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Patient Perspectives on Long-Term Use of a Pulmonary Telerehabilitation Platform: A Qualitative Analysis

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Abstract. To effectively develop patient-centered interfaces and functionality, it is essential to investigate different viewpoints on pulmonary telerehabilitation. The purpose of this study is to explore the views and experiences of COPD patients after the completion of a 12-month home-based pulmonary telerehabilitation program. Semi-structured qualitative interviews were conducted with 15 COPD patients. The interviews were analyzed using a thematic analysis approach to deductively identify patterns and themes. Patients responded with approval for the telerehabilitation system, particularly for its convenience and ease of use. This study offers a thorough investigation of patient viewpoints when utilizing the telerehabilitation technology. These insightful observations will be considered for future development and implementation of a patient-centered COPD telerehabilitation system to provide support tailored to patient needs, preferences, and expectations.

Keywords. Telerehabilitation, chronic obstructive pulmonary disease, qualitative analysis

1. Introduction

Chronic obstructive pulmonary disease (COPD) is one of the leading causes of morbidity and mortality worldwide. According to the World Health Organization, COPD will overtake heart disease as the third largest cause of death by 2023 [1]. There is strong data demonstrating that patients with COPD who participate in pulmonary rehabilitation experience improved functional ability, decreased dyspnea, and better clinical outcomes [2]. Traditional or center-based pulmonary rehabilitation (PR) programs involve weekly or biweekly in-person sessions at an outpatient clinic for 6–8 weeks though sustainable outcome improvement in COPD can be achieved only with life-long rehabilitation. Despite the advantages of center-based PR, adoption rates are still modest. Transportation difficulties, tight budgets, conflicting schedules, staff shortages, and lack of perceived benefits are barriers to participation [3]. Alternative PR delivery methods, such as home-based PR and telerehabilitation, have been shown to produce clinical effects that are equivalent to those of the typical in-person PR program offered at an outpatient clinic [4]. The results of previous studies evaluating the views of patients who underwent an 8-week home-based PR point to the program's high level of patient

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acceptance [4]. Patients also highly valued the flexibility and convenience of the homebased program. However, a thorough qualitative investigation of COPD patients' perceptions of long-term pulmonary telerehabilitation has not been conducted. The goal of this study is to explore the views and experiences of COPD patients who completed a 12-month home-based pulmonary telerehabilitation program.

2. Methods

The current study is part of a larger project with the goal of systematically assessing the impact of the Comprehensive Health Informatics Engagement Framework for Pulmonary Rehabilitation (CHIEF-PR) in a randomized controlled trial. The study was approved by the Institutional Review Board at the Icahn School of Medicine at Mount Sinai. Participants consisted of patients diagnosed with COPD who were hospitalized with COPD exacerbation at the Mount Sinai Health System in New York. Patients with an acute exacerbation of COPD within four weeks of enrollment were invited to participate in the study. Participants were recruited until thematic saturation when interviews generate few or no new information, ideas, themes, or codes [5]. Semistructured qualitative interviews were conducted with 15 participants who completed a 12-month home-based pulmonary telerehabilitation program which was previously described [6]. The qualitative interviews consisted of open-ended questions examining the participant's experience with the content, interface, and the process of using a webbased telerehabilitation system called Home Automated Telemanagement (HAT) [6]. The HAT system was created to support healthcare practitioners in treating, educating, and monitoring patients with COPD and to help patients adhere to their personalized PR program according to current clinical guidelines. The interviews were conducted remotely by a trained researcher using videoconference software. Each interview session lasted approximately 20 minutes. The responses for each open-ended question were recorded in separate de-identified documents using Microsoft Word which serves as the raw data set.

The qualitative data were analyzed using a thematic analysis method which consists of a six-phase process to organize, identify, and interpret key patterns and themes [7]. As part of the first phase of thematic analysis known as data familiarization, researchers reviewed and then utilized Microsoft Excel to consolidate and organize the raw textual data across all participants using a framework analysis approach. This systematic approach is essentially a comparative type of thematic analysis which uses an a priori structure of concepts to organize the raw data [8]. The data was organized in alignment with the three usability areas evaluated in the semi-structured qualitative interviews: content, interface, and process. During the second phase, initial codes were generated using a deductive or 'top-down' approach where codes are strongly linked to the data and map onto a specific research question or theme [7]. The codes were aggregated to identify and summarize into general themes and sub-themes as part of phases three and four. In phase five, the themes were reviewed and refined with clear descriptions and examples to illustrate each theme. The sixth phase consists of reporting the findings of the thematic analysis and is included in the following results section.

3. Results

3.1. Themes Related to the Content of the Pulmonary Telerehabilitation System

Users were asked to share their thoughts about the exercise program content, including the instructions, self-report options, performance feedback, and demonstrations on how to perform the exercise. The responses indicated that the exercise content was well received. Users described the exercise instructions as sufficient, informative, and easy to follow. Users also thought the exercise demonstrations were a good way to teach how to complete the exercises. When asked if there were any benefits to the guided exercise program, several users mentioned seeing an improvement in their physical functioning, breathing, and motivation to exercise. Users also mentioned the convenience and flexibility to complete the PR exercises at their home/office at their own leisure was beneficial. Overall, users did not have problems using the video exercise instructions to complete their PR exercises. The most frequent suggestions to improve the exercise content were questions in between the exercises, decreasing the length of the exercise sessions, and including an option for a more challenging exercise program. The following citation demonstrates a patient perspective on how the interactive content facilitated patient daily exercise: "Doing the exercises and the visual is better for me to focus on my breathing and how to do the exercises and to help me function a little better."

3.2. Themes Related to the Interface of the Pulmonary Telerehabilitation System

Most users felt comfortable using the exercise system independently. A few users stated needing support from the research staff to troubleshoot the tablet when experiencing technical difficulties with the tablet (i.e., tablet freezing, internet connectivity issues, login issues). Users discussed several benefits of the home-based exercise system including the accessibility and convenience of being able to access the exercise system at home. Users also thought the PR program helped increase their motivation to exercise and created a daily purpose/goal. Two users responded that the feedback and online support of the physical therapist (PT) were valuable and helped improve their motivation. Nearly all users thought the introductory practice session administered prior to starting their personalized PR program was informative and sufficient. When asked about their preference for the presentation of exercise prompts and steps (audible, visual, or both), the majority of users preferred both the audio and visual prompts and steps.

Users were asked if the inclusion of more diverse content would make the experience (e.g., images, video clips) enjoyable. Many users agreed the addition of diverse content would make the experience more enjoyable, specifically if there were included with different exercises. Users compared the ease of use between the exercise program interface and their home TV remote control. Seven users responded that their TV remote control is easier to operate due to familiarity and ease of use. Five users stated that the exercise system is easier to navigate than their TV remote control. Three users thought that both the exercise system and their TV remote control are simple to operate. When users were asked if there was any aspect of the system that would make them refrain from using the exercise system to help with completing their exercises at home, users reported external factors such as health limitations and competing demands. Users also stated that limited motivation to exercise, difficulty finding an appropriate space to use the tablet, and connectivity issues were deterrents to using the exercise system. Users were asked how the exercise system can be improved. Three users suggested improving

functionality and connectivity of the tablet. Two users suggested including the option to change the level of difficulty and the length of the exercise sessions. The following citations exemplifies how the structured system interface facilitates patient engagement in pulmonary telerehabilitation: *"I think it is good because it gives me more structure about what to do, not just picking up a piece of paper and reading it. It gives me purpose"*

3.3. Themes Related to the Process of the Pulmonary Telerehabilitation System

Overall, users responded positively when asked how they felt about using a computerguided program to complete the PR exercises. Users stated that they like the idea of using a computer-guided individualized exercise program at home. When compared to going to the gym or using other exercise programs/tools, 11 users thought the exercise program was better because it was home-based, cost-effective, decreased the risk of COVID-19, and allowed users to review the exercise demonstrations at their own pace. One user stated that the two-way remote communication with the telerehab team and feedback from PT helped improve their motivation. Majority of users thought that the PR program will help improve their physical ability to exercise, motivation to complete the exercises, and maintain a workout routine. Nearly all users reported that the exercise program would improve their confidence in completing the exercises at home.

When users were asked to describe what the best feature exercise program is, users responded that the increase in motivation to exercise and the convenience and flexibility of the at-home exercise program were beneficial. One user stated that submitting an exercise log and being monitored by the PT was beneficial. Most users reported having no problems or concerns with using the exercise program. Three users mentioned experiencing issues with the tablet including the transmission of data and connectivity.

Users were asked what additional features could be added to the exercise program to make the system more effective. Most users reported no suggestions to make the exercise program more effective. Four users suggested increasing the variety of exercises, additional breathing exercises, an option to increase the level of exercise difficulty, and making the system more interactive. Two users mentioned including the option to change the background music. The following citation demonstrates patient perspective on the telerehabilitation process enabling ongoing participation in the program: *"The major benefit is that you feel that there is someone there helping you. I felt that there was a person there helping me."*

4. Discussion

Past studies investigating patient perspectives on home-based PR consisted of an 8-week intervention. In this qualitative study, we examined the perceptions of patients regarding their participation in a 12-month home-based pulmonary telerehabilitation program. The salient features of the exercise program that emerged from the qualitative data related to the accessibility of the guided exercise instructional videos, the ability to review the exercise demonstrations and self-correct, the convenience of the at-home exercise program, and perceived improvement in physical health, breathing, and motivation to exercise. Patients felt comfortable using the exercise system to complete their prescribed exercises. Despite the reported concerns with tablet operation, system connectivity, and setbacks brought on by health restrictions, patients persisted in making an attempt to overcome any technical issues or seek adjustments to their workout regimen

as necessary. The consistent feedback and communication with the PT helped improve the motivation to exercise and continue participation in the home-based program with minimal disruptions. Overall, COPD patients have enthusiastically embraced the telerehabilitation program, rating it highly for usefulness and satisfaction. Many patients expressed the desire to continue using the exercise system beyond the 12-month study period.

5. Conclusion

We evaluated an online pulmonary telerehabilitation platform with 15 COPD patients. The findings of this qualitative study show that patients had a positive acceptance and high levels of satisfaction with the pulmonary telerehabilitation system which allowed them to successfully follow their individualized exercise programs for 12 months. This study offers a thorough investigation of patient viewpoints when utilizing telerehabilitation technology. These findings will be considered during the future design and deployment of a patient-centered COPD telerehabilitation system tailored to patients' requirements and preferences, and it can be extended to other rehabilitation areas [9-10].

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References

- Mei F, Dalmartello M, Bonifazi M, Bertuccio P, Levi F, Boffetta P, Negri E, La Vecchia C, Malvezzi M. Chronic Obstructive Pulmonary Disease (COPD) mortality trends worldwide: An update to 2019. Respirology. 2022;2(11):941-50.
- [2] Zeng X, Chen H, Ruan H, Ye X, Li J, Hong C. Effectiveness and safety of exercise training and rehabilitation in pulmonary hypertension: a systematic review and meta-analysis. Journal of Thoracic Disease. 2020;12(5):2691.
- [3] Lahham A, McDonald CF, Mahal A, Lee AL, Hill CJ, Burge AT, Cox NS, Moore R, Nicolson C, O'Halloran P, Gillies R. Home-based pulmonary rehabilitation for people with COPD: a qualitative study reporting the patient perspective. Chronic respiratory disease. 2018;15(2):123-30.
- [4] Holland AE, Mahal A, Hill CJ, Lee AL, Burge AT, Cox NS, Moore R, Nicolson C, O'Halloran P, Lahham A, Gillies R. Home-based rehabilitation for COPD using minimal resources: a randomised, controlled equivalence trial. Thorax. 2017;72(1):57-65.
- [5] Weller SC, Vickers B, Bernard HR, Blackburn AM, Borgatti S, Gravlee CC, Johnson JC. Open-ended interview questions and saturation. PloS one. 2018 Jun 20;13(6):e0198606.
- [6] Bedra M, McNabney M, Stiassny D, et al. Defining patient-centered characteristics of a telerehabilitation system for patients with COPD. Stud Health Technol Inform. 2013;190:24-6.
- [7] Braun V, Clarke V. Using thematic analysis in psychology. Qualitative research in psychology. 2006;3(2):77-101.
- [8] Ritchie J. and Spencer L. Qualitative data analysis for applied policy research. Analyzing Qualitative Data. 1994; 9:1-22.
- [9] Feasibility of post-acute hip fracture telerehabilitation in older adults. Stud Health Technol Inform. 2015;210:469-73.
- [10] Jeong IC, Karpatkin H, Finkelstein J. Physical Telerehabilitation Improves Quality of Life in Patients with Multiple Sclerosis. Stud Health Technol Inform. 2021;284:384-388.