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*Published in:*  
Patient Education and Counseling

*DOI:*  
[10.1016/j.pec.2016.12.021](https://doi.org/10.1016/j.pec.2016.12.021)

2017

*Document Version:*  
Peer reviewed version (aka post-print)

[Link to publication](#)

*Citation for published version (APA):*  
Ivarsson, B., Rådegran, G., Hesselstrand, R., & Kjellström, B. (2017). Information, social support and coping in patients with pulmonary arterial hypertension or chronic thromboembolic pulmonary hypertension-A nationwide population-based study. *Patient Education and Counseling*, 100(5), 936-942.  
<https://doi.org/10.1016/j.pec.2016.12.021>

*Total number of authors:*  
4

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**Information, social support and coping in patients with pulmonary arterial hypertension or chronic thromboembolic pulmonary hypertension - A nationwide population-based study**

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## **Abstract**

**Objective:** Pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH) decrease life expectancy for affected patients. The aim was to describe the perceptions of received information regarding diagnosis, treatment and management, as well as social support and coping perceived by patients with PAH or CTEPH.

**Methods:** A descriptive, national cohort survey that included patients from all PAH-centres in Sweden. A quantitative methodology was employed where all patients received three questionnaires, QLQ-INFO25, Mastery Scale and Social Network & Support Scale.

**Results:** The response rate was 74% (n=325), mean age 66±14 years, 71% were female and 69% were diagnosed with PAH and 31% with CTEPH. Sixty percent of respondents were satisfied with the received information and felt it was helpful. Best experiences were of information in the areas of medical tests (70%) and the disease (61%). Forty-five percent wanted more information. Men described their social network as more accessible than women (p=0.004). Those living alone had a lower coping ability.

**Conclusion:** Despite a high level of satisfaction with the received information, almost half of the patients wanted more information.

**Practice implications:** Regular repeating or giving new information should be an ongoing process in the care of patients at the PAH-centres.

**Keyword:** Chronic illness, Communication, Mastery, Professionals-patient relations

Pulmonary hypertension, Social support

## **1. Introduction**

Pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH) are rare diseases [1] that decrease life expectancy, limit daily activities and affect quality of life [2]. New targeted treatments have improved the situation immensely for these patients. However, side effects and cost of treatment as well as complicated investigations at diagnosis and follow-up [3, 4] makes it crucial that the patients are cared for at designated PAH-centres. At these centres an inter-professional team with physicians and nurses, as well as physiotherapists, dieticians, psychologists, technicians and other disciplines should be involved [5, 6]. Given the poor prognosis [7] and that compliance to treatment and follow-up is of utmost importance, patients need to acquire coping mechanisms to live with these chronic and life threatening diseases [8, 9]. Hence, information and social support at time of diagnosis as well as during follow-up is essential [10], and may have great impact on the outcome by reducing stressors and support coping behaviours [11].

Patients with chronic diseases often have changing and different needs for information as the illness progresses and treatment strategies change [12]. The patient receive verbal and written information from their specialist teams [10, 13] as well as social media-based information from individual patients and patient organizations [13-15]. The healthcare professionals are commissioned to provide adequate information and timely support that is adapted to health status, needs and preferences [5]. It is also crucial to help patients and their families to deal with living with the disease and the uncertain future it brings [10, 15-17].

The aim of this study was to describe the perceptions of received information regarding diagnosis, treatment and management, as well as social support and coping perceived by patients with PAH or CTEPH.

## **2. Methods**

### **2.1 Design and participants**

This study was a descriptive, cross-sectional, nationwide investigation including patients registered in SPAHR (the Swedish national PAH register). All Swedish PAH-centres, located to the seven University Hospitals in Sweden participate in SPAHR [18]. The study was conducted from May through July, 2015. All adult patients diagnosed with PAH or CTEPH, registered in SPAHR and alive at time of study start were screened for participation in the study. Exclusion criteria were inability to communicate in Swedish and severe mental or medical reason or placed on the wait list for lung transplantation. All eligible patients were invited to participate.

An invitation to participate in the study was sent out by ordinary mail. The invitation included a letter explaining the intent and design of the study, an informed consent to be signed, a return envelope, questions about socio-demographic information and three self-assessment questionnaires concerning the patient's perspective on coping with the disease. If a patient did not respond within four weeks, a reminding letter was sent out by mail. The project was administered from the Department of Cardiothoracic Surgery at the Skåne University Hospital in Lund.

### **2.2 Questionnaires**

The EORTC QLQ-INFO25 is a 25-item questionnaire originally developed for cancer patients, but has previously been tested for PAH and CTEPH patients [10]. The questionnaire comprises four multi-item dimensions (information about the disease, medical tests, medical treatments and other healthcare services) and eight single items (e.g., places of care, things that patients can do to stay well, written information, information satisfaction and usefulness). The instrument uses dichotomous (yes/no) response items for 4 questions and a 4-point Likert

scale (1=not at all, 2=a little, 3=quite a bit, 4=very much) for the remaining 21 questions. In addition, the respondent can add written comments about their desire to receive more or less information. A Global score was calculated using the mean values for all patients on each subscale which are then added and divided by the number of subscales. All items and scales were transformed to a linear scale of 0 to 100 before statistical analyses [19]. A higher number indicate a high level of information. Psychometric testing of EORTC QLQ-INFO 25 in the present study resulted in a standardized Cronbach's alpha of 0.92 for the whole scale and raw Cronbach's alphas of 0.77 (disease), 0.85 (medical tests), 0.83 (treatment), 0.76 (other service) for the four subscales.

The *Mastery scale* is a seven item questionnaire evaluating the patients ability to cope with their disease [20], measuring to which extent a person feel they are in control of their own lives. The questionnaire uses a 4-point Likert scale. The possible score range from 7 to 28, where a higher score indicates higher ability to cope with the effects of the disease. In the present study, Cronbach's alpha was 0.82.

The *Social Network & Support Scale (SNASS)* [21, 22] includes 19-items to map the patients social support network by an assessment of their level of emotional and practical support as well as homogeneity and approachability. Seventeen of the 19 items use a point score where 1 point= Yes, absolutely; 2 point=Yes, partly and; 3=No and where a lower score indicates a stronger support<sup>30</sup>. In the two remaining items, patients were asked to answer the following questions: "Which person is most important in your social network?" and "What person gives you the best support?" Cronbach's alpha for the 17 SNASS point score questions was 0.89.

### **2.3 Ethics**

This study was in accordance with the Declaration of Helsinki and was approved by the directors of participating PAH centres. Approval by the Regional Ethical Review Board in

Lund, Sweden was obtained (LU 2015/112). The patients received an explaining letter that assured confidentiality and a written informed consent was obtained.

## **2.4 Statistical methods**

Descriptive statistics was used to characterize the data. Statistical comparisons included Student's t-test for continuous and Chi-square tests or when applicable, Kruskal-Wallis test for ordinal variables. Internal consistency was assessed using Cronbach's alpha and a score above 0.7 was considered acceptable. Bivariate associations between dimensions of QLQ-INFO25, the Mastery Scale, and SNASS were assessed using Spearman rank correlations. All analyses were carried out by use of the SAS statistical software (SAS 9.4). A p-value of 5% or less was considered as significant and in the case of a statistically significant result the probability value (p-value) has been given.

## **3. Results**

The questionnaire was distributed to 440 patients whereof 325 (74%) replied. The mean age of those who responded was  $66\pm 14$  years, 58% were female (Table 1). PAH-specific were administered to 99% of patients with PAH respectively and 85% of patients with CTEPH. An additional 19% of CTEPH-patients had undergone pulmonary endarterectomy and half of those did not receive any PAH-specific treatment after surgery.

### **3.1 Received information according EORTC QLQ-INFO25**

The mean Global score of the EORTC QLQ-INFO 25 was  $42\pm 15$  points. Best experienced information was obtained in the area aim, results and procedure of the medical tests (score  $70\pm 23$ ), followed by information about disease ( $61\pm 22$ ). Respondents living alone reported

receiving less information about medical tests ( $65\pm 24$  vs.  $72\pm 22$ ,  $p=0.011$ ) and treatment ( $46\pm 20$  vs.  $54\pm 22$ ,  $p=0.004$ ) than those who were married/living with a partner.

Forty-five percent answered yes to the question “*Do you wish to receive more information?*” and of those, 79% specified in which topics (Table 2). This included areas already mentioned in the questionnaire; rehabilitation service, especially physiotherapy and occupational therapy.

Among new areas, the most desired information was about the possibility to be cured.

Respondents with higher education indicated a higher need for more information (level of education high  $51\pm 50$ ; medium  $50\pm 50$ ; low  $32\pm 47$ ,  $p=0.009$ ) compared to low educated respondents. Only 3% wanted to receive less information and of those, three comments indicated they did not want to receive information about the life-threatening nature of the disease.

### **3.1.1 Gender and age**

Women were younger than men ( $64\pm 15$  vs  $69\pm 12$  years,  $p=0.006$ ), more often living alone (77% vs. 23%,  $p<0.001$ ) and more often diagnosed with PAH (80% vs. 53%,  $p<0.001$ ), and subsequently receiving more PAH-specific treatment (98% vs 91%,  $p=0.005$ ). There was no gender difference in level of education.

Both men and women gave high ratings as to how they experienced the given information about medical tests and the disease (Figure 1, Panel A) but men expressed more satisfaction with the information than women ( $64\pm 28$  vs.  $55\pm 32$ ,  $p=0.009$ ). Despite this, both genders expressed need for more information (Figure 1, Panel A).

Patients were stratified by age, using 65 years as the divider. Younger patients (<65 years) were more often women (71% vs. 52%,  $p<0.001$ ), more often diagnosed with PAH (81% vs. 62%,  $p<0.001$ ) and had higher level of education (upper secondary school, 90% vs. 58%,



$p < 0.001$ ) than those  $\geq 65$  years old. There was no difference in marital status, PAH-specific treatment between age groups.

Patients  $< 65$  years were significantly more satisfied with the received information about diseases, medical tests, other services and how to help yourself to a better health than patients  $\geq 65$  years old (Figure 1, Panel B).

### **3.2 Coping, social network and support according to Mastery Scale and SNASS**

The mean total score for coping ability on the Mastery Scale was  $20 \pm 5$  points (Table 1).

Those living alone had a lower coping ability according to the Mastery Scale ( $19 \pm 5$  vs.  $20 \pm 5$ ,  $p = 0.008$ ) and the coping ability was stronger among men than women (Table 3). Patients with high education reported a less dense network to spend time with (high  $9.0 \pm 1.9$ ; medium  $9.2 \pm 1.9$ ; low  $8.2 \pm 1.9$ ,  $p = 0.002$ ) compared to patients with low education.

Patients were generally satisfied with their social network and the support it provided (Table 1). Women and men reported similar access to available and coherent social network and expressed satisfaction with the emotional and practical social support they received, but men described their social network as more accessible than women. Concerning homogeneity of the patient's network, younger patients had a significantly denser network who spent time with them than older patients (Table 3).

### **3.3 Relation between information, coping, social network and support**

Perception about received information and satisfaction with it (EORTC QLQ-INFO) was significantly correlated with coping ability (Table 4). With the exception of information about other services, all other information variables correlated to social network approachability as

well as practical and emotional support. The correlations remained after adjusting for age and gender (not shown).

#### ***4. Discussion and Conclusion***

##### **4.1 Discussion**

The main finding was that most PAH and CTEPH patients were satisfied with the received information but still, almost half of them wanted more information. As these patients are seen at the PAH-clinic every 6 to 12 months and repeating or giving new information should be an ongoing process, the results demonstrate that there is need for improvement in this area.

A majority of patients reported receiving information about the disease, medical tests and treatment and that they thought the information was helpful. This was associated with an amiable social network, good support as well as a good coping ability. There were no gender difference in how the patients experienced receiving information, however, women were significantly less satisfied with the given information than men. One might speculate that as men reported a larger social support and network and more often living with a partner, this might have helped them to access and comprehend information. In addition, women having less social backing is in concordance with a previous study where a diagnosis of PAH, which is a predominantly female disease, caused a reduction in social support [23]. Thus, it is vital that healthcare professionals make an effort to support patients, in the discussions on positive coping strategies include the importance of involving the next of kin in what it means to live with a lifelong disease.

In the present study, patients younger than 65 years were more satisfied with information concerning their disease, medical tests, other available services and how to accomplish self-care than those 65 years and older. This is in line with previous studies showing that higher

age limited the recall of health information [24] and that more than half of PAH-patients have cognitive impairment and memory problems being the most common issue [25]. In addition, age related vision and hearing loss might affect the ability to perceive information correctly. Awareness of these age related problems are important, in particular with the increasing age among the PAH- and CTEPH-populations [18, 26]. As new and effective treatments improve survival, the PAH-teams now care for the patients over a long time. This increases the demand for both repeating and updating the given information on a regular basis.

The present study also showed that those with higher levels of education wanted more additional information than those with low-level education. It has previously been shown that those with lower level of education remembered less of the given health information than those with higher education and that this might influence the aptitude of what to ask for next [24]. One might also speculate that in higher education one is taught to question and seek information and thus, these patients will ask for more, independent of the initially received information. It is worth noticing that some patients wanted less information. This does not necessarily mean that they do not want information, it may just imply that they want it in their own time. Overall, wishes for more as well as less information underlines the importance of a perceptive and individualised approach when giving information to these patients.

Information about things patients can do to help themselves to get well was not effectively communicated to participants in the present study. In addition, two thirds said they lacked information about other healthcare services and places of care like rehabilitation and psychological support. The PAH teams should act as a bridge to other health care providers regarding self-management and healthcare services. For example physiotherapists and occupational therapists play a great role in self-management by providing advice on physical activity as well as management of pain, fatigue and stress [27]. As most PAH-clinics are centralized to University hospitals and these cover big areas, finding local support for basic

needs might be an advantage for the patients. Referral to the primary health care system, on the condition that it includes social workers, psychologists and physiotherapists who can work closely with the PAH-teams, might be an option. It is important to remember that in order to support and provide optimal care, the patient should be seen as a person with individual needs in all aspects of what the health care system can offer [28].

#### **4.2 Limitations and strengths**

The high response rate in this study is a strength and also indicates that there was an interest among the patients for the questions raised in the study and that the questionnaires were easy to understand and complete. It is also a strength that the patient population represents all Swedish PAH-centres, which allow us to interpret and generalize the results to the whole PAH and CTEPH population in Sweden. A limitation in the study was that QLQ-INFO25 did not capture how the quality of the received information was experienced by the patient or whether the patient needed information within the various dimensions.

#### **4.3 Conclusion**

Despite a high level of satisfaction with the received information almost half of the patients wanted more information. This shows that repeating or giving new information should be an ongoing process in the care of these patients.

#### **4.4 Practice implications**

The findings in the present study should be considered when planning the strategies for how the PAH-team interacts with PAH or CTEPH patients. In addition, when needed, the PAH teams should act as a bridge to other health care providers regarding self-management and healthcare services. The goal for healthcare professionals must be to find ways of communicating information that give the patient the support they need and want from time of

diagnosis to end of life. Repeating or giving new information should be an ongoing process in the care of patients. Information should be delivered in a perceptive and individualised approach to assure that all information is received and processed in a timely manner. When healthcare professionals discuss coping strategies with the patients, it is vital to include the importance of involving the next of kin in what it means to live with a lifelong disease.

### **Conflict of interest**

Bodil Ivarsson and Barbro Kjellström reports no conflicts of interest related to the present study. Göran Rådegran reports unrestricted research grants from Anna-Lisa and Sven-Erik Lundgren's, Maggie Stephen's, ALF's, Skåne University Hospital's Foundations and Actelion Pharmaceuticals Sweden AB, during conduct of the study; and personal lecture fees from Actelion Pharmaceuticals Sweden AB, Bayer Health Care, Glaxo-SmithKline, Nordicinfu Care AB and Sandoz/Novartis outside the submitted work. He is, and has been, primary- or co-investigator in; clinical PAH trials for Glaxo-SmithKline, Actelion Pharmaceuticals Sweden AB, Pfizer, Bayer Health Care and United Therapeutics; and in clinical heart transplantation immunosuppression trials for Novartis; and has also been involved in research advisory boards for Actelion Pharmaceuticals Sweden AB, Bayer Health Care, Eli-Lilly and Sanofi Aventis. Roger Hesselstrand reports unrestricted research grants from the Swedish Research Council, the Medical Faculty of Lund University, the Swedish Rheumatism Association, King Gustaf V 80-year Fund, the Österlund Foundation, the Kock Foundation, and the EULAR Orphan Disease Program; as well as personal lecture fees from Actelion Pharmaceuticals Sweden AB, and Glaxo-SmithKline outside the submitted work.

### **Contributions**

Conception and study design: BI, BK, GR,RH; Data collection: BI; Data analysis and draft of manuscript: BI, BK; Revision for content: BI, BK,GR,RH; Approval of final manuscript: BI, BK,GR,RH

### **Acknowledgements**

We would like to thank all patients and the staff who care for the patients at the PAH-centres and those who register the patients in SPAHR. Their help to screen and find eligible patients

for the study is greatly acknowledged. We also thank Uppsala Clinical Research Centre (UCR) for developing and administering the platform for SPAHR.

### **Funding**

This study was supported by Medicine Service University Trust, Region Skåne and by unrestricted research grants from the Swedish Society of Pulmonary Hypertension (Bayer AB, Actelion Pharmaceuticals Sverige AB) and The Swedish Heart and Lung Association.

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### **Figure legend**

Figure 1. Satisfaction with information in certain areas measured by EORTC QLQ-INFO 25.

Panel A shows mean score and SD by gender. Panel B shows mean score and SD by age

groups <65 and  $\geq$ 65 years. A high number indicate high satisfaction. \* = **p<0.05**.

Table 1. Patient characteristics, socioeconomic factors as well as coping ability and social network and support. Data are shown as mean±SD or number (%).

	All (n=325)
Age, years	66±14
Gender, female	190 (58)
Time from diagnosis, years	4.7±4.4
<i>Diagnosis</i>	
PAH	224 (69)
CTEPH	101 (31)
<i>Treatment (n=316)</i>	
PAH specific drug	299 (95)
Pulmonary endarterectomy (CTEPH n=101)	18 (19)
<i>Marital status</i>	
Married/living with partner	217 (67)
Single/divorced/widowed	108 (33)
<i>Education</i>	
Low, ≤ 9 years	100 (31)
Medium, 10-12 years	130 (40)
High, University	93 (29)
<i>Mastery scale</i>	
Coping ability	20±5
<i>SNASS</i>	
Practical support	6.2±1.8
Emotional support	7.7±2.6
Homogeneity	8.8±2.0
Approachability	3.1±1.1

PAH=pulmonary arterial hypertension, CTEPH= chronic thromboembolic pulmonary hypertension, SNASS=Social Network and Support Scale

Table 2. Areas in which patients wished more information (n=115 patients)

<b>Areas included in the questionnaire</b>	<b>No. of comments</b>	<b>New areas</b>	<b>No. of comments</b>
- Rehabilitation service	13	- Possibility to become cured	18
- Psychological support	11	- Medical advances/research	16
- Whether disease is under control	10	- End of life issue	16
- Side effects of treatments	10	- Everything	11
- Diagnosis	9	- Appropriate forms of exercise	9
- Things to help themselves	8	- Information to next of kin	5
- Etiology	7	- Co-morbidity	3
- The severity of the disease	5	- Risks and benefit of surgery	3
- Individually written information	3	- Transplant opportunity	3
- Results of medical tests	2	- Nutrition	2
- Purpose of medical tests	2	- Pain	2
- Sexual life	2	- Patient association	2
		- Heredity	1
		- Alternative medicine	1

Table 3. Coping ability and social network and support by gender and age. Data are shown as mean±SD.

	<i>Best score</i>	<b>Female</b> n=190	<b>Male</b> n=135	<i>p-value</i>	<b>&lt;65 years</b> n=126	<b>≥65 years</b> n=199	<i>p-value</i>
<i>Mastery scale</i>							
Coping ability	28 <sup>a</sup>	19±5	21±5	<0.001	20±5	20±5	0.486
<i>Social Network and Support Scale (SNASS)</i>							
Practical support	4 <sup>b</sup>	6.2±1.9	6.3±1.7	0.824	6.2±1.9	6.3±1.8	0.758
Emotional support	6 <sup>b</sup>	7.8±2.7	7.7±2.3	0.926	7.7±2.6	7.7±2.6	0.999
Homogeneity	5 <sup>b</sup>	8.9±2.1	8.7±1.8	0.308	9.4±1.7	8.5±2.0	<0.001
Approachability	2 <sup>b</sup>	3.2±1.2	2.9±0.9	0.004	3.1±1.1	3.0±1.1	0.316

<sup>a</sup>=high score indicate high coping ability, <sup>b</sup>=low score indicate a strong support

Table 4. Nonparametric Spearman rank correlation coefficients of associations between patients' perceived received information and their social support and ability to cope. (r = Spearman rank-order coefficient)

Information area	Mastery scale		Social Network & Support Scale (SNASS)							
	Coping ability		Homogeneity		Approachability		Practical support		Emotional support	
	r	p-value	r	p-value	r	p-value	r	p-value	r	p-value
Information about disease	0.25	<0.001	-0.03	0.628	-0.20	<0.001	-0.10	0.080	-0.19	<0.001
Information about medical tests	0.36	<0.001	-0.10	0.089	0.26	<0.001	-0.15	0.007	-0.28	<0.001
Information about treatments	0.23	<0.001	-0.08	0.138	-0.23	<0.001	-0.14	0.013	-0.22	<0.001
Information about other services	0.15	0.006	0.04	0.436	-0.11	0.055	-0.09	0.108	-0.07	0.188
Info about things to help yourself	0.25	<0.001	-0.02	0.685	-0.20	<0.001	-0.06	0.265	-0.12	0.033
Satisfaction with information	0.33	<0.001	-0.10	0.072	-0.26	<0.001	-0.13	0.016	-0.27	<0.001
Overall the info has been helpful	0.33	<0.001	-0.09	0.105	-0.25	<0.001	-0.20	<0.001	-0.30	<0.001
Global score	0.24	<0.001	-0.05	0.340	-0.20	<0.001	-0.13	0.020	-0.19	<0.001