measures. The following were rejected:

- The Sickness Impact Profile;
- The Beck Depression Inventory;
- The Duke Activity Status Index; and
- All of the dietary habit measures.

Following discussion it was agreed that formal exercise testing would not be recommended; firstly, because we wished to facilitate long term follow-up of patients by post, secondly, because many rehabilitation programmes do not have the resources to exercise test patients, and thirdly, because many patients (such as those who are elderly) are incapable of completing an exercise test.

Each of the 10 focus group participants administered the remaining measures to 10 consecutive patients going through their programme. After completing each questionnaire the patients were asked to score it (using two visual analogue scales) for:

- The appropriateness of the questions; and
- The ease with which they could be completed.

b) Second meeting of the focus group

The panel members met two months later to consider the results and to discuss their experience of using the questionnaires. Their conclusions were that the SF-36 and Dartmouth COOP Charts were both good measures but the latter is shorter and just as sensitive to change as the SF-36 for assessing health-related quality of life¹⁹. The patients had scored both as equally relevant and equally easy to complete. The Physical Activity Questionnaire was regarded as being too long for routine clinical use.

Therefore, the measures recommended by the panel were the Hospital Anxiety and Depression Scale and both the SF-36 and the Dartmouth COOP Charts. No measures of activity or of dietary habit survived all of the criteria.

Because physical inactivity is a major coronary risk factor and preventing physical inactivity is a major aim of cardiac rehabilitation we felt it essential to include a measure. Therefore, we relaxed the criteria that the measure must have been validated in a UK population. An instrument that has been used in the US and Canada in cardiac and general populations and found to have adequate psychometric properties is the Short Measure of Physical Activity²⁰ (reproduced later in this paper). A copy of the questionnaire was sent to panel members, all of whom agreed with the adoption of the measure. However, the example activities given on the scale may not reflect the lifestyle of the average cardiac patient as they are focussed on sporting activity. It would be interesting to assess whether a version with everyday examples of daily activities yields more accurate results. This possibility could only be examined through further research.

Unfortunately, despite contacting many experts in nutrition we were unable to find a clinically viable and validated measure of dietary habit. Rather than reduce the degree to which to these measures are evidence based we have omitted a measure of dietary habit.

Stage 4: Compiling the minimum data set

a) Minimum data sets from other countries

Datasets from the UK, USA, Canada, Australia and Europe were examined and the items extracted.

b) Discussion with clinicians

These items were presented to the second meeting of the focus group and an agreed minimum dataset was compiled. Members of the focus group felt that, as the data set might be used to compare results across programmes, it was important to include co-morbidities in the minimum data set. The Charlson Co-morbidity Index²¹ has been widely used as a predictor of mortality in studies with cardiac patients and we have included it in the data set.

Other important comparisons and measures of quality in cardiac rehabilitation are the number of patients excluded due to barriers such as lack of transport, waiting lists and hospital policy that restricts on age or condition.

Cardiac rehabilitation is known to suffer from problems of voluntary non-attendance and early attrition from treatment and the panel felt it was important to record both the attendance and "drop out rate" and where possible the reason.

c) Expert review

The revised copy was circulated to representatives of:

- Cardiology;
- Cardiac rehabilitation;
- Primary care;
- The British Heart Foundation;
- The British Cardiac Society;
- The British Association for Cardiac Rehabilitation; and
- The Scottish Intercollegiate Guidelines Network.

Feedback from a number of individuals and organisations showed a strong preference for the Dartmouth COOP Charts as the SF-36 was regarded as too complex for clinicians to use. Dr David Cunningham provided information about the Central Cardiac Audit Database and Myocardial Infarction National Audit Project and, where possible, the data fields in the record were harmonised with these.

The proposed data set is shown later in this paper in the form of a patient record sheet that can be freely photocopied or downloaded from the Public Health Observatory's website (www.nypho.org.uk).

Discussion and conclusions

The failure to measure health-related quality of life and psychosocial state is a serious deficit in the current monitoring of cardiac treatments. It is particularly relevant in the case of cardiac rehabilitation, which aims to maximise the patients' psychosocial health and general well-being, but it should be considered an important outcome in all treatments.

The Dartmouth COOP Charts and the Hospital Anxiety and Depression Scale have been validated in cardiac populations and are available in many languages. Their inclusion in the National Service Framework for Coronary Heart Disease data set would be a significant improvement on the exclusively biomedical measures currently collected.

This work has revealed the lack of an easy to complete, valid, reliable and clinically relevant measure of dietary habit. In view of the great number of chronic illnesses in which diet is implicated it would seem important that such a measure should be developed. It might be argued that body mass index and lipid assay are "hard" measures of dietary change and are all that need to be collected. However, there is increasing evidence that the constituents of diet may be protective in the absence of weight loss or alterations in lipid profile and it is clear that this is a major omission from the proposed data set.

There can be no ideal set of measures that will meet all of the needs of all of the patients in cardiac rehabilitation or record all of its potential benefits. Some of the domains we have not considered are educational needs, symptoms, vocational needs or sexual difficulties. There is, of course, nothing to prevent clinicians using other questionnaires to measure these domains for clinical purposes. For example, the Cardiovascular Limitations and Symptoms Profile is an appropriate measure, sub-scales of which already appear in the

National Service Framework for Coronary Heart Disease. Unfortunately, it was too late to include it in this work as the paper reporting its validation was still in press²².

Despite the recognition given to cardiac rehabilitation by the National Service Framework for Coronary Heart Disease, it remains very much a Cinderella service and we recognise that, in many centres, the collection of data is extremely difficult. Whilst clinicians may feel that the needs of patients must be met before time can be devoted to data collection, it is only by collecting data that we can demonstrate the need for further resources or demonstrate the gains that could be produced. Therefore, we would urge clinicians to make the time to collect outcome data even if this reduces the amount of face-to-face contact with patients.

Much of this data is already being collected by others and programmes should request software that can be linked to hospital and general practice systems to extract the biomedical data leaving them more time to gather the rehabilitation specific data. In the hope that this will be the case, and with the help of Dr David Cunningham, Technical Director of the Central Cardiac Audit Database, we have specified data fields (e.g. race) that are the same as those in the Central Cardiac Audit Database.

Finally, although this project was designed to meet the needs of cardiac rehabilitation, the measures may be equally valid in secondary prevention and in all aspects of cardiac care.

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Notes on the use of the measures and record form

One record form to be completed for each episode of rehabilitation.

Assessment number: 1 = baseline (i.e. before intervention); 2 = the first follow-up; 3 = second follow-up and so on....

The Charlson Co-morbidity Index: This is copyright free and is reproduced as part of the record form for the data set (see following pages). It indicates the risk of mortality and is included to allow comparison of the case mix when comparing the results from programmes. It may also help to explain changes in health-related quality of life if new serious illnesses occur in that patient. Finally, it may be useful as a reminder for rehabilitation programme staff of other problems suffered by the patient.

Medications: These reflect the National Service Framework for Coronary Heart Disease guidelines. "NP" is used to indicate where in this patient that drug is contra-indicated as opposed to simply not having been prescribed. Therefore, for each drug one of the three options should be circled.

Date of Initiating Event: This refers to the date of the acute event leading to entry to the rehabilitation programme (MI, surgery, etc.).

Date Started Rehabilitation: This refers to the date the patient entered this phase of rehabilitation.

Date Completed Rehabilitation: This refers to the date the patient was discharged from this phase of rehabilitation.

The Hospital Anxiety and Depression Scale: This is copyrighted. To use the scale it is necessary to purchase a starter pack from NFER-NELSON Customer Services which can be obtained by phone (01753) 858961 or by e-mail information@nfer-nelson.co.uk. The pack includes the administration manual and 100 copies of the questionnaire. The current cost of the starter pack is £49.85 + VAT. Once this pack has been purchased, questionnaires can then be purchased in packs of 100 for £33.20 + VAT.

The Dartmouth COOP Charts: These are copyrighted. To use the Dartmouth COOP Charts it is necessary to purchase an information pack from The Dartmouth / Northern New England COOP Project; this can be done by phone +001 (603) 650-1220 or by e-mail Deborah.J.Johnson@Dartmouth.EDU. The pack includes a photocopy master of the COOP Charts and information on scoring. The current cost of the introduction pack is \$20 (including shipping). Once this pack has been purchased and the recipient has registered with the COOP Project the Charts can be photocopied and used without further cost.

The Short Measure of Physical Activity: This is copyright free and is reproduced on the next page.

THE SHORT MEASURE OF PHYSICAL ACTIVITY

1. Considering a **7-day period** (a week), how many times on the average do you do the following kinds of exercise for **more than 15 minutes** during your **free time** (write the appropriate number in the boxes)?

TIMES PER WEEK

A. VIGOROUS ACTIVITIES (HEART BEATS RAPIDLY)

(e.g. running, jogging, hockey, football, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming, vigorous long distance cycling)

B. MODERATE ACTIVITY (NOT EXHAUSTING)

(e.g. fast walking, tennis, baseball, easy cycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing)

C. MILD ACTIVITY (MINIMAL EFFORT)

(e.g. easy walking, yoga, archery, fishing, bowling, golf)

2. Considering a **7-day period** (a week), during your **leisure-time**, how often do you engage in any regular activity long enough to **work up a sweat** (heart beats rapidly)?

A. **OFTEN**

B. **SOMETIMES**

C. **NEVER/RARELY**

Data Set for Cardiac Rehabilitation: Record Form

Name of Patient:		Date:	
NHS number:		Local Patient Identification Number:	
Post Code:		Assessment Number (baseline =1):	
Date of Birth:		Date of Death (if known):	
Gender: female male		Mortality: alive deceased	
Ethnic Group (please circle): Caucasian / Black / Asian / Oriental / Other / Not Known			
Marital Status (please circle): Single / Married / Permanent Partnership / Divorced / Widowed			
CO-MORBIDITY INDEX (Charlson) (tick each diagnosis present in the case notes and then total the score):			
1	Myocardial Infarction	2	Hemiplegia
1	Congestive Heart Failure	2	Moderate to severe renal disease
1	Peripheral Vascular Disease	2	Diabetes with End Stage Organ Damage
1	Cerebrovascular Disease	2	Any Tumour
1	Dementia	2	Leukaemia
1	COPD	2	Lymphoma
1	Connective Tissue Disease (<i>incl. Rheum. Arthritis</i>)	3	Moderate to Severe Liver Disease
1	Mild Liver Disease	6	Metastatic Solid Tumour
1	Diabetes	6	AIDS
Total Co-morbidity Score:			
MEDICATIONS (Please circle correct answer) NP = Not Prescribed			
Beta Blocker	Yes No NP	ACE Inhibitor	Yes No NP
Anti-platelet Agent	Yes No NP	Statin	Yes No NP
INITIATING EVENT FOR CARDIAC REHABILITATION (Please circle main reason for referral to rehabilitation)			
Myocardial Infarction	Angioplasty	Valve Surgery	L V Assist Device
Bypass Surgery	Angina	Heart Failure	ICD
Transplant			
REHABILITATION PROGRAMME			
Date of Initiating Event	Date Commenced	Date Completed	
Did the Patient Complete the Rehabilitation Programme? Yes No			
REASONS FOR NOT ATTENDING REHABILITATION (Please circle those that apply)			
Patient not Interested/Refused	Too Far to Travel	Returned to Work	Mental Incapacity
Ongoing investigations	Physical Incapacity	Holidaymaker	Died
No Transport Other			
MAJOR RISK MARKERS			
Blood Pressure:		BMI:	
Cholesterol: TC:	HDL:	LDL:	Ratio: Triglycerides:
Has the Patient Smoked in the Last Four Weeks? (Please circle one) Yes No Not Known			
PSYCHOLOGICAL DISTRESS (HADS)			
HAD anxiety score:		HAD depression score:	
PHYSICAL ACTIVITY (Godin & Shepard)			
1a. Vigorous:	1b. Moderate:	1c. Mild:	
2a. Often:	2b. Sometimes:	2c. Never/ Rarely:	
HEALTH-RELATED QUALITY OF LIFE (Dartmouth COOP)			
Physical:	Emotional:	Daily Work:	
Pain:	Social Support:	Social Activities:	
Change in Health:	Overall Health:	Quality of Life:	

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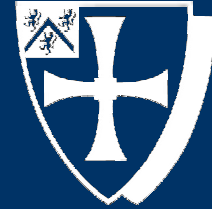
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