



Tool Development to Measure Dyspnea among Patients with Advanced Cancer Stage

Huda Anshasi* - Muayyad Ahmad

Faculty of Nursing, the University of Jordan

mma4jo@yahoo.com

Abstract: Dyspnea is a distressing symptom of terminal cancer patients. Lack of an appropriate assessment tool for dyspnea disturbs the establishment of proper management. The purpose of this study was to develop a reliable and valid measure which assesses the multidimensional nature of dyspnea among patient with advanced stage of cancer. The tool was administered by the principal investigator to the participants. The developed dyspnea scale contains 12 items under three domains; these domains are 'Physical triggers', 'psychological triggers', and 'environmental triggers.' It is recommended to apply the tool in with different types of advanced cancer disease for more psychometric confirmation.

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1. Introduction and Background:

Dyspnea is one of the most distressing symptoms of terminal cancer patients. It is frequent and difficult to manage during the advanced cancer stages. However, there has been considerably less emphasis in the literature on the appropriate characterization and management of this symptom compared to other cancer-related symptoms, such as pain. It is defined as a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity (Al-Ghabeesh & Ahmad, 2012; Ben-Aharon, 2008). It is frequently described by patients with terms such as fatigue upon breathing, air hunger, suffocation, choking or heavy breathing (Al-Ghabeesh & Ahmad, 2012).

Patients usually have multiple causes for dyspnea, including chronic disease (heart failure, neuromuscular disease, etc.); acute, superimposed illness (pneumonia, pulmonary embolism, etc.); and cancer-induced complications (tumor growth, bronchial obstruction, pleural effusions) (Ahmad, Alasad & Nawafleh, 2010; Dardas & Ahmad, 2015). Other causes are anemia, ascites, anxiety, and depression. Hence, cancer patients with dyspnea should undergo a comprehensive assessment. The main target of the assessment and therapeutic intervention is the patient's expressed intensity of dyspnea rather than the objective findings of disease. The prevalence of dyspnea has been reported to be around 50% among population with cancer (Dudgeon, 2001). This proportion figures up to 90% in patients with advanced cancer (Reuben, 2010).

Lack of an appropriate assessment tool for dyspnea seems to disturb establishment of management strategy. Some scales evaluating the intensity of dyspnea subjectively, such as Borg's scale (Borg, 1998) and the Visual Analog Scale of dyspnea (Atkin, 1969), are simple and widely used, but multidimensional assessment cannot be achieved with them. Some other scales, which objectively measure physical effort evoking dyspnea, such as Hugh-Jones scale. The purpose of this study was to develop a reliable and valid measure which assesses the multidimensional nature of dyspnea among patient with advanced stage of cancer.

This scale should comprise multidimensional aspects. It should be self-rating because dyspnea is subjective. In addition, the scale should be easy and simple to be completed by patients troubled by dyspnea, be evaluated not by physical effort evoking dyspnea, but by perceived dyspnea itself so that even bedridden patients can complete it. Have its reliability and validity in cancer patients confirmed, and be sensitive to clinical changes due to treatment or progression of the disease over time.

2. Literature Review:

The experience of dyspnea includes four categories: 'Triggering factors' included circumstances contributing to dyspnea, which comprised physical, psychosocial and environmental triggers (Stulbarg & Adams, 2000; Ahmad & Dardas, 2016). The psychological distress of cancer patients is mainly characterized by anxiety and depression

(Ahmad, 2015). It is reported that lung cancer patients had higher emotional distress than those with other cancers, and that patients with advanced disease were particularly emotionally vulnerable (Tanaka et al, 2002; Tawalbeh & Ahmad, 2013; Alslman, Ahmad, Bani Hani, Atiyeh; 2015). Many studies have shown significant correlations between dyspnea and psychological status (Al-Ghabeesh & Ahmad, 2012; Dardas & Ahmad, 2014).

It is hypothesized that there might be several aspects of dyspnea; however, few studies about subtypes of dyspnea in cancer patients have been done. Furthermore, an appropriate assessment tool for dyspnea in this population has not been established. Available scales are not appropriate for understanding the etiologies and establishing a therapeutic strategy for them. Some scales evaluating the intensity of dyspnea subjectively, such as Borg's scale (Borg, 1998) and the Visual Analog Scale of dyspnea (Atkin, 1969), are simple and widely used, but multidimensional assessment cannot be achieved with them. Some other scales, which objectively measure physical effort evoking dyspnea (Medical Research Council Committee, 1965; American Thoracic Society, 1978; McGavin et al, 1978), are not feasible for patients whose activity is limited by other symptoms or disability. They are sometimes not useful because perceived dyspnea has not always been found to be correlated with the results of exercise tests and respiratory function tests (Burdon et al, 1983; Stoller et al, 1986; Maler et al, 1987). Development of a new measure is crucial to investigating the etiology and establishing a therapeutic strategy for dyspnea (Bruera et al, 1998). The scale should: 1) comprise multidimensional aspects; 2) be self-rating, because dyspnea is subjective; 3) be easy and simple enough to be completed by patients troubled by dyspnea; 4) be evaluated not by physical effort evoking dyspnea, but by perceived dyspnea itself so that even bedridden patients can complete it; 5) have its reliability and validity in cancer patients confirmed; and, 6) be sensitive to clinical changes due to treatment or progression of the disease over time.

3. Conceptual Definition:

Dyspnea is derived from the Greek dys: meaning painful or difficult and pneuma meaning breath and is used to describe a variety of sensations experienced when breathing is difficult, uncomfortable, or labored or when the subject feels a need for more air. This sensation of breathlessness is experienced by healthy individuals under stress and patients with a wide spectrum of diseases. It is multifactorial being influenced by many modifying factors (e.g. psychological, social) and is clearly distinct from other symptoms like tachypnea and hyperinflation.

The American Thoracic Society defined dyspnea as: 'a term used to characterize a subjective experience of breathing discomfort that is comprised of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological and behavioral responses (Stulbarg & Adams, 2000).

4. Measurement Framework:

It is important to identify and employ a conceptual framework for determining what is to be operationalized, it is equally important to identify and employ a measurement framework to guide the design and interpretation of the measurement (Waltz, Stickland & Lenz, 2005). The two major framework for measurement are the norm-referenced and the criterion-referenced approaches.

A norm-referenced approach is employed when the interest is in evaluating the performance of a subject relative to the performance of other subjects in the same well-defined comparison or norm group. Our scale is 12-item norm-referenced measure of the dyspnea experienced by patients with advanced cancer stages. The scores on each item in the scale range from 1 to 5 points, depending on the patient's degree of agreement with the item. A high score indicates high level of dyspnea for that item, and a low score indicates low dyspnea level. The maximum total score is 60 and the lowest possible score is 12 points. The value for a given person takes on meaning when it is considered in light of the scores obtained by other patients who responded to the same tool.

5. Strategies for Designing Measurement Tool and Procedure:

Essential steps in the design of a norm-referenced measure are (1) selection of a conceptual model; (2) explicating the objectives for the measure; (3) development of a blueprint; and (4) construction of the measure including administration, item set, and scoring rules and procedures.

5.1. Explicating the Objective for the Measure:

The second step in developing a tool is explicating the objective. The behavioral objective of the tool are stated by using Tyler and Kibler approach, where the objective is composed of three components: (1) a description of the respondents; (2) delineation of the kind of behavior the respondent will exhibit to demonstrate accomplishment of the objective (3) a statement of the kind of content to which behavior relates (Waltz, Stickland & Lenz, 2005). The objective of this tool is to assess the multidimensional nature of dyspnea among patients with advanced cancer.

5.2. Blueprinting

Given a set of objectives reflecting the process or outcomes to be assessed by the measure and a content outline representative of the domain of interest, the next step is to develop a blueprint to establish the specific scope and emphasis of the measure. From the blueprint, one can readily tell the topics about which questions to be asked and the type of critical behaviors subjects will be required to demonstrate (Waltz, Strickland, & Lenz, 2005; Alasad et. Al, 2015). To assess the multidimensional nature of dyspnea among advanced cancer patient in the blueprint, the measure was spread over three domains: physical, psychological, and environmental triggers.

5.3. Construction of the Measure

5.3.1. Administration

In this study, the tool was administered by the principal investigator who developed this tool. The participants received information about the measure. The information included measure's purpose, how to record their responses to items, assurance for their anonymity and confidentiality, voluntary participation without coercion, and their right of withdrawal or refuse to participate without any penalty. In addition, participants were informed that the time to complete the scale 3 to 5 minutes. All this information was summarized in the cover letter.

The reading skills is needed to complete the scale, however for participants who are unable to read or focus a structured interview was used, the data collector was available until the participants complete the scale to explain and clarify any queries. This measure is composed of two questionnaires; the first will obtain the demographic characteristics of the participant and the second will be regarding the dyspnea scale.

Pilot testing of the instrument used to check for understanding, clarity and time required for filling dyspnea scale. Specific concerns such as item difficulty, item discrimination, internal consistency, response rates, and parameter estimation in general are all relevant.

5.3.2. Items

This dyspnea scale contains 12 items under three domains. These domains were named as 1) "Physical triggers", physical dyspnea or dysfunction of ventilation with organic causes worsened on exertion (five items), 2) "psychological triggers", affected or amplified by psychological status (four items), and 3) "environmental triggers", environmental influences mostly concerned the weather (three items).

In the first development phase, items which describe, represent and evaluate dyspnea were collected in the following ways: (a) by interviewing 22 dyspneic cancer patients closely in a clinical setting, (b) by brainstorming with 4 oncologists, 3 consultant in care palliative unit, 10 nurses engaged in palliative care unit for more than 4 years of experience, and one psychology expert in palliative patients and (c) by picking up from reported papers on dyspnea. After collecting a huge pool of items, omit the items that may: (a) be difficult for anyone to understand, that is, local dialect, jargon and vague vocabulary;(b) overlap each other, that is, linguistically synonym;(c) items are not related to objective of this tool is to assess the multidimensional nature of dyspnea; and (d) be confounded with symptoms other than dyspnea, for example, description of cough and sputum.

Inappropriate items that met the following criteria were than eliminated from the draft scale: (a) items which quite a few patients required further explanation to complete, (b) items whose correlation with VAS of dyspnea was not significant, (c) items given a rating of quite relevant /very relevant by both raters involved see below in part Validity, and (d) items whose standard deviation of response was less than 1.0. In the development phase, 101 terms were listed; most came from brainstorming and the remaining from interview and checking reviews, these items were reduced according to the criteria described above. The instrument was translated into Arabic language. A translation and back translation was carried out by linguistic professionals.

5.3.3. Scoring

The scoring of item is a 5- point Likert scale ranging from 1 (not at all) to 5 (very much). The maximum total score is 60: 25 points for "physical triggers", 20 for "psychological triggers", and 15 for "environmental triggers." The higher the score is, the more the severe the patient's dyspnea.

5.3.4. Translation

The original measure from which this tool is developed is available in English language. Thus, the modified tool that is developed in this study is translated into Arabic language in order to be used here while maintaining the meaning of the items, then it was back translated into the original language which resulted in an equivalent forms.

6. Methods:

6.1. Design

This is a cross-sectional study to assess the psychometric properties of the dyspnea scale with patients with advanced cancer disease.

6.2. Sample

A convenience sample of 30 patients with the following eligibility criteria: (a) to have been pathologically diagnosed as having cancer and to have been informed of their diagnosis, (b) diagnosed as having cancer in advanced stage (i.e. in clinical stage IIIa [un-resectable], IIIb, or IV) or recurrent stage, (c) to be 18 years or older, (d) to be able to complete the scale, and (e) agree to participate voluntarily in this study.

6.3. Setting

The sample was selected from the palliative care unit at a specialized cancer care center in Amman. It has a capacity of 180 beds and treats both adult and pediatric patients. KHCC treats over 3,500 new cancer patients each year from Jordan and the region. KHCC has established programs that focus on all stages of comprehensive cancer care: from prevention and early detection, through diagnosis and treatment, to palliative care.

7. Psychometric Analysis and Validation

7.1. Validity

7.1.1. Construct validity

Construct validity (i.e. whether each item represents and correlates with each domain) was evaluated by factor analysis followed by Varimax rotation (Ahmad, 2010). The strength of the correlation between items was evaluated by calculating Pearson's correlations. Convergent validity (i.e. the strength of the correlations between the items and aggregate, and other validated measures of dyspnea) was assessed by Pearson's correlations with VAS of dyspnea completed at the same time. Content validity was evaluated by two experts in the field.

The primary concern in determining the construct validity is the extent to which relationships among items included in the measure are consistent with the theory and concepts as operationally defined. One of the methods to assess the construct validity of an instrument is the exploratory factor analysis (Waltz, et al., 2005; Ahmad, 2014). The ultimate goal is to explain the most variance in the set of variables or items with the fewest number of factors as determined using a statistical criterion such as having an eigenvalue greater than 1.0, or the percent of variance explained.

The data were analyzed by Principal Component Analysis with Varimax rotation, the default criterion to retain the factors was the fixed number of factors to be extracted with three factors (Dardas & Ahmad, 2014). This was selected because the initial factor extraction with eigenvalue greater than 1.0 resulted in six factors. This factor solution

extracted and rotated only three factors that had eigenvalues greater than one, results are shown in Table 1.

Rotated factor loading were examined to assess the nature of the three fixed, extracted, retained and Varimax-rotated factors. Five items had high clean loadings with factor one. Four items also had high clean loadings with factor two, three items had clean loadings with factor three.

Table 1: *Construct validity: factor loading pattern (followed by varimax rotation) in the validation phase.*

Item number and content	Factor 1	Factor 2	Factor 3
10. Narrower	0.82	0.16	-0.25
12. Stuck in the airway	0.74	0.31	0.01
4. Short of breath	0.69	0.16	-0.27
8. Shallow	0.63	-0.29	0.26
6. Panting	0.61	0.35	-0.25
7. Breathing difficulty that one doesn't know what to do	0.11	0.85	-0.19
9. Breathing may stop	0.25	0.81	-0.15
5. Accompanied by palpitations and sweating	0.38	0.67	0.01
11. As if drowning	0.45	0.65	-0.08
12. whether	-0.16	-0.11	0.94
13. room environment	-0.29	-0.01	0.91
14. Breath slowly	-0.18	-0.17	0.88
Percent of Explained Variance	27	21	14
Total Variance Explained	62%		

Although it was difficult to interpret the meaning of each factor on the basis of the wording of the questions alone, it was hypothesized that these three factors indicate the following: Factor 1, "Physical triggers", physical dyspnea or dysfunction of ventilation with organic causes worsened on exertion; Factor 2, "psychological triggers", affected or amplified by psychological status; Factor 3 "environmental triggers", environmental influences mostly concerned the weather.

The first factor, accounting for 27% of the total variance, consisted of five items, the second, accounting for 21%, contained four items, and the third, accounting for 14% consisted of three items. There were significant correlations for all pairs of the subscale. The mean value of the inter-subscale correlation coefficient was 0.48. (Table 2).

Table 2: *Inter-subscale correlation of Dyspnea Scale factors*

	Factor 1	Factor 2	Factor 3
Factor 2	.65		
Factor 3	.49	.31	
Total score	.91	.76	.75

P < 0.01

The lack of definite independence of each factor was observed in the following findings. First, there were significant inter-correlations between each factor (average 0.48). Second, some items loaded not for one, but for both two factors. This occurred may be because of small sample size.

Finally the results of factor analysis showed some factors had well loadings, but items overlapping across the factors made the extraction a difficult, this could be because of small sample size.

7.1.2. Content Validity Index (CVI)

The tool was given to two experts in the field of oncology/ palliative care to rate the relevance of the items to the objective on a 4-point Likert scale. (1) not relevant, (2) somewhat relevant, (3) quite relevant, and (4) very relevant. There was agreement about 10 items that are quite/very relevant, and 2 items somewhat relevant (items asking about the duration of nausea). The Content Validity Index (CVI) is defined as the proportion of items given a rating of quite relevant /very relevant by both raters involved (Waltz, Strickland, & Lenz, 2010). The results are displayed in table 3. For this tool, the CVI= 10/12 or 0.83 which considered an acceptable level of CVI (Dardas & Ahmad, 2014).

Table 3: *Content Validity for the 12 items of the tool judged by two experts*

	Judge 1		Score	
	(1 or 2) not/somewhat relevant	(3 or 4) quite/very relevant		
Judge 2	(1 or 2) not/somewhat relevant	2	0	2
	(3 or 4) quite/very relevant	0	10	
Total		2	10	12

7.1.3. Convergent validity

Each of the factors significantly correlated with VAS of dyspnea (average $r = 0.57$, $P < 0.001$) and with modified Borg's scale (average $r = 0.52$, $P < 0.001$). The results are shown in the Table 4.

Table 4: *Convergent validity by correlations between two Scales*

	VAS of dyspnea	Borg's Scale
Factor 1	.77	.72
Factor 2	.53	.41
Factor 3	.40	.44
Total score	.72	.67

7.2. Reliability

The attributes of reliability assessed with this tool is internal consistency (Cronbach's alpha coefficient), which is equal in value to the mean of the distribution of all possible split-half coefficients associated with a specific set of items. Cronbach's alpha coefficients of the subscale were 0.83, 0.81, and 0.94, respectively (average 0.89). It considered high (Nunnally & Bernstein, 1994). All statistical procedures were performed using SPSS version 17.

8. Limitations:

The limitations of this project are: (1)we need large sample size and heterogeneous group to generalize the pilot study results of this tool, (2) Due to the time constraint, there was no IRB form submitted to KHCC, and the patients were approached socially to fill the scale, and this is considered a limitation of this pilot study. For the future development of the tool, ethical approval should be considered in early stage of the study, (3) cross-cultural validation was also not performed. Further improvements and validation are needed.

9. Conclusion

This tool developed in this study is a brief, self-rating scale that assesses the multidimensional nature of dyspnea. Its feasibility, reliability and validity are satisfactory for clinical use, although a few problems still remain in its construction. Further study of correlated factors on this might contribute to better understanding the etiology of dyspnea and establishing a therapeutic strategy.

Corresponding Author:

Muayyad Ahmad, Prof.
Faculty of Nursing, the University of Jordan.
E-mail: mma4jo@yahoo.com

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