The mapping of emotions in a respiratory illness: Transferability of illness experience from Pulmonary Arterial Hypertension to COVID-19

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Abstract. *Objectives*: Covid-19 poses an existential threat that has increased death anxiety at the individual and societal levels. In prior work, we have examined existential conversations in patients with Pulmonary Arterial Hypertension (PAH), an incurable respiratory disease with symptom overlap. In this mixed method study, we analyse the emotional qualities of these conversations in PAH. By understanding the emotions in PAH, we may learn something about the feelings that can also be evoked in people coping with Covid-19. *Methods*: We interviewed 30 PAH patients from 2016-2018 about the meaning and impact of illness on their lives. We analysed transcripts and audio recordings for heightened emotional moments and categorised the emotional responses and topics that were discussed. A multiple correspondence analysis was conducted to identify the associations between emotions and topics. Clinical illustrations are provided for interpretation. *Results*: Mean age and illness duration was 52 and 6 years, and 77% were female.

Participants had a mean of 5 emotional moments, each lasting on average 20 seconds. Half occurred in the first 20 minutes. Coping with diagnosis and the healthcare system was accompanied by feelings of shock and unfairness; relational issues involving close others evoked complicated feelings of isolation, worthlessness, and self-blame; and the experience of physical limitations and mortality salience elicited much anger and fear. *Conclusion*: People confronted by the threat of mortality from disease may have powerful feelings that they would benefit from sharing. These emotions are readily expressed because opportunities to discuss them are rare. Psychoeducation about illness experiences may help healthy people to relate to the medically ill and destigmatise the discussion of illness-related concerns. Research on coping with existential distress may be applied to the illness experience of Covid-19.

Keywords: Chronic Lung Disease; Emotion; Existential Distress; Illness Experience; Progressive Illness; Pulmonary Arterial Hypertension; Covid-19

Background

The 2019 coronavirus disease (Covid-19) poses an existential threat that has increased death anxiety at the individual and societal levels. Over 50% of Canadians with Covid-19 are asymptomatic (Oran & Topol, 2020), and in those who will eventually develop symptoms, peak infectivity occurs before onset (He et al., 2020). 10.2% of Canadians have severe symptoms requiring hospitalization with 19.2% of these people receiving intensive care (Bignami & Van Assche, 2020) and there is an unknown percentage who may continue to have chronic symptoms following a negative test result (Honigsbaum & Krishnan, 2020). The mortality rate in Canada is 4.6% of confirmed cases as of Oct 25, 2020 (Infection Prevention and Control, 2020). This transmission and symptom profile raises tremendous anxiety and uncertainty as to who is sick and who will die from this illness. We have previously studied existential conversations in patients coping with a chronic respiratory disease called Pulmonary Arterial Hypertension (PAH) during which we asked about the meaning and life impact of their illness (Lo et al., 2019; Martin et al., 2020). In the present paper, we analyse the emotional qualities of these conversations with PAH patients. By understanding the emotions in PAH we may learn something about the feelings that can also be evoked in people coping with Covid-19.

PAH is a progressive illness characterized by right heart dysfunction due to increased pressure in the pulmonary vasculature (Boucly et al., 2017). It is rare, more prevalent among women, and has a 1 year survival rate of 93% and 5 year survival of 77% (Wang et al., 2017). The mean age of diagnosis for PAH is 48 years old (*SD*=14) with the majority of those younger than 50 having an idiopathic disorder and those older than 50 having co-morbidities and more severe outcomes (Thenappan et al., 2012; Lau et al., 2017). Symptom overlap between PAH and Covid-19 can include breathlessness and fatigue resulting in reduced functional capacity, increased dependency needs, and premature death (Lan et al., 2018; Bignami & Van Assche, 2020). Prognostication for PAH is difficult and

patients may be in a prolonged state of uncertainty about their illness progression (Khirfan et al., 2018) which resembles the uncertainty as to whether you would develop severe Covid-19 symptoms if infected. Although PAH and Covid-19 are substantively different pathologies, there are similarities that may allow for some transferability of psychological findings. Younger people can find themselves unexpectedly sick with either respiratory illness; death and deterioration can occur suddenly; and there is a profound uncertainty and sense of the unknown involved in both. We propose that there is value in studying the emotional experiences of PAH patients as a comparison to the experiences of people coping with Covid-19.

In this paper, we took a mixed method approach to identify and categorise moments of heightened emotion during conversations with PAH patients about their illness and its meaning and impact on their lives. Such emotional moments could encompass a single word utterance or extend over lengthier passages, with the key feature that the emotional tone was urgent, highly expressive, and often overwhelming for individuals. Specific emotions and feelings could be identified by self-declarations of emotional state, quality and tone of voice, and emotive vocalizations such as crying (Kraus, 2017). Our goal was to analyse the emotional responses to illness-related topics during a clinical research interview.

Methods

Ethical Approval

The University Health Network Research Ethics Board approved this investigation from May 2016 to May 2019, allowing for further data analysis and manuscript writing (#13-5964-CE).

Design

This was a cross-sectional mixed method interview study. Our aim was to purposively sample 30 participants with variation in age, gender, race (Caucasian/non-Caucasian), education, and length of illness. This sample size was evaluated as allowing for saturation of themes/codes based on general guidelines and prior experience. Participants were interviewed by telephone using a semi-structured format with conversations lasting from 20 to 60 minutes. Details about data mixing are described under Data Analysis.

Participants and Procedure

Adult patients from Toronto General Hospital who were diagnosed with Group 1 PAH or mixed Group 1 and 2 features were recruited from June 2016 to April 2018. Group 1 refers to PAH caused by the narrowing of arteries due to idiopathic or heritable causes; Group 2 is PAH associated with left heart disease (Rose-Jones & Mclaughlin, 2015). Exclusion criteria included a diagnosis of psychotic disorder and PAH caused by HIV. These PAH patients were recruited pre-Covid-19.

Patients were approached by clinic staff and asked if they would be willing to participate in an interview study. A research assistant then described the study, obtained written informed consent and scheduled an interview time. Interviews were conducted by CL and undergraduate research assistants with interview training.

Data Analysis

We examined the interview transcripts and listened to audio-recordings to identify moments of heightened emotion. These moments were often marked by the expression of very negative feelings and patients could be heard crying or audibly struggling to control their emotions. We used quantitative content analysis to characterise several features of corresponding transcript passages, including how long each moment lasted; when it occurred in the transcript; the topic under discussion; and the feelings or emotions that were expressed. We allowed for the coding of multiple feelings or emotions as being expressed during a moment. Categorizations were verified between two independent coders with discrepancies resolved by discussion within the research group.

A multiple correspondence analysis was used to analyse the associations between emotional responses and topics. A multiple correspondence analysis is a form of factor analysis that extracts underlying dimensions found in categorical data (Mori et al., 2016). It produces graphical plots in which categories that cluster together further away from the origin are more strongly associated with one another. Lastly, we provide illustrative cases from the interview data to interpret how these quantitative relationships may present clinically.

Results

Sample Descriptive Statistics

39 PAH patients consented to the study, 1 of which did not meet eligibility criteria and 8 were lost to assessment (1 confirmed death, 7 unreachable by phone). The M age of the 30 participants was 52 with SD=18; and 77% were female and 57% Caucasian. For education, 33% had completed high school, 33% college or trade school, 30% undergraduate university, and 3% postgraduate or professional school. About disease characteristics: 93% were Group 1 and 7% had mixed features; 40% had Connective Tissue Disorder; and 10% needed oxygen support. The M WHO functional status=2.3, SD=0.74; M duration of disease=6.3 years, SD=5.3, range=0.5 to 24; and 17% were diagnosed with depression.

Characteristics of Emotional Moments

Across the 30 interviews, 110 moments of heightened emotion were identified. A moment refers to a period of time during which patients expressed a passionate outburst of emotion. These were easily identified when compared to neutral portions of the interview. ES and VM reviewed the interviews together and established agreement about the number and

timing of heightened emotional moments that occurred and their coding. A moment could extend over different lengths of time.

On average, a moment lasted for 20 seconds, $SD=58$. 12% of moments occurred 5 to 10 minutes into the interview, another 21% occurred between 10 to 15 minutes in, and another 15% between 15 to 20 minutes. The remaining 52% of emotional moments occurred sporadically after 20 minutes until the end of the interviews. Of 30 participants, there was an average of 5.2 emotional moments per person, $SD=3.9$. The mean number of emotions that occurred during a moment was 2.5, $SD=0.95$.

Categorization of Emotions

We initially identified and coded 34 different emotions or feelings that were expressed by participants. For parsimony, we collapsed these initial categories into 14 higher-order emotional responses based on similarity in affect (see Table 1 for their frequency). Anger was most common, occurring in 34% of moments, followed sadness (25%) and feelings of apprehension (22%).

Table 1: *Frequency of emotional responses*

Emotional Responses	Percent (freq/n)
Anger	34 (37/110)
Sadness	25 (28/110)
Apprehension	22 (24/110)
Worthlessness	17 (19/110)
Hopelessness	17 (19/110)
Self-blame	17 (19/110)
Unfairness	11 (12/110)
Pressure	13 (14/110)
Isolation	8 (9/110)
Acceptance	8 (9/110)
Jealousy	8 (9/110)
Shock	7 (8/110)
Appreciation	6 (7/110)
Dependency	5 (6/110)

Note. These emotional responses are not mutually exclusive and could co-occur within a moment, hence percentages do not sum to 100%.

Categorization of Topics of Discussion

We coded the topic under discussion in each moment, identifying a total of 9 topics (see Table 2). Table 3 shows their frequency. Talk about family and the impact of diagnosis were most common, with each occurring in 21% of moments, followed by discussion of functional limitations (15%).

Table 2: *Topics and their descriptions*

| Topic	Description
Health care system	How a patient is treated in the health care system, the resources available to them and the ease of getting care
Diagnosis	The experience of receiving a diagnosis of PAH, including information about prognosis, and its life impact
Limitations	A topic that focuses on activities or tasks that the participant was once capable of but no longer because of illness, their adjustments to this circumstance, and need for help
Infertility	The inability of the patients to have children due to their condition
Family	Topics that focus on those whom the participant considers their family, excluding marital situations unless they are discussed as affecting family more generally
Relationships	The patient's intimate and romantic relationships with a partner, including dating, marital life, sex and their future
Others	Topics that focus on broader social relations, including interactions with friends and strangers, and often involving how other people generally view the participant or react to their disease
Death	The participant's thoughts on dying and the processes surrounding it
Time	This topic refers to ideation about having limited time left, of having wasted time (especially before diagnosis), or that one's end may be approaching soon

Table 3: *Frequency of topics*

Topic	Percent (freq/n)
Family	21 (23/110)
Diagnosis	21 (23/110)
Limitations	15 (16/110)
Death	11 (12/110)
Health Care System	10 (11/110)
Infertility	9 (10/110)
Relationships	5 (6/110)
Time	5 (5/110)
Others	4 (4/110)

Note. Topics are mutually exclusive and percentages sum to 100% with rounding error.

Multiple Correspondence Analysis

We used a multiple correspondence analysis to analyse the pattern of association or co-occurrence between emotional responses and topics. We extracted only the first 2 dimensions, which explained 15% of the total variation. Although this may appear to be a small percentage compared to a conventional factor analysis, our examination of additional dimensions showed only modest enhancements of associations that were evident from plotting 2 dimensions (see Figure 1). Figure 1 demonstrates the association of categories based on their pattern of clustering. Topics and emotions that are closer together and away from the origin were more likely to co-occur, hence the proximity between death talk and apprehension. Note that topics could be associated with multiple emotions.

Figure 1: *Multiple correspondence analysis of emotional responses and topics of discussion*
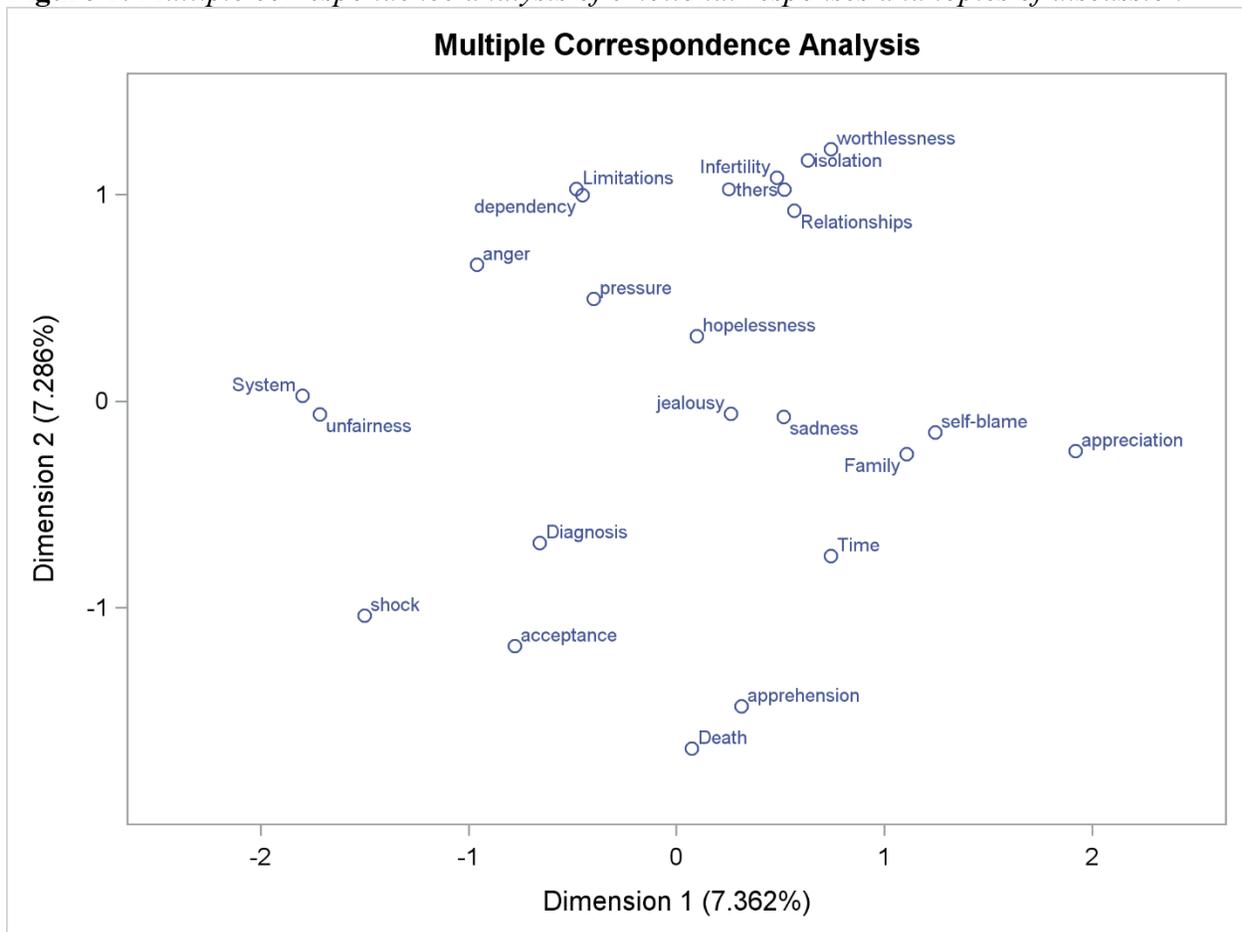
Common Emotional Responses to Topics

Table 4 presents some of the most common emotional responses to topics, as informed by the multiple correspondence analysis, and provides supporting quotes. All topics are listed in Table 4 except for Time, which did not show consistent association with any single emotional response (see Figure 1).

Table 4: *Common emotional responses to topics with illustrative quotes*

Topic	Emotional Responses	Participant	Illustrative Quote
Diagnosis	Shock	259	"I neeeever thought pulmonary hypertension would put me where I am today."
	Acceptance	260	"It's not a great thing but it's not going to kill you tomorrow."
Limitations	Dependency & Anger	259	"**And you have a lot of different limitations that you didn't think you would have?** Absolutely. **And does that make you angry or sad?** Um… bitter. Frustrated, ripped off… I think these go back to anger more than anything. Just nothing is easy."
Others	Isolation	259	"Sometimes it is an ignorant thing… it's nothing personal… they don't have the information… but sometimes when they cast [the disease] off as if it is nothing that is hurtful too."
System	Unfairness	259	"I came back to the clinic and said you… being the staff and the program… that you need to inform women like myself, of my age that [getting pregnant] cannot happen and why… which is that it poses a risk to me dying… the maternal death rate."
Infertility	Worthlessness	261	"We had numerous conversations about it and he has actually mentioned it straightforward that I want children… [he says] if you are unbearable if we cannot have children, why should we continue this relationship." (cries)
Relationships	Worthlessness	261	"2 years, it is just a waste of time to be with me."
Family	Self-blame	251	"**Do you feel bad about it at all?** Of course I feel bad about it, why he have to take so much stress for me?"
Death	Apprehension	243	"You know there's that in the back of my mind, maybe I won't be here tomorrow."

Note. The interviewer's speech is indicated by bold text

Clinical Illustrations

Note that Participant ID codes are merely identifiers and should not be interpreted as an indication of the number of patients recruited. Participant 259 provides an example of someone still adjusting to her illness despite its length. She was in her mid 30s and had been living with PAH for 7 years. She was relatively high functioning, able to work and to maintain her social life. However, the possibility of further deterioration was a major source of stress and frustration. She had hoped to have a family of her own and "*never thought pulmonary hypertension would put [her] where [she is] today.*" She talked about the many ways in which she had been held back in life.

She was angry about her physical limitations and dependency needs compared to others her age. She admitted that "*nothing is easy*" while living with PAH and often felt "*bitter. Frustrated [and] ripped off.*" Patient 259 explained that although she still feels capable of doing most tasks when not going through a flare, this only brought into view how limited patients can eventually become. While her friends enjoy their adult independence, she is forced to realize that she may be left out of those experiences.

She explained that it did not make dealing with the illness any easier when her friends and family do not understand PAH and have difficulty providing the support she needs. The average person does not have an abundance of knowledge about respiratory disorders and she noted that this has greatly affected her social life. Her friends "*don't have the information*" to appreciate or empathise with her circumstance, giving her no outlet to express her concerns. Occasionally her friends will even "*cast [the disease] off as if it is nothing,*" which she finds hurtful as PAH is a constant battle. She recognizes that it may be hard for others to grasp just how serious this illness can be without explaining it to them and being referred to as "*the sick girl*".

Patient 259 was engaged to be married and while others in her life were having children, she cannot. Carrying a child to term can be dangerous for a patient with PAH and Patient 259 struggles emotionally with infertility. She recounted that as a patient, she had to terminate a pregnancy due to the health risks. She had felt caught off guard when health care providers explained the situation and felt unfairly treated by the health care system as she had not known at the time that becoming pregnant could "*pose a risk to [her] dying.*"

Participant 261 was also in her mid 30s and had been diagnosed for 2 years. She too had struggled with the consequences and meaning of her infertility which had greatly undermined her sense of security about her romantic relationship. She was worried about whether they had a future together and repeatedly expressed feelings of personal worthlessness when talking about the topic. She recognized that there was an expectation to get married and to have children. She cried as she recounted that when she had stated her health concerns to her boyfriend, he had responded that if they cannot have children, then there is no reason to continue their relationship.

She felt hurt yet also found herself agreeing with his statement that the past couple of years with her had been a waste of time. She feared that she served no purpose in his life, which caused her great emotional distress throughout her interview.

Discussion

We interviewed 30 patients with lung disease and examined their emotional responses to illness-related topics. Participants displayed an average of 5 moments of heightened emotion, with each moment lasting about 20 seconds. Half of these moments occurred in the first 20 minutes, indicating that people have powerful feelings to share and that there is a clinical need to be met. We found 14 major emotional responses evoked by 9 recurring topics of discussion. The most common emotions were anger, sadness, and apprehension. Their most frequent concerns included the impact of illness on family relationships, the meaning of their diagnosis, and coping with functional limitations and mortality. Most topics tended to evoke between 2 to 3 emotional responses, indicative of the complexity of feelings. These emotions were often overwhelming, and participants sometimes lacked clarity about how and why they felt this way, despite consistent associations between topics and emotions.

Some emotional responses to disease-related topics may be transferable across medically ill populations. Coping with diagnosis and the complexities of the healthcare system was found to be accompanied by feelings of shock, confusion, and unfairness. Although the diagnosis of any illness can be shocking, half of PAH cases are under 48 years of age and many of those are idiopathic, meaning that the disease appeared spontaneously without prior history, making this diagnosis particularly unsettling (Thenappan et al., 2012; Lau et al., 2017). There may be a parallel to the experience of younger people and Covid-19. People weigh their risks of becoming ill based on a cognitive appraisal of their age, current well-being, and the feelings of control afforded by their health-seeking behaviours (Li et al., 2020). There is a widespread view that Covid-19 primarily affects the older population or those who are particularly vulnerable to illness. However, diagnosis of Covid-19 in Canada is most common in those 20-29 years old, with this group comprising 18.6% of all infections as of December 2020 (Statistics Canada, 2020a).

Patients with PAH struggled with symptoms of breathlessness and fatigue and their physical limitations elicited anger and negative feelings of dependency. Although most Covid-19 patients are expected to recover, there are also patients referred to as Covid-19 "long-haulers" whose longer-term symptoms begin to resemble a chronic condition (Honigsbaum & Krishnan, 2020), and this group may best mirror the PAH experience of the frustrations of a sustained decrease in quality of life. Adapting to Covid-19 has raised our awareness of dependency needs for those who are required to quarantine must rely on others to deliver necessary living supplies and because of the hospitalisation of Covid-19 patients. Even among

symptomatic individuals who have recovered, some have continued to need assistance to return to the activities of daily living (Vaes et al., 2020).

Death talk is difficult for people to engage in and avoidance can be common (Martin et al., 2020). Mortality salience elicited fear and anxiety and was an omnipresent topic that infused every conversation even when not explicitly discussed. The perceived threat of death posed by Covid-19 can be high due to the uncertainty of infection and the public health crisis to control its spread (Li et al., 2020). In other research, perceived mortality has shown to be 11 times the actual mortality rate with a mean estimate of 22% chance of death, when it may be closer to 2% of all cases (Menzies et al., 2020). Fear for one's health during the pandemic has varied over time, with 36% of Canadians being very or extremely anxious about their own health in March during the first wave of infection and dropping to 27% in July when the curve had flattened (Statistics Canada, 2020b). Now that we have entered the second wave in the late fall of 2020, this number may be expected to rise again.

In July 2020, 90% of Canadians stated that they would take preventative measures such as avoiding crowds and keeping distance from other people (Statistics Canada, 2020b). Although fear may motivate people to engage in important preventative measures (Pakpour & Griffiths, 2020), it can also trigger psychological and existential distress in the general public (Torales et al., 2020). Throughout the pandemic the number of people suffering from mental health disorders has increased as seen by the global shift in prevalence of anxiety disorders from a range of 3.8-25% prior to Covid-19 (Remes et al., 2016), to a range of 6.3-50.9% (Xiong et al., 2020). In a sample of 46,000 Canadians, 57% of females and 47% of males reported that their mental health had worsened due to the pandemic (Moyser, 2020).

Close relationships can become strained in the presence of illness with some patients feeling alone, worthless, or blameworthy for being ill. The specific reasons for interpersonal conflict depend on the symptom profiles of an illness (e.g. infertility). However, the feeling of being disconnected from others and of disappointing oneself and those closest may be universal responses to the experience of infirmity and physical vulnerability (Trindade et al., 2017). This may be especially true for Covid-19 long-haulers who have prolonged symptoms. Due to the public health social distancing regulations, family members have been unable to comfort one another, have had to deal with the risk of spreading the virus to those they see daily and being unable to provide financially for their family due to employment loss (Haller et al., 2020). These situations can cause feelings of guilt and shame similarly to the reaction we saw in patients with PAH who were no longer able to provide for their family or fulfill important social responsibilities. Just as we are now more familiar with the experience of emotional isolation.

Whereas Covid-19 is known to the public, PAH is not. Part of the shock of a diagnosis of PAH relates to lack of knowledge about its existence

and its idiopathic nature. The shock of diagnosis with Covid-19 likely has to do with its unexpectedness, whether someone had taken precautions or had felt invulnerable to illness. There can be the added uncertainty of how you had gotten infected and whether you had infected others. Both respiratory illnesses entail uncertainty about prognosis and the severity of symptoms, although PAH is progressive whereas most Covid-19 patients will recover. PAH is rare in the population and there may be an analogous small group of Covid-19 long-haulers who will continue to experience prolonged quality of life issues. Both PAH and Covid-19 patients may have had to face the frustrations that accompany an inability to function as one normally would, the loneliness of social isolation, and the fear of mortality and premature death.

Limitations to this study include the lack of follow-up interviews, lack of face-to-face interviews, and sample size. We were unable to conduct subgroup analyses that could clarify the illness experiences of individuals at the intersection of different social determinants. The study was not designed to examine these effects on illness experience. The interviewer therefore did not explore these issues and there was insufficient sampling of diversity to offer reliable assessments of difference. This research would benefit from follow-up with a PAH sample to explore ways in which they have been impacted by Covid-19 and the study of individuals and families who are coping with or have coped with Covid-19.

Conclusion

People confronted by the threat of mortality from disease may have powerful feelings that they would benefit from sharing. These emotions are readily expressed because opportunities to discuss them are rare. Psychoeducation about illness experiences may help healthy people to relate to the medically ill and destigmatise the discussion of illness-related concerns. Research on coping with existential distress may be applied to the illness experience of Covid-19.

Ethics statement

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Conflict of Interest
There is no conflict of interest.

Availability of data and materials
Data will be made available upon reasonable request.

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Authors' contributions

All authors significantly contributed to the preparation of this manuscript.

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