# A survey of community nurses' knowledge and strategies used to relieve breathlessness in people with chronic obstructive pulmonary disease

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hronic obstructive pulmonary disease (COPD) is the third leading cause of global deaths (WHO, 2017). The WHO estimates that there are 251 million people diagnosed globally with moderate to severe COPD (WHO, 2017). In Australia, approximately 4.8% of people aged over 45 years have COPD, costing the Australian health system over AUD 970 million, or 24% of the chronic respiratory disease expenditure (Australian Institute of Health and Welfare, 2020). People with COPD incur frequent clinical exacerbations; in later stages, there is a progressive deterioration in physical status, a high symptom burden, increased social restrictions and psychological stressors that impact on quality of life (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2020).

## Abstract

Background: Little is known about community nurses' knowledge of breathlessness and its management in chronic obstructive pulmonary disease (COPD). Aim: To explore the community registered nurses' knowledge of COPD and the strategies that they use to manage breathlessness in people with COPD. Methods: A cross-sectional survey study of community registered nurses was conducted using the 65-item Bristol COPD Knowledge Questionnaire and an open-ended item to outline breathlessness strategies. Findings: A total of 59 nurses participated. The total mean Bristol COPD Knowledge Questionnaire Score was 43. The breathlessness category was the lowest scoring category. There were three themes that synthesised: the community nurse's role in monitoring self-management of medications to relieve breathlessness; the use of non-pharmacological strategies to relieve breathlessness; the nursing skills used to monitor breathlessness in people with COPD.

Keywords: Breathlessness • community nursing • chronic obstructive pulmonary disease • survey

In Australia, community nursing services are an integral part of primary healthcare and are often provided in the home for people with chronic diseases, as they are ideally placed to provide symptom management (Wagner, 2000). Community nurses in Australia and the UK share many similiar tasks and activities including: health promotion; disease prevention; chronic disease management; rehabilitation and palliation (WHO, 2017). In both countries, these skills are supported by self-management models that have focused on improving motivation, resilience and confidence of people with chronic diseases to manage their condition (Wagner, 2000).

Breathlessness is a debilitating symptom experienced by people with COPD. It is recognised as a subjective experience influenced by physiological, emotional, social and environmental factors (Parshall et al, 2012). Physiological changes contribute to breathlessness of varying intensity and duration, which impact on quality of life, psychological wellbeing and function (Spathis et al, 2017). For people with COPD, the experience of worsening breathlessness can increase hospital presentations (Prekker et al, 2014; Hutchinson et al, 2017). A higher symptom burden, associated with decreased cardiovascular fitness, can negatively impact on mortality (Parshall et al, 2012). Best practice treatments such as pulmonary rehabilitation-where people with COPD learn self-management-can improve outcomes, but chronic breathlessness often persists (Parshall et al, 2012).

A few validated tools have been used to assess COPD knowledge, such as the Bristol COPD Knowledge Questionnaire (BCKQ) (White et al, 2006; Blackstock et al, 2018). The BCKQ is recognised in international 0 pulmonary rehabilitation guidelines as best suited to assessing COPD knowledge before and after education (Blackstock et al, 2018). For example, Guo et al (2018) undertook a cross-sectional survey using the BCKQ to compare the COPD knowledge, attitudes and intentions to refer people with COPD to pulmonary rehabilitation. Total BCKQ score ranges from 0 to 65; higher scores indicate better knowledge. For generalist nurses (n=191) the mean total BCKQ score was 58, and 61 for specialist respiratory nurses (n=93)(Guo et al, 2018). Ma et al (2019) translated the BCKQ into Chinese and compared the COPD knowledge of acute care respiratory and non-respiratory nurses. The total mean BCKQ score was 35, with 39 for respiratory nurses and 33 for non-respiratory nurses. Respiratory nurses' knowledge deficits were in the epidemiology, breathlessness, oral steroids and inhaled steroids categories (Ma et al, 2019).

Community nurses predominately work in the home environment, where they undertake, assess and manage treatment for people with COPD (Guo et al, 2018). Evidence suggests that people with COPD feel supported by community nurses at home (Wong et al, 2012). However, little is known about community nurses' knowledge of breathlessness and management of COPD breathlessness. Some research reveals that community nurses predominantly manage the symptom burden of COPD using a pharmacological model (Kirkpatrick et al, 2012), suggesting this could result in missed opportunities to provide effective, non-pharmacological symptom management.

Edwards and Singh (2012) evaluated the COPD clinician knowledge in primary and secondary care COPD services. The mean BCKQ score was 50 (range 24–62). Knowledge deficits were reported in the breathlessness category and in the inhaled steroid category.

To date, the BCKQ has not been used to evaluate nonspecialised community nurses' knowledge of COPD. Therefore, the purpose of this study was to explore community registered nurses' knowledge and the strategies they used to manage breathlessness in people with COPD.

## Methods

#### Study design

This study was a cross-sectional survey. The study was reported with reference to the Checklist for Reporting of Survey Studies (CROSS) (Sharma et al, 2021).

#### Site

The study was conducted across six local community nursing centres within a community nursing service in a metropolitan Local Health District (LHD), in Sydney, Australia. The community nursing service is funded by the Australian and New South Wales State governments and provides general and specialist nursing care to people in their homes.

Clinicians, such as community nurses, undertake patient monitoring by performing routine measurements to detect changes in health status (Stedman, 2016). The parameters that determine respiratory disease monitoring are guided by evidence of acute or chronic disease, and this varies between the hospital and home settings. In the home setting, community nurses undertake chronic respiratory disease monitoring using physical assessment, symptom monitoring and history taking.

#### Participants

A convenience sample of registered nurses working in a community nursing service (n=140) were approached to participate. Inclusion criteria included: registered nurses working either fulltime, part-time or casual. Enrolled nurses were excluded as they did not undertake respiratory monitoring within this service.

#### Data collection

#### Survey

The anonymous survey comprised of 73 items, including the BCKQ (65 items) (White et al, 2006). Demographic items included employment status, years of experience, attendance at chronic respiratory education fora and postgraduate qualifications. There were two items based on a five point Likert scale (from: 1-not at all, to 5-always) to evaluate confidence with respiratory monitoring and COPD knowledge, developed by the researcher and an open-ended item requesting community nurses to outline breathlessness strategies they used in clinical practice. The items were developed to capture an understanding of the potential impacts of working autonomously on the knowledge and confidence of community nurses in relation to managing COPD (Schutz et al, 2013). The eight items were pilot tested by four experienced specialist clinicians, who indicated that the survey had face validity and reflected expectations of community nurses' scope of practice.

#### Bristol COPD Knowledge Questionnaire

The BCKQ was used with permission of the developers. The BCKQ is a validated tool and comprises 65 questions and 13 categories, each with 5 multiple choice items requiring a 'true' or 'false' response. The COPD knowledge categories explore aetiology, prevention, management and symptoms including breathlessness. To determine COPD knowledge deficits, responses to each category are summed. The total mean score is determined by adding all the correct responses in each category and dividing by the number of items (Range: 0-65; higher scores indicate better knowledge). The BCKQ categories were considered to be representative of the COPD knowledge that might be expected of community nurses. The BCKQ has been validated and has good internal consistency (Cronbach's alpha: 0.73) and good test-retest reliability (r=0.71; n=54; P < 0.001) (White et al, 2006). For the purpose of the current study a mean score below 40 indicated a knowledge deficit.

The researcher (JC) attended each of the community centres in which the registered community nurses worked, on two separate occasions to provide information about the study and to invite the nurses to participate. The paper surveys were placed at the back of the education room by the researcher, who left the room so that nurses were able to voluntarily and anonymously complete the survey. Community nurses who agreed to participate completed the survey and placed it in a secure box, which the researcher later collected.

#### Data analysis

A sample size was not estimated for this study; all community nurses working within the study community nursing service were invited to participate. Descriptive statistics (frequencies, percentages, means and standard deviations) were calculated and summarised the quantitative data. An inductive approach to thematic analysis was undertaken for the data, for the responses to the open-ended item requesting participants to outline the breathlessness strategies they used in clinical practice to support people with COPD. Gibb's framework (2018) was used, which included:

- Initial familiarisation and data transcription
- Building codes and patterns
- The development of themes
- The consolidation and interpretation of data.

This resulted in identification of patterns that provided the researcher a context for the respondents' clinical practice. These patterns were discussed by the authors who then reviewed the coding of themes and their interpretation. One of the authors (MF), who is an expert qualitative researcher, verified the coding and themes.

#### **Ethical considerations**

Ethical and governance approval was provided by the Northern Sydney Local Health District (NSLHD) Human Research Ethics committee (HREC:LNR/17/Hawke/395) and the NSLHD Executive. Potential participants were fully informed about the study aim and purpose, and the researcher's interest in understanding their knowledge and management of breathlessness that they provided to people with COPD. No personal details were collected, ensuring the privacy and confidentiality of participants. Participants were informed that completing and returning the survey implied consent. Data were stored in a password locked computer in Excel and NVivo v12.

#### **Results**

A total of 59 community registered nurses completed the survey (response rate: 42%; n=59/140 community nurses). There were no missing items. The administration time was approximately 20 minutes. Most respondents (n=55; 93%) were female, with a mean of  $22\pm20$  (range: 2 days-50 years) years registered nurse experience. Respondents had a mean 11.2  $\pm10$  (2 days-33.4 years) years' community nurse experience (*Table 1*). The majority worked full-time (n=45; 75%) and had attended a chronic respiratory education forum (n=40; 67.8%).

Over 50% of the respondents (n=31) ranked their confidence with COPD knowledge as moderate. Their

confidence to provide respiratory monitoring ranged between 3 (moderate) (n=28; 46.6%), to 4 (quite a lot) (n=20; 34.4%).

The total mean BCKQ score was 43. The highest scoring categories were 'vaccination' and 'infections'. The breathlessness category (35.2) scored the lowest (*Table 2*).

Community nurses identified a range of breathlessness strategies that targeted self-management principles, comfort and medication management. Some three themes were synthesised:

- The community nurse's role in monitoring selfmanagement of medications to relieve breathlessness
- The use of non-pharmacological strategies to relieve breathlessness
- The nursing skills used to monitor breathlessness in people with COPD.

#### Theme 1: the community nurse's role in monitoring self-management of medications to relieve breathlessness

To manage breathlessness in people with COPD, community nurses monitored and assessed prescribed respiratory medication compliance during each home visit. Prescribed medications were incorporated into the care plan as a key breathlessness management strategy. Many community nurses prioritised this, by frequently providing education on respiratory inhaler use, and assessing patient technique:

'I ensure they know and take their medications and (respiratory) puffers, and have a plan of care that they can understand' (Respondent 31)

'I correct the use of medications-inhalers and prescription medications to support breathlessness.' (Respondent 52)

In addition to using respiratory inhalers to control chronic breathlessness, some respondents reported reviewing and monitoring flow rate and consumption of oxygen therapy. These nurses optimised the person's activities using oxygen to better manage breathlessness. To illustrate:

*'(we should) utilise oxygen therapy (if used) prior to and during activities.' (Respondent 47)* 

Oxygen therapy monitoring was a requirement of the nurses' role; however, it was prescribed by a medical officer.

Community nurses also reported assessing the impact of anxiety and existential distress associated with breathlessness on activity. Part of this assessment included reviewing medications and availability of prescribed analgesics and anxiolytics:

"Assistance with activities of daily living—ensuring help is available...prescription medications to support decrease in shortness of breath and relieve anxiety, that is, Ordine<sup>®</sup>. (Respondent 57)

Theme 1 highlighted how respondents supported people with

nurses (n=59)					
Characteristic	Statistic				
Gender, n (%)					
Female	55 (93)				
Male	4 (6)				
Employment status, n (%)					
Full-time	45 (75)				
Part-time	13 (22)				
Casual	1 (2)				
Nursing experience, years Mean±SDª (range)					
Registered nursing	22±20 (2 days–50 years)				
Community nursing	11±10 (2 days–33.4 years)				
CRN <sup>b</sup> respiratory forum attended, n (%)	40 (68)				
Time period CRNb respiratory forum attended, n (%)					
2016–2018	16 (40)				
2014–2015	4 (10)				
2009–2013	3 (7.5)				
No date provided	13 (32.5)				
Before 2009	4 (10)				
Post graduate qualifications, n (%)					
Postgraduate certificate	5 (8.5)				
Graduate diploma	1 (1.7)				
Masters	2 (3.4)				
Enrolled in Masters program	2 (3.4)				
Note: astandard deviation, Community Regist	ered Nurse				

Domographic data for community registered

COPD to use prescribed medications to relieve breathlessness. The use of medication, oxygen therapy, morphine and anxiolytics was a key component of the nurses' care plan to enhance self-management of COPD patients. For these community nurses, education and ongoing monitoring were the cornerstone to practice.

#### Theme 2: the use of non-pharmacological strategies to relieve breathlessness

This theme encompassed the non-pharmacological strategies that the respondents used for people who were experiencing breathlessness. Assessing and providing education about active controlled breathing techniques was a frequently identified strategy, for example:

'Practice breathing (in through nose, out through pursed lips).' (Respondent 31)

The nurses' played a role in providing support for energy conservation. They reported the actions used to support the conservation of energy; when to rest, to pace, to avoid rushing and how to manage activities, reserve energy, and to use short bursts of activity.

Nurses reported assessing symptom recognition by the person with COPD and how they self-managed an exacerbation of breathlessness. Additional statements indicated that they liaised with general practitioners to authorise medications to manage exacerbations in the person's COPD action plan. For example:

## 'Give patient COPD action plan, have GP fill in and then provide education.' (Respondent 24)

Nurses promoted attendance at pulmonary rehabilitation exercise programmes or supported home-based self-directed physiotherapy prescribed exercises. Some nurses reported the use of non-pharmacological strategies to manage breathlessness, such as use of a fan and meditation.

Nurses eased breathlessness by promoting a combination of breathing exercises, energy conservation and exercise programmes. Management of exacerbation symptoms were supported with a medically completed COPD action plan as the key self-management strategy.

# Theme 3: the nursing skills used to monitor breathlessness in people with COPD

Ongoing monitoring, documenting and assessment for COPD deterioration was achieved by measuring vital signs and undertaking chest auscultation. This assessment was used to determine the appropriate intervention. For example:

'Check the vital signs—if symptoms persist or desaturation/ symptom worsening, assess for a hospital transfer.' (Respondent 34)

'Observations: Especially oximetry and respiratory rate (monitor and assess symptoms, especially, why are they breathless?).' (Respondent 12)

History-taking included assessing factors that might precipitate the onset of breathlessness. Nurses liaised with other healthcare professionals for additional support or specific treatments to support people with breathlessness. Healthcare professionals included: occupational therapists, general practitioners, respiratory physicians, physiotherapists and specialised respiratory nurses.

#### **Discussion**

This study revealed that community nurses have detailed knowledge of COPD—its aetiology, symptoms and treatments. COPD knowledge evaluated using the BCKQ revealed good COPD knowledge. Mean total BCKQ scores were lower than those reported by both Guo et al (2018) and higher than those reported by Ma et al (2019). However, the low mean scores in the breathlessness category, were consistent with earlier studies (Wong et al, 2012; Ma et al, 2019). This is concerning, as there is a risk of under treatment when clinicians do not recognise breathlessness in people with COPD (Lung Foundation Australia, 2020). People with COPD rely on community nurses to recognise and assess signs of increased breathlessness, and to have the knowledge to support them with appropriate self-management strategies to minimise discomfort and chronic disease (or existential) distress.

Community nurses' knowledge of infection and vaccinations for people with COPD in the BCKQ categories were good. A study on respiratory nurses in China reflected similar levels of knowledge in these categories (Ma et al, 2019). These consistent findings are arguably not unexpected, since the symptoms of infection are less subjective than those of breathlessness and the knowledge of vaccination can be rote learned.

The findings of this study suggest that community nurses help people with COPD to self-manage their breathlessness by providing strategies to support them in their home. The nurses implemented an array of non-pharmacological strategies to ease breathlessness and support the relief of exacerbating symptoms. The strategies included: improving function through physical activity; energy conservation; breathing exercises; and body positioning. Many of these are taught by multi-disciplinary teams in pulmonary rehabilitation programmes (Bolton et al, 2013; Spruit et al, 2013; Lung Foundation Australia, 2020).

Community nurses provided support through written COPD action plans, liaising with medical and allied health teams as suggested in the COPD-X Plan: Australian and New Zealand Guidelines for the management of COPD, and the GOLD report (GOLD, 2020; Lung Foundation Australia, 2020). While written COPD management plans are known to reduce hospital presentations secondary to respiratory distress, there is more to understand about the support provided by community nurses. An appreciation of this may further improve outcomes for those who self-manage in their home (Zwerink et al, 2014; Howcroft et al, 2016; Blackstock et al, 2018).

There is limited evidence about nurses' or other health professionals' use of individualised non-pharmacological strategies in their clinical practice (Spathis et al, 2017). However, this study did highlight that respondents reported informing people with COPD, about non-pharmacological strategies to relieve breathlessness and making referrals to allied health clinicians, and specialist respiratory services.

People with COPD often rely on their medications to manage breathlessness (GOLD, 2020) and are encouraged to self-manage exacerbations of breathlessness, which includes using correct inhaler technique, taking respiratory medications as prescribed and recognising symptoms that require rescue medications (GOLD, 2020; Lung Foundation Australia, 2020). Evidence from the current study indicates that community nurses provided symptom recognition education to improve appropriate medication use.

Community nurses provide medication support; they assess administration abilities, educate people about medications, introduce supportive tools, identify

Торіс	a	b	C	d	e	Total mean		
Epidemiology	45 (76)	19 (32)	53 (90)	41 (70)	25 (43)	36.6		
Aetiology	26 (44)	53 (90)	44 (75)	43 (73)	49 (83)	43.0		
Symptoms	35 (59)	51 (86)	43 (73)	52 (88)	46 (78)	45.4		
Breathlessness	46 (78)	22 (37)	45 (76)	22 (37)	41 (70)	35.2		
Phlegm	27 (46)	29 (49)	25 (42)	56 (95)	52 (88)	37.8		
Infections	52 (88)	49 (83)	43 (73)	54 (92)	43 (73)	48.2		
Exercise	31 (52)	57 (97)	36 (61)	34 (58)	44 (75)	40.4		
Smoking	36 (61)	43 (73)	58 (98)	17 (29)	53 (90)	41.4		
Vaccination	57 (97)	58 (98)	59 (100)	54 (92)	25 (42)	50.6		
Inhaled bronchodilators	42 (71)	45 (76)	50 (85)	48 (81)	30 (51)	43.0		
Antibiotics	45 (76)	44 (75)	59 (100)	47 (80)	39 (66)	46.8		
Oral steroids	55 (93)	56 (95)	45 (76)	8 (14)	43 (73)	41.4		
Inhaled steroids	55 (93)	35 (59)	41 (69)	53 (90)	13 (22)	39.4		

## Table 2. Bristol COPD Knowledge Questionnaire correct responses (n=59)

Note: a, b, c, d, e: mean correct score for each item in the category, n (%) Total mean: total mean scores per category

problems with medication and liaise with prescribers (Griffiths et al, 2004). Future studies should explore patient safety risk factors and the community nurse's role in supporting people with COPD, in the use of oral morphine in their own homes.

Barriers that clinicians face in developing, understanding and applying their knowledge of breathlessness include: access to appropriate breathlessness education; paucity of breathlessness relief resources; and inadequate processes to support strategies to relieve breathlessness (Johnston et al, 2020). To date, there is little research that identifies what clinicians need to know about breathlessness to help people self-manage COPD. However, evidence is emerging that education, which focuses on the rationale for individualised support for chronic breathlessness, has improved health professionals' confidence and attitudes when making treatment decisions (Johnston et al, 2020). Future co-designed research including people with COPD and breathlessness could better support self-management of this condition.

#### Limitations

There was the possibility of sample bias, as not all nurses were at work at the time the survey was distributed. The majority of respondents worked fulltime; part-time or casual nurses may have had different views. Secondly, the breathlessness strategies reported by respondents may not reflect what they did in practice, as there was no direct observation of clinical practice. Lastly, the roles

### Key points

- Community nurses' knowledge of chronic obstructive pulmonary disease (COPD) was good although deficient for breathlessness
- Community nurses reported using non-pharmacological strategies to relieve breathlessness and described nursing skills they used to monitor breathlessness in people with COPD
- The findings suggest that community nurses play a key role in managing health care for people with COPD
- Further research is required to explore the detail of the individualised support community nurses provide in order to improve outcomes

## **CPD reflective questions**

- Complete the Bristol COPD Knowledge Questionnaire and identify knowledge strengths and weaknesses
- Reflect on the last encounter you had with a person living with COPD and how you assessed the level of distress related to breathlessness
- Reflect on your practice of supporting people with breathlessness and the advice you give them about managing breathlessness. Specifically consider the evidence base of your advice and where you might find current evidence to treat this symptom

of community nurses are complex and while they have a diverse range of healthcare skills, it was possible that they did not report the full complement of breathlessness strategies used at all stages of the COPD health trajectory.

#### Conclusions

This study identified that for this group of community nurses, knowledge of COPD was similar to other groups of nurses evaluated in earlier studies. This study identified that community nurses use a range of pharmacological and non-pharmacological strategies to ease breathlessness, with a focus on promoting the principles of self-management. Current evidence-based practice indicates that clinicians should focus on treatments and supportive breathlessness strategies that are tailored to individual needs. **BJCN** 

Accepted for publication: February 2023

**Acknowledgments:** The authors wish to acknowledge the time and contribution of the study participants and thank them sincerely for their contribution.

#### Declaration of interest: None

**Ethical approval:** Northern Sydney Local Health District Human Research Ethics Committee Registration number: HREC:LNR/17/Hawke/395 Canadian Thoracic Society/British Thoracic Society Workshop Report. Ann Am Thorac Soc. 2018;15(7):769-784. https://doi.org/10.1513/ annalsats.201804-253ws

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