

THINKING ABOUT PREMs AND THE PATIENT EXPERIENCE OF PULMONARY REHABILITATION

Hi everyone, and welcome back to LungFIT Pulmonary Rehabilitation Podcast. In the last episode, I talked about PROs and PROMs, which stand for Patient-Reported Outcomes and Patient-Reported Outcome Measures. In addition to outcomes that can be fairly easily quantified, like 6 minute walk distance or muscle strength, PROMs are those symptoms and other disease attributes (such as dyspnea, fatigue or pain) that can't be directly observed but are instead reported by patients using various scales and other tools. Those measures are very important, as they reflect outcomes that patient tell us are of primary concern and have a large impact on their day-to-day lives.

But there is also a different kind of outcome measure that isn't used or talked about as much in pulmonary rehabilitation, and those are the PREMs – or patient-reported experience measures. What is a PREM?

The Canadian Institute of Health Information states that PREMS really capture the process of health care. They state that PREMS “...Captures the patient's view of what happened during their healthcare visit (process of healthcare)” – e.g. communication and trust in staff, cleanliness, timeliness.” Now you might be thinking, “oh we do get that information, we have a patient satisfaction questionnaires”. Patient satisfaction questionnaires can be very helpful, but there is now a realization that patients will often report high satisfaction, especially in scenarios with scarce resources, because sometimes any service can feel very satisfying compared to no service at all. But when used appropriately, a PREM can inform you on what aspects of your program can be improved.

So in response to a general need in health care to understand patient experiences, the Canadian Institute of Health Information developed the Canadian Patient Experiences Reporting System. I expect there are similar systems available in other countries. There is a system for inpatient hospital care and one for residential care, but I think we should lobby for a rehab one.

But even though the most developed one is for inpatient care, there are several relevant questions that work for rehabilitation that I'd like to go through.

1. During this stay, how often did [nurses][doctors] treat you with courtesy and respect? listen carefully to you? explain things in a way you could understand? Of course, the health care professionals in the question can be adapted to reflect your program.

2. Before giving you any new medicine, how often did hospital staff tell you what the medicine was for? describe possible side effects in a way you could understand? This could be changed to asking, before starting you on the exercise program...

3. Using any number from 0 to 10, what number would you use to rate this hospital during your stay? Would you recommend this hospital to your friends and family? This could be changed to ask for a rating of your program.

4. Before coming to the hospital, did you have enough information about what was going to happen during the admission process? Was your admission into the hospital organized? Did you have to wait too long before getting there? This is an excellent set of questions, and can be adapted to ask about admission to the program.

Do you feel that there was good communication about your care between doctors, nurses and other hospital staff? How often did doctors, nurses and other hospital staff seem informed and up-to-date about your hospital care? Knowing this would be helpful, and could be clarified to mean within program communication, as well as communication with the referring physician.

Were you involved as much as you wanted to be in decisions about your care and treatment? Were your family or friends involved as much as you wanted? Very relevant, especially as PR requires goal setting and behavior change on the part of the patient.

When you left the hospital, did you have a better understanding of your condition than when you entered?

Overall, do you feel you were helped by your hospital stay? Please answer on a scale where 0 is "not helped at all" and 10 is "helped completely." These two questions can be changed to say 'program' instead of 'hospital'.

Overall, I had a [very poor]...[very good] experience.

These questions may form the basis of an experience 'assessment' that you might consider for your own program. What could be added to make it relevant to a rehab context? You could consider questions related to the group experience, or the individualization of the program.

A patient experience questionnaire can also explore elements of systematic racism or discrimination, especially based on the answers to the first question *1. During this stay, how often did [nurses][doctors] treat you with courtesy and respect? listen carefully to you? explain things in a way you could understand?* Understanding the extent to which systematic racism and discrimination exists in your institution and program requires learning and questioning far beyond what the answer to this one question may be, and of course patients may not feel that there is a safe space to answer the questionnaire honestly. Nevertheless, if the questionnaire can be answered and returned to the program staff in an anonymous way, it may help to uncover some of these serious issues that face most settings in health care.

Which leads me to the next point – what do you do with the results from these questionnaires, now that you have them. I want to acknowledge the challenge we face as health care professionals when faced with critical feedback. Many of us pour our heart and soul into these programs. Often we may be the sole charge health care professional, and carry the full weight of program development, implementation, and evaluation. It can be hard for people to work hard to make the program a success, only to be faced with critiques from the patients. This is especially true if the critiques point to limitations of aspects of the program for which we have no control. Its hard not to take criticism personally.

As someone who receives a lot of regular feedback related to my teaching and my research, I have a few recommendations for you.

1. The first is to collect enough experiences before you look at the information. You can be overallly influenced by one or two opinions if your sample size is small. Perhaps wait until you have two or three cohorts of program participants before you summarize and look at the information, to get a good understanding of what the general feedback is.

2. The second recommendation is to cultivate a sense of gratitude that people have taken the time to give you feedback. I know that might sound a little woo-woo for some people, but really, if you can decide ahead of time that you will accept the feedback with some grace and not expect everyone to be completely positive about their experience, you'll feel more appreciative and realistic about reviewing the results.

3. If you get feedback about an aspect of your program that shows participants are not having a good experience, look at each category carefully. What things are in your control that can be altered? Perhaps you can't change the program to address the limitation, but perhaps you can better communicate the limitation to the participant ahead of time so they are better prepared? For example, if you have a program that has no air conditioning and the room gets overly hot in the summer, you may not be able to change the heating and cooling system, but information about what to expect can be incorporated into your program assessment visit. Patients may decide to postpone their start date if they know they have a particular problem exercising in that setting.

4. Don't be floored by one or two very negative comments. Don't ignore them, they may be alerting you to a real problem. But your patients have complex lives, like all of us, and they are dealing with a serious chronic disease. They may be having real struggles which may be reflected in their answers, and may not all be directed at you and your program. So see all the answers as an opportunity to further grow and improve your program, but also take care of yourself in the process.

I encourage you to have a look at the Canadian Institute of Health Information website, as well as searching for information on Patient-Reported Experience Measures in the published literature. Using PREMs in PR hasn't quite hit the mainstream, but I'm hopeful that we will see these measures developed for use in a wide variety of pulmonary rehabilitation settings. As programs move to home, community, and telerehabilitation settings, understanding the patient experience of rehabilitation in these places becomes even more important.

Thank you for joining me on this episode, and until next time, keep moving!