

# Barriers to accessing specialist care for older people with chronic obstructive pulmonary disease in rural New Zealand

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## ABSTRACT

**INTRODUCTION:** Access to health care for people living in rural areas presents many challenges. For people who live with chronic obstructive pulmonary disease (COPD), the ability to access specialist health services facilitates improved health outcomes, however many barriers to accessing specialist health care have been identified. This paper reports on the challenges people living with COPD in rural New Zealand (NZ) face in accessing specialist health care services.

**METHODS:** Nine people living with COPD in a small NZ rural town were interviewed in 2007.

**FINDINGS:** Data analysis, using a general inductive approach found that difficulties with transportation, physical access, communication and finances collectively added up to significant barriers to accessing specialist care for this group of people.

**CONCLUSION:** The findings raise questions about the model of care needed to improve health care for rural people with COPD. Collaborative multidisciplinary teams with specialist respiratory nurses working in the community are proposed to improve care coordination and improve communication for this group of people.

**KEYWORDS:** Rural health services; health services accessibility; pulmonary disease; chronic obstructive; community health nursing

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## Introduction

People living in rural areas experience inequitable access to primary and specialty health care. Multiple issues related to health care access for rural people are identified in the literature. These include transportation difficulties,<sup>1-11</sup> low population density with an associated lack of social infrastructure to provide services,<sup>10-13</sup> limitation of finances associated with low levels of income and employment,<sup>2,3,5,7-12,14-16</sup> social isolation,<sup>3,12</sup> inadequate funding,<sup>7,8,12,14</sup> limited choice and availability of specialist physicians,<sup>2-4,7,9-12,14,17,18</sup> poor quality professional care,<sup>2-5,10,14,15</sup> and differences in cultural needs.<sup>9,10,17,18</sup>

The NZ Health Strategy<sup>19</sup> was introduced in 2000 with a focus on reducing inequalities in

health care. Access and appropriateness of services for rural people was recognised as problematic. People who reside in rural areas of NZ have the disadvantage of a relative lack of local health care professionals, often need to travel distances to access care, have high levels of deprivation synonymous with rural regions and have high transport costs.<sup>20</sup> Distances from specialist services and difficulties in recruiting and maintaining appropriate health care providers contribute to barriers to accessing care.<sup>21</sup>

Recent NZ statistics<sup>22</sup> show that 1:15 adults over the age of 45 years have a diagnosis of chronic obstructive pulmonary disease (COPD), a chronic, progressive disabling condition characterised by airway inflammation and airflow limitation

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that cannot be fully reversed and results in a significant deterioration in quality of life over time. Early access to specialist care is a priority for the person with COPD in order to ensure effective management of the condition and in facilitating the attainment of improved quality of life.<sup>23</sup> Specialty services can enhance primary care to ensure diagnostic accuracy, provide pulmonary rehabilitation and education and assist facilitation of self-management of disease exacerbations.<sup>24</sup>

Effective chronic disease management programmes utilise team-based approaches, frequently incorporating nurse case managers or nurse specialists.<sup>25</sup> A NZ programme<sup>24</sup> which focussed on ensuring collaboration between patients, general practitioners (GPs), hospital specialists and nurse specialists reduced hospital admissions for people with COPD, with information sharing between the health professionals involved in the patient's care important.

This paper describes a study exploring access to specialist health care services for older people with COPD in rural New Zealand.

## Methods

The study was undertaken in 2007 in a rural Waikato town with a population of 6306. Potential participants were identified via disease Read Coding from a local Medical Centre database and were initially approached by the practice nurse. Several patients declined to participate. Recruitment ceased when data saturation was reached. The final number of participants was a purposive sample of nine.

Criteria for inclusion included people with rural status (using the local District Health Board [DHB] criteria of living greater than 30 minutes by car from the major general hospital as defining rural status) and aged between 50 and 80 years with a diagnosis of COPD. The age bracket was lowered from 55 to 50 years to avoid the possibility of excluding Maori.

The method of data collection was in-depth semi-structured interviews guided by a topic format. This methodology allows for understanding of the individual's needs.<sup>26</sup> All interviews were

undertaken in the participants' homes and were audio-taped and transcribed verbatim.

Ethical approval for this study was granted by the Northern Y Regional Ethics Committee.

## Analysis

The data was analysed utilising a general inductive approach. Transcripts underwent multiple readings with broad categories coded and the raw text data condensed to enable the establishment of clear links between the research objective and findings.<sup>27</sup> A random sample of interview transcripts were read and coded by a secondary investigator to strengthen consensus of coding and overall validity. Four broad themes emerged.

## Findings

Participants were in the older age bracket (seven were aged over 70 years), the majority were of European descent (only one identified as Maori) with almost equal numbers of male and female represented. Two-thirds were married. Most participants (seven) were ex-smokers with one a current smoker.

## Challenges to accessing health care

Four main challenges to accessing specialist care emerged: transportation, physical access, communication and financial constraints.

### Transportation

Difficulty with transportation was a barrier when accessing specialist respiratory care. The distance involved in travelling to the nearest urban centre posed problems through tiredness and with concerns relating to being a hazard on the road when feeling drowsy. Long driving distances were also a problem and although people might be happy to drive within their rural town, they were reluctant to drive longer distances.

*'I do drive. But I don't drive outside of [name of rural town]. That's more or less self imposed... going anywhere means a distance and coming back, I get drowsy in the afternoon...'*

Relying on others for the provision of transport also proved difficult. Not wanting to cause inconvenience to family members who were busy with their own lives or having to rely on older friends were further transportation barriers:

*'...I have a daughter round the corner but she works. It's not convenient for her. What I have done in the past, the son living in [name of town]..., he comes all the way over here and takes me to [name of urban centre] and back.'*

*'Ring a friend they say, dial a friend! But then my friends are getting old!'*

The logistics of accessing an alternative form of transportation in the form of a shuttle service that serviced the town was too difficult to consider. The early pick up time was associated with stress at being ready on time. Waiting time at the end of the day after appointments and the length of the day involved was also a barrier:

*'There is a service... that picks up in [name or rural town], but it only goes early in the morning and then it doesn't leave again 'til probably four or five in the afternoon.'*

Once the actual destination was reached parking became an almost insurmountable barrier:

*'Well you've got the parking. It's absolutely horrendous to try and find a park.'*

Associated with parking difficulties was the lack of availability of 'disability' car parks which were considered to be an essential commodity in maintaining independence and as a successful end point to the negotiation of transportation. Frustration experienced with the inability to find a disability car park is portrayed:

*'...then I've got my mobility parking thingy which is essential otherwise I could not do it. Even then, there are quite a lot of mobility parks but you're lucky if you can find one!'*

#### Physical access

Travel to the nearest urban centre to access specialist care was a requirement. Significant levels

### WHAT GAP THIS FILLS

**What we already know:** This paper provides original research into the difficulties people living rurally with chronic illness face in New Zealand. While there is extensive international literature highlighting the many challenges for such people, there are few New Zealand published studies.

**What this study adds:** The implications for health practitioners in terms of improving access to specialist care and improving communication are highlighted with specialist community based respiratory nurses working in the community proposed as a solution.

of anxiety were experienced in attempting physical access to specialist appointments especially in relation to the limitation of the disease and the physical location of the respiratory clinic. A new parking building constructed to ease parking difficulties was seen as a barrier because of its distance from the respiratory clinic:

*'Organising yourself from here... possibly the biggest thing... which affects you too... when you start to panic. You know, um, especially in any chronic [referring to people with COPD], they panic, short breath.'*

### Four main challenges to accessing specialist care emerged: transportation, physical access, communication and financial constraints

*'I just see they're building this new parking building over there. And how far is it away from the respiratory place?'*

Inclement weather conditions also played a significant part in physically accessing care:

*'That windy weather we had a little while ago in the winter. It was a foggy, grey day. Well I get quite tight. Getting to the hospital and struggling with that...'*

*'I'd have to postpone it. If it was heavy rain I wouldn't like to tackle it.'*

Timing of appointments and the length of time required to prepare for such an appointment was

crucial to easing access difficulties. Several hours were often required to get ready for an appointment as breathing difficulties associated with COPD are generally worse in the morning. This coincided with their desire for appointments to be scheduled in the afternoon:

*'It takes me a long time to get myself motivated in the morning and that is with my breathing. If we have an early appointment at the hospital I have to get up about five. I find that breathing is a little hard for me in the morning.'*

The availability of a visiting specialist in the rural town which would enable more frequent follow-up was seen as a way in which physical access could be improved. This would ease barriers of physical access attributed to lack of time and the distance travelled:

*'Well if a specialist visited [name of rural town] once a week or whatever, that would be... well a short drive.'*

## Care for rural clients with COPD may be poorly coordinated with unclear pathways, difficulties in accessing specialist care, inadequate information sources and poor support services

*'Really the ideal thing would be if we had perhaps a specialist come from [name of hospital] every... month? Or something like that so that you could have appointments with the specialist here without having to travel and perhaps going more frequently than you would when it's a special trip to [name of hospital].'*

### Communication

Many people living with COPD are experts in the treatment decisions required to manage their condition. Treatment of acute exacerbations was for some a combined effort with the GP and specialist. For others there was a lack of a collaborative relationship and miscommunication with their GP which resulted in difficulties accessing specialist care. 'Shopping around' to find the GP

who listened to their needs in providing the care that they knew they needed was a solution:

*'I've changed doctors twice. I'm happy with the one I'm going to but he also listens to me when I say, you know, if I say I need prednisone or if I say, you know, something this or that where the other one doctor was sort of... didn't like prednisone... OK if we had to use it, obviously because that's the only tool that we have against it when you know, it gets bad. The second doctor didn't like antibiotics, which was just as bad! The doctor I'm going to now, well... I think he listens to me as well as I'm listening to him so that's fine, between us we get there.'*

*'I felt, with this doctor, he wasn't controlling my asthma, he'd made up his mind it was COPD. He said, "No we can't do anything." He said, "Well you're COPD, we can't do anything for you." So I changed my doctor. What annoyed me was that my doctor was saying it's all COPD and I felt it wasn't all and I'm sure I was right because sure I'm saying there is an element of lung damage there but my asthma is a lot better controlled.'*

Specialist care was considered important, with the perception that care required was beyond the scope of the GP:

*'They can't specialise in everything. And I do believe that I'm at first specialist stage.'*

*'I still think, as good as [doctor's name] is... he really hasn't got that day to day ongoing, hands on with respiratory problems...'*

*'You have your GP and he's not trained specifically for COPD or any respiratory illness, he's just... he is a GP. Therefore he's got no specialist knowledge of, you know, really what you need.'*

Feeling that on-referral for specialist care was not always given consideration was reflected in frustration and disappointment at not always being listened to:

*'He'd set his mind to what it was and he gave me some pamphlets on how to handle it. And of course I kept on saying to him this Becotide or whatever it was, it's not working! Is there a better... ? "Well you're on the best." You know, saying that it wasn't*

*working you'd think [he'd refer]... but he thought he knew that my lungs were past repair or... and you know he gave me these pamphlets and I didn't even read them!*'

*'Sometimes I think you go to the doctors and they say, "We can't find nothing" and send you on your merry way. You know, so I think they've got to have a good understanding. They've got to listen.'*

Communication between the GP and patient was often lacking:

*'So I've just had a test but what the results were I don't know. I didn't hear anything more but I had to have that because of the Spiriva.'*

Difficulties in communicating with specialist physicians was also an issue. This was because of a lack of personal knowing and the perception that specialists did not allow sufficient time. Specialist physicians were perceived to be 'superior', and this resulted in barriers to reciprocal communication. In most cases this meant a reluctance to ask questions:

*'The other thing I feel is, would he be as friendly and as nice as they are in the hospital? [referring to local rural hospital] Because you know what some specialists are like. They're a little bit arrogant and a little bit... whatever. I just feel that at the [local] hospital I've had a lot of attention. I never feel as if they're pushing me or anything and I always find that whatever I ask them they're quite happy to sit there and discuss it. Whereas some specialists which I've had before...don't want to do that.'*

#### Financial constraints

Finances for many were limited. Maintaining a balancing act with finances when it came to accessing specialist care was essential when the majority relied on a government benefit as their sole source of income. Because of the importance placed on specialist appointments, considering doing without other things in order to be able to attend was however a given:

*'Well we're only on the pension. It's the only income that we have. Well, it's not a barrier because if you've got to do it then you've got to do it.'*

Travelling costs (principally petrol) and parking costs also posed a significant consideration when balancing extremely tight budgets.

In 2005 the NZ Government developed the National Travel Assistance (NTA) Policy<sup>28</sup> to assist in improving access to specialist care for those with the greatest need. This was aligned to the guiding principles and objectives of the NZ Health Strategy.<sup>19</sup> Ineligibility for this subsidy and frustrations at negotiating the complexities of the system only to find that they did not qualify was an issue:

*'They took the subsidy away for running your vehicle over! Because the eligibility is 80km, well we're 60. And OK, another criteria is that you have to be referred by a specialist! We won't get to [urban centre] before we even see a specialist to start with!'*

The possibility of accessing a private specialist if they thought they could be seen sooner than in a public hospital system even though this came at a cost was a consideration:

*'It's more expensive. But if I had to go to a specialist because there was a concern, and I had to wait six months to get one [public specialist] and I could get a private guy in a week, I would... if it was serious.'*

## Discussion

### Summary of main findings

The challenges of providing chronic illness care for rural people are considerable.<sup>29</sup> The findings of the study indicate that care for rural clients with COPD may be poorly coordinated with unclear pathways, difficulties in accessing specialist care, inadequate information sources and poor support services. Identified difficulties with transportation, physical access, communication and finances collectively added up to significant barriers to accessing specialist care. Transportation barriers included long driving distances, tiredness, reluctance to rely on others for transport, difficulties associated with negotiating alternative forms of transport and parking problems. Negotiating transport barriers were associated with significant levels of anxiety. Physical access barriers included inflexible appointment



times, weather conditions, physical limitations of the disease and the physical location of the clinic and parking building. Communication barriers included the lack of a collaborative relationship and miscommunication with the GP causing people to 'shop around', dissatisfaction with GP care, and a lack of dissemination of results, lack of on-referral for specialist care and poor communication with specialists. Financial barriers identified were a lack of personal income, cost of petrol and parking and the inflexibility of the NTA policy in easing financial barriers.

### Study limitations

This study was centred on a small sample of COPD clients appropriate for the qualitative methodology; however there are limitations with the size and diversity of the population. The age of participants was skewed towards older clients. This is due to the nature of COPD as a chronic progressive condition that results in gradual decline in quality of life over time. There was also a significant lack of Maori participants highlighting the need for different approaches to capture any specific cultural aspects of barriers to accessing care. Limitations of generalisability are identified due to the single geographical area sampled as well as the qualitative nature of the study and purposive sampling. Rural regions in NZ differ greatly in size, population density and distance to and availability of specialist services. Further research in other rural regions of NZ would strengthen the results of this study.

### Interpretation of findings in the context of previous research

The findings highlight several areas that could be addressed in order to ease access for this group of people. Cost is an important barrier for many people in accessing health care and is especially prevalent amongst those with the greatest need and the worst health status.<sup>30</sup> The NTA policy may, for example, require revisiting if it is to assist all people who travel long distances to access specialist care.

The lack of coordinated multidisciplinary care and the barriers in accessing specialist care

highlight the need to consider improved models of care for rural people with COPD. Specialty outreach clinics are reported in the literature<sup>15</sup> as an initiative to increase accessibility of specialist services. Review of the evidence has supported the assumption that specialist outreach does improve access to specialist care across a continuum of client-centred measures including clinically important health outcomes and a reduction in the unnecessary use of hospital-based services.<sup>15</sup> Outreach clinics for the people in this study could overcome the practicalities of accessing specialist care which is hospital based. As with other initiatives, such care would need to involve multidisciplinary involvement and collaboration between primary care and specialists.

Shared care between primary and specialist care is described by Smith, Allwright and O'Dowd<sup>31</sup> where the most appropriate professional cares for the patient as part of a team, thus potentially providing benefits over the longer term for those captured in the earlier stages of their disease process through the intervention of improved prescribing of medications.

In the Rea et al. NZ study<sup>24</sup> a COPD disease management programme incorporating patient-specific care plans and collaboration between patients, GPs, practice nurses, specialist physicians and nurse specialists demonstrated reduced hospital admissions and also an improvement in chronic respiratory fatigue. A respiratory nurse specialist available in the community provided professional support for the practice nurse and GP and linkages to specialist and other secondary care support.

Wagner<sup>25</sup> describes effective teams for chronic illness as involving professionals outside those working in a single practice, noting that frequently the team is more effective with the addition of nursing case management and other disciplines such as pharmacy. Medical specialist input can be mediated through nurse case managers.<sup>25</sup> Doolan-Noble and Tracey<sup>29</sup> highlight the importance of a team-based approach in a NZ rural primary health organisation, including a focus on guidelines and resources to enhance primary care clinical management of chronic illness.

It has been suggested that specialist community gerontology nurses working in rural communities<sup>32</sup> may provide a cost-effective solution for improving access to specialist support for elderly and in assisting them maintain a good quality of life. A similar model is described in the United Kingdom with specialist respiratory community nurses.<sup>33</sup> Nurses in both these reports work in a collaborative manner, strengthening communication across disciplines and providing specialist support.

Other authors<sup>34</sup> also stress the value of a collaborative model of care in chronic illness where there is a shared understanding of the patient's problems, patient education and sup-

COPD. The authors do note that the data was sparse and the focus of the reviewed studies was neither on collaborative multidisciplinary approaches nor on improving access to specialist services for rural people.

Improving relationships and communication between professionals and rural COPD patients and easing difficulties of access for these patients are important aspects of improving quality of care. Katon et al.,<sup>34</sup> when discussing the optimal roles for nurses in chronic illness care, state that nurses provide active follow-up, education, counselling, support and outreach to patients resulting in improved treatment adherence.

## Other authors also stress the value of a collaborative model of care in chronic illness where there is a shared understanding of the patient's problems, patient education and support and facilitation of communication between the patient and primary and specialist professionals

port and facilitation of communication between the patient and primary and specialist professionals. The role of nurses is recognised as important and, for example, a shared care or collaborative approach with outreach respiratory nurses improved community access for people with COPD in South Australia,<sup>35</sup> and, while not reducing health care utilisation, health-related quality of life scores improved. The most consistent factor leading to reduced hospital admission in Martin et al.'s<sup>35</sup> pilot study on the benefit of care plans for COPD patients is reported as frequency of contact with specialist respiratory nurses.

In a systematic review, however,<sup>36</sup> of randomised control trials to determine the effectiveness of nurse-led approaches for patients with COPD, the authors conclude that there is little evidence to support the widespread implementation of nurse-led management interventions for

Improving access to specialist services for rurally-based people living with COPD requires reconsideration of how services are delivered. In NZ, nurses in specialist community respiratory roles are well placed to improve care co-ordination across services, foster strong intersectoral links, improve communication and strengthen collaboration within multidisciplinary teams in rural settings.

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## COMPETING INTERESTS

None declared.