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# Danish translation and linguistic validation of the multidimensional dyspnea profile

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## Background

The World Health Organization (WHO)estimates that approximately 21,8 million people annually die due to cardio-pulmonary diseases[1]. Dyspnea is prevalent in cardio-pulmonary diseases [2], and often a cardinal symptom in classifying the severity of the disease [3,4] and subsequent level of treatment and care.

Dyspnea is a subjective debilitating symptom across cardio-pulmonary diseases, neuromuscular diseases, and cancer, and at the end of like dyspnea affects up to 50% of all hospitalized patients and 40% of out-patient clinic patients treated in the USA [5]. Dyspnea is defined as 'a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity' [5]. The intensity of dyspnea increases with the progression of the disease independent of etiology. Dyspnea is strongly associated with anxiety, depression, reduced physical activity, deconditioning, impaired quality of life, hospitalization and death [6–12].

In addition to being used as a clinical outcome in research studies and as a proxy for disease severity, dyspnea is also used as a prognostic variable in several clinical guidelines [3,7,13–15]. Most assessment scales describe dyspnea by either breathlessness descriptors, intensity or by the functional impact of the symptom [16]. According to the American Thoracic Society statements, different but distinct sensory-perceptual mechanisms generate specific body-sensations, that varies in intensity. The sum of the sensations is processed and expressed as the individual patient's experience of dyspnea that may generate different emotions such as, e.g. anxiety, fear and depression. Thus, dyspnea is a complex multidimensional symptom that needs not only to be described but also measured as such. Despite this, dyspnea is most often measured on an unidimensional scale describing either the intensity of the symptom by, e.g. Visual Analogue Scale (VAS) [17], Numeric Analogue Scale (NRS) [18] or in relation to physical activity by, e.g. Borg-dyspnea scale or Medical Research Council breathlessness-scale (MRC) [19]. Alternatively, dyspnea can be assessed as part of a Health-Related Quality of Life instruments as, e.g. The Chronic Respiratory Questionnaire [20], EORTC-QLQ-30 [21], EORTC-QLQ-Pal [22], HeartQol [23], or SF-36 [24], all of which evaluates dyspnea over a period of days or weeks based on recall. All tools contribute with useful information, especially with respect to outpatient clinic patients, but none of them have been developed or validated for experimentally induced dyspnea or dyspnea in acute settings [25]. Their semantic structure generates a risk of that dyspnea being underreported due to lack of dimensions, low sensitivity and specificity in the most severe and frail patients with the potential risk that multiple aspects of the symptom will be unnoticed and untreated [26,27].

Different assessment scales with different terminologies, developed for different patient populations, with different timeframes, makes it challenging to compare effects across studies and evaluate interventions targeting dyspnea.

The Multidimensional Dyspnea Profile (MDP) was developed in 2012 by DR. Robert Banzett [28] and is a comprehensive instrument designed to measure sensory and affective dimensions of dyspnea independent of activity and with a timeframe defined by users [25,28]. It is designed for clinical and laboratory use allowing a better translation across laboratory and clinical settings by describing dyspnea in a manner equally relevant to experimental subjects or patients independent of settings. The MDP consist of 12 items: A global assessment of dyspnea consisting of five items describing unpleasantness in

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breathing by intensity 0–10 (0 = neutral, 10 = unbearable) followed by five items describing the sensory quality (SQ) of dyspnea assessed by presence (1/0), best match (one choice out of five items described), followed by rating scales of 0 to 10. Last page of the questionnaire assesses the emotional response to dyspnea rated from 0 to 10. The fact that all items are measured on rating scales of 0 to 10 with 10 representing high intensity/distress, makes the tool highly sensitive and capable of measuring dyspnea in the most vulnerable and inactive patients.

The fact that the MDP can be completed within 10 minutes makes it clinically feasible in most settings. The MDP has proven its reliability in an acute setting with test-retest intervals of 2 hours and an outpatient setting by a test-retest interval of 36 days [28]. The MDP has been tested for reliability and validity [28] and translated into several languages: French, German, Dutch, American/English, Norwegian, and Swedish [25,29–32]. The MDP has currently not been translated into Danish.

## Aim

We aimed to translate the MDP and make a linguistic validation that was: conceptually equivalent to the original and comparable across languages, culturally relevant to the context of the target country, easily understood by the people to whom the translated instrument is administered. All of the above in accordance with MAPI Research Trust guidelines [33]

## Methods

We made a translation agreement with the Mapi Research Trust group (Mapi SAS, language services Unit, Lyon, France) and the author and copyright holder of the Multidimensional Dyspnea Profile(MDP). We obtained the original American English version of the MDP to make a Danish version. We conducted the translation and validation process according to international guidelines given by Mapi Research Trust group [33], existing literature [34,35] and in close corporation with the developer.

## Ethical consideration

The ethical principles of the Declaration of Helsinki were followed [36]. According to the Danish National Committee on Health Research, Ethics approval is not required in interview studies. Therefore, this study was not registered under the committee act. Patients were informed both in writing and verbally about the aim of the study and its voluntary nature, and all patients signed informed consent before the interviews. All data were anonymized and carefully stored in a secure place. The chief nurse and physician on theDepartment of Respiratory Medicine approved the study.

## Translation

The translation and linguistic validation consisted of three phases; 1) Forward translation; 2) Backward translation, and 3) Patient testing.

The multistage process was conducted in a structured and transparent manner with each phase resulting in a detailed report sent to the developer of the original instrument for input and acceptance.

## Forward translation

A workgroup was established consisting of the four authors of this article, all of whom were native target language speakers and bilingual in the source language. The first author participated in the group as a local coordinator [33]. All members of the workgroup conducted an individual forward translation (A, B, C and D) of the source instrument. After discussing linguistically, culturally, and conceptual definitions a reconciliation was agreed. Special considerations in the reconciliation-process were reported in the first Danish version of the MDP. The full proces of the forward translation is illustrated in figure 1 below

## Backward translation

A translator who is a native source-language speaker and bilingual target language speaker translated the Danish target language version 1 back into the source language. In the translation process, the translator had no access to the source instrument only the reconciled version of the forward translation. The backward translation was compared with the source instrument and sent to the author and developer of the source instrument in a report. A review of the back translation was performed by the developer and colleagues and they pointed out three issues that needed clarification. The first issue pointed out by the developer was to make sure the Danish wording described "Sensation in the sense of something that the senses detect". The second issue was to make it clear that there were no wrong answers on the global scale. Third and last, the developer wanted to make sure that the Danish wording did not describe the sensation of choking as 'An obstruction of the upper airway near the larynx – either by an inhaled foreign body or by compression of the neck,' but merely implying a lack of air.

The three issues were discussed, clarified, and corrected based on consensus within the workgroup.
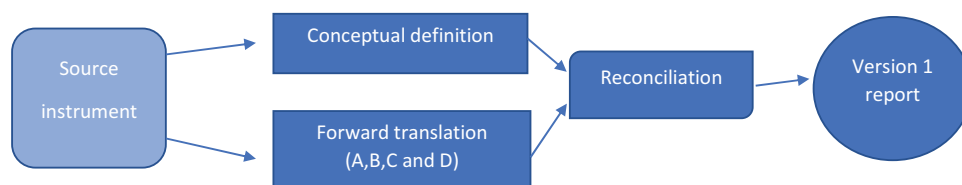
**Figure 1.** Forward translation. Figure 1 illustrates the forward translation process as described by the MAPI guidelines [33].

## Patient testing

To make a linguistic validation of the Danish translation of the MDP, we conducted cognitive interviews and tested the questionnaire on six patients admitted in the respiratory wards of two university hospitals in the capital region of Denmark. Patients were selected to represent a variety of age, gender and diagnoses (see Table 1). Patients with very severe pulmonary disease were included, while patients in the late-terminal-stage or patients with cognitive impairment were excluded. Number and variation of patients are in accordance with linguistic validation literature [29].

The local coordinator (CSB) tested the questionnaire and interviewed all the patients bedside. Patients were asked to read all text and answer all questions. They were asked to focus on the period of; 'today' on each page. After finishing each page, they were asked if they had any difficulties understanding the text, answering any of the questions or if they had any additional thoughts? Their considerations were transcribed verbatim by the interviewer.

## Results of patient testing

Based on the cognitive patient interviews, we found that the MDP was easy to read, understand and fill in for all included patients. There were no comments on any of the rating scales, except for one patient who could not make up her mind on 'best match' and put in only one cross as all sensations were equally relevant to her. Five out of six patients needed to clarify if they had to describe their breathing sensation in relation to an activity or when sitting still. The introduction to the questionnaire on page 1 was interpreted as too long, confusing and irrelevant by four out of six patients.

**Table 1.** Characteristics of patients interviewed for the study (*n* = 6).

| Male/female (n) | 4/2 |
|---|---|
| Age, median year (range) | 69 (54–86) |
| Diagnoses | • Chronic Obstructive Pulmonary Disease [2]<br>• Heart failure [1]<br>• Pneumothorax [1]<br>• Asthma [1]<br>• Acute respiratory insufficiency [1] |

Out of these four, two patients pointed out that the first sentence 'On this page, we ask you to tell us how unpleasant your breathing feels' was enough and fulfilling information for them. Patients made statements like:

... it's a long explanation that confuses me ... . it should be short and consistent. (male patient)

... if you have some difficulties understanding things, if you are tired, it will be hard for you to understand this. I understood but 20 other persons might not ... (female patient)

Furthermore, one patient pointed out that the sentence 'Use these scales to rate the intensity of the breathing' (first sentence page 3) would be enough for him to understand and fill out the rating scales on the page.

The MDP is easy to understand and use except for a radio-analogy that in some cases caused confusion. Our linguistic validation process has generated no suggestions for rephrasing only for potential shortening of radio-analogy.

Based on patient cognitive interviews and the revisions made by the workgroup and local coordinator and review comments from developers and colleagues, a report with a third version of the MDP was sent for acceptance and final agreement.

## Discussion

The MDP was developed to measure dyspnea across diseases. The source language MDP was tested for reliability and validity in a mixed population (n = 151) with cardiac or respiratory disease presented at an emergency department with respiratory distress [26]. In this study patients with coronary syndromes or malignant neoplasms of the head, neck, thorax or abdomen were excluded [28]. The MDP has been extensively tested by both psychophysical and psychometric testing to determine reliability, validity and responsiveness [25]. Our study has provided a linguistic validated Danish version of the MDP based on a population with primary pulmonary diseases. This may be considered as a limitation, but as we have presented full transparency in our process, we

believe that we have provided the readers with the opportunity to determine whether the population influences the linguistic validation of the translation.

The Swedish translation of MDP has been validated in terms of underlying factor structure, internal consistency, test-retest reliability and concurrent validity in a population with cardiorespiratory diseases by Ekstöm et al. 2019 [37]. Our study with the Danish translation and linguistic validated version of MDP is available for independent validation in populations with different etiological background.

The MDP makes it possible to assess dyspnea according to different timeframes by allowing the user to specify a 'focus period' [25]. Studies validating MDP have used terms such as 'right now', 'the past 15 days' or "the last two weeks" [28,30,37]. Despite different timeframes, Williams et al. and Ekstöm et al. have shown the validity of MDP in terms of convergent, discriminant and concurrent validity to be similar to the validity found in American, English and French studies [37–39]. These findings indicate that the ability of MDP to measure breathlessness across settings and timeframes are consistent. A future study aims to evaluate the relationship between experienced and recalled breathlessness [38]. This is a very important aspect in the assessment of dyspnea as it may explain potential differences in dyspnea experiences in, e.g. hospitalized and unstable patients where intensity in dyspnea is expected to have great variation within short timeframes.

Currently, there is an increased awareness of palliative care needs in non-malignant diseases such as: COPD and heart failure. The clinician's ability to treat or alleviate the intensity of the symptom dyspnea warrants the identification of the symptom, understanding the burden, trajectories, and measurement of the symptom [26,40,41]. It is shown that burdensome dyspnea defined as intensity ≥4 in a 0–10 point scale with 10 anchored at 'unbearable' was present in 43% of patients admitted with respiratory diagnosis and in 25% of patients admitted with cardiovascular diagnosis [11]. We believe that MDP is an important tool for assessing both the incidence and intensity of dyspnea, not only in relation to research, but also as a method of assessing and alleviating dyspnoea in the clinical treatment of patients with lung disease.

The Danish translation of the MDP will be used to assess and measure sensory and emotional aspects of dyspnea in two different Randomized Controlled Trials (RCTs) in the Capital region of Denmark. One RCT includes patients admitted with COPD (N = 200) and another includes patients admitted with heart failure or ischemia (N = 60), reflecting the possibility of using MDP regardless of disease etiology. It is our hope that the MDP will be used in future studies assessing symptoms in non-malignant palliative settings.

## Conclusion

A final certified and linguistic validated Danish translation of the MDP has been agreed upon and can be obtained from MAPI Trust Research.

## Disclosure statement

The authors have no conflict of interest to declare.

## Disclosure of interest

The authors report no conflict of interest

## Notes on contributors

*Charlotte Sandau Bech* is a RN and a Ph.D fellow at the University of Copenhagen with a degree of MSc in Health Science and a prior clinical experience within respiratory medicine. She has a special interest in the symptomatology of patients with COPD and non-malignant palliative care.

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