

PROS & PROMS – WHAT ARE THEY? THE DYSPNEA EXAMPLE.

Hi everyone, and welcome back to LungFIT Pulmonary Rehabilitation Podcast. Hard to believe that the podcast is already 6 months old! I want to start by thanking all our listeners for your support. It's so exciting to look at our podcast statistics and see the numbers of downloads grow, and see that our listeners are from all over the world. It's been a ton of fun to produce, I hope you've found at least some of the information helpful in your pulmonary rehab program.

For this episode, I want to talk about outcomes, and specifically those that the patient reports – versus ones that you as the pulmonary rehab health care professional measure. So we're going to talk a bit about PROs, also known as patient-reported outcomes, and PROMS, which are patient-reported outcome measures. What are they, and why are they important in pulmonary rehabilitation?

Let's start by talking about outcomes in general. We know that pulmonary rehab improves aerobic capacity and muscle function. This is shown by work that showed improvements in VO₂peak, or maximal workload, and or six minute walk test distance. And there has been a number of studies which have explored the mechanisms by which these improvements may occur, such as changes in muscle structure and function, cardiovascular conditioning, or improvements in technique. So these outcomes are related to changes that occur in large part due to physiological and/or performance-related mechanisms. And they can be directly observed and measured, in some way. So we can directly measure the distance someone walks, or can measure VO₂peak, as long as we have the skills and resources to do this.

But we know that there are other improvements in health-related outcomes that we are not able to directly observe, and that require the patient to tell us about them or rate them for us in some way. Probably, in the context of PR, one of the most obvious ones is the symptom of dyspnea, or shortness of breath.

Our patients have told us, via research studies, or via communication with us as health care professionals, that dyspnea is one of the most challenging symptoms they must deal with, as part of having a chronic lung disease. Dyspnea limits the ability to be physically active, it can trigger anxiety and is also made worse by anxiety, it affects overall quality of life, and it can progress to the point where even the most basic activities of daily living, such as getting dressed, are difficult. It is also a symptom that many patients fear when they consider what happens at the end of their life, and palliative care includes treatments to alleviate dyspnea in those moments.

So, it was a key outcome to be able to measure, to see if pulmonary rehabilitation would have an impact on dyspnea. But, as you all know, we, as health care professionals, can't directly observe dyspnea. We can see if someone appears short of breath, or not, based on observation of their work of breathing and their breathing frequency. But we can't provide the subjective context to their apparent shortness of breath – it is hard, somewhat hard, distressing, appropriate? Only the patient can report on their dyspnea. We have all seen patients who appear to be very short of breath, but when asked to rate it, they call it 'mild'. And conversely, we have had patients that don't appear short of breath at all, but rate their dyspnea hard or worse. It is precisely the interplay between the physiological breathing and the psychological or subjective experience of that breath that factors into the concept to dyspnea, and so it requires the patient to report this themselves, instead of having it rated by the health care professional.

So why is it important to PR programs to include patient-reported outcomes? Well, it's hard to appreciate the impact of any measured gain in pulmonary rehab without understanding the context. I want to share with you a quote from a research study I did, in the last century! that explored some elements of patient-reported outcomes. I'd like to read you this quote from a woman who had completed pulmonary rehab. She said.... *I didn't get excited about anything [prior to the program]. I didn't think I was depressed. But I didn't feel great pleasure about anything or great remorse about anything.*

(After rehab) I'd been watching television and it was particularly funny. And it just tickled my funny bone and I started to laugh. And I couldn't stop laughing. And all of the sudden I looked at my husband and he wasn't looking at the television. And I said, "What's the matter?" and he said, "You know, this is the first time in about three years I've seen you laugh?"

Now, it's not depression that kept me from laughing, it was fear of losing my breath...Now it's wonderful! It's just marvelous. To hear a joke and laugh at it...after years I have been able to laugh again and enjoy.

You can see that understanding the patient-reported outcomes, such as dyspnea, is so important to understanding the impact these programs have on people's lives. I'm sure you heard similar comments from your own patients. And other patient-reported outcomes have also been noted as important to patients, in addition to dyspnea. These include fatigue, pain, anxiety, depression, confidence in managing their condition, and overall quality of life.

So, if patient-reported outcomes are important (as patients and health care professionals have indicated), how can they be measured. To measure them, we need PROMS, or patient-reported outcome measures. It's important that the PROM are suitable for pulmonary rehab – they should be valid and reliable in the patient population you are using them with, and they should be able to measure any changes that happen over time, specifically the time frame of your pulmonary rehab program. For example, if you have a measure of fatigue that asks "How fatigue have you been over the last year", then any change in fatigue related to pulmonary rehab may be lost in a measure where the patient has to consider an overall average level of fatigue over a long time period.

So I'd like to highlight a few commonly-used patient-reported outcome measures for use with people with COPD. You may be already using these, but perhaps you haven't really looked closely at them before.

The first one is the modified MRC dyspnea scale. I'll put a link to the scale in the show notes. This is used to measure, what I'll call here, functional dyspnea. There are five statements, and the patient selects the statement that reflects their current status with respect to their shortness of breath. I'll read them out... Grade 0 is "Not troubled with breathlessness, except during strenuous exercise". Grade 1 is "Troubled by shortness of breath when hurrying or walking up a slight hill". Grade 2 is "Walks slower than people of the same age due to breathlessness or has to stop for breath when walking at own pace on a level surface". Grade 3 is "Stops for breath after walking about 100 m or after a few minutes on a level surface". Grade 4 is "Too breathless to leave the house or breathless when dressing or undressing".

The instructions for this scale are:

1. Instruct the patient to choose the one best response.

2. Can read the statements to the patient.
3. No half-marks, encourage the patient to choose the best one.

If you have used the modified MRC Dyspnea Scale, you may have had patients who have questioned Grade 4, “or I am breathless when dressing”. This has always been a bit problematic for patients with COPD answering this, they may be only at a Grade 1 or 2 for their day-to-day lives but are always breathless when bending over to put on socks or shoes. I have often focused more on the first part of the phrase I have to say when I use this scale.

This measure is a strong predictor of mortality, and is responsive to PR in that participants can decrease their score by 1 or 2 values. It is a good indicator of the day-to-day impact of dyspnea. So how can this measure be used in your clinical practice. Here are some suggestions for you:

1. Take a baseline mMRC measurement to assess the level of dyspnea in a person’s day to day life.
 - *Does dyspnea have a major impact on their day-to-day life?*
 - *What strategies can you use to reduce this impact? [breath control during hill walking or stair climbing, strategies to reduce dyspnea when getting dressed, pacing during walking?]*
 - *Do you have the resources to support this patient? [your own training, resources, equipment]*
2. Take the measure during and/or after the end of the pulmonary rehabilitation program to measure the impact of the program on their dyspnea level. Plus or minus 1 grade has been shown to be a clinically important difference to the patient.
3. Calculate average dyspnea level at baseline and the average change after rehabilitation of your patient population
 1. *Compare your patient population with research populations, or change over time in your program, or compare with other regional programs*

You can see how this one measure can be used in several different ways.

The next one I’d like to talk about is the Borg Breathlessness scale, the one using the 1-10 scale. This is another patient-reported measure of dyspnea, but its best used to measure dyspnea during activity. It’s an indication of how your patient is responding to the exercise in your program and when they are out on their own. I’ve linked to this scale in the show notes. As you can see, it’s a 1-10 scale, with numbers to indicate the severity, and text descriptions related to those numbers. The Pulmonary Rehabilitation Toolkit from the Lung Foundation of Australia has this suggested script: “This is a scale that asks you to rate the difficulty of your breathing. It starts at number 0 where your breathing is causing you no difficulty at all and progresses through to number 10 where your breathing difficulty is maximal. How much difficulty is your breathing causing you right now?”

How can this scale be used in your pulmonary rehabilitation program? Here are some suggestions for you:

4. Take a resting and during/after exercise BORG measurement to assess the level of dyspnea at rest and with activity. *Is the level of dyspnea greater than you expect? Are other comorbid*

conditions contributing to dyspnea? Does the resting dyspnea level indicate a change in the patient's status?

5. Take a measurement during exercise. The Borg scale is a good way to gauge the patient's response to the exercise intensity. Generally speaking, the patient should be exercising at an intensity where the Borg Dyspnea scale is 3-5, which is moderate to somewhat hard.
6. Take a Borg measurement at the same initial exercise intensity as when your patient first started the program. For example, if initially in their program they were able to walk on the treadmill at a speed of 2kmh, 0% grade for 10 minutes and their Borg rating was 5, if they were to do the same exercise – same speed, grade and time – would their Borg rating change? Its possible that with increased fitness, their perception of dyspnea may have decreased at that exercise intensity. Its another way of showing patients the impact of pulmonary rehab on their dyspnea level.

These are just two measures of dyspnea. There are others, for example: the Baseline Dyspnea Index and the companion Transition Dyspnea Index, which rate the initial level of dyspnea and how that dyspnea has changed. There is the University of California San Diego Shortness of Breath Questionnaire, which assess the level of dyspnea with several activities of daily living. And dyspnea as a domain also shows up in several quality of life questionnaires.

I've linked to several of these measures in the show notes. And I would encourage you to have a look at these different measures, and see how they may be used in your program. What additional information do they provide, that will help you understand your patient as part of a detailed assessment, assess their level of dyspnea both during exercise with you and as part of their day to day activity? How can the results of the measure help you and your patient understand the impact of the program on their dyspnea, and how can you report this to the patient and to their referring physician?

I hope this episode got you thinking about Patient-Reported Outcomes and Patient-Reported Outcome Measures in general, and dyspnea measurement in particular. In future episodes, I'll discuss other outcome measures, patient-reported and otherwise, and how they can be used to benefit your pulmonary rehabilitation program.

Thanks for listening, and until next time, keep moving!