Dyspnoea-12: a translation and linguistic validation study in a Swedish setting

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ABSTRACT
Background Dyspnoea consists of multiple dimensions including the intensity, unpleasantness, sensory qualities and emotional responses which may differ between patient groups, settings and in relation to treatment. The Dyspnoea-12 is a validated and convenient instrument for multidimensional measurement in English. We aimed to take forward a Swedish version of the Dyspnoea-12.

Methods The linguistic validation of the Dyspnoea-12 was performed (Mapi Language Services, Lyon, France). The standardised procedure involved forward and backward translations by three independent certified translators and revisions after feedback from an in-country linguistic consultant, the developer and three native physicians. The understanding and convenience of the translated version was evaluated using qualitative in-depth interviews with five patients with dyspnoea.

Results A Swedish version of the Dyspnoea-12 was elaborated and evaluated carefully according to international guidelines. The Swedish version, ‘Dyspné−12’, has the same layout as the original version, including 12 items distributed on seven physical and five affective items. The Dyspnoea-12 is copyrighted by the developer but can be used free of charge after permission for not industry-funded research.

Conclusion A Swedish version of the Dyspnoea-12 is now available for clinical validation and multidimensional measurement across diseases and settings with the aim of improved evaluation and management of dyspnoea.

INTRODUCTION
Reduction of symptoms is a major treatment goal in chronic cardiac and respiratory diseases. Dyspnoea is the cardinal symptom in cardiopulmonary diseases, including heart failure, chronic obstructive pulmonary disease (COPD) and interstitial lung diseases such as idiopathic pulmonary fibrosis (IPF). Dyspnoea is strongly associated with impaired health-related quality of life in COPD and IPF and with increased mortality in COPD, IPF and heart failure. Despite this fact, clinical practice often focuses on underlying diseases and not on the management of the often chronic symptom of dyspnoea itself.

Strengths and limitations of this study
► The linguistic validation of the Dyspnoea-12 to Swedish was performed using a structured multistage process in accordance with international guidelines, involving translations by two independent certified translators, a backward translation for quality check and review by clinicians and test on patients with dyspnoea before establishing the final Swedish version.
► A Swedish version of the Dyspnoea-12 will enable to conduct clinical validation studies across patient populations and settings, and will bring a new possibility to deepen the understanding of breathlessness and to value the impact of different dimensions of breathlessness.
► The translated version of the Dyspnoea-12 still needs to be psychometrically validated in a clinical Swedish population.

Multiple dimensions of dyspnoea
Traditionally, dyspnoea has been assessed as an indirect measure of functional limitation due to breathlessness, as with the Medical Research Council (MRC) scale, or using a single rating scale such as a visual analogue scale (VAS) or Borg scale during exercise tests. However, growing attention has been paid to the fact that dyspnoea consists of multiple important dimensions besides the overall intensity or unpleasantness, such as sensory and affective qualities, associated emotional responses and the functional impact on the person’s life. This makes it difficult to compare findings between patient populations and between differences in responses of separate treatments of dyspnoea. Thus, standardised measurements with different dimensions of dyspnoea are needed.

Dyspnoea-12
The Dyspnoea-12 instrument was developed to be a concise instrument for quantification of different aspects of dyspnoea, valid across different cardiorespiratory diseases.
In the original study establishing the final version of the Dyspnoea-12, the instrument was associated with the MRC scale in COPD, IPF and heart failure. The subsequent validation study showed a good internal reliability and test–retest reliability, and the Dyspnoea-12 was significantly correlated to the Hospital Anxiety and Depression Scale, the MRC scale, the forced expiratory volume in 1 s and the 6 min walking distance test. After the initial validation, further studies have validated the use of the Dyspnoea-12 in interstitial lung disease and COPD, but also in asthma, pulmonary arterial hypertension, bronchiectasis and tuberculosis destroyed lungs.

The Dyspnoea-12 is available in English, Arabic and Korean, but has to our knowledge not been translated into any other European language except English. A multidimensional instrument for assessment of dyspnoea in cancer, the Cancer Dyspnoea Scale, has been developed and validated in Swedish, and recently the Multidimensional Dyspnoea Profile has been linguistically validated in Swedish. However, a brief and convenient multidimensional instrument that allows comparison across diseases would be of additional value. Until now, there has been no multidimensional instrument for measurement of dyspnoea available in Swedish. A Swedish version of Dyspnoea-12 should be of great importance for further research in the field of breathlessness, especially to be able to make comparisons across populations. We therefore aimed to develop a linguistically validated Swedish version of the Dyspnoea-12.

**METHODS**

**The Dyspnoea-12 instrument**

The Dyspnoea-12 instrument includes 12 descriptors assessed on a 4-point scale such as none (score 0), mild (score 1), moderate (score 2), or severe (score 3), resulting in a total score from 0 to 36 where a higher score corresponds to more severe breathlessness. The first seven items constitute a physical domain assessing whether the breath does not go in all the way, the patient cannot get enough air, feels short of breath or has difficulty catching breath, and the breathing requires more work, is uncomfortable or exhausting. The remaining five items constitute an emotional domain where the items describe whether the breathing is distressing, irritating or makes the patient feel depressed, miserable or agitated. A physical and an emotional component score can be calculated, with maximum score of 21 and 15, respectively. A minimal important clinical difference of three units has been recommended.

**Linguistic validation**

The linguistic validation of the Dyspnoea-12 into Swedish was performed in a structured multistage process in accordance with international guidelines, in collaboration with a company specialised in translation and validation of patient-reported outcome measures (Mapi Language Services, Lyon, France; hereafter referred to as ‘Mapi’). Permission to translate the Dyspnoea-12 into Swedish was obtained from the developer. The role of Mapi was to supply translators and to perform quality checks in collaboration with the developer. The whole process is summarised in figure 1.

**Translation**

Two independent certified translators, native speakers of Swedish and living in Sweden, translated the original instrument developed in British English into Swedish. These two forward translations were analysed and reconciled by an in-country consultant into a first translated version. After a quality check from Mapi, the first Swedish version was translated back into English and compared with the original British version by the developer and by the in-country consultant, to establish a second translated Swedish version.

**Clinicians’ review**

The second translated version was reviewed by three native Swedish-speaking specialists in internal and/or respiratory medicine, including the authors of this paper, to provide detailed feedback on the wordings from a clinical perspective. The feedback from the clinicians was considered by Mapi again with input from the in-country consultant and the developer, resulting in a third translated Swedish version.

**Patients’ interviews**

The third translated version was evaluated using a validated method of individual in-depth interviews with five Swedish patients with dyspnoea, recruited by Mapi and the in-country consultant, to investigate if the instrument was easy to understand, assimilate and accept. The patients were selected by convenience. No patients denied participating. Data saturation was not discussed, as the number of patients were decided according to Mapi’s guidelines on linguistic validation. Two of the patients were males and three females, and their main conditions were asthma, heat failure or anxiety disorder. The patients were interviewed face-to-face by the local consultant, and the interviews took place at the consultant’s office during 7–10 August 2015. The consultant was female, her occupation was physiotherapist and she had 20 years of experience of patient interviews. The consultant had no personal relationship to the patients and no bias to report to the patients before the interviews. No one else except the consultant and the patient were present during the interviews. The patients were asked to complete the questionnaire and subsequently make general comments and answer two specific questions for each item. They were told that the intention was to assess whether the questionnaire was comprehensible and acceptable for them, but not to evaluate their answers to the items. The first question was “What does the instructions/question/response choice mean for you?”, and encouraged the respondents to reword the item using other words that those
used or to give examples. The second question was “Did you have difficulty understanding the instructions/question/response choice?” and also included follow-up questions if there were words that were difficult to understand and suggested changes of the wording. The patients were encouraged to speak and to express their feelings about the questions without being interrupted. The consultant was attentive to any non-verbal or verbal signs betraying the way the respondents felt. The interviews took approximately 1 hour each, and were transcribed verbatim. Notes were made by hand in Swedish and translated to English after the interviews. No audio recording was used. The transcripts of the interviews were not returned to the patients and the interviews were not repeated. The feedback from the patients on their understanding and suggested alternative formulations for each item was used for revision and establishment of the final linguistically validated translation. As the purpose of the interviews was only to test the understanding of the Swedish version of Dyspnoea-12, the results of the interviews were not coded or presented in themes or using quotations. The questions used in the interviews were pilot tested in the original English version.

**Ethics**

The study was approved by the regional ethics committee at Lund University (DNr: 2016/16). Written informed consent for the translation process and clinicians’ review was not required as no personal data on participants were collected. Oral consent was received from the five patients for the in-depth interviews.

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**Figure 1** Flow chart for the linguistic validation process.
**RESULTS**

The final certified, linguistically validated Swedish translation of the Dyspnoea-12 is found in figure 2. The Swedish version, ‘Dyspné−12’, has the same layout as the original version, including 12 items. The clinicians review resulted in several small linguistic adjustments, after which the instrument was conceptually equivalent to the original but uses the corresponding adequate clinical words and expressions in Swedish. The in-depth interviews with five patients did not result in any further changes. The time

![Figure 2](SwedishversionoftheDyspnoea-12.jpg)

**Figure 2** Swedish version of the Dyspnoea-12.
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tination of the current state, and thus the term ‘these
The developer of the Dyspnoea-12 recommends that
A Swedish version of the Dyspnoea-12 is now available for

REFERENCES
1. Bestall JC, Paul EA, Garrod R, et al. Usefulness of the Medical
Research Council (MRC) dyspnoea scale as a measure of disability
in patients with chronic obstructive pulmonary disease. Thorax
1999;54:581–6.
2. Nishiyama O, Taniguchi H, Kondoh Y, et al. Health-related quality
of life in patients with idiopathic pulmonary fibrosis. What is the main
contributing factor? Respir Med 2005;99:408–14.
3. Nishimura K, Izumi T, Fuskino M, et al. Dyspnea is a better predictor
of 5-year survival than airway obstruction in patients with COPD.
Chest 2002;121:1434–40.
4. Casanova C, Marin JM, Martinez-Gonzalez C, et al. Differential
effect of mMRC dyspnea, CAT and CCQ for symptom evaluation within the
new GOLD staging and mortality in COPD. Chest 2015.
5. Mura M, Porretta MA, Bargagli E, et al. Predicting survival in newly
diagnosed idiopathic pulmonary fibrosis: a 3-year prospective study.
Eur Respir J 2012;40:101–9.
6. Nishiyama O, Taniguchi H, Kondoh Y, et al. A simple assessment of
dyspnoea as a prognostic indicator in idiopathic pulmonary fibrosis.
Eur Respir J 2010;36:1067–72.
7. Ekman I, Cleland JG, Swedberg K, et al. Symptoms in patients who
have been diagnosed with heart failure are predictive: insights from COMET. J Card Fail 2005;11:286–92.
8. Johnson MJ, Currow DC, Booth S. Prevalence and assessment of
breathlessness in the clinical setting. Expert Rev Respir Med 2014;8:151–61.
9. Mahler DA, Wells CK. Evaluation of clinical methods for rating
dyspnea. Chest 1988;93:580–6.
10. Lanning RW, Moosavi SH, Banzett RB. Measurement of dyspnea:
word labeled visual analog scale vs. verbal ordinal scale. Respir Physiol Neurobiol 2003;134:77–83.
11. Borg GA. Psychophysical bases of perceived exertion. Med Sci
Sports Exerc 1982;14:377–81.
12. Parshall MB, Schwartzstein RM, Adams L, et al. An official
American Thoracic Society statement: update on the mechanisms,
assessment, and management of dyspnea. Am J Respir Crit Care Med 2012;185:435–52.
13. Banzett RB, O’Donnell CR, Guilfoyle TE, et al. Multidimensional
Dyspnea Profile: an instrument for clinical and laboratory research.
Eur Respir J 2015;45:1681–91.
14. Yorke J, Moosavi SH, Shuldham C, et al. Quantification of
dyspnoea using descriptors: development and initial testing of the
Dyspnoea-12. Thorax 2010;65:21–6.
15. Yorke J, Swigris J, Russell AM, et al. Dyspnea-12 is a valid and
reliable measure of breathlessness in patients with interstitial lung
disease. Chest 2011;139:159–64.
16. Alyami MM, Jenkins SC, Lababidi H, et al. Reliability and validity
of an arabic version of the dyspnea-12 questionnaire for Saudi
nations with chronic obstructive pulmonary disease. Ann Thorac Med 2015;10:112–7.

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CONCLUSION
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clinical validation and multidimensional measurement
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uation and management of dyspnoea.
17. Yorke J, Russell AM, Swigris J, et al. Assessment of dyspnea in asthma: validation of the Dyspnea-12. *J Asthma* 2011;48:602–8.
18. Yorke J, Armstrong I. The assessment of breathlessness in pulmonary arterial hypertension: reliability and validity of the Dyspnea-12. *Eur J Cardiovasc Nurs* 2014;13:506–14.
19. Lee BY, Lee S, Lee JS, et al. Validity and reliability of CAT and Dyspnea-12 in Bronchiectasis and tuberculous destroyed lung. *Tuberc Respir Dis* 2012;72:467–74.
20. Al-Gamal E, Yorke J, Al-Shwaiyat MK. Dyspnea-12-Arabic: testing of an instrument to measure breathlessness in Arabic patients with chronic obstructive pulmonary disease. *Heart Lung* 2014;43:244–8.
21. Tanaka K, Akechi T, Okuyama T, et al. Development and validation of the Cancer Dyspnea Scale: a multidimensional, brief, self-rating scale. *Br J Cancer* 2000;82:800–5.
22. Hønch I, Bergman B, Gaston-Johansson F. Validation of a Swedish version of the Cancer Dyspnea Scale. *J Pain Symptom Manage* 2006;31:353–61.
23. Ekström M, Sundh J. Swedish translation and linguistic validation of the multidimensional dyspnoea profile. *Eur Clin Respir J* 2016;3:32665.
24. Yorke J, Lloyd-Williams M, Smith J, et al. Management of the respiratory distress symptom cluster in lung Cancer: a randomised controlled feasibility trial. *Support Care Cancer* 2015;23:3373–84.
25. Wild D, Grove A, Martin M, et al. Principles of good practice for the translation and cultural adaptation process for Patient-Reported outcomes (PRO) Measures: report of the ISPOR Task Force for translation and cultural adaptation. *Value Health* 2005;8:94–104.
26. Wild D, Eremenco S, Mear I, et al. Multinational trials-recommendations on the translations required, approaches to using the same language in different countries, and the approaches to support pooling the data: the ISPOR Patient-Reported Outcomes Translation and Linguistic Validation Good Research Practices Task Force report. *Value Health* 2009;12:430–40.
27. Mapigroup 2016. http://mapigroup.com/.
28. Morélot-Panzini C, Gilet H, Aguilaniu B, et al. Real-life assessment of the multidimensional nature of dyspnoea in COPD outpatients. *Eur Respir J* 2016;47:1668–79.
29. Williams MT, John D, Frith P. Comparison of the Dyspnea-12 and Multidimensional Dyspnoea Profile in people with COPD. *Eur Respir J* 2017;49:160073.