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

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### **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 multidisciplinary specialist team responsible for the patient, i.e. the PAH team, must have the knowledge and resources to support 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 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.

### **Data Analysis**

Transcripts about support from interviews resulted in 110 double-spaced pages of data and the transcribed interviews were analysed using Microsoft Word’s Tools [15] by means of qualitative content analyses based on the method of Burnard [16]. The analysis was conducted in different stages. In the first stage the text was read through as a whole to get an overall understanding. In the second stage the text was read through again focussing on identifying meaning units that were related to the aim of the study. In stage three the meaning units were extracted from the text and condensed. This was done by BI and confirmed by TS. Based on the codes, sub-categories and categories were developed in stage four. There was an ongoing dialogue between the authors BI and TS throughout these stages, and in the fifth stage the subcategories were carefully discussed until three categories could be identified cf. [17]. As stated by Graneheim and Lundman [17] seeking agreement between co-researchers strengthens credibility. In order to demonstrate the trustworthiness, the results have been supported by quotations from patients’ statements.

### **Result**

Three categories were found that described the patients’ experience of support: Support linked to healthcare; support linked to the private sphere; and support linked to persons outside the private sphere. Categories and sub-categories are presented in Table 2.

#### **Support Linked to Healthcare**

### **Attitude to pharmacological treatments**

Most patients felt that they benefited greatly and that their health was improved by the modern pharmacological treatments they were prescribed. As PAH and CTEPH are relatively rare diagnoses, patients' experience was that the physicians tested the best individual form of medical treatment. Some patients who had been involved in drug trials said that they could immediately feel whether they received the active drug or placebo due to the instant improvement after taking the active substance. Most patients felt secure with the physicians who took them seriously when they felt that they had side-effects from their drugs and consequently changed them quickly. A few patients reported that they waited to inform their physician of the side-effects and neglected to take the medication. This was not due to poor support from the attending physician, rather, caused by mental instability due to their illness and the fact that they have to rely on drugs for their survival.

*“I live my life as if I wasn't sick, you could say, I respond very well to medicine directly and I've only got better as the years have passed. ... I had a small downturn a year ago. Then they put me on a new medicine and that helped. I work half-time and I live my life fairly much as before, but at a slightly slower tempo.” (P 6)*

### **Management of medicines**

Most PAH drugs are expensive, and patients found it positive that Sweden has an upper limit (around €238) for how much a person needs to pay a year for drugs. However, despite this, there were concerns about how much the medicine costs society.

*“You read in the newspapers that they [the doctors] aren't allowed to prescribe it and that medicine ... it's not productive any more. Soon maybe they'll say that the PAH medicine costs too much.” (P 1)*

Some of the drugs used are licensed medications and the patients had difficulties when trying to collect their medication at the pharmacies; moreover, the waiting time was up to one week for these

special drugs. The patients stated that they had to be careful and keep track of the validity of the prescriptions; how much medicine they had at home, the prescription time by the physician and the pharmacy handling times. Patients stressed the support they received from PAH nurses in dealing with this.

### **Professional counselling**

Many of the patients described the importance and necessity of having someone they could talk to about their emotions and life situation. Although most seemed happy about being able to speak with the PAH team, some patients expressed a desire to have a contact outside the PAH centre and some had arranged this themselves. Some patients said that they had no psychological problems and had declined an offer to speak with a social worker.

*“I don't know if I've been receptive to support before. But then I was given the opportunity ... the therapist knows nothing about the disease itself, it's more a matter of handling things like this existentially. That's good. (P12)*

### **Support Linked to the Private Sphere**

#### **Everyday life**

The majority of patients described how they missed being able to do physically demanding things such as lifting, carrying, climbing stairs or walking long distances. They reported that they adapted themselves to an appropriate tempo to accomplish things but that it took time to accept their reduced energy level. Sometimes they felt anger, disappointment or even shame over not being their former selves.

*“If I had to go up one floor and there was no one else in the lift hall to see me, then I preferred to take the lift, but I was ashamed of it.” (P 14)*

The patients described how relatives helped them with heavy indoor duties and gardening, as well as managing transportation and carrying grocery bags and other physically demanding actions. The

patients also reported that some relatives acted as interlocutors and gave emotional support. Some patients described how their sexual life had changed due to the disease and the accompanying fatigue. They expressed concerns about their partners, due to the absence of a physically fulfilling sexual life. On the other hand, they also said that intimacy can consist of many different components.

*“My partner thinks our sex life has been affected because I’m too tired to have the same energy as before.” (P 7)*

### **Contact with minors**

The patients who had young children or grandchildren knew that they could not fully support them or be able to participate in physical play and felt disappointment over this. At the same time, they said that small children usually were amazing at adapting to what the patients could do. Some patients felt that adults became too overprotective due to the illness and hampered the patients’ contact with children.

*“I’m not allowed to look after the grandchildren, so I asked why. The children’s answer was that they were afraid I would get sick, but I said that if I felt worse there were telephones.” (P 11)*

### **Support linked to persons outside the private sphere**

#### **Confined social life**

Most friends and even neighbours gave support of a social and practical nature. They adapted to patients’ speed of walking, cycling and partying or other physical activities. However, the patients often felt that others forgot or did not understand the limits of the patient’s physical capacity.



*“They don’t understand properly, they think that I should get out and walk and build up my strength, but it’s not a matter of getting my strength back, it’s so hard to explain. But I feel their support all the same, but I also feel that [they] don’t really understand.” (P 15)*

There were concerns about the lack of support, which could make it easier to travel abroad. The patients had in mind the risk of infections and other situations that could arise suddenly. They were unsure of what opportunities they had to get medical treatment and other forms of support. Some were sad that it was difficult to arrange assistance at airports and the possibility of contacting the airline company because of the need of support. Some patients were discouraged by their physicians to fly because of pressure changes in aircraft cabins.

#### **Attitudes to the workplace situation**

Patients in work said that the work meant a lot to them. In most cases their employer or superior was supportive. They had arranged for the patients to work part-time or for the patient to partly determine their working hours and duties. Sometimes the officials at the social security office did not understand how sick the patient was, so the responsible physician had to provide additional certificates.

*“The national insurance office wanted me to work more hours and they had a long inquiry ... I felt that I wasn’t up to working more. So I had to contact my doctor again and he wrote that if this patient wears herself out more than she is doing now, she will die in the very near future. That helped.” (P 17)*

#### **Involved workmates**

Some patients still working said that they had been completely open with colleagues about their illness, while others kept it to an inner circle. Most felt great support from colleagues who did much to make things easier for the patient, while some patients felt that they could give something back in the

form of their professional experience. Some patients who were on sick leave or had retired said that they felt support from earlier co-workers who still kept contact.

### **Peer support**

Some patients reported that they were involved in a patient association for PAH or CTEPH and the association organised sporadic lectures in different locations in the country. The lectures were focussed on giving advice and information about research. It would be helpful, however, if these events could occur more often. Several patients described themselves as very active on Facebook, where they were members of different PH groups, which have participants all over the world. The patients said that they were supported by reading about other patients with the same diagnosis, sharing their experiences, asking questions and receiving adequate answers.

*“I have talked to others who have PAH, I’m on Facebook and I have lots of friends there who have the same disease and the same symptoms and not just Swedes ... that’s a great advantage. There’s a doctor doing research and he’s good at this, but he doesn’t know what it’s like to have the disease [as a patient].” (P 14)*

### **Non-benefit peer support**

Some patients commented that they had met other PAH or CTEPH patients through meetings organised by the patient association for PAH. They found this experience confronting when they thought about their own uncertain future. Most frightening was meeting with other patients who had difficulties with their breathing, were in need of constant oxygen supply, wheelchairs, and dependent on escort help. Such things aroused anxiety because these patients were in worse condition than themselves and the support that the meeting was intended to provide for those patients did not occur.

*“I hadn’t identified with that type of patients before when I saw that they could hardly manage the stairs and sat getting their breath back. Then I understood that I was relatively well and how badly you can feel. It was rather frightening, actually.” (P 7)*

## Discussion

This study indicates that PAH and CTEPH patients are overall satisfied with the emotional, informational and instrumental support they received. However, this does not necessarily mean that all their individual requirements and expectations have been fulfilled. It is encouraging that most patients found that the prescribed PAH or CTEPH specific drugs helped them or at least did not worsen their self-perceived health. Although the drugs used, e.g. endothelin receptor antagonists, phosphodiesterase type-5 inhibitors, and prostanoids, have demonstrated improvements in PAH and CTEPH patients regarding clinical worsening or mortality, many patients still have symptoms and a poor prognosis (1). The PAH team have an ongoing mission to provide the patients with support in the form of information, advice about drugs and management of medicine. Calculations in this population of patients regarding adherence to medication have shown that around 50% of the patients do not take the drugs according to prescriptions [18].

The patients felt that they were supported by the PAH team, particularly regarding their medical treatment. Many patients wished to talk about the challenges of daily life with some professional in or outside the PAH team. Given the burden of disease-specific symptoms such as anxiety, depression, financial and relationship difficulties [19, 20], healthcare professionals should take a more holistic view and provide psychosocial support for improvement of PAH and CTEPH patients' well-being. Furthermore, the support needs to be tailored to fit patients and their families' unique situation. Medicine, as the healthcare system applies it today, has led to great improvements in the care of numerous diseases and conditions. The advances have been tremendous. The improvements for PAH- and CTEPH-patients are mere examples of continuous improvements over the last 15-20 years. Still there are many fields that need further attention. One such domain is the relationship between healthcare professional and patient. Historically this relationship has often had "paternalistic" features. The healthcare professional has told the patient what to do, expecting the patient to follow the advice. We are, however, all aware that the relationship is not always that straightforward. Patients often

report that they lack honest information and, unfortunately, on occasion genuine respect from the healthcare professional. In not so few cases they report a feeling of being at a disadvantage. The healthcare professional needs to move away from the traditional one-way relationship and move towards a true partnership with the patients, and often also with relatives. By transforming the way we handle the relationship we have the possibility to explore the full potential of patient's engagement. This is also fundamental if we want to benefit from the possibilities of value-based medicine. The present study may offer one piece of guidance and inspiration when we take steps in this direction.

The patients in the present study said that they did not have enough strength to manage their daily lives as they had wished. A review has shown that PAH patients can achieve greater endurance, reduced symptoms, and improved quality of life with exercise as an adjunct to pharmacological treatment [21]. Therefore, PAH and CTEPH patients should be offered training with the help of a physiotherapist with special experience of PAH or CTEPH and in close cooperation with the PAH team. Patients should also be offered support by occupational therapists based on daily activities. It can be about developing physical, cognitive and social skills or adapting the physical environment.

As previously shown, most patients reported that close relatives provided the best support [22]. Despite this, patients' experiences of some relatives' behaviour in the form of overprotection, fear or ignorance show that optimal support should also include relatives throughout the entire treatment path. If the patients agree, the relatives should be provided with information from healthcare professionals about the symptoms and possible complications, good communication regarding the treatment process and disease development. Some patients in both the current study and that of Guillevin et al. [23] described how their fatigue caused sexual problems for themselves and their partner. Fatigue is common in chronically ill patients, and patients may need to rest before sexual activity, or when the fatigue is too pronounced, stick to gentle massage or caresses [24]. As this type of problems exists, it is important for the PAH team to ask and dare to talk about sex and intimacy.

It is understandable that spontaneity is limited regarding trips abroad. These patients have to plan for possible hospital visits at the place of stay and maybe even arrange with a physician if an oxygen supply is necessary during the flight, which is not uncommon [25]. Moreover, it is ultimately a matter for each responsible airline captain to give permission to use oxygen during a flight, although a physician can provide information and certificates on request from the airline company. A study confirmed that a lot of PAH patients need support with travel support [23]. Patient associations may have a mission to convey patients' experiences of travelling and to give advice and support.

In this study several patients reported being forced to change their job, to reduce working hours or to quit work because of their bad health. Although some patients in work did not look upon themselves as fully adequate for their tasks, they felt a lot of support from managers and colleagues. The biggest problem was that insurance agencies were not familiar with what PAH and CTEPH means and, according to the patients, failed to collect the necessary knowledge to handle this group of patients. At the Swedish National Board of Health and Welfare work is underway to incorporate straightforward information in the Public Rare Disease Database, which hopefully will increase awareness in the community.

This study emphasises that peer support inside and outside a patient organisation as expected is essential support for many patients. The internet has opened up the opportunity to share stories, exchange practical advice and receive and give support in cases of anxiety. It can also give a sense of being close to someone who understands one's situation [26]. There were also patients who did not want to have contact with other PAH or CTEPH patients. They wanted to maintain a view of being healthy and not be reminded of morbidity by meeting others with a similar disease. This has also been described in chronic illness literature as not being emotionally ready [27]. Therefore PAH teams must be sensitive about whether and when they should facilitate peer support from other patients with personal experience.

The main limitation of this qualitative study is the small number of patients and the fact that it was carried out at a single PAH centre. The variation in terms of sex, age, education, diagnosis and time since diagnosis in the study group may strengthen the results. The reader must of course determine whether the results are transferable to other contexts [17].

### **Conclusions and Implication**

This study provides insight into patients' experiences of emotional, informational and instrumental support. The results may seem obvious but indicate the need for healthcare organisations to be more collaborative in order to detect patients' need for support and to develop patients' own skills to manage their daily life. Support on their own premises is fundamental for patients. This knowledge is vital and could be helpful for healthcare professionals in PAH teams, but also the other healthcare professionals caring for and supporting PAH or CTEPH patients, in order to gain insight into and understand the need for support and to promote a real partnership between patients/relatives and the healthcare system in the care of the patients.

Given the suggestion that value based medicine might offer a natural next step in improving healthcare, further studies should explore experience and outcome measures as understood by the patients. How do our patients define value of interventions?

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#### Contributions

Study design: BI, BE, TS

Data collection and analysis: BI, TS

Manuscript preparation: BI, BE, TS

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

Sex	13 women/4 men
Age:	
Mean $\pm$ SD	56 $\pm$ 15
Median (range)	60 (28–73)
Years since diagnosis:	
Mean $\pm$ SD	5 $\pm$ 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:	
$\leq$ 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

Table 2. A summary of categories and sub-categories.

Categories	Sub-categories
<b>Support linked to healthcare</b>	Attitude to pharmacological treatments
	Management of medication
	Professional counselling
<b>Support linked to the private sphere</b>	Everyday life
	Contact with minors
<b>Support linked to persons outside the private sphere</b>	Confined social life
	Attitudes to the workplace situation
	Involved workmates
	Peer support
	Non-benefit peer support