

## RESEARCH IN PULMONARY REHAB – IT TAKES A VILLAGE

Hi everyone, and welcome to this episode of LungFIT pulmonary rehab podcast. I hope things are well with you all. Today I'd like to share with you a paper that we recently published from my Pulmonary Rehabilitation Research Laboratory. The title of the paper is "Photovoice exploration of physical activity norms and values among rural and remote pulmonary rehabilitation participants in British Columbia, Canada" and it is published in the journal "Disability and Rehabilitation". I'll put the link in the show notes.

I thought it would be interesting to share the results of this project with you, and also comment on the involvement of the many individuals that were part of this study. We all read journal articles but we might not appreciate just the many roles and responsibilities of the people involved in the research process.

The purpose of this study was to explore physical activity norms and values among people with COPD living in remote and rural locations, who were recruited from pulmonary rehab clinics. The idea for this study actually came from another study we were conducting, related to perspectives of telerehabilitation. We were interviewing people for that study and in that process we heard many individuals who were living in remote and rural locations talk about what physical activity was like for them. They commented on how they would spend some time in the morning before rehab taking care of something on their property, often being very active (and breathless!), then coming to the program and sitting on the exercise bike for 30 minutes. Not very transferable or relevant to their day to day lives. So that led to us being curious about what does physical activity look like for people with COPD who don't live in urban centres?

Then our colleagues Alanna, Karin, and Cory, who at that time all worked for the Interior Health Authority, told us about an opportunity to apply for a grant. We took this idea and together put in an application, and received grant money from the health authority.

Then what? Well, this was a rather complicated study, which included people wearing GPS devices as well as participating in interviews. And we wanted to talk to people who were somehow linked to pulmonary rehab, either as a participant, or someone who was referred. So we needed to collaborate with pulmonary rehab programs.

That led to introductions by Alanna, Karin and Cory to the programs in this very large health authority, and then subsequent meetings and approvals. We needed to submit our project to ethics review boards, at our university as well as the health authority, and get site approvals as well. And we needed to meet and provide training to all the health professionals at the different sites who would help us coordinate the study.

So already we have our team of investigators, plus the grant review board, the ethics boards, the various managers, health care professionals, and all the people who support the financial, human resources etc. aspects of the project. And there's more to come, I'll get to them in a moment.

So what did we do for this Photovoice part of the study? And what is Photovoice? We knew we wanted to talk to people about the sorts of physical activity they do, how they value it, how life with COPD has changed their physical activity, and how living in a remote or rural community affects their activity. One way to understand these things is through qualitative research, where through interviews

or focus groups, for example, people can answer in detail questions put to them. But I had recently learned of the research method called Photovoice. Photovoice is a method whereby you ask people to take photos related to the questions or topics you ask. These photos are then the basis for the conversation. It relies on the old saying: a picture is worth a thousand words. What people choose to take pictures of is another way of understanding the importance of something in their lives.

So our health professional colleagues recruited participants and instructed them in all aspects of the study. For the photovoice part, we asked the participants to take pictures of aspects of physical activity for them, in both summer and winter months. We mailed cameras to everyone – not many people had smartphones then! In this part of Canada, the summers are quite hot, and the winters are cold with lots of snow. So these months present different challenges to physical activity. The participants could take pictures regarding activities they enjoy, or ones they find too difficult now, or conditions which promote activity or prevent it. Our rehab colleagues then facilitated getting the pictures and cameras back to us in the lab.

Once this was done, 1:1 interviews were then booked. Karin and our research coordinator Ashley conducted these, and it was an enormous endeavor, to schedule and conduct all those interviews, as well as organize the photos. Once all the interviews were done, time for analysis! We had the help of additional team members for this part, with trainees and summer staff helping with the coding.

During this time, PhD student Justin came to us, and took on the task of the analysis and writing up the paper. This happens in research a lot, where some team members have to leave a project early, and others come on once the project is underway. So if you are interested in research, and you know of a researcher in a local university, don't be afraid to reach out and volunteer! Projects often need an extra set of hands.

For Justin, however, it enabled him to get involved in a project that could strengthen his qualitative analysis skills, while also getting his unique perspective as an occupational therapist. The study investigators are physical and respiratory therapists, so it was great getting a different view.

So what were the results? We recruited 12 participants with COPD who together completed 20 interviews. Participants' age ranged from 65 to 87 years. The photovoice exercise was quite successful, with the 12 participants submitting 288 photos to us in total. One participant took 48 photos. The photos and interviews together, when analysed, translated into three themes.

The first theme was exemplified by the comment: There is a sense of pushing against a downhill slope, in that living with lung disease poses challenges to staying active. Individuals commented about the progressive nature of the disease, and how once enjoyable activities were becoming more and more difficult. The participants often had challenging responsibilities to maintain a rural property – large properties that needed to be checked and maintained for safety and accessibility. These activities were difficult, yet participants also noted they didn't want to stop doing them – "I don't want to quit, its like giving up on a life", which was the second theme. The participants talked about how they were motivated to keep active based on what they had learned about its benefit in pulmonary rehab, in terms of both physical, social, and mental health benefits.

The third theme was about geography, weather and weather-related events. In some cases this also meant weather events related to climate change. It is common for this part of the world to get a lot

of snow, and participants commented on the impact of winter weather. Summer, however, which would normally be a time when many participants could be active, was now a time when physical activity was often restricted. And this was due to the presence of wildfire smoke, a common occurrence in Canada.

This analysis required a lot of discussion, led by Justin and Karin. Then came the writing, the submission, the peer reviews, and the final checks.

What a lot of people involved! From the team, to the study sites, to the participants, to the research support staff in the university, hospitals and health authority, to the journal staff, editors and reviewers, the number is pretty big. And, I have to acknowledge, this was a pretty small study. But I think it was a helpful one to raise our awareness of what physical activity looks like, for people with COPD who live in remote and rural spaces. There aren't always safe, accessible, and feasible spaces to be active when you live in these places. Something to think about when we talk to our patients about how to be active, to think about the context of where they live and what the challenges may be.

So to our lungFIT listening audience, this gives you a small glimpse into the research process. It does take a village, and you are already part of it. It's a shame that in many places of the world, and in many practice settings, the research pulmonary rehab world and the clinical pulmonary rehab world are really separate. But it doesn't have to be, and it just takes ways to connect. Like this podcast! Ideas for studies most often come from clinicians and patients, either informally, like this one, or formally, perhaps through a panel discussion or task force. Many clinicians in pulmonary rehab, like the ones in this study, are often involved in research in some fashion – perhaps by helping recruit patients, participating in data collection, or leading the study. Or in the knowledge translation phase as well, talking about new research with colleagues, students, patients, and stakeholders, writing to the authors about the papers they are publishing, sharing your thoughts, and identifying ways to get more involved in research.

I hope you enjoyed this episode and hearing a bit about the research, and research process, that happens in the UBC Pulmonary Rehabilitation Research Laboratory. Stay well everyone!