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Coping, social support and information in patients with pulmonary arterial hypertension or chronic thromboembolic pulmonary hypertension: A 2-year retrospective cohort study

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Abstract

Objectives: Pulmonary arterial hypertension and chronic thromboembolic pulmonary hypertension are severe diseases with complicated treatment that need care at specialist clinics. The aim was to investigate changes in the patients' perceptions on coping, social support and received information when attending a newly started nurse-coordinated pulmonary arterial hypertension-outpatient clinic.

Methods: The present study was a descriptive, questionnaire-based cohort study including 42 adult patients. To evaluate coping, the Pearlin Mastery Scale was used. Social support, information and health-related quality of life were measured using Social Network and Support Scale, QLQ-INFO25 and the EQ-5D.

Results: Attending the pulmonary arterial hypertension-outpatient clinic increased coping ability (Mastery Scale) significantly (baseline 16.0 ± 3.3 points vs 2-year follow-up 19.6 ± 5.2 points, $p < 0.001$) while there was no difference in social network and support or in perception of received information after. Patients who improved their coping ability (67%) were younger, had better exercise capacity, experienced better health-related quality of life and were more satisfied with received information about treatment and medical tests than those who reduced the coping ability. There was no difference in gender, diagnosis, time since diagnose, pulmonary arterial hypertension–specific treatment, education level or civil status between the two groups.

Conclusion: This study suggests that the pulmonary arterial hypertension-team, in partnership with the patient, can support patients to take control of their disease and increase their health-related quality of life.

Keywords

Communication, chronic disease, health-related quality of life, mastery, professionals–patient relations, patient preference

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Introduction

Pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH) are rare, progressive and fatal diseases affecting the pulmonary circulation.[1] As recommended by recent guidelines, these patients should be treated by inter-professional specialist teams with experience and special interest in pulmonary hypertension.[1] The number of PAH-related hospitalizations and emergency department visits are decreasing. While the availability of PAH-specific treatment contributes to a large part of this improvement, the specialized health care teams likely play an important role as well.[2] Studies among PAH

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and CTEPH patients have stressed a desire for access to nurse-coordinated outpatient clinics and more support in dealing with the disease effect on daily life as well as coping with the feeling of uncertainty that a chronic health problems cause.[3–5] The experiences of how to cope with their disease, how they perceive their social support and how information is received are all of great importance for patients with chronic illness.[6,7] Reports on nurse-coordinated PAH-outpatient clinics are lacking. Cancer patients with a similar prognosis and with potent and sometimes expensive treatment[8] report that nurse-coordinated clinics are feasible.[9] At the nurse-coordinated outpatient clinics in cancer care, the nurses provided information, support and education to patients and their next of kin.[10] They also monitored symptoms and treatment side effects and support relieve of these problems.

The aim of the present study was to investigate how the patients perceptions on coping, social support and received information was affected by attending a newly started nurse-coordinated PAH-outpatient clinic (PAH-outpatient clinic).

Methods

This was a retrospective, descriptive study investigating patients followed at one PAH-center in Sweden. Patients answered questionnaires at two occasions. The first investigation was performed 1 year prior to the start of the PAH-outpatient clinic and the second investigation, 1 year after its start.

Study population

All adult patients with PAH and CTEPH, followed at the PAH-center at the University hospital in Lund and registered in the Swedish National PAH Registery (SPAHR) in 2013 were screened for participation in the study. Exclusion criteria were inability to communicate in Swedish, severe mental or medical reason or placed on the wait list for lung transplantation. All eligible patients received an invitation by ordinary mail, including 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. Two years later, in 2015, those who had participated in the baseline investigation and were still alive received a follow-up invitation, containing the same information as at the baseline investigation. Only patients who participated in both the baseline and follow-up were included in the analysis. Details of the baseline study[11] and the full setting and sample in this study[12] have been described previously.

The study was approved by the Regional Ethical Review Board in Lund, Sweden (LU 2011/364 and LU 2015/112). The principles outlined in the Declaration of Helsinki were followed throughout the study. All patients signed an informed consent at both occasions (2013 and 2015) before any data were included and analyzed in the present study.

Nurse-coordinated PAH-outpatient clinic

Prior to the start of the PAH-outpatient clinic, PAH and CTEPH patients were seen by PAH-specialist physicians within the ordinary routines of the clinic. Initiating PAH-therapy was generally performed in an in-hospital setting while optimizing therapy and routine follow-up visits was done in an outpatient setting. In 2014, a PAH-outpatient clinic was started. PAH-specialist nurses inform and educate about the disease treatment as well as monitor physical status, blood tests, exercise capacity (6-min walk test; 6MWT), compliance to medical treatment and its side effects. The nurses also inform about possibilities in community care and offer psychosocial support to the patients and their next of kin. In addition, they co-ordinate follow-up investigations and visits within the PAH-team.[1] The staff at the PAH-outpatient clinic is available by phone at office hours.

Questionnaires

The *Mastery Scale* is a seven-item questionnaire that evaluates coping capacity[13] by measuring to which extent a person feel he or she is in control of their own life. The questionnaire uses a 4-point Likert scale ranging from strongly agree to disagree. The possible score range from 7 to 28, where a high score indicates high ability to cope with the effects of the disease

The *Social Network and Support Scale* (SNASS)[14] use 19 items in four subscales to assess social network and support by assessing the 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. A low score indicate a strong emotional support and practical assistance.

The *QLQ-INFO25*[15] evaluates how the patients experience the information they received. The instrument incorporates four multi-item scales (information about; the disease; medical tests, medical treatments and other health care services) and eight single-item questions (e.g. places of care, things that patients can do to stay well, written information, information satisfaction and usefulness). Except for four dichotomous response alternatives (yes/no), all other items are answered on a 4-point Likert scale. A high score reflects a higher (better) level of information. The Likert scale scores were transformed on a linear scale of 0 to 100 before statistical analyses.[16]

The *EQ-5D*[16] is a general measure of the patient's health-related quality of life (HRQoL). The EQ-5D is based on five different health dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) each with answers at three levels (1 = no, 2 = moderate and 3 = severe). By summarizing the five scores, a total measure of an

Table 1. Patient characteristics and socioeconomic factors at follow-up discriminating patients with improved or reduced coping ability (Mastery Scale) from baseline to follow-up.

	Improved coping ability (n = 28)	Reduced coping ability (n = 14)	*p*-value
Age, years	65 ± 16	73 ± 8	0.055
Gender, female	15 (54)	11 (79)	0.116
Diagnosis PAH/CTEPH	17/11 (61/39)	7/7 (50/50)	0.508
Time from diagnosis, years	6 ± 3	5 ± 4	0.363
Walked distance, m	399 ± 148	248 ± 106	0.002
PAH-specific treatment	24 (86)	14 (100)	0.137
Marital status			
Married/living with partner	20 (71)	6 (43)	0.072
Single/divorced/widowed	8 (29)	8 (57)	
Education			
Low, ≤9 years	8 (29)	7 (50)	
Medium, 10–12 years	9 (32)	6 (43)	0.087
High, university	11 (39)	1 (7)	

PAH: pulmonary arterial hypertension, CTEPH: chronic thromboembolic pulmonary hypertension.
Data from follow-up are shown as mean ± SD or number (%).

individual's HRQoL is created. The EQ-5D also captures a self-rating of health status on a 20-cm vertical visual analog scale (VAS) anchored at 100 (best imaginable health state) and 0 (worst imaginable health state).

Analysis and statistical methods

In the primary analysis of changes in the questionnaire scores after the patients had been followed at the nurse-coordinated PAH-clinic for 2 years, only the Mastery Scale, reflecting the patients cooping abilities, had changed significantly. As a result, an ad hoc analysis of the Mastery Scale was performed. Patients were divided into two groups, those whose coping ability had increased or remained unchanged (improved coping ability) or decreased (reduced coping ability) since baseline.

Descriptive statistics was used to characterize the data. Statistical comparisons included Student's t-test for continuous and chi-square tests or when applicable, the Kruskal–Wallis test for ordinal variables. A p-value of <0.05 was considered as significant. All analyses were carried out using the SAS statistical software (SAS 9.4).

Result

The 2013 baseline questionnaire was completed by 68 adult patients, of those 49 were still alive in 2015 and received an invitation to participate in the follow-up study. In the 2015 cohort, 42 patients (86%) responded and were subsequently included in the study.

From baseline to follow-up, the patients coping ability (Mastery Scale) increased significantly (baseline 16.0 ± 3.3 points vs 2-year 19.6 ± 5.2 points, $p < 0.001$) while there was no difference in social network and support (SNASS) or in perception of received information (QLQ-INFO25).

In a cluster analysis, patients were divided into those that had improved coping ability (n = 26 increased, 2 unchanged) or reduced coping ability (n = 14) since baseline. Those who had improved were younger, had better exercise capacity (Table 1) and experienced better HRQoL (a lower total EQ-5D sum and higher EQ-VAS; Table 2) than those who reduced the coping ability. They also reported having a higher level of emotional and practical support and more access to their social network as well as being more satisfied with received information about treatment and medical tests (Table 2). There was no difference in gender, diagnose, time since diagnose, PAH-specific treatment, education level or civil status between the two groups (Table 1).

Discussion

In the present study, the patients feeling of control of their own life (Mastery Scale) improved significantly after being followed at the PAH-outpatient clinic for 2 years. Information on the patients' medical status over time was not collected. However, those who had improved their coping ability also experienced better HRQoL and better exercise capacity at that time. Whether this improvement could be accredited to the establishment of a PAH-outpatient clinic is unclear, but continuity as well as easy access to the staff by phone may have been of importance.[9,10] When asked, patients with chronic diseases perceived that nurses had more time to listen than physicians.[17] Hence, nurses have a key role to help patients acquire and maintain abilities and coping skills.

In contrast, the patients experience of their social network and support did not change over time. One reason might be that the experience was relatively good already in the baseline survey and did not leave much room for improvement. However, those who improved their coping ability also

Table 2. Comparing groups at follow-up who improved or reduced coping ability (Mastery Scale) from baseline to follow-up.

	Improved coping ability (n = 28)	Reduced coping ability (n = 14)	*p*-value
Mastery Scale[a]			
Coping ability (28 best case)	22 ± 4	14 ± 2	<0.001
EQ-5D			
Total sum (5 best case)	6.4 ± 1.5	8.4 ± 3.4	0.012
EQ-VAS scale (100 best case)	73 ± 15	46 ± 22	<0.001
SNASS[b]			
Practical support (4 best case)	6.0 ± 1.6	7.6 ± 2.2	0.001
Emotional support (6 best case)	6.8 ± 1.6	10.0 ± 3.8	<0.001
Homogeneity (5 best case)	8.8 ± 1.8	9.9 ± 3.3	0.179
Approachability (2 best case)	3.0 ± 1.1	3.9 ± 1.4	0.025
EORTC QLQ-INFO25 (100 best case)			
Global score	43 ± 14	33 ± 19	0.076
Received written information	57 ± 50	36 ± 50	0.200
Information about disease	64 ± 21	54 ± 26	0.205
Information about medical tests	75 ± 21	48 ± 24	<0.001
Information about treatments	55 ± 23	37 ± 26	0.031
Information about other services	30 ± 26	28 ± 32	0.820
Information about different places of care	29 ± 32	24 ± 40	0.681
Information about things to help yourself	30 ± 35	29 ± 37	0.918
Wish more information	54 ± 51	57 ± 51	0.832
Satisfaction with information	56 ± 33	36 ± 36	0.075
The info has been helpful	55 ± 30	43 ± 30	0.239

Data from follow-up are shown as mean ± SD.
[a]High score indicates high coping ability.
[b]Low score indicates a strong support.

reported higher levels of emotional and practical support than those who did not improve.

Collaboration in a health care team that includes diverse skills complementing each other is a cornerstone in person-centered and safe health care.[1] Seeing patients and their next of kin as participants in the team will provide an opportunity for the patient to participate and make decisions in their own care as well as increase the health care staffs understanding of living with a chronic disease.[18] This approach requires that there is time provided to listen to the patient and time to give the required support. In the present study, about half of the patients did not experience or recall that they had received sufficient information about the disease and its implications, neither at baseline, nor at follow-up. These findings are similar to previous reports among patients with PAH or CTEPH[11,12] as well as cancer patients.[10] This further stresses the importance of giving and repeating information as well as check what the patients recall from prior meetings and based on that, individualizes the information to fit each patient's needs at the given moment. In another approach, asking heart failure patients to prepare questions at home and bring to the clinic visit gave them a sense that they had received the information they desired, and that it was related to their personal situation in a higher degree than in a control group.[19] Thus, asking the patient to write down questions in advance, to be answered during the clinic visit, ensures that the information is tailored to the patient's particular situation and needs. This approach might also be further enhanced using available information technology to increase contact between the patient and the health care system. When heart failure patients were given easy access to a nurse led heart failure clinic they improved their treatment adherence,[20] a very important part in symptom control and survival. Treatment adherence was not measured in the present study, but patients who improved their coping ability also reported receiving more information about PAH-treatment and medical tests. The PAH-outpatient clinic should provide education, advice and support for medical routine, emergency or palliative care. In addition, they should work as a link between the patient and the PAH-team, local health care providers and when needed, the next of kin. Working in an inter-professional care team, such as the PAH-team, is associated with a higher degree of work satisfaction[21] and a satisfactory and effective teamwork will benefit the patients.[22]

Methodological considerations

The current study is, to the best of our knowledge, the first to report on how PAH and CTEPH patients perceptions on mastery, social support and received information were affected by attending a newly started PAH-outpatient clinic.[23] All

patients were diagnosed prior to the first survey, for example, no patients who were diagnosed with PAH or CTEPH after the PAH-outpatient clinic was started were included in the study. During the 2 years that elapsed between the two surveys, 28% of the patients died and another 14% did not answer the survey (not included in the present study). This is what can be expected in a patient population with a severe and progressive disease and a high symptom burden. In 2013, when this study started, the SPAHR[24] reported that there were 400 patients with PAH or CTEPH alive in the country and of those, 77 were followed at the PAH-center in Lund. Thus, this study initially included 88% of the patients at the PAH-center in Lund and 17% of the patients in Sweden. Though the study sample is too small to make a nationwide generalization, its unique character should make it useful by health care professionals in relation to other patients suffering from similar conditions in comparable contexts.

Conclusion

Patients with CTEPH and PAH seen at a newly started nurse-coordinated PAH-outpatient clinic improved their coping ability. This suggests that the PAH-team, in partnership with the patient, can support patients to take control of their disease and increase their HRQoL. Further analyses are needed to evaluate nurse-coordinated PAH-outpatient clinic impact on hospitalization, morbidity and survival.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

The study was approved by the Regional Ethical Review Board in Lund, Sweden (LU 2011/364 and LU 2015/112).

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Informed consent

Written informed consent was obtained from all subjects before the study.

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