

# Chronic Pulmonary and Chronic Cardiac Rehabilitation: Staff Perspectives and Patient Experiences

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## Research Article

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### ABSTRACT

**Background:** Cardiac (CR) and Pulmonary Rehabilitation (PR) programs have been shown to enhance self-management, improve quality of life and decrease dependence on healthcare services. Patient Outcome Measures (POMs) such as Quality of Life (QoL) questionnaires are essential to evaluate these programs' ability to measure treatment effectiveness. However, many of the present QoL instruments either underestimate or overestimate the response to the change in health status in these programs.

**Aim:** This study sets out to analyse discussions by patients and staff engaged in CR and sPR. These discussions occurred both pre and post program to compare and contrast what changes for these patients.

**Study design:** This is a qualitative descriptive study.

**Methods:** This study analyses the data collected both pre and post program, from those patients and staff participating in outpatient CR and PR programs. Focus groups and individual interviews were audio-taped and transcribed verbatim. Transcripts were analysed, tabulated and coded for common themes, then a cohesive story was formulated to explain the concepts put forward.

**Results:** Patients and staff discussed some common themes however terminology was different between the two groups. There is also a change in patient's perspective from pre to post rehabilitation, patient's expectations change from wanting to get back to a "normal" state of health to accepting living within "certain limits".

**Conclusion:** This qualitative study clearly shows a "Response Shift" in patient perceptions pre to post CR and PR program and that language used by patients is very different to that of health staff and often is different to present POMs used in these programs.

## INTRODUCTION

Function is the ability to participate and be active whereas disability is identified as being the result of impaired interaction between individuals and the environment <sup>[1]</sup>. Impairments due to chronic cardiac and pulmonary disease have become increasingly common causes of disability. These impairments are often brought about by long periods of relative inactivity, so it is important for chronic disease patients to regain their physical functioning as early as possible after an illness episode and avoid prolonged hospital stays <sup>[2]</sup>.

Cardiac and Respiratory Rehabilitation have been shown to enhance self-management, improve quality of life and decrease dependence on healthcare services. The length of these rehabilitation programs are around six-weeks in duration and are provided at a number of locations around the Hunter New England Health district <sup>[3]</sup>.

Patient Outcome Measures (POM) is one way to measure an individual's perception of their health and life quality, and they are essential to evaluate a patient's experience of Chronic Cardiac (CR) and Chronic Respiratory (PR) Rehabilitation Programs.

Individuals perceive and weigh aspects of their lives in ways that are particular to them and as such POMs provide the ability to measure treatment effectiveness [4-6].

Current POMs used in Cardiac and Respiratory Rehabilitation do not always detect changes when patients improve or deteriorate. This failure to detect response to change in rehabilitation can be problematic in the evaluation of these programs and making comparisons across programs [7] (Figure 1).

This qualitative study is part of a larger project that sets out to establish a new instrument that will be more “responsive” to the change caused by the program and therefore capture the patient’s experience of its effectiveness more accurately.

### DESIGN AND METHODOLOGY

This study uses a qualitative descriptive research methodology to determine the changes in perception before and after the rehabilitation process. While evaluating conversations with patients participating in the program, it is valuable to measure the perspectives of staff as well [8,9].

Focus groups and open-ended interviews were held with staff and patients. These focus groups and individual interviews were audio-taped and transcribed verbatim. Transcripts were analyzed using a comprehensive, thematic, qualitative, content analysis [10]. These discussions were then examined and all statements that contributed to answering the research question were tabulated and coded. This coding took the form of both placing statements in common topics and in common conceptual categories [11-14]. Tables generated by this data analysis enabled the researcher to determine the areas that were felt to be both common and important discussion points and so place these discussion points into themes or domains.

A cohesive story was formulated to explain the concepts put forward and data were validated with another senior qualitative researcher.

### INTERVIEW QUESTIONS

Focus groups and individual interviews commenced with an initial question to stimulate a free-flowing, unstructured discussion.

“What do you perceive to be the change that the rehabilitation process brings about?”

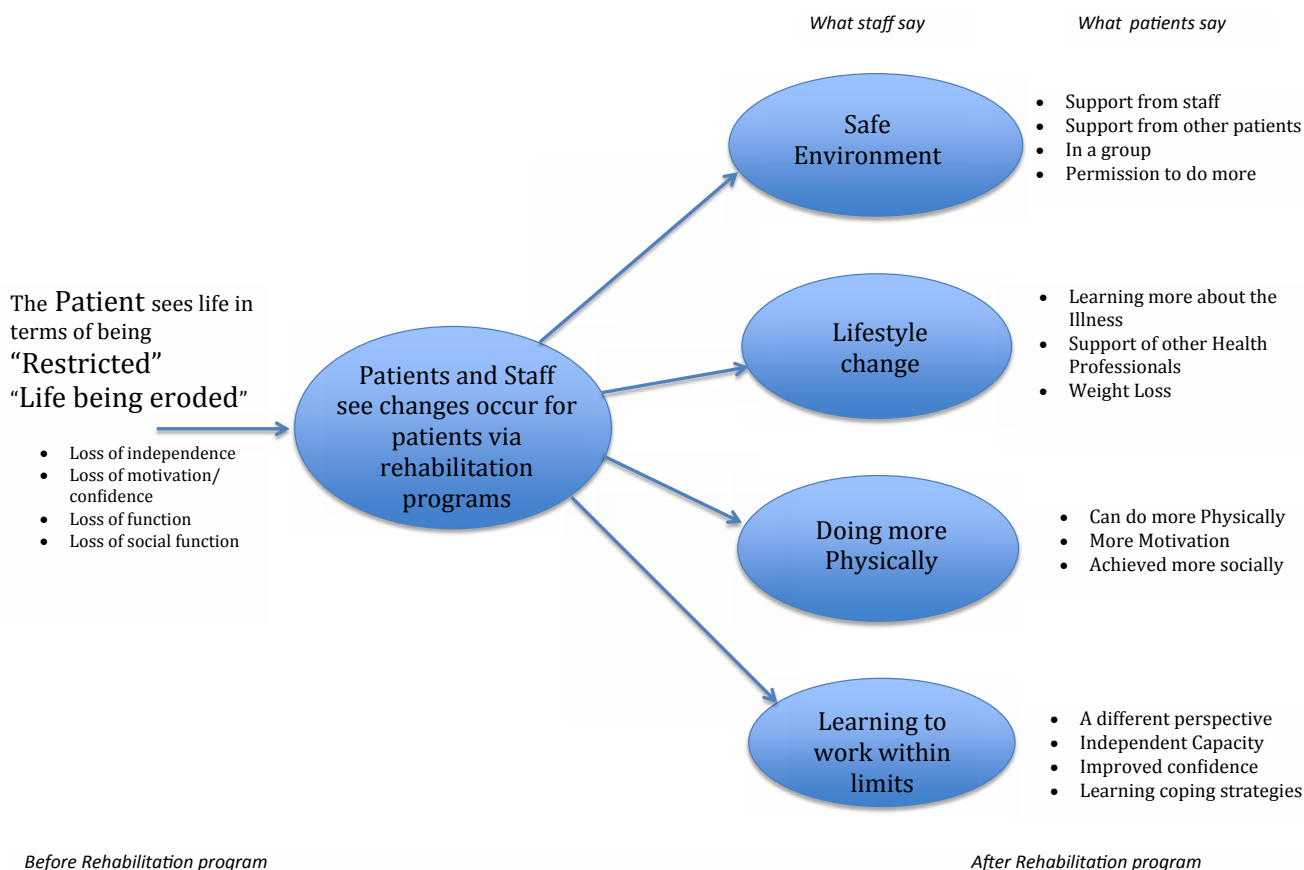


Figure 1. A composite summary of views from patients and staff regarding what has changed for the patient during the Cardiac and Respiratory Rehabilitation programs. Patients go from seeing themselves as “ill” to having a “workable option”.

This question was adapted for the different circumstances of staff focus groups, pre-rehabilitation and post-rehabilitation patient interviews and focus groups

### Participants

Patient focus groups were initially conducted pre and post rehabilitation programs; they however presented a number of logistical challenges in terms of data collection as they were enrolled into the rehabilitation programs on a rolling basis and were at different stages when the focus groups were arranged. Individual interviews were conducted for the rest of the patient data set.

Staffs directly involved in the rehabilitation programs, allied health professionals and nursing staff were interviewed in two focus groups, 6 in the one group and 10 in the other. Individual interviews were conducted for 2 doctors and 1 nurse who were not actively involved in the 6 week rehabilitation program.

Ethics application to access patients was sought and acquired from the Ethics committee of Hunter New England Health. Patients and staff were recruited from both regional and urban rehabilitation programs. Most programs provide separate cardiac and respiratory rehabilitation, although one provided a generic program that encompassed both forms of rehabilitation.

## RESULTS

### Results - Patients

There were 41 patients participating in interviews and focus groups, of these participants, 25 patients (11 men and 14 women; 5 were respiratory and 20 were cardiac) were involved in pre-program discussions and 16 (7 men and 9 women; 3 respiratory and 13 cardiac) were involved in post-program discussions. The 16 staff members from the focus groups were mainly female with only one male staff member.

### Pre-Rehabilitation

The topic discussed with patients, was “What do you hope will change in terms of your illness in the rehabilitation program?” This elicited responses that appeared to resonate with the patients’ concept of identity. Below is a comment from one of the patients as to how their illness had effected and changed their life.

“I used to look after my grandson before I got sick and he’s only eighteen months old and I haven’t got the confidence to start looking after him again. Um cos I’m worried he might be a bit too much for me um. I look after my ninety one year old mum, um I’ve noticed that I’ve backed-off a lot doing for her what I used to um in case I have another heart attack you know what I mean, it’s always I’m always conscious of it, always conscious of it” (part-6B).

Patient discussions ranged from “I cannot do any of the things I used to do” (part-19B) due to their illness to “I need a sort of kick start” (part-6B); their responses can be grouped into three categories; the past... “What I was” ...the present... “What I am” ...and the future... “What I can be”.

“What I was”

Patients spoke of having a *social function*, being socially active, “I used to go to the club” (part-5B), with friends and family. They spoke of being *independent*, “I used to walk the dog” (part-1NB) and *physical functionality* “I used to swim a kilometer every morning and then it got less and less and less...” (part-7B) and also “I used to walk everywhere...” (part-13B).

“What I am”

At the beginning of the rehabilitation program patients expressed feelings of being *overwhelmed* by their illness... “anger and frustration” (part-21B), of... “starting to worry a bit” (part-10B) concerning their illness, that their lives were about *compromise*, “I have got around it in another way” (part-8B)... “I should be limiting what I do” (part-15B). They expressed frustration about their physical welfare and *loss of function* “I can hardly walk from here even to the door” (part-1NB), that their illness was affected by *other problems* “my hip’s getting worse” (part-2) and that they *could not be bothered* “It’s like it’s not worth it” (part-5B).

“What I want to be”

Patient’s expectations of what they would like to see occur due to the rehabilitation programs were expressed as... “What I want to be”. They generally had expectations of *change* “any change is a bonus” (part-5B) and this encompassed gaining *information* such as, “advice on how much activity I can do and advice on diet and do’s and don’ts” (part-15B). They expected to find more *motivation and confidence* “to get going a bit better” (part-6B) and that they could *function* again, “I just want to go back to playing bowls” (part-19B) and “I’d like to be able to walk without having to stop” (part-20B).

### Post-Rehabilitation

The discussion for patient’s post- rehabilitation centred upon the question “What has changed for you in terms of your illness due to the rehabilitation program?” The changes that occurred for patients from the beginning to the end of the rehabilitation program could have been a natural progression of their healing process, however many expressed concepts, that were in line with

what staff believed. Patients felt a change physically as expressed by one participant (part-22C).

“It’s given me a lot more confidence to go out and do the exercise um it made me realize it can make a difference and I think that was probably the biggest thing that I found that beforehand I wouldn’t go out and exercise quite as much and wouldn’t push myself to make that effort whereas now I find that if I push myself to make an effort and do it I feel better within myself not only because of what’s happened to me, but I feel better, I feel happier um I’m a lot clearer with my thinking and things like that.”

And they also felt that change had been brought about by an increase in knowledge (part-25C);

“Yea I think during the rehab I think because it’s giving me more clearer thinking and all that it’s made a positive change in the way I relate with my relationships in life and all that so I think it’s definitely been a big improvement and with the information that I’ve got through the rehab I’ve been able to pass that on and it’s also given other relatives and other people around me the knowledge of what’s expected of me and what I need to do to get back to being fit and healthy.”

Overall there was an overwhelming sense for patients that change had been brought about due to their participation in the rehabilitation program... “I feel like I got a reason to live like I want to do things now” (part-3C). Once more patients expressed this change generally in terms of...comparing the past... “What I used to be like”; to the present... “but now”. Patients would also describe in greater detail... “All the things that I can do now” and at times would explain what they intend to do in the future... “What I plan to do”.

“What I used to be like...” to “...but now...”

Within this context patients started interviews often differentiating *what they were like* before they commenced the rehabilitation program; “last year I walked in a place and looked like death...” *and now*; “got more color in my face” (part-24C). When describing what they *would have done* previously “I’d go and crawl in to bed every afternoon, like a big sook...not now I go outside” (part-3C). For another patient there was a *lack of knowledge*, “...I didn’t know how much I was allowed to do, I thought that I was a cripple...” And now... “Here we are whizzing around on bikes...” (part-7C). For another patient it was a *change in attitude*; “I think now what am I gonna do this afternoon...where before I’ll go and lay in bed”. Also for some patients they observed a *mood change*; “I was very short tempered as the grandkids will tell ya...” And now “I’m not as short tempered as I was...” (part-3C).

“All the things I can do now”

There were many descriptions of what patients had achieved in the program in terms of *functionality*, “I don’t get puffed. I walk more...” (part-3C) and an *understanding of their illness*, “I have a better understanding of my heart, my body and how everything works...” (part-10C). Some patients expressed a marked *change in attitude*, “I enjoy life now...” (part-9C) *mood*, “just feel a lot happier that’s all...” (part-9C), *motivation*, “it does give you a lot more motivation to get amongst it...” (part-18C) and *confidence*, “I’ve gained some confidence back in myself...in your ability to do things and knowing the capacity of your body” (part-10C).

Social interaction with *other patients* was a major factor in their rehabilitation, “there are other people that have been through what you have been through...” (part-10C) also “you get to know the faces...” (part-10C) and “well at least I’ve socialized with some people here... (part-6C). *Interaction with the staff* was important as well, for many of the patients, “I’m not as worried I feel the girls have looked after me...” (part-8C) and *other professionals* who were involved with the program, “listening to the professionals how to handle stress has been a big plus...” (Part-1C).

There was a *change in relationships* with family, friends and other social networks as part of the rehabilitation process that occurred for patients,

“I feel better than what I did before, I even visit my sisters and that’s a rarity” (part-3C) and “I’m back at the croquet...last week I won two championship games” (part-5C).

“What I plan to do”

Many patients spoke of plans to continue their rehabilitation even after the program finished, “I actually got my exercise bike out of the garage” (part-10C), others were also motivated to continue with other types of exercise “I’ve even talked to a girlfriend about maybe going swimming this year” (part-8C).

## Results-Staff

Staff discussed the concept of what change they saw and how it affected patients throughout the rehabilitation program.

Staff saw the rehabilitation participant as progressing from a patient who “sees themselves as ill” (part-3A) to a person “when people feel better they want to do a little more” (part-6A).

A comment from one of the staff puts this in context, “I generally see a Weller patient and that reflects the whole process that improves the control of heart failure and there are many, many different little components of that. I generally see a patient who’s doing more than I had expected them to be able to do from how sick they were when they were in hospital and I generally see a patient who smiles and says “giddy doc, I don’t feel too bad”. That’s a very satisfying response to get from a patient; particularly you know how sick they were and how sick their heart remains.”

Staff comments about patients essentially focused on 2 areas of change and the different aspects that these areas contributed to.

One area of change came about through providing information, which was supported by a variety of health professionals. It encompassed changes in smoking, diet and energy conservation. Patients became more receptive to lifestyle change including exercise; there was a feeling of doing more... "able to have a shower, get dressed and walk up the steps without too much distress" (part-6A). This change was brought about by social interaction, by patients supporting each other in a group... "in the same boat" (part-14A).

The staff felt the rehabilitation programs brought about a second area of change; here patients learned coping mechanisms to... "work within their limitations" (part-15A) and... "building confidence" (part-18A) and patients were able to *overcome boundaries* to... "overcome their fear" (part-11A) of setback by being in a... "safe environment" (part-8A) . Rapport between patients themselves and between staff and patients allows for a feeling of trust and *acceptance*... "if people are heard, they are listened to" (part-5A).

Many of the comments were often followed up by the staff with anecdotes of their experience with and interaction with patients within the program, such as the comment below which tries to explain the change in patient's overall change from the beginning of the program to the end of the program... "you can see it on their face, you know, they have this I don't know...fear.... and then at the end of the program they've just blossomed" (part-7A) and "I have a patient who is just finishing up and when he started he couldn't hold his three year old child and now he can he's so delighted" (part-17A).

### **What Changed for Patients: Functional and Behavioural Change?**

This qualitative study of patients and staff involved in cardiac and pulmonary rehab programs identified different perspectives on the role of these programs. These programs bring about change for the patients. To enable them to function in a more independent capacity and behavioral change which is supported by information gain and risk factor modification<sup>[3]</sup>. And both of these changes are brought about and encouraged by interaction with other patients, staff and other health professionals.

Behavioural change is closely tied to functional change, with lifestyle modification to reduce risk factors and encouragement to lead an independent life. This change is dependent on the team process to help patients gain information and make informed decisions by listening and facilitating these changes. It is also helped by the encouragement of fellow patients in the group process of the rehabilitation program.

Both patients and staff believed overwhelmingly that the cardiac and respiratory rehabilitation were worthwhile programs to participate in.

#### **Patients: Pre to Post Rehab**

The change in demeanour in patients from pre to post program was quite marked, this was reflected in their statements, they went from a feeling of being overwhelmed "I'm just not managing" ...to... "feel a lot better now...just feel a lot happier"(part-9C). It was the loss of physical independence for patients and the normalization of the illness process; that is, taking medication, and becoming dependent on medical specialists, that seemed to erode patients' views of themselves.

The social support that the rehabilitation team imparted to patients allowed them to feel in a safe environment... "I've just exerted myself that much in class and I didn't drop down dead" (part-7C). This seemed to enable them to initiate the change... "I can do more things" (Part-10C) that was necessary for them to once again engage in a fulfilling life. This life they saw as sometimes being slightly different to the one before but still seemed to allow patients to participate and be engaged.

#### **Staff Pre to Post Rehab**

The staff involved in these programs believed that working on a patient's physical function and increasing their knowledge of their illness appeared to benefit the patient's feeling of well-being and helped them to both come to terms with their illness and to move on towards a more normal life. By teaching patients how to adjust to their illness and to self-manage, the staff felt that the rehabilitation experience was of great importance.

One main aspect of the program that was discussed frequently and appeared to be of relevance to staff was the rapport and support that patient's appeared to give and receive from each other, the group approach for them was a major benefit of the programs. They also were aware and agreed that the rapport and support that the staff and other specialist health workers gave to patients in the course of the rehabilitation period allowed for patient's to work through problems that they may normally not have discussed in other shorter types of clinical programs. This group dynamics was a major discussion point and one that staff believed was underestimated by administrators of the rehabilitation programs. Staff and patients discussed some common themes, the main being the loss of physical function due to illness and then the increase once again in physical functionality due to the exercises patients performed within the program. Also both groups believed that the support of patients, staff and other

medical personnel was an essential and necessary component of the program. Patients however whilst they acknowledged the change due to an increase in physical functionality saw the second change as an increase in knowledge, and did not recognise this in terms of being a “behavioural” change.

## **DISCUSSION**

The major difference between staff and patients is in the terminology used. Staff used sentences such as “education in lifestyle change and energy conservation” and “acceptance of working within limits”. Patients on the other hand spoke of “being able to do more” and how they “knew more” at the end of the program.

To evaluate a patient’s participation in the rehabilitation process often POMs are used, these questionnaires are seen as essential to measure an individual’s perception of their health and life quality. However these measures come with a number of issues. The main issue is that these current POMs are not always as “responsive” to the rehabilitation process as researchers and clinicians expect them to be. The result is that often these POMs either overestimate or underestimate the patient’s response to treatment in this setting. This study highlights two particular problems that can arise with charting a patient’s experience of the rehabilitation process.

Firstly, the differences in terminology between a patient’s and a health professionals perception of what is changing for the patient as a result of participation in these rehabilitation programs is not exactly expressed in the same terms. This is consistent with the literature and shows that it is important to consult the patient when describing their experience and language must reflect what the patients themselves would use. The language that health professionals use is not always easily understood by patients, therefore if this language is also used in POMs, patients may not be responding correctly to the questions asked.

Another important problem is seen in the difference between the pre and post rehabilitation program conversations with patients. In the pre-rehab phase patient’s hope that the change the rehabilitation program brings is that they will be back to a state of normality. That is that their health will return to the state that it was before their “illness” occurred. In the post-rehab conversations we see that this has changed to an acceptance of living within certain limits and those patients are content to accept those limitations and can now work and live a fulfilling life within those limits. This is Response Shift (RS) and it is a reflection of the change in internal evaluation standards that exists in one individual regarding a specific construct. The construct here is the change in health status that an individual believes occurs due to the rehabilitation process <sup>[15,16]</sup>.

POMs in the rehabilitation setting do not fully take into account response shift. Each questionnaire has a set number of constructs; they allow an evaluation of those constructs but do not allow for a change in those constructs. If those constructs no longer are relevant for the patient this is not reflected by the POM. The patient’s responses to the POM may once again overestimate or underestimate the patient’s response to treatment.

## **CONCLUSION**

This study highlights the differences in perspectives and experiences between patients and staff involved in Cardiac and Respiratory rehabilitation programs. Existing POMs do not take into account these differences and as a result lead to an under- or over-estimation of true treatment effects in this population of patients.

The results from this study go towards support of the concept that individualized instruments subscribe to and that is, it is important to seek the opinion of the patient when attempting to describe their experience.

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