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# The Dyspnea Experience in Korean Immigrants with Asthma and COPD

by

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DISSERTATION

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[redacted]

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# ABSTRACT OF THE DISSERTATION

## The Dyspnea Experience in Korean Immigrants with Asthma and COPD

By

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Doctor of Philosophy in Nursing

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This dissertation reports findings from a descriptive, cross-sectional study on the dyspean experience of Korean immigrants who have asthma and/or COPD; the research is reported in three papers. Little is known about the dyspnea experience and symptom experience in immigrant population in the United States, including Koreans. All data were collected through interviews and structured questionnaires which measure mood, symptoms, dyspnea intensity, dyspnea sensations, dyspnea coping strategies, and functioning.

The research reported in the first paper showed that unique descriptors for Korean immigrants with asthma and COPD were *blocked chi* and they tended to describe dyspnea sensation as *rapid*. This paper confirmed that dyspnea sensations of Korean immigrants were relatively similar to those of studies of Caucasians. Korean immigrants experience a variety of symptoms other than dyspnea. Multiple symptoms and fatigue were significantly associated with the level of dyspnea, stressing the importance of the assessment of multiple symptoms and continuous effort to manage fatigue in persons with chronic obstructive lung diseases.

The research reported in the second paper showed that Korean immigrants used problem-focused strategies (e.g., breathing techniques) more than emotion-focused strategies (e.g., relaxation technique) and reported that emotional strategies were less effective than problem-focused strategies to relieve dyspnea. However, some emotion-focused strategies were more beneficial to Korean immigrants with asthma than with COPD. Korean immigrants have learned coping strategies by trial; little education was provided. They preferred the use of traditional therapies, such as acupuncture or herbs. In addition, their family played an important role caring for them. Therefore, incorporating traditional Korean therapies in pulmonary rehabilitation education as well as enlisting the family participation may improve efficacy in managing dyspnea for this population.

Third paper reported that Korean immigrants with asthma and COPD experience a broad range of symptoms that may be the result of multiple coexisting conditions. Age, multiple symptoms, mood, dyspnea, and level of education explained 29.9% of variance in functional performance ($F_{6,78} = 5.534$, $p = .001$). Dyspnea was the most significant predictor of functional performance. This study’s findings suggest that continuous emphasis on dyspnea management is warranted to improve functioning in this Korean immigrants.

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# CHAPTER ONE

## Introduction

### *Significance of the Problem*

The Asian born population had increased from 5.1% in 1960 to 25.5% in 2000 of the total foreign born, since the adoption of the 1965 Immigration Act (Current Population Reports, 2002; Singh & Siahpush, 2002). The Korean population in the United States (U.S.) had also increased from 568,000 in 1990 to 701,000 in 2000 (Current Population Reports, 2002).

In Korea, respiratory diseases were the primary cause of morbidity (WHO, 2006). The mortality from asthma and chronic bronchitis increased from 177.6 to 216.5 per 100,000 persons during the time period between 1983 and 2003 in Korea (the Statistics Department in Korea, 2005). The prevalence of chronic bronchitis and emphysema in Korea was 17.2% among subjects older than 45 years (n=1673) (Kim et al., 2005). In the U.S., the prevalence of chronic bronchitis, emphysema, and asthma has not been reported specifically for Korean immigrants. However, chronic bronchitis and emphysema were the fifth cause of death in the foreign-born population (Rubia, Marcos, & Muennig, 2002). The mortality rates ranged from 21.7 to 32.4 deaths per 100,000. According to the 2003 California Health Interview Survey, the prevalence of asthma was 9.7% in Asian adults living in California (American Lung Association, 2007).

Several definitions of dyspnea have been provided. Dyspnea is not tachypnea, hyperpnea, or hyperventilation (Comroe, 1966) but it is “difficult, laboured, uncomfortable breathing” (Howell, 1966, p.1). It is not painful but it is an unpleasant breathing and subjective sensation (Howell, 1966). Dyspnea appears to be a multi-factorial symptom. The American Thoracic Society has identified that dyspnea is “a term used to characterize a subjective experience of breathing discomfort…derived from interactions among multiple physiological, psychological, social, and environmental factors” (1999, p.322).

Precise data on the prevalence of the symptom of dyspnea in Koreans residing Korea or Korean immigrants have not been reported. Dyspnea is the most common symptom in people with emphysema, chronic bronchitis, and asthma. Dyspnea was reported by 94% of Caucasians with chronic obstructive pulmonary disease (COPD) (n=72) (Jablonski, Gift, & Cook, 2007) and also reported by 94% of Caucasians with COPD and asthma (n=100) (Blinderman, Homel, Billings, Tennestedt, & Portenoy, 2009).

In the last two decades, the symptom of dyspnea in Caucasian people with chronic lung diseases has been studied. Several investigators described different words for different sensations related to dyspnea mechanisms (Schwartzstein, 2005). Factors related to dyspnea, self-care strategies used by patients to manage dyspnea, and the effect of dyspnea on activities of daily living have been described (Carrieri-Kohlman & Janson-Bjerklie, 1986; Janson-Bjerklie, Carrieri, & Hudes, 1986; Renwick & Connolly, 1996). The effects of pharmacological and non-pharmacological treatments on dyspnea, primarily exercise training, self-management programs, and pulmonary rehabilitation have been documented (American Thoracic Society, 1999). However, the majority of these studies have been conducted with Caucasian patients. There has been little investigation of the experience of dyspnea in other ethnic groups, especially among immigrant populations. As the diversity of the U.S. population increases and the prevalence of chronic lung diseases increases, studies concerned with the perception of dyspnea, factors that may aggravate or alleviate dyspnea, and strategies used by immigrants with chronic lung diseases to manage symptoms must increase.

In addition to dyspnea, patients with asthma and COPD have also experienced a variety of other symptoms (Trochtenberg, Belue, & Piphus, 2008; Walke et al., 2007). In the past, investigators have focused on a single measure of occurrence, severity, or distress of one symptom. The theory of unpleasant symptoms emphasizes multidimensional and interactive characteristics of symptoms (Lenz, Pugh, Milligan, Gift, & Suppe, 1997). Recently, multiple symptoms, co-existing symptoms, and symptom clusters have been examined in populations with various chronic diseases and advanced diseases (Gift, Stommel, Jablonski, & Given, 2003; Gift, Jablonski, Stommel, & Given, 2004; Portenoy et al., 1994; Tranmer et al., 2003). However, all aspects of the symptom experience and symptom clusters associated with asthma and COPD have not been adequately described in the literature, especially among immigrant populations.

Culture has an influence on the perception and experience of symptoms, the labeling and evaluating of the disease, having a particular sick role, the decision to seek health care, and the application of treatments (Kleinman, 1980). The effect of culture on pain has been studied. Lipton and Marbach (1984) noted two major factors related to intra- and inter-ethnic differences in the perception and responses of the symptom of pain. The first is that culture has an influence on meanings of symptoms and the ways people deal with them. The second is the social effect symptoms have on people’s health and illness behavior, for example, how families or kin affect behavior. As with pain (Zazick & Dimsdale, 1990), there may be cultural differences in the perception and response to dyspnea, including the coping strategies used to manage the symptom on a daily basis, and in the perception of other symptoms.

In the U.S., each cultural group undergoes modifications that make it different from the original cultural group. Levels of acculturation, assimilation, age, gender, income, family structure, and foreign-born versus U.S. born status are all factors that affect the degree to which one's cultural group membership may influence their restructuring of cultural practices (Kagawa-Singer & Kassim-Lakha, 2003). Thus, the symptom experience of the Korean immigrant population may also be different from the Caucasian population and even patients in Korea. This study is an attempt to improve our understanding of the cultural differences in dyspnea perception and management by investigating the experience of dyspnea in one group of immigrants, first generation Koreans who have lived in the U.S. and have chronic asthma and/or COPD.

### *Statement of the Study Purpose*

There are three main objectives to this study and several specific aims:

1. To explore the sensation of dyspnea and multiple symptoms as experienced by Korean immigrants with asthma and COPD. Additionally, the relationship of dyspnea to selected variables and how these variables predict dyspnea were explored. Selected variables included age, gender, co-morbidities, smoking history, income, living situation, education, social support, various moods, and multiple symptoms.
2. To describe the coping strategies Korean immigrants with asthma and COPD use to manage dyspnea. The specific aims were to describe the types of strategies used, and the frequency and effectiveness of their use.

3. To describe concurrent symptoms, examine the presence of symptom clusters, examine the relationships between symptoms (i.e., a single symptom of dyspnea vs. symptom clusters vs. collective multiple symptoms) and functional performance, and determine the relative contributions of symptoms and sample characteristics to functional performance in Korean immigrants with chronic obstructive lung diseases. The selected sample characteristics included disease group, age, gender, living situation, education level, income, social support, mood, comorbidities, years in the U.S., and acculturation.

### *Content of the Dissertation*

The dissertation consists of three papers. The dyspnea experience, including sensations and factors related to the perception that were found in Korean immigrants with asthma and COPD, are reported in Chapter 2. This chapter also includes description of multiple symptoms that are correlates of dyspnea. The strategies for managing dyspnea used by Korean immigrants with asthma and COPD are described in Chapter 3. Chapter 4 includes a description of the relationships of symptoms, symptom clusters, selected sample characteristics to functional performance in Korean immigrants. Finally, a brief summary of the findings presented in all chapters and recommendations for future studies are presented in Chapter 5.

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# CHAPTER TWO

## The Sensations of Dyspnea and Multiple Symptoms as experienced by Korean Immigrants with COPD and Asthma

### ABSTRACT (max word; 150)

**Objectives:** The purpose of this study was to explore the sensation of dyspnea, multiple symptoms, and factors related to dyspnea in Korean immigrants with COPD and asthma.

**Methods:** Stable COPD (n=54) and asthma (n=32) outpatients were studied. Participants were asked to describe their dyspnea sensations, using an interview and structured dyspnea descriptor list. They were also asked to fill out a survey for demographic information and to complete mood and symptom instruments.

**Results:** The most frequently chosen descriptors were *rapid* and *effort* in participants with COPD and *tight* and *heavy* in participants with asthma. The most prevalent symptoms were shortness of breath, problems with urination, numbness, feeling drowsy, and cough. Variables significantly related to dyspnea were disease group, smoking status, fatigue, and multiple symptoms.

**Conclusions:** Participants with dyspnea resulting from various pathophysiological conditions experienced different sensations but also shared dyspnea descriptors. Findings from this study suggest the importance of assessment of multiple symptoms in populations with COPD and asthma.

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# The Sensations of Dyspnea and Multiple Symptoms as experienced by Korean Immigrants with COPD and Asthma

## Introduction

The primary cause of morbidity in Korea in 2002 was respiratory diseases.[1] The mortality of asthma and chronic bronchitis increased from 177.6 per 100,000 in 1983 to 216.5 per 100,000 persons in 2003 in Korea. [2] The prevalence of chronic bronchitis, emphysema, and asthma has not been reported specifically for Korean immigrants living in the United States. Chronic bronchitis and emphysema are the fifth cause of death in the foreign-born population in the United States[3] and 1 in 10 Asian adults (9.7%) living in California has been diagnosed with asthma at some point in their life.[4] Dyspnea or shortness of breath is the most common disabling symptom in people with chronic diseases, including emphysema, chronic bronchitis, and asthma. There are no precise data on the prevalence of the symptom of dyspnea in Koreans residing Korea or Korean American immigrants. In the past two decades, dyspnea in patients with chronic obstructive pulmonary disease has been studied but no research studies have reported the experience of dyspnea in immigrant populations. As the diversity of the United States population and the prevalence of chronic lung diseases continue to increase, there is a need to understand the symptom of dyspnea as experienced by immigrant populations.[5]

Language used by people to describe their sensation when they are short of breath has been studied for the last two decades (Table 2.1). Investigators have identified unique descriptors of dyspnea for different disease groups and various dyspnea mechanisms.[6,7] Broncho-constriction is a common feature of asthma. The descriptor *my chest feels tight* may originate from airway receptors.[8] The *work* or *effort* of breathing chosen by patients with COPD may be due to the loss of elastic recoil, and differences in diaphragm position may be responsible for differences in the sensory experience.[9] The findings of different dyspnea sensations have contributed to better understanding the mechanisms of breathlessness. Studying dyspnea language may also assist patients in articulating the nuances of their respiratory sensations and support patients in communicating effectively with their health care providers and encourage them to self monitor their diseases.[8,10]

Currently, words used to describe dyspnea are derived from samples of primarily Caucasian subjects and do not reflect the impact of other cultures and languages on symptom perception. Relatively few studies have focused on the sensation of breathlessness among patients with different cultural backgrounds.[11-13] One study[13] examined dyspnea sensations in Koreans residing in Korea with chronic lung diseases and found that words used to describe dyspnea sensations are similar to the ones used by Caucasians. In a sample of Chinese living in China, the descriptors of the affective component of dyspnea, *compressed chest, blocked chi in the chest, tight* or *lump in the throat*, or *blocked chi in the throat* were unique descriptors.[11]

In addition to dyspnea, patients with asthma and COPD experience a variety of symptoms.[14,15] In the past, investigation has focused on one symptom, such as fatigue, pain, or nausea. More recently there has been an emphasis on symptom clusters or symptom burden. Recent studies have described symptoms from a multidimensional perspective in patients with various types of cancer, [16] AIDS, [17] and other chronic diseases, such as heart failure and cirrhosis.[18,19] A few studies [18, 20-22] have been conducted to describe multiple symptoms experienced by patients with COPD and asthma. Little is known about multiple symptoms, especially among immigrants.

The American Thoracic Society (1999)[23] defines dyspnea as a subjective sensation originating from an interaction of physiological, psychological, social, and environmental factors. Because of the multi-factorial nature of dyspnea, the relationship between breathlessness and physiological measurements depends on the role of psychological and sociological factors. To better understand dyspnea, information about the objective indicators and factors related to dyspnea need to be examined. Studies have been conducted to determine the relationship between physiological variables [i.e., end expiratory lung volume (EELV) and forced expiratory volume in 1 second (FEV1)] and the levels of dyspnea.[24-26] Psychological factors such as moods (i.e., anxiety, depression, and fatigue) have been related to dyspnea.[21,27-33] Other related factors are gender,[30,32] age,[32] economic status,[32] smoking history,[32,34] and educational level.[32] Social support is also an important variable that has been related to dyspnea.[30] Only a few researchers have described multiple symptoms experienced by patients with COPD.[15,21,22] Knowledge of how other variables are related to dyspnea or how multiple symptoms affect dyspnea is limited among providers caring for immigrants.

The purpose of this study was to explore the sensation of dyspnea and multiple symptoms in Korean immigrants with COPD and asthma. The relationship of dyspnea to selected variables and how these variables predict dyspnea were explored. Selected variables (Figure 2.1) included age, gender, co-morbidities, smoking history, income, living situation, education, social support, various moods, and multiple symptoms.

## Methods

### *Design*

The design of this study was cross-sectional and descriptive.

### *Sample & Settings*

A convenience sample of COPD or asthma outpatients was recruited through advertisements, four Korean Internal Medicine Outpatient Clinics, and one Adult Day Care Center in a predominantly Korean neighborhood in a large urban area in the Western United States between June and October of 2008. Subjects included adult Korean outpatients (≥19 years) who had a medical diagnosis of COPD or asthma, had shortness of breath with daily activities or on exertion during the last 12 months, were born in Korea, were able to speak, write, and read Korean, and had immigrated to the U.S. as an adult (age ≥19 years). Those who had a diagnosis of cognitive impairment were excluded. Subjects were referred to the investigator through the staff who had access to their charts in the Adult Day Care Center.

### *Measures*

#### *Demographic and Clinical Characteristics*

Demographic and clinical information were obtained by interview. Variables included participants' age, gender, educational level, marital status, annual income, length of stay in the United States, co-morbidities, medication use, oxygen use, smoking history, working status, and recent pulmonary function test results.

#### *Dyspnea Sensations*

One open-ended question and the dyspnea descriptor list[9] were used to describe participants' dyspnea sensations. The open-ended question was "Can you describe in your own words how it felt when you were short of breath?" The fifteen-item dyspnea descriptor list[9] was used to describe dyspnea sensations. The reliability and construct validity of the dyspnea descriptor list have been demonstrated with various populations.[8,9,35] In this study, participants were asked to indicate their sensation when short of breath on a scale of 0 (not at all) to 10 (very severe).

*Dyspnea*

A Visual Analog Scale (VAS) and Modified Medical Research Council (MRC) scale were used to describe dyspnea. A Visual Analog Scale (VAS) was used to quantify intensity of dyspnea. Participants were asked to indicate their usual and worst dyspnea intensity on a vertical 100 mm line. This line was anchored at either end with the words “no breathlessness” and “worst imaginable breathlessness.” Test-retest reliability and concurrent validity of the VAS have been documented with patients with various pulmonary diseases and in a variety of settings.[36-38] The Modified Medical Research Council (MRC) scale was used to quantify how dyspnea affected the participants’ daily activities. Participants were asked to indicate their activity level on a scale from Grade 0 to 4. The higher the grade the more dyspnea affected their daily activities. Inter-rater reliability and concurrent validity of MRC have been documented in patients with cardiac and pulmonary diseases.[25]

*Mood & Symptoms*

The Memorial Symptom Assessment Scale (MSAS) and Profile of Mood States-Short Form (POMS-SF) were used to describe multiple symptoms and mood. MSAS uses a Likert scale to measure the frequency, severity, and distress of 32 physical and psychological symptoms during the previous week. A participant may indicate that a symptom was not experienced by checking a column labeled ‘did not have.’ If a participant experienced a particular symptom, he or she was asked to rate frequency on a scale of 1 to 4, severity on a scale of 1 to 4, and distress on a scale of 0 to 4 for each symptom described. A symptom score for each symptom was then calculated by averaging the scores on the frequency, severity, and distress scales. A higher score indicated a more severe, frequent, and distressed symptom. The MSAS Psychological Symptom (PSYCH) subscale, MSAS Physical Symptom (PHYS) subscale, Global Distress Index (GDI), and MSAS total score were calculated. MSAS total score was calculated by averaging the symptom scores for all 32 symptoms. The concurrent validity and reliability of this instrument have been tested in cancer populations.[16]

POMS-SF was used to describe the mood of participants. POMS-SF describes emotional states that are transient and responsive to changes in the environment. POMS-SF consists of 30 item adjectives with five point rating scales from 0 (not at all) to 4 (extremely), and six subscales entitled Tension-Anxiety, Depression-Dejection, Anger-Hostility, Vigor-Activity, Fatigue-Inertia, and Confusion-Bewilderment. The Total Mood Disturbance score was obtained by summing the scores on the six primary mood factors with Vigor weighted negatively. The reliability and concurrent validity of POMS have been demonstrated with various populations.[39]

#### *Social Support*

Eight-item Emotional/ Informational Support subscale from the Medical Outcomes Study (MOS) Social Support Survey was used to describe the support system of participants. Participants were asked to indicate how often each of the eight supports is available to them when they need it on a scale of 1 (none of time) to 5 (all of the time). Mean score was calculated by averaging scores from eight items. The reliability and validity of this instrument have been reported in patients with chronic diseases.[40]

### *Procedures*

This study was approved by the Committee on Human Research at the University of California, San Francisco. All instruments were translated into Korean by two native Koreans and then back-translated into English by two different persons who were fluent in spoken and written Korean and English. The Korean version of the dyspnea descriptor list[11] was used to clarify the translation of some wordings in Simon's dyspnea list and in the back-translation process. A previously translated Korean version of POMS[34] was used for the present study. The translation of an instrument verbatim into another language may not adequately account for linguistic and cultural differences. Therefore, translators examined the wording of the items to evaluate their cultural relevance and conceptual equivalence of the translated items. Major revisions were found to be unnecessary.

The investigator described the study, answered the questions, and obtained written informed consent from subjects. A survey of demographic and clinical information was obtained, interviews were conducted, and study questionnaires were administered. This procedure was conducted in participants' homes, offices of outpatient clinics, and public places. All procedures were conducted by the investigator.

### *Statistical Analysis*

Data were analyzed using SPSS version 15.0 statistical software. All continuous variables were expressed as mean and standard deviation. Categorical variables were presented as percentage, frequency, or median. Similar terms were grouped together and percentages and frequencies were used to analyze dyspnea descriptors from the open-ended question in the interview. The continuous variables were compared between groups and the gender effect was examined using Univariate Analysis of Variance. The ordinal data and number of symptoms chosen in MSAS between groups or between genders were compared using the Mann-Whitney U-test. In the analysis of Simon's descriptor, participants who rated "0 (not at all)" in the descriptor were classified as saying "no" to that sensation, whereas participants who rated "≥1" in that descriptor were classified as saying "yes" to that sensation. Chi-square was used to compare the number of participants between groups who chose each descriptor. The relationships between selected variables and dyspnea were analyzed using Pearson Product Moment Correlation Coefficients. Multiple linear regression analysis was used to determine whether selected variables predicted usual and worst dyspnea intensity. The investigator first identified potential predictors of usual and worst dyspnea intensity that were statistically related more than $r=.30$ in the Pearson correlation analysis. These variables were then evaluated by multiple regression for their independent effects on dyspnea intensity. Logistic regression was used to determine how selected variables were associated with dyspnea as measured by MRC. Possible variables were evaluated by using logistic regression for their independent effects on dyspnea as measured by MRC. Results were presented as odds ratios (OR) with a confidence interval. Because of unequal distribution in scores of MRC, participants with Grades 0, 1, and 2 were combined as Group 1, whereas participants with Grades 3 and 4 were combined as Group 2. A $p$-value of less than 0.05 was considered statistically significant. To attain a power of .80 for a medium effect size, a sample of 90 was needed to test a maximum of five independent variables in a multiple regression model.[42,43]

## Results

### *Sample*

Eighty-six participants completed this study. As summarized in Table 2.2, the number of participants with COPD and asthma was 54/32, the total number of males and females was 60/26, and the asthma group had more females than the COPD group. The participants were 74.4 ± 7.3 years of age (range: 55-89), the mean age for participants with COPD was 75 ± 7.1, and the mean age for participants with asthma was 73.3 ± 7.8. Most were married or lived with someone (n=61, 70.9%), and half had at least a bachelor's degree (n=44, 51%). Most participants were retired (12.8% were working). Most had a low yearly income (69.7% had incomes below $20,000). Participants represented the moderate to severe end of the spectrum of pulmonary disease. The mean expiratory volume in 1 second (FEV1) was 57.7%; however, it was available only in 41 participants. Twenty participants (23.3%) were currently smoking. Most of the participants had co-morbidities (n=70). Participants have lived in U.S. for a mean of 25.8 years (range: 2-50 years).

### *Dyspnea*

Scores on the VAS rating usual and worst dyspnea intensity and scores in MRC for both groups are shown in Table 2.3. The asthma group reported statistically higher worst dyspnea intensity than the COPD group (77.4 vs. 62.5, *p*=.001). The grade of breathlessness in the asthma group was also higher than in the COPD group, although this difference was not statistically significant. There were no significant gender or group interactions in mean scores of usual and worst dyspnea intensity.

### *Dyspnea Descriptors*

All interviews were conducted in Korean. It was difficult for participants to describe the sensations they had when having difficulty breathing. Three participants said that they could not think about anything else and could not find a word to describe it. One participant stated she felt like dying from dyspnea. The most frequent phrases used by participants in the interview were *short of breath* (n=44, 51%), *felt tight* (n=26, 30%), *felt like my breathing stopped* (n=8, 9%), and *felt smothered* (n=8, 9%). Specifically, participants with asthma described their dyspnea sensations as *constricted chest*, *felt like someone put a stone on my chest*, *blocked chi*, *narrowed bronchi*, and *compressed neck (choking feeling)*.

For the analysis of Simon's 15-item dyspnea descriptors, participants (n=14) who had other pulmonary diseases or CHF, in addition to COPD or asthma, or had both a COPD and asthma diagnosis, were excluded. As presented in Table 2.4, participants with asthma chose the following descriptors from the list, *I feel I am smothering*, *I feel a hunger for more air*, *my chest feels tight*, *I feel I am suffocating*, and *I cannot get enough air*, to describe their dyspnea significantly more than participants with COPD. The mean number of descriptors chosen by the total sample was 9.81 ± 4.52 (out of 15 descriptors). The mean number of descriptors chosen by each group was not significantly different.

### *Symptoms and Mood*

Mean scores on the POMS and MSAS for both groups are reported in Table 2.3. There were no significant differences in POMS subscales and POMS total mood disturbance between participants with COPD and those with asthma. Significant differences between genders are shown in the subscales in Tension-Anxiety ($F_{1, 82}$=5.04, *p*=.027), Depression-Dejection ($F_{1, 82}$=6.72, *p*=.011), Confusion-Bewilderment ($F_{1, 82}$=5.98, *p*=.017), and Total Mood Disturbance ($F_{1, 82}$=7.16, *p*=.009). Females were more anxious, depressed, and confused than males, regardless of groups. Total Mood Disturbance score was significantly higher in females than in males, regardless of groups.

There were no significant differences in mean scores from MSAS scales (MSAS-PSYCH, MSAS-PHYS, GDI, and MSAS total score) and the number of symptoms chosen by participants with COPD and asthma. There were also no significant differences in mean scores from MSAS scales (MSAS-PSYCH, MSAS-PHYS, GDI, and MSAS total score) between genders. However, women (n=26) reported more symptoms than men (n=60) (12.42 ± 6.47 vs. 8.95 ± 5.29, $p$=.011). The most frequently reported symptoms in MSAS by participants with COPD were shortness of breath (80%), problems with urination (63%), numbness/ tingling (59%), feeling drowsy (56%), and lack of energy (44%) whereas participants with asthma reported shortness of breath (75%), cough (66%), problem with urination (63%), feeling drowsy (59%), and numbness/ tingling (56%). Table 2.5 includes the number and percentage of the total sample reporting "frequent" to "almost constant" in symptom frequency, "moderate" to "very severe" in symptom severity, and "quite a bit" to "very much" in symptom distress for the most prevalent symptoms.

### *Relationships between selected variables and dyspnea*

The results of univariate correlations between selected variables and dyspnea are shown in Table 2.6. Generally mood and symptoms were significantly related to usual and worst dyspnea, and dyspnea as measured by MRC. The results of the multiple regression analysis are shown in Table 2.7. Twenty-two possible predictors were evaluated at prescreening criterion with a correlation of r=.30 or higher, before predictors were put into the multiple regression model. The symptom score for shortness of breath in the MSAS total score was excluded for this analysis, since dyspnea was the main dependent variable. The three predictors, POMS-Depression Dejection (DD), POMS-Fatigue Inertia (FI), and MSAS total score, met the prescreening criterion for usual dyspnea intensity. Two variables, disease group and MSAS total score, met the prescreening criterion for worst dyspnea intensity. The predictors for each dependent variable were put into the multiple regression model simultaneously. Using usual dyspnea intensity as the dependent variable, POMS-Depression Dejection (DD), POMS-Fatigue Inertia (FI), and MSAS total score explained 26.3% of variance in usual dyspnea ($p$=.0001). Participants who were more depressed and fatigued, and reported higher MSAS total score had more severe usual dyspnea. Using worst dyspnea intensity as the dependent variable, disease group and MSAS total score explained 20.5% of variance in worst dyspnea ($p$=.0001). In this study, participants with asthma who reported higher MSAS total score reported more severe worst dyspnea.

Logistic regression was used to determine how selected variables were associated with dyspnea as measured by MRC. Again, the symptom score for shortness of breath in MSAS total score was excluded for logistic regression analysis. Three variables showed statistically significant relationships to dyspnea as measured by MRC. Those who were more fatigued (OR: 1.34, CI: 1.04-1.73) and reported higher MSAS total score (OR: 12.23, CI: 1.19-125.26) were more likely to have severe dyspnea as measured by MRC. Those who were current smokers were less likely to have severe dyspnea as measured by MRC (OR: 0.11, CI: 0.02-0.80).

## Discussion

Our findings were consistent with Yang's report[13] with Korean patients living in Korea with COPD. Participants described their sensation as primarily *short of breath* and *tight* in open-ended question in Yang's study.[13] Our study participants also described their sensation as *short of breath, felt tight, felt like my breathing stopped,* and *felt smothered.* Some descriptions by Korean participants with asthma and COPD were unique, such as *blocked chi*. Our participants tended to describe the dyspnea sensation as *rapid*, which was also consistent with reports by Yang[13] using dyspnea descriptor checklists. Participants in Yang's study [13] tended to choose *tight* and *smothering* more often than other descriptors. This finding may be related to the fact that participants in Yang's study [13] were more unstable than ours.

Our findings were consistent with the findings of other studies focusing on Caucasian populations. Our participants chose several descriptors to describe the sensation of dyspnea and shared many descriptors for their dyspnea. Mahler et al.[8] reported that an average of 10 descriptors out of 15 were chosen by 218 outpatients with COPD, whereas our participants chose at least nine descriptors to describe the sensation of dyspnea. Both groups shared many descriptors, such as *rapid*, *heavy*, and *out of breath*, similar to reports of others with Caucasian populations (Table 2.1). Participants with COPD tended to choose descriptors, such as *effort*, whereas participants with asthma chose the sensation of *tight* in this study, which is also consistent with other reports.[8, 9, 44-47] Korean participants in this study favored the words *heavy* and *rapid* to describe their dyspnea sensation, which is inconsistent with other reports with Caucasian populations. Participants with asthma in this study reported *tight*, *suffocating*, *can't get enough air*, *smothering* and *a hunger for more air*. The descriptors of *suffocating* and *smothering* were usually used by populations with CHF in other studies.[6] The reason why our participants used those descriptors remains unclear.

Methods of administering the questionnaire differed among studies. Participants tended to report a majority of descriptors regardless of the length of the checklist.[44,45,47] However, some investigators asked participants to endorse any descriptors they considered relevant and then limited their choice to three that best conveyed what their breathing felt like in other studies.[8,9] Limiting descriptor choices to a fixed number ignores some choices participants make. Furthermore, it is important to notice the differences in questions that were given to participants. In this study, the investigator asked participants to describe their past sensations of short of breath. In other studies, participants were asked to recall their experience of breathlessness provoked by activities,[8] to recall their breathing discomfort during exercise,[44] and to describe how their breathing felt when they decided to come to Emergency Department.[47] The questions used to describe their sensation of dyspnea may account for variability in the responses of selections of participants who have the same diagnosis in that they ask for data under differing circumstances and environments.

Other factors may also influence terms participants use to describe dyspnea sensations, such as heterogeneity of diagnoses, acuity levels, recall bias, and culture. In other studies, participants with multiple diseases were not always excluded.[8,47] Our sample was stable and community based participants, whereas the sample in Parshall's study[47] was COPD participants with an exacerbation of their disease. It is reasonable to conjecture that descriptors chosen by unstable participants who have multiple diseases may be different from ones chosen by participants in a stable phase of their illness. Most researchers asked participants to recall the sensation and experience of dyspnea, which may affect the validity of descriptors. However, evidence has shown that participant's recall regarding sensation is accurate.[48] Culture also influenced the language of dyspnea.[11,12] This study also showed that sensation of dyspnea in Korean immigrants may be different from one of Caucasians, for example, the expression of *blocked chi*.

The studied Korean immigrants experienced a variety of symptoms, similar to other populations with chronic diseases.[18,19] The symptoms that Korean immigrants reported in the present study are commonly experienced by chronically ill individuals in general, along with some that are disease specific. Our participants exhibited similar symptoms to earlier studies in populations with COPD and asthma,[20-22] such as shortness of breath, lack of energy, dry mouth, cough, worrying, and drowsiness, but also distinctly reported the following symptoms more, i.e., problems with urination and numbness/ tingling. They also reported the following symptoms less, i.e., sad, feeling irritable, and feeling nervous. This difference in prevalence of symptoms may be because our participants were older than those samples in other studies.[20-22] It also may be due to cultural differences in reporting emotionally-related symptoms. The Asian culture places value on the control of expressive behavior; therefore, strong feelings may not necessarily be overtly expressed.[49]

Compared with the work by Jablonski, Gift, and Cook[22] with those with COPD, Korean immigrant participants reported lower prevalence, severity, frequency, and distress of symptoms, in general. A comparison of the various MSAS subscales in our study with others with COPD could not be made, because findings were provided as medians rather than as means in the study of Blinderman et al.[20]and findings were not reported in the study of Jablonski, Gift, and Cook.[22] Korean immigrants reported lower scores in all subscales of MSAS than one reported by inpatients with cancer[16] or by hospitalized medical-surgical patients.[50] This may be related to the fact that cancer patients or hospitalized patients are much sicker and therefore experience more symptoms than did our participants.

Variables that were significantly related to usual and worst dyspnea intensity, and dyspnea as measured by MRC were mainly disease group, current smoking status, fatigue, and MSAS total score. Disease group was the most significant variable related to the experience of worst dyspnea in Korean elderly, which is consistent with reports of others with Caucasian participants.[30] This finding may be related to the difference in dyspnea sensation between participants with COPD and asthma, as previously reported by Janson-Bjerklie, Carrieri, and Hudes.[30] An especially interesting aspect is the finding that active smokers reported lower level of dyspnea as measured by MRC, which is consistent with the report of others with asthma populations.[32] The reason why smoking status is related to dyspnea is unclear. We did not find a relationship between dyspnea and smoking habit as expressed as number of pack years, which is inconsistent with the report of others in patients with asthma.[34] The inconsistent and unclear findings of the relationships between smoking habit and dyspnea need to be examined further.

The level of fatigue was related to dyspnea as measured by MRC. A significant relationship between fatigue and dyspnea has been demonstrated in several populations.[21,30] Guyatt, Townsend, Berman, and Pugsley[51] identified fatigue as one of the important disease-related problems adversely affecting the lives of patients with COPD. Fatigue is experienced by approximately 58% of patients with COPD.[21]

Respiratory muscle weakness may have an important role in the dyspnea associated with some chronic conditions.[52]

MSAS total score was significantly related to dyspnea, which is consistent with the findings of Bestall et al.[53] The Symptom subscale in St. George's Respiratory Questionnaire used in Bestall et al.'s study[53] measures a limited number of disease-specific symptoms, but the MSAS measures 32 symptoms from a multidimensional perspective. This study is the first to describe multiple symptoms as a correlates of dyspnea. Multiple symptoms were the strongest correlate and predictor for various dimensions of dyspnea, regardless of which instrument was used to measure symptoms. This finding stresses the importance of assessment of other symptoms in populations with chronic obstructive lung diseases, in order to alleviate dyspnea.

Other variables, such as age, co-morbidities, income, living situation, education, gender, and social support, were not significant predictors for dyspnea. Significant gender differences were found in moods and the number of symptoms reported in the present study, but not in dyspnea intensity. We did not find a significant relationship between dyspnea and social support, which is inconsistent with the work of one study.[30] This finding may be related to participants' age differences. There were larger age variations in their study[30] as compared to ours. It is well known in the literature that certain moods, such as anxiety and depression, are related to dyspnea. However, mood was not a significant predictor for dyspnea. These inconsistent and insignificant relationships between other variables and the level of dyspnea must be examined in greater detail.

These findings must be considered within the limitations of this study. Participants for this study were recruited from primary care settings in a Korean ethnic neighborhood in a large urban area in the Western United States. Participants in this sample tended to be physiologically stable. Most participants had co-morbidities and were older than populations in other studies. Therefore, findings from this study can be only generalized to stable, elderly Korean immigrants. This is the first time the 15 item dyspnea descriptor list developed by Simon[9] has been used with a Korean population. Descriptors in this 15 item dyspnea descriptor list were based on descriptors used by Caucasians, which therefore has its limitations when applying this instrument to Korean immigrants. The investigator interviewed participants with an open-ended question before administering this instrument. Some descriptors in the structured dyspnea descriptor list[9] were used and some were not used to describe their sensation in Korean participants, compared to the findings with the open-ended question. However, the questionnaire was applicable to participants and was not difficult for the Korean older adults to complete. The participants gave their response quickly and few asked about the meaning of sentences in questionnaire.

In conclusions, this report highlights the sensation of dyspnea among Korean immigrants living in the United States. The sensory quality of dyspnea appears to be multidimensional. Participants with breathlessness resulting from various pathophysiological conditions experienced different sensations, but also shared some dyspnea descriptors. Unique descriptors for Korean participants with asthma and COPD were *blocked chi* and they tended to describe the dyspnea sensation as *rapid*. Dyspnea sensations of Korean immigrants were relatively similar to those of studies of Caucasians. Dyspnea assessment tools for other ethnic groups may be applicable to Korean immigrants. However, the combination of a structured interview using Western descriptor lists along with an open-ended question provides the most information about dyspnea sensations. Korean immigrants with COPD and asthma experience a variety of other symptoms besides dyspnea. Among various participants' characteristics, multiple symptoms and fatigue were factors that were significantly associated with the level of dyspnea, stressing the importance of the assessment of multiple symptoms and continuous effort to manage fatigue in populations with chronic obstructive lung diseases. An understanding of these relationships helps explain the great variability seen in individuals with dyspnea. These findings may help health care providers better understand symptom of dyspnea and other symptoms as experienced by Korean immigrants and eventually help expand the development of assessment tools for symptoms. These findings may also lay a foundation for the development and testing of individualized therapies for this population. Further study is needed to confirm these findings with populations in hospital settings and to examine other factors that have shown an insignificant relationship with dyspnea. Further study is also needed to explore the existence of symptom clusters from multiple symptoms as experienced by populations with chronic obstructive lung diseases. Experimental studies are needed to determine effective combinations of interventions to manage symptoms that are experienced simultaneously.

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Table 2.1

*Main descriptors in patients with COPD and asthma from structured dyspnea descriptor lists*

| Study | COPD | Asthma | Description of population | Instruments |
|---|---|---|---|---|
| Han et al.[11] | | $N=42$<br>***Wheezing Factor***<br>Whistling while breathing<br>Whistling in throat<br>Whistling in exhalation<br>Breathing more,<br>Exhaling more | Chinese patients in 3 hospitals in China | 61 descriptors in the respiratory symptom checklist |
| Yang[13] | $N=46$<br>Tight, Rapid, Work<br>Smothering<br>Can't inhale like before | | Korean patients in Korea with exacerbated COPD in ED | Parshall's 16 descriptors [47] |
| Current study | $N=43$<br>Rapid, Effort, Heavy,<br>Out of breath | $N=29$<br>Tight. Heavy, Rapid, Shallow,<br>Out of breath | Korean Immigrants in Community dwelling outpatients in U.S. | Simon et al.'s 15 descriptors[9] |
| Janson-Bjerklie, Carrieri, & Hudes[30] | $N=26$<br>Short of breath<br>Hard to breathe<br>Feel like need air | $N=23$<br>Short of breath<br>Hard to breathe<br>Feel like need air<br>Wheezing<br>Hard to get air out<br>Chest tightness<br>Chest congestion | Caucasian inpatients or outpatients | Asthma Symptom Checklist & Bronchitis-Emphysema Symptom Checklist |
| Simon et al.[9] | $N=16$<br>Requires effort<br>Requires more work<br>Out of breath<br>Hunger for air<br>Cannot get enough air | $N=7$<br>Requires effort<br>Requires more work<br>Not go out all the way<br>Constricted, Tight | Caucasian in patients or outpatients in pulmonary clinics | 15 descriptors[9] |

| | | | | |
|---|---|---|---|---|
| Elliot et al.[44] | *N=39*<br>Out of breath, Work, Shallow, Can’t get enough air.<br>Gasping for breath<br>Hunger for more air | *N=31*<br>Out of breath, Work, Shallow, Can’t get enough air<br>Wheezy<br>Tight | Caucasian inpatients & outpatients | 45 dyspnea descriptors |
| Mahler et al.[8] | *N=85*<br>Effort<br>Out of breath<br>Can’t get enough air | *N=56*<br>Can’t get enough air<br>Tight<br>Effort | Caucasian outpatients in pulmonary clinics or pulmonary function lab | Simon et al.’s 15 descriptors [9] |
| Parshall [47] | *N=104*<br>Out of breath, Effort, Not enough air, Work, shallow, Hunger for air, Heavy, Smothering,<br>Not go in all the way | | Caucasian patients with exacerbated COPD in ED | 16 descriptors [47] |
| Wilcock et al.[45] | *N=34*<br>Not get enough air<br>Hunger for air<br>Tight/ Constricted | *N=37*<br>Tight/ Constricted<br>Not enough air<br>Work/ effort<br>Out of breath | British inpatients and outpatients | Simon et al.’s 15 descriptors [9] |
| Caroci et al.[46] | *N=30*<br>Out of breath<br>Not get enough air<br>Suffocating<br>Air hunger<br>Not go out all the ways<br>Effort | | Caucasian outpatients | Simon et al.’s 15 descriptors [9] |

Table 2.2

*Demographic and Clinical Characteristics of Total Sample (N=86)*

| | Mean ± SD (range) | Frequency (Percentage) |
|---|---|---|
| Age | 74.4 ± 7.3<br>(range; 55-89) | |
| Gender (M/F) | | 60/26 |
| Education (n=85) | | |
| High school & less | | 41 (48%) |
| Bachelor & higher | | 44 (51%) |
| Income (n=79) | | |
| <$20,000 | | 60 (69.7%) |
| >$20,000 | | 19 (22%) |
| Living situation | | |
| Alone | | 25 (29.1%) |
| Married or Living with someone | | 61 (70.9%) |
| Working | | 11 (12.8%) |
| Years of stay in U.S | 25.8 ± 9.8 | |
| Current smoker | | 20 (23.3%) |
| Pack years of current smoker | 44.9 ± 23.6 | |
| Past smoker | | 36 (41.8%) |
| Pack years of past smoker | 41.8 ± 33.0 | |
| FEV1 % pred. (n=41) | 57.7 ± 17.5 | |
| Co-morbidities | | 70 (81%) |
| Hypertension | | 20 |
| Heart diseases | | 11 |
| TB | | 12 |
| Other pulmonary diseases | | 9 |
| Stomach ulcer | | 14 |
| Diabetes | | 21 |
| BPH | | 12 |
| Rheumatoid arthritis | | 23 |
| Liver disease | | 8 |
| Cancer | | 8 |
| Other diseases | | 12 |

Table 2.3

*Comparison of Study Variables between participants with COPD and asthma (N=86)*

| Variables (possible range) | Total (N=86) | COPD (N=54) | Asthma (N=32) |
|---|---|---|---|
| ***Dyspnea*** | | | |
| Usual Dyspnea Intensity | 16.2 ± 17.1 | 15.5 ± 17.2 | 17.3 ± 17.2 |
| Worst Dyspnea Intensity | 68.0 ± 20.6 | 62.5 ± 19.3 | *77.4 ± 20.0 |
| MRC | 1.98 ± 1.13 | 1.89 ± 1.11 | 2.13 ± 1.12 |
| ***Mood & Symptoms*** | | | |
| POMS-Tension Anxiety (0-20) | 4.96 ± 4.77 | 3.87 ± 3.5 | 6.81 ± 6.0 |
| POMS-Depression Dejection (0-20) | 4.71 ± 4.92 | 4.03 ± 4.34 | 5.84 ± 5.64 |
| POMS-Anger Hostility (0-20) | 4.74 ± 4.73 | 4.19 ± 4.0 | 5.69 ± 5.69 |
| POMS-Vigor Activity (0-20) | 5.31 ± 5.00 | 5.28 ± 4.85 | 5.38 ± 5.31 |
| POMS-Fatigue Inertia (0-20) | 5.45 ± 4.94 | 4.6 ± 4.42 | 6.9 ± 5.48 |
| POMS-Confusion Bewilderment (0-20) | 2.71 ± 3.03 | 2.13 ± 2.72 | 3.69 ± 3.31 |
| POMS-Total Mood Disturbance | 17.27 ± 21.39 | 13.54 ± 17.64 | 23.56 ± 25.63 |
| MSAS-PSYCH subscale (0-4) | .74 ± .77 | .71 ± .72 | .79 ± .86 |
| MSAS-PHYS subscale (0-4) | .66 ± .53 | .58 ± .51 | .79 ± .55 |
| MSAS-GDI subscale (0-4) | .96 ± .82 | .92 ± .77 | 1.04 ± .89 |
| MSAS-Total score (0-4) | .67 ± .46 | .62 ± .41 | .77 ± .52 |
| MSAS-Total number of symptoms | 10.00 ± 5.86 | 9.35 ± 5.46 | 11.09 ± 6.41 |

*; p<.05 comparison of variables between COPD and asthma groups

A higher score indicates more severe, frequent, and distressed psychological or physical symptoms in MSAS, and more severe mood in POMS.

Table 2.4

*Comparison of Simon's Descriptors between participants with COPD and asthma (N=72)*

| | COPD (N=43) | Asthma (N=29) |
|---|---|---|
| | Number of subjects who chose descriptor (%) | Number of subjects who chose descriptor (%) |
| 1 My breath does not go in all the way. | 28 (65.1%) | 21 (72.4%) |
| 2 My breathing requires effort. | 34 (79.1%) | 20 (69.0%) |
| 3 I feel that I am smothering. | 18 (41.9%) | 20 (69.0%)* |
| 4 I feel a hunger for more air. | 22 (51.2%) | 22 (75.9%)* |
| 5 My breathing is heavy. | 32 (74.4%) | 24 (85.7%) |
| 6 I feel out of breath. | 31 (72.1%) | 23 (79.3%) |
| 7 My chest feels tight. | 22 (51.2%) | 25 (86.2%)* |
| 8 My breathing requires more work. | 29 (67.4%) | 19 (65.5%) |
| 9 I feel that I am suffocating. | 13 (31.0%) | 18 (62.1%)* |
| 10 My chest is constricted. | 18 (41.9%) | 16 (55.2%) |
| 11 I feel that my breathing is rapid. | 38 (88.4%) | 24 (82.8%) |
| 12 My breathing is shallow. | 29 (67.4%) | 23 (79.3%) |
| 13 I feel that I am breathing more. | 29 (69.0%) | 21 (72.4%) |
| 14 I cannot get enough air. | 23 (53.5%) | 23 (79.3%)* |
| 15 My breathing does not go out all the way. | 24 (55.8%) | 19 (65.5%) |

*: $p<.05$

Table 2.5

*Prevalence, Severity, Frequency, & Distress of Symptoms in MSAS by total sample (N=86)*

| | | Degree when symptom present | | |
|---|---|---|---|---|
| Symptoms | Number of subjects who had symptom (%) | Number of subjects who had "Moderate to Very Severe" symptom (%) | Number of subjects who had symptom "Frequently to Constantly" (%) | Number of subjects who had "Quite a Bit to Very Much" distressed symptom (%) |
| shortness of breath | 67 (77.9%) | 59 (88.1) | 31 (46.3) | 22 (32.8) |
| problems with urination | 54 (62.8%) | 35 (64.8) | 30 (55.6) | 14 (25.9) |
| numbness/ tingling in hands/ feet | 50 (58.1%) | 36 (72.0) | 16 (32.0) | 11 (22.0) |
| feeling drowsy | 49 (57.0%) | 33 (67.3) | 23 (46.9) | 3 (6.1) |
| cough | 45 (52.3%) | 25 (55.6) | 12 (26.7) | 7 (15.6) |
| dry mouth | 40 (46.5%) | 25 (62.5) | 20 (50.0) | 7 (17.5) |
| lack of energy | 37 (43.0%) | 29 (78.4) | 16 (43.2) | 4 (10.8) |
| dizziness | 36 (41.9%) | 21 (58.3) | 10 (27.8) | 8 (22.2) |
| worrying | 35 (40.7%) | 30 (85.7) | 18 (51.4) | 11 (31.4) |
| difficulty sleeping | 35 (40.7%) | 27 (77.1) | 15 (42.9) | 6 (17.1) |
| constipation | 34 (39.5%) | 21 (61.8) | NE | 4 (11.8) |
| pain | 32 (37.2%) | 26 (81.3) | 17 (53.1) | 10 (31.3) |
| feeling nervous | 32 (37.2%) | 22 (68.8) | 17 (53.1) | 9 (28.1) |

Note: NE; not evaluated

Table 2.6

*Univariate Correlation between selected variables and dyspnea (N=86)*

| | Usual Dyspnea Intensity | Worst Dyspnea Intensity | MRC |
|---|---|---|---|
| Disease Group (asthma) | .05 | .35** | .10 |
| Age | -.01 | -.23* | -.05 |
| Gender (female) | -.01 | .13 | .22* |
| Co-morbidity (numbers of diseases) | .17 | .11 | .17 |
| Current smoker (yes) | .12 | .16 | .19 |
| Total pack year | .14 | .02 | .03 |
| Income (>$20,000) | -.05 | .07 | .06 |
| Living (married or living with someone) | -.03 | .00 | -.06 |
| Education (bachelor or higher) | -.26* | -.16 | -.24* |
| Social Support Survey total score | -.01 | -.03 | -.17 |
| POMS-Tension Anxiety | .29** | .26* | .22* |
| POMS-Depression Dejection | .34** | .27* | .32** |
| POMS-Anger Hostility | .29** | .30** | .24* |
| POMS-Vigor Activity | -.22* | -.07 | -.46** |
| POMS-Fatigue Inertia | .34** | .24* | .31** |
| POMS-Confusion Bewilderment | .21 | .12 | .18 |
| POMS-Total Mood Disturbance | .37** | .27* | .43** |
| MSAS-PSYCH subscale | .37** | .17 | .34** |
| MSAS-PHYS subscale | .45** | .32** | .30** |
| MSAS-GDI subscale | .44** | .23* | .39** |
| MSAS-total score except shortness of breath symptom score | .51** | .34** | .42** |
| MSAS-total number of symptoms | .45** | .33** | .39** |

**; p<.01, *; p<.05

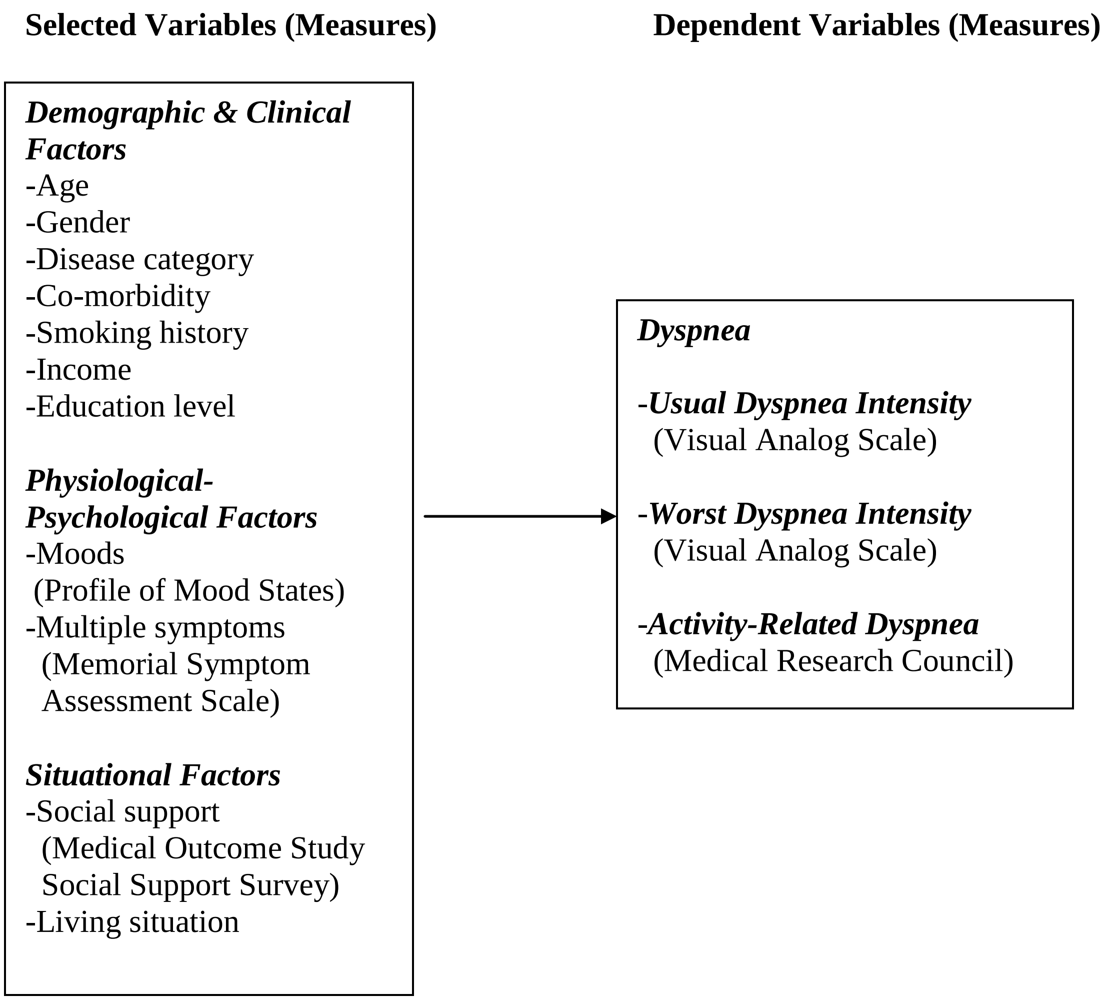
Table 2.7

*Multiple Regression Analysis of the Predictors for Usual Dyspnea Intensity and Worst Dyspnea Intensity in participants with asthma and COPD (N=86)*

| Source | $R^2$ | Beta | % of Explained Variance | df | F | p |
|---|---|---|---|---|---|---|
| ***Predictors for Usual Dyspnea Intensity*** | | | | | | |
| Overall | 26.3 | | | 3, 82 | 9.742 | .0001 |
| POMS-Depression Dejection | | .052 | 0.1 | | | .720 |
| POMS-Fatigue Inertia | | .008 | 0.001 | | | .958 |
| MSAS- total score | | .475 | 12.74 | | | .0001 |
| ***Predictors for Worst Dyspnea Intensity*** | | | | | | |
| Overall | 20.5 | | | 2, 83 | 10.733 | .0001 |
| Disease Group | | .302 | 8.8 | | | .003 |
| MSAS-total score | | .291 | 8.2 | | | .004 |

Figure 2.1

*The relationship between demographic, clinical and biopsychosocial factors to selected dimensions of dyspnea*



# CHAPTER THREE

## Dyspnea Self Management Strategies used by Korean American Immigrants with COPD and asthma

### ABSTRACT (max word 400)

***Background:*** Individuals with chronic obstructive pulmonary disease (COPD) and asthma develop many strategies and skills on their own over time and come to rely on self-management strategies to control their shortness of breath. South Korean men have the highest rate of smoking in the world, and in 2002, the primary cause of death in Korea was respiratory diseases. While no data exist on the prevalence of respiratory diseases among Korean Americans, the rate among Asian adults in California is 10%. Yet, little is known about dyspnea management of Korean immigrants with COPD and asthma in the United States (U.S.).

***Objectives:*** To describe the coping strategies used by Korean American immigrants with COPD and asthma to manage their dyspnea.

***Design:*** Cross-sectional, descriptive study

***Settings:*** Primary care settings in a Korean ethnic neighborhood in a large urban area of Western U.S.

***Participants:*** Stable COPD (n=54) and asthma (n=32) outpatients

***Methods:*** Open-ended questions and the Modified Self-Efficacy and Dyspnea Self-Strategies Scale were used to describe participants' own strategies to manage dyspnea. Dyspnea intensity and distress were measured with Visual Analog Scales. Dyspnea severity was measured with the Modified Medical Research Council Instrument. The Item Total Correlation (ITC) form of the Suinn-Lew Asian Self-Identity Acculturation

Scale was used to describe the degree of acculturation. Inferential statistics and Univariate Analysis of Variance were used to compare patients with COPD and asthma.

***Results:*** The most prevalent strategies used by participants with COPD and asthma were "I keep still or rest," "I move slower," and "I avoid strenuous activities." The mean number of coping strategies was 14.1 ± 5.88 (range: 5-32). "I avoid irritants such as smoke" was used with the greatest frequency. "I use oxygen" was the most effective strategy to manage dyspnea. Korean immigrants preferred the use of traditional therapies, such as acupuncture or herbs, home remedies, and yoga or Tai-Chi. In addition, their family played an important role caring for them.

***Conclusions:*** Korean American participants learned dyspnea coping strategies by trial and error, with little or no instruction from health professionals. Problem-focused strategies were more effective, but some emotion-focused strategies were more beneficial to participants with asthma than with COPD.  Incorporating traditional Korean therapies in pulmonary rehabilitation education as well as enlisting the family participation may improve efficacy in managing dyspnea for this population.

***Key Words:*** Asthma, COPD, Dyspnea, Korean American immigrants, Self Management Strategies

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This manuscript will be submitted to International Journal of Nursing Studies and has been written to meet their publication guidelines.

**What is already known about topic?**

- Individuals with COPD and asthma develop many coping strategies and skills on their own over time and come to rely on self-management strategies to control their shortness of breath.
- Most research on dyspnea management in the western regions of the world addressed the Caucasian populations.

**What this paper adds?**

- Korean immigrants used the similar coping strategies for dyspnea to other ethnic groups but they preferred the use of traditional therapies, such as acupuncture, herbs, home remedies, and yoga or Tai-Chi, and their family played important role in caring for them.
- Both COPD and asthma groups used problem-focused strategies more than emotion-focused strategies; problem-focused strategies were more effective than emotion-focused strategies to relieve dyspnea in most patients.
- Some emotion-focused strategies were more beneficial to patients with asthma than with COPD.

## **Dyspnea Self Management Strategies used by Korean American Immigrants with COPD and asthma**

### INTRODUCTION

There is no universally accepted definition of dyspnea; however, several definitions have been provided. According to Commroe (1966), dyspnea is not tachypnea, hyperpnea, or hyperventilation. Dyspnea is “difficult, laboured, uncomfortable breathing” (Howell, 1966, p.1). It is not painful but it is an unpleasant breathing and subjective sensation (Howell, 1966). Dyspnea was also defined as “the sensation of feeling breathless or experiencing air hunger” (Wasserman and Casaburi, 1988, p.503). Dyspnea appears to be a multi-factorial symptom. The American Thoracic Society (ATS) has identified that dyspnea is “a term used to characterize a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity” (1999, p.322).

### SIGNIFICANCE

Dyspnea is the most common disabling symptom in people with emphysema, chronic bronchitis, and asthma (Trochtenberg et al., 2008; Walke et al., 2007). There are no precise data on the prevalence of the symptom of dyspnea in Koreans residing Korea or Korean American immigrants. However, the primary cause of morbidity in Korea in 2002 was respiratory diseases (WHO, 2006). The most recent data available show that mortality of asthma and chronic bronchitis increased from 177.6 per 100,000 in 1983 to 216.5 per 100,000 persons in 2003 in Korea (Statistics Department in Korea, 2005). In United States chronic bronchitis and emphysema was the fifth cause of death in the foreign-born population (Rubia et al., 2002). One survey has reported that 1 in 10 Asian adults (9.7%) living in California had been diagnosed with asthma at some point in their life (American Lung Association, 2007).

The most commonly encountered risk factor for chronic bronchitis and emphysema is smoking (Global Initiative for Chronic Obstructive Lung Disease, 2008) and South Korean men have the highest rate of smoking in the world (Gallop Korea, 2003). Smoking increases the risk of developing chronic bronchitis and emphysema. Koreans who smoked prior to immigrating to the U.S. and have resided within their own ethnic neighborhoods in the U.S., may continue to smoke because this behavior is more likely to be culturally condoned by their community.

Dyspnea diminishes a person’s quality of life, activities of daily living are restricted, and social isolation occurs because of disease-imposed physical inactivity. Because dyspnea is a multi-factorial and subjective symptom, these distressing consequences of dyspnea require complex daily self-management strategies. Individuals with chronic diseases develop many strategies and skills on their own and come to rely on self-management strategies to control their shortness of breath over time (Carrieri-Kohlman and Janson-Bjerklie, 1986). Healthcare professionals caring for Korean immigrants with COPD and Asthma would benefit from information regarding which strategies they use most frequently and find most effective in order to appropriately target their teachings and interventions.

## THEORETICAL FRAMEWORKS

The frameworks used for this study are “The Stress and Coping Paradigm” and “The Model of Illness Labeling.” The Stress and Coping Paradigm was developed by Lazarus (1980). Lazarus and Folkman (1984) define coping as cognitive and behavioral efforts used to manage the demands that exceed or stress the resources of an individual. Stress and coping are viewed by the individual through primary and secondary appraisal (Lazarus and Folkman, 1984). In primary appraisal, the situation is evaluated and the individual assigns meaning or significance to the event. During secondary appraisal, coping options or resources for coping are considered. Through the use of coping strategies, the individual can actually change or modify his or her response to the situation, thus affecting the impact the event imposes on the individual. Folkman and Lazarus (1980) proposed two types of coping strategies: problem-focused and emotion-focused. With problem-focused coping (e.g., breathing technique), the relationship between the stressor, the situation causing the stress, and the individual is altered. Coping that regulates stressful emotions is called emotion-focused coping (e.g., relaxation techniques).

"The Model of Illness Labeling" helps explain the impact of culture on the interpretations of physical and psychological states and on help-seeking behaviors (Angel and Thoits, 1987). The Model of Illness Labeling consists of four processes: 1) how individuals notice physical or emotional changes; 2) how they interpret those changes, that is, whether the changes are symptoms, whether changes are physical or psychological, and whether changes are considered serious; 3) how individuals choose to take action on the change; and, 4) how they re-evaluate physiologic or psychological change. Each of these processes is influenced by culture (Angel and Thoits, 1987) and therefore may be useful in understanding how culture influences Korean immigrants in their choices and uses of dyspnea management strategies.

## REVIEW OF THE LITERATURE

### *Socio-Cultural Context of Symptom Management*

Culture influences perception and experiencing of symptoms, the labeling and evaluating of the disease, the application of treatments, the decisions to seek health care, and having a particular kind of sick role (Kleinman, 1980; 2004). The influence of culture on pain has been studied (Defrin et al., 2009; Im et al., 2009; Yosipovich et al., 2004) but limited attention has been paid to the effect of culture on other subjective symptoms. From the physiological perspective, one might say that dyspnea is a culture-free symptom. However, no human activity is purely physiological (Helman, 2000). Voluntary reactions to any stimuli are especially influenced by culture, such as getting rid of the source of stimulus and using help-seeking behavior to relieve the symptom (Helman, 2000).

In most Asian cultures, stoicism is highly regarded. Hu and Fang (1989) found that traditional Chinese teachings emphasize composure and rationality over emotion, and tend to shun open displays of emotions. In Japan, the control of expressive behavior is highly valued. For the Japanese, emotional expression of anger is unusual, and a response to pain is often manifested as a stoic reaction (MaGoldrick et al., 2005). Non-verbal communication is also often considered to be a vital means of interpersonal connection in Asian cultures (Uba, 1994). Japanese place more emphasis on what is not said than on what is said, partly because they feel that emotions and sentiments cannot necessarily be captured or communicated by words (MaGoldrick et al., 2005). This communication style also plays an important role in interpersonal relationship in Korean culture (Kagawa-Singer and Blackhall, 2001). From these perspectives, emphasis on emotional control of expressive behavior and non-verbal communication in Asian cultures may affect symptom expression or reporting.

Cultural and social beliefs regarding anatomy, physiology, and the etiology of disease affect aspects of health behavior, such as the evaluation of symptoms and the utilization of non-mainstream medical services (Angel and Thoits, 1987). In the Western model of health, disease is viewed as a disruption in biological structures or physiological processes caused by some physical or chemical factor and as a function of cause and effect, whereas in Eastern medicine, disease is viewed as an imbalance within the body, and is categorized according to the concept of “hot” versus “cold” (Armstrong and Swartzman, 2001; Chung, 1996). The degree to which immigrants adopt the culture and behaviors of Western society may also affect their restructuring of cognitive categories or creating of new cognitive dimensions (Angel and Thoits, 1987). In general, the longer individuals are in the U.S. and the more they assimilate, the more likely they are to adapt American lifestyles and follow the Western model of health care. Leclere et al. (1994) found that the longer immigrants, including those of Hispanic origin and African Americans, remain in the U.S., the more their use of formal medical care resembles that of native-born Americans.

The difference between Eastern and Western concepts of self illustrates how help-seeking behaviors vary when an individual experiences symptom. The centripetal-interdependent orientation in the East is in stark contrast to the centrifugal-independent one in the West (Triandis, 1989). A strict authoritarian system based on a rigid hierarchical order has dominated Korean culture (Im and Choe, 2004). An order is assigned to every human relationship, and the order is determined by social class, gender, generation, and age (Im et al., 2004). Based on this order, the family has been regarded as both the basic unit of society and the fundamental social structure within which individuals live (Moon and Pearl, 1991). Asian populations preserve collectivistic family values (Triandis, 1989), a practice that includes reinforcing the importance of filial obligations over individual needs, obedience to parental authority, deference to elders, and conformity to a hierarchical, patriarchal family structure. This basic difference in self-representation strongly affects interpersonal relations, communication style, expression of emotion, life's goals, and attitudes toward life; consequently, all of these factors influence illness behavior (Nilchaikovit et al., 1993). For example, the family plays a key role in the selection of treatment choices for the members of a family in Asian cultures. Health care decisions may be made by the family based as much on what is best for family as on what is best for individuals (Tong and Spicer, 1994).

Spector (2004) explained that illness is not only a "condition" but also a social role or sick role that must be conferred on sick individual. Nilchaikovit et al. (1993) examined the effects of culture on illness behavior, comparing Asians with Americans, and found that the issue of dependency with the sick role is a major difference between these groups. In Asian cultures when a person is sick, much more permission for dependency is granted than when an American person is ill (MaGoldrick et al., 1982). Furthermore, conflict over losing independence and control is probably one of the most common conflicts found in American patients with serious illness, whereas it is usually not a major issue for most Asians (Nilchaikovit et al., 1993). For Asian patients, it is generally acceptable to be dependent, especially when sick. Some patients may even feel entitled to be taken care of by others.

### *Coping Strategies to Manage Dyspnea*

Studies investigating dyspnea self-management for Koreans are scarce (Table 3.1). Only one study was conducted to describe dyspnea management strategies used by Korean patients living in Korea with COPD and asthma (Bang, 2002). Positive attitude (96.2%), medicating or inhaling (92.5%), and moving slowly (90.6%) were the most frequently used strategies.

Few studies have been conducted to describe coping strategies used by other ethnic groups. Table 3.1 summarizes the results of coping strategies used by other ethnic groups with various diseases. Generally, dyspnea coping strategies used by patients with various pulmonary diseases were similar to ones used by patients with lung cancer. The important features of self-management were that people with dyspnea were more likely to use strategies that altered the physical problem causing dyspnea (problem-focused; i.e., breathing strategies and medications) than to attempt regulation of emotions associated with the symptom (emotion-focused; i.e., isolation and tension reduction). Dyspnea coping strategies used by Caucasians with various pulmonary diseases and lung cancer were also similar to ones used by other ethnic groups with chronic lung diseases or lung cancer. Only difference was that Chinese patients with lung cancer (Lai et al., 2007) reported use of traditional therapies to manage dyspnea.

While much is known about strategies used to manage dyspnea, little data provide insight into the strategies used by Korean American immigrants to cope with it, how often various strategies are used and whether the strategies are effective in managing dyspnea. Thus, the overall purpose of this study was to describe the coping strategies Korean American immigrants with COPD and asthma use to manage dyspnea. The specific aims were to describe the types of strategies used, and the frequency and effectiveness of their use.

## METHODS

### *Design*

The design of this study was a cross-sectional, descriptive study.

### *Sample & Settings*

Participants were recruited through advertisements or referrals by a physician or nurse from primary care settings (i.e., four Korean Internal Medicine out-patient clinics, and one Adult Day Care Center) located in a Korean ethnic neighborhood in a large urban area in Western United States between June and October, 2008. Inclusion criteria were: Adults ≥ 19 years old, a diagnosis of COPD or asthma, a history of shortness of breath with daily activities or on exertion during the last 12 months, born and raised in Korea, able to speak, write, and read Korean, and immigrated to the U.S. as an adult (age≥ 19). Those with a diagnosis of cognitive impairment were excluded. Most participants were recruited through referrals by an M.D. or R.N. The investigator explained inclusion and exclusion criteria to the M.Ds. or R.N.s who had access to participants' charts.

### *Instruments*

*Demographic and Clinical Characteristics.* Information regarding the participant's age, gender, educational level, marital status, yearly income, length of stay in the U.S., co-morbidities, medication use, oxygen use, smoking history, working status, and recent pulmonary function test results were obtained through interviews.

*Dyspnea Intensity & Dyspnea Distress.* A Visual Analog Scale (VAS) was used to measure participants' usual and worst dyspnea intensity and distress on a vertical 100 mm line anchored at either end with the words "no breathlessness" and "worst imaginable breathlessness" for dyspnea intensity, and "no distress" and "worst imaginable distress" for dyspnea distress. Adequate test-retest reliability and concurrent validity of the VAS have been documented with patients with various pulmonary diseases (Brown et al., 1986; Gift, 1989; Wilson and Jones, 1989).

*Dyspnea Sensation.* One open-ended question was used to describe participant's own dyspnea sensations; "Can you describe in your own words how it felt when you are short of breath?"

*Dyspnea Severity.* The Modified Medical Research Council (MRC) was used to quantify how dyspnea affects daily activities. Participants were asked to choose one of five sentences which were from Grade 0 (Not troubled with breathlessness except with strenuous exercise) to Grade 4 (Too breathlessness to leave the house or breathless when dressing or undressing). Inter-rater reliability and concurrent validity of MRC have been documented in patients with cardiac or pulmonary diseases (Mahler and Wells, 1988).

. *Dyspnea Coping Strategies.* The Modified Self-Efficacy and Dyspnea Self-Strategies Scale (SEADS) was used to document which strategies the participant used to manage dyspnea. In addition, the participants were asked two open-ended questions: "What helps your shortness of breath go away?" and "Have you had any classes or learned about your shortness of breath or attended a pulmonary rehabilitation program?"

The SEADS, developed by Kwiatkowski (1994), consists of 35 coping strategies and confidence subscales. Adequate reliability and validity of SEADS have been reported

(Tseng, 2000). Additionally, the investigator modified SEADS by adding a frequency subscale and including coping strategies that were reported by Caucasian patients in an open-ended question in a previous study. This scale includes 38 coping strategies and 1 additional item asking the participant's own strategy to manage dyspnea. First, participants are asked to answer yes or no to 39 items regarding whether or not they use each strategy. If they say yes, then participants are asked to answer the frequency of use on a scale of 1 (rarely) to 4 (almost constantly), and effectiveness of the coping strategies on a scale of 0 (not at all) to 10 (very much).

*Family Role.* One open-ended question was used to describe the role of family member of someone who has dyspnea symptom; "What things does your family do to help you when you are short of breath or help you to prevent your shortness of breath?"

*Acculturation.* The Item Total Correlation (ITC) form a brief version of the Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA), was used to describe the degree of acculturation. This instrument includes five questions asking about which language participants can use, speak, and read, ethnic origin of the participant's friends when they were young, and how they evaluate themselves in terms of ethnicity. Each item is rated on a 5-point Likert scale. A mean acculturation score is obtained by summing the values for all of the items and dividing the sum by the total number of questions. The scores range from 1 to 5. A higher score indicates greater degree of Western identification. Adequate internal consistency (Cronbach's alpha of .80 to .82) and concurrent validity of ITC and the full scale of SL-ASIA has been reported (Leong and Chou, 1998; Suinn et al., 1992). Correlation coefficients of SL-ASIA were .61 with total years attending school in the U.S. and .56 with years living in the U.S.

### *IRB Review*

This study was reviewed and approved by the Institutional Review Board overseeing the investigation.

### *Procedures*

All instruments were translated into Korean by two native Koreans and back-translated into English by two different persons who were fluent in written Korean and English. Two translators were doctoral students who have lived in the United States for at least five years, and two translators have master's degrees in history or computer science and have lived in the United States for more than 15 years. Translators examined the wording of the English and Korean questionnaires to evaluate the semantic content, cultural relevance, and conceptual equivalence of the translated items. There were no major differences between original instruments and translate-back translated versions. The investigator and one of the translators translated findings from open-ended questions into English.

When the health care providers referred potential participants to the study, the investigator then approached them, described the study, asked them if they wished to participate, and if so, obtained written informed consent from them. A survey of demographic and clinical information was obtained, interviews were conducted, and study questionnaires were administered. All interviews and data collection were performed by the investigator either at participants' homes, or in clinic offices, or in an isolated area in public places, such as in the lobby in participants' apartments.

### *Data Analysis*

Data were analyzed using SPSS version 15.0 statistical software. All continuous data were expressed as means and standard deviations. Categorical variables were presented with percentages, frequencies, or medians. Similar terms from open-ended interview questions regarding coping strategies were grouped together, using Lazarus theory of coping, into problem-focused, emotion-focused, or mixed strategies (Folkman and Lazarus, 1980). Percentages and frequencies were used to describe problem-focused, emotion-focused, or mixed strategies. Similar terms from other open-ended interview questions were also grouped together and percentages and frequencies were used to describe results. The dyspnea VAS scores of those with COPD were compared with those with asthma using Univariate Analysis of Variance. The ordinal data from MRC and the number of coping strategies were compared between these same two groups as well as between genders, using Mann-Whitney U-test. The frequencies for each strategy were compared using Chi-square test. Mean values of detailed frequency use and effectiveness of each strategy were compared between groups using independent t-tests. The relationship between worst dyspnea intensity and the number of strategies the patient used, and the relationship between frequency and effectiveness of strategies use were analyzed using Pearson correlation co-efficient. A $p < 0.05$ was preset based on a power analysis and considered statistically significant.

## RESULTS

Demographic and clinical characteristics of participants (n=86) are presented in Table 3.2. A greater number of participants with COPD completed than those with asthma (54 vs.32); more males participated than females (60 vs.26); and the asthma group had more females than the COPD group. Four participants had diagnoses of both

COPD and asthma. These four participants were grouped as COPD, according to NICE guidelines (2004) and results of expiratory volume in 1 second (FEV1). The mean age of participants was 74.4 ± 7.3 years (range: 55-89); most were married or lived with someone (n=61, 70.9%); and nearly half of them had a bachelor degree or higher education (n=44, 51%). Most participants were retired and only 12.8% were working. Most had a low yearly income (<$20,000; 69.7%). Mean expiratory volume in 1 second (FEV1) was 57.7%, the values of which were available only in 41 participants and which were provided verbally by participants during their interviews. The $FEV_1$ results of 27 of these 41 participants were confirmed by the participant's primary care physician. Twenty participants (23.3%) were currently smoking. Most participants had concurrent diseases (n=70). Participants had lived in U.S. for a mean of 25.8 years (range: 2-50 years). The participants' mean acculturation score was 1.48 out of a possible 5.0.

### *Dyspnea Intensity, Dyspnea Distress, Dyspnea Severity, & Dyspnea Sensation*

The asthma group reported statistically higher mean worst dyspnea intensity scores (77.4 vs. 62.5, $p<.001$) and mean worst dyspnea distress scores (66.9 vs. 46.8, $p=.006$) than the COPD group. There were no significant group differences in the mean scores of usual dyspnea intensity, usual dyspnea distress, or in the MRC scores, nor was there a significant interaction between gender and group in these mean scores.

A majority of participants (n=44, 51%) found it hard to describe how it felt when they had difficulty breathing. The first response to the question regarding their description of the dyspnea sensation was usually "I don't know," or "How can I describe it?" or "I cannot find a word for it," or "I cannot think about anything else. I was just short of breath." Others used phrases such as, "felt tight" (n=26, 30%), "felt like my breathing stops" (n=8, 9%), and "smothering" (n=8, 9%). One participant stated "felt like dying from it." Participants with asthma in particular described their dyspnea sensations as "constricted chest," "felt like someone put a stone on my chest," "blocked chi," "narrowed bronchi," and "compressed neck (choking feeling)."

*Dyspnea Self- Strategies*

The coping strategies reported in response to the question "What helps your shortness of breath go away?" are presented in Table 3.3. The most frequently used strategy was "keep still" (n=47), while many (n=25) used activity modification, such as "decreasing aggressive activity," "avoiding lifting heavy things," "driving instead of walking." Fifteen participants used home remedies, such as drinking water when short of breath, performing nasal irrigation with warm salt water, and taking special herbal medicines. Only two participants used breathing techniques, such as pursed-lip breathing. Participants with asthma in particular, avoided aggravating factors, such as hot weather, wind, smoke, dust, and special foods containing acid.

The coping strategies identified on the Modified SEADS questionnaire are presented in Table 3.4. The mean number of coping strategies used by total sample was 14.1 ± 5.88. There was a significant relationship between worst dyspnea intensity and total number of strategies the patient used (r=.474, *p*<.01).

Of particular interest for this population was the use of acupuncture or herbs (n=21, 24%), home remedies (n=16, 19%), and the use of yoga or tai-Chi (n=5 (6%). The home remedies included drinking water; drinking honey tea mixed with ground pear, apricot, or Chinese balloon-flower; or taking special oriental medications. When the relationship between the strategies used and acculturation was examined, there were no differences in the level of acculturation between participants who used acupuncture or herbs, Tai-Chi or yoga, and home remedies and those who did not.

There were no significant group differences in the number of coping strategies used except that women used significantly more strategies (16.69 ± 5.7) than men (12.95 ± 5.6, *p*=.006). There were significant differences in prevalence in five of the 39 strategies, including two strategies ("I use distraction, such as TV, read, or music" and "I avoid wind, fog, or extreme temperature") in the Table 3.4. The following three strategies were chosen by participants with asthma more than those with COPD; "I call doctor or nurse" (31.3% vs. 11.1%, *p*=.042), "I avoid infection" (62.5% vs. 25.9%, *p*=.001), and "I use home remedies" (28.1% vs. 7.4%, *p*=.014).

In general, participants with asthma tended to use strategies more frequently than participants with COPD. When the mean frequency of strategy use was compared between COPD and asthma groups, only three of the 39 strategies showed significant differences ("I keep still or rest," "I move slower," and "I decrease activity") (see Table 3.4).

The effectiveness of the most prevalent strategies is also shown in Table 3.4. Few participants (n=3) used oxygen, but if the participant used oxygen for dyspnea, it was rated highly effective (mean score=9.5-10). When the mean effectiveness of each strategy was compared between COPD and asthma groups, eight of the 39 strategies showed significant differences (see Table 3.4). One strategy not shown in the table due to its lower prevalence was "I try acupuncture or herbs." Those with asthma rated this strategy more effective than did those with COPD [7.11 ± 2.98 (n=9) vs. 4.33 ± 2.64 (n=12), *p*=.036].

The frequency of strategy use was significantly related to effectiveness of strategies use in 24 of the 39 strategies (r=.334 to .806). The frequencies of “I use cool, such as use fans or open windows” (n=28, r=.806) and “I use abdominal/ diaphragmatic breathing” (n=8, r=.751) have a strong relationships with effectiveness of these strategies.

### *Education for Dyspnea Management*

Only one participant in the sample received formal education about dyspnea management while in the hospital. Twenty participants received advice from physicians that they needed to stop smoking and were encouraged to follow their prescribed medication regimen and to exercise regularly. However, 85 of the 86 participants were not taught specific technique to manage their dyspnea, although 11 participants mentioned that they received education from nurses about dyspnea management. Participants reported that nurses have an important teaching role in helping them learn the correct breathing techniques and the correct way to take inhalers.

### *Role of Family*

Forty eight participants (56%) were doing everything for themselves most of the time. However, when they have severe symptoms or an asthma attack, they got help from family members, such as driving, preparing meals, and lifting heavy objects. Thirty eight participants (44%) received some help from family members or other caregivers on a daily or weekly basis. Support from family members included doing laundry, cooking, cleaning, and lifting heavy things for participants. One participant reported that “my daughter bought me oriental medicines to manage symptoms, made me healthy food, and taught me how to breathe in and out when having difficulty in breathing.”

## DISCUSSION AND CONCLUSIONS

More than half of Korean immigrants were not able to describe their breathing sensation, which may be attributed to cultural differences. Willingness to report or express symptoms in public may differ among cultures (Angel and Thoits, 1987). Value is placed on the control of expressive behavior; therefore, strong feelings are not necessarily overtly expressed in Asian cultures. One study (Hobara, 2005) showed that Euro-American subjects rated pain behaviors, such as, crying out and moaning in front of others, to be more acceptable than Japanese participants. Non-verbal communication, which can be either expressive or non-expressive, is also a vital means of interpersonal relationships in Asian cultures. For example, the terms “Zhih Yi” in Chinese, which means knowing what the other thinks and feels, “ishin denshin” in Japanese, which means mind-to-mind intuitive communication, and “nunchi” in Korean, which means the subtle art of listening and gauging another's mood, denote the importance of non-verbal communications in Asian cultures (Ishii, 1984; Kagawa-Singer and Blackhall, 2001). Therefore, symptoms may not be actually reported or expressed publicly in some cultures, but may be communicated non-verbally within members of one’s own ethnic group.

The participants in this study were not formally taught by a health care provider how to manage their dyspnea, but they were able to use their expertise and knowledge to develop and use their own personal dyspnea self-management strategies. It is difficult to compare findings of the present study with reports of Bang (2002) who studied Korean patients residing Korea because Bang did not provide detailed findings in her report. It appears that our participants used more strategies to manage their symptoms than her participants and ours used traditional treatments to cope with their symptoms. The findings of use of traditional treatments are consistent with the findings by Lai et al.

(2007) in Chinese patients with advanced lung cancer in Hong Kong. Coping behavior always occurs in a social context and is affected by the social context (Hastie et al., 2004). It is not surprising that both Chinese and Korean patients are dependent on traditional medicine to manage dyspnea. Traditional Korean medicine, although derived from the Chinese form, has developed its own characteristics (Pang, 1989; Parish and Parish, 1971). The Korean sample in this study consisted of older adults who lived traditional lives in a Korean ethnic neighborhood in a large urban area in Western United States. Yet 21 of the 86 participants used oriental herbs or acupuncture, which may indicate their cultural preferences in managing dyspnea. There were, however, no significant differences in acculturation scores between those who used oriental medicines and those who did not, which may be attributed to the small variation in these scores in this study.

Our findings are also consistent with reports of others with Caucasians and African Americans with chronic lung diseases and lung cancer, showing that types of coping strategies were relatively similar, regardless of ethnicity (Table 3.1). The only difference was the use of traditional medicine to cope with their symptoms. Consistent with Janson-Bjerklie and Shnell's study (1988), the number of strategies in this study was significantly correlated with worst dyspnea intensity scores. With severe dyspnea, it is reasonable to expect that participants will try various strategies and eventually find those that are most effective in improving their symptoms. Our study found that frequency of strategy use was significantly related to participants' rating of effectiveness in 24 strategies. It is also reasonable to expect that if someone finds an effective strategy, then he or she will use it more frequently to manage their symptoms.

All participants used problem-focused strategies to control their dyspnea more than emotion-focused strategies. Most participants responded to acute dyspnea by keeping still or moving slower. Carrieri-Kohlman and Janson-Bjerklie (1986) found that patients with asthma tended to become more motionless than slower. In our study, participants with asthma used “I keep still or rest” and “I move slower” relatively equally and used those strategies with greater frequency than participants with COPD. This difference in results may be due to the older age and greater dyspnea severity in participants with asthma in our study. The differences between the COPD and asthma groups were that participants with asthma rated the air-focused strategies (i.e., avoiding irritants and getting fresh air) more effective than participants with COPD.

Eighty five participants had never participated in any pulmonary rehabilitation program. Only one of 86 participants received formal education about disease management while in the hospital. Most participants were not taught specifically about dyspnea management. Few participants received education from health care providers. As Christenbery (2005) noted, the previous participation in pulmonary rehabilitation by their participants affected the findings of their study. In our study, the low frequency of using breathing techniques may reflect the lack of participation in any formal pulmonary rehabilitation programs.

In general, most participants rated emotion-focused strategies less effective than problem-focused strategies. However, Carrieri-Kohlman and Janson-Bjerklie (1986) found that patients with asthma tended to use more emotion-focused strategies such as relaxation techniques, when compared to patients with COPD. This study also found that participants with asthma felt “I calm myself down” and “I try not to think about it and don’t worry” effective to relieve their dyspnea more than participants with COPD. Emotion plays an important role in dyspnea perception and management. Therefore, emotion-focused strategies should also be emphasized in teaching patients with chronic lung diseases.

We found that most Korean immigrants were dependent upon and received support from family members, especially during an asthma attack or exacerbation period. Because of a strong collective sense of self, a problem, such as a patient’s illness, is seen as a family problem rather than just an individual problem. For this reason, families of Asian patients often appear to American healthcare professionals as being over-involved and, at times, even taking over responsibilities and making decisions for the patient. In the American context, where independence is highly cherished, patients seem to be ill at ease in dealing with their dependency needs (Nilchaikovit et al., 1993). On the other hand, Asian families tend to do everything for sick family member. Thus the collectivistic family value may affect how Asian patients self-manage their symptoms.

Several limitations must be considered when interpreting the results of this study. A convenience sample for this study was recruited from primary care settings rather than tertiary care settings. Participants in this sample tended to have stable pulmonary disease. Few participants used oxygen, indicating mild or moderate disease, compared to participants from another study (Christenbury, 2005). Most participants were not exposed to any kind of pulmonary rehabilitation program. The findings from this study are only generalizable to immigrant Korean populations in primary care settings. Most participants had multiple diseases besides COPD or asthma, and were older than those who participated in earlier studies. Furthermore, there was gender imbalance in each group; therefore, some of our findings may not reflect an accurate description of Korean immigrants' real life, although significant differences were not found in this study. All strategies in the modified SEADS were based on strategies used by Caucasians, which is of concern when applying this instrument to Korean immigrants. The investigator allowed enough spaces for participants to fill in their home remedies at the end of instrument and also interviewed them with an open-ended question before administering this instrument. Therefore, findings from this instrument should be interpreted cautiously. However, strategies identified from the interviews were similar to strategies from listed on the SEADS, indicating that the SEADS instrument may be useful in evaluating a Korean immigrant population.

In conclusion, Korean immigrants used self-management strategies similar to those used by other ethnic groups, but also incorporated elements of Asian medical practice and herbs. The Korean immigrant participants of this study had not been offered the benefits of a pulmonary rehabilitation program. Most participants used multiple strategies to manage dyspnea and have learned these strategies by trial and error, which would be similar to many patients in U.S. who have not had the opportunity of attending pulmonary rehabilitation programs. Such a program, tailored to the needs of the Korean immigrant in which some their traditional therapies are incorporated with the usual curriculum, may prove beneficial to those with COPD and asthma. Since the family has an important role in taking caring for a sick family member in Korean culture, families should be included in these education programs.

## Implications for Practice and Research

A central role of nursing is to help build on and supplement existing self-management knowledge and capabilities of patients with chronic diseases (Johnson, 1999). Thus, nurses need to be aware of individual coping strategies that promote more effective symptom management. Dyspnea management tools for other ethnic groups may also be applicable to Korean immigrants. However, knowledge of coping methods used by Korean participants, especially about their preferences for traditional medicines and various home remedies, and understanding of the role of family in Asian culture could help add to the nursing knowledge base in caring for and teaching this particular population how to cope with their symptoms on a daily basis and over time. More data are needed on why these participants are not referred to a rehabilitation program, whether the issue is the lack of referral, lack of compliance with recommendations, a lack of rehabilitation programs provided in Korean language, or whether participants cannot afford to undertake such a plan. Further study is needed regarding the lack of knowledge about the traditional therapies, especially about the herbs used. Some questions to ask are: What are the names of these herbs and how are they used? How do they interact with western medications that are prescribed? What types of signs and symptoms should health care providers monitor if these herbs are taken? Without knowledge of the mechanisms of action of traditional remedies, the health care practitioner is not able to accurately assess the efficacy of his or her prescribed therapies or be able to interpret the meaning of any adverse effects.

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Table 3.1

*Coping Strategies for dyspnea used by patients of various ethnicities with COPD, asthma, and lung cancer*

| **Study** | **Bang (2002)** | **Current study** | **Carrieri-Kohlman and Janson-Bjerklie (1986)** | **Janson-Bjerklie et al. (1992)** | **Christen bury (2005)** | **Nield (2000)** | **Brown et al. (1986)** | **Lai et al. (2007)** |
|---|---|---|---|---|---|---|---|---|
| **Population** | Korean patients (N=53) in Korea with COPD & asthma | Korean patients (N=86) in U.S. with COPD & asthma | Caucasians (N=68) with emphysema-bronchitis, asthma, vascular disease, & restrictive disease | Caucasians (N=95) with asthma | Caucasians & African Americans (N=79) with COPD | African Americans (N=29) with COPD & sarcoidosis | Caucasians (N=30) with lung cancer | Chinese (N=11) with lung cancer |
| **Sources** | 23 item coping strategy instrument | 39 item self-strategy instrument | Open-ended question | Open-ended question | 11 item Dyspnea Intervention Scale | Open-ended question | Open-ended question | Open-ended question |
| **Strategy** | | | | | | | | |
| ***Problem-Focused*** | | | | | | | | |
| *Position & Motion* | | | | | | | | |
| Move slower | x | x | x | | x | | x | x |
| Lie down | | | x | | | | x | |
| Keep still | | x | x | | x | x | | |
| Positioning | | x | x | x | | x | x | |
| *Breathing Strategies* | x | x | x | x | x | x | x | x |
| *Physical Distancing from Aggravating Factors* | x | x | x | x | | x | x | x |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| *Self-selected Treatments* | | | | | | | | |
| Use oxygen | x | x | x | | x | | | x |
| Use bronchodilators | x | x | x | x | x | | x | x |
| Home remedies | | x | x | x | | | x | x |
| Fresh air | x | x | x | x | x | | | |
| Percussion & vibration | | | | x | | | | |
| Acupuncture & herbs | | x | | | | | | x |
| *Seeks Medical Care* | | x | | x | | x | | |
| *Change in ADL* | x | x | x | | x | | x | |
| *Activity Modification* | x | x | x | x | x | | x | x |
| *Health Directed Behavior* | | | | | | | | |
| Increased exercise | | x | x | | | x | x | |
| Weight control | x | | x | | | | | |
| Change in job | | | x | | | | | |
| ***Emotion-Focused*** | | | | | | | | |
| *Self-Isolation* | | x | x | | | | x | |
| *Tension-Reduction* | x | x | x | x | | x | x | x |
| *Emphasizing Positive* | x | | x | x | | | x | |
| *Emotional Distancing* | | x | x | | | | x | |
| *Soothing Strategies; drinking alcohol* | | x | | x | | | | |
| ***Mixed*** | | | | | | | | |
| *Seeking Social Support* | x | x | x | x | | x | x | x |
| *Distraction-Diversion* | | x | x | x | | x | x | |

Table 3.2

*Demographic and Clinical Characteristics of Total Sample (N=86)*

| | Total (n=86) Mean ± SD n (%) | COPD (n=54) Mean ± SD n | Asthma (n=32) Mean ± SD n |
|---|---|---|---|
| Age | 74.4 ± 7.3 (range; 55-89) | 75 ± 7.1 | 73.3 ± 7.8 |
| Gender (M/F) | 60/26 | 49/5 | 11/21 |
| Education (n=85) | | | |
| High school & lower | n=41 (48%) | | |
| Bachelor & higher | n=44 (51%) | | |
| Income (n=79) | | | |
| <$20,000 | n=60 (69.7%) | | |
| >$20,000 | n=19 (22%) | | |
| Living situation | | | |
| Alone | n=25 (29.1%) | | |
| Married or Living with someone | n=61 (70.9%) | | |
| Working | n=11 (12.8%) | n=7 | n=4 |
| Years of stay in U.S | 25.8 ± 9.8 | | |
| Current smoker | n=20 (23.3%) | n=18 | n=2 |
| Pack years of current smoker | 44.92 ± 23.6 | 47.1 ± 23.9 | 25 ± 3.5 |
| Past smoker | n=36 (41.8%) | n=29 | n=7 |
| Pack years of past smoker | 41.77 ± 33.0 | 42.8 ± 32.9 | 37.6 ± 35.5 |
| Oxygen use | n=2 (2.3%) | n=2 | n=0 |
| FEV1 % pred. (n=41) | 57.7 ± 17.5 | 56.4 ± 17.8 (n=32) | 62.6 ± 16.4 (n=9) |
| Co-morbidities (Yes) | n=70 | n=42 | n=28 |

Table 3.3

*Dyspnea Coping Strategies used by Korean American Participants with COPD or Asthma, as reported during interview (N=86)*

| Coping Strategies | Total Sample (n=86) n (%) | COPD (n=54) (%) | Asthma (n=32) (%) |
|---|---|---|---|
| ***Problem-Focused*** | | | |
| *Position & Motion* | | | |
| Move slower | n=41 (48%) | 50% | 41% |
| Lie down | n=1 (1%) | 2% | |
| Keep still | n=47 (55%) | 63% | 41% |
| *Breathing Strategies* | n=2 (2%) | 2% | 3% |
| *Self-selected Treatments* | | | |
| Use oxygen | n=1 (1%) | 2% | |
| Use bronchodilators | n=28 (33%) | 30% | 38% |
| Home remedies | n=15 (17%) | 6% | 38% |
| Fresh air | n=5 (6%) | 2% | 13% |
| *Physical Distancing from Aggravating Factors* | n=24 (28%) | 28% | 66% |
| *Activity Modification* | n=25 (29%) | 26% | 32% |
| *Health Directed Behavior* | n=15 (17%) | 20% | 13% |
| ***Emotion-Focused*** | | | |
| *Tension-Reduction* | n=12 (14%) | 15% | 13% |
| ***Mixed*** | | | |
| *Seeking Social Support* | n=2 (2%) | 2% | 3% |
| *Distraction-Diversion* | n=1 (1%) | | 3% |

Table 3.4

*Prevalence, Frequency & Effectiveness of Most Frequently Reported Dyspnea Self-Strategies from Modified SEADS by Groups*

| Coping Strategy | Patients with COPD using strategy (n=54) | | | Patients with Asthma using strategy (n=32) | | |
|---|---|---|---|---|---|---|
| | n (%) using strategy | Frequency of strategy | Effectiveness of strategy | n (%) using strategy | Frequency of strategy | Effectiveness of strategy |
| I keep still or rest. | 47 (87%) | 2.98 ± .87 | 7.17 ± 2.08 | 27 (84%) | 3.41 ± .78* | 7.89 ± 1.67 |
| I move slower. | 41 (76%) | 3.02 ± .85 | 7.12 ± 2.12 | 27 (84%) | 3.44 ± .70* | 7.85 ± 1.77 |
| I get some fresh air. | 38 (70%) | 3.05 ± .84 | 6.68 ± 2.03 | 26 (81%) | 3.15 ± .83 | 7.69 ± 1.74* |
| I avoid strenuous activities. | 38 (70%) | 3.26 ± .92 | 7.00 ± 1.85 | 26 (81%) | 3.65 ± .63 | 7.81 ± 1.90 |
| I decrease activity. | 34 (63%) | 2.82 ± .87 | 6.76 ± 2.26 | 24 (75%) | 3.42 ± .72* | 7.92 ± 1.56* |
| I exercise, such as walking or any other exercise. | 33 (61%) | 2.76 ± .79 | 6.61± 2.59 | 24 (75%) | 2.79 ± .78 | 7.08 ± 1.84 |
| I take bronchodilators. | 33 (61%) | 2.97 ± .81 | 6.82 ± 2.33 | 24 (75%) | 3.29 ± .55 | 8.29 ± 1.60* |
| I avoid irritants such as smoke. | 32 (59%) | 3.56 ± .80 | 7.38 ± 1.96 | 25 (78%) | 3.72 ± .54 | 8.68 ± 1.44* |
| I try not to think about it and don't worry. | 31 (57%) | 2.84 ± .97 | 5.48 ± 2.34 | 21 (66%) | 3.05 ± .67 | 7.14 ± 2.06* |
| I pray or meditate. | 31 (57%) | 2.81 ± .70 | 6.06 ± 1.71 | 20 (63%) | 3.15 ± .75 | 6.95 ± 2.44 |
| I calm myself down. | 29 (54%) | 2.83 ± .97 | 6.07 ± 1.93 | 22 (69%) | 3.23 ± .61 | 7.50 ± 1.68* |
| I change position, such as lean on something. | 26 (48%) | 2.54 ± .81 | 6.62 ± 2.48 | 16 (50%) | 2.89 ± .90 | 7.44 ± 1.89 |
| I use distraction, such as TV, read, or music. | 24 (44%) | 2.96 ± .75 | 5.75± 2.93 | 7 (22%)* | 2.57 ± .54 | 6.00 ± 1.92 |
| I socialize and participate in leisure activities with others | 21 (39%) | 2.81 ± .75 | 6.33 ± 1.71 | 13 (41%) | 3.08 ± .64 | 7.31 ± 1.84 |
| I get support from friends and family. | 20 (37%) | 2.75 ± .85 | 5.65 ± 2.54 | 15 (47%) | 3.27 ± .80 | 7.20 ± 1.94* |
| I avoid wind, fog, or extreme temperature. | 18 (33%) | 2.67 ± .84 | 6.11 ± 2.78 | 25 (78%)* | 3.20 ± 1.00 | 7.28 ± 2.09 |
| I use cool, such as use fans or open windows. | 17 (31%) | 2.76 ± .97 | 6.29 ± 2.82 | 11 (34%) | 3.00 ± .78 | 7.45 ± 1.97 |

*; $p<.05$, comparison between COPD and asthma groups

# CHAPTER FOUR

## The Relationship between Symptoms and Functional Performance in Korean Immigrants With Chronic Obstructive Lung Diseases

### ABSTRACT (max word: 150)

The purpose of this study was to explore multiple symptoms, the presence of symptom clusters, and the effect of symptoms on functioning in Korean immigrants with chronic obstructive pulmonary disease (COPD) and asthma. Outpatients with stable COPD (n = 54) and asthma (n = 32) were studied. The Dyspnea Visual Analog Scale, Modified Medical Research Council Dyspnea Scale, Memorial Symptom Assessment Scale, and Functional Performance Inventory-Short Form were used to describe participants' dyspnea, symptoms, and functioning. Frequently reported symptoms were shortness of breath, problems in urination, numbness and tingling in hands and feet, drowsiness, cough, dry mouth, and lack of energy. Three factors emerged from 17 symptoms. Age, multiple symptoms, mood, dyspnea, and level of education explained significant variance in functional performance. Dyspnea was the most significant predictor of functional performance. This study's findings suggest that continuous emphasis on dyspnea management is warranted to improve functioning in the Korean immigrant population.

***Keywords:*** Dyspnea, Symptoms, Functioning, Korean Immigrants, COPD, Asthma

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# The Relationship between Symptoms and Functional Performance in Korean Immigrants With Chronic Obstructive Lung Diseases

In Korea, respiratory diseases are the primary cause of morbidity, and mortality from asthma and chronic bronchitis has been increasing (Statistics Department in Korea, 2005; WHO, 2006). In the United States (U.S.), no data are available on the number of Korean immigrants who have respiratory diseases, but the rate among Asian adults in California is 10% (American Lung Association, 2007). Chronic obstructive pulmonary disease (COPD), including emphysema and chronic bronchitis, incapacitates a person physically, psychologically, and socially (McSweeney, Grant, Heaton, Adams, & Timmes, 1982; Williams & Bury, 1989). Asthma is a chronic inflammatory disorder of the airways that leads to recurrent episodes of wheezing, breathlessness, chest tightness, and coughing (Global Initiative for Asthma, 2006). Management guidelines for COPD and asthma have focused on symptoms that are considered to be disease-specific (Global Initiative for Obstructive Lung Disease, 2008; NIH, 2007). Often, older adults with COPD and asthma have significant comorbidities, but the literature has not reported detailed information about the symptoms they experience. Concurrent diseases may further reduce functional status in patients with COPD and asthma. Generally, functional limitation does not reflect severity of disease but is commonly attributed to the symptoms of disease (Mahler et al., 1992; Graydon & Ross, 1995). Thus, identifying and alleviating symptoms are essential aspects of chronic disease management. As the diversity of the U.S. population and the prevalence of chronic obstructive lung diseases, including COPD and asthma, among Koreans continue to increase, the common symptoms of chronic obstructive lung diseases and their effects, including daily functioning, must be understood (Current Population Reports, 2002; Rubia, Marcos, & Muennig, 2002).

## Theoretical Framework

The theoretical framework for this study was adapted from the theory of unpleasant symptoms (Lenz, Suppe, Gift, Pugh, & Milligan, 1995; Lenz, Pugh, Milligan, Gift, & Suppe, 1997) which provides a framework for the evaluation of symptoms and insight into the effect of symptoms on functioning. The theory of unpleasant symptoms has three major components: the symptoms, the factors that affect symptoms, and the consequences of symptoms (Lenz et al., 1995; Lenz et al., 1997). Each symptom is conceptualized to be a multidimensional experience that incorporates the dimensions of intensity, timing, distress, and quality. Influencing factors, which are characterized as physiologic (pathological problems), psychologic (mood), and situational (social support), are interrelated and may influence the symptom experience. This theory posits that the symptom experience affects an individual's performance, including functional performance (i.e., physical activity, activities of daily living, social activities, and interaction) and cognitive activities (i.e., problem solving). According to this theory, multiple symptoms are experienced simultaneously; they are likely to be multiplicative rather than additive; and interventions directed towards one symptom may also affect other symptoms.

## Literature Review

### *Concurrent Symptoms and Symptom Clusters*

Recently, symptom burden, concurrent symptoms, multiple symptoms, and symptom clusters have been examined in populations with various advanced chronic diseases (Gift, Stommel, Jablonski, & Given, 2003; Gift, Jablonski, Stommel, & Given, 2004; Portenoy et al., 1994; Tranmer et al., 2003). Few research studies, however, have examined the symptoms of patients with COPD and asthma. Dyspnea and fatigue are the symptoms most often reported by patients with COPD and asthma (Blinderman, Homel, Billings, Tennestedt, & Portenoy, 2009; Gift & Shepard, 1999; Jablonski, Gift, & Cook, 2007; Tranmer et al., 2003; Walke, Gallo, Tinetti, & Fried, 2004; Walke et al., 2007). Other frequently reported symptoms include cough, dry mouth, and feeling nervous (Blinderman et al., 2009; Gift & Shepard, 1999; Jablonski et al., 2007). Less frequently reported feelings include irritability, sadness, drowsiness, and worry (Blinderman et al., 2009; Gift & Shepard, 1999; Jablonski et al., 2007) as well as limited activity, physical discomfort (Walke et al., 2004), appetite problems, anxiety, pain, and depression (Walke et al., 2007). All of these studies showed that patients with chronic obstructive lung diseases report similar symptoms.

Dodd, Miaskowski, and Paul (2001) defined a symptom cluster to be three or more concurrent symptoms that are related to each other and noted that symptoms in a cluster are not required to share the same etiology. In a study of patients with heart failure (Jurgens et al., 2009), shortness of breath, fatigue, and difficulty sleeping formed a cluster. Using principal components factor analysis, Walke et al. (2007) identified three symptom factors in patients with COPD, heart failure, and cancer: 1) the physical factor (physical discomfort, fatigue, problems with appetite, and pain); 2) the affective factor (feelings of depression and anxiety); and 3) the shortness-of-breath factor.

In studies of patients with lung cancer (Gift et al., 2003; Gift et al., 2004), a single cluster of seven symptoms was identified that included fatigue, weakness, weight loss, appetite loss, nausea, vomiting, and altered taste. Difficulty breathing did not emerge as part of the cluster in these studies. In study of patients with lung cancer, Sarna and Brecht (1997) identified four factors. Among these, the respiratory distress factor included insomnia, difficulty breathing, and cough, and the malaise factor included fatigue and poor concentration.

As is evident from the above studies, symptoms do not always merge into the same factor. For example, dyspnea and fatigue are sometimes merged into the same factor, but sometimes they fall into different factors. Researchers have observed that this could be attributed to differences in methods of data collection and analyses or actual differences in patients' symptoms as a result of their disease or treatments. Currently little is known about symptom clusters in patients with chronic obstructive lung diseases. Understanding sentinel symptom clusters could provide new avenues for intervention to minimize the effect of symptoms on health-related outcomes.

### *Predictors for Functioning*

Many researchers have examined the link between symptoms and functioning and have investigated the effect of the single, most severe symptom or the collective disease-specific symptoms, as measured by Bronchitis-Emphysema Symptom Checklist (BESC), on the decrease in functioning in patients with COPD. The most common, physical symptom associated with functional decline in this population was dyspnea (Mahler et al., 1992). Dyspnea and functioning were measured by various instruments, but dyspnea was strongly associated with functioning (Moody, McCormick, & Williams, 1990) and a strong predictor for functioning in several studies (Hu & Meek, 2005 ; Kapella, Larson, Patel, Covey, & Berry, 2006; Keller, 1986; Lee, Graydon, & Ross, 1991; Reishtein, 2005; Yeh, Chen, Liao, & Liao, 2004; Weaver, Richmond, & Narsavage, 1997; Williams & Bury, 1989) and in native Koreans with COPD and bronchiectasis (Oh et al., 2002).

In addition to research on the symptom of dyspnea, investigators, using the BESC's somatic scale and the Sickness Impact Profile have found a moderate-to-strong, significant relationship between total collective symptoms and functioning, suggesting that overall symptom severity may be associated with poorer daily functioning (Graydon & Ross, 1995; Graydon, Ross, Webster, Goldstein, & Avendano, 1995; Lee, Graydon, & Ross, 1991). One recent study has investigated the relationship between seven collective symptoms and functioning in patients with COPD, heart failure, and cancer (Walke et al., 2007). Physical components, such as physical discomfort, fatigue, problems with appetite, and pain, were the only factor associated with functional disability (OR 1.5; CI 1.10-2.01).

Other factors that may influence or be associated with functioning in patients with COPD include the amount of available social support (Lee et al., 1991; Graydon & Ross, 1995); mood (Graydon & Ross, 1995; Lee et al. , 1991; Yeh et al., 2004); age (Graydon et al., 1995; McSweeney et al., 1982; Williams & Bury, 1989); socioeconomic status (Keller, 1986; McSweeney et al., 1982); and gender (Leidy & Traver, 1995).

Few studies have examined the relationship between symptoms and functioning in patients with asthma (Nejjari et al., 1994; Oh, 2008), perhaps because such patients usually experience symptoms intermittently. However, people with asthma, particularly older adults, have unpredictable and recurrent episodes of symptoms and decreased physical and psychological functioning that affect their lives in many ways (Gruffydd-Jones, 1997; Nejjari et al., 1994; Nocon & Booth, 1991). Oh (2008) found that symptom distress in patients with asthma (i.e., shortness of breath, wheezing, cough, and chest tightness) explained a significant amount of variance in functioning. Nejjari et al. (1994) also found that older adults with asthma, compared with a control group matched for age and sex, experienced poorer functioning, and dyspnea appeared to be the main factor of disability.

Most studies have been conducted with Caucasians. Little is know about the level of functioning in immigrant populations. Korean patients who experience severe symptoms, such as breathlessness and coughing, may curtail their participation in social activities. Many immigrants also experience other stressors, such as acculturation, conflicts between their heritage and the new host culture, and language problems. All of these factors may affect the level of functioning in daily activities.

Thus, this study’s purposes were (a) to describe concurrent symptoms, (b) to examine the presence of symptom clusters, (c) to examine the relationships between symptoms (i.e., a single symptom of dyspnea vs. symptom clusters vs. collective multiple symptoms) and functional performance, and (d) to determine the relative contributions of symptoms and selected sample characteristics to functional performance in Korean immigrants with chronic obstructive lung diseases. The selected sample characteristics included disease group, age, gender, living situation, education level, income, social support, mood, comorbidities, years in the United States, and acculturation.

## Methods

### *Design*

The design of this study was cross-sectional and descriptive.

### *Sample and Settings*

Adults with COPD and asthma attending internal medicine outpatient clinics and an adult day health care center in an ethnic Korean area of a large metropolitan area in the Western U.S. were recruited for this study. Subjects were recruited during four months in 2008 (June to October). The study inclusion criteria were that potential subjects had to be adult Korean immigrants with COPD or asthma. They also had to have reported shortness of breath in their daily activities or with some type of exertion in the last year. Subjects had to have immigrated to the U.S. as an adult (≥19 years old) but had to speak, write, and read Korean. Excluded were individuals diagnosed with cognitive impairment (e.g., dementia).

### *Measures*

#### *Demographic and Clinical Characteristics*

The participants' age, gender, educational level, marital status, yearly income, length of stay in the United States, comorbidities, medication use, oxygen use, smoking history, working status, and recent pulmonary function test results were obtained by interview.

#### *Dyspnea*

The Visual Analog Scale (VAS) and the Modified Medical Research Council (MRC) were used to measure dyspnea. The VAS was used to describe the participants' usual dyspnea intensity on a vertical 100 mm line anchored at one end with the words *no breathlessness* and at the other end with *worst imaginable breathlessness*. The MRC, which measures how dyspnea affects daily activities, consists of five sentences from Grade 0 (*not troubled with breathlessness except with strenuous exercise*) to Grade 4 (*too breathlessness to leave the house or breathless when dressing or undressing*).

Participants were asked to select one descriptor. Adequate test-retest reliability and concurrent validity of the VAS have been documented in patients with various pulmonary diseases (Brown, Carrieri-Kohlman, Janson-Bjerklie, & Dodd, 1986; Gift, 1989; Wilson & Jones, 1989). Inter-rater reliability and concurrent validity of the MRC have been documented in patients with cardiac or pulmonary diseases (Mahler & Wells, 1988).

### *Symptoms*

The Memorial Symptom Assessment Scale (MSAS) is a self-report questionnaire designed to measure the multidimensional experience of symptoms (Portenoy et al., 1994). The MSAS contains a list of 32 physical and psychological symptoms. Participants were asked to indicate if they had experienced any of the symptoms during the previous week. If a participant had symptoms, he or she was asked to rate frequency on a scale of 1 to 4, severity on a scale of 1 to 4, and distress on a scale of 0 to 4 for each symptom. A score for each symptom was then calculated by averaging the scores on the frequency, severity, and distress scales. A higher score indicated more severe, frequent, and distressed symptoms.

The MSAS Psychological Symptom (PSYCH) subscale, the MSAS Physical Symptom (PHYS) subscale, the Global Distress Index (GDI), and the MSAS total score were calculated. The MSAS-PSYCH subscale is the average of the frequency, severity, and distress scales' ratings for six psychological symptoms: feeling sad, worrying, feeling irritable, feeling nervous, difficulty sleeping, and difficulty concentrating. The MSAS-PHYS subscale is the average of the frequency, severity, and distress scales' ratings for 12 physical symptoms: lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness.

The MSAS-GDI was calculated by taking the average of the frequency of four psychological symptoms (feeling sad, worrying, feeling irritable, and feeling nervous) and the distress of six physical symptoms (lack of appetite, lack of energy, pain, feeling drowsy, constipation, and dry mouth). The MSAS total score was calculated by averaging the symptom scores for all 32 symptoms. The concurrent validity and reliability of this instrument have been tested in patients with cancer (Portenoy et al., 1994).

### *Mood*

The negative mood scale of the Profile of Mood States-Short Form (POMS-SF) was used to measure the participants' mood. It measures tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, and confusion-bewilderment. The POMS-SF consists of 30 adjectives with 5-point rating scales from 0 (*not at all*) to 4 (*extremely*). The total mood disturbance score was calculated by summing the scores of the six primary mood factors with *vigor* weighted negatively. Only the total mood disturbance score was used for this study. A higher score means more severe mood disturbance. The reliability and concurrent validity of the POMS-SF have been demonstrated for various populations (McNair, Lorr, & Droppleman, 1992).

### *Social Support*

The 8-item Emotional-Informational Support subscale of the Medical Outcomes Study Social Support Survey was used to describe the participants' support system. Participants were asked to indicate how often each of the eight supports is available to them when they need it on a scale of 1 (*none of time*) to 5 (*all of the time*). A mean score was obtained by summing the values for all of the items and dividing the sum by the total number of questions. A higher score means greater support system. Reliability and validity of this instrument have been reported in patients with chronic diseases (Sherbourne & Stewart, 1991).

### *Acculturation*

The Item-Total Correlation form, a brief version of the Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA), was used to describe the degree of acculturation. The instrument's five questions address the language participants can use, speak, and read, the ethnic origin of the participant's friends when they were young, and how they evaluate themselves in terms of ethnicity. Each item is rated on a 5-point Likert scale. A mean acculturation score is obtained by summing the values for all of the items and dividing the sum by the total number of questions. The scores range from 1 to 5. A higher score indicates greater degree of Western identification. Adequate internal consistency and concurrent validity of the Item-Total Correlation form and the full scale of the SL-ASIA have been reported (Leong & Chou, 1998; Suinn, Anuna, & Khoo, 1992).

### *Functional Performance*

The Functional Performance Inventory-Short Form (FPI-SF) was used to describe the participants' functional performance, defined as an individual's physical, psychological, social, occupational, and spiritual activities or the extent to which people execute certain activities or behaviors in their normal activities of daily living (Leidy, 1994). The FPI-SF was developed to measure functioning in populations with COPD (Leidy, 1999), but since each component of the scale measures general functioning rather than disease-specific or symptom-related functioning, we decided to use this instrument in our group of elderly patients with asthma.

This instrument's 32 items are organized into six subscales: body care, household maintenance, physical exercise, recreation, spiritual activities, and social activities. Response choices for each item range from 3 (*do easily*) to 0 (*do not do because of health reasons or choose not to do for reasons other than health*). A higher score indicates greater functional performance. Validity and reliability of the FPI-SF have been tested in patients with chronic airway obstruction (Leidy & Knebel, 1999). The FPI-SF is internally consistent ($\alpha = .93$) and reproducible ($r = .88$) (Leidy & Knebel, 1999). Concurrent validity has been reported with the Duke Activity Status Index ($r = .65$) (Leidy & Knebel, 1999).

### *Procedures*

Prior to enrollment of subjects in this study, the research was approved by the Committee on Human Research, University of California, San Francisco. The study instruments were not available in Korean and so were translated and back translated. The initial translation to Korean was performed by two native Koreans and the back-translation was completed by two different individuals. At the completion of the back translation, the original instruments and the Korean version were consistent.

Potential subjects were referred to the investigator by physicians and nurses from Korean internal medicine outpatient clinics (n=4) and one adult day care center. After the study was explained to potential participants, a convenient time was arranged for data collection for those who were interested and signed informed consent form. Data collection took place in a private area where confidentiality could be maintained in the participants' homes, offices of the outpatient clinics, and public places, such as the lobbies in the participants' apartment buildings. Participants provided demographic and clinical information and completed study questionnaires.

### *Statistical Analysis*

Data were analyzed using SPSS version 15.0 and MPlus version 5.0 statistical software (Muthan & Muthan, 2008). All continuous variables were expressed as mean and standard deviation. Categorical variables were presented with percentage, frequency, or median. The differences between groups in continuous variables were compared using univariate analysis of variance. The ordinal data and number of symptoms chosen in MSAS were compared between groups using the Mann-Whitney *U* test.

Symptoms that were reported by more than 25% of the sample in MSAS were used to perform factor analysis. This criterion was chosen because most symptoms reported by less than 25% of the sample were related to cancer treatment, and sufficient variation in the data was not available to perform factor analysis. An exploratory factor analysis was done to determine the number of symptom clusters based on symptom severity ratings, which were chosen because of larger variations in their scores than any other ratings in the MSAS. The simple structure was estimated using the method of robust unweighted least squares with geomin (oblique) rotation, because of the relatively small sample size (Muten & Kaplan, 1985; Muthan & Muthan, 2008). The number of factors was considered sufficient to explain the symptom correlations if the model's chi square was not significant, its comparative fit index (CFI) was $\geq 0.95$, and root mean square error of approximation (RMSEA) was $\leq 0.06$ (Raykov & Marcoulides, 2006). Mean scores of items (symptom severity) within each factor were calculated for each of the factors.

Pearson correlation coefficient was used to examine the relationships among various study variables and the FPI-SF. Multiple linear regression analysis was used to determine whether selected sample characteristics and symptoms predicted functional performance. For these multiple linear regressions, the investigator first identified potential predictors of functional performance that were statistically related more than r = 0.25 in Pearson correlation analysis. These variables were then evaluated by using multiple regression for their independent effects on functional performance. A *p* value of less than 0.05 was considered statistically significant.

## Results

### *Sample*

Eighty-six participants completed this study (Table 4.1). Of those, 54 were diagnosed with COPD and 32 with asthma; most were men (60 men, 26 women) who were married or lived with someone (n = 61, 70.9%), with a mean age of 74.4 ± 7.3 years (range: 55-89). Most of the participants were well-educated (at least a bachelor's degree; n = 44, 51%). Many participants were retired (>80%) and were low income persons(< $20,000; 69.7%). Participants (n=41) had moderate-to-severe pulmonary disease as measured by their mean forced expiratory volume in the first second of expiration ($FEV_1$) of 57.7%. Twenty participants (23.3%) were current smokers. Most (>80%) of the participants had comorbidities and the mean number of comorbid conditions was 1.71, although the range was none to five. The types of comorbid conditions were diverse. Participants had lived in the United States for a mean of 25.8 years (range: 2-50 years).

### *Homogeneity of Groups*

As presented in Table 4.2, no significant differences between the two groups in mean scores for dyspnea intensity, the MRC, MSAS subscales and total score, and the FPI-SF were found; therefore, all data from these participants were combined for further analyses.

### *Symptom Prevalence, Frequency, Severity, Distress, Subscales, and total score from MSAS*

Table 4.3 shows the frequency, severity, distress ratings for each symptom on the MSAS in this sample of participants with COPD or asthma. The average number of symptoms reported per person was 10.0 ± 5.86. The most commonly reported symptoms were shortness of breath (n = 67, 77.9%) and problems with urination (n = 54, 62.8%).

Participants rated the severity of each symptom included in the MSAS. Symptom severity was rated on a range of 1 (*slight*), 2 (*moderate*), 3 (*severe*), and 4 (*very severe*). Symptoms reported as being the most severe were pain (2.38 ± 0.83) and shortness of breath (2.22 ± 0.65), corresponding to moderate-severe on the severity scale. Symptoms reported as being severe, in addition to pain and shortness of breath, included worrying (2.17 ± 0.71), difficulty sleeping (2.14 ± 0.85), and numbness and tingling in hands and feet (2.10 ± 0.86).

When a symptom was present, participants experienced it with varying degrees of frequency, ranging from 1 (*rarely*), 2 (*occasionally*), 3 (*frequently*), to 4 (*almost constantly*). The most persistent symptoms were pain (2.84 ± 0.88), worrying (2.74 ± 0.82), feeling nervous (2.69 ± 0.90), difficulty sleeping (2.66 ± 0.84), lack of energy (2.65 ± 0.82), and shortness of breath (2.54 ± 0.64).

Participants also rated the distress of each symptom on a scale of 0 (*not at all*), 1 (*a little bit*), 2 (*somewhat*), 3 (*quite a bit*), and 4 (*very much*). The symptoms that created severe distress were shortness of breath (2.25 ± 0.80), worrying (2.11 ± 0.93), feeling nervous (2.00 ± 0.92), pain (1.84 ± 1.08), and feeling sad (1.81 ± 0.83).

The mean values of the MSAS subscales and total score are as follows: MSAS-PSYCH subscale: 0.74 ± 0.77; MSAS-PHYS subscale: 0.66 ± 0.53; MSAS-GDI subscale: 0.96 ± 0.82 MSAS total score: 0.67 ± 0.46.

### *Factor Analysis with MSAS*

Symptoms experienced by less than 25% of the sample were not included in the Factor Analysis. As presented in Table 4.4, a three-factor solution indicated a good fit between the data and the model (i.e., $\chi^2 = 42.9$, $p = .16$, CFI = .96, RMSEA = .05). Seven symptoms (pain, feeling nervous, numbness and tingling in hands and feet, difficulty sleeping, shortness of breath, feeling sad, and worrying) were loaded on Factor 1, eight symptoms (lack of energy, cough, dry mouth, feeling drowsy, feeling bloated, sweats, itching, and dizziness) on Factor 2, and two symptoms (problems with urination and constipation) on Factor 3. Cronbach’s alpha was 0.80 for Factor 1, 0.77 for Factor 2, and 0.39 for Factor 3.

### *Relationship of Symptoms and Sample Characteristics to FPI-SF in Univariate Analysis*

As presented in Table 4.5, dyspnea, the MRC, various MSAS subscales, mean severity scores from factors, and the number of symptoms reported were significantly negatively related to subscales of the FPI-SF (body care, household maintenance, physical exercise, and social activities) and FPI-SF total score. Generally, all correlation coefficients between study variables and the FPI-SF were small to moderate, especially the relationships between sample characteristics and FPI-SF, which were mostly nonsignificant, except for age, the level of education, mood, and acculturation level. The MRC showed the strongest relationship with the FPI-SF's total score (r = -0.43, $p < 0.01$). Among the MSAS scales, mean severity score of the seven symptoms in Factor 1 had the strongest relationship with the FPI-SF's total score (r = -0.34, $p < 0.01$), similar to the single symptom of dyspnea as measured by the VAS (r = -0.27), and the MSAS total score (r = -0.29).

### *Predictors for Functional Performance*

The FPI-SF total score was examined as a dependent variable. The six variables correlated with the FPI-SF total score at greater than 0.25 were age, level of education, usual dyspnea intensity, MRC score, mood, and mean severity score of seven symptoms in Factor 1. The mean severity score of seven symptoms in Factor 1 was chosen and examined in multiple regression, because of the strongest relationship of the mean severity score of seven symptoms in Factor 1 to the FPI-SF's total score, among the various MSAS subscales. Using the FPI-SF's total score as the dependent variable, these variables explained 29.9% of variance in functional performance ($F_{6,78} = 5.534$, $p = .001$) (see Table 4.6). In this study, participants who were younger, had higher education, and reported a lower usual dyspnea intensity, lower MRC score, lower score in mood disturbance, and lower severity score of seven symptoms in Factor 1 showed greater functional performance.

## Discussion

The prevalent symptoms that Korean immigrants reported in this study were commonly experienced by chronically ill individuals in studies of other ethnic groups.

Our participants reported symptoms such as shortness of breath, lack of energy, dry mouth, cough, worrying, and drowsiness, that were similar to earlier studies (Blinderman et al., 2009; Gift & Shepard, 1999; Jablonski et al., 2007), but distinctly reported problems with urination and numbness and tingling more often and reported sadness, feeling irritable, and feeling nervous less often. This difference in prevalent symptoms may be due to the fact that our participants were older and that there were more men in this study than in other studies. It also may be due to cultural differences in reporting emotionally-related symptoms. The Asian culture places value on the control of expressive behavior; therefore, strong feelings may not necessarily be overtly expressed (Hobara, 2005).

The Korean immigrants who participated in this study generally reported lower prevalence, severity, frequency, and distress of symptoms than patients with COPD in Jablonski et al.'s study (2007). All MSAS subscales for this sample, including the number of symptoms reported, were also lower than symptoms reported by inpatients with cancer (Portenoy et al., 1994) or by hospitalized medical-surgical patients (Kris & Dodd, 2004). This study's participants were chronically ill. Thus, it is reasonable that they did not experience more severe symptoms than cancer patients or hospitalized patients.

The MSAS was developed to measure the symptoms of patients with cancer. Thus, some MSAS subscales may not be applicable to patients with chronic obstructive lung diseases. Jablonski et al. (2007) revised the MSAS specifically for patients with COPD, based on prevalence of symptoms only and without performing a factor analysis. This revised MSAS consists of 19 symptoms compared to the 17 symptoms that we identified from the 32 symptoms listed in the MSAS. Like Jablonski et al. (2007), we included common symptoms experienced by patients with COPD. Unlike that study, however, we did not include these symptoms: problems with sexual interest or activity; swelling of arms and/or legs; changes in skin; I don't look like myself; and feeling irritable. Symptoms such as itching, dizziness, problems with urination, and constipation were included in our study, but not in theirs.

Our final three factors, consisting of 17 symptoms, comprised most of the psychological symptoms of the original MSAS and symptoms that are commonly reported by chronically ill patients. The integrity of the factors is not compromised by the deletion of low prevalent physical symptoms, as evidenced by high internal consistency of Factors 1 and 2. Fifteen symptoms from Factors 1 and 2 showed strong internal consistency, indicating that they can be used specifically for patients with COPD and asthma. However, the classic COPD symptoms of shortness of breath, lack of energy, and cough did not group into the same factor. This finding could be attributed to the analytic methods used to create symptom clusters or to the demographic and clinical characteristics. Thus, a future study is warranted to examine this issue.

This study is the first to show the detailed effect of multiple symptoms on various functional performance components in participants with chronic obstructive lung diseases. We found that symptoms affected body care and physical exercise activities the most. This study also found that a high level of both usual dyspnea and activity-related dyspnea is associated with a decrease in functional performance, consistent with earlier work (Reishtein, 2005). The relationship of a single symptom of dyspnea, as measured by the VAS, the mean severity score of seven symptoms in Factor 1, and the MSAS total score to the FPI-SF was relatively small and similar, which may confirm the findings of Walke et al. (2007), who concluded that combinations or clusters of symptoms may not have a greater effect on health outcomes than individual symptoms. These findings are inconsistent with oncology research and the theory of unpleasant symptoms which hold that multiple symptoms or symptom clusters may have a synergistic effect on health outcomes (Dodd et al., 2001; Gift et al., 2004; Lenz et al., 1997). Further study is needed to examine this finding.

Our study found that age, level of education, usual dyspnea intensity, the MRC score, mood, and mean severity score of seven symptoms in Factor 1 explain the significant variance for functioning. Dyspnea, as measured by the MRC, and age predicted most of the variance in functional performance, which is consistent with past reports from several studies (Hu & Meek, 2005; Keller, 1986; Lee et al., 1991; Reishtein, 2005; Weaver et al., 1997). The MRC measures activity limitation related to dyspnea; thus, it may be reasonable that it explained more variance for functioning than dyspnea, as measured by the VAS. Several investigators have studied the effect of dyspnea or collective disease-specific symptoms on functioning in populations with COPD (Graydon et al., 1995; Graydon & Ross, 1995; Weaver et al., 1997). Ours is the first to examine the effect of nonspecific multiple symptoms on functioning in a stable immigrant population. However, this study found that the unique contribution of multiple symptoms was not significant. This finding suggests that multiple coexisting symptoms should be evaluated but confirmed that alleviating dyspnea may be the best approach to improve daily functioning in people with chronic obstructive lung diseases.

This study has several limitations. Its cross-sectional design precludes a definitive determination of the direction of the relationships. Participants were recruited from primary care settings rather than tertiary clinical settings; thus, their illnesses were stable rather than in the acute exacerbation phase. Most participants had multiple diseases in addition to chronic obstructive lung diseases and were older than those in earlier studies, which may have influenced our findings. Moreover, the interpretation of the findings may be compromised by elements that were not included in the analysis, and which might explain more variance in functioning for patients with COPD, including information about treatment of the disease itself (i.e., medication use) or other physiological indicators (i.e., $FEV_1$).

In conclusion, this study showed that participants with asthma and COPD experience a broad range of symptoms that may be the result of multiple coexisting conditions. The findings suggest that disease management should focus on other concurrent symptoms as well as disease-specific symptoms. Our results also show that symptoms, especially dyspnea, have the greatest effect on levels of functioning, even in populations with stable chronic obstructive lung diseases. Thus, helping patients to control their symptoms should be a central focus of clinical practice. Proper symptom management must anticipate and control for dyspnea and the numerous coexisting symptoms that exist in Korean immigrant populations. Further studies are needed to examine symptom clusters in much sicker populations with chronic obstructive lung diseases. A study is also needed to explore the relationship between symptoms and functioning with all other potential variables (e.g., $FEV_1$) and the relationship of symptoms to other health outcomes, such as quality of life and self-rated health.

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Table 4.1
*Demographic and Clinical Characteristics of Total Sample (N=86)*

| | Mean ± SD (range) | Frequency (Percentage) |
|---|---|---|
| Age | 74.4 ± 7.3<br>(range; 55-89) | |
| Gender (M/F) | | 60/26 |
| Education (n=85) | | |
| High school & less | | 41 (48%) |
| Bachelor & higher | | 44 (51%) |
| Income (n=79) | | |
| <$20,000 | | 60 (69.7%) |
| >$20,000 | | 19 (22%) |
| Living situation | | |
| Alone | | 25 (29.1%) |
| Married or Living with someone | | 61 (70.9%) |
| Working | | 11 (12.8%) |
| Years of stay in U.S | 25.8 ± 9.8 | |
| Acculturation | 1.48 ± .38 | |
| Current smoker | | 20 (23.3%) |
| Pack years of current smoker | 44.9 ± 23.6 | |
| Past smoker | | 36 (41.8%) |
| Pack years of past smoker | 41.8 ± 33.0 | |
| FEV1 % pred. (n=41) | 57.7 ± 17.5 | |
| Co-morbidities | | 70 (81%) |
| Hypertension | | 20 (23%) |
| Heart diseases | | 11 (13%) |
| TB | | 12 (14%) |
| Other pulmonary diseases | | 9 (10%) |
| Stomach ulcer | | 14 (16%) |
| Diabetes | | 21 (24%) |
| BPH | | 12 (14%) |
| Rheumatoid arthritis | | 23 (27%) |
| Liver disease | | 8 (9%) |
| Cancer | | 8 (9%) |
| Other diseases | | 12 (14%) |

Table 4.2

*Mean Values of Study Variables in participants with COPD and asthma (N=86)*

| Variables (possible range) | Total (N=86) | COPD (N=54) | Asthma (N=32) |
|---|---|---|---|
| ***Dyspnea*** | | | |
| Usual Dyspnea Intensity –VAS (0-100) | 16.2 ± 17.1 | 15.5 ± 17.2 | 17.3 ± 17.2 |
| MRC (1-5) | 1.98 ± 1.13 | 1.89 ± 1.11 | 2.13 ± 1.12 |
| ***Symptoms*** | | | |
| MSAS-PSYCH subscale (0-4) | .74 ± .77 | .71 ± .72 | .79 ± .86 |
| MSAS-PHYS subscale (0-4) | .66 ± .53 | .58 ± .51 | .79 ± .55 |
| MSAS-GDI subscale (0-4) | .96 ± .82 | .92 ± .77 | 1.04 ± .89 |
| MSAS-Total score (0-4) | .67 ± .46 | .62 ± .41 | .77 ± .52 |
| MSAS-Total number of symptoms | 10.00 ± 5.86 | 9.35 ± 5.46 | 11.09 ± 6.41 |
| ***Moods*** | | | |
| POMS-Total Mood Disturbance | 17.27 ± 21.39 | 13.54 ± 17.64 | 23.56 ± 25.63 |
| ***Social Support*** | | | |
| Social Support Survey (1-5) | 2.74 ± 1.14 | 2.62 ± 1.08 | 2.95 ± 1.23 |
| ***FPI-SF*** | | | |
| FPI-SF-Body Care (0-3) | 2.85 ± .30 | 2.89 ± .26 | 2.78 ± .35 |
| FPI-SF-Household Maintenance (0-3) | 1.64 ± .76 | 1.60 ± .78 | 1.72 ± .73 |
| FPI-SF-Physical Exercise (0-3) | 1.68 ± .62 | 1.71 ± .58 | 1.64 ± .68 |
| FPI-SF-Recreation (0-3) | 1.74 ± .64 | 1.71 ± .70 | 1.78 ± .54 |
| FPI-SF-Spiritual Activities (0-3) | 1.64 ±1.09 | 1.52 ± 1.17 | 1.86 ± .91 |
| FPI-SF-Social Activities (0-3) | .76 ±.78 | .80 ± .78 | .68 ± .80 |
| FPI-SF-Total Score | 1.72 ±.48 | 1.70 ± .48 | 1.74 ± .48 |

No significant differences between groups in any of these variables

A higher score indicates more severe dyspnea in VAS and MRC, more severe, frequent, and distressed psychological or physical symptoms in MSAS, more severe mood disturbance in POMS, greater support system in Social Support Survey, and greater functional performance in FPI-SF.

Table 4.3

*Prevalence, Severity, Frequency, & Distress of Symptoms in MSAS by total sample (N=86)*

| Symptoms | Number of subjects who had symptom (%) | Degree when symptom present | | |
|---|---|---|---|---|
| | | Severity (%)* | Frequency (%)* | Distress (%)* |
| shortness of breath | 67 (77.9%) | 88.1 | 46.3 | 32.8 |
| problems with urination | 54 (62.8%) | 64.8 | 55.6 | 25.9 |
| numbness/ tingling in hands/ feet | 50 (58.1%) | 72.0 | 32.0 | 22.0 |
| feeling drowsy | 49 (57.0%) | 67.3 | 46.9 | 6.1 |
| cough | 45 (52.3%) | 55.6 | 26.7 | 15.6 |
| dry mouth | 40 (46.5%) | 62.5 | 50.0 | 17.5 |
| lack of energy | 37 (43.0%) | 78.4 | 43.2 | 10.8 |
| dizziness | 36 (41.9%) | 58.3 | 27.8 | 22.2 |
| worrying | 35 (40.7%) | 85.7 | 51.4 | 31.4 |
| difficulty sleeping | 35 (40.7%) | 77.1 | 42.9 | 17.1 |
| constipation | 34 (39.5%) | 61.8 | NE | 11.8 |
| pain | 32 (37.2%) | 81.3 | 53.1 | 31.3 |
| feeling nervous | 32 (37.2%) | 68.8 | 53.1 | 28.1 |
| sweats | 28 (32.6%) | 64.3 | 50.0 | 25.0 |
| feeling bloated | 27 (31.4%) | 55.6 | 40.7 | 14.8 |
| feeling sad | 27 (31.4%) | 70.4 | 33.3 | 18.5 |
| itching | 27 (31.4%) | 63.0 | 37.0 | 11.1 |
| change in the way food tastes | 21 (24.4%) | 61.9 | NE | 19.0 |
| feeling irritable | 21 (24.4%) | 71.4 | 38.1 | 0.0 |
| swelling of arms or legs | 20 (23.3%) | 60.0 | NE | 10.0 |
| lack of appetite | 19 (22.1%) | 73.7 | 47.4 | 21.1 |
| difficulty concentrating | 19 (22.1%) | 35.0 | 30.0 | 10.0 |
| weight loss | 16 (18.6%) | 50.0 | NE | 12.5 |
| hair loss | 16 (18.6%) | 50.0 | NE | 6.3 |
| mouth sores | 14 (16.3%) | 64.3 | NE | 7.1 |
| diarrhea | 14 (16.3%) | 64.3 | 14.3 | 14.3 |
| change in skin | 12 (14.0%) | 50.0 | NE | 8.3 |
| difficulty swallowing | 12 (14.0%) | 58.3 | 25.0 | 16.7 |
| nausea | 10 (11.6%) | 30.0 | 20.0 | 10.0 |
| I don’t look like myself | 6 (7.0%) | 40.0 | NE | 20.0 |
| vomiting | 3 (3.5%) | 66.7 | 0.0 | 0.0 |
| problems with sexual interest or activity | 2 (2.3%) | 50.0 | 0.0 | 0.0 |

Note: NE; not evaluated

*Percentage of patients with the symptom reporting moderate to very severe (Symptom Severity)

*Percentage of patients with the symptom reporting frequently to constantly (Symptom Frequency)

*Percentage of patients with the symptom reporting quite a bit to very much (Symptom Distress)

Table 4.4

*Factor Structure from 17 symptoms in MSAS (N=86)*

| Symptoms | Factor 1 | Factor 2 | Factor 3 |
|---|---|---|---|
| pain | **0.50** | 0.32 | -0.03 |
| feeling nervous | **0.67** | 0.28 | -0.02 |
| numbness/ tingling in hands/feet | **0.52** | 0.15 | -0.14 |
| difficulty sleeping | **0.64** | -0.06 | -0.20 |
| shortness of breath | **0.51** | 0.14 | 0.33 |
| feeling sad | **0.71** | 0.03 | 0.15 |
| worrying | **0.91** | -0.02 | 0.14 |
| lack of energy | -0.02 | **0.55** | 0.19 |
| cough | -0.02 | **0.57** | 0.34 |
| dry mouth | 0.33 | **0.55** | 0.06 |
| feeling drowsy | -0.01 | **0.56** | 0.06 |
| feeling bloated | 0.12 | **0.54** | -0.20 |
| sweats | 0.37 | **0.59** | -0.01 |
| itching | 0.08 | **0.55** | 0.01 |
| dizziness | 0.01 | **0.71** | -0.47 |
| problems with urination | 0.14 | 0.03 | **0.55** |
| constipation | 0.03 | 0.22 | **0.51** |

Extraction method: robust unweighted least squares: geomin (oblique) rotation

Table 4.5

*The Correlation Coefficients between study variables and FPI-SF (N=85)*

| | FPI-SF-Body Care | FPI-SF-Household Maintenance | FPI-SF-Physical Exercise | FPI-SF-Recreation | FPI-SF-Spiritual Activities | FPI-SF-Social Activities | FPI-SF-Total Score |
|---|---|---|---|---|---|---|---|
| Disease Group (asthma) | -.17 | .01 | -.05 | .05 | .15 | -.07 | .04 |
| Age | -.05 | -.25* | -.23* | -.15 | -.07 | -.30** | -.26* |
| Gender (female) | -.21 | -.05 | -.19 | -.01 | .29** | -.09 | .01 |
| Co-morbidity (numbers of diseases) | -.23* | -.19 | -.26* | .04 | -.01 | -.13 | -.16 |
| Income (>$20,000) | -.07 | -.09 | -.08 | .08 | -.01 | .09 | -.01 |
| Education (bachelor or higher) | .24* | .26* | .22* | .12 | .07 | .34** | .28** |
| Living (married or living with someone) | -.07 | -.15 | .04 | .16 | -.09 | .17 | .02 |
| Acculturation Level | .18 | .21 | .26* | .13 | .01 | .23* | .22* |
| Years of Stay | .07 | .11 | .19 | .14 | .22* | .04 | .20 |
| Social Support Survey | .13 | .09 | .03 | .08 | .30** | .04 | .19 |
| Mood | -.36** | -.22* | -.31** | -.05 | -.04 | -.30** | -.27* |
| Usual Dyspnea Intensity | -.25* | -.18 | -.37** | -.08 | -.14 | -.18 | -.27* |
| MRC | -.47** | -.35** | -.55** | -.18 | -.16 | -.27* | -.43** |
| MSAS-PSYCH subscale | .-32** | -.18 | -.20 | -.12 | -.04 | -.24* | -.23* |
| MSAS-PHYS subscale | -.30** | -.22* | -.30** | -.20 | -.03 | -.21* | -.27* |
| MSAS-GDI subscale | -.35** | -.28** | -.26* | -.17 | -.08 | -.30** | -.31** |
| MSAS-Total Score | -.38** | -.24* | -.35** | -.16 | -.04 | -.24* | -.29** |
| MSAS-Total number of symptoms | -.40** | -.20 | -.35** | -.21 | -.01 | -.19 | -.27* |
| Mean severity score of symptoms in Factor 1 from MSAS | -.35** | -.28** | -.35** | -.16 | -.10 | -.28** | -.34** |
| Mean severity score of symptoms in Factor 2 from MSAS | -.25* | -.18 | -.24* | -.14 | -.05 | -.11 | -.21 |
| Mean severity score of symptoms in Factor 3 from MSAS | -.32** | -.16 | -.22* | -.09 | -.04 | -.12 | -.19 |

** $p<.01$ * $p<.05$

Table 4.6

*Multiple Regression Analysis of the Predictors of Functional Performance Inventory-SF-total score (N=78)*

| Source | R2 | Beta | % of Explained Variance | df | F | *p*-value |
|---|---|---|---|---|---|---|
| Overall | 29.9 | | | 6, 78 | 5.534 | .001 |
| Age | | -.256 | 6% | | | .011 |
| Education Level | | .130 | 1% | | | .210 |
| Usual Dyspnea Intensity | | -.047 | 0.1% | | | .705 |
| MRC | | -.375 | 9% | | | .003 |
| POMS-Total Mood Disturbance | | -.036 | 0.07% | | | .787 |
| Mean severity score of symptoms in Factor 1 from MSAS | | -.107 | 0.5% | | | .453 |

# CHAPTER FIVE

## Dissertation Summary

The major purposes of this study were to explore the sensation of dyspnea, to describe dyspnea coping strategies and the multiple symptoms experienced, and to examine factors related to dyspnea, the presence of symptom clusters, and the relationship of symptoms to functional performance in Korean immigrants with asthma and chronic obstructive pulmonary disease (COPD). The papers in this dissertation addressed the effect of culture on dyspnea sensations and dyspnea coping strategies in Korean immigrants with asthma and COPD. This study also described the symptom experience from a multi-dimensional perspective in Korean immigrants with asthma and COPD.

### *Chapter Highlights*

### Chapter 1

This chapter provided epidemiological data on the prevalence and mortality of asthma and COPD in Koreans in Korea and Korean immigrants and information about the increase in the Korean immigrant population in the United States (U.S.) that supports the need to examine dyspnea and other symptoms as experienced by this culturally different population.

### Chapter 2

The purpose of this chapter was to explore the sensation of dyspnea, describe multiple symptoms, and examine factors related to dyspnea in Korean immigrants with asthma and COPD. Eighty-six stable COPD (n=54) and asthma (n=32) outpatients were studied. Participants were 74.4 ± 7.3 years of age (range; 55-89) and have lived in U.S.

for 25.8 years (mean). Participants were asked to describe their dyspnea sensations using an open-ended interview and a structured dyspnea descriptor list. They also filled out a survey for demographic information and completed various instruments, measuring moods and presence of other symptoms. The most frequently chosen descriptors by participants with asthma were *tight* and *heavy* and *rapid* and *effort* for participants with COPD. The most prevalent symptoms were shortness of breath, problems with urination, numbness and tingling in hands and feet, feeling drowsy, and cough. Variables that were significantly related to dyspnea were disease group, smoking status, fatigue, and multiple symptoms. Participants with dyspnea resulting from various pathophysiological conditions experienced different sensations, but also shared dyspnea descriptors. Findings from this study suggest that typical sensations may be used to expand the assessment of dyspnea and that it is important to assess multiple symptoms in populations with asthma and COPD.

Chapter 3

Caucasians with asthma and COPD develop many strategies and skills on their own over time and come to rely on self-management strategies to control their shortness of breath. However, little is known about the dyspnea management strategies used by Korean immigrants in the U.S.  The purpose of this chapter was to describe the coping strategies Korean immigrants with asthma and COPD use to manage dyspnea. The number of strategies used, frequency of use, and effectiveness of those strategies were described. Open-ended questions and the Modified Self-Efficacy and Dyspnea Self-Strategies Scale were used to describe participant’s own strategies to manage dyspnea. The most frequently used strategies were “I keep still or rest,” “I move slower,” and “I avoid strenuous activities." The mean number of coping strategy used by total sample was 14.08 ± 5.88. Both groups used problem-focused strategies more than emotion-focused strategies and felt emotional strategies were less effective than problem-focused strategies to relieve dyspnea. However, some emotion-focused strategies (i.e., "I calm myself down") were more beneficial to participants with asthma than with COPD. Korean immigrants have learned coping strategies by trial and error and had no or little experience of education provided by rehabilitation program. Korean immigrants preferred the use of traditional therapies, such as acupuncture or herbs, home remedies, and yoga or Tai-Chi. In addition, their family played an important role caring for them. Therefore, incorporating traditional Korean therapies in pulmonary rehabilitation education as well as enlisting the family participation may improve to be efficacious in managing dyspnea for this population.

## Chapter 4

The purpose of this chapter was to describe multiple symptoms, to examine the presence of symptom clusters, and to examine relationships between symptoms and functional performance in Korean immigrants with chronic obstructive lung diseases. The Dyspnea Visual Analog Scale, Modified Medical Research Council Dyspnea Scale, Memorial Symptom Assessment Scale, and Functional Performance Inventory-Short Form were used to describe participants' dyspnea, symptoms, and functioning. Frequently reported symptoms were shortness of breath, problems in urination, numbness and tingling in hands and feet, drowsiness, cough, dry mouth, and lack of energy. Three factors emerged from the 17 symptoms. Age, multiple symptoms, mood, dyspnea, and level of education explained significant variance in functional performance. Dyspnea was the most significant predictor of functional performance. This study's findings suggest that continuous emphasis on dyspnea management is warranted to improve daily functioning in the Korean immigrant population.

### *Limitations*

This cross-sectional design precludes a definitive determination of the direction of the relationships. Participants for this study were recruited from primary care settings in one Korean ethnic neighborhood in a large urban area in the Western U.S. Participants in this sample tended to be physiologically stable. Most participants had co-morbidities and were older than populations in other studies. Therefore, findings from this study can be only generalized to stable, elderly Korean immigrants.

Descriptors in this 15 item dyspnea descriptor list and strategies in the modified Self-Efficacy and Dyspnea Self-Strategies Scale (SEADS) were based on descriptors and strategies used by Caucasians, which therefore has its limitations when applying this instrument to Korean immigrants. The investigator interviewed participants with an open-ended question before administering these instruments. Some descriptors in the structured dyspnea descriptor list were used and some were not used to describe their sensation in Korean participants, compared to the findings with the open-ended question. In contrast, all strategies identified from the interviews were similar to strategies from listed on the SEADS, indicating that the SEADS instrument may be useful in evaluating a Korean immigrant population.

### *Directions for Future Research*

Further study is needed to examine symptom clusters in much sicker populations with chronic obstructive lung diseases. Experimental studies are needed to determine effective combinations of interventions to manage symptoms that are experienced simultaneously. A study is also needed to explore the relationship between symptoms and functioning with all other potential variables (e.g., $FEV_1$) and the relationship of symptoms to other health outcomes, such as quality of life and self-rated health.

More data are needed on why Korean immigrants are not referred to a pulmonary rehabilitation program, whether the issue is the lack of referral, lack of compliance with recommendations, a lack of rehabilitation programs provided in Korean language, or whether participants cannot afford to undertake such a plan. Further study is also needed regarding the lack of knowledge about the traditional therapies, especially about the herbs used.

### *Conclusions*

Unique descriptors for Korean participants with asthma and COPD were *blocked chi* and they tended to describe the dyspnea sensation as *rapid*. Dyspnea sensations of Korean immigrants were relatively similar to those of studies of Caucasians. Therefore, dyspnea assessment tools for other ethnic groups may be applicable to Korean immigrants.

Among various participants' characteristics, multiple symptoms and fatigue were factors that were significantly associated with the level of dyspnea, stressing the importance of the assessment of multiple symptoms and continuous effort to manage fatigue in populations with chronic obstructive lung diseases. An understanding of these relationships helps explain the great variability seen in individuals with dyspnea. These findings may help health care providers better understand symptom of dyspnea and other symptoms as experienced by Korean immigrants and eventually help expand the development of assessment tools for symptoms. These findings may also lay a foundation for the development and testing of individualized therapies for this population.

Korean immigrants used self-management strategies similar to those used by other ethnic groups, but also incorporated elements of Asian medical practice and herbs. Such a program, tailored to the needs of the Korean immigrant in which some their traditional therapies are incorporated with the usual curriculum, may prove beneficial to those with asthma and COPD. Since the family has an important role in taking caring for a sick family member in Korean culture, families should be included in these education programs.

Korean immigrants with asthma and COPD experience a broad range of symptoms that may be the result of multiple coexisting conditions. The findings suggest that disease management should focus on other concurrent symptoms as well as disease-specific symptoms. Our results also show that symptoms, especially dyspnea, have the greatest effect on levels of functioning, even in populations with stable chronic obstructive lung diseases. Thus, helping patients to control their symptoms should be a central focus of clinical practice. Proper symptom management must anticipate and control for dyspnea and the numerous coexisting symptoms that Korean immigrant people describe.

# APPENDIX A

# HUMAN SUBJECTS CONSENT FORM

# UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
# CONSENT TO PARTICIPATE IN A RESEARCH STUDY

**Study Title:** The Dyspnea Experience in Korean Immigrants with asthma and COPD

This is a research study about exploring the experience of shortness of breath in Korean Immigrants with asthma and COPD. The study researchers, Soo Kyung Park, a doctoral student, and Dr. Carrieri-Kohlman, a professor, from the Department of Physiological Nursing at University of California, San Francisco (UCSF) will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to participate in this study because you have COPD (emphysema or chronic bronchitis) or asthma and you have shortness of breath with your daily activities or exertion.

## Why is this being done?

The purpose of this study is to learn about how Korean Immigrants with emphysema, chronic bronchitis, and asthma perceive their shortness of breath, what factors are related to shortness of breath, and how they cope with their shortness of breath.

This study will be supported by personal funds from Graduate Division at University of California, San Francisco.

## How many people will take part in this study?

About 90 people will take part in this study.

## What will happen if I take part in this research study?

If you agree to be in this study, the following will happen:
You will complete a series of paper and pencil questionnaires and interviews about your medical history, shortness of breath, various symptoms, emotions, and functioning.

All these procedures will be done at a private office.

## How long will I be in the study?

Participation in the study will take a minimum of 90 minutes.

## Can I stop being in the study?

Yes. You can decide to stop at any time. Just tell the study researchers right away if you wish to stop being in the study.

Also, the study researchers may stop you from taking part in this study at any time if he or she believes it is in your best interest, if you do not follow the study rules, or if the study is stopped.

**What side effects or risks can I expect from being in the study?**
Some questions may make you feel uncomfortable, but you are free to decline to answer any questions you do not wish to.

**Are there benefits to taking part in the study?**
There is no direct benefit to you from participating in this study. However, the information that you provide may help health professionals better understand about symptom management of Korean Immigrants with asthma and COPD.

**What other choices do I have if I do not take part in this study?**
You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. You will not lose any of your regular benefits, and you can still get your medical care the way you usually do.

**Will information about me be kept private?**
We will do our best to make sure that the personal information gathered for this study is kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

Organization that may look at your research records for research, quality assurance, and data analysis includes UCSF's Committee on Human Research.

**What are the costs of taking part in this study?**
You will not be charged for any of the study procedures.

**Will I be paid for taking part in this study?**
In return for your time and effort, you will be given $25 grocery gift card at the end of the study.

**What are my rights if I take part in this study?**
Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way. You will not lose any of your regular benefits, and you can still get your medical care the way you usually do.

**Who can answer my questions about the study?**
You can talk to the researchers about any questions or concerns you have about this study. If you have any questions about the study, you may call the study investigator, Soo Kyung Park at (415) 876-2142.

**If you have any questions, comments, or concerns about taking part in this study,** you should first talk with the researcher (above). If for any reason you do not wish to do this, or you still have concerns after doing so, you may contact the office of the

**Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights).

You can reach the committee office between 8:00 am and 5:00 pm, Monday through Friday, by calling **(415) 476-1814**, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA, 94143.

**CONSENT**

You have been given a copy of this consent form.

PARTICIPATION IN RESEARCH IS VOLUNTARY.
You have the right to decline to be in the study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

| | |
|---|---|
| ________________ | ________________________________ |
| Date | Participant's signature for Consent |
| ________________ | ________________________________ |
| Date | Person Obtaining Consent |

# APPENDIX B

# STUDY INSTRUMENTS

## 1. Survey for Demographic & Clinical Characteristics

**Patient Number:_________**

**Please choose the appropriate answers or fill in the blank with requested information**

1. Age; ________ years old

2. Gender; Male ____ Female ____

3. What kinds of diseases have you had? (Please list all diseases you have had)

| | No | Yes | How long |
|---|---|---|---|
| 1. Heart Attack | | | |
| 2. Congestive Heart Failure | | | |
| 3. Stroke, cerebrovascular accident, blood clot or bleeding in the brain, or transient ischemic attack | | | |
| 4. Asthma | | | |
| 5. Emphysema, chronic bronchitis, or chronic obstructive lung disease | | | |
| 6. Any other pulmonary diseases | | | |
| 7. Stomach ulcer or peptic ulcer disease | | | |
| 8. Diabetes | | | |
| 9. Kidney disease | | | |
| 10. Rheumatoid arthritis | | | |
| 11. Liver disease | | | |
| 12. Any type of cancer | | | |
| | | | |
| | | | |
| | | | |
| | | | |

4. What medications do you take currently?

| Name of Medication | Dose | Number of times I take it every day |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

5. Are you currently using oxygen for your shortness of breath? Yes ___ No ___
If yes, using continuously ____
a) on and off during every day ____hrs/day
b) on and off during the week ____hrs/wk
c) with exercise only ____
d) Other ________________

6. Are you currently smoking? Yes ___ No ___
If YES, how much do you presently smoke? ______ packs/ day
How many years have you smoked? ______years
If NO, have you ever smoked? YES ___ NO ___
If yes, how much did you smoke? ______ packs/ day
How many years did you smoke? ______years
How long ago did you quit? ____ years

7. Are you currently working? Yes ____ No ____
   If YES, what type of work do you do?____________________
   How many hours/week?__________________

8. What is your current average annual income <u>for your household</u>?
   1) ___ less than $10,000/yr
   2) ___ less than $20,000/yr
   3) ___ less than $30,000/yr
   4) ___ less than $40,000/yr
   5) ___ less than $50,000/yr
   6) ___ greater than $50,000/yr

9. Living situation? Alone ____
   Married ____
   Living with someone ____

10. What is the highest level of school completed? (Check only one)
    Middle high school graduate ______
    High school graduate _______
    Bachelor's degree ______
    Graduate degree _______
    Others (specify) ____________

11. How long have you been in United States? _____ years

12. Do you know your recent spirometry results?

    Pulmonary Function Tests: date ________
    Baseline FEV1_____L ( _____ % pred.)
    FVC _____L ( _____ % pred.)
    FEV1/ FVC _____L ( _____ % pred.)

    Post-bronchodilator; FEV1_____L ( _____ % pred.)
    FVC _____L ( _____ % pred.)
    FEV1/ FVC _____L ( _____ % pred.)

13. Please choose appropriate number if you have this history.

| History | | |
|---|---|---|
| Smoker or ex-smoker | 1. nearly all | 2. possibly |
| Symptom onset <35 years | 1. rare | 2. common |
| Chronic productive cough | 1. common | 2. uncommon |
| Breathlessness | 1. persistent and progressive | 2. variable |
| Nighttime waking with breathlessness and wheeze | 1. uncommon | 2. common |
| Significant diurnal or day-to-day variation of symptoms | 1. uncommon | 2. common |

# 2. Dyspnea Interview

**Patient Number:_________**

1. Have you ever had a problem with shortness of breath? Yes_______ No________
   If yes, tell me about the last time you were short of breath
   How frequently do you have shortness of breath? Daily ______
   Weekly ______
   Monthly ______

2. What things bring on your shortness of breath or make it worse?

3. Can you describe in your own words how it felt when you are short of breath?

4. What sensations did you notice when you were short of breath?

5.What helps your shortness of breath go away?

6. Have you ever had any classes or learned about your shortness of breath or attended a pulmonary rehabilitation program? Yes_____ No_____

6a What kinds of classes?

6b Who has taught you about how to manage your shortness of breath?

6c Have you ever been taught or learned things you can do to make you more comfortable when you are short of breath? Yes _____ No______

6d What kinds of things were you taught to make you more comfortable when you are short of breath?

7. What things does your family do to help you when you are short of breath or help you to prevent your shortness of breath?

## 3. Visual Analog Scale for Usual Dyspnea Intensity

**Patient Number:_________**

How short of breath are you **in the past 1 month on the average**?
**Please mark a line to indicate your usual level of "shortness of breath".**
Bottom of the line means "no breathlessness" and top of the line means "worst imaginable breathlessness".

Worst imaginable
breathlessness

No breathlessness

## 4. Visual Analog Scale for Usual Dyspnea Distress

**Patient Number:_________**

How bothersome is your shortness of breath **in the past 1 month on the average**?
"Breathing distress" is defined as the amount of upset or bothersome associated with breathing.
**Please mark a line to indicate your usual level of "distressfulness" of breathing.**
Bottom of the line means "no distressfulness" and top of the line means
"worst imaginable distressfulness".

Worst imaginable
distress

No distress

## 5. Visual Analog Scale for Worst Dyspnea Intensity

**Patient Number:_________**

How short of breath are you **at the worst time**?
**Please mark a line to indicate your worst level of “shortness of breath”.**
Bottom of the line means “no breathlessness” and top of the line means “worst imaginable breathlessness”.

Worst imaginable
breathlessness

No breathlessness

## 6. Visual Analog Scale for worst Dyspnea Distress

**Patient Number:_________**

How bothersome is your shortness of breath **at the worst time**?
“Breathing distress” is defined as the amount of upset or bothersome associated with breathing.
**Please mark a line to indicate your worst level of “distressfulness” of breathing.**
Bottom of the line means “no distressfulness” and top of the line means “worst imaginable distressfulness”.

Worst imaginable
distressfulness

No distressfulness

## 7. Modified Medical Research Council

**Patient Number:_________**

Read each statement and then select the appropriate number to the right of the statement to indicate which best fitted your shortness of breath.

_____ Grade 0: Not troubled with breathlessness except with strenuous exercise

_____ Grade 1: Troubled by shortness of breath when hurrying on the level or walking up a slight hill

_____ Grade 2: Walks slower than people of the same age on the level because of breathlessness or has to stop for breath when walking at own pace on the level

_____ Grade 3: Stops for breath after walking about 100 yards or after a few minutes on the level

_____ Grade 4: Too breathless to leave the house or breathless when dressing or undressing

# 8. The Simon's Dyspnea Descriptor Checklist

**Patient Number:_________**

This is a list of 15 statements to describe your "uncomfortable breathing". Read each one carefully and please circle appropriate number between 0 and 10 to describe how severe you felt each sensation when you were short of breath. "0" means no sensation at all and "10" means "you felt that sensation very severe".

| | ***How severe did you feel this sensation when short of breath?***<br>Not<br>At all | | | | | | | | | | Very<br>Severe |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **1. My breath does not go in all the way.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **2. My breathing requires effort.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **3. I feel that I am smothering.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **4. I feel a hunger for more air.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **5. My breathing is heavy.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **6. I feel out of breath.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **7. My chest feels tight.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **8. My breathing requires more work.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **9. I feel that I am suffocating.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **10. My chest is constricted.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **11. I feel that my breathing is rapid.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **12. My breathing is shallow.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **13. I feel that I am breathing more.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **14. I cannot get enough air.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **15. My breathing does not go out all the way.** | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

# 9. Modified Self-Efficacy and Dyspnea Self-Strategies Scale

**Patient Number:_________**

These are some strategies patients have used to manage shortness of breath. If you don’t use the strategy, please mark an “X” in the space of “Did not use”. If you use these strategies, then ***choose a number*** from one to four to indicate how often you use the strategy. **Then *choose a number*** from zero to ten to indicate how much you think the strategy is effective to relieve your shortness of breath.

| Activities | Do not use | If YES, how often do you use this strategy? | | | | If YES, how much do you think the strategy is effective to relieve your shortness of breath? | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Rarely | Occasionally | Frequently | Almost constantly | Not at all | | | | | | | | | | Very Much |
| 1.I change position, such as lean on something. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 2. I avoid wind, fog, or extreme temperature. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 3. I keep still or rest. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 4. I change dressing habits. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 5. I move slower. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 6. I decrease activity. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 7. I avoid exercise. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 8. I exercise, such as walking or any other exercise. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 9. I use other transportation. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 10. I plan activities in advance. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 11. I rely on others to help me with routine activities. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

| Activities | Do not use | If YES, how often do you use this strategy? | | | | If YES, how much do you think the strategy is effective to relieve your shortness of breath? | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Rarely | Occasionally | Frequently | Almost constantly | Not at all | | | | | | | | | | Very Much |
| 12. I do pursed-lips breathing. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 13. I use abdominal/ diaphragmatic breathing. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 14. I use cool, such as use fans or open windows. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 15. I call doctor or nurse. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 16. I get some fresh air. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 17. I avoid irritants such as smoke. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 18. I use oxygen. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 19. I take bronchodilators. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 20. I change eating habits. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 21. I use assistive devices, such as walker or cane. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 22. I avoid strenuous activities. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 23. I drink alcohol. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 24. I smoke cigarettes. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 25. I avoid infection. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 26. I calm myself down. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

| Activities | Do not use | If YES, how often do you use this strategy? | | | | If YES, how much do you think the strategy is effective to relieve your shortness of breath? | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Rarely | Occasionally | Frequently | Almost constantly | Not at all | | | | | | | | | | Very Much |
| 27. I try not to think about it and don't worry. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 28. I use distraction, such as TV, read, or music. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 29. I pray or meditate. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 30. I talk to others with same disease and dyspnea. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 31. I socialize and participate in leisure activities with others. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 32. I get support from friends and family. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 33. I do leisure activities by myself. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 34. I decrease social participation and try to be alone. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 35. I read about dyspnea and disease. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 36. I try to pay attention to breath. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 37. I try Tai-Chi or yoga. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 38. I try acupuncture or herbs. | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

| Activities | Do not use | If YES, how often do you use this strategy? | | | | If YES, how much do you think the strategy is effective to relieve your shortness of breath? | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Rarely | Occasionally | Frequently | Almost constantly | Not at all | | | | | | | | | | Very Much |
| 39. I use home remedies, such as: | | | | | | | | | | | | | | | | |
| ____________________ | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| ____________________ | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

## 10. Memorial Symptom Assessment Scale

**Patient Number:_________**

**Section I:** We have listed 24 symptoms below. Read each one carefully.
If you have had the symptom **during this past week**, let us know **how often** you had it, **how severe** it was usually and **how much it distressed or bothered** you by circling the appropriate number.
If you **did not have** the symptom, make an "X" in the box marked **"did not have".**

| During the past week, did you have any of the following symptoms? | Did not have | **If yes, how often did you have it?** | | | | **If yes, how severe was it usually?** | | | | **If yes, how much did it distress or bother you?** | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Rarely | Occasionally | Frequently | Almost constantly | Slight | Moderate | Severe | Very severe | Not at all | A little bit | Somewhat | Quite a bit | Very much |
| Difficulty concentrating | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Pain | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Lack of energy | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Cough | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling nervous | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Dry mouth | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Nausea | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling drowsy | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Numbness/ tingling in hands and feet | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Difficulty sleeping | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling bloated | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Problems with urination | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |

| During the past week, did you have any of the following symptoms? | Did not have | **If yes, how often did you have it?** | | | | **If yes, how severe was it usually?** | | | | **If yes, how much did it distress or bother you?** | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Rarely | Occasionally | Frequently | Almost constantly | Slight | Moderate | Severe | Very severe | Not at all | A little bit | Some-what | Quite a bit | Very much |
| Vomiting | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Shortness of breath | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Diarrhea | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling sad | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Sweats | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Worrying | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Problems with sexual interests or activity | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Itching | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Lack of appetite | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Dizziness | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Difficulty swallowing | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Feeling irritable | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |

**Section II:** We have listed 8 symptoms below. Read each one carefully. If you have had the symptom **during this past week**, let us know **how severe** it was usually and **how much it distressed or bothered** you by circling the appropriate number. If you **did not have** the symptom, make an “X” in the box marked **“did not have”.**

| During the past week, did you have any of the following symptoms? | Did not have | **If yes, how severe was it usually?** | | | | **If yes, how much did it distress or bother you?** | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Slight | Moderate | Severe | Very severe | Not at all | A little bit | Some-what | Quite a bit | Very much |
| Mouth sores | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Change in the way food tastes | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Weight loss | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Hair loss | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Constipation | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Swelling of arms or legs | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| “I don’t look like myself” | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| Change in skin | | 1 | 2 | 3 | 4 | 0 | 1 | 2 | 3 | 4 |
| If you had any other symptoms during the past week, please list below and indicate how much the symptom has distressed or bothered you. | | | | | | | | | | |
| Other: | | | | | | 0 | 1 | 2 | 3 | 4 |
| Other: | | | | | | 0 | 1 | 2 | 3 | 4 |
| Other: | | | | | | 0 | 1 | 2 | 3 | 4 |

# 11. Profile of Mood States-Short Form

**Patient Number:_________**

Below is a list of words that describe feelings people have. Please read each one carefully, then circle the appropriate number to the right of the statement to indicate **how you have been feeling during the past week including today.**

| | Not at all | A little | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|---|
| **1. Tense** | 0 | 1 | 2 | 3 | 4 |
| **2. Angry** | 0 | 1 | 2 | 3 | 4 |
| **3. Worn out** | 0 | 1 | 2 | 3 | 4 |
| **4. Lively** | 0 | 1 | 2 | 3 | 4 |
| **5. Confused** | 0 | 1 | 2 | 3 | 4 |
| **6. Shakey** | 0 | 1 | 2 | 3 | 4 |
| **7. Sad** | 0 | 1 | 2 | 3 | 4 |
| **8. Active** | 0 | 1 | 2 | 3 | 4 |
| **9. Grouchy** | 0 | 1 | 2 | 3 | 4 |
| **10. Energetic** | 0 | 1 | 2 | 3 | 4 |
| **11. Unworthy** | 0 | 1 | 2 | 3 | 4 |
| **12. Uneasy** | 0 | 1 | 2 | 3 | 4 |
| **13. Fatigued** | 0 | 1 | 2 | 3 | 4 |
| **14. Annoyed** | 0 | 1 | 2 | 3 | 4 |
| **15. Discouraged** | 0 | 1 | 2 | 3 | 4 |

| | Not at all | A little | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|---|
| **16. Nervous** | 0 | 1 | 2 | 3 | 4 |
| **17. Lonely** | 0 | 1 | 2 | 3 | 4 |
| **18. Muddled** | 0 | 1 | 2 | 3 | 4 |
| **19. Exhausted** | 0 | 1 | 2 | 3 | 4 |
| **20. Anxious** | 0 | 1 | 2 | 3 | 4 |
| **21. Gloomy** | 0 | 1 | 2 | 3 | 4 |
| **22. Sluggish** | 0 | 1 | 2 | 3 | 4 |
| **23. Weary** | 0 | 1 | 2 | 3 | 4 |
| **24. Bewildered** | 0 | 1 | 2 | 3 | 4 |
| **25. Furious** | 0 | 1 | 2 | 3 | 4 |
| **26. Efficient** | 0 | 1 | 2 | 3 | 4 |
| **27. Full of pep** | 0 | 1 | 2 | 3 | 4 |
| **28. Bad-tempered** | 0 | 1 | 2 | 3 | 4 |
| **29. Forgetful** | 0 | 1 | 2 | 3 | 4 |
| **30. Vigorous** | 0 | 1 | 2 | 3 | 4 |

## 12. Medical Outcomes Study Social Support Survey

**Patient Number:_________**

The following are some questions about the support that is available to you.

1. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?
Number of close friends and close relatives: _____

People sometimes look to others for assistance, or other types of support.
How often is each the following kinds of support available to you if you need it?
Please circle the number that best describes how often you receive support.

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|---|---|---|---|---|---|
| 2. Someone you can count on to listen to you when you need to talk (or write) | 1 | 2 | 3 | 4 | 5 |
| 3. Someone to give you good advice about a crisis | 1 | 2 | 3 | 4 | 5 |
| 4. Someone to give information to help you understand a situation | 1 | 2 | 3 | 4 | 5 |
| 5. Someone to confide in or talk to (or write to) about yourself or your problems | 1 | 2 | 3 | 4 | 5 |
| 6. Someone whose advice you really want | 1 | 2 | 3 | 4 | 5 |
| 7. Someone to share your most private worries and fears with | 1 | 2 | 3 | 4 | 5 |
| 8. Someone to turn to for suggestions about how to deal with a personal problem | 1 | 2 | 3 | 4 | 5 |
| 9. Someone who understands your problems | 1 | 2 | 3 | 4 | 5 |

## 13. The Item Total Correlation Form of Suinn-Lew Asian Self-Identity Acculturation Scale

**Patient Number:_________**

Read each statement and then select the appropriate answer to indicate which best fitted you.

1. What languages can you speak?
    ____ a) an Asian language only (e.g., Chinese, Filipino, Korean, etc.)
    ____ b) Mostly Asian, some English
    ____ c) Asian and English about equally well (bilingual)
    ____ d) Mostly English, some Asian
    ____ e) Only English

2. What languages do you prefer to use?
    ____ a) Asian only (e.g., Chinese, Filipino, Korean, etc.)
    ____ b) Mostly Asian, some English
    ____ c) Asian and English about equally well (bilingual)
    ____ d) Mostly English, some Asian
    ____ e) Only English

3. Do you read:
    ____ a) Only an Asian language?
    ____ b) An Asian language better than English
    ____ c) Both Asian and English about equally well
    ____ d) Read English better than an Asian language
    ____ e) Only English?

4. What was the ethnic origin of the friends and peers you had a child up to age 6?
    ____ a) Almost exclusively Asians, Asian Americans, Orientals
    ____ b) Mostly Asians, Asian Americans, Orientals
    ____ c) About equally Asian groups and Anglo groups
    ____ d) Mostly Anglos, Blacks, Hispanics, or other non-Asian ethnic groups
    ____ e) Almostly exclusively Anglos, Blacks, or other non-Asian ethnic groups

5. How would you rate yourself?
    ____a) Very Asian
    ____b) Mostly Asian
    ____c) Bicultural
    ____d) Mostly Anglicized
    ____e) Very Anglicized

## 14. Functional Performance Inventory-Short Form

**Patient Number:_________**

This questionnaire asks about how your health usually affects your day-day activities. Please circle the number that best describes **how difficult it is for you, in general, to do the following activities.** If you have never done, or choose not to do, an activity for reasons other than your health, please circle n/a (not applicable).

| | Do with….. | | | Don't do because.. | |
|---|---|---|---|---|---|
| | No difficulty | Some Difficulty | Much Difficulty | Health Reason | Choose not to |
| **Body Care** | | | | | |
| Dressing & undressing | 1 | 2 | 3 | 4 | n/a |
| Showering or bathing | 1 | 2 | 3 | 4 | n/a |
| Caring for your feet | 1 | 2 | 3 | 4 | n/a |
| Washing your hair | 1 | 2 | 3 | 4 | n/a |
| Shaving or applying makeup | 1 | 2 | 3 | 4 | n/a |
| **Maintaining the household** | | | | | |
| Groceries & meals: | | | | | |
| Preparing meals/ cooking | 1 | 2 | 3 | 4 | n/a |
| Grocery shopping | 1 | 2 | 3 | 4 | n/a |
| Carrying groceries | 1 | 2 | 3 | 4 | n/a |
| Activities around the house or apartments, such as: | | | | | |
| Vacuuming or sweeping | 1 | 2 | 3 | 4 | n/a |
| Moving furniture, changing sheets, or washing windows | 1 | 2 | 3 | 4 | n/a |
| Cleaning bathrooms or washing floors | 1 | 2 | 3 | 4 | n/a |
| Mowing the lawn, shoveling snow, raking, or heavy gardening | 1 | 2 | 3 | 4 | n/a |
| Going to appointments (such as doctors or dentists) | 1 | 2 | 3 | 4 | n/a |
| **Physical exercise** | | | | | |
| Regular stretching, moving, or lifting light weights | 1 | 2 | 3 | 4 | n/a |
| Walking up and down a flight of stairs | 1 | 2 | 3 | 4 | n/a |
| Short walks around the neighborhood or mall | 1 | 2 | 3 | 4 | n/a |
| Long fast walks (more than 20 minutes) | 1 | 2 | 3 | 4 | n/a |
| Activities such as swimming or bicycling | 1 | 2 | 3 | 4 | n/a |

| | Do with….. | | | Don't do because… | |
|---|---|---|---|---|---|
| | No difficulty | Some Difficulty | Much Difficulty | Health Reason | Choose not to |
| **Recreation- activities for personal pleasure** | | | | | |
| Taking vacations | 1 | 2 | 3 | 4 | n/a |
| Activities away from the house or apartment | | | | | |
| Indoor activities such as shopping or museums | 1 | 2 | 3 | 4 | n/a |
| Going to the movies | 1 | 2 | 3 | 4 | n/a |
| Activities in and around the house or apartment | | | | | |
| Sitting outside | 1 | 2 | 3 | 4 | n/a |
| Reading | 1 | 2 | 3 | 4 | n/a |
| **Spiritual activities** | | | | | |
| Attending religious services | 1 | 2 | 3 | 4 | n/a |
| Going to religious ceremonies | 1 | 2 | 3 | 4 | n/a |
| Personal reading, meditation, or prayer | 1 | 2 | 3 | 4 | n/a |
| Visits from spiritual friends or teachers | 1 | 2 | 3 | 4 | n/a |
| **Social interaction- family and friends** | | | | | |
| Dinner, cards, bingo or other activity | | | | | |
| In your home | 1 | 2 | 3 | 4 | n/a |
| Places other than your home | 1 | 2 | 3 | 4 | n/a |
| Helping family or friends: | | | | | |
| Going to the store, giving rides, doing repairs or other favors | 1 | 2 | 3 | 4 | n/a |
| Helping in the care of children | 1 | 2 | 3 | 4 | n/a |
| Distant or overnight travel to visit others | 1 | 2 | 3 | 4 | n/a |

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