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# Expectations about treatment of idiopathic pulmonary fibrosis: Comparative survey of patients, carers and physicians (the RESPIR French survey)

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## A B S T R A C T

**Context.** – Idiopathic pulmonary fibrosis (IPF) is a severe chronic disease during which anxiety and depression are frequent comorbidities. Better knowledge of patients' expectations is needed to inform an action plan to improve medical care.

**Aim.** – To describe feelings and expectations of patients suffering from IPF and of their carers about antifibrotic therapy and compare them to what is perceived by their pulmonologist.

**Methods.** – National prospective study on practices and perceptions. Specific questionnaires were e-mailed to all 3276 pulmonologists in France who, in turn, invited patients and carers to participate in a survey.

**Results.** – 147 pulmonologists, 161 patients and 144 carers participated in the survey. The role of the carer was evaluated as “important” or “very important” by more than 90% of participants, i.e. pulmonologists, patients or carers. Inconsistencies between how patients felt and how pulmonologists perceived them were identified: 88% of patients responded that they understood quite well what IPF is (vs. 75% of patients according to pulmonologists); 85.5% of patients said they were determined to fight the disease (vs. 68.0%); 61.7% of patients wanted to be kept informed of potential complications before they occurred (vs. 69.6%) and 81.2% wanted to be involved in therapeutic decisions (vs. 43.1%). Globally, patients had a more positive view of antifibrotic therapies than expected by pulmonologists: 41.5% evaluated their advantages superior to what they had expected (vs. 29.1% of patients according to pulmonologists) and 76.5% had a positive image of the benefits/disadvantages ratio (vs. 62.4%). Although pulmonologists had the impression that they were keeping their patients well-informed about exacerbations, hospital stays and the possible negative evolution of the disease despite antifibrotic therapies, 34.0%, 42.0% and 22.0% of patients respectively declared not being aware of these aspects.

**Conclusion.** – The feelings of patients suffering from IPF regarding their disease and treatment globally proved more positive compared with how pulmonologists perceived them. Taking into account the expectations and needs of patients may allow healthcare professionals to better address their needs and priorities.

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## 1. Introduction

Idiopathic pulmonary fibrosis (IPF) is the most frequent and most serious form of adult idiopathic interstitial pneumonias [1]. The annual incidence of the disease, which appears to increase with time, is estimated between 3 and 9/100,000 in Europe and in the United States [2]. At least 4400 new cases are said to be reported in

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France each year, with a prevalence of at least 9000 patients [3]. The progressive and irreversible worsening of fibrosis is responsible for an inexorable decline in pulmonary function which, without any treatment leads to respiratory failure and death within a median period of 3 to 5 years following diagnosis [1–4]; thus, the median survival of patients diagnosed with IPF is lower than the rate associated with many solid tumors [5]. However, the evolution can vary from one patient to another and is quite unpredictable [6]. A French study has shown that, over 5 years, 87% of patients stayed in hospital at least once for an acute complication, and these stays were associated with high mortality rates (17 to 36% depending on the type of complication) with a median cost from 3200 to 5400 € [7]. In total, more than 21,600 hospitalizations associated with IPF were identified over a period of 5 years.

Before the availability of antifibrotic therapies (pirfenidone [8,9] and nintedanib [10,11]), the treatment of IPF was mainly based on symptom alleviation and lung transplantation. In a personalized approach to care, IPF treatment must adapt to the particularities of each patient to optimize their care. To this aim, therapeutic decisions should be shared with the patient and take into account the patient's personal history, quality of life, and perspectives, priorities and expectations [12]. Several studies often with small numbers have been conducted in some European countries to better understand the feelings of patients with IPF, their expectations and needs, as well as the perception of their carers [13–19]. However, patients' perceptions and expectations may vary greatly by country and culture, and few studies have involved patients, carers and pulmonologists in parallel.

The aim of the RESPIR study (Regards croisés : fibroSe Pulmonaire Idiopathique et tRaitements - overlapping perspectives on idiopathic pulmonary fibrosis and therapies) was to evaluate patients' expectations of antifibrotic therapy and to benchmark them with expectations and feeling of their carers and pulmonologists, in order to orientate changes in management to better address patients' priorities.

## 2. Methods

RESPIR was a French prospective study conducted among pulmonologists, patients with IPF and their carers. The methodology was developed by a scientific committee comprised of seven pulmonologists. This national study on practices and perceptions was composed of two successive stages: a survey of pulmonologists followed by a mirror survey of patients and carers. During the preparatory phase (July to November 2017), the scientific committee designed three questionnaires intended for pulmonologists, patients and carers, respectively. The last two had previously been tested and adapted during interviews with two couples of patients and carers.

The questionnaire for pulmonologists was mailed to 3276 French pulmonologists on 21th November 2017. Pulmonologists were then invited by mail and e-mail to become a "support pulmonologist" for the second part of the survey, i.e. to invite their patients and respective carers to participate in the survey. Pulmonologists were asked to not to select patients and to give the questionnaires to those who gave oral consent. After being given the questionnaire, patients and carers who agreed gave written consent, completed the questionnaire on their own, and mailed it back anonymously within the following days or months. All patients diagnosed with IPF were eligible for inclusion in the survey. Data were collected between November 2017 and October 2018.

Questionnaires for pulmonologists, patients and carers included 40 to 47 items, divided into several categories (Table 1).

Variables were analyzed by descriptive statistics: mean values, standard deviations, medians and interquartile ranks for

quantitative data; numbers and percentages for categorical data. Pulmonologists were divided into three groups: 1) competence center or reference center (expert center) for rare pulmonary diseases in university-affiliated hospital; 2) university-affiliated hospital or general hospital; 3) private practice or other structure. Chi-square homogeneity tests were conducted to evaluate the significance of differences between these groups with level of significance (alpha risk) of 5%.

## 3. Results

Questionnaires were completed by 147 pulmonologists (i.e. 4.5% response rate), 161 patients and 144 carers.

### 3.1. Pulmonologists

The majority of pulmonologists who completed the survey did not work in a competence/reference center (75.5%). Among the 31 pulmonologists who enrolled patients and carers, 27 (87.1%) worked in a competence or reference center. In total, 97% of patients and carers were recruited by a pulmonologist working in a competence center.

The main characteristics of pulmonologists who completed the survey are presented in Table 2. Institution of work was relatively balanced between expert centers, other university-affiliated hospitals, and private practice and other structures. The median number of patients suffering from IPF who were personally cared for in their practice was 10 (Q1-Q3: 5–20) and was higher for pulmonologists working in a competence or reference center (20) than for the other groups (10).

### 3.2. Patients

The main socio-demographic characteristics of the included patients are presented in Table 2. Patients were mainly male (81.9%), with a median age of 72 years. For the most part, they were married or in a relationship (73.3%) and most were retired (88.8%). The median time since diagnosis of IPF was three years.

### 3.3. Carers

Carers were the patient's partner or child in respectively 79.3% and 12.1% of cases. Two thirds of carers were retired and one quarter had a professional activity. 8.8% declared that their relative's IPF had an impact on their own professional activity.

### 3.4. IPF care

35.9% of patients indicated that they were followed by at least two pulmonologists from different centers for their IPF. 71.7% of patients declared that they would always or most of the time attend the consultation accompanied by a carer. More than 90% of all participants in the survey (pulmonologists, patients or carers) declared the role of the relative (or carer) to be "very important" or "important" in the patient's care. The role of the general practitioner or family physician was considered as "very important" or "important" more frequently by the pulmonologists (95.6%) than by the carers (85.0%,  $P < 0,001$ ) or patients (75.8%,  $P < 0,001$ ).

### 3.5. Patients symptoms and priorities

The majority of patients (56.4%) had dyspnea  $\leq$  MRC 2 (no discomfort or shortness of breath when brisk walking or up a slight hill), which indicates a moderate severity of IPF. About one quarter of patients (23.3%) indicated that they observed benefit from

**Table 1**  
Division of items for the pulmonologist, patient and carer questionnaires.

	Pulmonologist questionnaire	Patient questionnaire	Carer questionnaire
General information	✓	✓	✓
IPF care	✓	✓	✓
Feeling about IPF and its care		✓	✓
Perceptions and expectations of patients about antifibrotic therapies	✓	✓	
Perceptions and expectations of carers about antifibrotic therapies			✓
Experience/feeling of patients about antifibrotic therapies	✓	✓	
Experience/feeling of carers about antifibrotic therapies	✓		✓

**Table 2**  
Characteristics of the respondents.

Characteristics of the patients	
Gender	
Men, %/median age, years	82.0/72
Women, %/median age, years	18.0/72
Way of life, %	
In a relationship	73.3%
Single	18.0%
With a family	6.2%
In a retirement home	1.9%
Other	0.6%
Current professional situation, %	
Retired	88.8%
Working	4.4%
Partial or total disability	2.5%
Work stoppage	3.8%
Seeking employment	0.6%
Housewife/househusband	0%
Professional activity (current or past if retired), %	
Employee	23.0%
Executive, senior intellectual work	25.7%
Intermediate profession	18.4%
Workman/workwoman	13.8%
Craftsperson, tradesperson, company manager	13.2%
Farmer, fisherman	2.6%
Not concerned	3.3%
Characteristics of the practitioners	
Median age (years)	48
Male/female %	64.7/35.3
Area of practice	
Auvergne-Rhône-Alpes	14.5%
Burgundy-Franche-Comté	5.3%
Brittany	6.9%
Centre-Val-de-Loire	5.3%
Corsica	0.8%
Grand-Est	14.5%
Hauts-de-France	7.6%
Île-de-France	13.0%
Normandy	3.1%
Nouvelle-Aquitaine	3.1%
Occitanie	12.2%
Pays-de-la-Loire	4.6%
Provence-Alpes-Côte-d'Azur	7.6%
Location of main practice, n (%)	
IPF expert (reference or competence) centers	42 (31.1)
University-affiliated not being an IPF expert center, or General Hospital	37 (27.4)
Private practice, other	56 (41.5)
Median number of patients seen regularly in their practice (n)	10

pulmonary rehabilitation, whereas a greater percentage of pulmonologists thought so (median = 30%; non-significant difference NS). 14% of patients reported an impact of IPF on their professional life (e.g. early retirement or giving up work).

When asked about priorities, 78.9% of patients stated that they would rather live longer, even if that meant taking drugs that could cause adverse effects (vs. 83.3% according to pulmonologists and 81.9% according to carers; non-significant differences).

### 3.6. Patients knowledge and mindset

In the pulmonologists' opinion, 75% of patients had a good knowledge of IPF and understood the impact of the disease on their health. A numerically higher proportion of patients stated they had a good knowledge of IPF and its impact (87.8% and 88.7%, respectively; NS). Some discrepancy was also observed regarding the state of mind of fighting the disease: 85.5% of patients indicated that they were determined to fight their disease, whereas pulmonologists estimated this percentage to be 68.0% (NS).

In our survey, 69.6% of pulmonologists thought that IPF patients would know about the possible complications of the disease and of treatments before they occurred, and were appropriately prepared, versus 61.7% of patients and 59.8% of carers (NS). When asked whether they wanted to actively take part in the therapeutic decision-making process, 81.2% of patients and 59.4% of carers ( $P$ -value < 0.001 vs. patients) answered positively, whereas 56.9% of pulmonologists thought that the patient wanted to play an active role in the decision.

### 3.7. Perceptions and expectations regarding antifibrotic therapy

Among the patients who participated in the survey, 74.7% were receiving an antifibrotic therapy, and another 8.7% had previously received one. The pulmonologists' reactions regarding the prescription of antifibrotic therapies were contrasted: 69.3% declared that they prescribed an antifibrotic therapy to symptomatic patients as soon as IPF was diagnosed, and 69.3% indicated that they prescribed an antifibrotic therapy to asymptomatic patients (including 37.3% who did so as soon as IPF was diagnosed). Whereas 10.9% of pulmonologists never prescribed antifibrotic therapies, those working in an expert center significantly prescribed antifibrotic therapy to a larger proportion of asymptomatic patients with IPF (Fig. 1).

At the time of initiating treatment, 15.6% of patients and 15.9% of carers considered their quality of life as the priority, whereas it was thought to be a priority for the patient by 33.9% of pulmonologists ( $P$ -value = 0.002 vs. patients & = 0.001 vs. carers). Their perception was closer to reality regarding extension of life expectancy, as 16.4% of patients considered this to be a priority (versus 17.7% according to pulmonologists). However, most respondents indicated that they prioritized both quality of life and extension of life expectancy equally (Fig. 2).

The initiation of antifibrotic therapy was experienced as positive, bringing relief and hope to 75.8% of patients (82.1% of carers), and 76.1% of pulmonologists thought that patients had a positive feeling (NS).

Although pulmonologists had the impression that they were keeping their patients well-informed about the possibility of acute exacerbations of IPF (94.2% of pulmonologists), emergency hospitalizations (91.9%) and the possible negative evolution of the disease (95.6%) despite antifibrotic therapies, only 66.0% ( $P$  < 0.001), 58.0% ( $P$  < 0.001) and 78.0% ( $P$  < 0.001) of patients, respectively, declared they were aware of these potential consequences (Table 3). Information about the necessity to continue

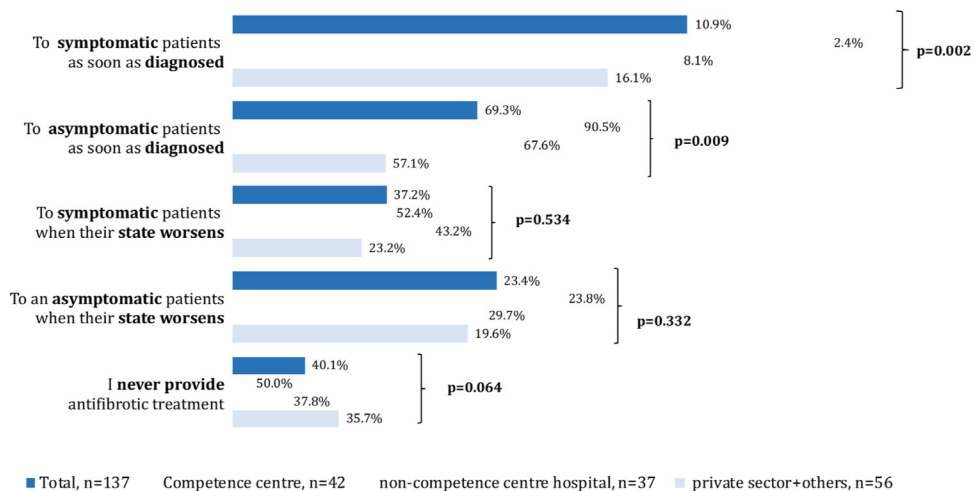
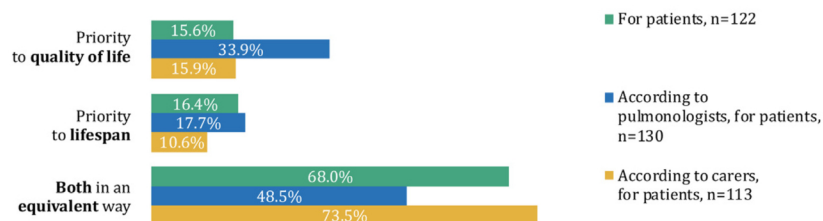


Fig. 1. Reaction of pulmonologists about the prescription of anti-fibrotic therapy.

### A. Patients' priorities at antifibrotic drugs initiation



### B. Patients' position about adverse events

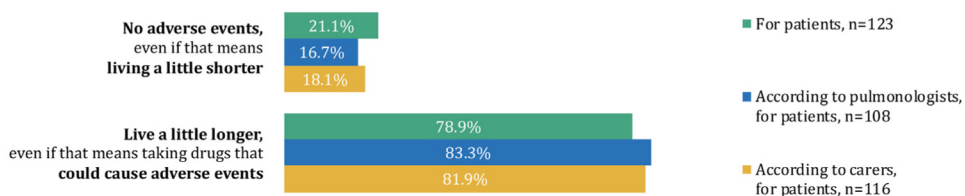


Fig. 2. Priorities of antifibrotic therapy and positioning towards adverse events of the therapies.

Table 3

Comparison between information delivered by pulmonologists and awareness of patients and carers.

Piece of information	Delivered by Pulmonologists			Awareness by Patients	Awareness by Carers
	Yes, systematically	Yes, sometimes	Total		
IPF can evolve negatively	81.0%	14.6%	95.6%	78.0*	84.8*
Exacerbations are possible	75.2%	19.0%	94.2	66.0*	70.3*
Stays at the hospital are possible	60.3%	31.6%	91.9	58.0*	68.5*
Therapy must be continued for a long time, if not life	90.5%	8.0%	98.5%	96.2%	96.6%

\*  $P < 0.001$  vs. pulmonologists.

treatment for a long time, if not for the rest of the patients' life, was given by 98.5% of pulmonologists and was known by 96.6% of patients and 96.6% of carers (NS).

Most patients who had received antifibrotic therapy reported a positive effect of treatment on disease progression, cough and quality of life; a similar feeling was shared by carers (Fig. 3). Retrospectively, adverse effects of antifibrotic drugs were deemed less important than anticipated at treatment initiation by 72.6% of patients and 74.7% of carers (Fig. 4) (NS). Perceived benefits were deemed more important than anticipated by 41.5% of patients and 48.6% of carers (NS). The constraints of taking antifibrotic drugs were deemed more important than anticipated by 27.3%

of patients and 31.5% of carers (NS). Overall, 76.5% of patients estimated that antifibrotic therapy had more benefits than disadvantages, whereas 62.4% of pulmonologists indicated that the benefit/disadvantages ratio experienced by their patients would be positive ( $P=0.036$ ). Thus, 65.9% of patients surveyed versus 50% of patients according to pulmonologists would have liked to have been prescribed antifibrotic treatment earlier in their disease course (NS).

As an exploratory analysis, the opinion of pulmonologists from expert centers was compared to that of pulmonologists working in a different setting; no significant difference was found between groups (data not shown).

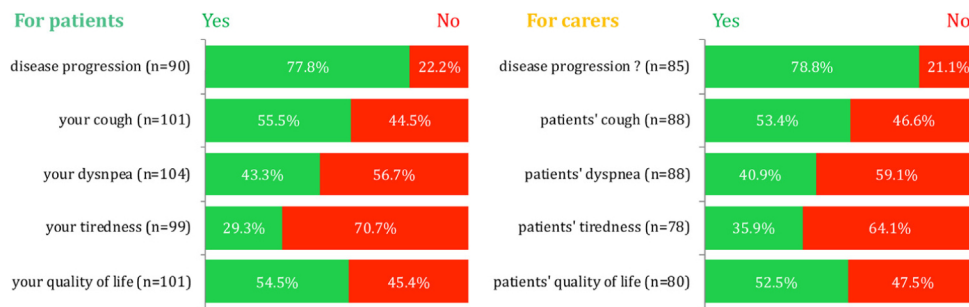


Fig. 3. After experiencing antifibrotic therapies, would you say it had a positive effect on.

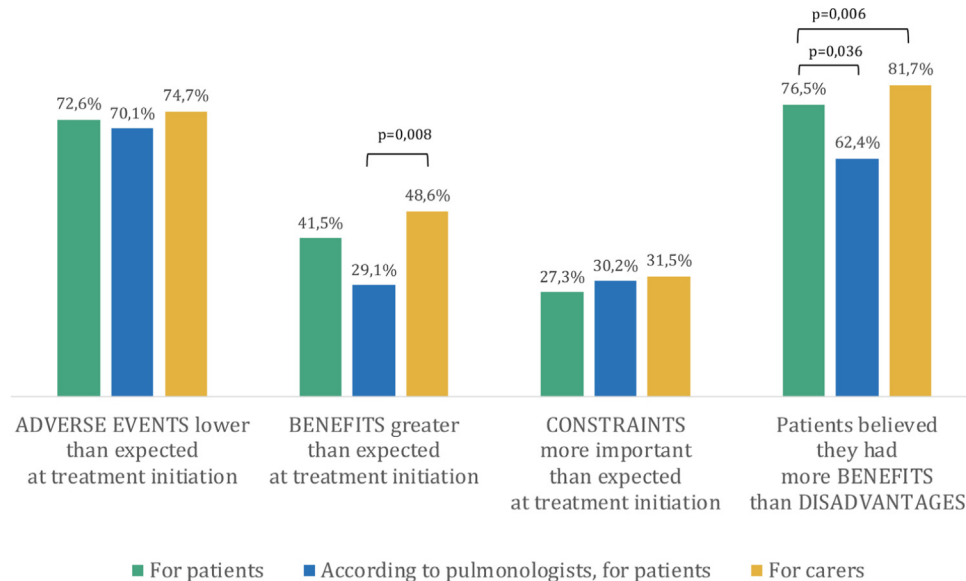


Fig. 4. Assessment of antifibrotic therapy following the experience of the patient.

#### 4. Discussion

The RESPIR survey has provided a description of expectations and needs of patients with IPF about their treatment in France, as well as the perception of pulmonologists and carers. The main lessons arising from RESPIR are that the feelings and expectations of patients do not always correspond to the perception that pulmonologists have in several areas; that patients have a globally more positive outlook concerning their antifibrotic therapy; that antifibrotic therapy is still being prescribed belatedly in some cases; and that carers play a key role.

Clinically, the severity of disease of the participants was moderate and seems representative of the population suffering from IPF. Indeed, in a French survey conducted in 2012 with 509 pulmonologists, 58% of their patients presented a mild to moderate IPF [20], a result corroborated by the result of a 2013 international survey [21]. Pulmonologists participating in this survey were globally representative of all French pulmonologists in terms of age, gender ratio and type of practice [22].

Regarding the patients', carers' and pulmonologists' perceptions, several lessons can be learnt. The carers' key role was deemed "important" or "very important" by more than 90% of respondents in all three groups. In this survey, the carers' perception was very close to the patients'; they had a good knowledge of the disease and of patients' expectations. Thus, carers could be involved more proactively in care, for example, within therapeutic education and psychological support sessions. It is, therefore, crucial to take their needs and expectations into account in such a way that they bring

the necessary support and play their part alongside patients. In that sense, a program developed in the Netherlands, consisting of meetings and debates led by various speakers (psychologists, pulmonologists, physiotherapists, among others) and including the patients' relatives, has proven beneficial to the patients' quality of life [23]. A multicenter study in France (The HELP-IPF study, [www.clinicaltrials.gov](http://www.clinicaltrials.gov), NCT04031690) is ongoing to evaluate the quality of life of caregivers of patients with IPF.

On the contrary, there are divergences between practitioners and patients regarding expectations and perceptions of the patient. The first discrepancy observed concerned the objectives of antifibrotic therapy: at treatment initiation, 33.9% of pulmonologists thought that patients' highest priority was quality of life whereas it was true for only 15.6% of them. This observation is corroborated by another survey in which 87% of patients thought that preventing disease progression was more important than the risk of potential side effects [15]. Similarly, pulmonologists had a tendency to under-estimate the percentage of patients determined to fight the disease (68.0% versus 85.5% when asking patients).

Pulmonologists also had a tendency to under-estimate the proportion of patients willing to actively participate in treatment decisions (56.9% vs. 81.2% when asking the patients). Shared medical decisions have proven useful in many pathologies to improve patient adherence to the treatment program and, in some cases, to help improve its results [24–26].

One last divergence between pulmonologists' perceptions and patients' statements concerned the understanding of IPF by patients: 88% of patients stated that they understood the disease

well vs. 75% according to pulmonologists. The question, therefore, is whether pulmonologists under-estimate patients' understanding or whether patients wrongly believe they understand the disease. Some surveys, notably older ones, have reported that most patients complained about a lack of information about IPF [13,14,27]. Insufficient information can fuel anxiety and lead to patients looking for information on the internet, with the risk of finding confusing data - including a prognosis that can be worse than in reality in individual patients [15]. The CaNoPy study carried out in the United Kingdom involving 27 IPF patients and 21 carers has shown a good understanding of IPF but a poor grasp of its progression and how this progression could be managed [16]. People surveyed had a difficult time translating overall explanations about the disease into consequences for their personal situation. Patients declared they had not received enough information on the practical aspects of care and wished they had had more concrete elements to adapt to an unpredictable future. This is consistent with our study since only 58% of patients surveyed said they were aware that, despite therapy, a worsening of their disease could lead to hospitalization. In other studies, patients have said they wanted "to learn how to live with this disease", to know what changes in their way of life could optimize their quality of life [17], and to have practical information to better manage their disease [13]. In total, theoretical and general information might be sufficient but patients need more concrete elements and tools to live with IPF. There would thus be a disconnection between the consultation and everyday life, underlining the important part of therapeutic education and of coordinating nurses.

In our survey, there was an important variation between pulmonologists stating they inform their patients of possible exacerbations, hospitalizations and negative progression despite therapy, and patients' feeling they were not informed in 34%, 42% and 22% of cases, respectively. The pulmonologists' explanation might have not been clear enough; patients and carers might not have heard what they did not want to hear or might have been unable to comprehend it. In a study of 161 patients with IPF and 168 carers in the Netherlands and Germany, a high proportion of patients and carers (>90%) declared that they wanted to know everything about the disease and its consequences [18]. In a British study (27 patients and 21 carers), as well as in a European study (Italy, Belgium, Ireland and England), participants were not so outright and expressed quite ambiguously the need for a "balance between honesty and hope" which should evolve depending on the stage of the disease [16-28]. In a Danish study (25 patients and 24 carers), patients and carers were ambivalent about the wish to have all information regarding diagnosis and progression: the fatal outcome of the disease being hard to take in, they estimated it was too stressful to get all the information at once and preferred for it to be given progressively [19]. Cultural differences can also be taken into account: in one study, 70% of Dutch people wanted to talk about things relating to end of life versus only 50% of Germans [18]. It can be difficult for pulmonologists to start on the question of prognosis. In an international study, Maher et al. have demonstrated that only 28% of pulmonologists felt at ease talking about it and 40% confessed they avoided the topic when talking to their patients.

After several years on the market, 69.3% and 37.2% of pulmonologists state they are ready to prescribe antifibrotic therapies at once to symptomatic and asymptomatic patients respectively, but with significant differences between practitioners since 90.5% of pulmonologists in expert centers prescribe antifibrotic therapies as soon as diagnosed to asymptomatic patients. A study carried out in five European countries has shown that patients with IPF and mild lung function impairment only had antifibrotic therapies in 29% of cases versus 59% and 40% for moderate and severe impairment, respectively [29]. Disease stability, lack of symptoms or the relative

preservation of pulmonary function can explain why pulmonologists are reluctant to prescribe antifibrotic therapies as soon as IPF is diagnosed [15]. However, according to the same study, patients were willing to have early treatment. There is still some work to do within the pulmonologist community to consider early treatment, should the patient be symptomatic or not, in accordance with current recommendations [3]. This need to improve habits was previously demonstrated by the 2012 French study with 509 pulmonologists attesting that, despite an acceptable knowledge of recommendations, participants only took therapeutic decisions in multidisciplinary meetings in one third of the cases [20].

The benefits of antifibrotic therapies on quality of life, although suggested in clinical studies and linked with the reduction of dyspnea and cough [30,31], have never been formally established in pivotal studies [32]. Moreover, there is not necessarily a connection between clinical parameters and quality of life reported by patients [12-33]. In our survey, 54.5% of patients reported an improvement in their quality of life after therapy initiation. Starting therapy probably has a psychological effect. This concurs with 76% of patients declaring that they had experienced the initiation of antifibrotic treatment as positive and hopeful. In more than 40% of cases, patients receiving antifibrotic therapies declared the benefits to be more important than they had first considered.

The RESPIR study has limitations. A recruitment bias could have occurred, since nearly all responding patients were recruited from expert centers, whereas most participating physicians worked outside of these centers. Respiratory physicians working in different settings may have different exposures to IPF patients and varying practice. However, in an exploratory analysis, no difference in opinion was found between pulmonologists working in expert centers or not.

RESPIR study results being declaration data, answers might have been influenced, notably for patients and carers, by the state of health (physical and psychological) they were in when completing the survey.

In our study, 23.3% of patients and 30% of pulmonologists indicated to have had some benefit from pulmonary rehabilitation (PR), as compared to 2.1% in the French ancillary study of Passport ([www.clinicaltrials.gov](http://www.clinicaltrials.gov), NCT02699879) which enrolled patients from 2012 to 2016 [34]. We speculate that this greater rate might be related to the French guidelines published in 2017 that recommended pulmonary rehabilitation in patients with IPF (3).

However, despite their imperfections, qualitative surveys bring precious knowledge of patients' feelings. To our knowledge, RESPIR is the first French study to have documented the expectations and needs of IPF patients about their treatment, in parallel with the perception of pulmonologists and carers. In addition, our study included more patients than most prior works and was carried out after antifibrotic therapies were on the market.

## 5. Conclusion

The RESPIR study has demonstrated discrepancies between pulmonologist's and patient's perceptions in France. The latter are globally more positive than their practitioners, determined to fight the disease, and wish to be involved in therapeutic decisions. Patients generally wish to be informed comprehensively, and are willing to actively participate in treatment decisions. They are ready to undergo undesirable side effects if treatments lengthen their life expectancy, whereas pulmonologists tend to prioritize their quality of life. Globally, patients surveyed seem ready for earlier treatment and a better sharing of decisions than what doctors think.

## Disclosure of interest

The authors declare that they have no competing interest.

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## References

- [1] Barratt SL, Creamer A, Hayton C, Chaudhuri N. Idiopathic Pulmonary Fibrosis (IPF): an overview. *J Clin Med* 2018;7:201, <http://dx.doi.org/10.3390/jcm7080201> [PMID: 30082599; PMCID: PMC6111543].
- [2] Hutchinson J, Fogarty A, Hubbard R, McKeever T. Global incidence and mortality of idiopathic pulmonary fibrosis: a systematic review. *Eur Respir J* 2015;46:795–806.
- [3] Cottin V, Crestani B, Cadranel J, et al. French practical guidelines for the diagnosis and management of idiopathic pulmonary fibrosis - 2017 update. *Rev Mal Respir* 2017;34:900–68 [Full-length version.].
- [4] Olson AL, Swigris JJ, Lezotte DC, Norris JM, Wilson CG, Brown KK. Mortality from pulmonary fibrosis increased in the United States from 1992 to 2003. *Am J Respir Crit Care Med* 2007;176:277–84.
- [5] Diamantopoulos A, Wright E, Vlahopoulou K, Cornic L, Schoof N, Maher TM. The burden of illness of idiopathic pulmonary fibrosis: a comprehensive evidence review. *Pharmacoeconomics* 2018;36:779–807.
- [6] Wuyts W, Cottin V. Idiopathic pulmonary fibrosis: time for greater expectations? *Eur Respir J* 2018;52:1801312, <http://dx.doi.org/10.1183/13993003.01312-2018> [PMID: 30072545].
- [7] Cottin V, Schmidt A, Catella L, et al. Burden of idiopathic pulmonary fibrosis progression: a 5-year longitudinal follow-up study. *PLoS ONE* 2017;12:e0166462.
- [8] King Jr TE, Bradford WZ, Castro-Bernardini S, et al. A phase 3 trial of pirfenidone in patients with idiopathic pulmonary fibrosis. *N Engl J Med* 2014;370:2083–92.
- [9] Noble PW, Albera C, Bradford WZ, et al. Pirfenidone in patients with idiopathic pulmonary fibrosis (CAPACITY): two randomised trials. *Lancet* 2011;377:1760–9.
- [10] Richeldi L, Costabel U, Selman M, et al. Efficacy of a tyrosine kinase inhibitor in idiopathic pulmonary fibrosis. *N Engl J Med* 2011;365:1079–87.
- [11] Richeldi L, du Bois RM, Raghu G, et al. Efficacy and safety of nintedanib in idiopathic pulmonary fibrosis. *N Engl J Med* 2014;370:2071–82.
- [12] Moor CC, Heukels P, Kool M, Wijsenbeek MS. Integrating patient perspectives into personalized medicine in idiopathic pulmonary fibrosis. *Front Med (Lausanne)* 2017;4:226.
- [13] Russell AM, Ripamonti E, Vancheri C. Qualitative European survey of patients with idiopathic pulmonary fibrosis: patients' perspectives of the disease and treatment. *BMC Pulm Med* 2016;16:10.
- [14] Schoenheit G, Becattelli I, Cohen AH. Living with idiopathic pulmonary fibrosis: an in-depth qualitative survey of European patients. *Chron Respir Dis* 2011;8:225–31.
- [15] Maher TM, Swigris JJ, Kreuter M, et al. Identifying barriers to idiopathic pulmonary fibrosis treatment: a survey of patient and physician views. *Respiration* 2018;96:514–24.
- [16] Sampson C, Gill BH, Harrison NK, Nelson A, Byrne A. The care needs of patients with idiopathic pulmonary fibrosis and their carers (CaNoPy): results of a qualitative study. *BMC Pulm Med* 2015;15:155.
- [17] Senanayake S, Harrison K, Lewis M, McNarry M, Hudson J. Patients' experiences of coping with idiopathic pulmonary fibrosis and their recommendations for its clinical management. *PLoS ONE* 2018;13:e0197660.
- [18] van Manen MJ, Kreuter M, van den Blink B, et al. What patients with pulmonary fibrosis and their partners think: a live, educative survey in the Netherlands and Germany. *ERJ Open Res* 2017;3.
- [19] Overgaard D, Kaldan G, Marsaa K, Nielsen TL, Shaker SB, Egerod I. The lived experience with idiopathic pulmonary fibrosis: a qualitative study. *Eur Respir J* 2016;47:1472–80.
- [20] Cottin V, Cadranel J, Crestani B, et al. Management of idiopathic pulmonary fibrosis in France: a survey of 1244 pulmonologists. *Respir Med* 2014;108:195–202.
- [21] Cottin V. Current approaches to the diagnosis and treatment of idiopathic pulmonary fibrosis in Europe: the AIR survey. *Eur Respir Rev* 2014;23:225–30.
- [22] [https://www.profilmedecin.fr/contenu/chiffres-cles-medecin-pneumologue/consulté le 3 octobre 2019](https://www.profilmedecin.fr/contenu/chiffres-cles-medecin-pneumologue/consulté%20le%203%20octobre%202019).
- [23] van Manen MJG, van't Spijker A, Tak NC, et al. Patient and partner empowerment programme for idiopathic pulmonary fibrosis. *Eur Respir J* 2017;49:1601596, <http://dx.doi.org/10.1183/13993003.01596-2016> [PMID: 28446554].
- [24] Ben-Zacharia A, Adamson M, Boyd A, et al. Impact of shared decision making on disease-modifying drug adherence in multiple sclerosis. *Int J MS Care* 2018;20:287–97.
- [25] Hauser K, Koerfer A, Kuhr K, Albus C, Herzig S, Matthes J. Outcome-relevant effects of shared decision making. *Dtsch Arztebl Int* 2015;112:665–71.
- [26] Lofland JH, Johnson PT, Ingham MP, Rosemas SC, White JC, Ellis L. Shared decision-making for biologic treatment of autoimmune disease: influence on adherence, persistence, satisfaction, and health care costs. *Patient Prefer Adherence* 2017;11:947–58.
- [27] Collard HR, Tino G, Noble PW, et al. Patient experiences with pulmonary fibrosis. *Respir Med* 2007;101:1350–4.
- [28] Masefield S, Cassidy N, Ross D, Powell P, Wells A. Communication difficulties reported by patients diagnosed with idiopathic pulmonary fibrosis and their carers: a European focus group study. *ERJ Open Res* 2019;5, <http://dx.doi.org/10.1183/23120541.00055-2019> [PMID: 31192248; PMCID: PMC6546939].
- [29] Maher TM, Molina-Molina M, Russell AM, et al. Unmet needs in the treatment of idiopathic pulmonary fibrosis—insights from patient chart review in five European countries. *BMC Pulm Med* 2017;17:124.
- [30] Noble PW, Albera C, Bradford WZ, et al. Pirfenidone for idiopathic pulmonary fibrosis: analysis of pooled data from three multinational phase 3 trials. *Eur Respir J* 2016;47:243–53.
- [31] Richeldi L, Cottin V, du Bois RM, et al. Nintedanib in patients with idiopathic pulmonary fibrosis: combined evidence from the TOMORROW and INPULSIS((R)) trials. *Respir Med* 2016;113:74–9.
- [32] Graney BA, Lee JS. Impact of novel antifibrotic therapy on patient outcomes in idiopathic pulmonary fibrosis: patient selection and perspectives. *Patient Relat Outcome Meas* 2018;9:321–8.
- [33] van Manen MJ, Geelhoed JJ, Tak NC, Wijsenbeek MS. Optimizing quality of life in patients with idiopathic pulmonary fibrosis. *Ther Adv Respir Dis* 2017;11:157–69 [4].
- [34] Jouneau S, Gamez AS, Traclat J, et al. A 2-year observational study in patients suffering from idiopathic pulmonary fibrosis and treated with pirfenidone. A french ancillary study of PASSPORT. *Respiration* 2019;98:19–28, <http://dx.doi.org/10.1159/000496735> [Karger, (hal-02119176)].