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Clinical Methods

Development and initial psychometric properties of the Pulmonary Arterial Hypertension Symptom Scale (PAHSS) ☆

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ABSTRACT

Aims: The aim of this study is to report the development and psychometric properties of the Pulmonary Arterial Hypertension Symptom Scale (PAHSS).
Background: Patients with pulmonary arterial hypertension (PAH) experience multiple symptoms such as dyspnea, fatigue and chest pain, yet there is no comprehensive, validated symptom assessment tool to date.
Methods: This study used a cross sectional design. Participants completed: socio-demographic and medical data form, the PAHSS, the Medical Outcomes Study Short Form-36 and the Profile of Mood States short form.
Results: The PAHSS contains 17 symptoms measured on a 0 to 10 scale. Principal components analysis demonstrated a three factor solution for the PAHSS: pulmonary, diffuse, and cardiac. Coefficient alphas were good. Statistically significant Pearson coefficients were found between the PAHSS and the Medical Outcomes Study Short Form-36 and the Profile of Mood States short form.
Conclusion: Findings show that the PAHSS is a promising scale to assess symptom severity.

1. Introduction

Pulmonary arterial hypertension results in increased pulmonary pressures leading to right ventricular dysfunction and ultimately death. Hemodynamically, diagnosis of PAH is by right heart catheterization where a mean pulmonary artery pressure of greater than or equal to 25 mmHg and a pulmonary capillary wedge pressure less than 15 mmHg is established (Galiè et al., 2009). Epidemiology of PAH is estimated at 7.6 cases per million and a prevalence rate of 26 cases per million (Peacock, Murphy, McMurray, Caballero, & Stewart, 2007). Approximately 50% of those diagnosed with PAH are idiopathic in origin. Other associated disorders causing PAH include systemic sclerosis, HIV, hemolytic anemia, portopulmonary hypertension, and drugs (e.g. anorexigens). The majority of patients with PAH are females with an average age of 50 years at diagnosis. PAH affects all races, although death is higher in African-Americans and Asians (Ling et al., 2012). Mortality is high, with a greater than 30% risk of death 3 years after diagnosis (Wu et al., 2013). Commonly reported symptoms are dyspnea on exertion and fatigue. Because symptoms of PAH mimic other cardiopulmonary disorders, diagnosis may be delayed for several years. Currently, there is no comprehensive measure for symptoms specifically for PAH. Therefore, there was a need to develop and test an all-inclusive symptom assessment tool for patients with PAH.

2. Background

The conceptual framework used for development of this symptom assessment tool was the revised University of California San Francisco (UCSF) Symptom Management Conceptual Model (Dodd et al., 2001). Symptoms are subjective experiences related to changes in biological and psychosocial function, perceptions or cognition (Dodd et al., 2001); in comparison, signs are defined as an abnormality that is detectable and observable by a person and others (Lathrop, 2008). The model incorporates signs when they are important in assessing the patient's status and the effectiveness of management strategies.

The UCSF Revised Symptom Management Conceptual Model is based on the following six assumptions Dodd et al., 2001). First, the gold standard of measuring symptoms is the patient's self-report. Second, the patient may be at risk for experiencing a symptom, but does not have to be experiencing the symptom at the moment to use the model. Three, interventions may be initiated before the patient experiences the symptom. Fourth, interpretation

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of symptoms by caregivers is appropriate. Fifth, the individual or family may be targeted for symptom control. Sixth, symptom control needs to be adjusted based on outcomes. Domains of the symptom management model include nursing science, person, health/illness and environment which influence the symptom experience and management approach.

Previous symptom studies have determined that patients with PAH have multiple symptoms that are prevalent and severe (Matura, McDonough & Carroll, 2012a, 2012b; McDonough, Matura, & Carroll, 2011). Some of the most prevalent and most intensely reported symptoms are dyspnea on exertion, fatigue and difficulty sleeping (Matura et al., 2012a, 2012b; McDonough et al., 2011). These symptoms impair patients' health-related quality of life (HRQOL). Patients with PAH state that they have to limit activities due to their symptoms (dyspnea, fatigue) (McDonough et al., 2011). To date, a comprehensive symptom severity scale with psychometrics has not been established. Creating such a tool is necessary in order to measure symptoms in PAH and responses to treatments and interventions.

3. Methods

3.1. Aim

The aim of this study was to describe the development and initial psychometric properties of the Pulmonary Arterial Hypertension Symptom Scale (PAHSS).

3.2. Design

A cross-sectional design was utilized to develop and validate the PAHSS instrument. This study was part of a baseline study to examine the symptom experience in patients with PAH.

3.3. Sample and setting

Convenience sampling was used to recruit a sample of patients with PAH from several sites: a PAH clinic, New England regional PAH support groups, an on-line pulmonary hypertension association discussion board along with recruitment at local and international PAH conferences. In the PAH clinic an advanced practice nurse approached potential participants to determine their interest in the study. If the patient was interested they were given the principal investigator's contact information. The principal investigator was introduced at monthly PAH support meetings and/or the conferences to discuss the study. Potential participants approached the principal investigator if they were interested in the study. The pulmonary hypertension association hosts a discussion board for patients with PAH and their family members, the Website administrator posted an advertisement for potential participant to contact the principal investigator.

Inclusion criteria were those participants self-identified with PAH who were equal to or greater than 18 years old and able to read and speak English. Enrollment was over a 24-month period (May 2009–May 2011). Two hundred seventy six were invited to participate, and 191 participants returned completed questionnaires resulting in a 69% response rate. A minimum sample of 100 participants is adequate for principal components analysis for instrument development (Sapnas & Zeller, 2002).

3.4. Instruments

3.4.1. Socio-demographic and clinical data form

Socio-demographics and clinical variables were collected by an investigator-developed tool via participant self-report. Socio-demographics included: gender, age, ethnicity, education, occupation and employment. Clinical variables included the date of PAH diagnosis, PAH etiology, initial symptoms of PAH, oxygen use and medications. World Health Organization (WHO) functional class for PAH was derived from assessment of self-reported symptoms by the principal investigator (LAM). WHO functional class I are those with PAH with or without dyspnea, fatigue, chest pain or near syncope with usual physical activity. WHO functional class II are those who are not symptomatic at rest, but usual activity causes dyspnea, fatigue, chest pain or near syncope. WHO functional class III are those who are comfortable at rest, but less than usual activity results in dyspnea, fatigue, chest pain or near syncope. Finally, WHO functional class IV are those who have symptoms at rest (Galiè et al., 2009).

3.4.2. Pulmonary Arterial Hypertension Symptom Scale (PAHSS)

PAH symptom severity was measured by the investigator-developed PAHSS developed from the literature and discussion with the research team and clinicians caring for patients with PAH, Fig. 1. Seventeen symptoms are included on the scale: shortness of breath (SOB) with exertion, SOB lying down, SOB at rest, awakening at night SOB, fatigue, difficulty sleeping, chest pain, abdominal swelling, swelling of ankles and feet, syncope, palpitations, dizziness, cough, nausea, loss of appetite, hoarseness and Raynaud's phenomenon (cold, numbness of extremities). Symptoms were rated on a 0–10 scale; zero represented absence of the symptom and 10 meant “extremely intense”. These symptoms were also verified by reviewing with 20 PAH participants and additional experts caring for patient with PAH in this study to determine face validity and if any symptoms should be added or removed from the scale. Participants are asked to rate their symptoms over the past month. The measure takes less than 5 minutes to complete. The component structure, reliability, and validity of the PAHSS will be assessed in this study.

3.4.3. Medical Outcomes Study Short Form (SF-36)

The SF-36 is a generic measure of health status which includes physical function and psychological well-being. The SF-36 contains eight subscales: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health that are combined to form physical and mental summary scores. The subscales of physical functioning, role emotional functioning, bodily pain and general health measures form the physical health composite score while subscores of vitality, social functioning, role functioning and mental health are combined to form the mental health composite summary score. Higher scores are interpreted as better perceived health with scores ranging from 0 to 100. Convergent and discriminate validity have been established. Internal consistency ranges are .73–.96 (Brazier et al., 1992).

3.4.4. Profile of Mood States (POMS) short form

The POMS short form measures psychological distress. The 30 items measure the mood states: anger, anxiety, depression, confusion, fatigue and vigor on a 5 point Likert scale. Scores range from 0 (not at all) to 4 (extreme). The modified Hopkins Symptom Distress Scales and Minnesota Multiphasic Personality Inventory-2 were used to establish concurrent validity. Total mood score ranges from −20 to 100. Higher scores specify more negative moods, except vigor which is reverse scored. Cronbach alpha ranged from .84 to .95 (McNair et al., 2009).

3.5. Procedures

The university and hospital ethic committees approved this study prior to recruitment of participants. Participants completed the following questionnaires: a demographic and clinical data form, the PAHSS, the SF-36 and the POMS short form.