

Similarity and Stability of Symptom Cluster in Severity and Distress among Persons with Chronic Obstructive Pulmonary Disease

Chomphoonut Srirat, Somchit Hanucharurnkul, Suparb Aree-Ue, Tiraporn Junda

Abstract : This study aimed to explore symptom clusters in severity and distress dimensions as well as similarity and stability, determined twice at 4-weekly intervals, among Thai persons with chronic obstructive pulmonary disease. The participants (n=250) were purposively selected to complete the Personal Information Form and the Bronchitis Emphysema Symptom Checklist. A Principal Component Analysis with a Varimax rotation was used to investigate symptom clusters in dimensions of severity and distress at Times 1 and 2, and the similarity and stability of clusters were determined with a numerical approach.

The results demonstrated clusters of symptom severity and distress existed both Times 1 and 2. The similarity in symptom clusters between both dimensions revealed six and five clusters, respectively at Times 1 and Time 2 with a replication rate of 75–100%. At Time 1, six similar clusters were: emotional problems, memory function decline, disease-related fatigue, respiration difficulty, sleep alteration, pain and unpleasant sensation, and chest discomfort, whereas the cluster of disease-related fatigue disappeared at Time 2. As for stability, the four core set of symptom severity and distress identified with a replication rate of more than 75%, were; 1) emotional problems, 2) memory function decline, 3) sleep alteration, and 4) pain and unpleasant sensation.

Findings from this study may enable nurses to assess symptoms as clusters in either distress or severity to develop a cost-effective intervention program for persons with COPD experiencing these clusters of symptoms.

Pacific Rim Int J Nurs Res 2015; 19(2) 89–106

Keywords: Chronic obstructive pulmonary disease; Symptom experiences; Symptom cluster; Symptom distress; Symptom severity

Introduction

Research related to the symptoms experiences in various group of persons living with chronic diseases has shifted from studying only single symptoms to multiple or clustering of symptoms.^{1–4} The group or cluster of symptoms refers to three or more co-existing symptoms that are related to each other.⁵ This shift to clustering also proposes a new way of symptom

Correspondence to: Chomphoonut Srirat^{*}, RN, PhD Lecturer, Division of Nursing Science, Faculty of Nursing, Chiang Mai University, Thailand.
E-mail: chomphoonut.s@cmu.ac.th

Somchit Hanucharurnkul, RN, PhD Professor Emeritus, Ramathibodi School of Nursing, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand. **Email:** somchit.han@mahidol.ac.th

Suparb Aree-Ue, RN, PhD Associate Professor, Ramathibodi School of Nursing, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand. **Email:** suparb.aree@mahidol.ac.th

Tiraporn Junda, RN, PhD Assistant Professor, Ramathibodi School of Nursing, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand. **Email:** tiraporn.jun@mahidol.ac.th

assessment and management.⁶ Most studies on symptom clusters have focused around persons with cancer.^{1,5,7-9} In fact, persons with chronic obstructive pulmonary disease (COPD) inevitably suffer from concurrent symptoms simultaneously in the course of the disease that greatly adversely impact on functional status and quality of life.^{10,11} To effectively and economically manage various symptoms occurring simultaneously, more knowledge on symptom clusters is needed. However, symptom experience is composed of three dimensions; prevalence (frequency), severity and distress^{12, 13} but severity and distress dimensions have the most impact on quality of life among persons with COPD.^{4,11} Thus, symptom management is usually based on these two dimensions.^{11, 13-14} However, the symptoms occurring might dynamically change to exacerbation and result in perceiving the severity and distress.¹³ This leads to the questions of whether clusters on these two dimensions are similar and whether they are stable over time. To extend knowledge in these aspects, a longitudinal study for exploring symptom clusters in severity and distress dimensions over time among persons with COPD is essential.

Literature Review

The concept of symptom cluster in nursing perspective was initially proposed by Dodd and associates⁵, and was defined as “three or more concurrent symptoms that are related to each other but are not required to share the same etiology”. Afterwards, Kim et al.⁶ refined this definition by adding that symptom clusters consist of stable groups of symptoms, are relatively free from other clusters, and may indicate specific underlying dimensions of symptoms. Relationships among symptoms within a cluster should be more powerful than those across different clusters. This concept has recently become prominent in symptom-related nursing research, especially in

cancer. Moreover, this eminent topic became important in nursing research of various chronic diseases as a result of multiple co-occurring symptoms leading to a lower quality of life, readmission, and cost of burden.²⁻⁴

Symptom clusters can be determined by applying one of two main approaches.¹⁵ For the first, clusters may be clinically predefined, and the relationship between symptoms within the cluster examined statistically. By using a limited number of targeted symptoms, less than 5, for which previous reports demonstrate clinical association, predefined clusters may exist.¹⁵ Another approach is the statistical analysis of large data sets in symptoms for which clusters might not be predetermined previously, that can be used in either factor or cluster analysis depending on the study objectives, the underlying assumptions, and the method of symptom assessment.¹⁶ Based on a matrix of correlation coefficients between the variables, factor analysis determines the associations among a number of variables (e.g. symptom severity).¹⁷ Meanwhile, cluster analysis is applied to explore underlying group of persons who have similar symptom experiences or profile.¹⁷

According to the Symptom Management Model (SMM)¹⁸, symptom experiences are composed of three aspects: perception, evaluation and response to symptom. Symptom evaluation and response perceived by the person are described as symptom severity and distress in this study.

Two previous studies^{4, 19} regarding symptom cluster among persons with COPD were found to be inconsistent. A study by Park et al.⁴ revealed that three clusters of symptom severity existed among Korean persons with COPD or asthma by using cluster analysis. They were: cluster 1 (pain, feeling nervous, numbness and tingling in the hands and feet, difficulty sleeping, shortness of breath, feeling sad and worrying), cluster 2 (lack of energy, cough, dry mouth, feeling drowsy, feeling bloated, sweats, and dizziness), and cluster 3 (problems with urination and constipation). In our

previous work¹⁹, seven clusters of symptom distress were found; respiration difficulty, disease-related fatigue, sleep alteration, pain and unpleasant sensation, emotional problems, memory function decline, and respiratory muscle weakness. These incongruent findings might be a result of the different measures and dimension used in these two studies. The first study used the Memorial Symptom Assessment Scale (MSAS) to assess symptom severity⁴ whereas the second applied the Bronchitis Emphysema Symptom Checklist (BESC).¹⁹ Also, differences in dimensions assessed may account for this disparity.

Kirkova and Walsh¹⁵ recommend that, stability/consistency, in a conceptual manner, may refer to consistent/replicated symptom clusters for a group of people at a point in time or over time, or in persons over time, including for the different groups as well. By means of the numerical approach, at least 75% of the symptoms within the primary cluster must remain over time including the most dominant or main symptom.¹⁵ In case of a cluster having four symptoms, for instance, at least three of them should appear, including the main or most dominant symptom. In addition, another issue in the study of symptom cluster is the evaluation of the multidimensional or parallel dimensions (e.g. severity, distress) in order to get a broader picture of symptom characteristics that can be an advantage for health care personnel to ameliorate the suffering from symptoms.²⁰

Little is known about the similarity of symptom clusters as assessed by two dimensions of symptom severity and distress and the stability of the clusters overtime (within 4 weeks). To fill this gap, this study aimed to:

1. Determine the similarity of symptom clusters in severity and distress dimensions at both Time 1 and Time 2, in persons with COPD.
2. Determine the stability of symptom cluster in both dimension over time (4 weeks apart) in persons with COPD.

Methods

Design

A prospective descriptive design with repeated measures was used in this study. It is a part of our large data set on a study of symptom experience, symptom cluster and management strategies in patients with chronic obstructive pulmonary disease, and extended a report previously published on Symptom Distress, Cluster, and Management in Thais with COPD.¹⁹

Ethical Considerations

Study approval was obtained from the Institutional Review Board of Mahidol University and the research ethics committee of the hospitals used as the study sites. The Protocol Number is ID 04-55-33. All participants were informed regarding: the study's purpose; assurance of privacy and confidentiality; their right to withdraw from the study without penalty or effect on their treatment; and the usefulness of the study outcome. Those agreeing to participate were asked to sign a consent form.

Sample and Setting

This study was primarily carried out for the study of symptom experiences and stability among persons with COPD as reported previously.¹⁹ That data set was obtained from the potential participants who had a confirmed diagnosis with COPD by a physician and were followed up at respiratory clinics in one university hospital and one provincial hospital. Those were approached by using purposive sampling with the following criteria: (1) aged 35 years or older (since most of COPD start from age 40²¹, thus, we identified the age of 35 as the lowest age which could be possible for this group); (2) willing to take part; and (3) could communicate in Thai language. Their medical records were also reviewed to assist with sample selection.

Also, the sample size derived from that study calculated the appropriate sample size by multiplying five times the number of 54 symptoms¹⁶ in the symptom assessment form, hence, the estimated number was approximately 270. After approaching the 270

participants the first time, however, only 250 completed the second data collection of this study and this number was an adequate size to determine the symptom clusters.²² Therefore, the sample size used in the study was 250.

Instruments

Two instruments were used; both of them were the same as our previous study¹⁹, the Personal Information Questionnaire and the Bronchitis Emphysema Symptom Checklist (BESC) Scale.

The Personal Information Questionnaire consists of two sections. The first section requests general information including age, gender, marital status, religion, education level, occupation, household income, adequacy of income and living expenses, eligible medical expenses, number of children, type of dwelling, history of cigarette smoking and liquor drinking, and the primary caregiver in the family. The second section obtained information in relation to the health status recorded in the medical chart, which is composed of weight, height, body mass index (BMI), co-morbidity diseases, duration of being confirmed having COPD, medication use, level of disease severity, and the use of oxygen therapy.

The Bronchitis Emphysema Symptom Checklist (BESC) is a 57-item questionnaire developed by Kinsman and colleagues²³ to measure symptoms, sensation, and feeling. This tool was translated to the Thai language according to the process of translation recommended by the World Health Organization (WHO).²⁴

The first author forward translated it into the Thai language and it was verified by a second author. After that, three bilingual nursing instructor panels, one specializing in COPD and two specializing in chronic care, validated this translation. Then, a Thai instructor, who earned a doctoral degree in language education from USA who did not have any knowledge about this tool, back translated it from Thai to English and found that 50 items of the 57 items matched when comparing between the back translation and the

original version, whereas, the remaining 7 items were somewhat similar in meaning. The author pre-tested this tool with 15 respondents with COPD and found it could be understood and described the meaning of symptoms by the respondents.

Symptom frequency is one dimension in the original version, which rated the frequency of each symptom occurring on a 5-point scale (0= never, 1= rarely, 2= sometimes, 3= almost always, and 4= always), higher scores indicate more frequent occurrence of symptoms. To identify the dimension of symptom severity and distress, they were added into this tool by applying a 5-point scale as follows: 1) symptom severity has been rated ranging from 1 to 5 (1= very slight, 2= slight, 3= moderate, 4= severe and 5= very severe). Higher scores indicate more severity of symptoms. 2) symptom distress has also been rated ranging from 1 to 5 (1= not at all, 2= a little bit, 3= somewhat, 4= quite a bit, and 5= very much). Higher scores indicate more distress of symptoms.

The psychometric properties of both dimensions were done. Initially, the content was validated by three experts specialized in COPD, who were two nursing instructors and one Advanced Practice Nurse (APN). The S-CVI for symptom severity and distress was .92 and .92 respectively. In addition, 4 redundant items were removed after the experts' suggestions: tired, chest congestion, irritable and forgetting things, and 1 item, pain in other regions, was added. Thus, the total number of items in this tool is 54. A pilot study with 10 persons with COPD was undertaken to test the internal consistency reliability. Cronbach's alpha was .94 and .95 for symptom severity and distress, respectively. For the main study, they were .95 and .96, respectively.

Data Collection

Before approaching the participants, the researcher obtained information regarding their health status from their medical records. Those willing to participate in the study were invited to a private room near the respiratory clinics, and the purposes and

methods of the study were explained, including ethical considerations. Informed consent was then obtained from all participants and they were asked to fill in the general data in the PIQ. They completed the BESC and SMSQ by themselves over approximately 30–45 minutes. In case the participants needed assistance due to illiteracy, visual problems or other reasons, the questionnaires were read to them, and verbal response obtained and written by the researcher in the tools. One-hundred and sixteen persons (46.4%) required this assistance. Both questionnaires were examined carefully to ascertain the completeness of data. After that, the researchers asked participants for another meeting four weeks later, depending on a convenient time and place, such as the clinic if participants were to be followed up in one month. For those who were followed up at more than one month later, data collection was taken at any convenient place, such as their home if they permitted or via postal mail without any payment. Also, the BESC was investigated carefully to verify completeness and then coded with a number and kept in a locked cabinet.

Data Analysis

The current analysis built on the previous study in which symptoms were reported by persons with COPD.¹⁹ This secondary data analysis was carried out by using SPSS version 17.0 (SPSS Inc. Chicago, IL, USA). Descriptive statistics were used to describe the characteristics of participants and symptom severity and distress at each time. A Principal Component Analysis (PCA) with a Varimax (orthogonal) rotation was carried out to investigate symptom clusters in each of severity and distress dimensions at Times 1 and 2. This technique is appropriate to identify clusters of symptoms, since the data structure was previously unknown. To examine the similarity and stability of symptom severity and distress clusters a numerical approach was used to compare the similarity and replication rate of 75% proportion of symptom in each cluster at Times 1 and 2.¹⁵

Results

Demographic characteristics: A total of 270 participants were approached to take part in the study at the beginning. However, 20 participants did not complete the second data collection. Reasons for their incompleteness were: unavailability (n=6), loss of interest (n=3), transfer to other towns (n=7), and having another illness (n=4). As described previously from the first study²¹, the mean age of participants was 71.03 years with a range of, 51–91 years. Most of them were male (n=168; 67.2%), Buddhist (n=231; 92.4%) and had primary school education (n=158; 63.2%). In terms of their living expense, the majority of participants reported its sufficiency (n=189; 75.6%) and having a monthly income of 5,000–10,000 baht (n=120; 48.0%). The universal health coverage scheme was used by 61.6% of the participants. One-third of them lived with a spouse and children (32.4%), and 20.4% needed a primary caregiver. With regard to clinical characteristics, being underweight (BMI<18.5) was reported by half of participants, most of them were past smokers (n=220, 88.0%), 8.0% (n=20) had never smoked and 4.0% (n=10) still smoked, whereas 45.6% had never drunk alcohol. Half of them (56.8%) had co morbid diseases and hypertension (33.6%). For the disease severity based on the GOLD criteria, the majority were in stage II (having $FEV_1/FVC < 0.7$; $50\% \leq FEV_1 < 80\%$ predicted with shortness of breath typically developing on exertion) and III (having $FEV_1/FVC < 0.7$; $30\% \leq FEV_1 < 50\%$ predicted with greater shortness of breath and reduced exercise capacity) (n=222, 88.8%). Approximately 24.4% of the participants used oxygen therapy at home.

Similarity of symptom clusters in both dimensions at Time 1: Seven clusters of severity existed and labeled as: emotional problems, memory function decline, disease-related fatigue, respiration difficulty, sleep alteration, pain and unpleasant sensation, and chest

discomfort. Meanwhile, clusters of symptom distress were formed into seven clusters as somewhat resembling with the clusters of severity. The similarity rate of both dimension in each cluster ranges from 75 – 100%. The overall detail is shown in Table 1.

Similarity of symptom clusters in both dimensions at Time 2: Table 2 illustrates the clusters of symptom severity and distress at time 2. For clusters of severity, six clusters were formed with the omission of the fatigue cluster. Whereas, five clusters of distress were grouped together, likewise cluster of severity, fatigue cluster disappeared. The similarity rate of both dimension in each cluster ranges from 95.4 – 100%.

Stability of symptom clusters in severity over time: From the orthogonal rotated component loadings, seven and six clusters were presented at Times 1 and 2, respectively. Six stable symptom clusters were identified as the group of core symptoms: 1) emotional problems (19 symptoms: for example, ‘feel like a cripple’, panicky, anxious, ‘feel like an invalid’, feel guilty, ‘feel like giving up’, want to die, feel helpless and feel hopeless), 2) memory function decline (4 symptoms: forget recent things, forgetful, poor memory, difficulty remembering), 3) respiration difficulty (2 symptoms: short of breath, shallow breathing), 4) sleep alteration (3 symptoms: poor sleep, trouble falling asleep, disturbed sleep), 5) pain and unpleasant sensation (4 symptoms: ‘pins and needles feeling’, leg aches, pain at other regions, tingling in arms & legs), and 6) chest discomfort (3 symptoms: chest tightness, chest filled up, mucous congestion). These core symptoms in clusters measured at Time 2 had a replication rate ranging from 50–100% in which cluster of respiration difficulty had the lowest of replication rate (50%). Core symptoms were replicated and other symptoms moved across clusters over time. Meanwhile, the cluster of fatigue-related disease vanished at Time 2. The result is displayed in Table 3.

Stability of symptom clusters in distress over time: Table 4 presents five stable symptom clusters

of distress symptom over time, which were: 1) emotional problems (19 symptoms), 2) memory function decline (4 symptoms; forget recent things, forgetful, poor memory, difficulty remembering), 3) respiration difficulty (4 symptoms; short of breath, shallow breathing, ‘hard to breathe’, mucous congestion), 4) sleep alteration (3 symptoms; poor sleep, trouble falling asleep, disturbed sleep), and 5) pain and unpleasant sensation (3 symptoms; ‘pins and needles feeling’, leg aches, pain at other regions). The replication rate in each distress cluster ranged from 66.7–100%. Cluster of respiration difficulty, which had the lowest rate of replication, was added with six symptoms at time 2, which were: ‘chest tightness’, ‘worried about getting air’, ‘feel like I need air’, ‘exhaustion’, ‘coughing’, and ‘chest filled up’. Likewise a cluster of severity, cluster of fatigue also collapsed over time.

Discussion

Similarity of symptom clusters of both dimensions of severity and distress

The result revealed that symptom clusters experienced by persons with COPD existed in both severity and distress dimensions when measured at Times 1 and 2 over a period of 4-weeks. The basic knowledge gained from this study provided a broader picture of symptom cluster from the previous studies^{4,19} regarding the similarity in the dimension of severity and distress. Taking the similarity of both dimensions into consideration at Time 1, six core sets of symptoms clusters in both dimensions existed, which were: emotional problems, memory function decline, respiration difficulty, disease-related fatigue, sleep alteration, and pain and unpleasant sensation (Table 1). The similarity rate ranged from 75–100% in six of these clusters. Meanwhile, five similar clusters of both dimensions emerged at Time 2 in which the similarity rate ranges from 95.4–100% (Table 2).

Table 1 Similarity of symptom cluster in both dimensions at Time 1 (n=250)

Severity Dimension			Distress Dimension		
Component/ Cluster label	Symptom	Factor loading	Component/ Cluster label	Symptom	Factor loading
1 /Emotional Problems	Feel like a cripple	.915	1 / Emotional Problems	Feel like a cripple	.929
	Panicky	.913		Panicky	.928
	Anxious	.881		Anxious	.883
	Feel like an invalid	.869		Feel like an invalid	.873
	Feel guilty	.868		Feel guilty	.876
	Feel like giving up	.859		Feel like giving up	.855
	Want to die	.857		Want to die	.872
	Feel helpless	.854		Feel helpless	.845
	Feel hopeless	.848		Feel hopeless	.832
	Unable to enjoy others	.841		Unable to enjoy others	.820
	Disinterested in things	.817		Disinterested in things	.829
	Disinterested in food	.770		Disinterested in food	.751
	Things smell differently	.759		Things smell differently	.788
	Frightened	.762		Frightened	.774
	Touchy	.724		Touchy	.750
	Embarrassed	.716		Embarrassed	.748
	Lonely	.704		Lonely	.698
	Scared	.684		Scared	.712
	Edgy	.679		Edgy	.667
	Short tempered	.662		Short tempered	.695
	Worried about getting air	.599		Worried about getting air	.585
	Feel like I need air	.475		Feel like I need air	.445
	Poor appetite	.437		Poor appetite	.416
	Gasping for breath	.462		Upset	.660
			Similarity rate 95.8%		
2 /Memory Function Decline	Forget recent things	.851	2 /Memory Function Decline	Forget recent things	.851
	Forgetful	.814		Forgetful	.794
	Poor memory	.799		Poor memory	.808
	Difficulty remembering	.794		Difficulty remembering	.791
	Get confused	.535		Get confused	.520
	Coughing	.516		Coughing	.578
			Sleep heavily		.363
			Similarity rate 100%		

Table 1 Similarity of symptom cluster in both dimensions at Time 1 (n=250) (cont.)

Severity Dimension Time 1			Distress Dimension Time 1		
Component/ Cluster label	Symptom	Factor loading	Component/ Cluster label	Symptom	Factor loading
3 /Disease– related Fatigue	Exhaustion	.769	4 /Disease– related Fatigue	Exhaustion	.790
	Fatigue	.722		Fatigue	.753
	No energy	.512		No energy	.587
	Upset	.652			
Similarity rate 75%					
4 /Respiration Difficulty	Short of breath	.817	3 /Respiration Difficulty	Short of breath	.794
	Shallow breathing	.809		Shallow breathing	.787
	Hard to breathe	.511		Hard to breathe	.593
	Numbness	.405		Numbness	.448
					.471
					.442
Similarity rate 100%					
5 /Sleep Alteration	Poor sleep	.833	5 /Sleep Alteration	Poor sleep	.835
	Trouble falling asleep	.831		Trouble falling asleep	.838
	Disturbed sleep	.762		Disturbed sleep	.741
Similarity rate 100%					
6 /Pain and Unpleasant Sensation	Pins and needles feeling	.746	6 /Pain and Unpleasant Sensation	Pins and needles feeling	.773
	Cramps	.731		Cramps	.744
	Leg aches	.597		Leg aches	.540
	Pain at other regions	.569		Pain at other region	.525
	Tingling in arms & legs	.419			
Similarity rate 100%					
7 /Chest Discomfort	Chest tightness	.688	7 /Respiratory muscle weakness	Weak	.742
	Chest filled up	.548		Chest filled up	.426
	Mucous congestion	.494		Tingling in arms & legs	.436

Table 2 Similarity of symptom cluster in both dimensions at Time 2 (n=250)

Severity Dimension Time 2			Distress Dimension Time 2		
Component/ Cluster label	Symptom	Factor loading	Component/ Cluster label	Symptom	Factor loading
1 /Emotional Problems	Feel like a cripple	.894	1 /Emotional Problems	Feel like a cripple	.900
	Feel helpless	.876		Feel helpless	.882
	Feel like giving up	.856		Feel like giving up	.863
	Disinterested in things	.855		Disinterested in things	.863
	Feel like an invalid	.834		Feel like an invalid	.835
	Panicky	.829		Panicky	.834

Table 2 Similarity of symptom cluster in both dimensions at Time 2 (n=250) (cont.)

Severity Dimension Time 2			Distress Dimension Time 2		
Component/ Cluster label	Symptom	Factor loading	Component/ Cluster label	Symptom	Factor loading
	Feel guilty	.809		Feel guilty	.831
	Want to die	.795		Want to die	.801
	Touchy	.789		Touchy	.789
	Feel hopeless	.764		Feel hopeless	.769
	Anxious	.749		Anxious	.732
	Upset	.740		Upset	.748
	Scared	.717		Scared	.733
	Frightened	.709		Frightened	.704
	Lonely	.671		Lonely	.647
	Unable to enjoy others	.669		Unable to enjoy others	.688
	Embarrassed	.635		Embarrassed	.655
	Things smell differently	.571		Things smell differently	.568
	Fatigue	.570		Fatigue	.567
	Disinterested in food	.529		Disinterested in food	.540
	Get confused	.502		Get confused	.502
	Edgy	.458		Gasping for breath	.432
				Similarity rate 95.4%	
2 /Respiration	Chest filled up	.781	2 /Respiration	Chest filled up	.777
Difficulty	Mucous congestion	.773	Difficulty	Mucous congestion	.795
	Hard to breathe	.620		Hard to breathe	.658
	Worried about getting air	.577		Worried about getting air	.581
	Chest tightness	.575		Chest tightness	.610
	Coughing	.547		Coughing	.488
	Feel like I need air	.496		Feel like I need air	.576
				Short of breath	.530
				Shallow breathing	.528
				Exhaustion	.523
				Similarity rate 100%	
3 /Memory	Forget recent things	.824	3 /Memory	Forget recent things	.834
Function	Poor memory	.800	Function	Poor memory	.809
Decline	Difficulty remembering	.774	Decline	Difficulty remembering	.801
	Forgetful	.731		Forgetful	.684
				Similarity rate 100%	
4 /Pain and	Pins and needles feeling	.821	4 /Pain and	Pins and needles feeling	.804
Unpleasant	Weak	.602	Unpleasant	Weak	.575
Sensation	Leg aches	.596	Sensation	Leg aches	.587
	Pain at other region	.534		Pain at other region	.653
	Tingling in arms and legs	.519		Tingling in arms and legs	.513
	Gasping for breath	.458			
				Similarity rate 100%	

Table 2 Similarity of symptom cluster in both dimensions at Time 2 (n=250) (cont.)

Severity Dimension Time 2			Distress Dimension Time 2		
Component/ Cluster label	Symptom	Factor loading	Component/ Cluster label	Symptom	Factor loading
5 /Sleep Alteration	Poor sleep	.855	5 /Sleep Alteration	Poor sleep	.874
	Trouble falling asleep	.780		Trouble falling asleep	.828
	Disturbed sleep	.765		Disturbed sleep	.746
	Numbness	.412		Numbness	.462
				Poor appetite	.391
				Similarity rate 100%	
6 /Breathless Induce Exhausted	Shallow breathing	.525			
	Short of breath	.524			
	Exhaustion	.496			
	Poor appetite	.483			

Clusters of symptom severity and its stability over time

Principal Component Analysis (PCA) with an orthogonal rotation was carried out identifying seven clusters of severity of symptoms among persons with COPD. They were: emotional problems, memory function decline, disease-related fatigue, respiration difficulty, sleep alteration, pain and unpleasant sensation, and chest discomfort. These clusters consisted of 3–22 symptoms due to the assessment tool used in the study comprising up to 54 items.

The first cluster of severity was emotional problems, which were related to a negative state among persons with COPD when faced with a difficult situation in managing their disease progression that brought about suffering from a psychological distress, for instance, ‘feeling hopeless’, ‘feeling like a cripple’, ‘wanting to die’. The cluster of memory function decline was identified and included four symptoms related to the inability to recall events in the past or memory decline. Four symptoms relating to the tiredness when performing an activity of daily living and/or working and/or dealing with their disease was grouped as disease-related fatigue.

The most powerful severity is the cluster of respiration difficulty including four symptoms representing

the abnormality of breathing pattern due to the pathophysiology of COPD. Sleep alteration comprised three symptoms related to the interference of a normal sleep pattern. The sixth cluster was pain and unpleasant sensation included five symptoms related to pain and abnormal sensation, which is an unusual prickling sensation that can happen in any part of the body. Three symptoms related to an uncomfortable feeling in thorax caused by COPD was finally clustered as chest discomfort.

Six clusters were identified at Time 2; emotional problems, memory function decline, respiration difficulty, sleep alteration, pain and unpleasant sensation, and chest discomfort, whereas the cluster of fatigue disappeared (Table 3). Based on the suggestion of Kirkova and Walsh¹⁹, six clusters of symptoms were determined to be stable over time from this finding. Also, identifying consistency with numerical approach, with the 75% replication of the first time, groups of symptoms were achieved in five clusters, ranging from 79.1–100%, although the cluster of respiration difficulty presents a replication rate of only 50%. It may be inferred that these six stable clusters had a high correlation between symptoms in each cluster and might also come from the same etiology / causal mechanism, even though time had elapsed.^{25, 26}

Table 3 Stability of symptom cluster in severity over time (n=250)

Time 1			Time 2				
Component/ Cluster label	Symptom	Factor loading	Component/ Cluster label	Symptom	Factor loading		
1 /Emotional Problems	Feel like a cripple	.915	1 /Emotional Problems	Feel like a cripple	.894		
	Panicky	.913		Panicky	.829		
	Anxious	.881		Anxious	.749		
	Feel like an invalid	.869		Feel like an invalid	.834		
	Feel guilty	.868		Feel guilty	.809		
	Feel like giving up	.859		Feel like giving up	.856		
	Want to die	.857		Want to die	.795		
	Feel helpless	.854		Feel helpless	.876		
	Feel hopeless	.848		Feel hopeless	.764		
	Unable to enjoy others	.841		Unable to enjoy others	.669		
	Disinterested in things	.817		Disinterested in things	.855		
	Disinterested in food	.770		Disinterested in food	.529		
	Frightened	.762		Frightened	.709		
	Things smell differently	.759		Things smell differently	.571		
	Touchy	.724		Touchy	.789		
	Embarrassed	.716		Embarrassed	.635		
	Lonely	.704		Lonely	.671		
	Scared	.684		Scared	.717		
	Edgy	.679		Edgy	.894		
		Short tempered		.662		Upset	.740
		Worried about getting air		.599		Fatigue	.570
		Feel like I need air		.475		Get confused	.502
		Gasping for breath		.462			
	Poor appetite	.437					
		</					

Table 3 Stability of symptom cluster in severity over time (n=250) (cont.)

Time 1			Time 2		
Component/ Cluster label	Symptom	Factor loading	Component/ Cluster label	Symptom	Factor loading
5 /Sleep Alteration	Poor sleep	.833	4 /Sleep Alteration	Poor sleep	.855
	Trouble falling asleep	.831		Trouble falling asleep	.780
	Disturbed sleep	.762		Disturbed sleep	.765
				Numbness	.412
				Replication rate 100%	
6 /Pain and Unpleasant Sensation	Pins and needles feeling	.746	5 /Pain and Unpleasant Sensation	Pins and needles feeling	.821
	Leg aches	.597		Leg aches	.596
	Pain at other regions	.569		Pain at other region	.534
	Tingling in arms & legs	.419		Tingling in arms and legs	.519
	Cramps	.731		Gasping for breath	.458
				Weak	.602
				Replication rate 80%	
7 /Chest Discomfort	Chest tightness	.688	6 /Chest Discomfort	Chest tightness	.575
	Chest filled up	.548		Chest filled up	.781
	Mucous congestion	.494		Mucous congestion	.773
				Hard to breathe	.620
				Worried about getting air	.577
				Coughing	.547
				Feel like I need air	.496
				Replication rate 100%	

However, the various additional symptoms grouped in cluster of chest discomfort and the vanishing clusters of fatigue among persons with COPD should be mentioned. For the cluster of chest discomfort, the additional four symptoms ('hard to breathe', 'worried about getting air', 'coughing', 'feel like I need air') were also grouped with them at Time 2 (Table 3). One possible explanation for the disappearance of these 4 symptoms at Time 1 may be due to not having the same etiology. With regard to Time 1, 'hard to breathe' grouped with short, and shallow breathing, and the cause may originate from the abnormal airway in which they had trouble to respire, whereas 'hard to breathe' grouped with 'chest discomfort' at Time 2. This might be due to the cause of a high pressure in chest cavity leading to an impact on not only respiration but also emotion.²⁷ Nevertheless, it is noted that all these seven symptoms seem to be closely

related to each other and have a high association to be grouped together. This phenomenon, thus, may be explained through the pathology of COPD progression. As a consequence of airflow limitation due to narrowed airway and abundant mucous production and also that the elastic recoil of lungs is impaired, there is an increase in airway resistance and lung hyperinflation causing incomplete expiration.^{28,29} From these mechanisms, persons with COPD may develop a feeling of their being chest filled up or tight, in addition, no abundant mucous production immediately triggers coughing to expel mucous from the airway, and also causing difficulty in breathing.³⁰ At the same time, during this suffering, all concurrent symptoms also cause persons with COPD psychological symptoms (e.g. worrying, fear).³¹

It is seen that the cluster of disease-related fatigue was collapsed and scattered to other clusters.

As we know, several terms were used as fatigue, for instance, energy deficiency, no energy, tiredness, or exhaustion. Moreover, fatigue can be assessed by classifying it as physical or mental fatigue.^{32,33} This may explain why the cluster of fatigue in this study collapsed when measured at Time 2, fatigue moved to the cluster with psychological symptoms, while exhaustion and no energy were grouped with physical symptoms. In addition, terms ‘fatigue and exhaustion’ in Northern Thai language can be understood both in the same way in physical and mental meaning. Perhaps, it may be due to a strong relationship between fatigue and dyspnea/respiration difficulty and share or come from same etiology.^{30, 32, 34}

Clusters of symptom distress and its stability over time

The clusters of symptom distress at Time 1 were similar to the clusters of severity, but not identical. They

were: emotional problems, memory function decline, respiration difficulty, disease-related fatigue, sleep alteration, pain and unpleasant sensation, and respiratory muscle weakness. Meanwhile, five clusters of symptom distress at Time 2 existed; emotional problems, memory function decline, respiration difficulty, sleep alteration, pain and unpleasant sensation (Table 4). The stability of clusters over time revealed the core four stable clusters of distress (emotional problems, memory function decline, sleep alteration, pain and unpleasant sensation), which achieved at least a 75% replication rate determining stability of clusters, even though the cluster of respiration difficulty showed only 66.7%. Obviously, they were similar to the clusters of symptom severity in terms of the number of clusters and the core sets of symptoms, as previously discussed regarding the realization of the concurrent symptoms from participants’ view.

Table 4 Stability of symptom cluster in distress over time (n=250)

Time 1			Time 2		
Component/ Cluster label	Symptom	Factor loading	Component/ Cluster label	Symptom	Factor loading
1 /Emotional Problems	Feel like a cripple	.929	1 /Emotional Problems	Feel like a cripple	.900
	Panicky	.928		Panicky	.834
	Anxious	.883		Anxious	.732
	Feel guilty	.876		Feel guilty	.831
	Feel like an invalid	.873		Feel like an invalid	.835
	Want to die	.872		Want to die	.801
	Feel like giving up	.855		Feel like giving up	.863
	Feel helpless	.845		Feel helpless	.882
	Feel hopeless	.832		Feel hopeless	.769
	Disinterested in things	.829		Disinterested in things	.863
	Unable to enjoy others	.820		Unable to enjoy others	.688
	Things smell differently	.788		Things smell differently	.568
	Frightened	.774		Frightened	.704
	Disinterested in food	.751		Disinterested in food	.540
	Touchy	.750		Touchy	.789
	Embarrassed	.748		Embarrassed	.655
	Scared	.712		Scared	.733
	Lonely	.698		Lonely	.647
	Upset	.660		Upset	.748
	Short tempered	.695		Fatigue	.567
	Edgy	.667		Get confused	.502
	Worried about getting air	.585		Gasping for breath	.432

Table 4 Stability of symptom cluster in distress over time (n=250) (cont.)

Time 1			Time 2		
Component/ Cluster label	Symptom	Factor loading	Component/ Cluster label	Symptom	Factor loading
	Feel like I need air	.445			
	Poor appetite	.416			
			Replication rate 79.1 %		
2 /Memory	Forget recent things	.851	2 /Memory	Forget recent things	.834
Function	Poor memory	.808	Function	Poor memory	.809
Decline	Forgetful	.794	Decline	Forgetful	.684
	Difficulty remembering	.791		Difficulty remembering	.801
	Coughing	.578			
	Get confused	.520			
	Sleep heavily	.363			
			Replication rate 100 %		
3 /Respiration	Short of breath	.794	3 /Respiration	Short of breath	.530
Difficulty	Shallow breathing	.787	Difficulty	Shallow breathing	.528
	Hard to breathe	.593		Hard to breathe	.658
	Mucous congestion	.442		Mucous congestion	.795
	Gasping for breath	.471		Chest tightness	.610
	Numbness	.448		Worried about getting air	.581
				Feel like I need air	.576
				Exhaustion	.523
				Coughing	.488
				Chest filled up	.777
			Replication rate 66.7 %		
4 /Disease- related	Exhaustion	.790			
fatigue	Fatigue	.753			
	No energy	.587			
5/ Sleep	Trouble falling asleep	.838	4 /Sleep	Trouble falling asleep	.828
Alteration	Poor sleep	.835	Alteration	Poor sleep	.874
	Disturbed sleep	.741		Disturbed sleep	.746
				Numbness	.462
				Poor appetite	.391
			Replication rate 100 %		
6 /Pain and	Pins and needles feeling	.773	5 /Pain and	Pins and needles feeling	.804
Unpleasant	Leg aches	.540	Unpleasant	Leg aches	.587
Sensation	Pain at other region	.525	Sensation	Pain at other region	.653
	Cramps	.744		Weak	.575
				Tingling in arms and legs	.513
			Replication rate 75 %		
7 /Respiratory	Weak	.742			
muscle	Tingling in arms and legs	.436			
weakness	Chest filled up	.426			

Nevertheless, several symptoms shifted across clusters from Time 1 to Time 2, interestingly, from emotional problems (psychological) to respiration difficulty (physical) cluster, or vice versa. At Time 1, 'worried about getting air' and 'feel like I need air' grouped in emotional problems cluster and shifted to group with cluster of respiration difficulty at Time 2, whereas 'gasping to breath' moved from the cluster of respiration difficulty to emotional problems. One possible explanation may be the close relationship in these symptoms in that they interact with one another to cause a vicious cycle of symptoms. It became apparent that the participants' experienced multiple concurrent symptoms, both physical and psychological, that formed as various clusters. As anticipated, respiration difficulty was the most distressing group of symptoms among people with COPD, it can feel very threatening, especially when gasping for breath occurred, and this provokes the development of anxiety or other psychological distress, for instance, worry or anxiety.^{35,36} This results increased severity of breathlessness or dyspnea to panic to breathe.³¹ Moreover, fear of dyspnea may lead to avoidance or limiting physical activities that cause breathlessness of exertion and be likely to further deconditioning.³⁷ This phenomenon may induce persons with COPD having a depressed mood that results in triggering the physical symptom evoked, and being a circular event, finally, persons with COPD have a lower quality of life.^{31, 37,38}

Limitations

The present study has some limitations that need to be taken into consideration. Since our participants were persons with COPD who had a moderate level of disease severity attending at COPD clinics from one province in the north of Thailand, our findings should not be generalized to those who had a high level of disease severity and not attending at COPD clinics

as well as those in other regions of the country. Assessing the fatigue symptom in the BESC tool should be cautious since it could be understood as physical vice versa mental in Northern Thai language. Although, this study tried to bridge the gap in the similarity and stability of symptom clusters over time by measuring symptoms two times in a 4-week interval, the cluster of severity and distress seemed to be stable over time. Thus firm conclusions could not be drawn after this period and further exploration to evaluate symptoms over a longer period is required.

Conclusions and Implications for Nursing Practice and Research

With regard to symptom cluster among persons with COPD, this is the first study that provided a preliminary finding in terms of its existence in dimensions of severity and distress including its similarity and stability of a core set of symptoms in clusters over time evaluating a second time in after a 4-week interval. Some recommendations for implications of nursing practice and research are presented.

For nurses and other health professionals, these findings may provide a better understanding of these phenomena among persons with COPD in order to design an intervention program to manage symptoms as clusters, rather than managing isolated symptoms. Also, the program can be modified if instability exists. In addition, symptom assessment should be focused on distress dimension since it reflects the severity as well. For future nursing research, a long-term follow-up study should be extended for a longer period such as six months to one year with monthly assessment.

Acknowledgments

The authors acknowledge all participants in this study as well as the Faculty of Nursing, Chiang Mai University for providing support of the study.

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ความเหมือนและความคงที่ของกลุ่มอาการที่รุนแรงและทุกข์ทรมานในผู้ป่วยโรคปอดอุดกั้นเรื้อรัง

ชมพูนุท ศรีรัตน์* สมจิต หนูเจริญกุล สุภาพ อารีเอื้อ อธิราภรณ์ จันทร์ดา

บทคัดย่อ: การศึกษาเชิงบรรยายครั้งนี้วัตถุประสงค์เพื่อสำรวจ ความเหมือนและความคงที่กลุ่มอาการในมิติของความรุนแรงและความทุกข์ทรมานในผู้ป่วยโรคปอดอุดกั้นเรื้อรัง โดยการประเมิน 2 ครั้ง ในระยะเวลาห่างกัน 4 สัปดาห์ กลุ่มตัวอย่างเป็นผู้ป่วยโรคปอดอุดกั้นเรื้อรังจำนวน 250 คนที่มีคุณสมบัติตามเกณฑ์ที่กำหนด เครื่องมือที่ใช้ได้แก่ แบบบันทึกข้อมูลส่วนบุคคล และแบบประเมินอาการ

ผลการศึกษาพบว่ากลุ่มอาการในมิติของความรุนแรงและความทุกข์ทรมานมีความเหมือนกัน 6 กลุ่ม เมื่อประเมินครั้งที่ 1 ได้แก่ 1) ความเจ็บปวดทางอารมณ์ 2) ความจำลดลง 3) ความอ่อนล้า 4) ความลำบากในการหายใจ 5) การนอนหลับเปลี่ยนแปลง และ 6) กลุ่มอาการปวดและเปลี่ยนแปลงการรับรู้ความรู้สึก เมื่อประเมินครั้งที่ 2 ไม่พบความเหมือนของกลุ่มอาการอ่อนล้า สำหรับความคงที่พบ 4 กลุ่มอาการหลักที่คงที่ในมิติของความรุนแรงและทุกข์ทรมาน ได้แก่ 1) ความเจ็บปวดทางอารมณ์ 2) ความจำลดลง 3) การนอนหลับเปลี่ยนแปลง และ 4) กลุ่มอาการปวดและเปลี่ยนแปลงการรับรู้ความรู้สึก

ข้อมูลเบื้องต้นที่ได้จากการศึกษาครั้งนี้ จะช่วยให้ผู้ให้บริการทางสุขภาพมีความเข้าใจเกี่ยวกับความเหมือนและความคงที่ของกลุ่มอาการทั้ง 2 มิติ ในผู้ป่วยโรคปอดอุดกั้นเรื้อรัง และนำไปสู่การประเมินกลุ่มอาการที่ทุกข์ทรมานและพัฒนาวิธีการจัดการได้อย่างมีประสิทธิภาพ รวมทั้งสามารถปรับเปลี่ยนให้เหมาะสมกับผู้ป่วยแต่ละราย ในกรณีที่กลุ่มอาการเกิดขึ้นไม่คงที่

Pacific Rim Int J Nurs Res 2015; 19(2) 89-106

คำสำคัญ: โรคปอดอุดกั้นเรื้อรัง ประสบการณ์การเผชิญอาการ กลุ่มอาการ อาการที่ทุกข์ทรมาน, อาการที่รุนแรง

ติดต่อที่: ชมพูนุท ศรีรัตน์*, RN, PhD. อาจารย์, กลุ่มวิชาการพยาบาล
อายุรศาสตร์ คณะพยาบาลศาสตร์ มหาวิทยาลัยเชียงใหม่

Email: chomphoonut.s@cmu.ac.th

สมจิต หนูเจริญกุล, RN, PhD. ศาสตราจารย์เกียรติคุณ, โรงเรียนพยาบาล
รามาธิบดี คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล

Email: somchit.han@mahidol.ac.th

สุภาพ อารีเอื้อ, RN, PhD. รองศาสตราจารย์, โรงเรียนพยาบาลรามาธิบดี
คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล

Email: suparb.are@mahidol.ac.th

อธิราภรณ์ จันทร์ดา, RN, PhD. ผู้ช่วยศาสตราจารย์, โรงเรียนพยาบาลรามาธิบดี
คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล

Email: tiraporn.jun@mahidol.ac.th