

Improving communication between healthcare providers and pulmonary arterial hypertension patients: a survey of patient preferences

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Abstract

Effective communication within the patient–provider relationship is a key aspect of shared decision-making and associated with several positive patient outcomes. Although previous studies suggest that patients’ and providers’ conceptualization of what constitutes effective communication differ, there is no available literature discussing patient preferences for communication. The objective of this study was to determine the words and phrases pulmonary arterial hypertension patients prefer to hear when discussing their disease with their physician. A total of 227 pulmonary arterial hypertension patients completed a survey that included a 20-item questionnaire specifically designed to assess patient preference for words and phrases when discussing their disease and treatment; statistically significant differences were observed across all items of the questionnaire. Patients preferred their physician ask them how they have “been feeling” (63%) rather than how they have “been doing”. In addition, 96% of patients indicated that they wanted to hear that this is “. . . the best medicine *for you*” rather than this is “the best medicine”. Considerably more patients (60%) indicated they want their physician to say, “We want you to have fewer symptoms” rather than “We want you to feel more normal.” They also indicated they wanted the “most effective” medicine (82%) rather than the “most aggressive” medicine (7%). The results of this study suggest that pulmonary arterial hypertension patients have strong preferences for the language their providers use when discussing their disease and treatment options. Given the role that effective communication has on important health outcomes, pulmonary arterial hypertension providers need to consider these findings when communicating with patients.

Keywords

pulmonary arterial hypertension, communication, patient centered

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Pulmonary arterial hypertension (PAH) is a rare, progressive, lifelong disease that is ultimately fatal despite significant advances.¹ PAH patients require frequent assessments of their response to therapy in order to monitor therapy efficacy and determine if changes to treatment are necessary.² There are currently 14 FDA-approved medications for the treatment of PAH providing both patients and clinicians numerous options.^{1,2} There is increased acknowledgment that patient engagement plays a vital role in the care of PAH patients.³ Shared decision-making contributes to

successful management of PAH. A key aspect of patient engagement is effective communication, particularly the communication of information from healthcare provider (HCP) to patient.^{3,4}

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Communication within the patient–provider relationship has long been identified as playing an essential role in medical care.⁴ Previous studies have found that effective communication has a significant impact on adherence, particularly in chronic conditions,^{5–7} increased trust in provider,^{8,9} self-efficacy and self-management,¹⁰ well-being,⁹ treatment decision-making,¹¹ and improved health outcomes.^{9,12} Effective communication within the patient–provider relationship also facilitates shared decision-making which imparts substantial benefits to patients.³ A recent study in PAH patients found that better coping ability was associated with higher satisfaction with information given about treatment and medical tests.¹³ Moreover, informed PAH patients who receive comprehensive guidance have better outcomes.¹⁴

Despite the importance of patient–provider communication, a number of studies have suggested that providers' perceptions of effective communication during appointments often differs considerably from those of patients.^{15–18} In fact, a meta-analysis reported that 10 of the 17 studies found that there was no correspondence between patient and provider in their judgments regarding communication.¹⁸ Moreover, poor to fair agreement was found in the remaining seven.¹⁸ These findings have also been echoed in the PAH literature, where studies have highlighted a lack of sufficient information exchange between PAH patients and their HCPs.^{13,19} Previous studies have suggested that when considering treatment options, HCPs tend to focus on clinical aspects of PAH (e.g., disease progression), while patients' expectations tend to focus on the effect of therapy on overall quality of life, treatment convenience, and the physiological and physical impact on their lives.^{3,19,20} PAH patients want more opportunities to discuss the impact their disease has on their daily activities and to be updated on the progress of their disease with their providers.^{13,21} Patients who report high satisfaction with the information received from the providers still indicate they want more.¹³

Given the importance of effective communication between provider and patient, coupled with the lack of congruency between provider and patient, the current study sought to determine what words and phrases PAH patients prefer to hear from their provider when discussing their disease and the treatment of their disease to improve understanding and acceptance of treatments.

Methods

Study design

A cross-sectional survey of PAH patients was conducted. The survey was administered through a Health Insurance Portability and Accountability Act compliant online platform and took approximately 15 min to complete and included questions assessing patient demographics, clinical characteristics, and preferences for HCP communication.

The names of patients and their responses were blinded. The protocol was approved by a central institutional review board and all participants completed an online informed consent form prior to initiating any activities.

Participants

Potential participants for the study were drawn from the Rare Patient Voice panel which consists of approximately 26,500 patients and over 300 medical conditions. Eligible patients were at least 21 years of age, currently being treated with medications for PAH, had a self-reported diagnosis of PAH for at least six months prior to participation, and able to read and write in English. Patients were paid an honorarium of \$25 for participating in the study.

PAH Physician Communication Questionnaire

Patient preferences for physician communication were assessed using a questionnaire specifically designed for use in the current study. Questions were developed after conducting research with both physicians and PAH patients. Questions in the survey were asked in reference to physicians with the understanding that all members of the health-care team actively engage with the patient as part of their care. The HCP input was obtained through telephone interviews with 12 participants which included physicians ($n = 5$) and nurses ($n = 7$). The interviews consisted of a role-playing scenario where the interviewer talked to the HCP as if s/he was a PAH patient. Interviews were recorded and transcribed with permission from each respondent. To elicit the input of PAH patients, 53 qualitative interviews (telephone and online) were conducted to test messages. Information obtained from these interviews with HCPs and patients was then used to create the questionnaire. Next, eight cognitive interviews with PAH patients were conducted to test the questionnaire. Based on these cognitive interviews, the format and wording of some of the questions were adjusted so that questions were made clearer to respondents.

The final questionnaire consisted of 20 items (see Table 2 for the PAH Physician Communication Questionnaire (PAH-P-CQ)) and consisted of four sections. The first section focused on assessing what patients prefer to hear from their physician relating to how they are doing overall and with respect to treatments. The second section explored patient preferences for information about and the science behind medications. The third section asked patients which statements they prefer regarding medications and their disease. The final set of questions were related to patient preference over discussion about medications. All the questions in the PAH-P-CQ were designed so that participants were asked to select their preferred communication response option from a set of two or more options.

Data analysis

One-sample chi-square tests were conducted for each question to determine if the proportion of patients selecting each response options was statistically different. For questions with three or more response options, a significant chi-square test was followed up by pairwise z-tests for multinomial proportions.

Results

Patient characteristics

A total of 227 individuals with PAH completed the survey from 24 to 30 January 2020. Patient characteristics are provided in Table 1. All participants resided in the United States. The sample ranged in age from 22 to 76 years old with an average age of 49 (SD = 12.31) years and 92% of the sample identified as female. On average, patients had been living with a diagnosis for 8.4 (SD = 8.27) years. At the time of PAH diagnosis, patients self-reported a WHO functional classification (FC) as follows: WHO FC I—4%, WHO FC II—24%, WHO FC III—38%, and WHO FC IV—34%. The patients' reports of their classification at the time of completing the survey were: WHO FC I—4%, WHO FC II—59%, WHO FC III—33%, and WHO FC IV—4%. The sample was also heterogeneous with respect to experience with different therapeutic approaches with

Table 1. Patient characteristics.

Characteristic	
Age, mean (SD)	49 years (12.31)
Female (%)	92%
WHO FC at time of PAH diagnosis (%)	
FC I	4%
FC II	24%
FC III	38%
FC IV	34%
WHO FC at time of survey (%)	
FC I	4%
FC II	59%
FC III	33%
FC IV	4%
Current therapy (%)	
Parenteral	44%
ERA and/or PDE5-I never on prostacyclin	37%
ERA and/or PDE5-I; experience with prostacyclin	19%
Treating healthcare provider is a PAH specialist, % yes	89%
Healthcare provider specialty area (%)	
Pulmonologist	69%
Cardiologist	20%
Not sure	5%
Not reported	6%

WHO FC: World Health Organization Functional Class; ERA: endothelin receptor antagonist; PDE5-I: phosphodiesterase type 5 inhibitor.

44% currently on parenteral therapy; 37% on an endothelin receptor antagonist (ERA) and/or a phosphodiesterase type 5 inhibitor (PDE5-i) and never on any form of prostacyclin therapy; and 19% of patients were on an ERA and/or a PDE5-i and had experience with inhaled or oral prostacyclin, either currently or in the past. Most of the sample (89%) reported that the physician treating their PAH was a PAH specialist. With respect to specialty area, 69% of patients reported that the physician treating their PAH was a pulmonologist and 20% were seeing a cardiologist.

Results of PAH Physician Communication Questionnaire

The results from the PAH-P-CQ are organized below around the four sections of the questionnaire (see Table 2 for results). Note that significant differences were observed for each of the PAH-P-CQ items.

PAH-P-CQ Section 1. When patients were asked (question 1), “Which question would you rather have your PAH doctor ask you during your regular visits” 63% preferred their physician ask them, “How have you been feeling?” as opposed to “How have you been doing?”. When asked if there was a preference for “slow disease worsening” or “slow disease progression”, over 90% of patients preferred the latter (question 2). More patients also indicated they want their physician to say, “We want you to have fewer symptoms” rather than “We want you to feel more normal” (question 3). More patients wanted to hear their physician tell them they wanted their lungs and heart to work “as normal as possible” (59%) as opposed to “as good as possible” (41%) (question 5). When asked, “Which would you rather hear from your PAH doctor” (question 4) 96% of patients selected “I believe this is the best medicine for you” over “I believe this is the best medicine.”

PAH-P-CQ Section 2. When patients were asked, “Which statement gives you the most confidence about a medicine?” (question 6), a majority of patients (55%) selected “Clinical trials have shown that this medicine helps PAH patients live longer” while 28% selected “Studies have shown . . .”, 15% selected “The science has shown . . .”, and only 2% selected “Experiments have shown . . .”. Patients were asked to fill in the blank to the following “Which statement would you want to hear the MOST from your PAH doctor about a medicine? This medicine has been shown to _____” (question 7); 35% selected “increase life expectancy” while 33% selected “improve long-term prognosis”. Twenty-one percent selected “help people live longer,” 10% selected “improve survival rates”, and less than 1% chose “reduce mortality”.

In a series of three questions that asked patients what they “want the most from PAH medicine” (questions 8, 9, 10), 83% of patients indicated they wanted to stay more “active” as opposed to “being able to walk farther”. While 48% of patients preferred “delay my PAH from

Table 2. PAH Physician Communication Questionnaire.

Questions	%	χ^2	p
(q1) Which question would you rather have your PAH doctor ask you when you have your regular visits?		14.31	.000
How have you been <i>feeling</i> ?	62.56%		
How have you been <i>doing</i> ?	37.44%		
(q2) Which would you rather hear from your PAH doctor:		157.36	.000
We want to slow disease <i>worsening</i>	8.37%		
We want to slow disease <i>progression</i>	91.63%		
(q3) Which would you rather hear from your PAH doctor:		9.73	.002
We want you to <i>feel more normal</i> .	39.65%		
We want you to <i>have fewer symptoms</i> .	60.35%		
(q4) Which would you rather hear from your PAH doctor?		188.76	.000
I believe that this is the best medicine.	4.41%		
I believe that this is the best medicine for you.	95.59%		
(q5) Which would you rather hear from your PAH doctor?		8.15	.004
We want your lungs and heart to work <i>as good as possible</i> .	40.53%		
We want your lungs and heart to work <i>as normal as possible</i> .	59.47%		
(q6) Which statement gives you the <i>most confidence</i> about a medicine, and which statement is the <i>second most confidence</i> about a medicine?		144.40	.000
<i>Studies have shown</i> that this medicine helps PAH patients live longer.	28.19% ^a		
<i>The science has shown</i> that this medicine helps PAH patients live longer.	14.54% ^b		
<i>Experiments have shown</i> that this medicine helps PAH patients live longer.	1.76% ^c		
<i>Clinical trials have shown</i> that this medicine helps PAH patients live longer.	55.51% ^d		
(q7) Which statement would you want to hear the <i>most</i> from your PAH doctor about a medicine?		100.12	.000
This medicine has been shown to <i>reduce mortality</i> .	0.44% ^a		
This medicine has been shown to <i>increase life expectancy</i> .	34.80% ^b		
This medicine has been shown to <i>improve survival rates</i> .	10.13% ^c		
This medicine has been shown to <i>improve long-term prognosis</i> .	33.48% ^b		
This medicine has been shown to <i>help people live longer</i> .	21.15% ^e		
(q8) Which do you want the most from PAH medicines?		100.45	.000
Staying more active.	83.26%		
Being able to walk farther.	16.74%		
(q9) Which of the following do you want most from your PAH medicines?		24.17	.000
Stabilize my PAH.	23.35% ^a		
Delay my PAH from progressing.	48.46% ^b		
Get my numbers back to normal.	28.19% ^a		
(q10) Which of the following do you want most from your PAH medicines?		45.21	.000
Help me feel better.	29.07% ^a		
Help me do more.	17.62% ^b		
Help me live longer.	53.30% ^c		
(q11) Which sounds better to you?		157.36	.000
A medicine that slows <i>disease progression</i> .	91.63%		
A medicine that slows <i>disease worsening</i> .	8.37%		
(q12) Which sounds better to you?		6.70	.01
A medicine that <i>can help you feel better</i> .	41.41%		
A medicine that <i>was shown to help patients feel better</i> .	58.59%		
(q13) Which sounds better to you?		147.63	.000
A medicine that helps you with your daily life.	90.31%		
A medicine that helps you get more exercise.	9.69%		
(q14) Which sounds better to you?		119.93	.000
A medicine that helps you when you are active.	13.66%		
A medicine that helps you with your daily activities.	86.34%		
(q15) Which sounds better to you?		83.96	.000
A medicine that helps you walk farther.	7.05% ^a		
A medicine that helps you do more activities.	36.56% ^b		
A medicine that helps you stay more active.	56.39% ^c		

(continued)

Table 2. Continued.

Questions	%	χ^2	p
(q16) Which sounds better to you?		34.89	.000
Studies have shown that this medicine works the best.	30.40%		
Studies have shown that this medicine works the best for people like you.	69.60%		
(q17) Which sounds better to you?		15.34	.000
A medicine that reduces symptoms of PAH in as early as 12 weeks.	37.00%		
A medicine that reduces symptoms of PAH in as early as 3 months.	63.00%		
(q18) For PAH, do you want your doctor to give you?		245.96	.000
The most aggressive medicine.	7.49%		
The most effective medicine.	82.38%		
The strongest medicine.	0.00%		
The most potent medicine.	0.00%		
The most proven medicine.	10.13%		
(q19) Which sounds the best to you, and which sounds second best? A medicine that ...		198.26	.000
Opens blood vessels	46.70% ^a		
Widens blood vessels	5.73% ^b		
Smooths out blood vessels	1.32% ^c		
Relaxes blood vessels	7.93% ^{b,c}		
Dilates blood vessels	38.33% ^e		
(q20) Some PAH therapies are given through a catheter or port in the chest or a needle under the skin. What do you call these therapies?		100.24	.000
Pump therapy	41.41% ^a		
Parenteral therapy	3.08% ^b		
Infusion therapy	55.51% ^c		

χ^2 : chi-square goodness of fit test.

^{a,b,c,d,e}Denote pairwise differences in means. Means with different superscripts are significantly different ($p < 0.05$) from one another.

progressing” over “get my numbers back to normal” (28%) or “stabilize my PAH” (23%). Most patients (53%) preferred “help me live longer” as opposed to “help me feel better” (29%) or “help me do more” (18%).

PAH-P-CQ Section 3. When describing a medicine as it relates to their disease, most patients preferred a medicine that slows “disease progression” (92%) over “disease worsening” (8%) (question 11). In regards to the potential efficacy of a medicine, patients preferred that a medicine “was shown” (59%) as opposed to “can help” patients to feel better (41%) (question 12).

Patients overwhelmingly indicated that they prefer a medicine that helps with their “daily life” (90%) as opposed to one that helps them “get more exercise” (10%; question 13). Similarly, 86% of patients indicated that they prefer to hear that a medicine would help with their “daily activities” as opposed to helping “when you are active” (question 14). In addition, patients preferred a medicine that helps them “stay more active” (56%) as opposed to “do more activities” (37%) or “helps you walk farther” (7%; question 15).

Interestingly, 70% of patients preferred “studies have shown that this medicine works the best for people like you” as opposed to “studies have shown that this medicine works the best” (question 16). Finally, when asked which patients prefer, a medicine that reduces PAH symptoms in as early as three months compared to in as early as

12 weeks, a majority of patients (63%) selected in as early as three months (question 17).

PAH-P-CQ Section 4. When describing a medication, over 80% of patients indicated they wanted their physician to give them the “most effective medicine” while a distant 10% preferred “most proven medicine”. Only 7% preferred “most aggressive medicine” and no patients selected “strongest medicine” or “most potent medicine” (question 18). When discussing effects of a medication almost half of patients (47%) indicated they would want a medicine that “opens blood vessels” followed by “dilates blood vessels” and very few patients selected “relaxes,” “widens,” or “smooths out” (question 19). When discussing administration of medication, more patients preferred the term “infusion therapy” (55%) followed by “pump therapy” (41%) and then “parenteral therapy” (3%) when referring to therapies that are given via a catheter/port in the chest or needle (question 20).

Discussion

The current study was one of the first to examine PAH patients’ preferences for words and phrases they would like their physician to use while discussing their disease as well as the treatment of their disease. The results of this survey provide an invaluable understanding in regard to

how patients prefer their providers communicate with them. How HCPs communicate with PAH patients may have an effect on the relationship and ultimately on acceptance of therapy, and hopefully, outcomes. Based on the current literature, this is the first study examining PAH patients' preferences for words and phrases they favor providers use while discussing their disease as well as the treatment of their disease. The results of this survey revealed several themes as to how to best communicate with patients.

First, patients indicated that they prefer their provider to ask them how they have "been feeling" rather than how they have "been doing". During the cognitive interviews, patients suggested that society had taught them to respond with "I'm fine" when asked how we are doing. Asking how you are *feeling* may aid in overcoming this societal bias. These patients also suggested that asking how you are feeling is more personal and invites a broader discussion, which can include both physical and emotional aspects of their disease.

When discussing PAH medicines, patients wanted to hear their physician say this medicine was right *for you*. Given that 96% of patients selected "... best medicine for you" adding the phrase "for you" at the end of the statement may have an impact on a patient's perception of this therapy. With PAH, there are a number of different treatment options available as well as differences in how patients respond to these options.^{1,22} From a patient's perspective, this suggests that their physician is paying attention to their individual needs. Given that PAH is a progressive and incurable disease, patients want to be assured that they are receiving the medicine that is most aligned with their individual situation and that their physician has tailored their care precisely for them.

Second, an overwhelming proportion of patients indicated they wanted the most "effective" medicine rather than the most "aggressive" medicine, which patients associated with increased side effects that could have a substantial impact on their quality of life.²³ Several questions suggested that patients preferred to hear that a medicine will help them "live longer" or "increase their life expectancy" when the evidence comes specifically from "clinical trials". Subsequently, patients preferred the phrase "was shown" as opposed to "can help" when referring to a medicine making them feel better. Once again, patients preferred the phrase that implies prior evidence.

Third, patients expressed that they preferred to hear that a medicine would allow them to remain "more active" as opposed to "walk farther". This is not surprising given that the term "active" appears to cover a broad spectrum of activities including walking. Similarly, patients chose the phrase that implies a broader domain of behaviors when selecting that they wanted a medicine that would help with "their daily life" as opposed to "get more exercise". This was also evident when they preferred a medicine that would help with "daily activities" as opposed to "staying

active". These findings are important given that PAH patients generally experience a significant reduction in mobility,²⁴ as well as reduced ability to engage in physical activities.^{21,25-27} This lack of mobility or activity results in a significant reduction in PAH patients' ability to independently perform activities of daily living.^{23,28}

Fourth, results from several questions suggested that patients prefer the phrase "slow disease progression" over "slow disease worsening" and furthermore, they prefer "slow" over "delay". This may be related to the fact that many PAH patients struggle to have a positive outlook, as there is a high rate of anxiety and depression in PAH patients.^{29,30} Patient interviews suggested that term "worsening" had a strong negative connotation. Patients also wanted to hear providers focus on "reducing symptoms" as opposed to making them "feel normal", which is expected, given that symptoms are associated with reduction in quality of life and increased burden in patients.^{23,28}

While the results of this study are important, they should be considered alongside several caveats. First, the study did not assess the extent to which physicians are using the terms and phrases most preferred by the patients. For example, patients prefer to be asked "How have you been feeling" but it was not assessed how often they are being asked this question. Nonetheless, the survey used to develop the patient questionnaire validates that the terms and phrases tested are used by PAH providers. This was not tested quantitatively, therefore further research is needed to determine the extent to which physicians' actual communications match the preferences of their patients. Second, the design of the questionnaire required patients to choose one option from a choice of two or more. It is possible that a Likert-type rating for each term or phrase may have captured more variability in patient preferences. It may be that one or more of the items offered to patients could have been edited in a way that made a difference, or an additional item that was not offered might have been preferred. Third, demographic information such as education level and ethnicity/cultural identity was not collected. This coupled with the fact that 92% of the sample identified as female constrains the generalizability of the results. Finally, given that study participants self-selected into the research panel that they represent a select group of PAH patients with perhaps higher than average health literacy, which may further constrain the generalizability of these results.

From a clinical perspective, it is important to emphasize that the results of this study clearly suggest that PAH patients have strong preferences for the language their providers use when discussing their disease and treatment options. Given the role that effective communication has on important health outcomes, providers on the PAH care team need to consider these findings and make any needed adjustments when communicating with patients.

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Authors' contributions

JB and MB contributed to the interpretation of the results and the writing of the introduction and discussion. DH contributed to the writing of the methods and results section and interpretation of the results. CH contributed to the interpretation of results and writing of the article.

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