

Prevention of Re-Hospitalization for Acute Exacerbations: Perspectives of People with Chronic Obstructive Pulmonary Disease: A Qualitative Study

Anna Hobman¹, William MM Levack¹, Bernadette Jones¹, Tristram R Ingham¹, James Fingleton², Mark Weatherall¹, Amanda A McNaughton³, Harry K McNaughton³

¹Department of Medicine, University of Otago, Wellington, New Zealand; ²Te Whatu Ora Capital, Coast and Hutt Valley, Wellington, New Zealand;

³Medical Research Institute of New Zealand, Wellington, New Zealand

Correspondence: Anna Hobman, Department of Medicine, University of Otago Wellington, PO Box 7343, Wellington, 6242, New Zealand, Tel +64 21 918 627, Email ahobman@gmail.com

Purpose: Current guidelines for prevention of acute exacerbation of chronic obstructive pulmonary disease (AECOPD) reflect clinical understanding of the causes of exacerbations but with a limited recognition of person-specific contributing factors. As part of a randomized trial of a person-centered intervention aiming to promote self-determination, we describe personal perspectives of those with chronic obstructive pulmonary disease (COPD) on what they saw as the causes and best ways to stay well and prevent rehospitalization after an AECOPD.

Patients and Methods: Twelve participants (mean age 69.3 years, six female, six male; eight New Zealand European, two Māori, one Pacific, and one other) were interviewed about their experiences of staying well and out of hospital. Data were collected via individual semi-structured interviews one year following an index hospital admission for AECOPD and focused on the participants' views and experiences of their health condition, their beliefs about staying well, and the causes of and factors preventing further exacerbations and hospitalizations. Data were analyzed using constructivist grounded theory methods.

Results: Three main themes were identified that described participants' views on what helped or hindered them to stay well and out of hospital: 1) *Being Positive*: The importance of having a positive mindset; 2) *Being Proactive*: Practical steps to reduce the risk of, and consequences from, episodes of AECOPD; and 3) *Being in Control*: Feeling in command of one's life and health. Each of these was affected by *Being Connected*: The influence of significant others, particularly close family.

Conclusion: This research expands our understanding of how patients manage COPD and adds patient perspectives to current knowledge on how to prevent recurrent AECOPD. Programs which promote self-efficacy and positivity would be beneficial additions to AECOPD prevention strategies, as could the inclusion of family or significant others in wellbeing plans.

Keywords: COPD, lived experience, self-management, rehospitalization, self-efficacy, taking charge

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a leading cause of death globally and is predicted to become more of a public health problem in the future.¹ Acute exacerbations of COPD (AECOPD) are associated with a decline in lung function and quality of life in patients, particularly when AECOPD leads to hospital admission. AECOPD is reported to account for approximately 70% of the total cost of COPD health care in the US.^{2,3} New Zealand, the country where this study was conducted, has one of the highest AECOPD hospital admission rates among member countries of the Organisation for Economic Co-operation and Development (OECD), with approximately 12,300 admissions per year costing approximately \$NZ59.9 million annually.⁴ Between 12 and 32% of patients with AECOPD relapse during the weeks immediately following hospital admission and as many as 15% of patients die within three months of hospital discharge.⁵

There are several causal factors for AECOPD. Respiratory tract infections, caused by virus or bacteria, environmental pollution, and pulmonary embolism account for up to 70% of AECOPD; however, the cause is unknown in a large proportion of those with AECOPD.⁶ There are limited reports from studies that have examined the personal perspective of patients regarding the causes of AECOPD.⁷ A sample survey of people with COPD in the US (n = 192) reported that the majority of respondents (50%) attribute their exacerbations to exercise, 35% to change in weather, and only 30% attributed AECOPD to respiratory infections.⁸ Discrepancies between the beliefs of people with COPD and their clinicians could potentially affect the successful uptake of health recommendations for AECOPD management.

The main purpose of the research reported in this paper was to explore the beliefs of people with COPD to determine if they hold knowledge that can further expand current understandings of AECOPD and its prevention. The motivation for this research came from our interest in the effects of a novel person-centered intervention for people after AECOPD, called “Take Charge”, which we were investigating via a randomized feasibility study. Take Charge is a brief intervention that promotes self-determination and self-management of disease conditions aiming to improve outcomes that are meaningful to the person with that condition. Take Charge has been found to be effective in terms of improvements in independence and health-related quality of life after stroke in two controlled trials, which recruited a total of 572 participants.^{9,10} The concept of “taking charge” is important to people with a range of health conditions,¹¹ but has not been investigated amongst people with COPD. The principles of Take Charge are aligned with Deci and Ryan’s Self-Determination Theory.¹² This theory posits that intrinsic motivation, composed of purpose, autonomy, mastery and connectedness to others, is a necessary condition for successful outcomes.¹³ We have suggested that psychologically informed interventions, like Take Charge, could be appropriate for people with COPD.¹⁴ To test this idea, we conducted the “Taking Charge of COPD” (TCC) trial: a randomized controlled trial of the “Take Charge” intervention compared to usual care for people discharged after a hospital admission for AECOPD. The results of this feasibility study are reported elsewhere,¹⁵ but as part of this trial, we also examined the beliefs and experiences of people with COPD about what contributed to repeat episodes of AECOPD and what they believe helped keep them out of hospital. This paper describes those beliefs and perspectives.

Materials and Methods

Study Design

The TCC trial (HRC 17/521; Trial Registration no.: ACTRN12617000952347p) ran from 2017 to 2019. The primary aim of that study was to test the feasibility of the Take Charge intervention for reducing AECOPD rates in a high-risk population of people with COPD. The qualitative study reported in this paper was based on interviews with people in both the intervention and control group one year after an index hospital admission for AECOPD. The interviews aimed to explore their perspectives on what kept them healthy, well, and out of hospital. This study employed constructivist grounded theory methods.¹⁶ Grounded theory is a qualitative research method suitable for generating new ideas and perspectives, particularly in areas where little is already known.¹⁷ While extensive information already exists based on the views and experiences of experts (researchers and clinicians) regarding rehospitalization for AECOPD,^{5,18,19} we wanted to understand patient perspectives and explore if new ideas could be generated.

The study was conducted according to the Declaration of Helsinki. Ethics approval for this study was provided by the Central Health and Disability Ethics Committee on New Zealand as an amendment to the feasibility study (HRC 17/CEN/122). All participants gave written informed consent, which included consent for us to record and report on anonymized data from participant interviews, hospital records and outcome measures collected. Pseudonyms are used in this paper when presenting extracts from interviews for illustrative purposes.

Participant Recruitment

The TCC study recruited 56 participants (22 (39%) men, 34 (61%) women; mean (SD) age 69.8 (10.7) years; 11 (20%) Māori, 6 (11%) Pacific, 39 (70%) non-Māori, non-Pacific). All participants were recruited to this study following an index admission to a medical ward of Capital and Coast District Health Board for AECOPD between January 2017 and January 2018. Participants were randomly assigned to a Take Charge intervention or control group. The intervention group received a brief self-management intervention a few weeks after their index admission to hospital for AECOPD.

The intervention was a single 60 to 90-minute visit from a researcher in the participant's own home. The researcher guided the participants through a workbook designed to help them to think of themselves as agents of change in their own lives by providing them with skills enabling them to take more active control over their health, and by promoting self-management strategies as manageable, effective, and relevant to their lives. Further details about the Take Charge intervention are provided elsewhere.^{15,20} People in the control group received an information booklet about COPD and no follow-up home visit.

Potential participants for the qualitative study were approached for participation during the 12-month data collection period for the randomized trial. We used purposeful sampling to select participants from a diverse range of backgrounds, including different genders, ethnicities, and severity of COPD symptoms, and to recruit people from both the intervention group and control group in the feasibility study. In line with grounded theory methods, as the study progressed, we used theoretical sampling to recruit people who might be best able to expand on, or challenge, some of the early themes that were identified in the preliminary analysis.¹⁶ We continued recruiting participants until reaching theoretical saturation in the data analysis.¹⁶

Data Collection

We use semi-structured interviews to collect data. All interviews were conducted at least a year after the index hospital admission, and for those who participated in the Taking Charge intervention, 10 to 12 months after receiving that intervention. The interviews used open-ended questions to prompt conversation about the participants' perspectives on their condition, their experiences of hospitalization for AECOPD, and their beliefs about causes and factors preventing further exacerbations and hospitalizations. All interviews were conducted by one researcher (AH, female, NZ European, a personal trainer for people with chronic health conditions). This interviewer was also involved in baseline and outcome data collection for the TCC trial but had not been involved in intervention delivery, was initially blinded to group allocation, and had no other involvement in the lives or healthcare of the participants. All interviews were audio-recorded and transcribed.

In addition, data were collected on each participants' gender, age, ethnicity, living situation, number of episodes of moderate or severe AECOPD in the 12 months since recruitment, disease-specific health status using the Chronic COPD Questionnaire,²¹ and mental health using the Hospital Anxiety and Depression scale.²² Episodes of moderate AECOPD were defined as those requiring treatment with oral corticosteroids or antibiotics but not hospitalization, and episodes of severe AECOPD were defined as those requiring admission to hospital.²³

Data Analysis

Consistent with grounded theory methods, data collection and analysis were carried out simultaneously and interview questions modified throughout the process to explore emerging themes in more detail.¹⁶ We used NVivo software (QSR International) to manage data analysis. Each transcript was read more than once, incorporating findings from additional data as the study progressed. Initial coding (open coding) identified initial ideas and concepts in the data, with subsequent analysis exploring the relationships between codes to develop higher order concepts. Two lead researchers (AH and WL) independently coded the first three interview transcripts, comparing and discussing findings after coding each transcript. Following this, the initial open coding was completed by one researcher (AH) for the remaining interviews, with discussion of the emerging analysis with a second researcher (WL) during weekly meetings. For these remaining interviews, WL read through but did not independently code each transcript. These meetings were also used to revise the approach to participant recruitment, ie, theoretical sampling, and to interview questions in subsequent interviews. Data collection and analysis continued until theoretical saturation was reached, ie when new data revealed no new ideas, no new questions, and no need to sample further.²⁴ Participants were offered an opportunity to read and comment on their interview transcripts, but none took up this offer. To enrich the depth of analysis and enhance self-reflectiveness, the researcher who conducted the interviews (AH) also wrote memoranda before and throughout the data collection and analysis, including journaling reflection immediately after each interview. This included consideration of ways the researcher's relationship with the participants influenced the production of data. Additionally, memoranda and diagrams were used to assist in the development of a multi-dimensional understanding of the data.²⁵

Results

Participant Characteristics

Of the 56 people in the randomized trial, 13 were approached for an interview and 12 agreed to take part. Participant characteristics are presented in Table 1. We judged theoretical saturation was reached around the ninth interview but completed three more interviews to test this assumption.

Five participants in this study had been in the intervention arm of the TCC study. Consistent with other “Take Charge” studies,^{9,10} only three of these five participants remembered receiving it, and some who did not receive the intervention thought they had. Those who correctly remembered the Take Charge intervention did not comment on it unless prompted, and then did not directly attribute health benefits to the intervention. As such, and given that we were unable to identify any other differences between the experiences or opinions of those who received the TCC intervention and those who did not, we pooled all data in a single qualitative analysis.

Overview of Study Findings

Overall, most participants (9/12; 75%) felt that their actions and behaviors had some impact on their health and wellbeing, including prevention of further AECOPD. Three participants felt they had no control over their health and that episodes of AECOPD were largely a matter of chance or subject to the decisions of health professionals rather than themselves. For those who felt able to influence their health, we identified three overlapping factors that they attributed to staying well, preventing recurrence of AECOPD, and preventing rehospitalization: 1) Being Positive (I have purpose), 2) Being Proactive (I can do this), and 3) Being in Control (I value taking charge), with these three factors being influenced in some way by 4) Being connected ie the involvement of significant others in the participants’ lives (see Figure 1).

Table 1 Participant Characteristics (n = 12)

Age (Years)	Mean 67.7 (SD 15.3); Range 29 to 84
Gender	7 male, 5 female
Ethnicity	2 Māori, 1 Pacific, 8 New Zealand European, 1 Other
Living status	4 living with spouse, 3 living alone, 3 living with family, 2 in hospital-level residential care
Smoking status	2 current smokers, 9 ex-smokers, 1 never smoked
Pack Years	Mean 37.2 (SD 24.1); range 0 to 82.5
Body Mass Index	Mean 25.8 (SD 9.32); range 19.4 to 36.2
On domiciliary oxygen	2 Yes, 10 No
Ever attended pulmonary rehabilitation	6 Yes, 6 No
“Take Charge” intervention arm	5 Yes, 7 No
Average number of moderate AECOPD events in the 12 months following the index hospital admission	Mean 2.4 (SD 3.2; median 1, range 0 to 10)
Number of severe AECOPD events in the 12 months following the index hospital admission	Mean 0.8 (SD 1.0; median 0, range 0 to 3)
Chronic COPD Questionnaire scores	Mean 2.7 (SD 1.5; median 2.2, range 0.4 to 5.2)
HADS – Anxiety	Mean 3.5 (SD 3.8; median 3; range 0 to 10)
HADS – Depression	Mean 4.5 (SD 1.8; median 4; range 1 to 8)

Abbreviations: AECOPD, acute exacerbation of COPD; COPD, chronic obstructive pulmonary disease; HADS, Hospital Anxiety and Depression Scale, SD, standard deviation.

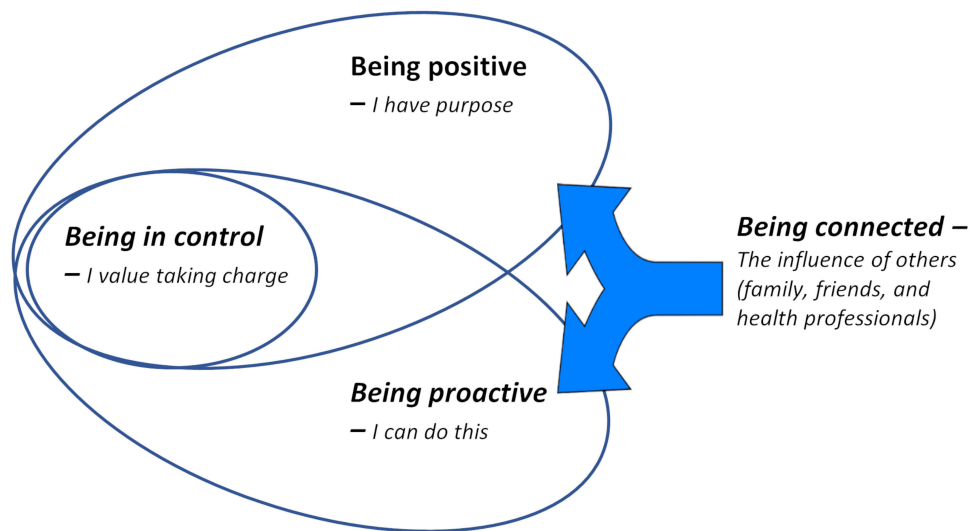


Figure 1 Factors attributed by people with COPD to staying well, preventing recurrence of AECOPD, and preventing rehospitalization.

Abbreviations: AECOPD, acute exacerbation of COPD; COPD, chronic obstructive pulmonary disease.

Being Positive (I Have Purpose)

Most participants believed that having a positive attitude and staying focused on enjoying life was crucial to their wellness. Some participants considered themselves to be naturally optimistic and believed that their attitude had a direct impact on their physical health and ability to keep out of hospital. These participants often talked about living in the now, and dealing with problems as they came, rather than wasting time worrying about the future.

If you can change things then you get out and do it, you don't think about it. But if you know certain things that's happening and you can't change it, you can't do anything about it, there's no point in worrying about it (Bill)

Other participants had to make a more conscious effort to maintain an optimistic outlook. They lived with some grief or regret regarding their condition but believed that focusing on the negatives would make things worse so instead chose to focus on the positive areas of their lives.

Because when I'm feeling down like that I do not cook myself proper meals and I don't look after myself. (Vera)

These participants had a range of strategies for reducing worry and maintaining a positive outlook. Socializing and relaxation were key to happiness for most participants. Other strategies that participants used to avoid becoming entangled in grief were physical activity, breathing exercises, consciously avoiding negative thoughts by keeping themselves busy, focusing on the enjoyable aspects of their lives, and being conscious that there were people worse off than themselves.

I don't think it's a secret [about how to be happy]. Every evening I sit down I have a couple of small brandies and water. (Bill)

Being Proactive (I Can Do This)

"Being proactive" involved the participants taking practical steps to look after their health. This included actions participants took daily to maintain optimal health (*health maintenance*) and specific actions they took when they detected that a threat was imminent (*avoiding threats* and *fighting back*). The amount of effort participants invested in these strategies varied widely, with extremes in both directions. One participant actively avoided paying attention to his health, focusing instead on living his life to the fullest, doing exactly what he wanted to do when he wanted to do it. His prior experience of watching his brother die of lung cancer had affected the way that he dealt with his own health:

I've gone and stuck my head in the sand. No, I don't think about these things [health-monitoring]. All I want to do is have a laugh – seriously, that's all I want to do. Smile and laugh every day. (Dennis)

Indeed, over half of participants also said that they paid little or no attention to their health and were very quick to shrug off or shut down any questions about health care actions or routines:

There's nothing I consciously think – I should do that because it's healthy. (Christine)

Other participants were focused more explicitly on their health, with some maintaining rigorous healthcare routines. A few participants were highly proactive about daily monitoring of their health status (eg, measuring resting heart rate, blood pressure, oxygen saturation, peak flow) to identify and treat potential exacerbations early. Others monitored their health regularly but in a less objective way, using subjective experiences of tiredness or changes in respiratory symptoms to guide decision-making:

I felt the bugs coming. I spat up the first lot of phlegm and I thought I'll get straight onto the antibiotics (Sheryl)

Exercise was important to all participants but in different ways and for different reasons. While all participants saw exercise as vital to staying well, what constituted exercise, and how they believed it contributed to their health, varied. Several participants viewed exercise as having a direct effect on their functional ability. These participants tended to stick rigidly to their exercise plans and saw them as a crucial part of their disease management.

I've got a course of exercises I do every other day. If I keep doing them, I find my lungs are a lot stronger and I have more energy and I can do more, and I've also managed to stay out of hospital... now I'm determined I'm going to keep doing the exercises. (Cynthia)

Many other participants maintained regular physical activity but did not engage in what they considered “exercise” for disease management purposes. They talked more about engaging in recreational activities for enjoyment, such as walking dogs or playing bowls. These participants were more inclined to talk about the psychological benefits of physical activity than the physiological benefits.

I don't know about the exercise because she [the dog] does more than I do. It's probably the fresh air; it's the social side of it because everybody talks to you. (Christine)

Food was viewed as important to the participants' overall wellbeing. But it was more important to most participants to eat when they were hungry and that they enjoyed their food than to eat specifically for nutritional purposes. Participants talked about enjoying meals with friends and family, or by themselves, but the key component was the enjoyment of the food.

I can spoil myself now if I want to eat well... if I want to eat something I can go out and buy enough just for me and I can cook it the way I like it cooked and I can eat it the way I like to eat it and I enjoy it thoroughly. (Vera)

Most participants avoided situations that they believed could lead to them becoming unwell: cold weather, environmental irritants (eg, cigarette smoke or dust), and exposure to other people with respiratory infections, even if this meant occasionally staying away from friends and family. One participant had a sign on her door that read: “Do not enter if you are sick.”

Despite their best efforts, participants still became unwell and suffered exacerbations. When an exacerbation became inevitable, participants' beliefs and attitudes were reflected in their reactions. Those who expressed a strong belief in having control over their outcomes engaged in more strategies to fight back compared to those who believed they had no control over the outcome. The primary strategy for fighting an exacerbation, on which all participants agreed, was having access to medication when needed. All participants had “back pocket” antibiotics and, in some instances, a prescription for steroids, given by the doctor for self-administration at the first sign of an infection.

My doctor's given me 40 Amoxil just to keep in my back pocket in case I need them. So as soon as I cough [I] start taking them. (Christine)

Drivers for deciding when to use these prescriptions differed between participants. Those who monitored their health using physiological measurements took antibiotics as soon as they noted any downward trends. Participants who were less precise about health monitoring tended to wait until symptoms were obvious, although they said this often meant that the medication was taken too late to prevent exacerbations getting out of control.

A handful of participants held strong beliefs in the importance of nutrition when they were becoming ill, reiterating the importance of eating regularly. Sickness made cooking and eating more difficult however – an issue one participant addressed by keeping prepared meals on hand:

And I'll put it in the deep freeze and then when I'm sick or not feeling like cooking or whatever. You'd be surprised what's in my deep freeze. (Vera)

Finally, the participants often talked about resting and relaxing more when they felt they were becoming unwell, but also about the importance of maintaining a semblance of their usual routine to avoid becoming sicker by behaving like a “sick person”.

You get up with a sick mentality, wandering around in pajamas and nighties and things all the time, whereas if you get dressed it's, yeah, okay, well, I can't be that sick because I've got my clothes on (Vera)

Being in Control (I Value Taking Charge)

“Being in control” describes the importance that participants placed on being able to influence their own wellbeing. While most participants believed they had some control over their health, a few felt their health was completely out of their control. These latter participants appeared to have little knowledge of their condition, a higher degree of dependence on others, and a general belief in luck as having a major influence on their health, on the emergence of exacerbations, and in their life in general.

I don't know what it is perhaps it is just luck of the draw. (Maureen)

Most participants, however, believed that to some extent their health was in their hands, although the degree to which they believed this and the ways in which it affected their health-related behaviors differed widely. Most participants believed they had moderate but not complete control over their wellbeing. This involved being in tune with their body, looking after it, knowing to what extent it could protect and heal itself from exacerbations, and knowing when to seek additional professional help:

Well, I know first of all I get chesty, then I wake up with headaches and cough, cough, cough, cough, so I go and have a hot bath, steam, coughing as much as possible, I do all these things for myself, increase my inhalers, all else failing I ring the GP [general practitioner] (Cynthia)

A few participants had a particularly strong sense of control over their own health that their body had the ability to heal itself and that they could fight off exacerbations without medical assistance. These participants could be skeptical of the additional value that doctors could provide:

I have a method of sort of saying, hey, it's going to go away, it's not serious and it eventually does go away if you keep sort of telling it to, you know. (Gerald)

This sense of being in control was not confined only to health but was reported to be associated with a general stubbornness in life, which at times resulted in rebellious and potentially detrimental behaviors.

I'm shivering and, yep, just thinking I know now that I should have just wrapped myself up and got myself home....my wife said should you go to hospital and I said like hell. (Gerald)

Nonetheless, this determined attitude was also associated with positive experiences that reinforced the person's sense of self-reliance, such as completing difficult tasks or building trusted relationships with health professionals.

He's [the GP] taken a while to get used to me because he's not used to somebody who listens to their body and also who has enough brains... Yes, it's taken me three years, but I've finally broken him in. (Vera)

Being Connected (The Influence of Others)

The beliefs, experiences, and actions of the participants with regard to being positive, being proactive, and being in control were all influenced by other people in their lives: notably significant others and close relatives, but also, to a much lesser degree, health professionals. In most cases, relationships with a spouse or family member encouraged proactive health care: cajoling the participants to engage in exercise, take medication, go to hospital, dress warmly, or stay indoors during poor weather. If participants were not “nagged” into actively caring for their health, they often did so to prevent loved ones from worrying.

So that's part of the reason I started to go to the doctor more because I don't want her [my daughter] to get all stressed. (Gina)

Conversely, there are some instances where close relationships were reported to cause the participants' stress and reduced their ability to prioritize their health. Two participants talked extensively about how their health had improved since leaving unhappy relationships:

After I left my husband and came right with that, everything [ill health experiences] disappeared. So, what's that telling you? (Sheryl)

While all participants said that their GP, practice nurse or pulmonary rehabilitation staff were their preferred source of information on COPD, most had little to say about the influence of health professionals over their ability to stay well. Many viewed their relationship with their GP as reciprocal or egalitarian. These participants worked with their GP to come up with a management plan and saw little need to return to them unless their health status worsened, while a small number of participants relied completely on doctors to make decisions on their behalf and had little or no involvement in decision-making:

People say what are you taking. I say I have no idea. I don't care. They just tell me to take it and I take it you know, if they give me poison, I'll take it yeah okay. (Gerald)

Discussion

This study explores the perceptions and experiences of people at high risk of AECOPD regarding what kept them well and prevented rehospitalisations. We identified three main elements: being positive, being proactive and being in control. Relationships with friends, family and health professionals had varying degrees of influence over these factors. It was apparent that while individual people prioritized these factors differently depending on their circumstances and personal beliefs, there was a high degree of interaction between these components. For instance, people who proactively pursued activities around managing their health and wellbeing felt more in control of their lives. People who were able to feel in control of their lives tended to maintain a more positive outlook.

As in other studies that have explored patient experiences of COPD,^{26,27} our findings highlight the differences between how people with COPD think about their health and wellbeing compared to how health professionals think. Arguably, health professionals tend to focus on a biomedical approach to treatment – the right medication, the right exercise, and doing the right things to look after one's physical body. In contrast, people with COPD, at least in this study, placed higher emphasis on more holistic elements (eg, on psychosocial wellbeing and on living a good life), although, for some, attention to medication and exercise was still considered important. For our participants, having a positive outlook on life was crucial to staying out of hospital and keeping in good health, but this perspective does not feature in any international guidelines on COPD management.^{28–30} In the Global Initiative for Chronic Obstructive Lung Disease's 2022 Report for instance, psychological factors are only mentioned in management of depression and anxiety as comorbidities associated with COPD.²⁸

There was a striking similarity in the main themes described here with the underlying principles of the “Take Charge” intervention. This is perhaps not surprising given that the “Take Charge” intervention was developed from primary qualitative research that involved asking participants with stroke, arthritis and pain syndromes: “What matters most to you?”.¹¹ In that study, the differences between diagnostic groups were fewer than the similarities, suggesting these perspectives are common to many conditions, including COPD. Specific sub-themes in that study were “ideas of acceptance/adaptation”, “sense of autonomy” and “a sense of moving on”, all part of the overall “Take Charge” concept and mirrored in the themes of the present study: being positive, being proactive, and being in control. One criticism of this conclusion that is difficult to rule out is that our understanding of “Take Charge”, as investigators, affected the participant responses and our analysis of these responses. However, the main interviewer (AH) was not trained in the Take Charge intervention or involved in its delivery during the study. Additionally, those participants who received Take Charge generally did not recall the intervention.

Support for the integrity of the current thematic analysis comes from the extensive literature on Self-Determination Theory, developed by Deci and Ryan¹² in the fields of education and psychology,³¹ which has informed development of the Take Charge intervention. Deci and Ryan’s concept of intrinsic motivation is supported by a combination of autonomy, competence and connectedness with others, and maps easily onto our themes of “Being positive” (intrinsically motivated), “Being proactive” (competence), “Being in control” (autonomy), and “Being connected” (connectedness). Furthermore, optimism, a personal disposition which is related to being positive, has previously been found to be associated with better health outcomes for people with COPD. One observational study involving 1967 participants found that more optimistic people with COPD were less likely to experience AECOPD, have less severe respiratory symptoms, and have higher functional capacity compared to their more pessimistic peers.³² While the direction of this effect has not yet been empirically established (ie optimism being a cause or effect of better health outcomes), multiple theories have been proposed regarding how higher optimism may contribute to better health outcomes. These include both behavioral mechanisms (eg by increasing a person’s pursuit of healthy life activities, goals, roles and relationships) and pathophysiological mechanisms (eg by directly modulating the body’s immune response).^{32,33}

Further support of this study’s findings comes from another qualitative study of a singing group for people with COPD over 12 months.³⁴ In that study, feelings of better physical and mental well-being were associated with “connection”, “meaningful physical activity” and “purpose and growth”. The participants in this study were also more inclined to talk about the value of physical activity as a consequence of doing things that they enjoyed (ie, meaningful physical activity) rather than “doing exercise” for its own sake, and some were explicitly against exercise, despite the recommendations of their health professionals.³⁴

If a person-centered approach is taken to these data, beginning with the assumption that people with COPD know more about what keeps them healthy than health professionals do, how can the findings from this study be used to inform the best approach to supporting people with COPD? The obvious response is that people with COPD should be considered unique individuals who are able to identify what is most important to them. This perspective is applied in the Take Charge intervention. The Take Charge intervention helps people with COPD express what (and who) is most important to them and allows them to explore ways of achieving personally meaningful goals. As reported in the TCC study, it is feasible for people with COPD recovering from an AECOPD to engage with the Take Charge intervention. Preliminary quantitative data from our main study (TCC) suggest that important outcomes, such as health-related quality of life, may be improved by this intervention.¹⁵

Secondly, instead of focusing too heavily on exercise prescriptions, within or separate from pulmonary rehabilitation programs, which we know suffer from issues of uptake,³⁵ adherence^{36,37} and long-term sustainability,³⁸ we could emphasize the role of activities that individuals with COPD enjoy and that they may be willing to maintain over the longer term. A good example of this is singing groups for COPD, with published evidence of very high adherence and associated improvements in 6-minute walking distance, sustained over 12 months, of similar order to those achieved with pulmonary rehabilitation programs.³⁹ There are plenty of other examples from Tai Chi,⁴⁰ to dancing,⁴¹ to outdoor walking.^{42,43} Qualitative evidence from the singing group trial emphasized the important role of “safe spaces” and the shared experience of living with COPD, but these need not be COPD-exclusive activities. However, we need to

acknowledge how socially isolated people with COPD can feel and support any efforts to improve their sense of connectedness with others.

Thirdly, health professionals must respect the decisions of people with COPD with regard to their own COPD management, even when we find some of those decisions difficult to understand. Simply validating the choices of the person with COPD and agreeing that they are “taking charge” can have potentially important positive effects on their sense of autonomy and mood, which in turn may reduce the risk of exacerbations or rehospitalization.

Finally, health professionals need to address the reality of moderate-to-severe COPD as a progressive, often fatal disease. In the context of a person with COPD setting goals for the future, health professionals can accept the opportunity, when the person with COPD considers it appropriate, to have conversations about the intensity of future care, advanced care planning, and palliative care options.^{44,45}

There are several issues to consider when interpreting the findings from this study. Qualitative research primarily provides a platform for exploring new concepts and new ideas, which we would argue has been a strength of this study. However, participants for this study were selected from those who remained available 12 months after participating in the parent TCC study, and who were happy to share their opinions. This may have biased the sample towards those with a more open or positive outlook on life. It is possible that people who were less ready to offer their opinions had very different experiences. A further limitation of this study was the small sample size consisting of mostly older adults and seniors with severe COPD. We also lacked cultural variability in our study cohort; only two participants were Māori – a group of people who are heavily overrepresented in COPD statistics in New Zealand.⁴⁶ While research on culturally meaningful connections for people with COPD has shown potentially positive effects,⁴⁷ analysis of the socio-cultural impacts on participants’ beliefs and experiences was outside the scope of this study. These issues limit the transferability of findings to other populations and other contexts.

Conclusion

This research expands our understanding of how patients manage COPD and adds a patient perspective to the current knowledge on how to prevent recurrent AECOPD. One aspect that is missing from AECOPD prevention guidelines, but which may be important to people living with COPD, is enjoyment of life and maintaining a positive outlook (being positive), coupled with taking charge of activities to support one’s own health (being proactive) and taking a leadership role in one’s own healthcare (being in control). Further understanding of the physical and mental processes that people with COPD are already following to enhance positivity, and finding ways to ensure more holistic approach to health, may be beneficial in decreasing hospitalization rates for AECOPD.

Data Sharing Statement

The datasets supporting this research are not publicly available because it is not possible to fully deidentify individual participant data in interview transcripts.

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Disclosure

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