

BMJ Open Quality Understanding the informational needs of patients with IPF and their caregivers: 'You get diagnosed, and you ask this question right away, what does this mean?'

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ABSTRACT

Background Idiopathic pulmonary fibrosis (IPF) is a progressive, incurable lung disease whose intrusive symptoms rob patients of their quality of life. Patients with IPF rely on their caregivers for support and assistance in amounts that vary according to patients' individual circumstances and disease severity. Knowledgeable and well-informed patients and caregivers are best suited to deal with life-altering conditions like IPF.

Methods We conducted two hour-long focus groups with 13 patients with IPF and 4 caregivers of patients with IPF to better understand their informational needs and in what format such information should be delivered.

Results Patients discussed the challenges IPF creates in their daily lives. They wanted information on how to live well despite having IPF, practical information on how they could remain active and travel and how they could preserve their quality of life despite living with a life-threatening disease like IPF. Caregivers wanted information on the general aspects of IPF, because it would help them understand what patients were going through. They also wanted specific information on how to give care to a patient with IPF, even when physical care may not be needed (as in earlier phases of the disease). Patients and caregivers both needed efficient information delivery from trustworthy sources, including the healthcare team involved in their care. They considered both spoken and written information valuable, and ease of access was critical.

Conclusion This study provides valuable insight regarding the informational needs of IPF patients and their caregivers. It is hoped that identifying or creating sources of this information, and insuring that patients and caregivers have access to it, will improve well-being for patients with IPF and their caregivers.

INTRODUCTION

Idiopathic pulmonary fibrosis (IPF) is a rare, incurable, life-shortening disease in which the lung parenchyma becomes progressively scarred.¹ Patients with IPF may have nagging, dry cough and profound fatigue; however, the hallmark symptom of IPF is debilitating

dyspnoea with exertion that worsens as the disease progresses. IPF is a disease often found in older adults. Patients are typically diagnosed in their seventh or eighth decade of life. To combat low blood oxygen levels, many patients with IPF will require supplemental oxygen therapy at some point in their illness. Median survival in cohorts of patients with IPF from centres around the world is a startlingly low 3–5 years from the time of diagnosis.^{1–3}

Making a diagnosis of IPF requires careful evaluation and integration of data from several sources, including high-resolution CT scans and, if warranted, surgical lung biopsy. Before ultimately being diagnosed with IPF, it is not uncommon for patients to endure symptoms for several months or years that are attributed to causes other than IPF.⁴ IPF Centers of Excellence can offer expertise to help shorten the time to arrival at a confident diagnosis of IPF thus facilitating the initiation of an appropriate IPF treatment plan.

In 2014, the Food and Drug Administrations approval of two medications for IPF (nintedanib and pirfenidone) spurred great excitement in the field and among patients with IPF. However, neither drug cures the disease nor even halt its worsening. On average, they slow progression of IPF but only to a modest degree, and neither has beneficial effects on symptoms.^{5, 6} Thus, patients with IPF—even those taking one or the other of these medications—continue to suffer with intrusive, ever-worsening, life-altering dyspnoea and impaired quality of life.⁷ Like people with other chronic, potentially terminal illnesses, patients with IPF rely on their informal caregivers (spouse, partner, adult children or other loved one) to provide emotional support and often, particularly in the latter stages of IPF, physical care.

Knowledgeable, informed patients and caregivers are best suited to face the challenges of living with IPF. Currently, it is unclear precisely what information patients and caregivers value and need, what the source of this information should be or how it should be delivered, particularly in the outpatient setting.⁸ Needs assessments for patients with IPF and caregivers of patients with IPF are becoming increasingly relevant, especially in discussion of palliative care interventions for improved quality of life.^{9 10} As part of an initiative to develop caregiver-centred and IPF patient-centred educational information, we conducted focus groups with patients with IPF and caregivers of patients with IPF. We sought to improve understanding of the of information they desired and believed they needed, how each could use the information to improve the patient's disease journey and in what format(s) the information should be developed.

METHODS

In 2016, two hour-long focus groups were conducted: one with patients with IPF (n=13) cared for in the Interstitial Lung Disease Programme at National Jewish Health and one with caregivers (n=4) of patients with IPF. The diagnosis of IPF had been made according to accepted guidelines.¹ Focus groups were led by a professional facilitator who worked for the consulting firm that collected data for various facets of the project. Both focus groups were audio-recorded and transcribed verbatim. Prior to implementation, the project was reviewed by the National Jewish Health Institutional Review Board and deemed to be exempt due to its focus on education and quality improvement. Patients and caregivers were recruited through database query or in person, and each gave written, informed consent to participate.

Two investigators (DR and JJS) conducted a conventional content analysis.¹¹ First, the caregiver transcript was analysed, then the patient transcript. Once each of those analyses was complete, a framework was developed to help explain the results from each and to identify and describe inter-relations between data sets.

The analysis started with each investigator reading and rereading the transcript under study to familiarise themselves with the data and to begin to formulate an understanding of its general content. Next, the transcript was coded independently by each investigator, who recorded initial impressions and thoughts in analysis notes. Throughout the analytic period, the investigators met weekly. In these meetings, notes were discussed, and transcripts were reviewed together, line by line, to develop consensus around codes and to generate definitions for consensus codes and categories/themes. Once the investigators had completed consensus coding and category formulation of both transcripts, each transcript was reviewed a final time against the backdrop of the coding scheme. A framework was conceptualised to explain inter-relatedness of findings between transcripts. We sought to formulate an understanding of the

Table 1 Baseline characteristics of patients and caregivers

| Characteristic | Patients n=13 (%) | Caregivers n=4 |
|-------------------------|----------------------|-------------------|
| Male sex, % | 7 (54) | 2 (50) |
| Caucasian race, % | 13 (100) | 4 (100) |
| Mean age, years | 68.1±7.2 | 63.3±7.7 |
| Supplemental oxygen | | N/A |
| None | 1 | |
| Exertion only | 5 | |
| Continuous | 7 | |
| Disease duration, years | 5.7±4.4 | N/A |

informational needs of patients and caregivers and of how patients' needs and values might be shaped by caregiver factors and vice versa.

RESULTS

Demographics

Thirteen patients and four caregivers participated in the focus groups. Their characteristics are displayed in [table 1](#).

Patients

In the first part of the focus group, informational needs were implicitly revealed in questions and comments patients voiced as they introduced themselves and spoke about IPF. They talked about the effects of the disease in general, when and how they were diagnosed and how they were dealing with the diagnosis on a day-to-day basis. In the latter part of the focus group, needs were stated explicitly in response to directed but open-ended questioning. Themes that emerged from the patient focus group included: putting a name to the diagnosis, generalised and individualised information and efficient information delivery. Content needs specific to the disease versus individuals is summarised in [table 2](#).

Putting a name to the diagnosis

In general, patients believed their diagnoses were not made in a timely fashion. They needed to know more promptly exactly what they were up against; not having a diagnosis left them frustrated, anxious and uncertain. One patient recalled '...a lot of the questions are, what is the diagnosis?' Another said, 'That's one of the most frequent questions asked when you get diagnosed, and you get to ask this question right away, what does this mean [for me]?' Another patient mentioned, 'I was struggling with it for about a year and a half when one of six doctors [they had seen in the evaluation of her/his symptoms] says, "This might be the situation, so go get a sophisticated diagnosis and care."'.

Once the diagnosis had been solidified, and patients overcame the 'shock' and fear of learning they had a terminal illness, patients wanted to '...hear about going forward and enjoying life going forward' and figure out

Table 2 Informational needs for the patient and caregiver

| Theme | Patient need | Caregiver need |
|--------------------------|--|--|
| Disease-specific content | <ul style="list-style-type: none"> ▶ naming the diagnosis ▶ typical symptoms ▶ typical prognosis ▶ therapeutic options ▶ effects of medications ▶ research being conducted | <ul style="list-style-type: none"> ▶ basic pathophysiology ▶ symptoms to look out for ▶ mental effects on the patient ▶ available therapies |
| Individualised content | <ul style="list-style-type: none"> ▶ what to do to improve/maintain quality of life ▶ what not to do (things detrimental to their quality of life) ▶ planning for trips away from home ▶ acquiring supplemental oxygen and insurance coverage ▶ success stories of patients who have surpassed prognostic timelines | <ul style="list-style-type: none"> ▶ how to manage medications ▶ managing supplemental oxygen (how to get it, how it should be used, how to encourage appropriate use) ▶ when to be concerned about patient symptoms, disease progression ▶ managing patients' and their own expectations ▶ preventing exposure to infection ▶ how to decrease stress and tension between themselves and patient |

how to ‘...live our lives to the fullest...’ despite any limitations IPF might impose. Putting a name—IPF—to the cause of their symptoms brought closure and gave them a sense of some control over the disease. They were finally allowed to envision a time when they could ‘take charge of informing’ their healthcare providers about their individual circumstances and request answers to questions, knowing they could finally ask the right ones and get some answers to help them in their disease journey.

Specific content: general and individualised information

Patients wanted reliable information about IPF in general: what is it? How does it develop? What research is being done on IPF? They also wanted general knowledge about its prognosis and therapies, including their potential beneficial and adverse effects. They stated it would be helpful at each visit to discuss with their providers ‘what [the field is] finding, any new drugs?’ and ‘what the reality is [ie, what the data supports] versus the publicity on them [the drugs for IPF]’, reflecting their desire for a trusted source of high-quality information.

They believed the acquisition of this general information could empower them to interact more effectively with the medical community at large: they could find out what they might need and get it when they needed. They mentioned that it is important for them to know what questions they should be asking their pulmonologists at clinic appointments. They stressed that what was most important to them was individualised information, like what did their own prognoses look like? And how they might expect their symptoms to change as the disease progressed. They craved practical guidance, for example, on how they could travel with supplemental oxygen, how to plan for trips away from home, how to navigate the choppy waters of getting supplemental oxygen equipment and insurance coverage for it.

Patients wanted to hear about what they could do to gain more control: ‘What can we do now to improve our

chances of survival? What should we do? What should we not do?’ They believed it was important for all people with IPF to have access to information germane to their own individual circumstances, with a focus on things that could be done to improve or maintain quality of life—‘focusing on tomorrow... focusing on your quality of life’. They desired information on how to minimise the influence of IPF on their day-to-day routines: ‘And so that’s what we’ve been doing, just fighting it off daily’. Instead of accommodating the disease by changing their lives, they discussed wanting information on how they might attain the lofty goal of making the disease fit into their daily lives. One patient mentioned, it was important to get information ‘... to help you get to the next day. And that’s the whole idea, you just keep putting those days together...’

Patients knew about the generally poor prognosis of IPF, but they wanted to know about their own prognoses: ‘If you look up the American Lung Association, that’s the first thing you see pulmonary fibrosis, 3 to 5 years. What? Seriously? Is that what this says?’ Given the poor prognosis of IPF and the possibility that patients and providers might dwell too much on the negative, patients wanted to hear success stories from their pulmonologists of other patients who had defied statistics regarding life expectancy. One patient noted ‘it would be wonderful to have, once-a-month, a highlight on somebody who says “yeah, I’ve been dealing with this for eleven years, this is what my life is like,” instead of reading some statistic...’

Information delivery: efficiency and options

Patients wanted accurate information they believed they needed, and they wanted to know which, aside from their pulmonologists, were trustworthy sources. Besides getting information from their physicians, patients wanted to be able to do their own research; for that, they needed to know ‘what [internet] websites are best to go on’, and they believed this ‘should be brought up at the first meeting

[when the diagnosis is confirmed: not to] run home and look it up [IPF on the internet]’.

Patients conveyed that they endured inefficient delivery of often incomplete information until the diagnosis of IPF was solidified and, often, afterwards for varying lengths of time. They considered efficient information delivery in the context of three factors: the style of the informant, the mode of delivery and the timing of delivery. Patients believed informants needed to be given adequate time to provide explanations, and they should never appear to be rushed, particularly when discussing sensitive topics like prognosis. They wanted informants to relay information candidly, to-the-point and on a level that patients can understand. As one patient mentioned: ‘When I see my doctor here, he talks to me like he [pointing to another participant in the group] is talking to you [on the same level]’.

Potential modes of delivery included spoken and written information. Spoken information could be delivered via inperson appointments with providers, educational presentations (at conferences) and within confines of a support group—either from support group leaders, from other participants or guest speakers. Non-verbal modes mentioned included pamphlets, brochures or books; social media; internet websites; and electronic patient portals. One patient praised the direct access an online portal gave him ‘you can’t get information that accurate, that quickly, other than that [through a portal] in my opinion...’.

Some patients preferred to receive information verbally, while the others desired to receive it in written format; in either case, patients expected both modes to be available and believed each could and should supplement the other. Patients liked the safety net of written information; it gave them something to refer to anytime they wanted, in case they ‘don’t understand necessarily the first time everything [they are] told...’. Written information could provide flexibility for patients to ‘sit down and step by step... [take] time at my own leisure to try to figure it out’ and even ‘go back and reread’ as needed. One patient mentioned that having written information would also give family members a better opportunity to understand his condition, stating they ‘can, in their own time, in a quiet place, read through this a couple of times, that helps them have a better understanding...’. Patients also wanted reliable, comprehensive online resources, including websites with sections for frequently asked questions. They mentioned they would welcome electronic reminders such as ‘remember to monitor your oxygen’ delivered via text or email.

Caregivers

Caregivers’ informational needs fell into two categories: (1) they needed to understand general aspects of IPF, particularly its effects on patients’ physical and emotional well-being and available interventions that might limit those effects and (2) they needed guidance on how to provide care to their patient loved-ones. Like patients,

caregivers believed having a foundation of knowledge about IPF would empower them to give the best care they could give. Subsequently, how they end up providing care was dictated, in part, by innate qualities each caregiver possessed. Themes that emerged from the caregiver focus group included: disease-specific informational needs, defining the logistics of the caregiver role and navigable information delivery. Their overall informational needs are summarised in [table 2](#).

Disease-specific information

The specific content and depth of information that caregivers needed appeared to be driven by the amount of disease-specific knowledge and experience the caregiver possessed at baseline, the amount of disease-specific knowledge their patient loved one possessed and was willing to share with the caregiver, the severity of IPF in the patient loved one and the therapeutic regimen they were using and, finally, the type of caregiver the person wanted—or was able—to be. A basic understanding of the pathophysiology of IPF would give caregivers a grasp on ‘the disease itself and what is going on [with their patient loved-one] and why it is happening...’. Beyond physical symptoms, caregivers desired an understanding of the mental impact of disease, so they could ‘look forward to try to help [the patient] on the bad days...’ or enlist the help of ‘someone to vent to or give [the patient] another opinion...’.

Defining the logistics of the caregiver role

Caregivers wanted practical information about their duties, including how to help manage medications and the ins and outs of supplemental oxygen—why it is prescribed, its potential benefits and hardships and what equipment is needed. Some of the caregivers already possessed knowledge they viewed as important for all caregivers to have. One knew the ‘effects of not getting enough oxygen, where it goes to first...your heart, your brain’ and how physically detrimental this was. Another caregiver identified their patient loved-one ‘obviously needs [oxygen] more than he wears...’, a third caregiver had the knowledge that allowed her to ‘manage the oxygen’ and advise the patient when to start wearing it more often during the day.

Caregivers also wanted to know when they should be concerned about patients’ symptoms and what to do if they acutely worsened. Seeing their patient loved ones breathing hard and fast was disquieting: ‘When you have somebody telling you through panting and puffing that they’re okay, are they really okay?’ Caregivers of patients with milder disease especially needed clarity about what their duties should be. There was no oxygen equipment to wrangle with, and their patient loved ones were entirely independent, having no need for physical care. However, caregivers in this situation struggled emotionally; they felt powerless, particularly because, despite being independent, their patient loved ones were symptomatic, often looking uncomfortable when they exerted. However,

caregivers felt they had little to offer other than advice. As one caregiver in this situation explained, 'I'm confused, because I become this caregiver that isn't giving any care, but more of a nag'.

Caregivers craved information on how to decrease the stress and tension that occasionally arose between them and their patient loved ones. 'In his mind, exertion is in the confines of a gym or on the treadmill. To me, if you put your shoes on and you can't catch your breath, that seems like exerting...'. After suggesting to the patient that he use oxygen whenever he exerts, '...he gets the oxygen, and he slings it over one shoulder' and carries it for the course of the day without using it to prove a point. Caregivers said, often, they believed their statements of concern and empathy were perceived by the patient as pity. A caregiver who offered to assist with tasks around the house said 'she'll [the patient] jump on me. 'You've got to let me do the things I can do'.

Another caregiver was more firm in her approach to offering support and advice: 'This is what I'm going to say, and this is the only time I'm going to say it. And then I leave it'. She attempted to find the right balance between being supportive and allowing her patient spouse to be independent: 'My approach changes...I can't keep doing everything for [him]'. Other caregivers saw the value of giving their patient loved one space: '...I stay out of her way. If I can help her do housework, I'm glad to do it.' Another mentioned, 'I offer help whenever I can. She knows I'm there for her'.

In two cases, there appeared to be little stress or tension. In one case, the patient was battling IPF, and the caregiver was dealing with his own chronic illness, which allowed him and his wife to '...do caregiving for each other. We both support each other. We both claim to have "half-zimers" so together we have a full brain and we figure things out together... our support system is two ways, even though I have been caregiver for her for such a long time...'. In the other case, the patient and caregiver would '...figure things out together'.

In general, caregivers wanted resources that fostered an honest approach to providing care for their patient loved ones based on realistic expectations. One caregiver revealed 'being stable in my opinion is a very big positive for my wife and me because she lost 80 percent of her lungs to the disease...'. Realising that respiratory infections could be particularly detrimental, caregivers wanted information on how to prevent exposure to infection. One caregiver acknowledged 'for the last 5 years I don't think she's been sick one day because we've been keeping everything very clean and... trying to work on anything we can do to not let mommy get sick...'

Information delivery: navigable information for the caregiver

Caregivers praised readily available, written materials, including reliable websites as 'something I can refer back to...I don't need to print it out and wonder where I put the copy I printed...'. Caregivers favoured the internet because it gave them the ability to peruse sites on their

own time, with their own agenda of questions driving their searches. One of the greatest verbal resources for caregivers was the patient themselves, who could be particularly knowledgeable about IPF, relay information to caregivers they had received from their physicians and, of course, provide information about their personal circumstances.

DISCUSSION

In this study, focus groups were conducted with patients with IPF and caregivers with the aim to better understand what kind of information each valued and needed and in what formats that information should be delivered. The results demonstrated that patients with IPF and their caregivers both believed that having a foundation of general knowledge about IPF—its risk factors, theories on its pathogenesis, general approaches to treatment and its natural history—was beneficial in myriad ways: this general understanding could help them both appreciate some of the mystery surrounding IPF (although some risk factors are known, it is entirely unclear why, when and in whom it develops), why the symptoms are what they are and what to expect from the disease over time.

Patients also wanted individualised information on specific things they could or should be doing (or not doing) to maintain or improve their quality of life. They desired straightforward content, so that they could formulate their own expectations. Once the diagnosis of IPF had been confirmed and patients moved through the initial shock and fear commonly experienced by people when a diagnosis of IPF is rendered, such information would be useful in helping them live their lives to the fullest but one day at a time. For many patients, a major component of living life to the fullest was the ability to travel. Finding out how they could take trips despite their need for supplemental oxygen was a specific informational need for them.

Caregivers hoped to receive information that could help them better understand why patients felt—physically and emotionally—the way they did. This, and more practical information—like how to effectively interact with the medical community, how to get medications or supplemental oxygen—would allow them to be more efficacious caregivers. In most cases, being a caregiver was challenging, at times physically, but most often emotionally. They needed advice on how to mitigate tension between themselves and their patient loved ones. This seemed particularly relevant to caregivers of patients with milder disease who needed little, if any, physical help. When caregivers did not need to carry, lift or take on other work for patients, they felt powerless. They believed they had no helpful capacities, except their voices. However, their words were often heard as pity by patients and as nagging by both patients and the caregivers themselves. The patients desired autonomy, and caregivers wanted to acquire

tactics to preserve and promote this autonomy—to give patients space—while still feeling fulfilled as caregivers. Caregivers who have their own chronic health issues may be more empathic and particularly well suited to care for and support patients with IPF.

Future research could include interviews with patient/caregiver dyads to help inform the development of strategies to improve these interactions. Overgaard and colleagues¹² interviewed 24 IPF patient/caregiver dyads with the goal of improving understanding of how patients and caregivers live with IPF. In this insightful study, the investigators focused primarily on how each member of the dyad attempted to cope with the disease, how IPF affected the relationship between them and how each dealt with those effects. In contrast, we sought to understand what goals patients and caregivers made for themselves and what information each needed to attain those goals. Patients wanted to understand why they developed IPF, why it caused the symptoms they experienced and, most importantly, to learn what they could do to maintain or improve their quality of life. Caregivers wanted much of the same general information about the disease, believing that knowledge would help them be better caregivers. They also wanted practical information on giving care to a patient with IPF: what should they be doing to help patients maintain quality of life, what should they not do, and what will their role look like as the disease progresses? Caregivers displayed various traits in providing care: they were at times intuitive, empathic, encouraging, methodical, accommodating or controlling. Which traits (or combinations) are used most often, and which are most effective in allowing both patients and caregivers to achieve their goals around IPF, is an area ripe for additional research.

Sampson and colleagues conducted a mixed-methods study aimed at defining support needs of patients with different IPF phenotypes (limited vs extensive disease, stable vs progressive course) and of caregivers.⁸ Their work reveals how caregivers are an integral component of the IPF management team. It also cautions that, as IPF progresses, caregivers are at risk for social isolation and a restricted lifestyle. This is a concept our research group has labelled the ‘Shrinking World Syndrome’.¹³ As IPF worsens, caregivers’ lives are constrained by patients’ declining physical ability and their increasing oxygen needs. Patients and caregivers in our study reminded us how the acquisition of information could be empowering and that empowered patients and caregivers are better suited to achieve their goals.

Patients and caregivers both wanted access to information in both spoken and written formats. The benefits of receiving information verbally, particularly when delivered by a practitioner with whom the patient has established a nurturing partnership, is that delicate topics can be discussed at the appropriate time (when patients and caregivers are ready to hear them), and information can be delivered empathically. Questions that arise from either

side can be addressed immediately, and practitioners can confirm that the information has been received correctly. Written materials (whether in hard copy or electronic) give people the opportunity to acquire information at the pace and depth they desire, and they can return to the information as often as needed.

This study has limitations. We enrolled patients (and caregivers of patients) from a single, academic institution with specialised care in IPF. So, opinions and perceptions may not reflect those of the broader universe of IPF patients and caregivers. Only four caregivers (all spouses) participated in the focus group, so results may not apply to other caregivers (eg, adult children and friends). However, there was a broad range of disease duration in their patient spouses, two of whom used oxygen continuously and two used it only when exerting. As in all qualitative research, the value of the data lies in its depth, not breadth.

CONCLUSION

Following the diagnosis of IPF, patients and caregivers want general information that gives them a sense of power and control over the disease. Patients also want specific, individualised information that they can apply to help maximise their quality of life. Caregivers want guidance on how they can provide the best care to their patient loved one throughout the course of IPF, even in its early stages when physical caregiving is not needed. Resources should be developed in multiple modalities and tailored to patients’ and caregivers’ needs and goals. This information should be easily accessible, navigable and update frequently as new data becomes available. Future research should explore the effectiveness of informational resources and ascertain whether certain caregiver personality traits, or whether the presence of chronic illness in the caregiver, are associated with better outcomes in the caregiver (burden) and/or patient (satisfaction).

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