Who Is Missing from Pulmonary Rehabilitation?

Hello everyone, and welcome to this episode of the podcast. This episode is actually a reprise of a talk I gave at last year's American Thoracic Society Scientific Meeting, which was entitled "Participation in Pulmonary Rehabilitation - Who Is Missing". I thought it might be interesting for listeners who didn't attend the conference and are interested in this topic of access to pulmonary rehabilitation, so that is why we have this episode today.

I was quite delighted, actually, to be able to talk to give that talk last year, and have it as a topic today, because it is something that I have certainly been thinking about for a number of years. In my practice and research over the last 20 years, I've noticed many patterns related to who comes to pulmonary rehab and who does not, and I am sure you have as well. So today, I'd like to take this opportunity to give you some of my thoughts and reflections about who's missing in participation in pulmonary rehab, and maybe what are some of the things we might want to do to address this.

Now, I'm being a bit facetious with the title of this talk: Who's Missing From Pulmonary Rehabilitation" because, of course, everyone is missing. Most patients with chronic lung disease don't have access to pulmonary rehab, and that has been demonstrated in a number of studies. Back in 2015, the Canadian Thoracic Society conducted a survey where we looked at all of the pulmonary rehab programs in Canada, and we found that 50% of facilities actually admit less than 50 patients per year. And so, when we did that calculation we found that the national capacity in Canada for pulmonary rehabilitation is only about 10,000 patients per year, over the whole country. And so, that means that only about 0.4% of Canadians with COPD have access to a pulmonary rehab program, and of course, if we think about all patients with chronic lung disease that might benefit from pulmonary rehab, that proportion of Canadians with chronic lung disease who have access to pulmonary rehab is likely much less. I'll put a link to that study in the show notes.

And, of course, it's not just a problem in Canada. A similar question was asked in the systematic review of seven pulmonary rehab surveys done in different countries: USA, Canada, the UK, Ireland, Australia, New Zealand, and Sweden. And with the data that was available from Canada, the UK, New Zealand, and Sweden, similar to what we found when we just looked at Canada, the capacity for pulmonary rehab to admit patients with COPD is about, well, it's less than 1.2% of people with COPD. So really, most people don't have access.

So, we recognized that most patients with chronic lung disease do not have access to pulmonary rehabilitation programs, but there are some patients who have even more barriers than others. One major barrier is just where you live in a particular country. So, in Canada, when we did this survey back in 2015 we found that by far most of the rehabilitation programs in Canada were located in hospitals, typically outpatient programs, delivered from outpatient departments in the hospital. And most of these hospitals were located in urban settings, and patients who lived in rural or more remote settings didn't have access to any pulmonary rehabilitation services at all. Telehealth

programs or home programs were basically non-existent at that time – although if there is a positive benefit from COVID, it's that the feasibility of telerehabilitation has been demonstrated, and hopefully some of those pulmonary telerehabilitation programs will be retained after the pandemic is over. Likely, when we redo these surveys in the near future, we're going to find where programs are located and how they are currently delivered has changed. But, for the most part, programs are located in hospitals in urban settings, and that can really rule it out for many patients that don't live in those places.

But, it's not just where you live that can have an impact on whether or not you can access pulmonary rehabilitation services. Diagnosis is also important. In our survey, we looked at the types of chronic lung disease diagnoses that the programs in Canada were able to have in their programs, and similarly, this was also done in the worldwide survey. We broke it down in terms of a number of different chronic lung disease conditions or diagnoses, and for the most part, well 100% of all programs accepted patients with COPD, but other programs were really not able, or chose not to accept patients with other types of chronic lung diseases. So, asthma and restrictive lung diseases, interstitial lung diseases were seen by about 70-75% of programs. Only about 50% of programs were able to care for patients that were either pre or post lung transplant. Patients with pulmonary hypertension or lung cancer - only 30-40% of programs were able to admit them to their programs for them. And then, other conditions such as post-ARDS, or patients with chest wall abnormalities, or cystic fibrosis, these people were really only seen by 20% or less of programs.

So, it's important to realize that even if you have a pulmonary rehab program in your community, if you have something other than COPD, asthma, or interstitial lung disease, you may actually find it difficult to access the programs. They might not have the skills, or expertise, or, in some cases, equipment related to being able to care for you. And, this sort of pattern was reflected, to some degree, in the worldwide systematic review. They didn't have quite as many categories, but nevertheless, about 100% of the programs were able to care for patients with COPD. When looking at patients with acute exacerbations of COPD, that was about 75% of programs, and similar numbers for patients with restrictive lung disease, asthma, or post thoracic surgery. What you have, in terms of a lung condition, may impact whether or not a program is able to admit you into their care.

And, other types of restrictions exist as well for patients. There are still programs out there that require patients to have quit smoking before they can come into the pulmonary rehab program. Patients who are obese, especially at very high weights, may not be accepted, because the program doesn't have the appropriate exercise equipment that can handle patients whose weight exceeds say 300-400 pounds, and so that might be a restriction. Some programs, of course, have issues or have challenges with accepting patients on oxygen, or who maybe have different oxygen demands during exercise, and this might also relate to the scope of practice that the clinicians may have in that particular setting. They may not be able to change or titrate the oxygen during exercise. And so, that may limit the patients in terms of their ability to really get

the best out of the program, in a sense. And, there are also a lot of programs that don't have access to supplemental oxygen, and so you may have a patient that might require oxygen during exercise, but not have access to oxygen already as any part of any kind of a home program. And so, those patients may have difficulty with exercise in your program if you do not have supplemental oxygen available.

Language is also a barrier in many places. In our setting, most programs are only offered in English in Canada or in French or other official language, so if you have patients who speak another language as their primary language, and that language is not the primary one of the country that they're in, they might not be referred to the program at all, and if they do come to the program they really may have challenges in getting the most out of the program.

Transportation can certainly be a barrier, and my program happens to be in an inner-city hospital, and many of the people that live in that neighbourhood do not have money for a car, do not have money for public transit, and so they would have to walk. And that could mean that even just those few blocks between the home and the program might be too much. And, of course, if you're living in a rural area, and the program is in an urban community, then you have to think about transportation there as well, and weather can have an impact on that, whether or not you're independent with your own transportation, or if you need to arrange for someone to help. All these are of course restrictions or barriers to getting into the pulmonary rehab, and being able to attend.

And then, of course, program fees. We've got a large community of listeners to this podcast, and of course, everyone belongs to a different kind of health system. Depending on where you live, your patients may have to pay for their own pulmonary rehab, or they have to copay, or there just isn't the funding available for them to attend. And so, of course, the "who is missing" can also be addressed in terms of thinking about language, who can access it physically, and who can afford to come. And so, one's socioeconomic status, and other abilities and supports really play a role in terms of who is able to get to pulmonary rehab, and who can't.

So, these ideas of who's missing really made me think a little bit about research that has happened in our field. And, when I think about that, I think about the 2015 Cochrane Review which addressed questions of the efficacy of pulmonary rehabilitation. I'll put a link to that citation in the show notes. There was also an associated editorial that was titled "this Cochrane Review is closed: deciding what constitutes enough research and where next for pulmonary rehab".

One interesting quote from this paper was "The primary reason, or the decision, for closing the Cochrane Review is that further research is very unlikely to change our confidence in the estimate of the effect.". And, they further went on to say, "A series of Cochrane Reviews of pulmonary rehabilitation for COPD published over 20 years have resulted only in the tightening of the confidence intervals around the common effect in most outcomes." In addition to this being strong evidence of the benefit of rehabilitation, it is also an indication that there has been a degree of repetition of very similar types of

research, but we haven't, I think, really started to explore questions around that effect in different groups of people, and whether or not the full population of people that should be getting pulmonary rehab, and would be eligible for pulmonary rehab are really being represented in the research that's done to date.

So, when we think about participation in pulmonary rehab, and who's missing, oftentimes our lens is looking at differences. So, are there differences between groups and access? Are there differences between groups with respect to outcomes? And so, often this lens has been binary, a two group comparison. We might look at gender differences. Are there differences between men and women in access? Or, socioeconomic status? Do people from a lower group have different access or outcomes compared to a group with higher socioeconomic status, or immigrant status? And when we look at differences, we have a homogeneity to our lens. We often assume that all members within a group are more similar, because they belong to that group, than they are different.

But in time now, our thinking around difference has matured. And, there is a new concept that is often discussed now in research, and in healthcare called intersectionality. So, what does that actually mean? Well, it's a recognition that when discrimination is considered, people are not binary, people don't just belong from one group or another, but that different forms of discrimination can combine, overlap, and intersect. For example, people aren't just a race, and distinctly from that, a class, and distinctly from that a gender, or an age. They have different levels of privilege and discrimination depending on where one exists in terms of all of these categories. So, you may be of a higher education which might not have as many discriminatory barriers against you compared to someone who has had lower education. But, if you are a person of colour, or if you are a woman, or if you don't speak the language, you may actually face certain kinds of discrimination that other people, in your same education category, do not. So, it's an appreciation that people aren't binary, we belong to a number of different groups, and it's oftentimes these layering of privilege that allows someone to be able to navigate healthcare, and be able to have access to services, versus someone who may have multiple different barriers in place.

And so, in pulmonary rehab we need to move beyond this binary reductionist approach when we think about who's missing, and not just ask "Who is missing?", but "Why are they missing?", and "How are they missing?". And so, understanding these multiple layers of discrimination, and how they can impact potentially a given person, or a given group of people, is a really crucial way to start to think about access and who may not be having the opportunity to come to pulmonary rehab programs, or be represented in pulmonary rehab research.

So, with this intersectional lens, I thought I would bring up a couple of examples of some ways that people may be missing from pulmonary rehab. We do understand that health literacy can have an enormous impact on how patients are able to access services, and also the benefit that they may receive from those services. When we think about health literacy this really means the ability to communicate and understand the

instructions and the requirements of the healthcare plan that the patient receives. And so, when we look at a very simple instruction like “Take two pills twice daily”, only a third of English speaking American patients in a low socioeconomic status were able to correctly understand this instruction. And so, those are people of whom English is a first language, but despite that, due to other reasons, they have challenges with health literacy and understanding what that simple instruction is. And then, when you think about, really, the enormous amount of different types of information that patients in pulmonary rehab need to be able to understand, and to actually act on. Things like understanding their different medications, how to use inhalers, the action plans that we give people around being able to monitor their bodies if they’re getting an exacerbation, and then be able to read instructions and act on them, and all of the other types of behaviour modification skills that we ask of our patients in order to manage their condition. And so, with a health literacy that’s low, these patients are going to find it very challenging to be able to both access a program, and get the benefit from it. And so, an intersectional approach allows you to consider different ways that people may be challenged in terms of being able to understand the information that comes through in a pulmonary rehab program. It could be related to language, it could be related to comprehension, it could be related to other factors in terms of how well they are understanding the instructions and the information that comes through in a pulmonary rehab program.

Another example of how an intersectional approach enables us to examine who is missing from pulmonary rehabilitation participation is when we address the barriers faced by Indigenous peoples in accessing care. In Canada, we’ve been going through a truth and reconciliation process with the First Nations peoples. And that process requires healthcare professionals and healthcare organisations to examine the many ways in which First Nations peoples cannot access care. So, this has resulted in research being done. For example, I’m undertaking work to determine if patient education content and the delivery of tele-rehabilitation is culturally-safe for First Nations people. It’s also happening in other jurisdictions. In Australia, Jenny Alison and David Meharg are also looking at the benefits of culturally-safe programs for Indigenous people. And, access to programs needs to be understood not just within the known limitations of cost, distance, and availability, but also with that intersectional lens understanding of multigeneration trauma, distrust, and discrimination within the health care system to whole populations of people. If you’d like to hear more about Dr. Alison and Mr. Meharg’s work, the American Thoracic Society Pulmonary Rehabilitation Assembly recently had a podcast episode with them, I’ll put that link in the show notes.

So, two examples of groups of people who may experience barriers to accessing pulmonary rehab: people with low health literacy, and Indigenous people. But, an intersectional approach to understanding barriers to accessing completion of pulmonary rehab encourages us to build on our understanding of who’s missing by bringing attention the synergistic effects of multiple factors. Although Indigenous people may experience significant barriers to accessing care, compared to non-Indigenous people, that is a binary lens, but these experiences will be felt differently by men versus women, by different age groups, or by different distinct Indigenous nations depending on their

geographical and cultural differences. So, an intersectional lens encourages us not to overemphasize differences based on a binary definition, like for example health literate vs not literate, and not to think about people in distinct silos, but instead to appreciate the multilevel factors that cause barriers to both accessing pulmonary rehab programs, and also successfully completing them.

So, while this Cochrane Review might be closed, as the editorial said, and we really have determined that pulmonary rehabilitation is safe and efficacious for the vast majority of people that take it, I think that there still is a lot of research opportunities that exist, and we really do want to think about who's missing from pulmonary rehab. Who's missing in terms of access. Who's missing in terms of the response to the care that we provide. Who's missing in terms of the design of pulmonary rehab programs, and does it meet the needs of the different groups that require those services. And do layers of barriers intersect to further reduce access.

In summary, of course we know that access to pulmonary rehab is limited across the board. But, when we start to think about who's missing, it's important for us to think about people outside of a binary approach by sex, by immigrants or non-immigrants, by one particular culture versus another, and realize that an intersectional approach to understanding access is really important. And, in order to do that, we really need to have more of a mixed methods, rigorous approach to our research, and we need to have a better appreciation of how these differences exist when we come to design our programs. And we really do need to have a participant approach, a really involved approach by people we think are missing – when we design programs, and also the design and conduct research studies.

In this episode, I hope I was able to pique your interest a little bit in some of these concepts. I'd like to end by acknowledging colleagues who work in feminist theory, cultural safety, Indigenous health or pulmonary rehabilitation. I've had the privilege of being able to have many interesting discussions with them about this idea of who's missing in pulmonary rehabilitation participation, in terms of both research, and our clinical programs. Thank you.