

Supplementary Item 1 - Search Strategy

The search strategy was derived from a Cochrane review protocol on the topic of interest (Howell et al., 2012) and included terms as follows:

Medline

1. Exp Dyspnea/ or Dyspn*.mp
2. breathless*.mp
3. (breath*adj5 (difficult* or labor* or labour* or discomfort or uncomfortabl* or distress*)).mp
- 4.(short*adj5 breath*).mp
5. 1 or 2 or 3 or 4
6. exp Self Care/
7. (self-manag* or selfmanag* or self-car* or selfcar* or self-monitor* or selfmonitor* or self-administrat* or selfadministrat* or self-medicat* or selfmedicat*).mp
8. exp Patient Education as Topic/
9. Pulmonary rehabilitation*.mp
10. 6 or 7 or 8 or 9
11. 5 and 10
- 12 exp Pediatrics/
- 13 exp Child/
14. 12 or 13
15. 11 not 14
16. limit 15 to (English language and humans)

CINAHL

- S1 (MH "Dyspnea+") OR "Dyspn*"
- S2 (MH "Self Care+") OR "Self Care"
- S3 (MH "Symptom Distress")
- S4 (MH "Self Administration+")
- S5 (MH "Patient Education+")
- S6 (MH "Rehabilitation, Pulmonary+")
- S7 S2 OR S3 OR S4 OR S5 OR S6
- S8 S1 and S7
- S9 S8 Not Child Not Pediatric Limiters – Publication date19610101-20180331; English language

Supplementary Item 2 - Outcomes of Interest

Instrument	Description	Reference
Adapted BORG Scale	Measures subjective breathlessness during physical activity.	1
Inhalation Technique	An ad hoc assessment using videotape scored by trained observers using a device-specific inhalation checklist.	2
Self-Efficacy Scale	Measured perceived Self-efficacy which reflects patient's ability to manage condition.	3
Chronic Respiratory Questionnaire Self-Administered-Survey (CRQ-SAS)	assesses health-related quality of life in respiratory conditions.	4
Clinical COPD Questionnaire (CCQ)	Consists of 10 items (each scored between 0 & 6), divided into three domains (symptom, functional, mental).	5
COPD Self-Management Interview (COPD-SMI)	Descriptions read to subjects based on three stages of an exacerbation (feeling well, early exacerbation & severe exacerbation). In each scenario, three self-management domains are assessed: medication use, healthcare seeking decisions and self-care.	6
Diary for respiratory symptoms	Patients rated their respiratory status on a four-point scale, using the categories: usual, mild, moderate or severe. The diary card recorded: prednisone & antibiotic use; contact with doctors, nurses, specialist, pharmacist & other comments.	7
Exacerbation	An ad hoc questionnaire designed to collect patient's exacerbation event as judged by medical officer to require a prescription for oral steroids.	8
Hospital Anxiety and Depression Scale (HADS)	Measures anxiety & depression in the medical setting	9
Medical Research Council Scale (MRC) Dyspnoea Scale	Assesses breathlessness severity with regard to the level of disability caused.	10
Number of Stops	An ad hoc measure that counts the number of stops required by patients to avoid breathlessness during physical activity.	11
Numeric Rating Scale (NRS)	used to measures patient-reported intensity of the worst & average breathlessness over the past 24 hours ('breathlessness severity'), 'distress' & 'coping' with breathlessness.	1, 12
Self-administered Knowledge Questionnaire	An ad hoc questionnaire designed by the study team with 18 items formulated by respiratory physicians & nurses	2
Self-management Questionnaire	Uses two rapid onset & two slow onset scenarios of exacerbations adapted from a validated qualitative questionnaire	13
St George Respiratory Questionnaire (SGRQ)	A disease-specific quality of life, measuring- 'Symptom' (distress due to respiratory symptoms), 'Activity' (effect on mobility & physical activity), & 'Impact' (assesses impact of disease).	14
Visual Numeric Scales (VNS)	adapted from the Visual Analogue Scale (VAS), was used to measure 7 HRQoL health indicators.	15

Supplementary item 2 describes the breathlessness-related outcomes utilised in the systematic review and narrative synthesis entitled “*Low-intensity educational interventions supporting self-management to improve outcomes related to chronic breathlessness a systematic review*”. Whilst some outcomes are not directly measuring breathlessness, they do have breathlessness-related dimensions as identified in our introduction – i.e. sensory-perceptive, affective or impact. These domains are featured in HRQoL measures such as the St George Respiratory Questionnaire (SGRQ). Some other symptoms – most notably anxiety, fatigue, insomnia and pain – commonly present with breathlessness as a cluster. Indeed, while the HADS ostensibly measures anxiety and depression in a generalised way, measurement of these constructs in people with chronic breathlessness is likely to at least in part be assessing the affective dimension of breathlessness.

References:

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