

Volunteer-led Community-based Exercise Programme Impact on Health Outcomes in Patients with Chronic Obstructive Pulmonary Disease in New Zealand

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ABSTRACT

Pulmonary rehabilitation improves the health of people with chronic obstructive pulmonary disease (COPD). Community-based maintenance programmes led by health professionals maintain these benefits; however, limited information is available on volunteer-led community programmes. We investigated the impact of a post-rehabilitation volunteer-led programme on the health of people with COPD. Attendees ($n = 19$) and non-attendees ($n = 24$) completed questionnaires to assess anxiety and depression (Hospital Anxiety and Depression Scale), COPD symptoms (COPD Assessment Test), and health-related quality of life (EQ-5D-3L-3L); a sit-to-stand test, and oxygen saturation before and after the programme, and 1–2 years later at follow-up. In addition, both attendees and non-attendees completed a social connectedness questionnaire and participated in a qualitative interview at follow-up. No significant differences ($p > 0.05$) were found at follow-up between attendees and non-attendees. Additionally, attendees' depressive and COPD symptoms and all other health variables had returned to baseline (pre-rehabilitation) levels by follow-up. In contrast, qualitative analysis showed positive themes for attending the programme, with the most common benefit of engaging with others with COPD. Our findings suggest that the impact of COPD on health may be profound even in motivated and engaged people. Further research to develop optimal models for maintenance programmes would support effective practice in the community.

Marshall, H., Goodall, T., Callahan, D., Halim, A., Olsen, P., Choukri, M., & Chen, D. (2023). Volunteer-led community-based exercise programme impact on health outcomes in patients with chronic obstructive pulmonary disease in New Zealand. *New Zealand Journal of Physiotherapy*, 51(2), 90–99. <https://doi.org/10.15619/nzjp.v51i2.354>

Key Words: Chronic Obstructive Pulmonary Disease (COPD), Community-based Exercise, Pulmonary Rehabilitation, Volunteer

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a broad term used to categorise emphysema, chronic bronchitis, and chronic asthma (Asthma + Respiratory Foundation New Zealand, 2023; Mannino & Buist, 2007; Telfar Barnard & Zhang, 2021). Approximately 35,000 New Zealanders have severe COPD; however, the disease is often undiagnosed and potentially as many as 200,000 people could have COPD in New Zealand (Asthma + Respiratory Foundation New Zealand, 2023). The principal symptom of COPD is dyspnoea, which can lead to decreased activity levels and therefore diminished cardiovascular

and muscular fitness (Asthma + Respiratory Foundation New Zealand, 2023). Consequently, pulmonary rehabilitation courses are often run to improve the overall health status, and cardiorespiratory and muscular fitness in people with COPD (Busby et al., 2014).

Pulmonary rehabilitation is a multi-disciplinary intervention or programme designed to improve the health of those affected by COPD. People typically participate in a 6–12-week exercise and education intervention to enhance their physical, mental, and social health (Grade A evidence) (Bolton et al., 2013). It is recommended that pulmonary rehabilitation programme

sessions should be run at least twice weekly, with participants gaining the most benefit by attending 12 or more supervised sessions (Bolton et al., 2013). These interventions have been found to improve overall health status and physical endurance, decrease the number of exacerbations, decrease hospital admissions, and reduce the financial burden of COPD (Busby et al., 2014; Kjærgaard et al., 2020).

A recent study conducted in Denmark (Løkke et al., 2021) determined that the direct health cost of people living with COPD (€28,969) was almost three times higher than that in the control non-COPD reference group (€10,693) in the 12-month follow-up period during which the costs were calculated. The direct cost included the cost of treatment and care of those with COPD. The indirect cost, which was referred to as the foregone earnings for the people living with COPD, was assessed to be €6,773 in the 12-month period. The costs related to COPD were found to increase with increasing disease severity. Similarly, substantial costs associated with COPD have been reported in New Zealand. A strategic overview of respiratory disease in New Zealand (National Health Committee of New Zealand, 2013) reported the direct cost of the care of people living with COPD to be between \$102 to \$192 million per annum, with an estimated cost of \$2,566 per person per year. Overall, COPD contributed to \$54 million in hospital admission costs, which were 20.3% of the total respiratory hospitalisation costs for the year.

Despite the success of pulmonary rehabilitation, benefits decrease after the intervention and most people return to baseline health status 6–24 months post rehabilitation (Bestall et al., 2003; Bratås et al., 2012). These benefits, however, can be sustained through maintenance programmes that have been shown to increase physical endurance and reduce hospital admissions compared to no intervention or usual care (Busby et al., 2014; Jenkins et al., 2018; Güell et al., 2017).

Research on community-based maintenance programmes for those with COPD is minimal. However, studies in the area have found physical and mental health benefits of these exercise interventions (Güell et al., 2017; Ries et al., 2003; van Wetering et al., 2010). A one-year community-based programme for people with COPD that was supervised by trained fitness consultants who had received exercise training from a physiotherapist significantly increased strength and endurance at 6 and 12 months relative to an earlier 6–12-week pulmonary rehabilitation programme. The community-based programme also maintained the improvements in quality of health measures achieved in the post-pulmonary rehabilitation programme measured using the Chronic Respiratory Disease Questionnaire (Beauchamp et al., 2013). Furthermore, a 2-year randomised controlled trial to determine the efficacy of a community-based COPD programme (van Wetering et al., 2010) found that participants in a physiotherapist-led intervention had a significantly better health-related quality of life (HRQOL), increased functional exercise capacity, and less breathlessness compared to the usual care control group. A recent study also found significant benefits for physical function (6 min walking distance), HRQOL, and dyspnoea after 4 years of an ongoing supervised self-help maintenance programme in a community setting: individuals participated in exercise training

(approximately 42 sessions/year), health education classes (6 hr per year), and psychological support (approximately 2.5 sessions per year) (Blervaque et al., 2021). Nevertheless, a Cochrane review suggested that the strength of evidence is limited to professional-led community-based programmes (Malaguti et al., 2021). While ongoing interventions supervised by healthcare professionals have been shown to be effective (van Wetering et al., 2010), resourcing to provide professionally-led support programmes may not be available (Beauchamp et al., 2013). Consequently, the efficacy of volunteer-led programmes compared to those led by healthcare professionals has been investigated.

Although research has not been conducted in people with COPD, similar improvements in physical function have been found during a weekly exercise programme conducted over a year for community-dwelling older adults in peer-led versus health professional-led programmes in New Zealand (Waters et al., 2011). A community-embedded, peer-led dual task exercise programme was also found to improve physical function and frailty status and reduce the number of falls and social isolation after 3 months (Merchant et al., 2021). Additionally, recent systematic reviews (Lim et al., 2021; Moore et al., 2021) and a meta-analysis (Moore et al., 2021) found that peer-led interventions improved both functional status (the ability to conduct activities of daily living and maintain independence) and physical function (this can be a range of measures including physical endurance, balance, strength, and flexibility) of older adults with a variety of health conditions. Peer-led exercise interventions for community-dwelling older adults have also found improvements in HRQOL (Izutsu et al., 2017; Lim et al., 2021) and perceived health (Merchant et al., 2021).

Additionally, from a patient perspective, qualitative studies indicate that a minimally supervised community programme increases feelings of accomplishment, achievement, and self-motivation, and is effective if interventions are well organised, structured, and specific to a patient's needs and disease (Desveaux et al., 2014a; Desveaux et al., 2014b). The need for programme specificity and belonging are common themes identified in these research studies, with patients expressing the importance of being with people of similar functional abilities, experiences, and conditions in the exercise programmes (Desveaux et al., 2014a; Desveaux et al., 2014b; Sinnerton & Gillen, 2009).

In New Zealand, pulmonary rehabilitation typically consists of 6–10-week interventions of twice-weekly exercise and education sessions, with some organisations also offering ongoing community-based exercise groups post-rehabilitation (Levack et al., 2012). In Canterbury, New Zealand, volunteer-led community-based exercise groups are offered to patients following pulmonary rehabilitation. While there has been some research on community-based programmes supervised by healthcare or fitness professionals (Beauchamp et al., 2013; Desveaux, et al., 2014a), to the best of our knowledge, no research has been undertaken on volunteer-led community-based exercise groups for those living with COPD, whereby the volunteers leading the programme have previously completed a pulmonary rehabilitation intervention. Therefore, the aim of this study was to determine the impact of a volunteer-led

community-based exercise programme on health outcomes in people with COPD. The secondary aim was to identify reasons or themes for non-attendance and participation in the community-based exercise programme.

METHODS

Study design

This study used a mixed-methods design, with quantitative and qualitative data collected from attendees and non-attendees of the volunteer-led exercise group. People in the study had initially completed an 8-week pulmonary rehabilitation programme, which was integrated within the community in 2010. Following the programme, they chose to participate or not participate in a volunteer-led exercise group. The exercise groups were established shortly after 2010 when a gap in ongoing exercise and support groups in the community was identified. Data were collected one week prior to (pre) and one week following (post) the 8-week rehabilitation programme, and 1–2 years after the rehabilitation programme (follow-up), to determine the effectiveness of a volunteer-led community exercise group in maintaining the physical and mental health of people with COPD at follow-up (primary aim). Participants were also interviewed at the follow-up, contributing qualitative data to provide additional insights into the primary aim. The qualitative data also addressed the secondary aim of the research, to identify the reasons for attendance and non-attendance.

Participants

All participants completed 8 weeks of pulmonary rehabilitation between December 2016 and November 2017. Participants were excluded if they were medically unstable, had a recent (< 4 weeks) acute medical event, or attended a support group led by an instructor (i.e., not a volunteer-led group). In the context of pulmonary rehabilitation, acute medical events include cardiac events and unstable and/or uncontrolled cardiac conditions such as angina or arrhythmias. Participants were recruited at five volunteer-led community-based exercise groups (attendees) or by telephone (non-attendees) using information from medical records. Nineteen people who attended the volunteer-led exercise groups (attendees) consented to participate in the study. People who had completed pulmonary rehabilitation but did not attend community exercise groups (non-attendees, $n = 394$) were contacted and 24 consented to participate in the study. Therefore, in total, 43 people (attendees, $n = 19$; non-attendees, $n = 24$) participated in the study. Ethical approval was obtained from the Institutional Ethics Board at Ara Institute of Canterbury (project number 1833). All participants provided informed consent to participate and allowed the use of their retrospective data, and the study conformed to the Declaration of Helsinki, 1964.

Data collection

Data were primarily collected by a summer scholarship student from Ara Institute of Canterbury (TG), with support from a Canterbury Clinical Network physiotherapist (DC).

Quantitative

Demographic and pre- and post-pulmonary rehabilitation data were accessed retrospectively from the Pegasus Health data storage system. Demographic data included age, gender, and ethnicity. Approximately 1–2 years following the completion of

the rehabilitation programme (M (SD) for attendees = 500 (139) days; non-attendees = 559 (141) days; $p = 0.10$), participants completed the same battery of tests as they did pre- and post-rehabilitation. The tests included three questionnaires relating to health measures: depressive symptoms (Hospital Anxiety and Depression Scale [HADS]; Breeman et al., 2015), impact of COPD symptoms (COPD Assessment Test [CAT]; Grufstedt et al., 2018), and HRQOL ([EQ-5D-3L]; Pickard et al., 2008); a 1 min sit-to-stand test; and resting oxygen saturation (SpO_2) was measured. The HADS, CAT, and EQ-5D-3L questionnaires are valid and reliable measures in COPD populations (Grufstedt et al., 2018; Jones et al., 2009; Mannino & Buist, 2007; Pickard et al., 2008; Yohannes & Alexopoulos, 2014). Physical function was measured using a 1 min sit-to-stand test, which simulates movements used in daily life and correlates well with clinical outcomes in patients with COPD (Crook et al., 2017; Morita et al., 2018; Spence et al., 2023).

At follow-up (1–2 years following pulmonary rehabilitation), an additional social connectedness questionnaire, based on the social connectedness domain of the 2016 Social Report (Ministry of Social Development, 2016), was administered. The questionnaire included eight questions related to access to information and support that were relevant to the COPD population in New Zealand. Five indicators were used to measure social connectedness: telephone and internet access, contact with family and friends, trust in others, loneliness, and voluntary work. An additional question relating to living situation was included in the questionnaire. The questions included both Likert scale and binary answers (yes/no) (see Appendix A).

Qualitative

A brief semi-structured, individual, interview (15–20 min) was conducted with all participants at follow-up. The aim of the interview was to establish themes for attendance and non-attendance at the volunteer-led community-groups. Interviews were conducted at the community venue (attendees) or at the participant's home (non-attendees) and were audio-recorded and transcribed verbatim for data analysis purposes. The interview questions for both groups can be found in Table 1.

Intervention

The volunteer-led community exercise groups involved in the current research were modelled on the original Christchurch Respiratory Relief Society support groups, which were physiotherapist-run exercise classes established in 1989 by a respiratory physiotherapist from Christchurch Hospital (Te Whatu Ora – Waitaha Canterbury). Participants met once a week on an ongoing basis to perform exercise at one of the five community groups. The group exercise sessions were 30–45 min long and consisted of low-impact aerobic exercises (such as “sit-to-stand”). Participants were encouraged to work between levels 3 and 5 on the modified Borg rating of perceived exertion, that is, from “moderate” to “severe” in terms of fatigue and breathlessness. The volunteer leaders selected from a variety of available equipment, such as stress balls, exercise bands, weights, and scarves, to make the exercise routine challenging and interesting for the attendees. The volunteers were encouraged and supported to attend a community exercise leader foundation course run by the Active Canterbury Network.

Table 1*Interview Questions*

Group	Questions
Attendees	<p>Can you outline the reasons why you took up the opportunity to attend a community respiratory support group?</p> <p>What are the benefits of attending the support group?</p> <p>Is there anything else you do (outside of the support group) to support your respiratory health?</p> <p>Is there anything about the support group that you would like to see changed/added/removed that you believe would further support your health?</p>
Non-attendees	<p>Can you outline the reasons why you did not take up the opportunity to attend a community respiratory support group?</p> <p>What activities do you currently take part in to support your respiratory health?</p> <p>Is there any alternative support that you would like to see provided by the community to benefit your respiratory health?</p>

Following the exercise, participants connected through shared kai and kōrero. The groups were led by volunteers who also had a chronic respiratory illness and had previously completed the pulmonary rehabilitation programme or had been a support person to a participant in the class. They were mostly recruited due to having personally experienced positive changes following pulmonary rehabilitation. The volunteer-led group was designed to be an independent and self-sustaining way of assisting people living with chronic respiratory conditions in the community. The support groups often invited guest speakers, such as people from Work and Income New Zealand, Citizens Advice Bureau, and Energy Action groups, to connect those attending with their community and to keep attendees up to date with information on health and disability support services and local politics.

Analyses**Quantitative data**

All quantitative data were entered in an Excel spreadsheet and analysed using SPSS Statistics (version 25.0). The Mann-Whitney U test was used to determine the difference in outcome measures between attendees and non-attendees of the volunteer-led community-groups. The Wilcoxon signed rank test was used to determine changes in outcome measures at pre- and post-pulmonary rehabilitation and the follow-up within each group (attendees and non-attendees). T-tests and chi-squared tests were used to determine any significant differences between the attendees and non-attendees for demographics and social connectedness. The significance level was set at 0.05.

Qualitative data

Interview audio recordings were transcribed verbatim into a Word document by the summer scholarship student. All transcriptions were anonymised, and then verified by another member of the research team for accuracy. After transcription, a thematic analysis was undertaken to identify main themes and important points with an inductive approach. Following in-depth discussions, a coding system was developed from the transcripts by identifying recurring themes that were considered particularly meaningful relative to the aim of identifying reasons or themes for non-attendance and participation in the community-based exercise programme.

RESULTS**Quantitative measures****Participant characteristics**

There were no significant differences ($p \geq 0.05$) between attendees and non-attendees in mean (*SD*) age (attendees = 73.4 (7.4) years; non-attendees = 71.8 (6.5) years). Participants were mostly female (attendees = 74%; non-attendees = 63%) and of European ethnicity (attendees = 84%; non-attendees = 92%), respectively; $p \geq 0.05$ for both). Additionally, the duration between the completion of pulmonary rehabilitation and the follow-up was similar (*M (SD)*: attendees = 500 (139) days; non-attendees = 559 (141) days).

Pulmonary rehabilitation

There were no statistically significant differences between the attendees and non-attendees in pre-pulmonary ($p = 0.28$ to 0.68) and post-pulmonary ($p = 0.10$ to 0.96) rehabilitation measures for SpO₂, CAT, HADS, EQ-5D-3L, and sit-to-stand (Table 2). However, at post-pulmonary rehabilitation, a trend suggested that the attendees' CAT score was lower than that of the non-attendees (*M (SD)*: attendees = 16.7 (5.3); non-attendees = 20.1 (6); $p = 0.06$), indicating a greater improvement in this measure and potentially less impairment (Table 2). Within the groups, there were significant improvements in health measures following pulmonary rehabilitation. The attendee group had significantly reduced impacts of COPD symptoms and depression (improved CAT and HADS-Depression scores; $p = 0.03$), and improvements in physical function (sit-to-stand) ($p = 0.08$) and HRQOL (EQ-5D-3L) ($p = 0.09$) approached statistical significance from pre- to post-rehabilitation. In contrast, the only statistically significant change in the non-attendee group was an improvement in physical function (sit-to-stand, $p = 0.01$) (Table 2).

Follow-up**Anxiety, depression, COPD symptoms, and overall health status**

There were no statistically significant differences in primary outcome measures ($p = 0.11$ to 0.82) at follow-up between attendees and non-attendees for SpO₂, CAT, HADS, EQ-5D-3L, and sit-to-stand (Table 2). The attendee group showed a

statistically significant increase of 42% for depression ($p = 0.04$) and 31% for COPD CAT scores ($p = 0.006$) at follow-up, relative to post-pulmonary rehabilitation measurements (Table 2), returning to pre-rehabilitation values. Changes in other primary outcome measures such as SpO₂, HRQOL (EQ-5D-3L), and sit-to-stand were not significantly different ($p = 0.24$ to 0.81) in the follow-up relative to post-rehabilitation data in the attendee group. No significant differences ($p = 0.17$ to 0.98) were found in the non-attendee group at follow-up compared to post-rehabilitation (Table 2). In both groups, minimal differences for all quantitative primary outcome measures were found at follow-up compared to pre-pulmonary rehabilitation ($p = 0.27$ to 0.98).

Social connectedness

At follow-up, attendees were more trusting of other people (attendees = 7.4; non-attendees = 6.3; $p = 0.02$) and tended to be more likely to do volunteer work (attendees = 37%; non-attendees = 13%; $p = 0.08$). In contrast, a larger proportion of non-attending participants had internet access at home (attendees = 63%; non-attendees = 88%; $p = 0.08$). There were minimal differences between the groups for other social connectedness measures including living situation of living alone (attendees = 29%; non-attendees = 56%) or with a partner (attendees = 44%; non-attendees = 53%); phone

access (100%); loneliness, with the majority reporting “none of the time” or “a little of the time”; and amount of contact with family and friends (the majority reported “about right”; attendees = 88%; non-attendees = 84%); $p = 0.22$ to 1.0).

Qualitative themes at follow-up

Attending group

We identified four key themes from the data (Table 3). The major themes identified by attendees were the psychological and physical benefits of attending the exercise groups. A common factor was that socialising with others who have the same condition was motivating and psychologically beneficial, for example: “Just understanding you’re not alone and support and friendships just been absolutely amazing because a lot of family and friends don’t understand how difficult it is to live with breathing problems on an everyday basis” (SU). The community exercise groups gave people a safe space to share information and talk about problems, while feeling comfortable coughing or taking it slow during exercise without being judged. Other reasons for participation were to maintain the health benefits gained through pulmonary rehabilitation, and classes motivated them to try harder in exercises and be more active at home. With regards to changes to the support group, many attendees indicated they were happy with the current volunteer-led groups. Participants also provided suggestions for change,

Table 2

Comparison of Pre- and Post-pulmonary Rehabilitation and Follow-up Outcome Measures for Attendees (N = 19) and Non-attendees (N = 19) of a Volunteer-led Exercise Group

Variable	Pre-pulmonary rehabilitation		Post-pulmonary rehabilitation		1–2 year follow-up	
	Attendees	Non-attendees	Attendees	Non-attendees	Attendees	Non-attendees
Sit-to-stand test						
<i>M</i> (<i>SD</i>)	19.7 (4.0)	17.7 (5.8)	21.8 (5.9)	21.9 (5.0) * ^a	19.6 (5.9)	18.0 (7.3)
<i>Mdn</i> [IQR]	19.5 [17.2, 23.0]	18.5 [14.8, 21.0]	21.5 [16.8, 24.5]	22.0 [19.0, 24.0]	19.0 [16.0, 22.0]	18.0 [14.2, 23.0]
SpO ₂						
<i>M</i> (<i>SD</i>)	95.9 (2.1)	96.2 (1.8)	95.8 (2.3)	96.7 (2.2)	95.5 (2.0)	95.7 (2.3)
<i>Mdn</i> [IQR]	96.0 [94.5, 98.0]	96.0 [95.0, 97.2]	96.0 [94.0, 97.0]	97.5 [95.8, 98.0]	95.0 [94.0, 97.0]	96.5 [94.8, 97.0]
CAT score						
<i>M</i> (<i>SD</i>)	19.2 (6.4)	21.6 (6.4)	16.7 (5.3) * ^a	20.1 (6.0)	21.8 (5.7) ** ^b	21.0 (7.7)
<i>Mdn</i> [IQR]	19.0 [15.0, 24.0]	21.0 [17.2, 27.8]	16.5 [14.2, 20.0]	21.0 [17.2, 24.8]	23.0 [17.5, 26.0]	22.0 [16.0, 25.2]
HADS–Anxiety						
<i>M</i> (<i>SD</i>)	6.0 (3.2)	7.2 (4.4)	5.8 (2.6)	6.8 (4.5)	5.6 (2.5)	6.3 (4.2)
<i>Mdn</i> [IQR]	6.0 [4.2, 7.8]	7.0 [3.5, 9.5]	6.0 [4.0, 7.5]	6.0 [5.0, 9.0]	6.0 [4.0, 7.0]	6.5 [2.8, 8.0]
HADS–Depression						
<i>M</i> (<i>SD</i>)	4.2 (2.3)	4.8 (2.8)	3.1 (2.0) * ^a	4.2 (2.9)	4.4 (2.0) ** ^b	4.8 (3.5)
<i>Mdn</i> [IQR]	4.0 [2.2, 5.0]	4.0 [3.0, 7.5]	3.0 [1.5, 4.0]	4.0 [1.5, 7.0]	5.0 [2.5, 6.0]	5.0 [2.5, 6.2]
EQ-5D-3L						
<i>M</i> (<i>SD</i>)	6.6 (1.6)	6.0 (1.7)	7.4 (1.2)	6.5 (1.6)	6.9 (1.7)	6.2 (1.7)
<i>Mdn</i> [IQR]	6.8 [5.5, 8.0]	6.0 [4.8, 7.1]	7.0 [6.6, 8.0]	7.0 [5.0, 7.0]	7.0 [6.1, 8.0]	6.2 [5.0, 7.5]

Note. Computing exact p values was not possible in Wilcoxon Signed Rank Test due to ties. CAT = chronic pulmonary disease assessment test; EQ-5D-3L = European quality of life 5 dimensions 3 level version (standardised measure of health status); HADS = hospital anxiety and depression scale; O₂ = oxygen.

^a significant change within group pre- versus post-pulmonary rehabilitation. ^b significant change within group post rehabilitation versus follow-up.

* $p < 0.05$. ** $p < 0.01$.

Table 3*Interview Themes and Subthemes*

Theme	Subtheme
Attendees	
Perceived benefits of attending programme	Physical benefits Psychological benefits Motivation
Recommended improvements to programme	Health professional visits Better spaces
Non-attendees	
Reasons for not attending programme	Personal barriers Accessibility/transport
Activities to stay active	Active at present No energy for more activity

including periodic visits from pulmonary physiotherapists and larger spaces to host the bigger groups. Participant SU indicated that:

The only thing I, that I've noticed is that on the days that we've been fortunate enough to have one of the tutors from the course such as [staff named] attend that's always more educating for us and very, very helpful so perhaps a little bit more support from the tutors on occasion would be great.

Other participants commented on the suitability of the space: "No there isn't enough space but that's nobody's fault" (PE) and "... we could do with a bigger room ..." (JA).

Non-attending group

There was a wide range of reasons for not attending the exercise groups such as illness, lack of time due to work and family commitments, lack of awareness of the groups, or believing that they were not beneficial based on their experience of the pulmonary rehabilitation programme. However, many non-attendees indicated that a main barrier to participation was a lack of transport or transport options, for example: "Well, it's a matter of transport that's the only reason I haven't gone to any ... I ended up with I have to get about three buses to get to one place" (AI). In terms of physical activity, approximately two-thirds of non-attending participants ($n = 16$) actively engaged in activities such as walking, housework, gardening, dancing, bowls, and exercising at home to support their respiratory health. Some participants mentioned that they felt that they were either already physically active enough, or that they had no spare energy for additional activities such as attending these groups. Those who did not participate in physical activity indicated reasons such as working full time, chronic illness, or disability.

DISCUSSION

We investigated the impact of attending or not attending a weekly volunteer-led community exercise programme on the health of people with COPD, 1–2 years after completing pulmonary rehabilitation. The 8-week pulmonary rehabilitation programme was retrospectively found to produce similar health benefits for the people with COPD as observed in previous

research (Busby et al., 2014; Jenkins et al., 2018). However, in the follow-up 1–2 years post pulmonary rehabilitation, minimal differences were found for all health measures between participants who had attended and those who had not attended a weekly exercise group. A within-group comparison also found that the attendee group had significant increases in depressive (HADS) and COPD symptoms (CAT) at follow-up relative to post-rehabilitation (1.3 and 5.1, respectively), and these variables along with all other primary outcome measures had returned to pre-rehabilitation or baseline levels. The change in depressive (HADS) and COPD (CAT) scores may be clinically relevant as they were approaching, or were greater than, the minimally clinically significant difference in HADS (≥ 1.5) and CAT (≥ 5.1) scores (Kon et al., 2014; Puhan et al., 2008). The decrease in these measures was unexpected, as the attendee group had responded well to pulmonary rehabilitation, and previous research on fitness and/or health professionals-led community exercise programmes showed that the benefits from pulmonary rehabilitation were maintained above pre-rehabilitation (baseline) for 6 to 24 months (Beauchamp et al., 2013; Ries et al., 2003; van Wetering et al., 2010). Additionally, a systematic review and meta-analysis found that volunteer-led programmes may improve physical function, although participants had a range of chronic conditions and the certainty of evidence was low (Moore et al., 2021). It is possible that the volunteer-led programme did not have a sufficient training load to increase or maintain physical endurance and alleviate symptoms such as dyspnoea, anxiety, and depression, as participants typically only attended the group once per week, whereas the pulmonary rehabilitation intervention had exercise sessions twice a week, in line with the British Thoracic Society guidelines (Bolton et al., 2013). Moreover, all participants in the current study had high CAT and HADS scores, indicating greater impairment, compared to normative data (Breeman et al., 2015; Pinto et al., 2014). For example, the normative mean (*SD*) of the CAT score across all age groups was 6 (5.1) and a score of ≥ 10 is considered high. Our participants' scores were > 16 at all time points: pre-rehabilitation, post-rehabilitation, and at follow-up. This means that our sample experienced higher than average COPD symptoms, which may have influenced the results. Another limitation is that we used convenience

sampling to recruit participants from the community exercise groups and medical records. This may have produced a biased sample in our groups and affected the validity of our findings. For example, when recruiting non-attendees, the researchers attempted to contact 394 people, of whom 24 or approximately 6% volunteered to participate; the most common reason for not participating was illness. The low response rate may have resulted in the non-attendee group being disproportionately healthy and not representative of non-attendees in general. This hypothesis is supported by the findings showing that two-thirds of the non-attendees indicated that they regularly participated in exercise. Irrespective of the non-attendee sample potentially not representing the population, our within-group findings for attendees indicated that participation in a weekly volunteer-led exercise group did not maintain the health benefits achieved in pulmonary rehabilitation.

In contrast to the quantitative data, qualitative data at the follow-up showed positive outcomes from attending the volunteer-led groups. The most common finding was the benefits of attending a group with others experiencing the same health condition. Attendance enabled participants to socialise, share information, talk about problems, feel comfortable coughing, and take it slow in exercises without embarrassment. A similar emphasis on socialisation was previously found to be reported by those who completed pulmonary rehabilitation, alongside the opportunity to share knowledge and support one another (Halting et al., 2010). Participation also motivated attendees to do better or try harder in the group exercises, be more active at home, and try to maintain health benefits from pulmonary rehabilitation. This is consistent with previous research, where participants voiced the importance of being with others of similar functional abilities, maintaining health benefits from rehabilitation, and peer-support provided motivation and encouragement to work through it together (Desveaux et al., 2014a; Desveaux et al., 2014b). Attendees also stated they would like pulmonary rehabilitation physiotherapists to visit them at the volunteer-led group sessions.

In the non-attendee group, the greatest barriers to participating in the exercise groups were illness, lack of time due to work and family commitments, transport difficulties, lack of awareness of the groups or the perception that they are not beneficial based on experience of the pulmonary rehabilitation programme, which are similar to barriers identified in previous research (Cox et al., 2017; Desveaux et al., 2014a; Desveaux et al., 2014b; Levack et al. 2018). Moreover, Candy et al. (2020) showed that increasing age, higher 6 min walk test distance at programme commencement, and European ethnicity were significant predictors of completion of the pulmonary rehabilitation programme. However, the authors found no difference in attendance by the distance from the centre, whereas transport was a major barrier for our participants. Patient belief about the effectiveness of pulmonary rehabilitation has been found to be a strong predictor of intervention attendance (Cox et al., 2017; Fischer et al., 2009). This may also be the case in our study, as some non-attendees did not think the initial rehabilitation programme was beneficial; consequently, attending the maintenance group was not perceived as worthwhile. Quantitative measures post-rehabilitation validate this

perception. The non-attendee group responded well physically with a significant increase in sit-to-stand post rehabilitation; however, other measures of health status such as COPD, and anxiety and depressive symptoms did not change significantly after pulmonary rehabilitation. Therefore, the non-attendee group may have been comprised of participants who were non-responders and/or were less engaged in the rehabilitation programme. A limitation of the study is that attendance was not monitored in either the pulmonary rehabilitation or volunteer-led maintenance programmes. However, examining social connectedness in the attendee and non-attendee groups was a unique aspect of the study. The non-attendee group had significantly lower levels of trust toward other people compared to the attendee group. This could be another reason for the non-attendees choosing not to attend a group, as they would rather associate with people who they know rather than with a group of strangers. In contrast, attendees liked to socialise; for example, they participated in the community exercise group, and tended to be more likely to volunteer compared to the non-attendee group (attendees = 37%; non-attendees = 13%). The finding that attendees were more likely to volunteer is interesting, as research suggests volunteering is likely to have positive benefits on mental health (Jenkinson et al., 2013). Given that the attendees' measure for depression reverted to baseline, despite participating in a peer-led exercise group and some volunteering, the impact of COPD on mental health may be profound even in a motivated, engaged, and socially active cohort of people.

It is unclear why pulmonary rehabilitation health benefits were not maintained at follow-up, or why minimal differences in health measures were found between those who attended or did not attend a weekly exercise group. A lack of progressive loading in the attendees' exercise training programme, combined with most non-attendees maintaining an active lifestyle, could be a potential explanation. Due to the wide range of maintenance programme designs used in COPD research, optimal models for maintenance programmes remain unclear. Despite this, the positive experiences of spending time with others in a similar situation appear to be invaluable.

CONCLUSION

Pulmonary rehabilitation produced significant health benefits for people with COPD; however, improvements were not maintained by attending a weekly volunteer-led community exercise group. Despite this, attendees found participating in the exercise group beneficial as it enabled sharing experiences with other people with COPD and increased their motivation to exercise. Barriers to attending the groups included illness, transportation, and a lack of time. Non-attendees were found to be less trusting of others while attendees were more likely to do volunteer work. The attendees' quantitative health outcomes reverted to pre-rehabilitation levels for measures such as depression, despite participating in an exercise group and volunteering. Therefore, the impact of COPD on mental health may be profound even in motivated, engaged, and socially active people. It is unclear why the pulmonary rehabilitation health benefits were not maintained in the current study but could be related to an insufficient exercise load to maintain the

acquired health benefits. However, the social connection with others in a similar situation was an important finding of the study. Further research to inform the development of optimal maintenance programmes would benefit the COPD community.

KEY POINTS

1. Pulmonary rehabilitation improves the health of people with chronic obstructive pulmonary disease; however, interventions led by healthcare professionals may not be cost-effective. Peer-led interventions have been shown to be as effective as maintaining health benefits following pulmonary rehabilitation compared to professional-led and are low cost.
2. We compared physical and mental health outcomes in people with COPD after a volunteer-led, community-based intervention post-pulmonary rehabilitation between attendees and non-attendees.
3. Improvements in COPD symptoms, depressive symptoms, and quality of life from pulmonary rehabilitation were not maintained by participants in a volunteer-led exercise group.
4. Group attendees found participating in the exercise group beneficial as it enabled sharing experiences with other people with COPD and increased their motivation to exercise.

DISCLOSURES

This study was supported by funding from Pegasus Health, Canterbury Clinical Network, and Ara Institute of Canterbury - Te Pūkenga. There are no conflicts of interest that may be perceived to interfere with or bias this study.

PERMISSIONS

Ethical approval was obtained from the Institutional Ethics Board at Ara Institute of Canterbury (project number 1833). All participants provided informed consent.

ACKNOWLEDGEMENTS

We would like to thank all participants for their valuable time.

CONTRIBUTIONS OF AUTHORS

HM, DCh, and DCa were primarily responsible for the design, conceptualisation, and research methodology. HM, TG and DCh managed the project administration, investigation, and data curation. HM, PO, MC, TG, and AH analysed the data. HM, TG, AH, and DCh prepared the original manuscript with review and editing undertaken by HM, TG, PO, and MC. Research supervision was provided by HM.

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Appendix A

SOCIAL CONNECTEDNESS QUESTIONNAIRE

Please circle one answer to each question below.

1. Living situation

Circle the option below that best identifies your living situation:

- I live alone
- I live with my partner/spouse
- I live with my partner/spouse and one or more of my children
- I live with one or more of my children
- I do not live with a partner/spouse or any of my children

2. Do you have access to a telephone, either landline or cellphone, at home?

- Yes
- No

3. Do you have access to the internet at home?

- Yes
- No

4. Please think about all the contact you have with **family members** who help and support you.

- Help and support can include:
- Lending or giving you things
 - Giving you emotional or moral support
 - Helping you out with tasks and chores
 - Giving you information or advice

How would you describe the amount of contact you have with family members who you **do not** live with?

- Too much contact
- About right amount of contact
- Not enough contact
- Don't know

5. Please think about all the contact you have with **friends** who help and support you.

How would you describe the amount of contact you have with friends who you **do not** live with?

- Too much contact
- About right amount of contact
- Not enough contact
- Don't know

6. In general, how much do you trust most people in New Zealand?

- 0 = not at all
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 = completely
- Don't know

7. In the last four (4) weeks, how much of the time have you felt lonely?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time
- Don't know

8. Have you done any voluntary work in the past 4 weeks for a group or organisation?

- Yes
- No

Thank you for taking the time to complete this survey!