

# Support Experienced by Patients Living with Pulmonary Arterial Hypertension and Chronic Thromboembolic Pulmonary Hypertension



Bodil Ivarsson, RN, PhD<sup>a,b\*</sup>, Björn Ekmehag, MD, PhD<sup>c</sup>,  
Trygve Sjöberg, PhD<sup>a</sup>

<sup>a</sup>Department of Cardiothoracic Surgery, Lund University and Skåne University Hospital, Sweden

<sup>b</sup>Medical Services, Region Skåne, Lund, Sweden

<sup>c</sup>Department of Public Health and Caring Science, Uppsala University, and Uppsala University Hospital, Uppsala, Sweden

Received 15 February 2015; received in revised form 21 March 2015; accepted 26 March 2015; online published-ahead-of-print 9 June 2015

## Background

As pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH) are debilitating and fatal diseases it is essential to increase the understanding of patients' experience of support. The aim was to describe patients' experiences of support while living with PAH or CTEPH.

## Methods

Seventeen patients (13 women and four men) aged 28–73 years were strategically selected from a regional PAH centre and individually interviewed. The answers were analysed using qualitative content analysis.

## Results

Three categories that describe patients' experiences of support emerged: Support linked to the healthcare; support linked to the private sphere; and support linked to persons outside the private sphere.

## Conclusion

Healthcare practitioners must work more in collaboration to detect patients' need for support and to develop the patient's own skills to manage daily life. The PAH teams should tailor interventions to provide emotional, informational and instrumental support and guidance to patients and their families.

## Keywords

Chronic disease • Peer support • Relationship • Social support • Supportive care

## Introduction

Pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH) are rare and often progressive diseases with high mortality, characterised by increased right ventricular load and eventually development of right heart failure [1]. There is evidence that modern treatment strategies have significant positive effects on survival [2,3]. Therefore it is of great importance to focus, as early as possible, on appropriate treatments to achieve symptom relief and improve quality of life for these vulnerable patients.

To further support the patients, it is important to highlight psychosocial issues<sup>4</sup>.

Given the poor prognosis, PAH and CTEPH have significant physical, mental and social consequences for the patients, leading to reduced health-related quality of life [4,5]. The patients must avoid harmful situations, take medication and have regular contact with the healthcare organisation [6,7]. To achieve person-centred care it is required that the patients are actively involved in their own care [8]. Therefore, the multi-disciplinary specialist team responsible for the patient, i.e. the PAH team, must have the knowledge and resources to support

\*Corresponding author at: Department of Cardiothoracic Surgery, Skåne University Hospital, SE-221 85 Lund, Sweden. Tel.: +46-76-8870467; fax: +46-46-17 60 54, Email: [bodil.ivarsson@med.lu.se](mailto:bodil.ivarsson@med.lu.se)

and provide information to the patients and their families to optimise quality of life [9]. The patients also need support from local hospitals and primary or municipal care units [6,9]. Patients with PAH or CTEPH should be given hope. This however should not deter healthcare professionals from communicating prognosis and in appropriate time, to provide an opportunity to discuss palliative care and end-of-life issues [10].

A review had identified three main types of support: emotional, informational and instrumental support to patients with cancer [11]. Emotional support focusses on empathy, encouragement, comfort and responsiveness. Informational support focusses on providing information and advice to support patients to understand and manage their illness and its symptoms. Instrumental support focusses on practical issues such as housework, transport, and financial help. The prognosis amongst PAH patients is similar to that associated with severe forms of cancer [12], and several authors outline the benefits of providing PAH patients with support [1,6,7,9].

Studies illuminating PAH or CTEPH patient's own experiences of support are rare, therefore, the aim was to describe patient's own experiences of support while living with PAH or CTEPH.

## Methods

### Design and Patients

The study used a qualitative, descriptive approach. Face-to-face interviews were conducted with 17 adult patients with PAH or CTEPH. Strategic sampling [13] was carried out in order to achieve variation in terms of sex, age, diagnosis, time since diagnosis. The characteristics of the patients and demographic data are listed in Table 1.

The investigation conforms with the principles outlined in the Declaration of Helsinki (Br Med J 1964;ii:177). The Regional Research Ethics Committee in Lund, Sweden, approved the study (LU 2011/364). The interviewer (BI) was not involved in the patient care. A social worker at the PAH centre was asked to provide counselling to the patients if necessary.

### Data Collection

In an introductory letter all the patients were given written information about the study and its aim. The patients were later contacted by phone and asked whether they agreed to participate, and if so, to choose a place and time for the interview.

Before the actual interview, the patients gave their written consent to participate in the study and were guaranteed confidentiality and the possibility to withdraw at any time without consequences. The interviews were semi-structured and covered the following topics: (a) demographic details such as age, education, marital status; (b) and questions about support. The patients were encouraged to speak freely and the introductory question was, "When you look back, please tell me about your experience and needs of support in connection with PAH or CTEPH?" A question about their

**Table 1** Demographic data and disease characteristics of the patients (N = 17).

Sex	13 women/4 men
Age:	
Mean ± SD	56±15
Median (range)	60 (28–73)
Years since diagnosis:	
Mean ± SD	5±3
Median (range)	4 (1–12)
Living situation:	
Single (n)	5
Living with partner (n)	12
Patients with dependent children at home (n)	4
Years of formal education:	
≤9 (n)	4
10–12 (n)	6
>12 (n)	7
Diagnosis:	
IPAH <sup>1</sup> (n)	6
APAH <sup>2</sup> (n)	1
IPAH+APAH(n)	1
APAH + SSC <sup>3</sup> (n)	4
CTEPH <sup>4</sup> (n)	3
CTEPH with surgery(n)	2
Drugs:	
ERA <sup>a</sup> +PDE <sup>b</sup> +Warfarin	7
ERA+PDE	4
ERA	1
ERA+Warfarin	1
ERA+CCB <sup>c</sup> +Warfarin	1
CCB	1
PDE	1
PDE+Warfarin	1
Current occupation:	
Full-time job (n)	3
Part-time job (n)	5
Disability/retirement pension	9

<sup>1</sup>Idiopathic pulmonary arterial hypertension

<sup>2</sup>Associated pulmonary arterial hypertension

<sup>3</sup>Systemic sclerosis-associated pulmonary arterial hypertension

<sup>4</sup>Chronic thromboembolic pulmonary hypertension

<sup>a</sup>Endothelin receptor antagonists

<sup>b</sup>Phosphodiesterase

<sup>c</sup>Calcium channel blockers.

experience of information in connection with PAH was also asked and has been reported in a separate article [14]. Clarifying questions were asked to follow-up the narratives and to continue the conversation. The interviews were all carried out from January 2012 to 1 October 2012 and were held in the patient's home (10) or at a neutral office in a healthcare facility (7). A verbatim transcription of tape-recorded interviews was made later.

Download English Version:

<https://daneshyari.com/en/article/5958980>

Download Persian Version:

<https://daneshyari.com/article/5958980>

[Daneshyari.com](https://daneshyari.com)