



‘A balancing act’. Living with severe chronic obstructive pulmonary disease in Southern New Zealand: a qualitative study

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ABSTRACT

INTRODUCTION: Chronic obstructive pulmonary disease (COPD) is a common chronic condition managed in primary care.

AIM: To understand how patients with severe COPD living in the Southern Health Region (Otago and Southland) experience and cope with the condition.

METHODS: Semi-structured interviews were undertaken with 23 patients with severe COPD (defined using the 2013 GOLD classification). A thematic analysis was conducted.

RESULTS: Patients' accounts of living with severe COPD revealed four themes: loss, adaptation, isolation and social support. All participants discussed their sense of loss in coming to terms with having COPD and the ongoing restrictions or changes that were associated with breathlessness and fatigue. These losses required adaptation in daily living. Some patients struggled to adjust to new limitations and needed to rely on others for support. Others found ways to adapt their surroundings or ways of doing things while trying to maintain the same activities. Isolation was described in two ways – direct (no longer being able to easily socialize because activities often caused breathlessness) and indirect (the feeling of being isolated from others because they do not understand what it is like to live with COPD). Social support, including support provided by group-based pulmonary rehabilitation, helped to address the problems of social isolation.

DISCUSSION: Living with severe COPD is a ‘balancing act’ between insecurity (loss and isolation) and resilience (adaptation and social support). Health-care providers need to be proactive in identifying and managing patients' unmet health needs and promote activities that reduce social isolation.

KEYWORDS: Chronic obstructive pulmonary disease; qualitative research

Introduction

In New Zealand (NZ), 14% of New Zealanders aged >40 years live with chronic obstructive pulmonary disease (COPD) and its prevalence increases with age.¹ The disease disproportionately affects Māori,

who have a prevalence twice that of people of other ethnic groups.² COPD causes progressive deterioration of lung function, associated with worsening breathlessness and fatigue, and results in an impaired quality of life.³ Disease progression is

J PRIM HEALTH CARE

2020;12(2)

doi:10.1071/HC20007

Received 31 January 2020

Accepted 29 April 2020

Published 20 May 2020

WHAT THIS GAP FILLS

What is already known: Severe COPD is considered to be a 'way of life' by patients and carers, where disease milestones occur in no particular order.

What this study adds: Living with severe COPD is an ongoing 'balancing act' between insecurity (loss and isolation) and resilience (adaptation and social support). Health-care providers need to proactively identify and manage patients' unmet health needs and promote activities that reduce social isolation.

variable, but typically occurs over many years depending on the timing of diagnosis, access to and engagement with treatment, as well as other external factors.³ People with severe COPD have worse symptoms and more frequent exacerbations and account for most COPD morbidity and mortality.^{3,4} They also often have physical and psychological comorbidities, further complicating management.⁵

A key finding from NZ^{6,7} and international research^{8–10} is that severe COPD is considered to be a 'way of life' by patients and carers where disease milestones (e.g. loss of participation in recreational activities, episodes of acute hospital care, long-term oxygen therapy, assistance with self-care) occur in no particular order. These findings pose challenges for health professionals in ongoing clinical management of patients and the delivery of planned care (e.g. addressing unmet health needs, initiating discussions about palliative care),¹¹ rather than reactive care (e.g. management of infective exacerbations).¹² An important intervention that should be offered to all patients with COPD is pulmonary rehabilitation.¹³ Pulmonary rehabilitation, usually delivered as a structured programme to a group of patients, can improve health outcomes for patients of all ages with COPD throughout the course of the disease.^{14,15}

This study is part of a larger research project exploring service utilisation and enablers and barriers to effective COPD care in the Southern District Health Board (DHB) region of NZ.^{16,17} The study aim was to understand how patients with severe COPD experience and cope with the condition.

Methods

Study setting

The Southern DHB is responsible for planning, funding and providing health and disability services to a population of >320,000 across Otago and Southland, and serves the largest geographic region of all NZ's DHBs. Its population is mainly NZ European/Pākehā (82.7%), 9.9% are Māori, 5.5% Asian and 1.9% Pasifika.¹⁸ The region has two main hospitals: Dunedin Public Hospital and Southland Hospital, Invercargill.

Design, sampling and data collection

We undertook interviews with patients diagnosed with severe COPD and admitted to the respiratory departments of Dunedin Public Hospital and Southland Hospital over the 11-month period from March 2016 to January 2017. The 2013 Global Initiative for Chronic Obstructive Lung Disease (GOLD) classification, used in this study, defines people with severe COPD as having both severe or very severe airflow obstruction and a high risk of exacerbations including hospital admission. GOLD divides these groups into Patient Group C (having fewer symptoms) and Patient Group D (having more symptoms), as assessed using validated symptom scores.³

Patients with severe COPD were identified upon hospital admission by a clinical nurse specialist (D. Hannah) and asked whether they would agree to be sent information regarding the study at discharge. An invitation and informed consent document was then mailed to patients who had expressed an interest. For eligible patients who wished to participate, interviews were arranged at a time and place preferred by the participant.

Interviews were all conducted at participants' homes, using a semi-structured topic guide. They ranged in duration from 60 to 90 min and were recorded. The topic guide was developed by the research team who used their experience, combined with available literature, to develop questions and question probes. It was not formally piloted. It covered two areas – the experience of living with COPD (reported here) and patients' views of services, what contact had they had, what worked

for them and what they thought was missing or needed improvement (reported elsewhere)¹⁷ (see Supplementary table S1 available at the journal's website). Interviews were undertaken by E. Tumilty and A. Latu between April 2016 and January 2017. Both E. Tumilty and A. Latu were research fellows with prior experience in health research participant interviews and who were not known to either groups of participants. Interviews ceased when data saturation was reached. All interviews were digitally recorded and transcribed verbatim.

Data analysis

A thematic analysis was conducted.¹⁹ E. Tumilty undertook initial open coding using NVivo V.10 (QSR International, Burlington, MA, USA) qualitative analysis software. A subgroup of the research team (E. Tumilty, F. Doolan-Noble, K. McAuley and T. Stokes) undertook category and theme development over multiple cycles and then discussed these with the broader research team for finalisation.

Ethics approval was obtained from the University of Otago Human Ethics Committee (H16/040 and H16/023).

Results

We interviewed 23 patients from across the Southern DHB region. The characteristics of participants are presented in Table 1. During the recruitment period, few Māori and Pasifika patients with COPD were admitted to either study site and, consequently, we were able to interview only one Māori and one Pasifika patient. These interviews covered many issues common to all participants, as well as cultural perspectives of care, including the role of whānau. We identified four key themes: loss; adaptation; isolation; and social support. Illustrative participant quotes are presented.

Loss

All participants discussed their sense of loss in coming to terms with COPD and the ongoing restrictions or changes that were associated with it. This sense of loss was complex, including feelings of fear, anxiety and sadness. It related not only to past experiences that could no longer be enjoyed, but

Table 1. Demographic characteristics of study participants

Location	
Dunedin	14
Invercargill	4
Provincial/Rural	5
Sex	
Male	11
Female	12
Age (years)	
<50	1
51–60	2
61–70	5
71–80	10
81+	5
Ethnicity	
Māori	1
Samoan	1
Other European/European not further defined	3
NZ European/Pākehā	18

Data are presented as *n*.

envisioned futures, such as buying a house or finding a new partner, which in their eyes were no longer possible. The recognition of having to finish paid work was described as difficult, with many participants having had physically demanding jobs, such as nursing, kitchen-work, farming, printing or engineering. All participants spoke about dealing with new physical limitations while living with COPD:

‘So I’ve gone from walking for miles every day and managing my life beautifully down to this.’ [Participant 5]

‘When it was wintertime, if I was home, I would get my dive gear out and go down to [location] and dive and get my paua and shoot my fish. I can’t do anything now.’ [Participant 7]

Breathlessness impaired their ability to do as much as they would have previously done and structured how they thought about activities (eg will it be possible to park closely enough?; will I be able to rest if I get tired?). These physical limitations had social knock-on effects. People described being unable to participate in a variety of social activities they would

have done previously, whether it be shopping with friends, church activities or sharing meals or drinks:

‘It was like the old beer with mates, rugby through the year. A couple of beers on a Friday which we did for years and years. Things like that you do miss.’ [Participant 9]

This was not solely related to problems of breathlessness over distances, but also embarrassment around taking oxygen tanks or needing wheelchairs, issues of coordinating talking over meals while breathing and avoiding inhaling food, fatigue and fear of breathless events in public.

Adaptation

Participants handled the losses associated with COPD in several ways. Some struggled to adjust to new limitations and relied on others (such as family or professional carers) for support. Others found ways to adapt their surroundings or ways of doing things while trying to maintain the same activities. Others again, found new things to do. These adaptations were evident in multiple ways. They involved recognising their limits (often through trial and error) and adjusting their homes or their ways of doing things to cope.

‘It takes me probably an hour or so to vacuum the floor because I vacuum a little, I have a rest. I do a little bit more, then I have a rest.’ [Participant 18]

There was also the need to adapt to a new reality where they were less independent than previously. This meant that family members, neighbours, home carers or cleaners had to come into their spaces and help them with daily activities such as shopping, cooking, washing or, in many cases, intimate activities, like showering:

‘I actually went ... [daughter] took me shopping. Not a big lot of shopping, but just into, just one shop it was. No, two maybe. Two shops. I haven’t been to town to a shop for over a year.’ [Participant 3]

‘Pretty private person and the biggest thing for me is the showering, or was.’ [Participant 6]

Participants learning to adapt to their new reality were also proactive about their mood and mental wellbeing. They discussed catching themselves

before becoming sad, frustrated or depressed about their situation. For some, religious faith was a big part of their mental wellbeing. For others, practical steps such as getting out the house, was their strategy for staying mentally well:

‘It will drag you down if you let yourself go to that place. If I’m feeling down and I’m not feeling well, I’ll think to myself, ‘I’m going to drag myself out to the car and go for a drive,’ just to get me out to make me feel better again, or even just a walk up to the corner and back.’ [Participant 1]

‘I’m not going to let myself be a prisoner in here ... I’m going to run this thing out the window and sit out there [in] my garden.’ [Participant 11]

For participants we interviewed who appeared to be coping, the key seemed to be proactively adapting to their situations.

Isolation

Participants spoke about social isolation in distinct ways. In one sense, direct – the isolation of no longer being able to easily socialise because activities often caused breathlessness or involved too many obstacles:

‘I love to go into Age Concern, but it was going to be too hard to get there ... I’ve got a walker, which is great, but because of all my problems I’ve got to take too much with me. If I want to go in the van they supply, they can take my walker but they can’t take my mobile oxygen, because the mobile oxygen is too big. ... If I go to Age Concern to play housie at lunch and meet all my friends, I need a smaller pack.’ [Participant 14]

In another sense, indirect – the feeling of being isolated from others because they do not understand the experience of the participant. This came both in the form of not understanding what it is like to feel breathless, but also not understanding the ways that people have to adapt what they are doing or be pre-emptive in preventing infection or exacerbations.

‘I don’t think anyone’s that not been breathless can ever understand what it’s like. That’s just unfortunate for them, really. Unfortunate.’ [Participant 12]

Social support

Participants reported that an important way of coping with isolation was personal or professional support. This support helped allow people to stay in their homes.

Some participants had good family support, community support (through church or other groups such as walking groups), supportive neighbours or friends:

‘Yeah. I’m very reliant on my friends. I’ve been very lucky this time, because of course I had six days in the hospital. They were good. One friend came and picked me up and brought me home. Some of them had brought me soup and stuff, which is good.’ [Participant 2]

Another important source of support was provided through the social contact of being involved in hospital-based programmes such as pulmonary rehabilitation:

‘The one thing, apart from everything else I do, I need to get to the [pulmonary rehabilitation] gym. It’s good to have other people to talk to.’ [Participant 12]

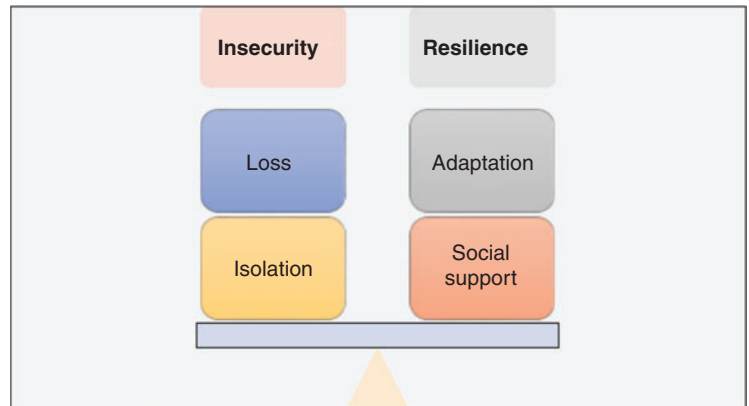
Most participants had either heard of, had previously had, or were receiving pulmonary rehabilitation. However, several participants were unaware of the existence of a local pulmonary rehabilitation programme.¹⁷

We suggest that these four themes relate to a patient’s ability to cope, where coping is understood as a ‘balancing act’ between insecurity and resilience (Fig. 1). For participants who had struggled to adapt or lacked support from their family or community, there was a sense that one additional thing could tip them over the edge in terms of being able to independently manage at home. We consider these themes to be in constant flux throughout the experience of living with COPD. Thus, participants described being isolated in some sense and supported in others, or described their sense of loss fluctuating through their disease experience.

Discussion

Patients’ accounts of living with severe COPD revealed four themes: loss, adaptation, isolation and

Figure 1. Balancing insecurity and resilience for people living with chronic obstructive pulmonary disease (COPD).



social support. All participants discussed their sense of loss in coming to terms with COPD and the ongoing restrictions or changes that were associated with breathlessness and fatigue. The losses associated with COPD required adaptation in daily living. Some patients struggled to adjust to new limitations and needed to rely on others (family or professional carers) for support. Others found ways to adapt their surroundings or ways of doing things while trying to maintain the same activities. Isolation was described in two ways: direct – no longer being able to easily socialise because activities often caused breathlessness; and indirect – the feeling of being isolated from others because they do not understand what it is like to live with COPD. Social support, both health professional and lay, helped address the problems of social isolation.

The term ‘severe’ COPD is used in this study as this is the GOLD 2013 classification⁴ that covers a range of patients who clinically experience moderate, severe and very severe symptoms and associated functional limitations. We recruited a broader sample of patients by disease severity than key NZ⁶ and international studies,^{9,20} which looked specifically at those having very severe symptoms who required non-invasive ventilation⁶ or were expected to die within the next 12 months.^{9,20} Our study design necessitated recruiting patients who had been hospitalised with severe COPD. Our recruitment of a sample with most participants aged over 70 years is consistent with the age distribution of NZ European patients admitted to hospital with COPD in recent national²¹ (mean age 72.3 years)

and Southern Region¹⁶ studies. This qualitative interview study also recruited a sample that was diverse in terms of location, sex and age, and we were able to achieve data saturation²² in interviews with NZ European/Pākehā participants. The choice of individual interviews with patients was appropriate as it allowed participants to talk openly about what it was like living with COPD.

A limitation of the study is that we were able to interview only one Māori and one Pasifika patient with COPD and so were not able to fully explore Māori and Pasifika experiences of living with COPD. This area warrants further research.²³

There is limited NZ literature on patients' experiences living with COPD.^{6,7} One NZ qualitative study recruited a similar patient population both in terms of age distribution and disease severity (GOLD classification – severe), but had a specific focus on how patients experience helplessness and its effect on COPD self-management.⁷ A second study recruited a more severely ill sample (participants requiring non-invasive ventilation) and explored palliative care needs, as well as living with very severe COPD.⁶ The researchers place their work on the milestones of deteriorating illness in patients living with very severe COPD within the conceptual framework of COPD as a 'way of life',⁶ developed in the international literature by Pinnock *et al.*⁹ In this framework, patients with severe COPD describe symptoms that cause a major disruption to normal life in terms of accepting these as a 'way of life' rather than as an 'illness' requiring medical attention. Our study, drawing from a wider group of patients in terms of disease severity, also found that patients with severe COPD experience COPD as a 'way of life' in which the identified themes fluctuate during the illness course. Our study adds a description of the complex process of adjusting to this way of life and how that adjustment is dynamic, given the progressive nature of COPD. Finally, factors influencing the uptake of pulmonary rehabilitation by both Māori and non-Māori with COPD in NZ have been explored.²³ A finding of this study, common to all participants regardless of ethnicity, was the importance of pulmonary rehabilitation in promoting a sense of social connection.²³ Our study, in addition, specifically identifies the importance of group-based pulmonary rehabilitation in reducing social isolation, as reported in the international (UK) literature.²⁴

Our finding that living with COPD is a 'balancing act' between insecurity (loss and isolation) and resilience (adaptation and social support) has two broad implications for clinical practice. First, patients' experience of loss of functioning and the consequent process of adapting to, and accepting, a new reality ('way of life') of being less independent fluctuates and continues throughout the disease process because of its progressive nature. Health-care professionals providing personal continuing health care to these patients over time, notably general practitioners and practice nurses, need to be aware that patients accepting COPD as a 'way of life' may not perceive the need for health care, as reported elsewhere.¹⁷ Therefore, general practitioners and practice nurses need to be proactive in identifying and managing unmet health needs in this group of patients.

Second, social isolation (both direct and indirect) is a major feature of living with severe COPD in this group of patients, who are often older adults with co-morbidities.¹⁶ General practices can collect information on these patients' social networks²⁵ and use this to tailor referral to a wide range of local non-clinical services (social prescribing²⁶) that can address social isolation. Social isolation can also be addressed through the social support provided by health-care programmes such as group-based pulmonary rehabilitation. Pulmonary rehabilitation, although clinically effective,^{14,15} has low uptake,²⁷ being offered to only 15% of patients in our linked case note review.¹⁶ Key barriers to accessing pulmonary rehabilitation in NZ's southern region include limited geographical availability and, from a patient perspective, limited awareness of its utility and inability to travel to main centres to attend pulmonary rehabilitation classes, as reported elsewhere.¹⁷ All these barriers need addressing if the uptake of pulmonary rehabilitation by patients with COPD is to be improved.

Conclusion

Living with severe COPD is an ongoing 'balancing act' between insecurity and resilience. Health-care providers need to be proactive in identifying and managing patients' unmet health needs and promote activities that reduce social isolation, including using social prescribing and attending group-based pulmonary rehabilitation.

Competing interests

The authors declare that they have no competing interests.

Funding

This study was funded by the New Zealand Health Research Council (HRC Research Partnerships for New Zealand Health Delivery Grant 15/655).

Acknowledgements

The authors would like to thank the patients and whānau who gave their time for interviews.

E. Tumilty was an Assistant Research Fellow in the Department of General Practice and Rural Health, Dunedin School of Medicine, University of Otago at the time of conducting the research.

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