## **Pulmonary hypertension patient perspectives** toward pulmonary rehabilitation

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**Funding information** None

#### Abstract

Pulmonary rehabilitation (PR) is a supervised exercise program for patients with chronic lung disease. Among patients with pulmonary hypertension (PH), PR has been shown to improve both quality of life and exercise capacity. The purpose of this study was to assess the prevalence of PR participation among PH patients, patient perspectives regarding PR, and to identify potential barriers to PR participation. We performed a cross-sectional survey of patients with self-reported PH who attended the Pulmonary Hypertension Association (PHA) conference in June 2022 in Atlanta, Georgia, and patients within the PHA listserv. A total of 429 participants completed the survey and were enrolled in the study. The average age of participants was  $61 \pm 14$  years with 83% of participants identifying as female, 51% of patients self-reported as having group 1 PH. Among patients who completed the survey, 41% had previously attended a PR program. Of those who had completed a PR program, 83% reported being satisfied or very satisfied with the program and 86% reported that they would recommend PR to other PH patients. After completion of a PR program, 76% of patients reported an improvement in their quality of life and 88% reported improvement in exercise capacity. Among the patients who had not previously participated in PR (n = 254), 63% reported an interest in participation while 64% cited a lack of discussion from their treatment team as the primary reason for the lack of PR participation. Limitations of the study include sampling and response bias. According to this cross-sectional survey, the majority of PH patients who have participated in PR report improvement in both quality of life and exercise capacity and would recommend PR to other PH patients. The majority of PH patients who have not participated in PR were interested in participation and cited a lack of discussion with their treatment team as one of the primary reasons for the lack of participation. PR is associated with self-reported improvements in quality of life and exercise capacity but remains underutilized among patients with PH.

#### **KEYWORDS**

patient perspective, pulmonary hypertension, pulmonary rehabilitation

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## INTRODUCTION

Pulmonary hypertension (PH) is a chronic, progressive cardiopulmonary disease characterized by elevated pulmonary arterial pressures due to a heterogeneous group of disorders and associated conditions, including chronic heart and lung disease.<sup>1</sup> Patients with PH often report dyspnea, fatigue, and impaired mobility as well as decreased emotional well-being and ability to carry out activities of daily living and exercise.<sup>1,2</sup> Although there have been significant advancements made in the pharmacological management of PH over the past decade, patients continue to report progressive exercise intolerance and impaired quality of life despite medical therapies.<sup>3,4</sup>

Pulmonary rehabilitation (PR) is a comprehensive intervention consisting of education, self-management strategies, and supervised exercise training designed to improve the physical and psychological well-being of patients living with chronic pulmonary conditions.<sup>5-7</sup> Supervised exercise training generally consists of both resistance and endurance training with aerobic exercise at a goal intensity of 2-3 metabolic equivalents for a duration of 20 min at least twice per week for 8-12 weeks.<sup>5,6</sup> PR is a core component of nonpharmacological care for people with chronic cardiopulmonary diseases such as PH.<sup>8,9</sup> The most recent guidelines recommend PR referral for patients with PH.<sup>10</sup> The benefits of exercise training in patients with PH are well-established and PR has been shown to improve both quality of life and exercise capacity.<sup>7,11,12</sup> However, despite these established benefits, PR continues to be underutilized and the reasons for this are poorly understood.<sup>13</sup> Barriers to PR may include a lack of patient or physician awareness regarding PR as an intervention, limited access to PR centers, inconvenience, or anticipated costs.<sup>13</sup> Currently, there is a lack of literature surrounding the utilization of PR in this patient population and limited understanding regarding barriers to participation.

We performed a large-scale cross-sectional survey of patients with PH to assess the prevalence of PR participation among PH patients, patient perspectives regarding PR, and to identify potential barriers to PR participation.

## **METHODS**

## Study design

We performed a cross-sectional survey of 429 patients with self-reported PH from June 2022 to March 2023.

## **Subjects**

This study was approved by the Mayo Clinic Institutional Review Board (22-003579). Patients aged 18 and above with a self-reported diagnosis of PH with the ability to complete an English-based written survey were deemed eligible for study participation. Patients with all World Health Organization (WHO) classifications of PH were included. PH diagnosis and classification were limited to patient-based reporting. Patients who attended the Pulmonary Hypertension Association (PHA) conference in June of 2022 were recruited for study analysis as well as those who were enrolled in the PHA community database listserv.

## Study testing

Eligible participants were either approached by research study personnel in person if they attended the PHA conference or via a targeted email sent to patients enrolled in the PHA listserv on 02/15/2023. Participants were able to access the REDCap survey via a web-based hyperlink or QR code. In-person conference attendees completed the RED-Cap survey on an iPad. The survey was anonymous and consisted of 22 Likert-scale questions used to obtain basic demographic information as well as detailed information regarding patient perspectives, attendance, and completion of PR (Supplementary Document S1).

## **Statistical analysis**

Descriptive statistics are reported as percentages for categorical variables and mean  $\pm$  standard deviation or median (interquartile range) for continuous variables. Participants in PR were compared to nonparticipants and in-person and online survey groups were compared using a two-sided *t* test for numerical variables and analysis of variance (or chi square or Fischer exact test as appropriate) for categorical variables. Statistical analysis was performed on SAS, version 9.4.

#### RESULTS

## **Patient characteristics**

The study cohort included 429 patients from across the United States and internationally who completed the survey; 30 patients completed the survey in person at the PHA conference in June 2022 and 399 patients completed the survey electronically. Participants largely identified **TABLE 1** Demographics and patient characteristics inrespondents who completed the survey.

Characteristic	n	Value
Age	429	61 (±14)
Female	429	360 (83%)
Ethnicity	426	
White		358 (84%)
Non-White		68 (16%)
Region	429	
Northeast (CT, ME, MA, NH, RI, VT, NJ, PA, NY)		64 (15%)
Midwest (IN, IL, MI, OH, WI, Iowa, KS, MN, MO, NE, ND, SD)		87 (20%)
South (DE, DC, FL, GA, MD, NC, SC, VA, WV, AL, KY, MS, TN, AR, LA, OK, TX)		149 (35%)
West (AZ, CO, ID, NM, MT, UT, NV, WY, AK, CA, HI, OR, WA)		105 (24%)
International		24 (6%)
Supplemental oxygen use		
No		196 (46%)
Yes		233 (54%)
24 h (rest, exertion, night)		78 (33%)
With activity only		12 (5%)
At night only		80 (34%)
With exertion and at night		36 (15%)
Other		32 (14%)
WHO pulmonary hypertension classification	428	
1		219 (51%)
2		40 (9%)
3		42 (10%)
4		36 (8%)
5		34 (8%)
Unsure		57 (13%)
Pulmonary hypertension specialist	424	
Pulmonologist		255 (60%)
Cardiologist		158 (37%)
Other		11 (3%)
Number of pulmonary hypertension medications		1.59 (±1.11)
When do you experience dyspnea?	429	
No dyspnea		47 (11%)
At rest		13 (3%)

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#### TABLE 1 (Continued)

Characteristic	n	Value
With mild activity		152 (40%)
With moderate activity		217 (57%)

*Note*: Data expressed as n, %, mean  $\pm$  standard deviation, or median (25th–75th percentile) as appropriate.

Abbreviation: WHO, World Health Organization.

as female (83%) and White (84%) with a mean age of  $61 \pm 14$  years (Table 1). All regions in the United States were represented and 59% of respondents were from the Southern or Western regions of the United States. Half of the patients identified as having group 1 PH (51%); however, all PH groups were represented (Table 1). The average number of PH-specific medications was  $1.59 \pm 1.11$  and 54% of participants indicated that they used some form of supplemental oxygen (Table 1). The majority of patients reported that their treating physician was a pulmonologist (n = 255, 59.4%). Eighty-nine percent of patients reported experiencing dyspnea, with most experiencing shortness of breath with either minimal or moderate activity (Table 1).

## **PR** referral and perspectives

Among patients who completed the survey, 45% had previously been referred to a PR program and 41% had participated in PR (Figure 1). The majority of patients indicated that their PH treatment team made the PR referral (76%) for the reason of underlying PH (80%) (Table 2). Of those who were referred to a PR program, 83% reported being very satisfied or satisfied with the program and 86% reported being likely or highly likely to recommend PR to other patients with PH (Table 2) (Figure 2). After completion of a PR program, 76% of patients reported an improvement in their quality of life and 78% reported an improvement in exercise capacity (as measured by participants who responded with "strongly agree" or "agree") (Figure 2). Among patients who had not previously participated in PR or were unsure if they had participated (n = 252), 63% reported an interest in participation and 64% chose a lack of discussion about PR from their treatment team as the primary reason for lack of PR participation (Table 2) (Figure 1). Cost, schedule, transportation, and Coronavirus-19 were uncommon (<5%) reasons cited for lack of participation (Table 2). Perspectives regarding home-based PR were mixed.

Patients also provided illustrative comments on their experience. One participant commented that PR "made a world of difference in my PH symptoms." One participant



**FIGURE 1** Patient participation in pulmonary rehabilitation (PR). (a) Percent of survey respondents referred to PR. (b) Percent of survey respondents who participated in PR. (c) Percent of non-PR participants interested in PR.

noted that following PR, they "went from barely able to make it from a parking [lot] to parking further away" and even "joined the hospital fitness center." Others commented that the program provided support and safety with one respondent emphasizing that they felt "safe to exercise because a qualified personnel was there to help. I was taught safe way to exercise." A participant also mentioned that PR "taught me how to breathe properly during exercise and gave me confidence to exercise despite my PH diagnosis."

# Comparison of PR participants versus nonparticipants

Compared to patients who never participated in PR, those who participated were more likely to use supplemental oxygen (69% vs. 46%; p < 0.001), more likely to identify as having group 1 or 3 PH, and less likely to

**TABLE 2** Survey responses regarding perspectives and experience with pulmonary rehabilitation.

Characteristic	n	Value
Did your physician discuss PR with you?	429	
Yes		213 (50%)
No		201 (47%)
Unsure		15 (3%)
Physician discussing PR	213	
PH physician		162 (76%)
Combination (PCP + PH specialist)		27 (13%)
Other		23 (11%)
Did your physician refer you to PR?	429	
Yes		191 (45%)
No		226 (53%)
Unsure		12 (3%)
Physician making PR referral	191	
PH physician		142 (74%)
PCP		11 (6%)
Combination (PCP + PH specialist)		14 (7%)
Other		23 (12%)
Reason for PR referral among those referred	188	
РН		150 (80%)
COPD		8 (4%)
ILD		5 (3%)
Combination (PH + COPD/ILD)		23 (12%)
Other		2 (1%)
Participated in PR, % of those referred	191	175 (92%)
Attitude toward PR after completion	175	
Very satisfied		91 (52%)
Satisfied		54 (31%)
Neutral		16 (9%)
Dissatisfied		7 (4%)
Very dissatisfied		7 (4%)
Would recommend PR to other patients with PH	174	
Very likely		117 (67%)
Likely		33 (19%)
Neutral		13 (7%)
Unlikely		5 (3%)
Very unlikely		6 (3%)
Participation in PR improved my overall quality of life	173	
Strongly agree		78 (45%)

#### TABLE 2 (Continued)

Characteristic	n	Value
Agree		54 (31%)
Neutral		26 (15%)
Disagree		7 (4%)
Strongly disagree		8 (5%)
Participation in PR improved my overall exercise capacity	174	
Strongly agree		78 (45%)
Agree		58 (33%)
Neutral		24 (14%)
Disagree		6 (3%)
Strongly disagree		8 (5%)
Reasons for not participating in PR	239	
Cost		3 (1%)
Inconvenient schedule		2 (1%)
Transportation		3 (1%)
Lack of perceived benefit		7 (3%)
Too ill		2 (1%)
COVID-19 concerns		1 (0%)
Lack of discussion from the treatment team		152 (64%)
Lack of follow-up after referral		6 (3%)
Other		31 (13%)
Combination		32 (13%)
Interested in PR participation	252	160 (63%)
Prefer a home-based PR program	428	
Strongly agree		73 (17%)
Agree		86 (20%)
Neutral		146 (34%)
Disagree		76 (18%)
Strongly disagree		47 (11%)

Note: Data expressed as n, %, mean  $\pm$  standard deviation, or median (25th–75th percentile) as appropriate.

Abbreviations: COPD, chronic obstructive pulmonary disease; ILD, interstitial lung disease; PCP, primary care provider; PH, pulmonary hypertension; PR, pulmonary rehabilitation.

endorse shortness of breath at rest (Table 3). There were also regional variations between the groups (Table 3). There was no significant difference between age, gender, or ethnicity between the two groups and no difference in the number of PH medications or specialty of PH treating physicians.

## In-person versus electronic participants

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A comparison of patient responses between those who attended the PHA in-person conference and those who completed the survey electronically via the PHA listserv email is demonstrated in Table S1. Compared to patients who completed the survey electronically, those who completed the survey in person at the PHA conference were similar with respect to age, gender, ethnicity, region, and PH classification. Patients who completed the survey in person were more likely to be prescribed supplemental oxygen (70% vs. 53%; p = 0.004) and were treated with a higher number of PH medications  $(2.23 \pm 0.83 \text{ vs. } 1.54 \pm 1.11; p < 0.001)$ . Compared to those who completed the survey online, respondents who attended the conference were more likely to have their physician discuss PR (83% vs. 47%; p < 0.001), more likely to be referred to a PR program (77% vs. 42%; p < 0.001), and were more likely to have attended PR (67% vs. 39%; p = 0.011) (Table 3). Perspectives regarding the benefit of PR on quality of life and exercise capacity were similar between the groups.

## DISCUSSION

In this study, we utilized a questionnaire to assess patient experience and perspectives toward PR. We found that the majority of patients with PH who have participated in PR report improvement in both quality of life and exercise capacity and would recommend PR to other PH patients. Patients who participated in PR were more likely to use supplemental oxygen and were more likely to identify with having group 1 and 3 PH than those who did not participate in PR. Of note, we did not assess participation in cardiac rehabilitation which group 2 PH patients may have been more likely to participate in. The majority of PH patients who had not participated in PR were interested in participation and chose a lack of discussion with their treatment team as one of the primary reasons for the lack of participation. In addition, those who completed the survey at the conference were more likely to have had their physician discuss and refer them for PR and were more likely to have participated in PR. This may be due to the higher degree of motivation and awareness of PR and its benefits among patients who attended the conference in person. In addition, this discrepancy may serve to highlight the need for education regarding PR in the PH population among those who may not have access to additional resources. The differences between in-person conference attendees and electronic respondents also highlight the importance of



**FIGURE 2** Patient attitudes toward pulmonary rehabilitation (PR). (a) Attitude toward PR among participants. (b) Likelihood to recommend PR to other pulmonary hypertension patients. (c) Participation in PR improved my overall quality of life. (d) Participation in PR improved my exercise capacity.

capturing patient perspectives with multiple survey modalities.

Compared to other studies, participants reported a higher degree of participation in a supervised exercise program. Similar to a prior survey by Chia et al., patients were largely female, middle-aged, and presented with WHO group 1 PAH.<sup>14</sup> In addition, participants in both studies highlighted a similar degree of perceived importance of exercise and a high desire to participate in a supervised exercise program. In contrast to our study, participants in other studies cited a lack of PR accessibility as a primary barrier to PR, while participants in the current study cited a lack of discussion from treatment teams as a primary barrier. It is important to note that our study did not include a lack of PR accessibility as a specific survey response option so the studies cannot be directly compared. Additionally, the lack of PR discussion may have been driven by a lack of PR availability, particularly in rural or resource-limited settings.

The current body of literature suggests that patients with PH who complete PR and an exercise training program can experience improvement in exercise capacity and quality of life.<sup>5,15</sup> A supervised exercise program with close monitoring, such as center-based PR, can serve as part of a multimodal treatment approach to the management of PH. A randomized control trial by Grunig et al. indicated that patients with PAH showed significant improvement in exercise capacity and quality of life with the addition of a

supervised exercise program in addition to pharmacologic treatment.<sup>15</sup> In addition, the 2022 ERS guidelines indicate that patients with PAH should be encouraged to participate in exercise training.<sup>10</sup> Despite these guidelines recommendations and well-established benefits, PR remains underutilized with less than half of patients reporting prior participation in PR. This represents an area for quality and practice improvement. This study highlights the importance of PR participation as recommended by patients as part of a multidisciplinary approach to disease management and highlights the lack of discussion by the treatment team as the major barrier to participation. The incorporation of checklists or other systematic approaches to improve PR referral rates and participation should be considered.

## LIMITATIONS

Limitations of the study include sampling and response bias. Additionally, we included a heterogeneous group of PH patients where PH diagnoses and classification were self-reported. Patient experience with PR and improvements in exercise capacity and quality of life were also self-reported and not objectively quantified. Another limitation was that the survey was only offered in English, which may also contribute to bias and limit the racial and ethnic diversity of participants.

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TABLE 3 Demographics and survey responses in respondents who participated in PR and who did not participate in PR.

	n	PR participants	n	PR nonparticipants	p Value
Female gender	175	150 (85.7)	244	204 (83.6)	0.56
Age	175	$62.0 \pm 14.0$	243	$60.3 \pm 13.8$	0.21
Ethnicity	174		242		0.55
White		149 (85.6)		202 (83.5)	
Non-White		25 (14.4)		40 (16.5)	
Region	175		244		0.02
Northeast		31 (17.7)		31 (12.7)	
Midwest		45 (25.7)		42 (17.2)	
South		57 (32.6)		87 (35.7)	
West		38 (21.7)		65 (26.6)	
International		4 (2.3)		19 (7.8)	
Supplemental oxygen use	175	120 (68.6)	244	112 (45.9)	<0.001
PH group	175		243		0.01
1		96 (54.9)		118 (48.6)	
2		16 (9.1)		23 (9.5)	
3		25 (14.3)		16 (6.6)	
4		11 (6.3)		24 (9.9)	
5 or unsure		27 (15.4)		62 (25.5)	
PH Meds	175		244		0.08
0		29 (16.6)		66 (27.1)	
1		41 (23.4)		47 (19.3)	
2		59 (33.7)		69 (28.3)	
3+		46 (26.3)		62 (25.4)	
PH physician	175		244		0.45
Pulmonologist		109 (62.3)		144 (59.0)	
Cardiologist		62 (35.4)		89 (36.5)	
Other or unsure		4 (2.3)		11 (4.5)	
Shortness of breath	175		244		0.03
At rest		1 (0.6)		12 (4.9)	
With minimal activity		69 (39.4)		80 (32.8)	
With moderate activity		90 (51.4)		122 (50.0)	
None		15 (8.6)		30 (12.3)	

*Note*: Data expressed as n, %, or mean  $\pm$  standard deviation as appropriate (used two-sided *T* test with independent samples, assume equal variances, or  $\chi^2$  with Fischer's exact test as appropriate). Bolded *p*-values represent statistical significance.

Abbreviations: Meds, medications; PH, pulmonary hypertension; PR, pulmonary rehabilitation.

## CONCLUSIONS

Patients with PH who participated in PR reported improvement in both quality of life and exercise capacity and would recommend PR to other PH patients. The majority of PH patients who did not participate in PR were interested in participation and cited a lack of discussion with their treatment team as one of the primary reasons for the lack of participation. PR is associated with self-reported improvements in quality of life and exercise capacity but remains underutilized among patients with PH.

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## AUTHOR CONTRIBUTIONS

All listed authors made a substantial contribution to the project design, data acquisition, analysis, and manuscript preparation.

## ACKNOWLEDGMENTS

The author(s) received no financial support for the research, authorship, or publication of this article.

#### CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

#### ETHICS STATEMENT

This study was approved by the Mayo Clinic Institutional Review Board (IRB # 22-003579) and adheres to all institutional ethical standards.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Bailey M, DuBrock HM. Pulmonary hypertension patient perspectives toward pulmonary rehabilitation. Pulm Circ. 2024;14:e12338. https://doi.org/10.1002/pul2.12338

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