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## Quality of life and psychological symptoms in patients with pulmonary hypertension

Tania T. Von Visger, APRN, MS, CNS, CCNS, PCCN<sup>a,b,\*</sup>, Kristin K. Kuntz, PhD<sup>a</sup>, Gary S. Phillips, MAS<sup>a</sup>, Vedat O. Yildiz, MS<sup>a,c</sup>, Namita Sood, MD, FCCP<sup>a</sup>

<sup>a</sup>The Ohio State University Wexner Medical Center, Columbus, OH

<sup>b</sup>The Ohio State University College of Nursing, Columbus, OH

<sup>c</sup>The Ohio State University College of Medicine, Columbus, OH

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### ABSTRACT

**Background:** Pulmonary arterial hypertension (PAH) has a delay in diagnosis that makes time since diagnosis of interest in this population.

**Objectives:** To assess psychological conditions, perceived stress, QOL, and interpersonal support and to explore whether these factors may correlate with time since diagnosis in patients with PAH.

**Methods:** Participants at an academic medical center ( $n = 108$ ) completed psychological questionnaires (Cambridge Pulmonary Hypertension Outcome Review, Patient Health Questionnaire-9, Perceived Stress Scale-10, and Interpersonal Support Evaluation List-Short Form).

**Results:** Prevalence of psychiatric disorder, major depression, and "other depressive disorder" were 29.6%, 15.7%, and 9.3%, respectively. Participants reported adequate social support, high perceived stress, and average quality of life. Time since diagnosis was positively associated with greater perceived social support ( $\rho = 0.174$ ,  $p = .075$ ) and greater perceived stress ( $\rho = 0.191$ ,  $p = .048$ ), but no other psychological factor.

**Conclusions:** Routine psychological assessment and timely referral for mental health services are suggested. Social support may buffer patients from stress.

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### Introduction

Pulmonary arterial hypertension (PAH) is a rare and severe clinical condition affecting approximately 15 individuals per million annually.<sup>1</sup> According to the largest national data registry, the average time from onset of symptoms to diagnosis was 2.8 years.<sup>1</sup> The delay

in diagnosis makes time since diagnosis a factor of interest in this population. So, also are depression and anxiety disorders. The prevalence of depression and anxiety disorders is higher in patients with PAH compared to patients with inflammatory rheumatic disease and patients seen in primary care settings, and depression and anxiety in patients with PAH increase with disease progression.<sup>2</sup> A qualitative analysis of 549 PAH patients' comments from an online discussion board revealed the following psychological concerns: (1) disease uncertainty, (2) guidance and validation, (3) support, and (4) refocusing life.<sup>3</sup> While these qualitative reports provided unique understanding of how patients with PAH may deal with the progression of the disease, they did not provide quantitative measurement of how psychological factors and QOL may change with time since diagnosis.

Using an ethnographic qualitative approach to explore psychological coping in patients with PH, researchers identified three distinct phases: "pre-diagnosis," "diagnosis," and "living with PH" that revealed different psychological descriptors and QOL among these phases.<sup>4</sup> Patients and families described feelings of "frustration," "anger," and "uncertainty" during the PAH diagnosis phase.<sup>5</sup> After the PAH diagnosis, patients recounted mixed emotions of "relief" and "scare."<sup>5</sup> A qualitative observational study of patients living with PAH<sup>6</sup> reported two themes with which patients struggled:

**Abbreviations:** CAMPBOR, Cambridge Pulmonary Hypertension Outcome Review; ISEL-SF, Interpersonal Support Evaluation List-Short Form; NYHA, New York Heart Association Functional Class; PAH, Pulmonary Arterial Hypertension; PH, Pulmonary Hypertension; PHQ-9, Patient Health Questionnaire-9; PSS-10, Perceived Stress Scale-10; QOL, quality of life; SD, standard deviation; SMT, Symptoms Management Theory.

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\* Corresponding author. Fax: 614-293-7632.

E-mail address: [von-visger.2@osu.edu](mailto:von-visger.2@osu.edu) (T.T. Von Visger).

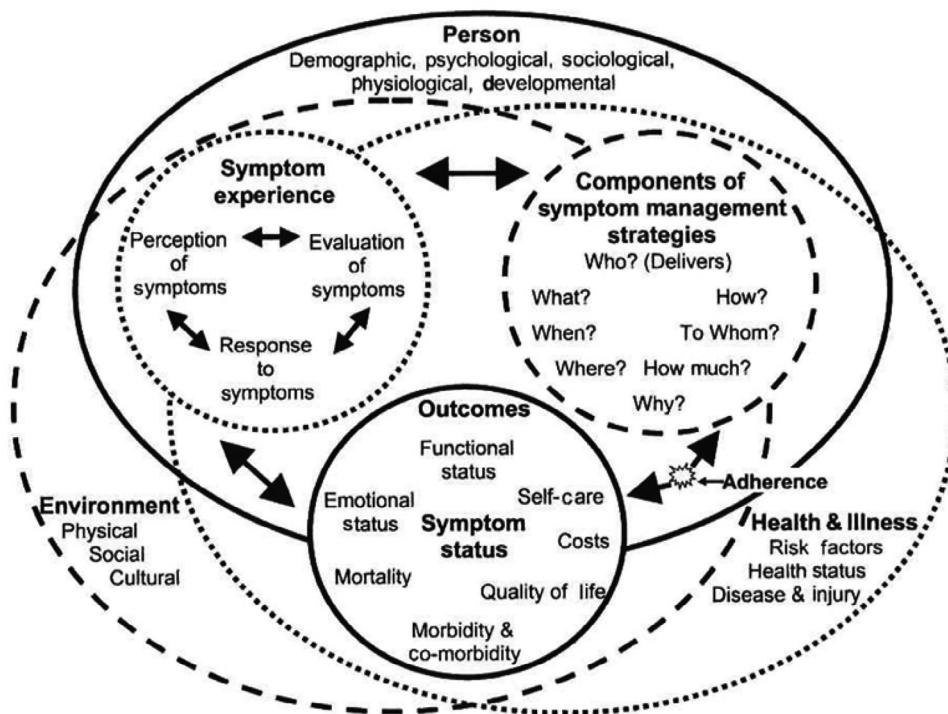


Fig. 1. Revised Symptom Management

(1) coping with uncertainty and (2) living life with treatment.<sup>6</sup> Living life with uncertainty was also reported in a study suggesting that patients with PAH used different coping styles at various illness trajectory time points.<sup>5</sup> Immediately after diagnosis, patients reported high levels of anxiety related to lack of knowledge about PAH diagnosis and management.<sup>4</sup>

Patients with PAH have to perform many self-management activities, and this can be hampered by psychological factors and poor quality of life (QOL). Data from two pulmonary hypertension centers in the United States indicated that 50% of patients with PAH reported depressive symptoms.<sup>7</sup> Therefore, we undertook a study to assess psychological conditions, perceived stress, QOL, and interpersonal support and to explore whether these factors may correlate with time since diagnosis in patients with PAH.

QOL is one's perception of how good or bad her or his life is.<sup>8</sup> Subjective assessment of QOL and psychological factors may change over time, depending on health status,<sup>3</sup> mental states, developmental stage,<sup>9</sup> disease progression,<sup>10</sup> and medical treatment.<sup>11</sup> PAH-related QOL includes PAH-related symptoms, activity limitation, and the individual's perception of QOL.<sup>12</sup> Data suggest that there are temporal changes in the psychological adaptation of patients with PAH that occur from the time before PAH diagnosis<sup>5</sup> to years after the diagnosis.<sup>3</sup> Thus, it would add to the literature to understand better whether time since diagnosis is associated with psychological factors, perceived stress, QOL, and interpersonal support in patients with PAH.

The purpose of this study was to assess the psychological health of patients with PAH and how it may change over time. We conducted a descriptive, correlational study with the following aims: (1) to describe the prevalence of psychological conditions (anxiety disorder, panic disorder, depressive symptoms), and assess the QOL, interpersonal support, and perceived stress of patients with PAH. (2) to determine if psychological conditions (anxiety disorder, panic disorder, depressive symptoms), QOL, interpersonal support, and perceived stress correlate with the length of time since diagnosis of PAH.

*Theoretical framework*

We conceptualized QOL in patients with PAH within the biopsychosocial framework of the Symptom Management Theory (SMT; Figure 1).<sup>13</sup> In the SMT, QOL is an outcome of symptom management. Table 1 lists the theoretical concepts in the SMT, along with the corresponding study factors and measurement tools used in this study.

Health and Illness Domain factors were the New York Heart Association (NYHA) classification and time since PAH diagnosis, respectively. Person Domain factors were age, sex, race/ethnicity, and psychological factors. The Environment Domain factor was

**Table 1**  
SMT Theoretical Concepts, Factors, and Measures

| Concepts  | Factors   | Measurement Tools                              |
|---|---|--|
| <sup>a</sup> Health & Illness                               | PH Severity<br>Health Status<br>Age<br>Sex  | NYHA Classification<br>Time since PH diagnosis |
| <sup>a</sup> Person   | Race/Ethnicity<br>Psychological Distress:<br>1) Major Depression<br>2) Other Depression<br>3) Panic Disorder<br>4) Anxiety Disorder | Demographic<br>PHQ-9                           |
| <sup>a</sup> Environment<br><sup>b</sup> Symptom Experience | Social Support<br>Symptom Presence<br>Symptom Severity<br>Quality of life   | ISEL-SF<br>CAMPHOR-Symptom                     |
| <sup>b</sup> Symptom Status & Outcomes                      | Functional Status<br>Emotional Status   | CAMPHOR-QOL<br>CAMPHOR-Activity<br>PSS         |

Abbreviations: CAMPHOR = Cambridge Pulmonary Hypertension Outcome Review; ISEL-SF = Interpersonal Support Evaluation List-Short Form; PHQ-9 = Patient Health Questionnaire-9; PSS-10 = Perceived Stress Scale-10.

<sup>a</sup> Theoretical Domain Concept.

<sup>b</sup> Theoretical Dimension Concept.

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