Respiratory Medicine 226 (2024) 107624

Contents lists available at ScienceDirect

Respiratory Medicine

journal homepage: www.elsevier.com/locate/rmed

Original Research

Swedish translation and psychometric testing of the Self-Conscious Emotions in COPD Questionnaire

Sara Lundell [a,1,*], Ulf Isaksson [b], Anna-Britt Coe [a,2], Samantha L. Harrison [c], Senada Hajdarevic [b,d]

[a] Umeå University, Department of Sociology, Umeå, 901 87, Sweden
[b] Umeå University, Department of Nursing, 901 87, Umeå, Sweden
[c] Teesside University, School of Health and Life Sciences, Centuria Building, Middlesbrough, TS1 3BA, UK
[d] Umeå University, Department of Public Health and Clinical Medicine, Family Medicine, 901 87, Umeå, Sweden

ARTICLE INFO

Keywords:
Chronic obstructive pulmonary disease
Emotions
Self-consciousness
Psychometry
Reliability
Validity

ABSTRACT

Assessment of self-conscious emotions is important to develop tailored interventions for people with chronic obstructive pulmonary disease (COPD). Previous instruments have largely been developed for mental health populations. The Self-Conscious Emotions in COPD Questionnaire was the first instrument to assess self-conscious emotions in people with COPD, but it was only available in English.

The aim was to translate the Self-Conscious Emotions in COPD Questionnaire into Swedish and to evaluate its psychometric properties and internal structure in a Swedish context.

The translation process included forward and backward translation, a multidisciplinary meeting, assessment of content validity, and cognitive interviews. The translated instrument was tested in a sample of 173 people with COPD between September 2021 and September 2022. Parallel analysis (PA), exploratory factor analysis (EFA), and test-retest reliability was performed.

The content validity index (CVI) for the instrument was 0.88. Based on the PA, an EFA with a two-factor solution was conducted, with a high Cronbach's alpha (0.786–0.821), and one item about self-blame was excluded. The two factors were labelled: *The burden of living with a disability* and *The desire to hide vulnerability*. Test-retest reliability showed no difference between scale scores on factor or item level, except for one item.

The Swedish Self-Conscious Emotions in COPD showed good validity and reliability. One item was excluded from the two subscales, indicating that the instrument needs to be further developed to cover the concept of self-blame. The instrument is expected to be a valuable tool for assessing self-conscious emotions in people with COPD.

1. Introduction

Chronic obstructive pulmonary disease (COPD) is one of the most common non-communicable diseases and among the top three causes of death worldwide. COPD is a heterogeneous condition characterized by respiratory symptoms such as dyspnea, coughing, and sputum production. The most common and well-known cause for COPD is long-term tobacco smoking [1]. Diseases believed to be caused by unhealthy individual behaviours or lifestyles, such as smoking, are frequently perceived as self-inflicted and, thereby, stigmatized [2]. Stigma has been identified as a core component of the lived experience of people with COPD, negatively affecting health behaviours [3]. Stigma can generate negative self-conscious emotions, such as shame, guilt, embarrassment, and self-blame, since there is a relationship between responsibility, shame, and blame [4,5]. Self-conscious emotions in people with COPD have also been shown to be associated with elevated symptoms of

Abbreviations: COPD, chronic obstructive pulmonary disease; CVI, content validity index; EFA, exploratory factor analysis; GOLD, Global Initiative for Chronic Obstructive Lung Disease; I-CVI, item content validity index; PA, parallel analysis; S-CVI, scale content validity index.

* Corresponding author.
E-mail addresses: sara.lundell@umu.se (S. Lundell), ulf.isaksson@umu.se (U. Isaksson), anna-britt.coe@kau.se (A.-B. Coe), S.L.Harrison@tees.ac.uk (S.L. Harrison), senada.hajdarevic@umu.se (S. Hajdarevic).
[1] Present address: Umeå University, Department of Community Medicine and Rehabilitation, 901 87 Umeå, Sweden.
[2] Present address: Karlstad University, Department of Social and Psychological Studies, Rum 5 A 427, 651 88 Karlstad, Sweden.

https://doi.org/10.1016/j.rmed.2024.107624
Received 20 December 2023; Received in revised form 25 March 2024; Accepted 30 March 2024
Available online 1 April 2024

anxiety and depression, reduced mastery and heightened emotional response [6].

Self-conscious emotions are experienced in social interactions when people evaluate and judge themselves through the eyes of others, based on cultural norms. In turn, emotions such as shame and guilt trigger strategies to avoid losing social status in the eyes of others or to deal with losing face in public [7]. Self-conscious emotions differ from basic emotions, such as fear, disgust, and joy, in that the former require self-awareness and self-representation and do not have discrete, universally recognized facial expressions. Laboratory measures, such as using photographs or film clips, of self-conscious emotions are less effective than measures of basic emotions [7]. Thus, self-reported measures are important for assessing self-conscious emotions.

Using self-reported measures to assess self-conscious emotions is, however, not without problems. The emotions are not always experienced on a conscious level, which makes them difficult to assess [8]. In addition, assessing self-conscious emotions can bring up negative and painful emotions. For example, shame can be a painful emotion since it concerns the self and is linked to feelings of being devalued or even worthless in the eyes of others. Meanwhile, guilt is an emotion focusing on actions and behaviours, i.e., that one has done something wrong, which is less devastating [7]. Self-conscious emotions are complex and some concepts underpinning these can be difficult to process and understand.

Assessment of self-conscious emotions in people with COPD is important to develop tailored interventions that facilitate self-management, healthy behaviour, and adherence to treatment. Previous scales for assessing self-conscious emotions have largely been developed to study people with mental illness, with items being generally formulated. Considering the stigmatization of COPD due to previous long-term smoking, and the visible signs of the disease (breathlessness and cough) affecting people's self-management behaviour, it is important to develop disease-specific questions to assess self-conscious emotions. The Self-Conscious Emotions in COPD Questionnaire was developed based on semi-structured interviews aiming to understand self-conscious emotions in people with COPD recruited from respiratory clinics at West Park Health Care Center, Toronto, Canada [6]. The aim was to assess the extent of self-conscious emotions in people with COPD, which only had been explored in qualitative research and subsequently in very small samples previously. Using disease-specific questions was intended to make them more relevant to the affected population. During the analysis of the interviews, five themes were identified: grief and loss, spectrum of blame, concern about the view of others, concealment, and worry about the future. Ten items were formulated to cover all five themes: grief and loss (item 7), spectrum of blame (item 1), concern about the view of others (item 2), concealment (items 3, 4, 8–10, and worry about the future (items 5 and 6) [6].

The Self-conscious Emotions in COPD Questionnaire [6] is the first instrument to assess self-conscious emotions in people with COPD. It is, however, only available in English. Emotions are a phenomenon, which expressions are created in relation to specific cultures and can therefore vary according to different social settings [9]. Studying self-conscious emotions in different cultural contexts has been recommended to be able to study cultural variation [10]. Therefore, it is important to translate and evaluate the instrument in a Swedish version, to assess the extent of self-conscious emotions in Sweden.

1.1. Aim

This study aimed to translate the Self-Conscious Emotions in COPD Questionnaire from English into Swedish and to evaluate its psychometric properties and internal structure in a Swedish context.

2. Material and methods

2.1. Questionnaire

The Self-Conscious Emotions in COPD Questionnaire consists of ten items which enquire about self-conscious emotions related to a COPD diagnosis. Each item consists of contrary statements (negative vs positive) and is answered on a five-point scale, where 1 indicates a strong agreement with the statement indicating a negative statement. In contrast, 5 indicates a strong agreement with the statement indicating a positive statement. Finally, 3 states no strong feelings towards either statement or a neutral opinion.

Seventy individuals with COPD were recruited from consultant-led outpatient respiratory clinics at West Park Health Care Center, Toronto, Canada. Convergent validity was evaluated, and significant low to moderate correlations ($p < 0.01$) were shown with other questionnaires investigating self-conscious emotions [6].

2.2. Translation and cultural adaptation procedure

The translation process followed the guidelines by Sousa et al. [11] as presented in Fig. 1.

First, three bilingual translators with Swedish as the mother language translated from English to Swedish independently. One of the translators had lived and worked in the healthcare sector in an English-speaking country, while the other two had extensive experience working in other sectors in English-speaking contexts. The first author (SL) compared and compiled the three Swedish versions to Swedish version 1. Discrepancies were discussed with authors ABC and SH. Secondly, two independent translators with English as the mother language translated the Swedish version 1 back to English, unaware of the original version. Both translators speak Swedish fluently, live and work in Sweden, and one is knowledgeable in healthcare terminology. Thirdly, the two back-translations were compared with the original version and discussed at a meeting of selected professionals from multiple disciplines, i.e., a multidisciplinary meeting [11]. The meeting included the first author (SL), the developer of the original questionnaire (SLH), a healthcare professional with extensive experience in COPD care, one of the forward translators, and one of the backwards translators. During the multidisciplinary meeting, some words in the Swedish version were revised (Swedish version 2). The main issue that arose and was discussed included translating "self-conscious emotions" into Swedish since there is no satisfactory translation for the concept. In the Swedish version, the title was "Känslor om självuppfattning", which could be translated as "Emotions about self-perception". Agreement was reached by consensus.

An expert panel was then consulted to evaluate the content validity of each item in the questionnaire, as recommended [11]. The panel consisted of three professors and two post-doctoral researchers with backgrounds in physiotherapy, medicine, psychology, and sociology. Three had extensive experience working with people with COPD in clinical settings, and for all, Swedish was their mother language. They were asked to rate the relevance of each item related to the concept of self-conscious emotions using the following scale: 1 = not relevant, 2 = less relevant/unable to assess the relevance, 3 = quite relevant, or 4 = very relevant and succinct, as well as give suggestions on potential changes. They were also asked to evaluate if the introductory text and instructions were clear enough or needed any changes. As a result, a few minor changes were made, and a short definition of self-conscious emotions was included in the questionnaire's introduction.

After these revisions, cognitive interviews [12] were conducted with five persons with COPD, for whom Swedish was their mother language. Purposive sampling was used to recruit participants from a previous research project. The participants were women and men of different ages, disease severity and places of residence (different parts of the country and rural and urban areas). During the cognitive interviews, the persons with COPD were asked about their experience completing the

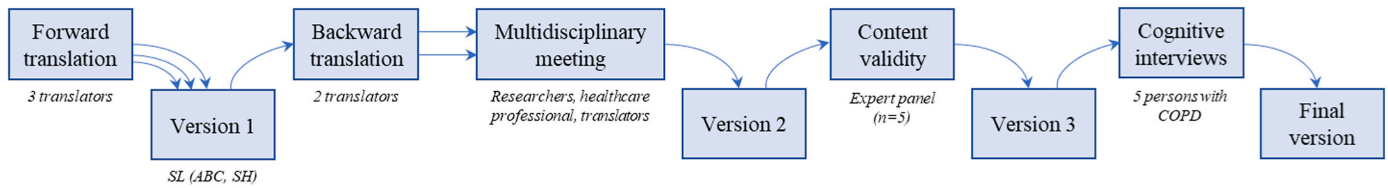

Fig. 1. The steps of the translation process.

questionnaire, how they interpreted and reasoned when they answered the items, how important and relevant each item was perceived, and how easily each item was understood. The cognitive interviews revealed that the instrument was considered easy to understand, with relevant questions. However, minor revisions were needed in the introductory text to minimize the feeling that they were being blamed for their disease and to simplify the description of how to answer the items, i.e..

- Include the aim of the instrument as the first sentence “This questionnaire aims to explore your emotions about self-perception in relation to your lung disease”.
- Include the sentence “The statements below describe different ways of thinking or feeling about oneself, both negative and positive feelings.”
- Clarify that both answers 1 and 2 mean that you agree with the statement to the left, and that answers 4 and 5 mean that you agree with the statement to the right.

The changes were validated with two of the five persons who completed a cognitive interview, and the questionnaire was finalised.

2.3. Participants

The final version of the Swedish Self-Conscious Emotions in COPD Questionnaire was tested in a sample of people with a verified COPD diagnosis according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) [1]. Participants were recruited by healthcare professionals in primary care and speciality care in eight Swedish healthcare regions and through advertisements on COPD-related webpages, groups on social media, newsletters via email, and lectures directed to people with pulmonary conditions. Data were also collected about background variables, such as demographics and disease-related information. In addition, a smaller sample (n = 31) was asked to complete the questionnaire once again after 2–3 weeks for a test-retest analysis. The recruitment period ranged from September 2021 to September 2022.

In total, 320 participants were recruited, where 185 completed and submitted the questionnaire, giving a response rate of 58%. Twelve participants were excluded due to no verified COPD diagnosis according to GOLD [1] (n = 11) or no signed consent form submitted (n = 1). Hence, 173 participants were included, where 25 (14%) answered the questionnaire a second time and were included in the test-retest analysis. The demographic data of the included participants are presented in Table 1.

2.4. Statistical analysis

In cases where a participant had given two answers for an item on the Self-Conscious Emotions in COPD Questionnaire, it was considered a missing answer and excluded from the analysis. This was only made for three items distributed among two participants (0.2% of all items).

An item (I-CVI) and scale (S-CVI) content validity index [13] was calculated based on the assessment of the expert group. The S-CVI was calculated as the mean agreement between experts for the whole scale.

After testing the questionnaire in the sample of people with COPD, each item’s distributional properties (distribution in percent) were assessed. To determine the number of common factors in the questionnaire, a parallel analysis (PA) was performed. The underlying structure of the questionnaire was explored using exploratory factor analysis (EFA), where the ten items were forced into a two-factor solution. Since data were not assumed to be normally distributed and correlations between factors were expected, principal axis factoring was used as the extraction method with direct oblimin rotation [14]. All items with a factor loading above 0.4 were included in the analysis. Cronbach’s alpha estimated internal consistency. Test-retest reliability, i.e., the stability of item and factor response over time, was evaluated using Wilcoxon rank since the data were not normally distributed. Statistical software used was Jamovi 2.2.5 and IBM SPSS Statistics 28.

Table 1
Demographic data of the included participants.

Characteristics	Total	Test-retest, n = 25
Sex (n = 173)		
Women, n (%)	118 (68)	17 (68)
Men, n (%)	55 (32)	8 (32)
Age (n = 172), mean (SD)	74.0 (7.99)	74.1 (8.43)
Disease severity (n = 171)		
Mild COPD, GOLD 1, n (%)	10 (6)	1 (4)
Moderate COPD, GOLD 2, n (%)	73 (43)	8 (32)
Severe COPD, GOLD 3, n (%)	64 (37)	12 (48)
Very severe, GOLD 4, n (%)	24 (14)	4 (16)
Oxygen use (n = 173), n (%)	6 (4)	1 (4)
CAT (n = 171), points, mean (SD)[a]	16.6 (7.69)	19.4 (6.35)
mMRC (n = 173)[a]		
0, n (%)	5 (3)	0 (0)
1, n (%)	58 (34)	9 (36)
2, n (%)	36 (21)	7 (28)
3, n (%)	35 (20)	5 (20)
4, n (%)	39 (23)	4 (16)
Smoking status (n = 172)		
Smoker, n (%)	18 (10)	2 (8)
Ex-smoker, n (%)	150 (87)	23 (92)
Never-smoker, n (%)	4 (2)	0 (0)
Length of diagnosis (n = 156), year, mean (SD)	11.3 (7.71)	11.7 (7.82)
Living alone (n = 169), n (%)	73 (42)	9 (36)
Level of education (n = 173)		
Primary school, n (%)	71 (41)	9 (36)
Upper secondary school, n (%)	65 (38)	7 (28)
Tertiary education, n (%)	37 (21)	9 (36)

Abbreviations: CAT, COPD assessment test; COPD, Chronic obstructive pulmonary disease; GOLD, Global initiative for chronic obstructive lung disease; mMRC, modified Medical research council; SD, Standard deviation.

[a] A higher number indicates increased symptoms/dyspnea.

3. Results

3.1. Content validity

The I-CVI varied between 0.6 and 1.0 for the ten items in the Swedish version of the Self-Conscious Emotions in COPD Questionnaire, and the S-CVI was 0.88 (Table 2).

3.2. Distributional properties

The analysis of response distribution showed a floor or ceiling effect, i.e., ≥15 % of the responses in the highest or lowest points in the scale, in

Table 2
Content validity, median and distribution in percent for each item and response alternatives of Swedish Self-Conscious Emotions in COPD questionnaire (n = 173).

	Item	Median	1	2	3	4	5	Missing[a]	I-CVI
1	I believe that my own behaviour caused my lung condition/I believe that my behaviour in no way contributed to my lung condition *Jag tror att mitt eget beteende har orsakat* min *lungsjukdom/Jag tror inte att mitt beteende på något sätt har bidragit till* min *lungsjukdom*	2	39.9	24.3	17.3	5.2	12.1	1.2	1.0
2	I am often embarrassed by my coughing/I am never embarrassed by my coughing *Jag är ofta generad över* min *hosta/Jag är aldrig generad över* min *hosta*	3	11.0	13.3	27.7	15.6	32.4	0.0	0.6
3	I always try to hide my lung disease/I never try to hide my lung disease *Jag försöker alltid dölja* min *lungsjukdom/Jag försöker aldrig dölja* min *lungsjukdom*	4	9.8	8.7	22.0	19.7	39.3	0.6	1.0
4	I am embarrassed to tell people about my lung disease/I am never embarrassed to tell people about my lung disease *Jag är generad över att berätta för andra om* min *lungsjukdom/Jag är aldrig generad över att berätta för andra om* min *lungsjukdom*	4	10.4	7.5	16.8	16.8	48.6	0.0	1.0
5	I worry all the time about the future with my lung disease and what will happen/I never worry about the future with my lung disease and what will happen *Jag oroar mig hela tiden för hur* det *kommer att bli att leva med* min *lungsjukdom i framtiden/Jag oroar mig aldrig för hur* det *kommer att bli att leva med* min *lungsjukdom i framtiden*	3	13.3	26.0	24.9	23.7	11.6	0.6	0.8
6	I worry all the time about what will happen with my breathing if I perform a certain activity or action/I never worry about what will happen with my breathing if I perform a certain activity or action *Jag oroar mig hela tiden för att få andnöd när jag utför vissa aktiviteter/Jag oroar mig aldrig för att få andnöd när jag utför vissa aktiviteter*	3	10.4	23.1	24.9	26.0	15.6	0.0	0.8
7	I always think about what I can no longer do because of my lung disease/I never think about what I can no longer do because of my lung disease *Jag tänker alltid på vad jag inte längre kan göra på grund av* min *lungsjukdom/Jag tänker aldrig på vad jag inte längre kan göra på grund av* min *lungsjukdom*	3	12.1	26.6	26.6	20.2	14.5	0.0	0.8
8	I feel I am a burden on my family/friends/I never feel I am a burden on my family/friends *Jag känner att jag är en börda för* min *familj/vänner/Jag känner aldrig att jag är en börda för* min *familj/vänner*	4	8.1	13.3	23.1	22.0	31.8	1.7	1.0
9	I feel my family/friends have no understanding of my lung condition/I feel my family/friends completely understand my lung condition *Jag känner att* min *familj/vänner inte har någon förståelse för* min *lungsjukdom/Jag känner att* min *familj/vänner har full förståelse för* min *lungsjukdom*	4	3.5	6.4	18.5	30.1	41.0	0.6	0.8
10	I do not feel I deserve any treatment and/or care for my lung condition/I feel I deserve the best treatment and/or care for my lung condition *Jag känner att jag inte förtjänar någon behandling och/eller vård för* min *lungsjukdom/Jag känner att jag förtjänar den bästa behandlingen och/eller vården för* min *lungsjukdom*	5	2.9	2.3	11.6	23.1	59.5	0.6	1.0
								S-CVI	**0.88**

English version in plain text, Swedish in italics.
[a] Percentage of internal missing items.

all items except items 5 and 7. Item 1 showed a floor effect, while items 2, 3, 4, 6, 8 and 10 showed a ceiling effect. Four items had no missing answers and were completed by all participants, while the number of missing answers was low (0.6–1.7 %) for the rest of the items (Table 2).

3.3. Exploratory factor analysis

A PA based on minimum rank factor analysis was conducted to determine the minimum number of factors in the Swedish Self-Conscious Emotions in COPD questionnaire. According to the analysis, the recommended number of factors was two (Fig. 2).

Based on the PA, an EFA with a three-factor solution was conducted. With the three-factor solution, one factor included only two items. Therefore, an EFA with a two-factor solution was conducted. Item 1 was not included in any of the factors. The factors were labelled through a discussion among the researcher group. The factor *The burden of living with a disability* included items 5, 6, 7 and 8, with factor loadings of 0.575–0.880. The factor *The desire to hide vulnerability* included items 2, 3, 4, 9 and 10, with factor loadings of 0.431–0.868. Internal consistency for the two factors, estimated by Cronbach's alpha, was high (0.821 and 0.786 respectively), and the instrument could explain 45 % of the total variance (Table 3).

3.4. Test-retest reliability

A test-retest analysis showed no difference between scale scores on item level or factor level at baseline and 2–3 weeks later, except for item 5 (Table 4). The absolute agreement between first and second occasion (e%) for the items was between 28 and 60%.

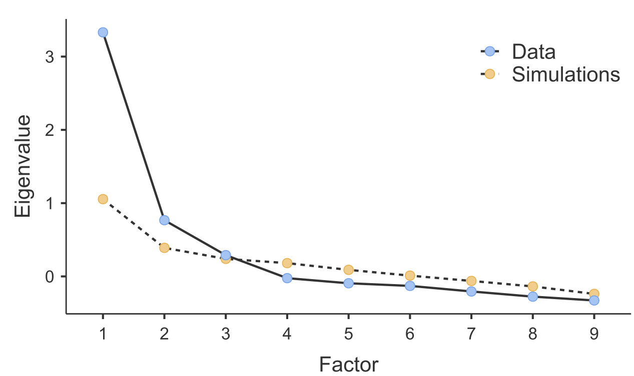

Fig. 2. Scree plot of parallel analysis of the Swedish Self-Conscious Emotions in COPD questionnaire.

4. Discussion

This study aimed to translate the Self-Conscious Emotions in COPD Questionnaire into Swedish and to evaluate its psychometric properties and internal structure in a Swedish context. Five experts judged the content validity of the instrument. S-CVI was close to 0.9 that is

Table 3
Items, factor loadings, total variance explained, and Cronbach's alpha for the two-factor structure of the Swedish version of the Self-Conscious Emotions in COPD questionnaire.

		The burden of living with a disability	The desire to hide vulnerability
Item 6	I worry all the time about what will happen with my breathing if I perform a certain activity or action/I never worry about what will happen with my breathing if I perform a certain activity or action	0.880	
Item 7	I always think about what I can no longer do because of my lung disease/I never think about what I can no longer do because of my lung disease	0.749	
Item 5	I worry all the time about the future with my lung disease and what will happen/I never worry about the future with my lung disease and what will happen	0.647	
Item 8	I feel I am a burden on my family/friends/I never feel I am a burden on my family/friends	0.575	
Item 3	I always try to hide my lung disease/I never try to hide my lung disease		0.868
Item 4	I am embarrassed to tell people about my lung disease/I am never embarrassed to tell people about my lung disease		0.794
Item 2	I am often embarrassed by my coughing/I am never embarrassed by my coughing		0.542
Item 10	I do not feel I deserve any treatment and/or care for my lung condition/I feel I deserve the best treatment and/or care for my lung condition		0.485
Item 9	I feel my family/friends have no understanding of my lung condition/I feel my family/friends completely understand my lung condition		0.431
Item 1	I believe that my own behaviour caused my lung condition/I believe that my behaviour in no way contributed to my lung condition		
	Total variance explained (%)	22.6	22.3
	Cronbach's α	0.821	0.786

Table 4
Test-retest reliability for the items and factors in the Swedish Self-conscious Emotions in COPD Questionnaire.

		Test, mean (SD)	Retest, mean (SD)	p-value	e%
Item 1	I believe that my own behaviour caused my lung condition/I believe that my behaviour in no way contributed to my lung condition	2.29 (1.46)	2.17 (1.37)	0.830	48%
Item 2	I am often embarrassed by my coughing/I am never embarrassed by my coughing	3.12 (1.33)	3.24 (1.17)	0.521	52%
Item 3	I always try to hide my lung disease/I never try to hide my lung disease	3.52 (1.28)	3.48 (1.08)	0.958	28%
Item 4	I am embarrassed to tell people about my lung disease/I am never embarrassed to tell people about my lung disease	3.44 (1.42)	3.36 (1.25)	0.778	52%
Item 5	I worry all the time about the future with my lung disease and what will happen/I never worry about the future with my lung disease and what will happen	2.75 (1.19)	2.29 (1.08)	**0.013**	40%
Item 6	I worry all the time about what will happen with my breathing if I perform a certain activity or action/I never worry about what will happen with my breathing if I perform a certain activity or action	2.92 (0.95)	2.72 (1.02)	0.325	48%
Item 7	I always think about what I can no longer do because of my lung disease/I never think about what I can no longer do because of my lung disease	2.60 (0.91)	2.92 (0.95)	0.131	44%
Item 8	I feel I am a burden on my family/friends/I never feel I am a burden on my family/friends	3.75 (1.33)	4.00 (0.89)	0.239	36%
Item 9	I feel my family/friends have no understanding of my lung condition/I feel my family/friends completely understand my lung condition	3.88 (0.78)	4.04 (0.84)	0.331	60%
Item 10	I do not feel I deserve any treatment and/or care for my lung condition/I feel I deserve the best treatment and/or care for my lung condition	4.20 (0.82)	4.48 (0.77)	0.168	56%
Factor 1	The burden of living with a disability	12.0 (3.45)	11.8 (3.13)	0.628	N/A
Factor 2	The wish to hide vulnerability	18.2 (3.59)	18.6 (4.03)	0.570	N/A

Abbreviations: e% = exact agreement, SD = standard deviation.

considered as an excellent content validity [13], while I-CVI was at a level considered as a good content validity [15], which all the items except item 2 reached. The low value was because the psychologist and the sociologist scored two on the item (about being embarrassed about coughing), however they were not specifically competent in COPD and its consequences. The items in the study had few missing answers (0.2%), but a ceiling effect was observed in six items. This was, however, considered positive since it shows that most people did not experience negative self-conscious emotions. The PA suggested a two-factor solution, and the two-factor model (*The burden of living with a disability* and *The desire to hide vulnerability)* showed high internal consistency. Item 1 was not included in the two-factor model. Finally, the test-retest reliability showed stability over time for both factors and all items except for item 5.

The Self-Conscious Emotions in COPD Questionnaire was translated from English to Swedish. Overall, the translation was unproblematic, but the term "self-conscious emotions" was difficult to translate. No satisfying translation to Swedish was found, since the direct translation was considered difficult to understand for laypeople. In previous lexical studies, a vast difference in the number of terms available to describe self-conscious emotions has been found between languages. For example, the English language seems to have few names for many self-conscious emotions and cluster emotions such as guilt, shame, and embarrassment closely together. In contrast, other languages have a more apparent distinction between such emotions [10]. Chinese can be mentioned as an example, where 113 terms have been found for the concept "shame", which can be divided into subgroups with different meanings [16]. We have, however, found no study about words used to describe self-conscious emotions in Swedish.

One item, item 1, was excluded from the EFA. In the analysis, we tried to force the EFA into a different number of factors, but item 1 was never included in any factor. In the development of the instrument, the aim of item 1 was to understand the extent to which people harbour feelings of self-blame for their condition [6]. Besharat et al. [5] define self-blame as "*the holding of oneself responsible for such an event or relationship and its negatively perceived consequences*". It is possible that the phenomena self-blame is too complex to capture with only one item.

Interestingly, the item did not discriminate people with COPD and healthy individuals [6]. According to Besharat et al. [5] self-blame can be defined by three criteria; causality, responsibility, and negative feelings, and that a fourth criteria – negative tone of voice – determines the depth and severity of blame. In the example of COPD, the individual can have a sense of *responsibility* for their previous long-term smoking that later caused the disease (*causality*) and experience dissatisfaction (*negative feelings*) for their previous behaviour. Item 1, i.e. "I believe that my own behaviour caused my lung condition" only includes the criteria of causality. To be able to triangulate the issue of self-blame, the instrument probably needs 2–3 questions to also include the criteria of responsibility and negative feelings. Still, it might be difficult to capture emotions of self-blame depending on how the individuals have responded to such feelings. Self-blame itself does not have to be negative, it might make you take more responsibility now. In a previous interview study [8] with people with COPD in Sweden, few participants expressed feelings of guilt regarding previous smoking behaviour. Several different attitudes emerged; those who did not blame themselves since they were unaware of the risks of smoking or blamed other factors, those who had processed their guilt, accepted the past and instead were looking forward, and those who knew about the risks of smoking but didn't care since smoking was experienced as enjoyable [8]. In addition, the relationship between perceived responsibility, self-blame and stigma seems to be mediated by the culture and healthcare system [17]. The criteria of responsibility might be difficult to capture, since one strategy to cope with stigma-related emotions seems to be to attribute a broad range of complex factors to a diagnosis of COPD (e.g. occupation), rather than assigning smoking behaviour as the only cause [8,18]. Finally, it might have been a mistake to put the item about self-blame as number one in the instrument. Both in the cognitive interviews and during the development of the instrument [6], some participants reacted with anger or irritation about starting the instrument with this item. They experienced that the item itself were blameful. This could be solved by moving it further down in the instrument since it is important to build a trusting relationship with the person before asking such emotive question. Overall, future studies are needed to investigate how to capture emotions of self-blame among people with COPD.

Item 5, i.e., the item about worries about the future and what will happen, showed a significant difference between responses taken at the two time-points in the test-retest reliability analysis. In the English version, item 5 is two statements in one, but in the Swedish version it is only one statement. Worries about long-term health is common among people with COPD, along with fear of premature death because of COPD [19]. We can't explain the reason for the significant difference between measure points, if it is related to the translation or the cultural context, or if something has happened to the individuals between the two measures. Most people with changes in their answers (60%) report more worries the second time, but mostly small changes. The data collection for the present study was conducted between September 2021 and September 2022, a period where most people above 65 years in Sweden had been vaccinated for COVID-19. During this period, there were still restrictions related to the pandemic, and the first omicron variant of the virus came to Sweden, which lead to increased spread of the infection and a high burden on the healthcare system. People with COPD have reported significant difficulties with self-management due to worry or fear because of the COVID-19 pandemic [20]. Thus, this was a turbulent time for people with COPD and 2–3 weeks may have been too long time for the test-retest analysis. Worries about the future may have differed from day to day and even small events could trigger worries, e.g., meeting grandchildren and start thinking about if you will be able to see them grow up. Perhaps, the item makes the participants start thinking about the future, which was indicated in the cognitive interviews. People with COPD have expressed the value of observing and talking to peers, since that help them to get perspective on their situation and have a more optimistic view on the future [21]. Despite the significant difference in the test-retest reliability analysis for item 5, the factor *The burden of living with a disability*, where item 5 is included showed stability between measure points which motivates keeping the item in the instrument. In addition, if item 5 were excluded, the internal consistency (Chronbach's α) for the factor decreased (from 0.821 to 0.791).

Use of this instrument in clinical setting is of great importance since it can help healthcare professionals to identify and acknowledge self-conscious emotions in patients with COPD. For patients with high scores in the items, no further actions might be required, while for those with low scores it can be an indicator to healthcare professionals that they need to be mindful in their actions. Consequently, the instrument can be used to facilitate conversations about self-conscious emotions between healthcare professionals and patients and thereby improve uptake and adherence to healthcare interventions and self-management. Whether and how severity of the COPD or other individual characteristics influence the responses in the instrument is also interesting and will further be investigated in upcoming studies.

4.1. Methodological considerations

A strength with this study is that it was conducted according to guidelines for translation and psychometric testing of instruments [11]. Following these the translation procedure included forward translation, blinded backward translation, a multidisciplinary meeting, and cognitive interviews. The use of backward translation has, however, been criticised in previous literature because it can be an unsecure approach to finding problems with the translation [22,23]. The results can vary depending on the researcher awareness when comparing the back translation with the original version [22]. Efforts are suggested to be directed to ensure quality in the translation, e.g., by using a team approach [22,23]. The strength of this study is that, after the backward translation, a multidisciplinary team thoroughly discussed the different versions of translation and compared them to both the original version and the Swedish version. It's a strength that the multidisciplinary team included both the developer, translators, and people with extensive experience of COPD in a Swedish context, as well as both people with Swedish and with English as the mother language.

For this study, participants were recruited from several healthcare regions in Sweden, both in primary care and specialty care. About two thirds of the sample were women, which is corresponding to our previous study, where men with COPD were more prone to decline participation [24]. In other aspects, the participants represent a diversity of disease severity, educational levels, and ages, which increases the generalisability of the study results.

The floor and ceiling effects for several items indicate that the instrument's responsiveness to interventions, at a group level, is uncertain in its current form. However, this will not influence its usefulness in clinical practice.

5. Conclusions

This study shows good validity and reliability for the Swedish Self-Conscious Emotions in COPD Questionnaire. Two subscales were found; *The burden of living with a disability* and *The desire to hide vulnerability*. One item related to self-blame was excluded from the subscales, and the instrument needs to be developed further to include the concept of self-blame. An item about worries about the future was sensitive to changes during a period of 2–3 weeks, which could not be explained. However, the data collection was conducted during a turbulent period, and the factor which the item was included in was stable over time. The Swedish Self-Conscious Emotions in COPD requires further development but as it stands it is still expected to be a valuable tool for assessing self-conscious emotions in people with COPD.

Funding

This study was supported by FORTE – the Swedish Research Council for Health, Working Life and Welfare [dnr. 2020–01129].

S.L,Harrison [Advanced Fellow NIHR300856] is funded by the National Institute for Health and Care Research.

Conflicts of interest/Competing interests

The authors have no competing interests to declare that are relevant to the content of this article. SLH developed the original instrument but have no financial interests in it.

Ethics approval

The study was performed in line with the principles of the Declaration of Helsinki. Approval was obtained from the Swedish Ethical Review Authority (Dnr. 2021–02367).

Consent to participate

The participants received written information about the study. They were informed about the aims of the study, that participation was voluntary, that they could withdraw at any time and that confidentiality was assured. Written informed consent was obtained from all participants included in the study.

Consent for publication

Not applicable.

Availability of data and material

The data that support the findings of this study are available from the corresponding author, SL, upon reasonable request.

Code availability

Not applicable.

CRediT authorship contribution statement

Sara Lundell: Writing – review & editing, Writing – original draft, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Ulf Isaksson:** Writing – review & editing, Formal analysis, Conceptualization. **Anna-Britt Coe:** Writing – review & editing, Formal analysis, Conceptualization. **Samantha L. Harrison:** Writing – review & editing, Validation. **Senada Hajdarevic:** Writing – review & editing, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Sara Lundell reports financial support was provided by Forskningsrådet för hälsa arbetsliv och välfärd. Samantha L. Harrison reports financial support was provided by National Institute for Health and Care Research. Samantha L. Harrison developed the original instrument but has no financial interests in it. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to acknowledge all participants who contributed with their valuable time to this study by answering the questionnaire, and healthcare professionals who helped with recruitment.

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