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Idiopathic pulmonary fibrosis: Educational needs of health-care providers, patients, and caregivers

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Abstract

Idiopathic pulmonary fibrosis (IPF) is a progressive disease associated with poor quality of life. Debilitating symptoms and the reality of shortened survival impact patients' physical and emotional well-being and constrain the lives of patients' caregivers. This study assessed the informational needs of medical providers who care for patients with IPF, IPF patients themselves, and their caregivers. Tailored surveys were sent electronically to providers, patients with IPF, and caregivers of patients with IPF collected on a rolling basis in March of 2017. Providers answered questions regarding their own informational needs and what information they believed patients needed. Patients and caregivers identified their own informational needs and the perceived needs for each other. About 2636 surveys were sent to providers, including 2041 to physicians, of whom 156 completed it. One hundred sixty patients and 29 caregivers responded to the survey via a link on a website. Eighty-six percent of providers described themselves as physicians who diagnose and treat IPF patients themselves. Providers ranked information on "making the diagnosis of IPF" as their top informational need. Patients and caregivers chose "disease progression/what to expect" as the most important informational need for themselves and for each other. Providers want to make a correct diagnosis when IPF is in the differential diagnosis. Patients and caregivers desire clarity around how IPF will behave over time and what their futures with IPF will look like. Resources for patients and their caregivers should include information on disease natural history in empathically worded, clear, and easily accessible formats.

Keywords

Idiopathic pulmonary fibrosis, educational needs

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Introduction

Idiopathic pulmonary fibrosis (IPF) is a progressive lung condition typically diagnosed in people older than 60 years, and it is associated with shortened survival and poor quality of life. Obtaining an accurate diagnosis of IPF can be challenging, because symptoms of exertional dyspnea, cough, and fatigue are nonspecific and often attributed to more common medical conditions like asthma, chronic obstructive pulmonary disease, or pneumonia.[1] In a previously published study, 55% of 600 patient survey

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respondents reported one or more alternative diagnoses before they were ultimately diagnosed with IPF or another interstitial lung disease (ILD), and 19% identified a 3-year gap from presentation to diagnosis.[2] Given the potential challenges in making an accurate diagnosis and the relative obscurity of IPF, many medical providers, patients, and their caregiver loved-ones have a poor understanding of IPF, its diagnostic criteria, its natural history, strategies for its management and how patients with IPF should be followed over time.[2–4]

Several studies have been conducted to gauge physicians' perceptions of IPF and to identify unmet informational needs of providers and patients.[4–8] None has compared and contrasted views of patients, caregivers, and providers around these topics. Identifying discrepancies and leveraging areas of agreement could enhance quality of care and empower patients and their caregivers as they live with IPF.[9] The aim of this study was to identify disease-related informational needs—and perceived needs—of providers, patients with IPF, and caregivers of patients with IPF, to expose differences, highlight similarities, and propose a path forward for meeting those needs.

Methods

In March 2017, medical providers, patients with IPF, and caregivers of patients with IPF were asked to complete a provider-, patient-, or caregiver-specific survey as appropriate. Health-care providers included only general practitioners, pulmonologists, physician assistants, nurse practitioners, respiratory therapists, and registered nurses who were included in a database of people who had previously attended any educational program sponsored by National Jewish Health (NJH) within the last 5 years. We did not perform purposive sampling of providers based on the geographic location of the practice.

Patients and caregivers, who were enrolled in a research contact registry, were e-mailed and invited to visit the patient/caregiver survey website and complete their survey electronically. As members of the contact registry, patients and caregivers had to be 18 years of age or older and elect to receive e-mails with English language content. Survey respondents were not explicitly assessed for literacy level. Additional patient and caregiver recruitment was performed through targeted social media outreach and solicitation through IPF support groups across the country. Because of this recruitment strategy, it is impossible to know the numbers of patients or caregivers who had the opportunity to complete the survey. All survey invitees were located within the United States.

Survey structure

Surveys were written by study personnel and tailored to the three types of potential respondents: providers, patients, and caregivers (see Online Appendix for full survey content). The over-arching objective of the project was to gather data on the disease-related informational needs of each group and to develop electronic and hard copy educational resources. All three surveys included drop-down menu response options for certain items and a few open-ended questions with space to write in answers.

Response options for each survey were developed by senior study personnel, who are experts in the field of IPF. The surveys were designed to capture information relevant to each group, as informed by clinical experience and expertise and the conduct of prior studies.

To learn their comfort level with the diagnosis and management of IPF, provider-respondents were asked how they or their practice typically handles patients in whom IPF is in the differential diagnosis. Their surveys focused on what IPF-related information they needed and what information they viewed as important for their patients to have.

Patient-respondents were surveyed about their informational needs and the information they believed caregivers of patients with IPF needed to be most effective in giving care. Caregiver-respondents were asked about their own informational needs and what they believed were the informational needs of their IPF patient loved-ones. Surveys were sent out twice to increase response rates, and there were no incentives to complete the survey. The project was reviewed by the NJH Institutional Review Board and because it posed minimal risk, deemed exempt from full review.

Analytic methods

Respondents to each survey were asked to select their top three informational topics by checking boxes next to a predetermined list (see Online Appendix for specific layout). Simple summation was used to identify the rank order of topics (i.e. the topic whose box was checked most frequently was ranked highest). Topics with boxes checked the same number of times were given the same rank. For the open-ended questions, thematic content analysis was conducted by two investigators (DR and JS). Here, the investigators read

Table 1. Education/information need selections and providers' rankings for their own top three needs.

Selection options	Rank	Providers			
Epidemiology		Group 1	Group 2	Group 3	Group 4
Pathophysiology		($n = 146$)	($n = 8$)	($n = 24$)	($n = 4$)
Pathology	1	Making the diagnosis	Making the diagnosis	Making the diagnosis	Making the diagnosis
Making the diagnosis					
HRCT patterns	2	HRCT patterns	Epidemiology and pathophysiology	Pharmacological therapy	Pharmacological therapy
Pharmacological therapy					
Nonpharmacological therapies	3	IPF mimics	HRCT patterns	Pathophysiology	IPF mimics
Comorbid conditions					
IPF mimics					
Other					

HRCT: high-resolution computed tomography scan; IPF: idiopathic pulmonary fibrosis; ILD: interstitial lung disease; Group 1: providers who do not refer patients who have IPF but diagnose and treat patients themselves; Group 2: providers who provide initial care and testing and then refer IPF patients out; Group 3: providers who refer all their ILD patients to someone else when the diagnosis is suspected; Group 4: providers who refer patients for diagnosis and then manage and treat once the diagnosis of IPF has been confirmed.

through the responses multiple times to gain familiarity with the data and then, together, grouped similar responses into themes.

Results

Among 2636 surveys sent out to providers, 2041 were sent to physicians, 60 to physician assistants, 174 to nurse practitioners, 163 to registered nurses, and 198 to respiratory therapists. The number of patients and caregivers, who had the chance to respond to the survey, is unknown. Among providers, patients, and caregivers, 857 surveys were opened (33%), and 371 of those 857 were completed (43%): 182 by providers, 160 by patients, and 29 by caregivers.

Provider-respondents

Most providers were physicians (86%, 156/182); the remainder were physician assistants or nurse practitioners (9%, 17/182), respiratory therapists (4%, 7/182), or registered nurses (1%, 2/182). Eighty percent of providers ($n = 146$) stated that they did not refer outpatients who presented with symptoms raising suspicion for IPF; they diagnosed and treated IPF patients themselves (provider group 1). Thirteen percent ($n = 24$) provided testing and initial care and then referred IPF patients out for longitudinal care (provider group 2); 4% ($n = 8$) referred all patients to someone else when the diagnosis of IPF was suspected (provider group 3); and 2% ($n = 4$) referred patients suspected to have IPF to another provider for diagnosis and then managed and treated themselves (provider group 4).

For themselves. Providers in all four provider groups ranked information on "making the diagnosis of IPF" as their top informational need (Table 1). Those in provider group 1 ranked topics focused on diagnosing IPF, including "HRCT patterns" and "IPF mimics," as their other two top informational needs. None of the four groups selected "pathology," "nonpharmacological therapies," or "comorbid conditions" in their top three informational needs.

In the open-ended questions, providers said their own most pressing needs were for more educational materials (printed or internet-based) and for more support staff available to educate their patients. Multiple providers mentioned needing assistance with managing their patients' and patients' family's expectations around interventions. Other specific topics they, as providers, wanted more information on included lung transplantation, pulmonary rehabilitation programs, and how to access trials and other research opportunities for their patients.

For patients. Providers ranked "disease progression/what to expect" and "IPF drug therapy" as the most important topics for which they believed patients needed information (Table 2). Six percent ($n = 9$) of the 155 physician providers ranked "oxygen," as one of the top three most important informational topics for their patients; 12% ($n = 19$) ranked "palliative care" and 10% ($n = 15$) ranked "end-of-life/hospice care" in their top three for patients. In the

Table 2. Education need selections and rankings providers identified for their patients.

		Providers ($N = 182$)			
Selection options	Ranking	Group 1 ($n = 146$)	Group 2 ($n = 8$)	Group 3 ($n = 24$)	Group 4 ($n = 4$)
Comorbid conditions (e.g. PH and OSA) IPF diagnosis Exercise/pulmonary rehabilitation GERD/reflux management IPF drug therapy (options, risks, and benefits) Oxygen Research on IPF Tests (e.g. pulmonary function and oximetry) Longitudinal management of IPF Palliative care Disease progression/ what to expect End of life care/ hospice Other	1	Disease progression/ what to expect	Disease progression/ what to expect	IPF drug therapy	IPF drug therapy
	2	IPF drug therapy	IPF drug Therapy and IPF Diagnosis	IPF diagnosis	Disease Progression/ what to expect
	3	Longitudinal management	Longitudinal management and comorbid conditions	Disease progression/ what to expect	Exercise/pulmonary rehabilitation
	4	IPF diagnosis	Exercise/pulmonary rehabilitation and GERD/reflux	Tests	IPF diagnosis and longitudinal management and oxygen
	5	Exercise/ pulmonary rehabilitation	Tests	Exercise/ pulmonary rehabilitation	—

IPF: idiopathic pulmonary fibrosis; PH: pulmonary hypertension; OSA: obstructive sleep apnea; GERD: gastroesophageal reflux disease.

"other" category (i.e. not top three), providers wrote that patients needed information on smoking cessation, comorbid conditions, and lung transplantation.

Patient- and caregiver-respondents

Patients. For themselves, patients ranked "disease progression/what to expect" as their top informational need (Table 3). They ranked this and "end-of-life care" as the two most important topics about which caregivers needed information. Websites were patients' preferred means of acquiring disease-related, educational information. Answers to the open-ended questions centered around the following topics: emotional and psychosocial support, information regarding logistics of traveling and dealing with portable oxygen, how to best find the right doctor/specialist who is able to answer all questions about IPF, and an up-front discussion of lung transplant as a treatment option.

Caregivers. For themselves, caregivers, like patients, ranked "disease progression/what to expect" as their top informational need followed by "lung transplant option" (Table 3). Caregivers ranked "disease progression/what to expect" and "how doctors follow IPF over time" as the two most important topics patients needed information on. In the open-ended questions, caregivers mentioned a lack of emotional support, staying optimistic, and watching their patient loved-one suffer as major challenges related to caring for someone with IPF. To the open-ended question of additional topics that would be important to include on an informational hub, caregivers mentioned a variety of things including how caregivers might best communicate with the patient who is frustrated, angry, or depressed. Being realistic while remaining hopeful in the face of the uncertainty of the disease was mentioned by caregivers as an important characteristic for caregivers to possess.

Discussion

Summary of findings

We surveyed providers, IPF patients, and their caregivers to better understand the IPF-related

Table 3. Education need selections and rankings patients and caregivers independently identified for themselves and their caregiver.

		Patients ($N = 160$)		Caregivers ($N = 29$)	
Selection options	Rank	For self	For caregiver	For self	For patient
How doctors make an IPF diagnosis What tests doctors use with IPF patients	1	Disease progression/ what to expect	Disease progression/ what to expect	Disease progression/ what to expect	Disease progression/what to expect
How doctors follow IPF patients over time	2	Medications for IPF	End of life care	Lung transplant options	How doctors follow IPF over time
Medications for IPF (options and their risks and benefits) Supplemental oxygen	3	Research on IPF	Emotional health	Medications for IPF	Why and how to exercise and emotional health
Why and how to exercise with IPF Pulmonary rehabilitation Emotional health Disease progression and what to expect Acute exacerbations of IPF When to contact your medical provider Other medical conditions associated with IPF How acid reflux may be related to IPF Lung transplantation options End of life care Research on IPF Other	4	How doctors follow IPF over time	How doctors follow IPF over time	Acute exacerbations of IPF and research on IPF	Medications for IPF and pulmonary rehabilitation
	5	Why and how to exercise with IPF	Medications for IPF	How doctors follow IPF over time and supplemental oxygen	Supplemental oxygen and acute exacerbations of IPF and when to call your medical provider

IPF: idiopathic pulmonary fibrosis.

information they wanted and needed. Given the challenges in making a confident diagnosis—and the importance of doing so, now that therapies with potential beneficial effects are available—it is not surprising that providers ranked "making the diagnosis of IPF" as their number one informational need. This was true for all providers, regardless of how they dealt with patients whose presentations raised suspicion for IPF. In previously published studies, investigators observed similar needs among providers, especially those who did not necessarily identify themselves as IPF experts.[3,10–12]

Making a confident diagnosis of IPF can be challenging, because of its nonspecific symptoms and clinical mimics. Indeed, universally accepted guidelines developed by world experts suggest using multidisciplinary discussion in the diagnostic algorithm.[1] Making a correct diagnosis has implications not only for therapeutic intervention but also for interactions with patients and their caregivers who need to be aware that IPF is a progressive, incurable, likely life-shortening condition.

Providers, patients, and caregivers all ranked "disease behavior/what to expect" highly; this likely reflects the known variable natural history of IPF and the inability to accurately predict how IPF will behave in any one patient. Prediction models using population-level demographic and pulmonary physiology data are available,[13] but they cannot possibly incorporate patient-level attributes that affect disease behavior in an individual patient.

Despite the difficulty of accurately forecasting a patient's disease course, most providers believe it is

important for patients to understand the seriousness of IPF and what patients may experience (physically and emotionally) in its later stages. Providers want to be able to convey that message in a way that patients understand but in a manner that does not take away patients' hope. We believe, at the time of diagnosis, it is important to initiate the discussion of individual patients' goals, which then may naturally allow for the delivery of information focused on discrete topics. Setting expectations up front is ideal, but obviously, the delivery of information will occur over the course of care. Given the potential adverse emotional and psychological effects of hearing the diagnosis and living with a life-shortening condition, patients would likely benefit from hearing about coping strategies and being referred to resources available for emotional support.

Interestingly, providers who stated that they treat IPF patients themselves (group 1) as well as those who do initial care and testing but then refer their patients for longitudinal management (group 2) selected "disease behavior/what to expect" as their top informational need, while providers in groups 3 and 4 were more interested in IPF drug therapy for their patients. Providers in group 3 likely responded this way, because they managed their IPF patients (including prescribing and monitoring) after the diagnosis was confirmed elsewhere.

All groups of providers brought up exercise and pulmonary rehabilitation as an informational need they believed important for their patients. This was comforting to see and hopefully reflects that the days, when a patient got diagnosed with IPF and was told "there is nothing to do," are long gone.

We were surprised that providers did not rank end of life or palliative care highly; however, both patients and caregivers brought up these as informational needs for themselves and for one another. The discrepancy would suggest either providers already refer their patients to palliative and/or hospice care—which the literature suggests is not the case[14]—or that this is an opportunity for change: patients and caregivers want this information. Again, the delivery must be individualized, thoughtful and empathic, and timed appropriately.

The needs of each patient and their caregiver change along disease trajectory. Though both patients and caregivers chose "disease behavior/what to expect" as their greatest informational need, patients seemed to focus on living with the disease (medications and research on IPF), whereas caregivers focused on curative treatment options (lung transplant) when both groups were asked about knowledge for themselves. We believe information (particularly on prognosis) is most effectively delivered in a dosed fashion, over time, when patients and caregivers are ready to hear it and with emphasis on empathetic rapport underlining each conversation.

This is exemplified in work by Overgaard and colleagues in which they interviewed dyads of IPF patients and their caregivers to better understand the lived experience of IPF.[15]They asked patients and caregivers personal questions: "Are you sufficiently informed about your illness?" and "How are your expectations for the course of your illness?" Like us, they found that patients and caregivers desired information on disease progression, so patients could cling "... to a normal life while preparing for early death and the caregiver [could cling] to togetherness while preparing for loneliness." Morisset and her coinvestigators[16] conducted focus groups with ILD patients (12 of 24 had IPF) and providers with the intent of developing an ILD-specific educational resource that could be delivered as part of a standardized pulmonary rehabilitation program. End-of-life counseling emerged as one topic. Because the focus was not only on IPF, but on all ILDs—a heterogeneous group of disorders with varying prognoses—disease progression was not specifically discussed. Similarly, patient interviews performed by Holland and colleagues[17, 18] regarding specific educational topics delivered during pulmonary rehabilitation revealed that the patients desire to know "what the future might bring" in an honest and blunt conversation with the care team. End-of-life planning specifically was requested.

Strengths and limitations

Limitations of our study include the inherent bias of survey data: only a small fraction of surveys were answered (almost certainly by the most motivated respondents), and diagnosis and provider status were necessarily self-report. Studies with surveys are often sent to large databases of patients like ours, and response rates are often not included in the analysis because of the difficulty to ascertain the precise number of individuals who receive the survey.[19] The INTENSITY survey included electronic links sent to registered members of the Pulmonary Fibrosis Foundation and invitations to the survey was also posted on their online forum. Surveys were sent to 16,427

members to obtain a prespecified total of 600 respondents, which equates to a 3.6% response rate.[2] We were unable to ascertain numbers of patients and caregivers who had an opportunity to respond to our survey but did not.

Demographic information was not collected, but it could have been helpful to contextualize survey results and might have allowed comparisons between subgroups. To our knowledge, all respondents were located in the United States, so results may not be applicable to providers, patients, and caregivers in other countries. We did not involve outside providers-, patient-, or caregiver-advisors in the development of the surveys, and we did not generate a pilot survey. Doing so could have increased the validity of the survey by ensuring that questions and response options were on target. Although items were structured with response options provided, response options were thoughtfully generated by physician-investigators and educators with expertise in the diagnosis and management of IPF—and for the purpose of developing informational resources—and we believe the write-in questions provided respondents an opportunity to address issues the structured response options did not.

Implications for the future

Providers who evaluate and care for patients with IPF desire information that allows them to make a confident diagnosis. Patients and their caregiver loved-ones desire information on disease behavior and how their lives will look as the disease takes its typical progressive course. Care models are currently being devised to deliver comprehensive, patient-centered care—a major component of which is disease-related information.[19] The results of this study will be used to inform the development of provider-, patient-, and caregiver-specific informational materials. Future research efforts should focus on studying the effects of these materials on care delivery as well as patient and caregiver satisfaction. Models to deliver disease-related information/education in a dosed fashion should be explored, as we believe this is the most appropriate way to reach patients and caregivers at the level they desire. Disease trajectory and behavior of IPF are unknown topics currently being studied that could be incorporated into this educational material. Simulation-based training should be explored as a way to promote facility with the delivery of information.

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Supplemental material

Supplemental material for this article is available online.

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