

COPD disease knowledge, self-awareness and reasons for hospital presentations among a predominately Indigenous Australian cohort: a study to explore preventable hospitalisation

Arijeet Pal,¹ Timothy P Howarth ,^{2,3} Chris Rissel ,¹ Raelene Messenger,⁴ Siji Issac,⁴ Linda Ford,⁵ Christine Connors,⁶ Subash Heraganahally ^{1,3,4}

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For numbered affiliations see end of article.

Correspondence to

Dr Subash Heraganahally;
hssubhashcmc@hotmail.com

ABSTRACT

Background The prevalence of chronic obstructive pulmonary disease (COPD) is higher among Indigenous Australians than that of non-Indigenous Australians. However, no studies have investigated COPD disease awareness and knowledge among Indigenous Australians. In this study, we assessed the COPD disease awareness among Indigenous and non-Indigenous patients in the Top End Health Service region of the Northern Territory of Australia.

Methods Of a total convenience sample of 100 adults, 86 patients consented to participate in this study over a 15-month period. A structured interview was conducted to identify participant's level of knowledge about COPD, medications, self-management, healthcare interaction and utilisations.

Results Most (69%) participants were Indigenous and men (52%). Indigenous patients were significantly younger (mean 56 vs 68 years $p < 0.001$), with a higher proportion of remote residence and current smoking. COPD knowledge across the cohort was low, with 68% of Indigenous and 19% of non-Indigenous participants reporting they 'know nothing/had never heard of COPD'. Most patients self-reported use of puffers/inhalers and were able to identify medication used; however, adherence to therapy was observed in only 18%. Shortness of breath was the most common symptom for hospital presentation (83%) and 69% of Indigenous patients reported seeking medical attention during an exacerbation. Self-management and COPD action plans were poorly implemented. A significant proportion (49%) reported ≥ 2 hospital admissions in the preceding 12 months. During exacerbation, although the majority of Indigenous patients were transferred to a tertiary centre from remote communities, patient's preference was to be managed in their respective local communities.

Conclusions Awareness and understanding of COPD are low in this cohort on several domains. Tailored and culturally appropriate initiatives for both patients and health professionals alike are required to improve COPD disease management among Indigenous population. This will not only improve quality of life but also reduce recurrent hospitalisation, healthcare cost and utilisation.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Indigenous Australians are known to have a higher prevalence of chronic obstructive pulmonary disease (COPD) alongside higher healthcare utilisation.

WHAT THIS STUDY ADDS

⇒ This study demonstrated that COPD disease awareness/knowledge, self-management skills are poor among both Indigenous and non-Indigenous patients.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Health professionals caring for patients with COPD should take a more personalised and individualised approach in providing education to empower patients in managing their chronic respiratory conditions.

INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a preventable and yet irreversible chronic lung disease, which is characterised by chronic airway obstruction and airflow limitation, giving rise to the clinical manifestations of shortness of breath (SOB), chronic cough and mucous production along with considerable impact on quality of life.¹ Patients with COPD often require frequent hospitalisations due to exacerbation of the airway disease secondary to recurrent airway inflammation.¹ Despite significant medical advances, COPD remains an incurable condition.¹ Globally, COPD is a major cause of both mortality and morbidity and imposes a substantial burden on healthcare resources and expenditure. It is estimated that 320 million people or 3.9% of the world's population currently live with this disease.^{2 3} Furthermore, the incidence of COPD continues to grow in line with an



ageing population and increasing environmental and household air pollution across various ethnic and socio-economic spectrum.⁴

In the Australian context, rates of COPD in the Aboriginal and Torres Strait Islander population (henceforth respectfully referred to as Indigenous Australians/people/patients) are disproportionately higher when compared with non-Indigenous Australians, and more so among Indigenous Australians residing in the Northern Territory (NT) of Australia.⁵ The prevalence of COPD among Indigenous Australians has been estimated at 4%, a rate greater than two times that of the non-Indigenous Australians.⁶ Australian hospital separation data have demonstrated that hospitalisation proportions are generally much higher among patients with respiratory disorders,⁷ and this is more so for Indigenous Australians.⁸ Furthermore, Indigenous Australians in the NT have the highest proportion of hospitalisation rates in comparison to all other Australian states and territories, with COPD exacerbations as one of the most common conditions responsible for potentially preventable hospitalisations (PPH).⁷⁻⁹

Nevertheless, COPD is a life-long illness, which requires patient's awareness and self-management strategies to slow disease progression, prevent exacerbations and minimise the need for recurrent hospital admissions.¹⁰⁻¹² Although disease awareness and self-management among patients with COPD are imperative, the current published literature on patient knowledge and experience of their disease and the evidence surrounding self-management strategies is greatly varied, irrespective of which ethnic population is assessed.¹³⁻¹⁷ Moreover, COPD awareness and knowledge among lower socioeconomic populations has been observed to be very low.¹⁸

Despite overwhelming evidence in the literature to suggest COPD is highly prevalent among Indigenous Australians, especially those residing in the NT of Australia,¹⁹⁻²⁴ COPD self-awareness/management/knowledge and the patient experience have not been reported. Hence, it is of value to investigate these domains to gain insight into the patient experience and, thus, better tailor future self-management strategies and reduce hospital presentations for this unique population. Therefore, the aim of this study was to assess COPD knowledge, self-awareness/management, COPD specific pharmacotherapy and reasons for hospital presentation among a convenience sampled cohort involving predominantly adult Indigenous Australians within the Top End Health Service (TEHS) region of the NT of Australia.

METHODS

Setting

The NT is an Australian federal territory occupying the central-northern region of Australia covering approximately 135 million square kilometres. The NT is the least populated, and least dense state or territory in Australia, with a population density of just 0.16 people/

km². In 2021, the population of the NT is reported to be approximately 250 730, of which nearly half live in the capital city of Darwin. In Australia, two-thirds of Indigenous Australians reside in New South Wales, Queensland or Western Australia. However, in all three of these states, Indigenous Australians account for less than 5% of the state's entire population. In contrast, 30% of the NT population self-identify as Indigenous, the highest proportion of any Australian state or territory. Moreover, 80% of Indigenous people in NT live in rural, remote or very remote communities.²⁵ The Royal Darwin and Palmerston Hospitals situated in the capital city of Darwin are the only tertiary care, university affiliated teaching hospital for the TEHS region of the NT. The respiratory and sleep service based at the Royal Darwin Hospital (RDH) provides specialist adult respiratory and sleep services to the urban Darwin population as well as providing specialist outreach services across an average of 20 remote Indigenous communities annually, visiting each community between one to three times each year.¹⁹

Patient and public involvement

Patients actively participated in this study by providing informed consent in narrating their knowledge and experience of COPD. In the public involvement perspective, coauthor Associate Professor Linda Ford (Payi—Aboriginal birth name), NT Indigenous Australian woman, Mak Mak Marranunggu descendent from the Delissaville, Wagait Larrakia Aboriginal Land Trust and the Gurudju Aboriginal Land Trust, NT, and is a senior research fellow in the Northern Institute, College of Indigenous Futures, Education & Arts, Charles Darwin University, Darwin, NT, Australia, independently reviewed the study for its design, conduct, reporting, dissemination of our research work, in particular, the appropriateness and respect in relation to the Indigenous context represented in this study.

Study background

This study was conducted at the RDH and was undertaken as a part of a potentially preventable hospital admission (PPH) project, exploring COPD disease awareness and knowledge among patients with COPD in the TEHS region of the NT.

Study design, participants' inclusion and exclusion criteria

The study was a mixed methods study, with data collected during face-to-face structured interviews on patient presentation alongside a retrospective review of patients' electronic medical records. A convenience sample of 100 participants who initially consented to be interviewed over a 15-month period (July 2020 to October 2021) were recruited into this study. Prospective patients were identified on electronic hospital systems after admission to the Rapid Admissions Planning Unit (RAPU) at RDH due to an exacerbation of COPD or those admitted due to an unrelated medical reason but with a previously established

diagnosis of COPD. Patients were also recruited during the respiratory outreach visits to remote communities. Recruitment of study participants during hospital admissions took place only on those occasions when the researchers had time to carry out the interview without any other clinical commitments. Hence, the recruitment was random, rather than consecutive patients admitted to the hospital with COPD during the study period. For those patients recruited during outreach visits, patients who were identified to have had a prior hospital admission were approached to participate in the study. Once again, this was undertaken in a random fashion, only when the researchers had time to conduct the interview without compromising routine clinical care for patients presenting to respiratory outreach. For patients who presented two times during the study period (ie, at outreach visits and a hospital presentation), we included only their first (earliest) presentation.

Eligible patients were aged 18 years or older, residents of the TEHS region of the NT, with a clinically confirmed diagnosis of COPD. Patients were not approached to participate or excluded if they were too unwell to carry out the interview, did not speak English at a level allowing communication, those with mental health issues, which impeded their ability to participate in the interview, or those who did not give consent or withdrew consent during the interview process or did not want to continue with the interview.

Clinical and structured interview data

Following informed verbal consent from the study participants, a structured interview was conducted to collect information on the following five broad domains: (1) demographic information including self-reported Indigenous status, (2) knowledge and details of COPD-specific medication usage, (3) smoking status, (4) COPD disease understanding and perceptions, (5) reason for current hospital presentation, specifically if related to COPD. Other data collected from medical records included pulmonary function tests (PFT), with severity graded according to Australian concise tool for chronic obstructive pulmonary disease COPD-X¹⁷ or Global Initiative for Chronic Obstructive Lung Disease (GOLD)¹ criteria, medical comorbidities, details of airway-directed inhaled pharmacotherapy (short-acting bronchodilator, short-acting muscarinic antagonists, long-acting β -agonists, long-acting muscarinic antagonists, inhaled corticosteroids (ICS)), domiciliary oxygen therapy and any other relevant information.

Interview data

All interviews were conducted by a member of the research team, comprising medical students and two clinical respiratory nurse consultants from the respiratory service at RDH, under the direct supervision of a senior respiratory physician. Participants were asked a series of questions about their knowledge of COPD, and

actions in response to COPD symptoms or exacerbations. This included the participants' understanding of COPD itself, medication usage (type and daily and/or symptom based), what sort of impact COPD has had on daily life, what actions are undertaken in response to an exacerbation and how patients interact with healthcare in response to their COPD. Detailed notes of responses taken by investigators at the time of the interview were initially recorded onto a data entry sheet (hard copy) (online supplemental appendix 1) and then were entered electronically to a spreadsheet for analysis. A separate investigator, blinded to Indigenous status, age and sex then reviewed the responses and undertook a restricted thematic analysis using a deductive approach on the basis of previous literature. Themes categorised were 'Understanding of COPD', 'Medications', 'Symptoms', 'Exacerbations', 'Interactions with healthcare'. Within each of these themes, subthemes were identified and coded dichotomously as present or absent prior to being merged back to the master dataset (online supplemental appendix 2).

Statistical analysis

Quantitative data from patient presentation and medical records were presented as mean (SD) and/or number (percentage). Equality between the Indigenous and non-Indigenous cohort on presenting data was tested via two-tailed student's t tests for continuous data or two-tailed proportions z-test for categorical data. Interview data were transformed to dichotomous variables as described above and presented as number (%) of affirmative responses, with the denominator the number of participants who provided an answer in the relevant theme. No statistical significance testing of equality between Indigenous and non-Indigenous responses was conducted based on qualitative interview transformed data. Pearson's χ^2 was used to determine correlations between self-reported symptoms and airflow obstruction severity by COPD-X and GOLD criterion. Themes were identified in NVivo and data were analysed in STATA V.15.1 (StataCorp, Texas), and alpha set to 0.05.

RESULTS

Study participants, demographics and clinical parameters

Out of the 100 patients approached by the research team, one patient refused participation and seven later withdrew during the structured interview, six patients presented two times during the study period, resulting in 86 participants recruited for the study, of whom 52 (60%) were recruited from RDH/RAPU and 34 (40%) from respiratory outreach visits. The majority of participants were men (52%) and identified as Indigenous Australians (69%) (table 1). Indigenous participants were significantly younger (mean difference 11.6 years), with a higher proportion of current smokers (63% vs 35%) and a higher proportion of remote residence (52% vs 11%). Overall, 85% of the study participants were

Table 1 Demographic and clinical characteristics of the study participants by Indigenous status

Clinical parameters	Total (n=86)	Indigenous (n=59)	Non-Indigenous (n=27)	P value
Sex (female)	41 (48%)	31 (53%)	10 (37%)	0.182
Age (years) (mean (SD))	59.92 (10.97)	56.26 (9.76)	67.93 (9.14)	<0.001*
Outreach recruitment	34 (40%)	31 (53%)	3 (11%)	<0.001*
Residence	94	61	29	
Urban (Darwin)	47 (55%)	24 (41%)	23 (85%)	<0.001*
Remote	33 (39%)	30 (52%)	3 (11%)	0.001*
Homeless/long grass†	5 (6%)	4 (7%)	1 (4%)	0.572
Smoking status	91	61	28	
Current smoker	46 (54%)	37 (63%)	9 (35%)	0.017*
Former smoker	31 (36%)	15 (25%)	16 (62%)	0.003*
Comorbidities	86	58	28	
Hypertension	29 (36%)	18 (33%)	11 (42%)	0.370
Asthma	19 (23%)	14 (25%)	5 (19%)	0.537
Diabetes	18 (22%)	12 (22%)	6 (23%)	0.899
Ischaemic heart disease	12 (15%)	8 (15%)	4 (15%)	0.921
Bronchiectasis	10 (12%)	8 (15%)	2 (8%)	0.381
History of NTM/TB infection	6 (7%)	4 (7%)	2 (8%)	0.946
Congestive cardiac failure	6 (7%)	1 (2%)	5 (19%)	0.005*
Rheumatic heart disease	5 (6%)	5 (9%)	0 (0%)	0.113
Interstitial lung disease	3 (4%)	0 (0%)	3 (12%)	0.010*
Pulmonary HTN	2 (2%)	2 (4%)	0 (0%)	0.325
Pulmonary embolism	1 (1%)	1 (2%)	0 (0%)	0.489
Lung cancer	1 (1%)	1 (2%)	0 (0%)	0.489
Any comorbidity	69 (85%)	46 (84%)	23 (88%)	0.435

P value obtained from two-tailed z test of proportions for categorical parameters, and two-tailed students t-test for continuous parameters.

*Indicates significance at $p < 0.05$.

†Represents camp for homeless people in urban centres.

HTN, hypertension; NTM, nontuberculous mycobacterial; TB, Tuberculosis.

recorded to have a medical comorbidity, of which hypertension, asthma and diabetes were the most common conditions. Congestive heart disease and interstitial lung disease were noted significantly more commonly among the non-Indigenous participants, however, due to the low number of cases the CIs were wide. Of the 52 recruited from RAPU, 46 responded to what had prompted their hospital visit, with the majority ($n=38$, 83%) reporting SOB of whom one (3%) had additionally reported they were unable to see their general practitioner (GP) and one (3%) reported their medication had run out. The remaining eight participants (17%) reported other reasons for RAPU presentation, including chest pain, fever or infection.

Lung function data

A similar proportion of Indigenous (90%) and non-Indigenous (78%) participants had a formal PFT performed (figure 1). The majority of participants fell into either the severe according to the COPD-X,¹⁷ or stage

III–IV as per GOLD¹ severity categories, highlighting a significant and advanced presence of COPD disease burden among this population. A higher proportion

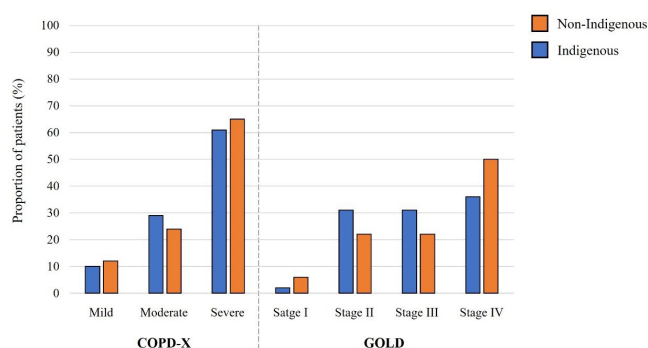


Figure 1 Severity grading of COPD by COPD-X and GOLD criterion for Indigenous and non-Indigenous participants. COPD, chronic obstructive pulmonary disease; GOLD, Global Initiative for Chronic Obstructive Lung Disease.

Table 2 Self-reported knowledge on COPD split by Indigenous status

Knowledge on COPD	Indigenous (n=57)	Non-Indigenous (n=27)
'Know nothing' and did not report 'bad lungs' nor identify any cause including smoking	31 (54%)	3 (11%)
'Know something' whether general understanding, awareness of 'bad lungs' or a cause including smoking	26 (46%)	24 (89%)

COPD, chronic obstructive pulmonary disease.

of Indigenous participants were noted to fall into the moderate to severe COPD-X spirometry severity criteria; however, this difference was not statistically significant.

Knowledge of COPD

Eighty-four participants responded to the interview question regarding their knowledge of COPD. Forty-four (54%) stated they had not heard of or knew nothing about COPD. This response was especially prevalent among Indigenous participants, with 39/57 (68%) responding to this effect, compared with 5/27 (19%) non-Indigenous participants. In contrast, 24/84 (29%) participants responded that they were aware of or had some knowledge about COPD, of whom 17 were non-Indigenous (17/27, 63%). Of those who responded that they had some knowledge; however, only 12 (50%) (Indigenous 4/57, 7% and non-Indigenous 8/27, 30%) were able to describe COPD further, expressing that it was a chronic condition, the obstructive element and/or knew about emphysema. Although many stated they knew nothing/had never heard of COPD, some were still able to recognise that their lungs were 'bad' in some manner and/or identify causes of lung damage, including mining or work with particulate matter and smoking (table 2). There was confusion around the current diagnosis of lung disease reported by several participants, stemming from medical miscommunication: 'The Doctor told me my lungs are alright, never heard of COPD'. 'The Doctors never told me anything, told me everything is fine, I have never heard of COPD'. and 'been told different things—not sure what my lung diagnosis is'.

Notably, 30 participants (Indigenous 15/57, 26% and non-Indigenous 15/25, 60%) noted that smoking in some way contributed to their lung disease. Of these, 17 (55%) (Indigenous 7/15, 47% and non-Indigenous 10/15, 67%) reported they were former smokers; however, 12 (45%) (Indigenous 8/15, 53% and non-Indigenous 4/15, 27%) reported that they were current smokers, smoking anywhere from 2 to 40 (mean 18.4, median 20) cigarettes per day. Misperception regarding the effect of smoking was also noted for several participants, with one participant questioning why their lungs were bad as they no longer smoked, while another stated '...my lungs are good because I'm not smoking, I stopped 20 years ago'.

Perception of COPD symptoms

The majority of participants (n=70, 80%) reported multiple symptoms associated with their condition: 'I get short wind, I breathe too fast, and cough up yellow sputum' 'I get short wind, I cough. I was, I feel less energy. Can't walk for short distances and get wheezy'. SOB and coughing were the most commonly reported symptoms, occurring in most patients (figure 2). However, Indigenous participants reported numerous symptoms significantly more commonly than non-Indigenous peers, including cough (61 vs 21%), fevers (39 vs 4%), difficulty walking (26 vs 13%) and phlegm production (24 vs 13%). Several correlations were noted between reported symptoms and airflow obstruction according to GOLD, PFT severity criteria. Cough ($r^2=0.277$, $p=0.024$) and phlegm production ($r^2=0.437$, $p<0.001$) showed significant and positive associations with Stage III airflow obstruction.

Overall, 68 patients reported on the frequency with which they attended primary healthcare for SOB. Indigenous participants reported attending a primary healthcare centre (PHC) significantly more commonly compared with non-Indigenous participants with 7/44 (16%) versus 1/24 (4%) attending at least once a week, and 14/44 (32%) versus 5/24 (21%) at least once a month.

Knowledge on COPD-specific medication

Eighty-five participants (58 Indigenous) reported on their medication usage during the structured interview. All reported use of puffers/inhalers, of whom 71/85 (84%) were able to identify them by name and/or colouration, seven participants reported the use of tablets, six home

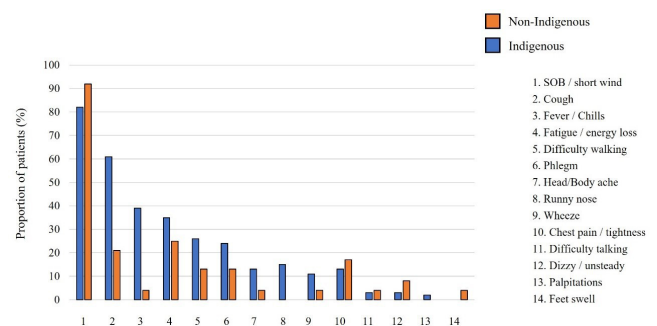


Figure 2 Self-reported symptoms of participants by Indigenous status. SOB, shortness of breath.

Table 3 Self-reported medications and medications recorded in the medical record for Indigenous and non-Indigenous participants

Pharmacotherapy details	Indigenous (n=59)	Non-Indigenous (n=27)
Self-reported puffer/Inhaler	57 (97%)	23 (85%)
Self-reported puffer/Inhaler could identify	48 (81%)	23 (85%)
Medical record of any medication	57	27
Medical record of SABA	56 (98%)	27 (100%)
Medical record of SAMA	12 (21%)	7 (26%)
Medical record of LABA	43 (75%)	21 (78%)
Medical record of LAMA	29 (51%)	18 (67%)
Medical record of ICS	37 (65%)	19 (70%)
Self-reported tablets	4 (7%)	3 (11%)
Medical record of theophylline	1 (2%)	1 (4%)
Self-reported home oxygen (DOT)	1 (2%)	5 (19%)
Medical record of home oxygen (DOT)	5 (9%)	9 (33%)
Self-reported multiple medications	35 (61%)	14 (52%)
Medical record of multiple medications	49 (86%)	25 (93%)
Symptomatic use self-reported	50 (88%)	23 (85%)
Daily use recommended (LABA/LAMA)	44	23
Daily use self-reported	9 (20%)	6 (26%)

DOT, domiciliary oxygen therapy; ICS, inhaled corticosteroids; LABA, long-acting β -agonists; LAMA, long-acting muscarinic antagonists; SABA, short-acting bronchodilator; SAMA, short-acting muscarinic antagonists.

oxygen and one each reported use of Indigenous traditional bush medicine or herbal supplement (table 3): ‘I use the Bush medicine and firewood smoke’. Although many participants reported the use of multiple medications, in comparing to the medical records of medications prescribed, there was a significant discrepancy. Among non-Indigenous patients, 52% self-reported multiple medication; however, medical records indicated 93% had multiple medications, while for Indigenous patients, this was 61% and 86%, respectively. Furthermore, a higher proportion self-reported use of ‘tablets’ compared with what was recorded in the patients’ medical records. However, several of these entries included paracetamol, or were otherwise unnamed/unidentified, so may reflect other non-prescription medication: ‘When really sick call the clinic, the doctor will give me the tablets’.

Most participants (73/85, 86%) reported need for use of medications for symptomatic relief for COPD-related symptoms, with only 15/85 (18%) reporting regular or daily use, although 67/86 (78%) had records of medication warranting regular/daily use. Six participants reported irregular use of medication with one noting forgetting after consuming alcohol and subsequently struggling to breathe, while others noted various reasons for irregular use of medication; ‘Steroids give you energy, once a day in the morning—sometimes I feel lazy but take it 2–3 times week’, ‘I take my two puffers whenever I feel like, sometimes I take it at night, sometimes I don’t take it, and sometimes I take it lots of times’ and ‘I know about my inhalers, however do not take them as the doctor

instructed’. Fifteen (18%) (Indigenous 9/59, 15% and non-Indigenous 6/27, 22%) told interviewers they were uncertain about their medication, did not know how or when to use it or demonstrated poor technique with puffers/inhalers and/or spacers.

COPD exacerbations

There was marked variation in participants’ actions when they first noted they were beginning to become unwell (table 4). Most (57/85, 67%) reported use of medication, typically a puffer/inhaler, though several noted use of home oxygen (n=5), bush medicine (n=2), tablets (n=1), herbal supplements (n=1) or marijuana (n=1): ‘Try the Bush medicine such as stringy bark wood in boiling water and drink it’. Two patients explicitly reported they avoided using their medication, instead waiting to reach PHC before the health staff administered any medication: ‘Call someone to take me to clinic where they give me medicine’. More than half of the participants (50/85, 59%) reported seeking aid from either PHC (41/50, 82%) or tertiary healthcare (9/50, 18%), with a large portion of those seeking healthcare as the only action taken (21/50, 42%): ‘Felt worse, called ambulance’. A higher proportion of Indigenous participants reported seeking assistance from healthcare compared with non-Indigenous (40/58, 69% vs 10/27, 37%), with a lesser discrepancy noted between those who sought healthcare without use of medication or activity modification (16/58, 28% vs 5/27, 19%) compared with

Table 4 Reported actions taken when exacerbation of COPD symptoms by Indigenous status

Action taken during COPD exacerbation	Indigenous (n=58*)	Non-Indigenous (n=27)
Any medication use	38 (66%)	19 (70%)
Puffer	34 (89%)	17 (89%)
Other	4 (11%)	5 (26%)
Any activity modification	26 (45%)	13 (48%)
Any PHC	32 (55%)	9 (33%)
Any THC†	8 (14%)	1 (4%)
Medication only	6 (10%)	5 (19%)
Activity modification only	1 (2%)	2 (7%)
PHC only	14 (24%)	4 (15%)
THC only	2 (3%)	1 (4%)
Medication and activity modification	11 (19%)	10 (37%)
PHC/THC in conjunction with medication / modification	24 (41%)	5 (19%)
PHC	18 (75%)	5 (100%)
THC†	6 (25%)	0 (0%)
In case of deterioration	52	21
PHC	24 (46%)	14 (67%)
<i>Sent from PHC to THC</i>	12 (50%)	10 (71%)
THC directly	28 (54%)	7 (33%)

*One patient did not respond to questions regarding actions in event of an exacerbation.
 †One patient reported visiting the hospital if primary healthcare was unavailable.
 COPD, chronic obstructive pulmonary disease; PHC, primary healthcare (including local clinic, nurse or GP); THC, tertiary healthcare (including emergency department and ambulance calls).

those who sought healthcare in conjunction with medication use or activity modification (24/58, 41% vs 5/27, 19%). Notably, PHC/GP was used significantly more often among Indigenous participants (32/58, 55%) than among non-Indigenous (9/27, 33%): ‘Lie down and rest drink plenty of water, ask family to let the clinic know to come and visit me’. When looked at by place of residence, a lower proportion of Indigenous patients who resided in an urban location (10/24, 42%) reported using PHC/GP in response to an exacerbation.

In the case of COPD symptoms not resolving or the exacerbation worsening the second course of action for participants was to seek advice from healthcare. The majority (38/73, 52%) reported going to PHC, of whom 58% (22/38) reported being referred to tertiary health centre, while the remaining 48% (35/73) reported management only at the tertiary health centre. Six (one

non-Indigenous) reported that in the case of a worsening exacerbation, after seeking help from local PHC, the clinic would have to organise air transport for them to RDH: ‘I use puffers and oxygen, if not resolved I usually get care flight to hospital’.

Healthcare utilisation with COPD

Only four participants (all non-Indigenous) reported regular follow-up with primary healthcare outside of COPD exacerbations, while 59 (Indigenous 46/59, 78% and non-Indigenous, 8/27, 30%) reported visiting PHC on a symptomatic basis only. Several elaborated on why they did not seek regular check-ups with PHC; ‘Meant to be once a month but no money for bus—family really busy to take me to appointments’, ‘I see my GP in town so have to arrange it around my fly in fly out shift as there is no GP out at (place name)’, while five participants explained they did not have a regular or consistent GP to see.

Fifty-four participants reported the number of times they had presented to hospital for COPD in the previous 12 months, with a median 2 (IQR 1, 3) visits among Indigenous (excluding one participant recorded to have had 38 admissions) and 3 (IQR 1, 4) among non-Indigenous participants (table 5). There did not appear to be any significant difference in COPD admissions by Indigenous status, nor on the basis of COPD knowledge, nor actions taken in initial response to an exacerbation.

Nineteen participants (16 Indigenous) reported that they would rather have treatment in the local clinic, as opposed to travelling to RDH for treatment with one stating ‘Don’t want to come to hospital. The clinic needs to fix me’, and another ‘Fix me and send me home, I hate Darwin’. The issue of family was also raised by several Indigenous participants if a hospital admission was required, with one participant reporting her son lived in the community and reluctance/fear to leave him there alone, and another stating ‘I expect ‘you’ health staff to fix me, look after me, help me, contact my family and reassure me’. On the other hand, several participants noted that their family should be involved in their treatment and management; ‘I am pretty happy with my involvement in my treatment. The doctors and other people speak to my sisters so that everyone understands’. and ‘My daughters are meeting with doctors today to discuss action plans and management plans’.

Most participants (91%) reported that they did not have a COPD action plan (figure 3). When participants were informed of and offered an action plan, only one-third (36%) were willing to receive one or follow-up with their GP about one.

DISCUSSION

To the best of the author’s knowledge, this is the first study to document COPD disease perceptions and knowledge among Indigenous patients, particularly from the

Table 5 Hospital admissions for COPD in 12 months preceding interview by Indigenous status

Hospital admissions for COPD	Indigenous (n=49)	Non-Indigenous (n=21)
Indeterminate response*	16	0
No admissions	4 (12%)	3 (14%)
Single admission	9 (27%)	4 (19%)
Two admissions	9 (27%)	2 (10%)
Three admissions	4 (12%)	5 (24%)
Four admissions	2 (6%)	2 (10%)
Five admissions	0 (0%)	3 (14%)
6+admissions	5 (15%)	2 (10%)
Median admissions (median (IQR))	2 (1, 3)	3 (1, 4)
Disease knowledge		
No knowledge of COPD (n(median (IQR)))	22(2 (1, 3))	3((0, 1, 4))
Some knowledge of COPD (n(median (IQR)))	20(2 (1, 5))	17(3 (1, 4))
Exacerbation response		
Medication or activity modification only (n(median (IQR)))	14(1.5 (1, 6))	14(3 (1, 5))
Visited PHC (n(median (IQR)))	21(2 (1, 2))	6(2.5 (0, 4))

*Participants reported 'don't know', 'several times', 'lots of times'. COPD, chronic obstructive pulmonary disease; PHC, primary healthcare (including local clinic, nurse or GP).

NT of Australia. This study has demonstrated several key insights:

1. Indigenous patients with COPD are much younger and the majority reside in remote/rural communities in comparison to non-Indigenous patients.
2. SOB is the most common reason for hospital presentation.

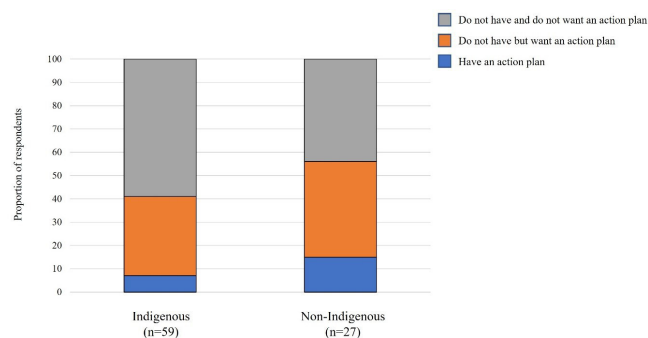


Figure 3 Proportion of participants with a written COPD action plan, and those who wanted or did not want one. COPD, chronic obstructive pulmonary disease.

3. Indigenous patients report different symptom manifestations compared with non-Indigenous patients, with a higher prevalence of cough, fever and sputum production.
4. Universally 'poor' knowledge of COPD was observed across study participants, with only 7% of Indigenous and 30% of non-Indigenous patients demonstrating an adequate understanding of COPD.
5. Though regular medication use was prescribed for three quarters of the cohort, only a quarter reported regular usage and a proportion of them reported uncertainty about the use of their medication.
6. 59% of patients reported presenting to a primary or to a tertiary healthcare during an acute exacerbation.
7. Only a minority of patients reported having a written COPD action plan. Moreover, only 36% were receptive to having a COPD action plan.
8. Most patients had at least one prior hospital admission in the preceding 12 months; however, many Indigenous patients reported they would prefer that their respiratory condition managed in their local community.

Indigenous people worldwide, including Indigenous Australians, are reported to have a higher respiratory disease burden alongside higher healthcare utilisation.^{5-9 19-24 26-29} Poor disease awareness and self-management strategies of COPD are not uncommon among various ethnic populations, including in high-income countries.^{16 18 27 30} Despite literature portraying higher healthcare utilisation and hospital admission rates among Indigenous Australians due to COPD, there has been no prior studies illustrating the underlying reasons for this observation. Hence, demonstrating Indigenous patients' perception of their disease, in particular, in relation to COPD self-management, knowledge on medications usage and healthcare utilisation as illustrated in this study is of a significant value in enhancing our knowledge in this arena for future interventions.

In this current study, we observed universally low disease awareness, though with a heightened presence among our Indigenous cohort. Several aspects of COPD disease perception from our study participants have been well illustrated in the Results section above. Previously, knowledge and adherence to pharmacotherapy among patients with COPD have consistently been reported to be low.³¹ In this study, the majority of patients were noted to have been prescribed with airway-directed inhaled pharmacotherapy, more specifically, ICS/long-acting β -agonists or ICS/long-acting β -agonists/long-acting muscarinic antagonists. Although most study participants had some knowledge of their medications, in particular, for inhalers, adherence to therapy as per recommendation appeared to be poor, at around 18%. There is sparse evidence in the literature addressing the utility and appropriate use of airway-directed inhaled pharmacotherapy among Indigenous patients with COPD. A recent study has demonstrated much higher yearly decline in forced expiratory volume in one second

(FEV₁) among Indigenous patients prescribed ICS with airway disease.³² Although oral theophylline is recommended and could be considered in the management of patients with COPD,^{17 33} in this study, theophylline was noted to be prescribed very infrequently. However, a significant proportion of Indigenous patients reported taking a tablet for their illness. It is not clear at this stage whether a 'tablet' like theophylline could be more applicable to Indigenous patients rather than inhalers, given the low adherence to inhaled pharmacotherapy observed in this study.

We also observed that only a negligible number of patients recalled having been provided with or had knowledge of having a COPD action plan. This is despite COPD action plan tools that have been developed specifically for Indigenous patients nearly a decade ago.³⁴ Moreover, only a third of participants were receptive to having a COPD action plan, instead preferring to seek help from local PHC during COPD exacerbation. This may indicate that our approach to chronic disease management pathways may need differing strategies among Australian Indigenous remote population. Nonetheless, in the absence of well-established COPD management guidelines for Indigenous people, treatment interventions have to be tailored to individual patients' preference and needs, along with education on their disease condition in a clinically and culturally relevant manner.

Lung function parameters are generally observed to be lower for Indigenous population in comparison to non-Indigenous.^{35–40} Direct comparisons of lung function data against patient experience of COPD symptoms and the effect of symptoms on daily life activities have not been explored in the past among Indigenous Australians. In the current study, a higher proportion of Indigenous patients were observed to have more severe airflow obstruction compared with non-Indigenous patients with COPD. This may indicate a more severe COPD disease burden among Indigenous patients. Previous studies have demonstrated that with more severe disease as measured by FEV₁, the rate of hospitalisation increases.⁴¹ It is unclear if this is the case for the study participants in this study. Furthermore, symptoms reported differed between Indigenous and non-Indigenous patients, with a higher prevalence of cough, sputum production and fever noted among the former. There appeared to be a significant association between these symptoms and more severe airflow obstruction. However, given these symptoms were present at a higher rate among the Indigenous patients, and severity of airflow obstruction was marginally higher among the Indigenous cohort, it is uncertain if these symptoms are associated with severity, indigeneity or some coupling of both and the subsequent aftermaths.

Previous studies among Indigenous patients from the TEHS, NT region have reported a higher prevalence of concurrent presence of COPD and bronchiectasis.^{19–24} It may be reasonable to speculate that the disparity in symptom manifestations (cough and sputum) noted among Indigenous patients could be attributed to

coexistent bronchiectasis and COPD. Airway clearance manoeuvres are paramount in the management of bronchiectasis;⁴² however, implementation or intervention outcomes are sparsely reported in the literature in the management of chronic respiratory conditions among Indigenous people.^{21 43} It is plausible that by providing dedicated chest physiotherapy/airway clearance programmes that are accessible and available for Indigenous people living in remote communities that we would see benefits not only in the overall management of chronic respiratory conditions but also in terms of outcomes such as recurrent hospital admissions due to exacerbations of airway disease.

As mentioned above, hospital admission data demonstrates unprecedented higher hospital admission rates for Indigenous patients with COPD.^{5–9} In this study, SOB was the predominant reason for hospital presentation. A recent study also demonstrated that SOB was the most common reason for hospital presentation.²⁸ Additionally, a higher proportion of Indigenous patients were transferred to tertiary care hospital from other remote/regional health centres.²⁸ In the current study, the majority of Indigenous patients resided in remote communities and preferred to seek help from local health centres when they become unwell and lacked COPD action plans. Moreover, many expressed that they prefer not to be transferred to tertiary care centres when their symptoms worsen. In conjunction with the preference for community treatment, there appears to be a higher threshold before seeking care or being transferred to tertiary care centres compared with non-Indigenous patients. Implementing strategies, in particular, managing SOB and providing education and support to community health workers caring for Indigenous patients with COPD, alongside providing self-management strategies, may decrease hospital presentations and associated healthcare cost and utilisation.^{10 11 17} Moreover, such programmes, including respiratory coordinated care programme have been demonstrated to be useful in preventing recurrent hospital presentations.^{44–46} For Indigenous patients, implementing such strategies may be of significant benefit in fulfilling their preference to be managed in their community and avoiding lengthy and undesired visits to the city.

It has been proven beyond reasonable doubt that patient awareness and knowledge is paramount in the holistic management of COPD, including preventing recurrent hospital admissions.^{11–18 30 31 41 42 44 46–51} This current study offers valuable insight into the scope of understanding and perceptions held by both Indigenous and non-Indigenous patients about their conditions as well as the performance of our health service in providing effective education and COPD action plans to promote patient understanding of COPD and self-management. A major strength of the current study is the relatively high proportion of Indigenous Australian patients with COPD interviewed. Previous reports from our centre have identified 140–150 patients with radiologically confirmed



COPD.^{24 39} Furthermore, hospital linkage data using ICD code identified 110 Indigenous patients presenting with COPD from July 2020 to October 2021 (as yet unpublished). As such, it is plausible that the current study captured anywhere from 40% to 60% of current Indigenous COPD patients in the TEHS region. More recently, several aspects of respiratory health issues among Indigenous Australians from the TEHS region of the NT has been reported in the literature.^{19–24 28 32 35–40 52–66} Hence, this study could be considered as an important further step forward⁶⁷ in addressing COPD disease awareness and knowledge in an Indigenous population. The findings of this study highlight the need for further improvement and implementation of strategies to deliver education and empowerment for Indigenous patients with COPD. Patients with knowledge of their condition are better able to self-manage their chronic disease, ultimately reducing PPH and thereby reducing the burden on the already stretched health resources in the NT of Australia, in addition to enabling patients to manage their condition in a location where they feel comfortable and connected to family and land. Further studies are warranted involving First Nations people in codesign and coimplementation of health services for better access to COPD care and prevention in a culturally and clinically relevant manner specifically tailored to the Indigenous Australian population.⁶⁸

Limitations

The authors acknowledge the relatively small sample size, of which only 31% were non-Indigenous was less than would have been ideal to maximise statistical power; however, it is reasonable to accept this as a legitimate limitation given that the study scope in which patients were only opportunistically and randomly recruited from the RDH/RAPU admissions over a 15-month study period. Moreover, the interviews were conducted at the bedside/convenience of patients, directed and structured by healthcare staff. This leads to a potential authoritative imbalance, which may have impacted peoples' answers as well as a time factor (due to potential external demands on the healthcare staff), which reduced the potential to fully elaborate on or delve deeper into various topics. The fact that for most patients, the interviews were undertaken in a hospital setting, would have altered their perception of the disease as opposed to if it had been done at home or in the patient's community. The study population was limited to the subset of patients who presented to the RDH for COPD or unrelated reasons recruited by convenience sampling, including during the respiratory outreach visits. As a result, the population may not truly represent the entire population of Indigenous or non-Indigenous Australians in the wider TEHS, NT community with COPD. Nevertheless, this is the first study to represent COPD knowledge in an Indigenous Australian population and provides some invaluable key

insights for further, dedicated research that will help elucidate management of COPD in this population.

CONCLUSION

Poor COPD disease knowledge is prevalent among Indigenous and non-Indigenous Australians in the NT of Australia. Adherence to airway-directed pharmacotherapy is low, and self-management strategies and COPD action plans are rarely implemented. SOB is the main reason for seeking care at community health clinics and/or hospital admissions. The majority of Indigenous patients during COPD exacerbations are transferred to tertiary care centres from remote communities; however, Indigenous patients express that their preferred choice is to be managed in their respective local community. Dedicated efforts are required in educating both patients and healthcare professionals alike caring for Indigenous patients with COPD, not only to facilitate better quality of life but also to reduce the healthcare cost, utilisation and recurrent hospital admissions (PPH) and close the health gap.

Author affiliations

¹College of Medicine and Public Health, Flinders University, Adelaide, South Australia, Australia

²College of Health and Human Sciences, Charles Darwin University, Darwin, Northern Territory, Australia

³Darwin Respiratory and Sleep Health, Darwin Private Hospital, Darwin, Northern Territory, Australia

⁴Department of Respiratory and Sleep Medicine, Royal Darwin Hospital, Darwin, Northern Territory, Australia

⁵College of Indigenous Futures, Education & Arts, Charles Darwin University, Darwin, Northern Territory, Australia

⁶Department of Health & Community Services, Top End Health Service, Darwin, Northern Territory, Australia

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Patient consent for publication Consent obtained directly from patient(s)

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reported according to strengthening and reporting of health research involving Indigenous people, including consultation with local Indigenous Australian representatives. Participants gave informed consent to participate in the study before taking part.

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ORCID iDs

Timothy P Howarth <http://orcid.org/0000-0003-3028-0376>

Chris Rissel <http://orcid.org/0000-0002-2156-8581>

Subash Heraganahally <http://orcid.org/0000-0003-0788-7137>

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