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Disability and long-term breathlessness: a cross-sectional, population study

Slavica Kochovska ,[1] Diana Ferreira,[2,3] Sungwon Chang,[4] Vanessa Brunelli,[2] Deidre Morgan,[5] Thomas Similowski,[6] Miriam Johnson,[7] Magnus Ekström ,[8] David Currow [2]

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SK and DF contributed equally.

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For numbered affiliations see end of article.

Correspondence to
Dr Slavica Kochovska; slavica.kochovska@uow.edu.au

ABSTRACT

Introduction Disability, resulting from altered interactions between individuals and their environment, is a worldwide issue causing inequities and suffering. Many diseases associated with breathlessness cause disability but the relationship between disability and the severity of breathlessness itself is unknown.

This study evaluated associations between disability using the WHO's Disability Assessment Schedule (WHODAS) 2.0 and levels of long-term *breathlessness limiting exertion*.

Methods This population-based, cross-sectional online survey (n=10 033) reflected the most recent national census (2016) by age, sex, state/territory of residence and rurality. Assessments included self-reported disability (WHODAS 2.0 12-item (range 12 (no disability) to 60 (most severe disability)) assessed in 6 domains) and long-term *breathlessness limiting exertion* (modified Medical Research Council (mMRC) breathlessness scale; 0–4 (4—most severe)). Days in the last month affected by breathlessness were reported.

Results Of respondents (52% women; mean age 45), mean total disability score was 20.9 (SD 9.5). 42% (n=4245) had mMRC >0 (mMRC1 31% (n=3139); mMRC2 8% (n=806); mMRC3,4 3% (n=300)). Every level of long-term *breathlessness limiting exertion* was associated with greater levels of disability (total p <0.001; each domain p <0.001). The most compromised domains were *Mobility* and *Participation*.

In the last 30 days, people with severe breathlessness (mMRC 3–4): experienced disability (20 days); reduced activities/work (10 days); and completely forwent activities (another 5 days).

Conclusions Disability should be in the definition of persistent breathlessness as it is systematically associated with long-term *breathlessness limiting exertion* in a grade-dependent, multidimensional manner. Disability should be assessed in people with long-term breathlessness to optimise their social well-being and health.

KEY MESSAGES

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ More severe chronic breathlessness is known to affect most parts of a person's life: quality of life; social relationships; physical activity, workforce participation and sexual activity.

WHAT THIS STUDY ADDS

⇒ This study demonstrates a strong association between disability and long-term breathlessness at a population level, independently of health service contact.

⇒ Specifically, these data demonstrate that any level of long-term breathlessness increases the likelihood of disability, with more severe long-term breathlessness being associated with greater levels of disability.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ For policy, this study supports the inclusion of 'disability' in the WHO International Classification of Disease definition that underpins 'chronic breathlessness'.

⇒ For clinical practice, this study reinforces the need for clinicians to ask about the day-to-day impacts of chronic breathlessness on every part of the person's life.

INTRODUCTION

Disability is defined by the WHO as a multidimensional concept relating to decreasing function relative to a person's physical, individual and societal well-being[1 2] Disability is encapsulated as physical or mental impairment that substantially limits one or more of life's major activities.[3] Disabilities are prevalent and contribute to impaired well-being and health.

Long-term breathlessness is one of the most prevalent symptoms in people with chronic conditions such as respiratory, cardiovascular and neurodegenerative diseases, or cancer.[4] Approximately 10% of the population in high-income countries live with this debilitating symptom daily often for years or decades,[5] with prevalence increasing with age and burden of illness.[4–6] Long-term breathlessness significantly impacts the physical, social, emotional and sexual well-being of people who experience it,[7–9] including many everyday activities[10 11] which people may progressively forego when *breathlessness limiting exertion* becomes more severe. It also

impairs the physical and mental domains of quality of life.[12] When severe, breathlessness is perceived as a life and death, existential struggle generating immense, ongoing fear especially when each breath takes conscious effort.

Although 'shortness of breath or breathing difficulties that restrict everyday activities' is acknowledged in some documents as a 'disability' for employment purposes,[13] knowledge is limited about any relationship between disability and long-term *breathlessness limiting exertion* at a population level, although a body of literature suggests an association between disability and the conditions which are frequent causes of such breathlessness.[14–16] Disability arising from long-term breathlessness may be largely unrecognised by clinicians[17–19]; this may lead to suboptimal contact with health services resulting in under-reporting or undertreatment leaving people with potentially unmet needs.[20] Identifying disability related to long-term breathlessness is important as it can help to characterise further the spectrum of impacts the symptom has on people's lives, and provide impetus for clinicians to recognise better and respond more fulsomely to people with breathlessness in clinical practice. Identifying disability could also help to inform developing better management strategies and help people with long-term breathlessness to focus on issues to minimise disability.

The aim of this study was to evaluate any associations between the presence and level of disability in total and by each domain measured by the WHO Disability Assessment Schedule (WHODAS) 2.0 instrument and the intensity of long-term *breathlessness limiting exertion*.

METHODS

Study design

This was a cross-sectional, population-based online survey collecting data using the Qualtrics market research platform (Qualtrics, Provo, Utah). The online survey was distributed to adults (18 years or older) representative of the Australian population according to the most recent (2016) national census by age, sex, state/territory of residence and rurality.[21] Recruitment was stratified by quotas corresponding to these four key demographic parameters and remained open until the quota for each demographic 'cell' was filled.

Potential respondents were invited from the market research company's (Qualtrics) double opt-in database with over 800 000 registered, consenting members. Email invitations containing a unique survey link were sent to random members across multiple panels to create a blended sample, thus decreasing the selection bias. With approval from ethics, the email invitation only referred to 'health/well-being' rather than 'breathlessness' to decrease observational bias and bias through self-selection. All adults who consented to the survey were eligible to participate. The first 10 000 completions of respondents whose characteristics matched the demographics for each created cell (5 year age groups, sex, state/territory of residence, rurality) created the dataset for this study.

Respondents provided informed consent at three time points: upon initially joining the Qualtrics panel, before joining the survey and by continuing to respond to the survey. A participant information sheet with study details was made available before survey participation. Qualtrics follows national and international best practice research conduct for survey marketing companies.[22]

The survey was piloted with members of the University of Technology Sydney Improving Palliative, Aged and Chronic Care through Clinical Research and Translation Consumer Advisory Committee. This resulted in minor changes to wording and design to improve readability and comprehension. The survey was piloted with 110 participants from the market research company (21 June–29 June 2021) to establish face validity. No changes were made prior to fielding the survey (12 July–2 August 2021). (The entire survey was conducted during the COVID-19 pandemic, with lockdown restrictions in place in all Australian states and territories at the time.) This study is reported using the Strengthening of Reporting in Observational Studies in Epidemiology (STROBE) guidelines.[23]

Setting

Australia is a high-income country with a population of 28 million people. Approximately 90% of the population uses the Internet.[24] Universal health insurance is a foundation of the health system.

Assessments

Basic demographic data collected included: age, sex, state/territory of residence, rurality (calculated from postcodes using the Accessibility and Remoteness Index of Australia),[25] smoking history (current, former, never smoker), height and weight. Body mass index (BMI) was calculated from self-reported weight (kg)/height $(m)^2$ and categorised into four WHO levels: underweight (BMI <18.5), normal weight (BMI 18.5–25.0), overweight (BMI >25–30) and obese/morbidly obese (BMI >30).[26]

Disability

The WHODAS 2.0 is a generic health and disability assessment tool[27] which is designed to encapsulate the International Classification of Function, Disability and Health concepts of disability, standardised for health and disability across adult populations and cultures. Disability was self-reported using the WHODAS 2.0 12-item assessment tool (henceforth WHODAS-12). The tool assesses six domains each containing two questions: (1) *Cognition*—understanding, communicating; (2) *Mobility*—moving, getting around; (3) *Self-care*—hygiene, dressing, eating, staying alone; (4) *Getting along*—interacting with other people; (5) *Life activities*—domestic responsibilities, leisure, work, school; and (6) *Participation*—joining in community activities.

Each item was rated by participants as 'none' (one point), 'mild' (two points), 'moderate' (three points), 'severe' (four points) or 'extreme or cannot do' (five points). Scores for individual domains were calculated by adding the scores of the relevant two items, with individual domain scores ranging from 2 (no disability) to 10 (complete disability). A global disability score was calculated, ranging from 12 (no disability) to 60 (complete disability).[1]

Breathlessness

The severity of *breathlessness limiting exertion* was self-rated using the modified Medical Research Council (mMRC) breathlessness scale,[28] a measure initially developed for population studies. The mMRC is a 5-point ordinal scale of: 0=no breathlessness except on strenuous exercise; 1=shortness of breath when hurrying on the level or walking up a slight hill; 2=walks slower than people of same age on the level because of breathlessness or has to stop to catch breath when walking at their own pace on the level; 3=stops for breath after walking 100 m or after few minutes on the level; and 4=too breathless to leave the house, or breathless when dressing or undressing. Respondents who selected an MRC score ≥1 were asked to indicate the duration of their breathlessness (in months/years) and the underlying primary condition to which they attribute their breathlessness (multiple-choice item,[29] including a free text option for any other conditions not listed). The study questionnaire is available (https://osf.io/fhxkc).

Statistical methods

Data were analysed using Excel (Microsoft Office 16) and Statistical Package for the Social Sciences software, V.28.0 (IBM Corporation; 2016). Sociodemographic characteristics were compared between breathlessness groups (mMRC 0, 1, 2 and 3–4); for continuous variables, one-way analyses of variance were used for normally distributed data and the Kruskal-Wallis tests for skewed data, and χ^2 tests were used for categorical variables. Results are presented as mean (SD) or median (IQR) for skewed data, unless otherwise stated. Associations between disability (WHODAS-12 total score and each domain score) and *breathlessness limiting exertion* (mMRC categories) were analysed using multiple linear regression, adjusting for the respondent's age, sex, BMI, duration of breathlessness and smoking status as covariates. CIs for the WHODAS-12 total score and each domain's score were calculated by bootstrapping, using sampling with replacement. One thousand bootstrap samples were created, and the 2.5th and 97.5th percentiles were used to form the CIs. Bootstrap-derived CIs provide non-parametric estimates of dispersion. No data were imputed.

RESULTS

The survey was completed by 10 033 respondents (not including the 110 pilot cohort), of whom 52% were female, 30% lived in NSW and 78% in metropolitan areas. The mean age was 45 years (SD 18.6; range 18.0–99.0). Half of the respondents (50%) reported a history of smoking and 56% reported being overweight or obese (table 1).

Total disability (WHODAS-12) scores across all participants was a mean 20.9 (SD 9.5). Overall, the most compromised domains were *Mobility* and *Participation*, followed by *Life activities* and *Getting along*. Less adversely impacted were *Cognition* and *Self-care* (table 2).

Any breathlessness (mMRC>0) was reported by 42% (n=4245) of respondents, including 31% (n=3139) with mMRC 1, 8% (n=806) with mMRC 2 and 3% (n=300) with mMRC 3–4 (table 1). Median duration of breathlessness was 3 years; 36% attributed their breathlessness to a lung condition while 29% didn't know or preferred not to disclose this information (table 1).

Disability and long-term breathlessness limiting exertion

Higher long-term breathlessness scores were associated with higher levels of disability (table 2 and figure 1), both for the total disability score ($p < 0.001$) and for each disability domain ($p < 0.001$; table 2). People with long-term breathlessness (mMRC>0) had mean disability scores above the population mean (figures 1 and 2). Scores for each domain of disability were also explored for each intensity of breathlessness. Disability scores in each of the six domains increased with intensity of breathlessness. For people with mMRC ≥2, the most compromised domain was *Mobility* (domain mean scores 5.8 and 6.9 for mMRC 2 and 3–4, respectively), followed by *Participation* (domain mean scores 5.4 and 6.0 for mMRC 2 and 3–4, respectively) and *Life activities* (domain mean scores 5.2 and 5.8 for mMRC 2 and 3–4, respectively; table 2).

People with severe *breathlessness limiting exertion* (mMRC 3–4) experienced disability for up to two-thirds of the previous month (20/30 days), reducing their usual activities or work for 10 days and completely foregoing activities for another 5 days. People with more moderate *breathlessness limiting exertion* (mMRC 2) experienced disability issues for more than one-third of the previous month (13/30 days), including reducing their activities for 5 days and completely foregoing them for an additional 3 days (table 2).

In adjusted analyses, people with breathlessness had higher disability (WHODAS-12) total in individual domain scores after adjusting for age, sex, BMI, duration of breathlessness and smoking status (table 3). Even after multivariable adjustment, all total and domain WHODAS scores were higher at each level of long-term *breathlessness limiting exertion* (all $p < 0.001$).

DISCUSSION

This is the first population-based study to explore the relationship between disability comprehensively measured using the WHODAS 2.0 and long-term *breathlessness limiting exertion*. More severe *breathlessness limiting*

Table 1 Baseline characteristics of study participants* according to the modified Medical Research Council (mMRC) breathlessness scale (n=10,033)

	mMRC rating N (%)				Total (n=10 033)
	0 (n=5788; 57.7%)	1 (n=3139; 31.3%)	2 (n=806; 8.0%)	3–4 (n=300; 3.0%)	
Age-M (SD); (min, max)	46.2 (18.3); (18.0, 99.0)	44.7 (18.8); (18.0, 93.0)	41.8 (18.6); (18.0, 92.0)	47.73 (19.83); (18, 86)	45.4 (18.6); (18.0, 99.0)
Sex					
Male	2958 (51.1)	1298 (41.4)	355 (44)	146 (48.7)	4757 (47.4)
Female	2811 (48.6)	1813 (57.8)	439 (54.5)	149 (49.7)	5212 (51.9)
Other	18 (0.3)	26 (0.8)	9 (1.1)	3 (1.0)	56 (0.6)
Prefer not to say	1 (0.0)	2 (0.1)	3 (0.4)	2 (0.7)	8 (0.1)
State					
ACT	90 (1.6)	61 (1.9)	11 (1.4)	3 (1.0)	165 (1.6)
NSW	1761 (30.4)	914 (29.1)	250 (31.0)	84 (28.0)	3009 (30.0)
QLD	1133 (19.6)	673 (21.4)	158 (19.6)	73 (24.3)	2037 (20.3)
SA	398 (6.9)	246 (7.8)	67 (8.3)	29 (9.7)	740 (7.4)
TAS	191 (3.3)	123 (3.9)	24 (3.0)	10 (3.3)	348 (3.5)
VIC	1511 (26.1)	786 (25.0)	217 (26.9)	77 (25.7)	2591 (25.8)
WA	704 (12.2)	336 (10.7)	79 (9.8)	24 (8.0)	1143 (11.4)
Living remoteness					
Major cities	4552 (78.7)	2409 (76.8)	605 (75.2)	220 (73.3)	7786 (77.7)
Inner region	865 (15.0)	538 (17.2)	145 (18.0)	64 (21.3)	1612 (16.1)
Outer regional	326 (5.6)	168 (5.4)	48 (6.0)	15 (5.0)	557 (5.6)
Remote	36 (0.6)	17 (0.5)	7 (0.9)	1 (0.3)	61 (0.6)
Very remote	5 (0.1)	5 (0.2)	0 (0.0)	0 (0.0)	10 (0.1)
Body mass index (BMI)†					
Underweight (BMI <18.5)	206 (4.2)	113 (4.3)	29 (4.8)	5 (2.3)	353 (4.2)
Normal weight (BMI 18.5–25.0)	2058 (42.1)	968 (36.6)	218 (35.8)	73 (34.1)	3317 (39.7)
Overweight (BMI >25–30)	1712 (35.0)	808 (30.6)	154 (25.3)	42 (19.6)	2716 (32.5)
Obese (BMI >30)	913 (18.7)	753 (28.5)	208 (34.2)	94 (43.9)	1968 (23.6)
Smoking status					
Current smoker	1127 (19.5)	791 (25.2)	214 (26.6)	77 (32.2)	2229 (22.2)
Former smoker	1511 (26.1)	904 (28.8)	256 (31.8)	87 (36.4)	2775 (27.7)
Never smoked	3073 (53.1)	1416 (45.1)	325 (40.3)	70 (29.3)	4906 (48.9)
Prefer not to say	77 (1.3)	28 (0.9)	11 (1.4)	5 (2.1)	123 (1.2)
Duration of breathlessness in years‡		6.6 (9.5); 3.0 (2.0, 7.0)	6.8 (9.8); 3.1 (2.0, 7.6)	6.5 (7.3); 4.8 (2.0, 8.0)	6.6 (9.4); 3.2 (2.0, 7.0)
Underlying condition of breathlessness‡					Total (n=4161)
Lungs		1074 (34.8)	284 (36.1)	125 (42.7)	1483 (35.6)
Heart		330 (10.7)	134 (17.0)	42 (14.3)	506 (12.2)
Nerves/muscles		80 (2.6)	78 (9.9)	18 (6.1)	176 (4.2)
Cancer		32 (1.0)	15 (1.9)	4 (1.4)	51 (1.2)
Other		585 (19.0)	100 (12.7)	41 (14.0)	726 (17.4)
Don't know		932 (30.2)	149 (19.0)	47 (16.0)	1128 (27.1)
Prefer not to say		49 (1.6)	26 (3.3)	16 (5.5)	91 (2.2)

*A sample representative of the 2016 Australian census (5-year age group, sex, state/territory of residence, rurality).
†Numbers may not add up to 10 003 because of missing data.
‡Questions on duration of breathlessness and underlying condition of breathlessness only apply to mMRC ≥1.

Table 2 Descriptives of WHODAS 2.0 12-item with mean (SD) and median (IQR) total and domain simple sum scores by mMRC (n=10 033)

		mMRC				
WHODAS 2.0 12-item	All participants (n=10 033)	0 (n=5788)	1 (n=3139)	2 (n=806)	3–4 (n=300)	P value*
Total score (range: 12–60)	20.9 (9.5); 17 (13–27)	17.9 (8); 14 (12–21)	22.8 (8.9); 21 (15–29)	30.4 (9); 31 (23–36.25)	33.7 (10.8); 35 (26.25–41)	<0.001
Disability domains†						
1—Cognition	3.3 (1.7); 2 (2–4)	2.9 (1.5); 2 (2–3)	3.6 (1.7); 3 (2–5)	4.7 (2); 5 (3–6)	4.9 (2.1); 5 (3–6)	<0.001
2—Mobility	3.8 (2.1); 3 (2–5)	3.1 (1.7); 2 (2–4)	4.2 (1.9); 4 (3–6)	5.8 (1.9); 6 (4–7)	6.9 (2.4); 7 (5–9)	<0.001
3—Self care	3.0 (1.7); 2 (2–3)	2.6 (1.4); 2 (2–2)	3.1 (1.7); 2 (2–4)	4.4 (2.1); 4 (2–6)	5.1 (2.3); 5 (3–7)	<0.001
4—Getting along	3.5 (1.9); 3 (2–5)	3.1 (1.7); 2 (2–4)	3.8 (2); 3 (2–5)	4.9 (2.1); 5 (3–7)	5 (2.4); 5 (2–7)	<0.001
5—Life activities	3.5 (1.9); 3 (2–5)	3 (1.6); 2 (2–4)	3.9 (1.8); 4 (2–5)	5.2 (1.8); 5 (4–6)	5.8 (2.2); 6 (4–7)	<0.001
6—Participation	3.8 (2.0); 3 (2–5)	3.2 (1.7); 2 (2–4)	4.2 (1.9); 4 (3–5)	5.4 (1.9); 5 (4–7)	6 (2.2); 6 (4–8)	<0.001
H1: Overall, in the past 30 days, how many days were these difficulties present	7.6 (10.4); 2 (0–10)	4.8 (8.6); 0 (0–5)	10.1 (11); 5 (1–20)	14.8 (11.2); 13 (4–30)	17.8 (11.9); 20 (5–30)	<0.001
H2: In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?	2.9 (6.5); 0 (0–2)	1.7 (5.1); 0 (0–0)	3.4 (6.6); 0 (0–4)	6.9 (8.7); 3 (0–10)	11 (11.2); 5 (1–20)	<0.001
H3: In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?	4.1 (7.5); 0 (0–5)	2.4 (5.8); 0 (0–2)	5.3 (8); 2 (0–6)	9.2 (9.5); 5 (2–15)	12.3 (11.3); 10 (2–21)	<0.001

*ANOVA and Kruskal-Wallis test.
†Individual domain scores range from 2 (no disability) to 10 (complete disability). H1–H3 assess the effect of all encountered difficulties on a person's life.
ANOVA, analyses of variance; mMRC, modified Medical Research Council breathlessness scale; WHODAS, World Health Organisation Disability Assessment Schedule.

exertion was found to be associated significantly with increasing disability overall, and in each individual disability domain. Importantly, disability scores were above the population mean for all levels of breathlessness, including mMRC 1 ('shortness of breath when hurrying on the level or walking up a slight hill'). These findings highlight the strong relationship between disability and long-term *breathlessness limited by exertion*. Such breathlessness is not benign but affects every aspect of a person's life. Resulting disability was multidimensional, with the most marked effects being on *Mobility* and *Participation*.

Mobility was the most compromised domain for both moderate and severe breathlessness. Mobility disability

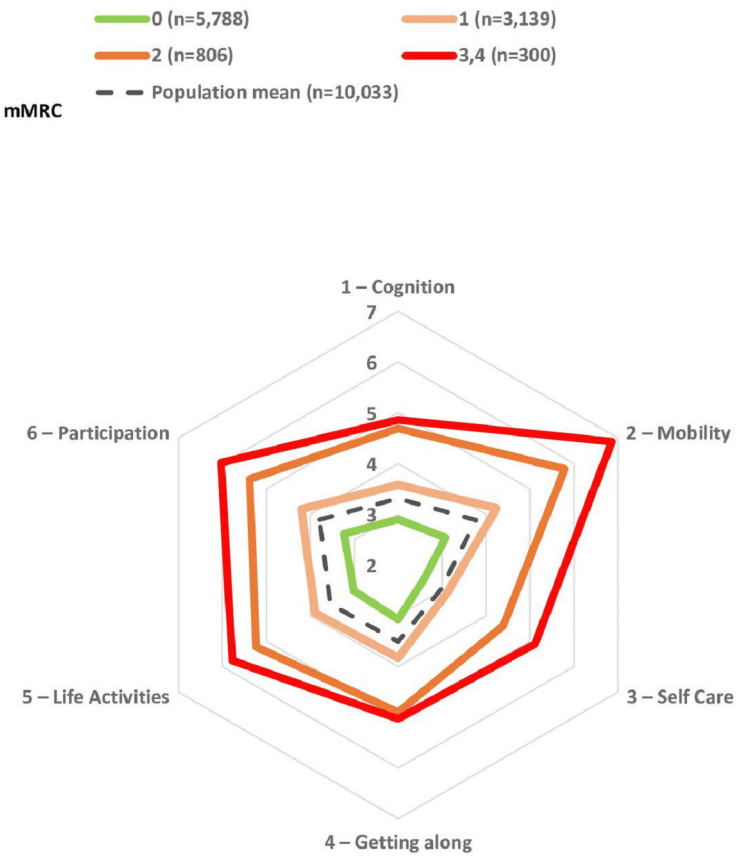

Figure 1 Mean domain-level disability scores (World Health Organisation Disability Assessment Schedule (WHODAS) 2.0 12-item) by severity of long-term *breathless limiting exertion* (modified Medical Research Council (mMRC) breathless scale) in a demographically representative Australian population (n=10 033).

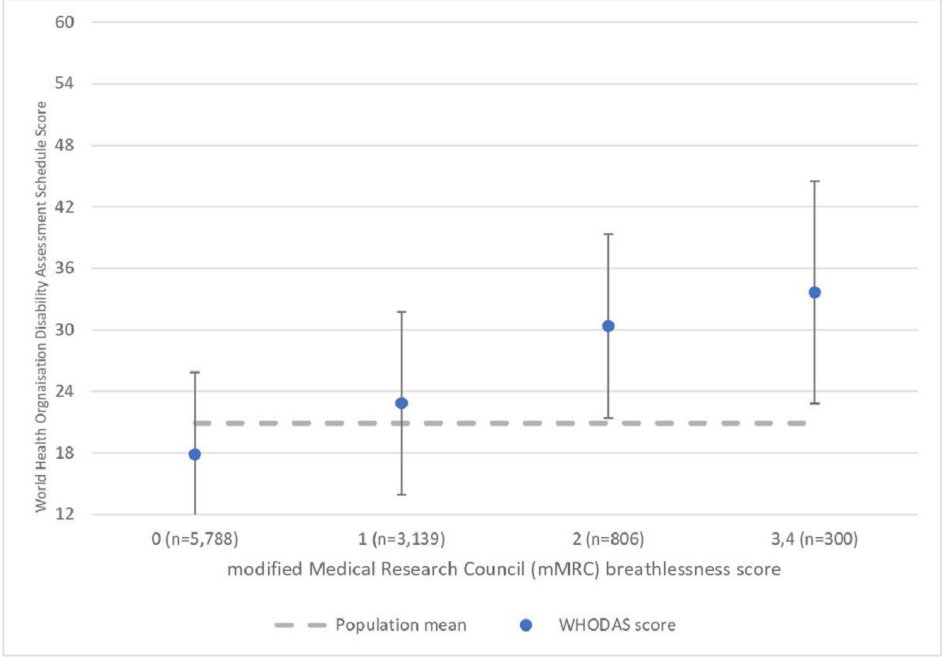

Figure 2 Disability as a function of the severity of long-term *breathlessness limiting exertion* in a demographically representative sample of the Australian population (n=10 033). Disability assessed using the World Health Organisation Disability Assessment Schedule (WHODAS) 2.0 12-item scale and long-term breathlessness using the modified Medical Research Council (mMRC) breathlessness scale.

Table 3 Adjusted marginal mean of WHODAS 2.0 12-item total and domain scores by mMRC

	Breathlessness group (mMRC) Adjusted marginal mean* (95% CI)			
Disability (WHODAS 2.0 12-item)	**mMRC 0**	**mMRC 1**	**mMRC 2**	**mMRC 3-4**
Total score	18.6 (18.3 to 18.9)	23.1 (22.7 to 23.4)	30.3 (29.5 to 31.0)	34.4 (33.1 to 35.8)
Domain 1—Cognition	3.0 (2.9 to 3.1)	3.6 (3.5 to 3.7)	4.7 (4.6 to 4.9)	5.0 (4.8 to 5.3)
Domain 2—Mobility	3.2 (3.2 to 3.3)	4.3 (4.2 to 4.4)	5.9 (5.7 to 6.0)	7.0 (6.8 to 7.3)
Domain 3—Self-care	2.7 (2.6 to 2.7)	3.2 (3.1 to 3.2)	4.4 (4.2 to 4.6)	5.2 (4.9 to 5.5)
Domain 4—Getting along	3.2 (3.1 to 3.3)	3.9 (3.8 to 3.9)	4.8 to (4.7 to 5.0)	5.2 (4.9 to 5.5)
Domain 5—Life activities	3.1 (3.1 to 3.2)	3.9 (3.8 to 4.0)	5.2 (5.1 to 5.4)	5.9 (5.6 to 6.2)
Domain 6—Participation	3.3 (3.3 to 3.4)	4.2 (4.1 to 4.3)	5.3 (5.2 to 5.5)	6.1 (5.8 to 6.4)

*Adjusted for age, sex, body mass index (BMI), total duration of breathlessness and smoking status.
mMRC, modified Medical Research Council breathlessness scale; WHODAS, World Health Organisation Disability Assessment Schedule.

is recognised as a major influence on health-related quality of life and is a significant barrier to social participation.[30–33] Mobility limitations also impact people's domestic and professional lives[30–32 34–36] and increase caregiver burden.[37] *Every* level of long-term *breathlessness limiting exertion* triggers mobility disability. Given that higher levels of reduced mobility are associated with poorer health outcomes[31] more markedly impacting older adults,[30] interventions to manage breathlessness that enhance or better maintain mobility such as pulmonary rehabilitation must be standard of care in this population, including earlier referral to such services. It is notable that the people with the most severe breathlessness are often not referred to pulmonary rehabilitation.[38] Other approaches, such as arts-related activities for improving health and well-being, may also be beneficial in alleviating aspects of disability associated with long-term *breathlessness limiting exertion*.[39]

Long-term *breathlessness limiting exertion* was also shown to be associated with disability in the domains of *Participation* and *Life activities*. These domains rely largely on a person's physical performance without which social life,[33] and household and work activities are likely to be compromised. These findings align with evidence that breathlessness has far-reaching consequences in people's day-to-day, domestic and professional lives.[7 10 11] The combined effects of these impacts mean that people with long-term *breathlessness limiting exertion* experience ever-shrinking social and physical worlds because of their reduced capacity to engage fully in everyday activities beyond their immediate environment. An altered sense of self can eventuate,[40] including a sense of stigma.[41–43]

People with severe long-term *breathlessness limiting exertion* reported a diminished ability to provide basic self-care compared with those rating their *breathlessness* as more moderate. This is consistent with recent findings that demonstrate that people living with breathlessness are able to maintain self-care until late in the course of the symptom's trajectory.[8] People will make every effort to provide for their own needs for as long as they can before seeking support.[19]

Why explore any relationship between disability and long-term breathlessness?

Disability due to breathlessness is typically overlooked by health professionals, most often because people avoid or reduce exertion that induces breathlessness by modifying, reducing or ceasing everyday activities that induce breathlessness.[19] This precipitates a spiral of physical deconditioning which, in turn, results in more intense breathlessness.[44] The modified lifestyle of people with long-term breathlessness means that the symptom and its impact are often missed in routine clinical consultations, with both patients and clinicians avoiding such discussions.[17 18 45] A recent population study showed that unless patients raise the topic of long-term breathlessness, clinicians were unlikely to do so.[18]

Economic implications need to be considered. More intense breathlessness is associated with lower workforce participation (including loss of income) in people of working age.[7] In people with advanced chronic conditions, disability that results from long-term breathlessness has been shown to be significantly associated with higher costs in informal and formal care (including hospital admissions), as well as direct healthcare costs.[46]

The rates of breathlessness (mMRC ≥2) reported in this study (11.0%) were comparable to those reported in an Australian online survey (9.5%; sample size n=10 072).[5]

Implications for clinical practice

Comparison with normative data would suggest that all levels of breathlessness (including mMRC 1) in our study fall within the range of clinically significant disability.[47]

The invisibility of breathlessness[48] contributes to the symptom being undertreated despite the availability of a range of evidence-based non-pharmacological

and pharmacological therapies.[49 50] Given the multidimensional nature and extent of disability experienced, improving the recognition of long-term breathlessness (including its presence and, if present, its severity and impact) in routine consultations and optimising its assessment and management are critical first steps.

Implications for research

This study paves the way to see which interventions for long-term breathlessness can most reduce disability. Prospective studies need to be conducted that consider whether early intervention in people with moderate long-term breathlessness can avoid disability worsening. The findings also suggest that evaluation of WHODAS 2.0 as an outcome for studies of pulmonary rehabilitation would have face validity.

Implications for policy

The first international consensus definition for 'chronic breathlessness'[51] included the word 'disability'. During deliberations for a change to the WHO International Classification of Disease 11th Edition to incorporate the newly defined entity, questions were asked as to whether long-term breathlessness is associated with disability.[52] This study's findings that any level of *breathlessness limiting exertion* is associated with disability support including 'disability' as part of the definition of chronic breathlessness.[52]

Strengths and limitations

The study surveyed a large, demographically representative sample of the Australian population. Recruitment was independent of health services contact and stratified by key demographic variables to ensure adequate representation of people living in the community. Although the survey's online delivery may have limited participation to those with internet capabilities, it may also have enabled participation of people with limited mobility or those reluctant to engage with the healthcare system. (An increasing number of public health issues have been addressed using web-based approaches over recent years.[53]) The survey was conducted under COVID-19, which might have potentially influenced self-reported prevalence rates of breathlessness; however, free text responses for the self-reported underlying condition for breathlessness did not indicate COVID-19 as the primary cause for any of the respondents. The cross-sectional design of the survey only allows for investigation of potential association between breathlessness and disability and precludes delineation of any causal effect.

Breathlessness was assessed using the mMRC breathlessness scale but, given the findings, the use of a multidimensional breathlessness measure that captures the affective domains of the symptom could be justified in subsequent studies.[54 55]

CONCLUSIONS

Long-term *breathlessness limiting exertion* is associated with disability in every domain measured. The resulting disability is multidimensional and reshapes physical and social engagement at home and in the community. Given that *any* level of breathlessness appears to be associated with increased levels of disability, the presence of breathlessness should be specifically sought in clinical encounters with individuals who are likely to experience it.

Author affiliations
[1]Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, New South Wales, Australia
[2]University of Wollongong, Wollongong, New South Wales, Australia
[3]Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, NSW, Australia
[4]University of Technology Sydney, Sydney, New South Wales, Australia
[5]Flinders University, Adelaide, South Australia, Australia
[6]service de pneumologie département R3S, Hopital Pitie-Salpetriere, Paris, Île-de-France, France
[7]Hull York Medical School, The University of Hull, Hull, UK
[8]Faculty of Medicine, Department of Clinical Sciences Lund, Respiratory Medicine and Allergology, Lund, Sweden

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ORCID iDs
Slavica Kochovska http://orcid.org/0000-0002-3531-0389
Magnus Ekström http://orcid.org/0000-0002-7227-5113
David Currow http://orcid.org/0000-0003-1988-1250

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