QUALITATIVE RESPONSES TO PULMONARY REHABILITATION – A REPORT OF THE CoHoRT STUDY OF PULMONARY REHABILITATION.

HE Horobin[1], CG Billings[2], JC Waterhouse[2], RA Lawson[2]
Sheffield Hallam University[1] and Sheffield Teaching Hospitals NHS Trust[2], Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Sheffield Hallam University

HTA

BACKGROUND

The NICE clinical guideline on chronic obstructive pulmonary disease (COPD) recommends that the NHS makes pulmonary rehabilitation (PR) available to all appropriate people with COPD.

PR is most frequently provided in a hospital setting. The facilities are thus limited and potentially inaccessible and not patient friendly.

- **PR performed in a community setting could be preferable in terms of access, and people might "buy in" to lifestyle changes more easily if these were instigated in the sort of place that you do something for yourself rather than a place where you go to have something done "to you"**
- **The study was funded by the National Coordinating Centre for Health Technology Assessment. The HTA however did not wish to fund any qualitative investigation of preferences and experience. We had been given ethical approval for this arm of the study and believed that the qualitative aspect would give valuable insight so funded a small study together with Sheffield Hallam University**

OBJECTIVE

- In addition to the quantitative measures required by the study, we conducted qualitative interviews for a patient perspective on pulmonary rehabilitation and the follow up support with the aim of adding meaning to the quantitative data

METHODS

There were five interrelated stages following ethics processes:

1. initial review of the research and preparation of the structured interviews
2. 2004 summer interviews recorded and transcribed
3. analysis of data with further development of structured interviews
4. 2005 summer interviews recorded and transcribed
5. further data analysis

PARTICIPANTS

17 full course attendees interviewed at 6 months
10 full course attendees interviewed at 12 months
5 full course attendees interviewed at 18 months
– all of these had been interviewed at 6 months
10 poor rehab attendees

Opinions stated are those of the participants and investigators and not the NHS

THE INTERVIEWS

- **Purposive sampling, recruited from clinic attendees and with telephone contact before hand –patients were interviewed prior to their physical testing in the hospital**
- **Semi structured interviews with questions focussed around the quantitative project. These lasted between 10 and 30 minutes (usually approximately twenty minutes)**
- **A quiet room was used and the conversation taped with simultaneous note taking**
- **All participants were guaranteed confidentiality and anonymity. Only 1 research participant refused to be interviewed**

THEMATIC ANALYSIS

- **Transcribed information was read, coded and themes generated**
- **One issue with this type of research is that the questions were formed according to the issues generated by the quantitative study, however participants were free to interpret these questions and also given opportunities to discuss the other issues that concerned them**

What did you think about the location of the pulmonary rehab?

- **Most came by car or taxi, approx a third by bus and a couple by hospital transport (hospital cars)**
- **Responses from drivers were dominated by parking and access issues, hospitals came in for particular criticism with patients sometimes spending a long time finding a parking space – parking at community locations was easier**
- **Public transport travelling tended to be more energy demanding for participants**
- **Community locations increased the time and money cost of travel, both through and increase in the number of buses taken and the non availability of 'hospital' transport**
- **Difficulties in transport were suggested as a cause of non attendance**
- **Other location Issues included: personal construct ideas, knowing where they were ,where they were going and how much energy this would take, safety, credibility and cost.**

Car Access Issues

'there was no problem parking because there was a little car park at the back you see' **community participant**

'it took me thirty minutes to an hour to park, I was j ust about to get the phone out and say that I wasn't coming, when someone pulled out and left a space across the road' **hospital participant**

'The hall location was good, as I could park close to home, it was a nice place and I preferrednot being in a hospital, it made it more sort of relaxed' **community participant**

'I hated trying to find somewhere to park at the hospital, I'd have preferred somewhere nearer to home' **hospital participant**

Bus Travel Issues

It was alright, the only thing was I found that there was a bus strike when I was doing it, and I don't have transport. I managed to get a bus into town, but then I had to walk to Endcliffe a couple of times. A couple of the chaps gave me a lift back into town a couple of times' **community participant** ***(town to Endcliffe is approx 2 miles)***

'I couldn't afford the bus fare,…' **community rehabilitation refuser**

'It took me two buses to get there, but I'm used to that, and after I'd go shopping, so it fitted in' **community participant**

'a place somewhere outside would have been much harder to get to' hospital participant

'I only lived 10 minutes away, so I walked to rehab and caught the bus back up the hill, getting to rehab anywhere's not really a problem for me' **hospital participant**

Personal Energy Considerations

'I was worried about parking, I worried about getting there most, rather than doing the thing itself' **hospital participant**

'Every time you get here, you're knackered, so that's a problem' **hospital participant (after walking from the car park)**

'in an area that everybody knows is good, because you don't know at a church hall, parking might be even worse' **community participant**

it was a big upheaval to get there' **community rehabilitation refuser**

Safety - Credibility - Cost

'You don't get the same environment, you sit up and listen to somebody in a white coat whereas in the community you might not take so much notice….I would probably walk into a church hall or something and think, well, this isn't exactly a medical centre' **hospital participant**

'coming to the hospital suited me well, I felt safe in the hospital' **hospital participant**

'It's cheaper to get to hospital, because if you're going to get hospital transport, it's free' **hospital participant**

'I had to pay for my own transport, a taxi, for the 2 sessions a week, it made it quite expensive' **community participant**

How did you find the follow up calls?

- **Many seemed to have forgotten that they had been called**
- **Of those that did remember, responses were generally positive as it was a demonstration of the hospitals continuing care**
- **Calls were not considered to have had an impact on them**

'I've forgotten that – I think there was something.. '

'nobody cares when you get to 70'

'it was nice, they encouraged me with my exercises'

If you'd been given the choice would you have preferred to have rehabilitation in the community or in a hospital?

- **There was a tendency for participants to like where they went for rehab and there was relatively little concern generally regarding location**
- **If a preference was expressed, it was for hospital – for a variety of reasons (familiar, safe, easy re public transport, not sure why)**

'I was dreading having to go to a church hall' **hospital participant**

'I think choice is a personal thing, it would be better in a hospital because that is where the medication is' **hospital participant**

'I don't mind where I go, assuming that they'd got all the equipment' **community participant**

'I preferred the hospital, the alternative was Handsworth and that's a long way, but also, one of the ladies on the course was taken quite badly and she was able to be seen straight away which was good' **hospital participant**

'I don't know why but I feel it's better coming to a hospital, but it was probably j ust as good in the church hall' **hospital participant**

What do you think you got out of rehabilitation?

Overwhelmingly what participants feel they achieve from pulmonary rehabilitation is a sense of control of their breathing, this tends to increase self reported confidence and reduced anxiety

' I really enj oyed rehab, it changed my attitude, I realised I wasn't alone. I had more energy and I'm still continuing with the exercises at home, I feel less short of breath now'

'..learning to control by breathing, learning to pace myself..'

'I benefited from the talks, it made me feel more motivated and I cope with my breathing better….it gave me a different outlook'

SUMMARY

- **The location of pulmonary rehabilitation is a complex and personally constructed issue and dealing with car transport alone will not address the problem for all – particularly non attendees.**
- **Participants in this project tended to prefer hospital based rehabilitation for a variety of reasons.**
- **Telephone follow up calls don't make any self reported difference to adherence.**
- **This research demonstrates that pulmonary rehabilitation results in a better sense of breathlessness control in participants. Participants are perhaps less aware of physical responses, or perhaps this 'breathing control' is how physical improvements are perceived (Nicholls 2003)**

Nichols DA (2003) The Experience of Chronic Breathlessness. Physiotherapy Theory and Practice. 19:123-136

PERCEIVED HEALTH BENEFIT AFTER PULMONARY REHABILITATION
A REPORT OF THE CoHoRT STUDY OF PULMONARY REHABILITATION.

JC Waterhouse[1] MC Clarke[1] SJ Walters[2] RA Lawson[1]

Sheffield Teaching Hospitals NHS Trust[1] and School of Health and Related Research, University of Sheffield[2]

BACKGROUND

The NICE clinical guideline on chronic obstructive pulmonary disease (COPD) recommends that the NHS makes pulmonary rehabilitation (PR) available to all appropriate people with COPD.

We are performing a study comparing effect of setting on the outcomes of PR. The primary outcome measure is change in Endurance Shuttle Walking Test (ESWT). This test is performed on the same 10 metre flat walking circuit as the Incremental Shuttle Walking Test (ISWT), but asks the subject to walk at a steady pace at approximately 85% of their estimated VO_2 max. This allows a comparison walk to be carried out at exactly the same walking speed, not forcing the subject to walk faster. It has a greater potential to reflect change in the endurance aspects of PR

Secondary outcome measures involve Health Related Quality of Life (HRQoL). Instruments used include Generic and Disease Specific Questionnaires.

The study was funded by the National Coordinating Centre for Health Technology Assessment

OBJECTIVE

- In a recent UK Health Technology Assessment Board funded study to assess the outcome of pulmonary rehabilitation, per cent change in Endurance Shuttle Walking Test (ESWT) was used as primary outcome measure. Whilst this is a robust, validated measure of exercise capacity, its relationship to perceived change in health is less clear.
- At each assessment visit post rehabilitation the subjects were asked to rate their health change since the last visit. All the HRQoL measurements including this one were completed BEFORE the patient had their endurance shuttle walking test measured.

THE QUESTIONNAIRE

- This questionnaire was administered after the subject had completed their other HRQoL questionnaires This was to benefit from them having been thinking of all the effects and was created to collect a "global" impression of HRQoL.

All opinions stated are those of the investigators and not the NHS

GLOBAL HEALTH CHANGE QUESTIONNAIRE

Since the last time you saw us, has there been any change in your overall health related quality of life?

Has your overall health related quality of life been;

Worse, about the same, better

Subjects answering worse or better were then invited to quantify the magnitude of change, with a choice of:

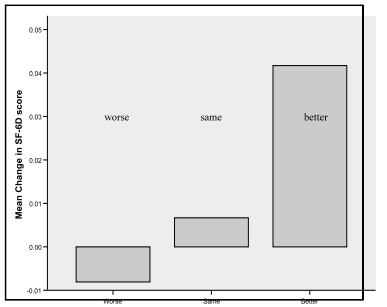
Almost the same, hardly any better (worse) at all
A little better (worse)
Somewhat better (worse)
Moderately better (worse)
A good deal better (worse)
A great deal better (worse)
A very great deal better (worse)

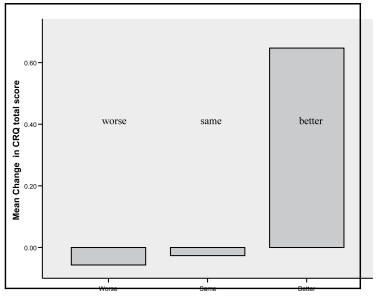
Description	n	Mean change in time (minutes)	% change in time
WORSE	16	0.15	21
SAME	46	4.39	78
Almost the same, hardly any better at all	0		
A little better	18	3.60	61
Somewhat better	12	5.20	100
Moderately better	27	4.90	92
A good deal better	30	5.98	110
A great deal better	9	6.24	114
A very great deal better	1		

- When self perceived change was classified into three levels (worse, same, better) there was significant evidence (p=0.07) of a difference in change in time walked in the expected direction (people feeling "better" having the greatest increase in walking time)

COMPARISON WITH OTHER HRQoL

Secondary endpoints in the study used HRQoL qustionairres (the generic SF36 version 2 and the disease specific Chronic Respiratory Questionnaire). Comparing the three groups (same, better worse) with these well validated instruments gave similar results





DISCUSSION

A significant group of patients have a large increase in ESWT but express no perceived benefit to their overall health. Physiologists performing the post rehab assessments had anecdotally noted that some people seemed very surprised that the increase in ESWT was so great. Other people were expecting to perform well and were looking forward to finding out just how much better they were.

It is interesting to speculate why this might be.

We suggest that those people who change their lives and are already doing more exercise have realised that they can do more and thus feel that their HRQoL has changed for the better. Those people who have done the PR sessions as a treatment but not extended the things that they do in real life are not aware of the benefits that they have gained from PR.

CONCLUSIONS

An increase in ESWT below 60% is unlikely to result in perceived benefit.

An increase of greater than 100% is required to be confident of benefit.

A significant number of people have objective but not subjective benefits from pulmonary rehabilitation

The global health change questionnaire is a robust instrument

For additional information please contact:

Judith C. Waterhouse
[Respiratory Function Unit
Royal Hallamshire Hospital, Sheffield

j.c.waterhouse@sheffield.ac.uk