An Evaluation of Factors That Influence Referral to Pulmonary Rehabilitation Programs Among People With COPD

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BACKGROUND: Pulmonary rehabilitation programs (PRP) are important for people with symptomatic COPD.

RESEARCH QUESTIONS: What proportion of people with COPD who are suitable for a PRP go on to be referred? Do clinical or sociodemographic characteristics influence the odds of whether those who are suitable for a PRP go on to be referred? What factors influence people’s interest in participating in a pulmonary rehabilitation program?

STUDY DESIGN AND METHODS: People with COPD who appeared appropriate for a PRP were sequentially recruited from three tertiary hospitals in Australia. Variables such as age, sex, lung function, smoking status, and interest in participating in a PRP were collected through interviews and reviewing the medical records. Referrals to PRPs were prospectively tracked through the electronic referral system, medical records, and discussion with the participant or the physiotherapists responsible for coordinating the PRPs.

RESULTS: Six hundred eighty-two people with COPD were approached, 468 consented, and data were available on 391 (No. [%] or mean ± SD; 215 males [55%], age 69 ± 10 years, FEV1 49 ± 19 %predicted). Of the 156 participants deemed suitable for a PRP, 74 (47%, 95% CI, 40-55) were referred to a PRP. Among participants who were deemed suitable for a PRP, the only variable that separated those who were from those who were not referred was interest in attending a PRP (mean difference in interest on the Visual Analog Scale [VAS]; 22 units, 95% CI, 12-32). Introverted personality traits and feelings of unworthiness reduced interest in attending a PRP.

INTERPRETATION: Among people with COPD who were suitable for a PRP, referral from the tertiary hospital setting was suboptimal. Suitable participants who were not referred showed lower interest in attending a PRP. There were novel complex individual barriers that reduced one’s interest in participating in a PRP.

KEY WORDS: behavior; COPD; exercise training; pulmonary rehabilitation; referral
Take-home Point

Study Questions: What proportion of people with COPD who are suitable for a pulmonary rehabilitation program (PRP) go on to be referred? Do clinical or sociodemographic characteristics influence the odds of whether those who are suitable for a PRP go on to be referred? What factors influence people’s interest in participating in a pulmonary rehabilitation program?

Results: Among people with COPD who were suitable for a PRP, referral from the tertiary hospital setting was suboptimal. Suitable participants who were not referred showed lower interest in attending a PRP. Introverted personality traits and feelings of unworthiness were some of the individual barriers that reduced interest in attending a PRP.

Interpretation: We demonstrated that there were complex individual barriers that influenced one’s interest to participate in PRPs. Collaborations among people with COPD, clinicians, and researchers presents a unique opportunity to develop novel strategies to enhance people’s interest and improve referral to PRPs among people with COPD in our tertiary setting.

Robust evidence indicates that for people with COPD, pulmonary rehabilitation programs (PRPs) that include supervised exercise training produce clinically important reductions in dyspnea and fatigue, as well as improvements in exercise tolerance and health-related quality of life.1 The editorial that accompanies the most recent Cochrane review on pulmonary rehabilitation states that “those who apply the intervention, those who receive it, and those who fund it can act with confidence,”2 and therefore PRPs should be considered a standard of care for people with COPD who are limited by dyspnea during their daily life.3,4 Nevertheless, the implementation of PRPs is problematic, with earlier work showing that the proportion of people with COPD who are actually referred to a PRP from primary or tertiary care is as low as 16%.5 Addressing this implementation gap is recognized as a global priority by international respiratory societies,3,8 and understanding the reasons for suboptimal referral behaviors is an important first step.

In this study, we aimed to explore referral patterns among people with COPD known to a tertiary hospital in Perth, Western Australia (WA). Our research questions were the following:

1. What proportion of people with COPD who are receiving specialist care through a tertiary hospital and appear suitable for referral to a center-based PRP go on to be referred?

2. What are the differences in characteristics between those who are suitable and referred and those who are suitable and not referred?

3. Do clinical or sociodemographic characteristics influence the odds of whether those who are suitable for a PRP go on to be referred?

4. From the patient perspective, what factors influence people’s interest in participating in a PRP?

Philosophical Positioning Underpinning Our Interpretation of Qualitative Data

Our study is informed by a critical realist perspective that has been described in detail elsewhere.9 Critical realism seeks to develop empirically supported explanations of phenomena via questions of how, why, and under what conditions.10 It is therefore important to appreciate our personal biases when we interpret these data to create meaning. S. H., V. C., and K. H. pay particular attention to PRPs not being prioritized in the tertiary setting, implicit biases of clinicians, and stigma and nihilism associated with COPD. These personal biases have developed from our clinical and research experience as physiotherapists. D. G. is a psychological scientist who represents “neutral ground” to ensure that our participant responses are respected, and our interpretation of these data are not clouded by these biases. The meaning we generate from the qualitative data can be appreciated as a raw, explicit, “tip of the iceberg” reflection of each participant’s opinion, while accounting for our influence to cultivate implicit meanings.

Study Design and Methods

Data reported in this study were collected between August 2020 and January 2021 as part of a mixed-methods study (the OPTIMAL study) that has been described elsewhere.7 Approvals from the local Ethics Committees were obtained before recruitment (RCS0000003704 and HRE2020-0095). Briefly, we sequentially screened all people with COPD who either attended an outpatient respiratory clinic appointment or were hospitalized for a suspected exacerbation of their condition across three tertiary hospitals (Fiona Stanley Hospital, Royal Perth Hospital, and Sir Charles Gairdner Hospital) in Perth, WA, for their suitability to participate in this study. Criteria were designed to find cases that appeared broadly...
appropriate for referral to a physiotherapist-led PRP, in either a hospital outpatient department or a community center in Perth. That is, participants were required to have a diagnosis of COPD, be able to understand English, and have a life expectancy of more than 6 months. Those recruited as outpatients needed to be independently ambulant, and those recruited during admission needed to have been independently ambulant before admission. Potential participants were excluded if they were living in supported residential aged care or had a cognitive impairment. Those recruited as outpatients were excluded if they had participated in either a PRP within the previous 12 months or a “maintenance” PRP within the previous 8 weeks because training-related gains are known to last for up to 12 months after completion of a PRP. People who met the study criteria were approached for written informed consent. Referrals of participants recruited as in-patients were prospectively tracked two weeks after hospital discharge and, where applicable, two weeks after their first respiratory outpatient appointment. Referrals of those recruited as outpatients were tracked 2 weeks after their first respiratory outpatient appointment. Referrals were tracked by reviewing the electronic referral system, reviewing the medical records and discussing with the participant or the physiotherapists responsible for coordinating the PRPs.

All statistical analyses were completed in Stata 17 (StataCorp 2021, StataCorp LLC) with normally distributed data expressed as mean ± SD, skewed data expressed as median (interquartile range), and count data expressed as frequency (percentage). Rather than conduct sample size calculations to inform hypothesis testing, we planned to sequentially recruit all eligible participants across the three tertiary hospitals for 5 months. This approach was used to provide us with a rich data set to explore factors associated with referral patterns to PRPs. Exposure variables selected for simple logistic regression were those thought to influence referral. This decision was informed by earlier work, as well as the clinical experience of the research team. We were careful to only include exposure variables that could be easily measured by clinicians, so if we found an association with group membership, these could be used to guide clinical practice. Multiple logistic models were run to control for the possible confounders that may bias estimates of the association with the exposure variables that were significant in the simple regression models. Responses to open-ended questions that considered factors that influenced participant interest in a PRP were extracted to QDA Miner Lite for content analysis. Fourteen theoretical domains and 10 mechanisms of action domains were used as a framework to categorize open-ended responses. Quotes were coded independently by S. H., who met regularly with D. G. to explore interpretations. Where quotes did not fit an existing category, miscellaneous constructs were generated. S. H. revised coding based on time spent interacting with the data and discussions with the research team.

Results
Flow of participants in the study is shown in Figure 1. Of the 682 people with COPD who were approached, 468 (69%) consented, and data were available on 391 (57%). Included participants were aged 69 ± 10 years, with a BMI of 28 ± 7 and FEV₁ of 49% ± 19% predicted. The sample was characterized by 215 (55%) males, and 234 (60%) were recruited from outpatient respiratory clinics. A total of 12 participants who were recruited during a hospitalization were already participating in a PRP before admission, and their data were excluded from further analysis. Of the remaining 379, 156 (41%) participants were deemed suitable. Of these, 74 (47%; 95% CI, 40-55) were classified as appropriate referrals, and 82 (53%; 95% CI, 45-60) were classified as missed referrals. Of the missed referrals, nine (11%) had been offered a referral but the health care professional (HCP) had not completed the referral to the PRP service providers, and 15 (18%) were offered a referral by an HCP but the participant declined. A total of 223 (59%) were deemed unsuitable for a PRP. Of these, 23 (10%; 95% CI, 6-14) were classified as inappropriate referrals and 200 (90%; 95% CI, 86-94) were classified as appropriate nonreferrals. Of the appropriate nonreferrals, 21 (11%) were offered a referral by an HCP but the participant declined. These proportions are summarized in Figure 2. Compared with those classified as missed referrals, participants classified as appropriate
referrals reported greater interest in participating in a PRP (Table 1). This result was largely unchanged in a multiple logistic regression model adjusted for potential confounders of age, sex, BMI, spirometry, smoking status, treating team, mMRC, and self-report exercise tolerance (OR, 1.26; 95% CI, 1.11-1.42; Hosmer-Lemeshow $\chi^2 = 5.21; P = .735$). Sensitivity analysis showed no difference in logistic regression results when those who declined a referral were removed from the analysis (e-Table 1). Compared with those classified as inappropriate referrals, there were no differences with those classified as appropriate nonreferrals (e-Appendix 1, e-Table 2).

Factors that influenced participant interest in a PRP were mapped as barriers or enablers to 13 (of 14) theoretical domains, six (of 10) mechanisms of action domains, and 11 miscellaneous constructs. Definitions of each domain are provided in e-Table 3. Examples of how each barrier or enabler quote was coded are provided in e-Appendix 1 and e-Appendix 3.
respectively. Barriers are presented in Figure 3. Frequently reported barriers were related to environmental context and resources factors (26%), such as problems with travel distance, transport and parking, or the inflexibility of programs leading to difficulties fitting it in around work or carer commitments. Less frequently reported barriers related to miscellaneous factors, such as attitudes of already doing enough exercise (5%), introverted personality traits (4%), and feelings of unworthiness (1%). Enablers are presented in Figure 4. Those frequently reported related to environmental context and resources facilitators (13%), positive past experiences (12%), and outcome expectancies (9%). Less frequently reported enablers were social influences such as social support from family or encouragement from HCPs (2%).

### TABLE 1 | Differences in Characteristics of the Missed Referrals vs Appropriate Referrals

<table>
<thead>
<tr>
<th>Variable</th>
<th>Missed Referrals (n = 82)</th>
<th>Appropriate Referrals (n = 74)</th>
<th>MD (95% CI)</th>
<th>Unadjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y</td>
<td>70 ± 10</td>
<td>68 ± 8</td>
<td>MD 2.02 (0.85 to 4.89)</td>
<td>OR 0.98 (0.94 to 1.01)</td>
</tr>
<tr>
<td>Sex, male</td>
<td>46 (56%)</td>
<td>38 (51%)</td>
<td>MD 1.05 (-1.25 to 3.36)</td>
<td>OR 0.98 (0.94 to 1.02)</td>
</tr>
<tr>
<td>BMI</td>
<td>28 ± 7</td>
<td>27 ± 7</td>
<td>MD 4.43 (-2.07 to 10.92)</td>
<td>OR 0.99 (0.97 to 1.00)</td>
</tr>
<tr>
<td>FEV1, % predicted</td>
<td>48 ± 20</td>
<td>43 ± 19</td>
<td>MD 1.05 (0.85 to 4.89)</td>
<td>OR 0.98 (0.94 to 1.01)</td>
</tr>
<tr>
<td>Current smoker, yes</td>
<td>30 (38%)</td>
<td>27 (36%)</td>
<td>MD 0.96 (0.50 to 1.84)</td>
<td>OR 0.98 (0.94 to 1.01)</td>
</tr>
<tr>
<td>IRSAD</td>
<td>3 [1 to 4]b</td>
<td>2 [2 to 4]b</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>Reference</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 OR 2.68 (1.08 to 6.65)</td>
<td>Reference</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 OR 2.38 (0.88 to 6.43)</td>
<td>Reference</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4 OR 1.28 (0.49 to 3.39)</td>
<td>Reference</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5 OR 1.14 (0.36 to 3.59)</td>
<td>Reference</td>
</tr>
<tr>
<td>Treating team, Respiratory</td>
<td>67 (82%)</td>
<td>64 (87%)</td>
<td>OR 1.43 (0.60 to 3.42)</td>
<td>Reference</td>
</tr>
<tr>
<td>Recruited from an outpatient clinic, Yes</td>
<td>45 (55%)</td>
<td>43 (58%)</td>
<td>OR 1.14 (0.60 to 2.15)</td>
<td>Reference</td>
</tr>
<tr>
<td>mMRC score</td>
<td>2 [1 to 2]p</td>
<td>2 [1 to 3]p</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0</td>
<td>Reference</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 OR 2.35 (0.23 to 24.51)</td>
<td>Reference</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>2 OR 2.83 (0.28 to 28.57)</td>
<td>Reference</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>3 OR 3.33 (0.32 to 34.99)</td>
<td>Reference</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>4 OR 1.50 (0.06 to 40.63)</td>
<td>Reference</td>
</tr>
<tr>
<td>Self-report exercise tolerance (m)</td>
<td>200 [100 to 400]b</td>
<td>200 [75 to 500]b</td>
<td>MD -22 (-32 to -12)</td>
<td>OR 1.24 (1.11 to 1.39)</td>
</tr>
<tr>
<td>Interest in attending a PRP (VAS)</td>
<td>55 ± 37</td>
<td>77 ± 25</td>
<td>OR 0.99 (0.99 to 1.00)</td>
<td>Reference</td>
</tr>
<tr>
<td>Who initiated the referral?a</td>
<td>NA</td>
<td>Consultant 22 (30%)</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physiotherapist 30 (41%)</td>
<td>Reference</td>
<td>Reference</td>
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<tr>
<td></td>
<td></td>
<td>Registrar 19 (26%)</td>
<td>Reference</td>
<td>Reference</td>
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<tr>
<td></td>
<td></td>
<td>Resident 1 (1%)</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other 2 (3%)</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td>Heard of a PRP, Yesa</td>
<td>49 (60%)</td>
<td>46 (62%)</td>
<td>OR 1.11 (0.58 to 2.11)</td>
<td>Reference</td>
</tr>
<tr>
<td>Previously participated in a PRP (Yes)a</td>
<td>31 (63%)</td>
<td>28 (62%)</td>
<td>OR 0.90 (0.39 to 2.07)</td>
<td>Reference</td>
</tr>
</tbody>
</table>

Data expressed as mean ± SD, median [IQR] or No. (%). IRSAD = Index of relative socio-economic advantage and disadvantage (a lower IRSAD score indicates relatively greater disadvantage and a lack of advantage in general); MD = mean difference; mMRC = modified Medical Research Council scale; NA = not applicable; PRP = pulmonary rehabilitation program; VAS = visual analog scale.

aDenotes missing data for the variable.

bIQR = interquartile range.

cVAS grouped in increments of 10 units.

dUnable to compare groups as cells with expected frequency of <5.
Discussion

The main finding of this study was that 47% of people with COPD who were known to one of three tertiary hospitals across Perth, WA, and were suitable for referral to a PRP were actually referred. Although suboptimal, the proportion referred in our study was considerably higher than what is reported in earlier work. That is, a recent study completed in the United Kingdom reported 16% of people with COPD were referred to a PRP. However, because this earlier study did not restrict the analyses to people who were deemed suitable for a PRP, these figures do not reflect the magnitude of the implementation gap. That is, it is impossible to distinguish missed referrals (which is the implementation gap) from appropriate non-referrals (which is an appropriate outcome) without first considering someone’s suitability for a PRP. In contrast, we considered first whether someone was suitable for referral to a PRP before classifying them according to whether they were referred. This methodological difference allowed us to examine the magnitude of the implementation gap (ie, missed referrals) and to explore the characteristics of this group of participants. Notably, the only variable that differed between the participants classified as appropriate referrals and missed referrals was their interest in the program. That is, those classified as appropriate referrals expressed more interest in participating in a PRP. Although implicit biases held by clinicians (ie, sex, smoking status, or socioeconomic status) can influence referrer decision-making, no differences in these variables were found between participants classified as appropriate referrals and missed referrals.

Figure 3 – Barriers to a pulmonary rehabilitation program mapped to theoretical domains framework and mechanisms of action. The size of each bubble relates to the frequency with which it was quoted. Definitions of each domain can be found in e-Table 3. BaCaps = beliefs about capabilities; BaCons = beliefs about consequences; FP = feedback processes; GAB = general attitudes and beliefs; In = intentions; Pes = pessimism; Pref = preferences; SI = social influences; SL = social learning and imitation.
missed referrals. Therefore, our data suggest that the decision to refer to a PRP was not influenced by implicit biases related to these factors.

Our data allowed us to explore the reasons why people who were suitable for referral to a PRP were not referred. That is, in our tertiary hospitals, the locus of barriers to referral are that HCPs are largely not offering referrals (71% not offered a referral when it needed to be offered, ie, missed referrals group), and for those who are offered a referral, some health care professionals do not complete the referral (11%), some patients decline (18%), and others are offered it when referral does not appear appropriate (11%). A combination of actions that optimize HCP understanding of PRPs, who is appropriate for a PRP, and prompts to complete referrals, as well as ways to}

target interest among people with COPD are required to boost referral behaviors.

Understanding reasons why those classified as missed referrals expressed less interest in participating in a PRP is important, especially if the reasons are modifiable. Consistent with earlier work, frequently reported barriers included environmental context and resource factors, such as difficulties with transport and parking costs, or the inflexibility of programs leading to difficulties fitting it in around work or carer commitments. However, just because these factors were frequently coded as barriers, they are not necessarily the most potent. Domains frequently coded likely represent what the participant was most willing to share without further probing. It is therefore important to reflect on barriers less frequently coded.
such as introverted personality traits and feelings of unworthiness. Our data are the first to demonstrate comments that suggest introversion being a barrier, for example: I don’t like crowds, I keep to myself. If I start panicking, I get breathless. I’m very much a loner, I’m not a people person. Further inquiry is needed to understand whether these people have had lifelong introversion or whether their COPD, which is often coupled with underlying feelings of unworthiness or being told to stay “away from germs” and shield from COVID-19, has led to this personality trait. Feelings of unworthiness, such as I felt I was taking up a place of someone who could benefit more, were also noted as barriers to participating in a PRP. Perhaps society unconsciously shapes this view. COPD is a leading cause of death and disability globally, yet respiratory diseases as whole accounted for approximately 2% of total research expenditure by funding bodies in Australia (2016-2019) and the United Kingdom (2012-2015). Introversion and unworthiness can cause social isolation and reduce help-seeking behaviors, and they may contribute to lower interest levels in a PRP.

Data from this study can be used to inform approaches to optimize people’s interest in participating in a PRP. For example, inflexibility of the program times and locations, or the attitude of not needing the program because they are already doing enough were reported as barriers to participation. These barriers have a negative influence on interest but are modifiable. For example, offering a “suite” of alternative models of delivery to choose from outside the traditional “group” format, offering programs outside usual business hours, and framing people’s expectations are some ways to modify participant-reported barriers and increase their interest. Participants frequently reported outcome expectancies as an enabler to participating in a PRP, for example To get me better, even a small improvement would be nice. Another frequently coded enabler was positive past experiences among those who had previously completed a PRP: I thought it was a brilliant program and would do it again. Using testimonials can be a powerful tool to attest to the benefits of a PRP and empower potential PRP candidates to participate. Because earlier work has demonstrated that showing inpatients co-designed video testimonials had no clear effect on referral or completion of PRPs on hospital discharge, a more interactive approach seems required. This might involve asking people with COPD who are recent class participants to champion PRPs in the hospital setting and share their lived experience with others. Perhaps offering social support and giving potential PRP candidates the opportunity to ask questions of someone with program experience, factors that were coded less frequently as enablers, may activate intrinsic motivation and regulate interest in participating in a PRP. Encouragement from HCPs was another less frequently coded enabler that has been previously reported, and although we collected data on who initiated the referral (Table 1), we did not have data on which HCPs missed referrals. Future research on referral behaviors should aim to capture such information, which could inform areas to target interventions.

Strengths and Limitations

A strength of this study is that we classified our participants according to their suitability for a referral to a PRP. This allowed us to accurately reflect the size of the implementation gap of PRPs in Perth. Possibly PRPs in other jurisdictions apply different suitability criteria, but to optimize the generalizability of our results, decision-making was escalated to a consensus group that involved PRP clinicians, and we were liberal with our decision-making (ie, if in doubt, deem them suitable for a referral). A further strength of this study is that data were collected prospectively, through face-to-face interviews with participants either during their hospitalization or after their outpatient clinic appointment. This contrasts with earlier work investigating the implementation gap of PRPs, which has used surveys or retrospective audits of notes, giving a superficial understanding of complex implementation barriers. Prospective data collection also minimized missing data and loss to follow-up. Approximately 25% of people with COPD who met the study criteria and were approached chose not to participate in our study. This finding was somewhat surprising, because this study was observational, required very little active participation (10 minutes), and had negligible burden or risk. Nonparticipation in research could be associated with nonparticipation in a PRP, so our cohort may have been influenced by a selection bias. Perhaps considering novel approaches to involve people with COPD in research for whom altruism alone is insufficient motivation is important. Engaging consumers as colleagues, whose expertise is their lived experience, is a novel approach to this limitation.
Interpretation

From our prospective observational study, we found that just under half of people with COPD known to one of three tertiary hospitals in Perth, WA, who were suitable for a PRP were actually referred. The only characteristic that differed between the appropriate referrals and missed referrals was their interest in participating in a PRP.

Factors that negatively influenced our participant’s interest in PRPs included environmental context and resource factors (ie, issues with travel, transport, parking, or program inflexibilities), introverted personality traits, and feelings of unworthiness. Collaborations among people with COPD, clinicians, and researchers present a unique opportunity to develop novel strategies to enhance people’s interest and improve referral to PRPs among people with COPD in our tertiary setting.

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Additional information: The e-Appendices and e-Tables can be found in the Supplemental Materials section of the online article.

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