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Research Article

# "The Will to Live!" The Perceptions of Patients with Idiopathic Pulmonary Fibrosis in Relation to Antifibrotic Treatment: A Qualitative Study

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## ABSTRACT

**Introduction:** Patients with Idiopathic Pulmonary Fibrosis (IPF) are typically treated with antifibrotic drugs, which act by slowing the progression of the disease, thus reducing the frequency of exacerbations and increasing survival. Although safe, such drugs have adverse effects and do not reduce the degree of dyspnoea or improve patient quality of life. In this study, we discuss the perceptions of individuals with IPF in relation to antifibrotic treatment.

**Methods:** This was a qualitative study of 17 patients with IPF on antifibrotic treatment for ≥ 6 months, followed at a referral centre for interstitial diseases. We collected data through semi-structured interviews and the six phases of thematic analysis was used.

**Results:** The results obtained allowed us to construct three thematic categories: the will to live; perceptions about improvement, delayed progression or worsening of the clinical condition resulting from the treatment; and perceptions about adverse effects of the treatment and their repercussions on daily life. The desire to stay alive or to reduce physical suffering was understood as a motivation to seek treatment. Some patients reported improvement in their clinical condition after starting antifibrotic. Tolerance to adverse effects was high among the participants, and even those who experienced significant drug-related adverse effects did not discontinue the treatment.

**Conclusion:** The will to live appears to motivate patients to use antifibrotics, even without the promise of a cure or changes in clinical status. In addition, adverse events, even when aggressive, do not seem to deter patients with a devastating disease from continuing treatment.

**Keywords:** Adverse effects; Nintedanib; Pirfenidone; Qualitative study; Pulmonary fibrosis; Interstitial lung disease

## INTRODUCTION

Idiopathic Pulmonary Fibrosis (IPF) is an Interstitial Lung Disease (ILD), of unknown aetiology, which leads to functional loss and progressive dyspnoea [1]. The course of IPF can be unpredictable and may include periods of acute deterioration, known as exacerbations, which are indicative of rapid progression of the disease [2].

In individuals with IPF, a multidisciplinary approach has been shown to be important to ensure an accurate diagnosis and the best treatment [3,4]. In 2015, the IPF guideline committee approved the use of nintedanibe and pirfenidone (antifibrotics) for the treatment of IPF [5]. However, neither has been found to provide a significant reduction in dyspnoea, the main symptom of IPF, or to improve quality of life [5]. Despite having proved safe, nintedanibe and pirfenidone have adverse effects [6,7]. The adverse effects most commonly associated with the use of nintedanibe are gastrointestinal, especially diarrhoea (in 62%

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of cases) [6]. For pirfenidone, the main adverse effects are also gastrointestinal, the most prevalent being nausea (in 35% of cases). In addition, skin rash and photosensitivity occur in 20% and 8%, respectively, of patients using pirfenidone [7]. Both drugs can alter liver enzymes [5].

The evaluation of patients before initiating treatment with pirfenidone at the time of its approval for the IPF concluded that the tolerance to the side effects of the therapy would be high justified by the scarcity of treatment options and the hopelessness of the disease [8]. Similarly, Maher et al. found that IPF patients were more concerned about slowing disease progression than about the side effects [9]. More recently, Moor et al. evaluated IPF patients in antifibrotic treatment after three and six months observed results positive and similar for nintedanibe and pirfenidone. Self-reported experiences with medication efficacy were the main factor associated with overall medication satisfaction [10].

Patients with IPF report significant limitations in their lifestyle [11]. Those limitations are mainly related to disorders such as depression, anxiety, fatigue and insomnia, as well as to the effects of IPF on physical conditioning [12]. The disease also affects family members and caregivers within the support network of the patient [13]. Russel et al. detected the beneficial role played by caregivers and interstitial lung disease specialist. Although most patients were keen for information on IPF, this was often of poor quality [14].

Despite all available knowledge, individuals with IPF report many unmet needs, particularly in relation to their access to information and psychosocial support [15]. Patients, caregivers, healthcare professionals and researchers have identified the expectation of a curative treatment and the search for the aetiology of IPF as a priority for research into this relentless, irreversible disease [15,16].

Considering the cultural, social and economic disparities in Brazil, we conducted the present study in order to evaluate the perceptions of individuals with IPF regarding the use of antifibrotics treatment, knowledge of the disease and its symptoms and factors related to daily life and family life.

## MATERIALS AND METHODS

### Study design and population

This was a qualitative study of IPF patients followed at the ILD Outpatient of Universidade Federal de Minas Gerais, Brazil, between May 25, 2019 and March 20, 2021. We included patients ≥ 18 years of age who IPF according the recommendations ATS/ERS/JRS/ALAT and antifibrotic treatment (with pirfenidone or nintedanib) for ≥ 6 months. Patients with another ILD were excluded. Of the outpatients evaluated, 24 were classified as having IPF [17]. However, two patients (with advanced IPF) declined to participate in the study and five were excluded because they had been on antifibrotic for less than 6 months. Therefore, the final sample comprised 17 patients.

### Data collection

Data were collected through semi-structured interviews that included questions about issues such as the repercussions for the patients and their families when they received the diagnosis of IPF; the motivation(s) for seeking specific treatment; the occurrence of adverse events related to the use of antifibrotic; the perception of which aspects of life did or did not change after the start of treatment; and future directions and expectations.

The interviews were scheduled during follow-up consultations at the outpatient clinic, for a date and location preferred by the individual. An experienced qualitative researcher (MGA) trained four medical students (MBL, MPM, MLMS and PLB) to conducted semi-structured interviews. All interviews were conducted in Portuguese, this was the only language of all participants. To preserve their privacy to avoid potential bias of responses, the participants were identified only as interviewee 1 (I1), etc. Sociodemographic and clinical data related to treatment were collected at the appointment closest to the interview, with a form developed specifically for this study.

### Data analysis

The data was analyzed using the thematic analysis technique, proposed by Braun and Clarke [18]. This analysis process consists of six phases and starts when the researcher begins to perceive and look for patterns of meaning, as well as questions of potential interest in the data, and ends reporting the content and meaning of themes in the collected data [18].

### Reliability

After conducting the interviews, the recordings were transcribed by one of the researchers (1st), and then he and two other researchers (2nd and 7th) carefully reviewed the transcripts to ensure that all information was typed. The authors are concerned with maintaining methodological rigor throughout the research process [19]. Thus, the transcripts of the interviews were read line by line and coded independently by the investigators, two of whom had experience in conducting qualitative studies (2nd and 7th authors). The researchers (1st, 2nd and 7th) met regularly to discuss the themes and the best sentences that exemplify them. Any differences were resolved through discussion to reach a consensus.

## RESULTS

Of the 17 interviewees, nine were using nintedanib and eight pirfenidone. Four patients died within 12 months after the interview. The clinical and functional characteristics of the patients are described in Table 1.

**Table 1:** Clinical and functional characteristics of patients with idiopathic pulmonary fibrosis.

| Characteristic | (N=17) |
|---|---|
| Age (years), median (IQR) | 69.06 (59–82) |
| Male, n (%) | 13 (73.5) |
| $SpO_2$ (%), mean (SD) | 94.53 (1.55) |
| mMRC dyspnoea score, n (%) | |
| <2 (less severe) | 8 (47.1) |
| ≥ 2 (more severe) | 9 (52.9) |
| FVC (L), mean (SD) | 3.06 (0.84) |
| FVC (%), mean (SD) | 79.66 (16.60) |

| | |
|---|---|
| DLCO (ml min-1 mmHg-1), mean (SD) | 11.91 (4.75) |
| DLCO (%), mean (SD) | 53.50 (15.26) |
| Antifibrotic drug in use, n (%) | |
| Nintedanib | 9 (52.9) |
| Pirfenidone | 8 (47.1) |
| Oxygen supplementation, n (%) | 4 (23.5) |
| Family history of fibrosis, n (%) | 6 (35.3) |
| Death, n (%) | 4 (23.5) |

**Note:** $SpO_2$: Peripheral oxygen saturation; mMRC: Modified Medical Research Council (scale); FVC: Forced vital capacity; DLCO: Diffusing capacity of the lung for carbon monoxide.

The results (interviewee statements) obtained allowed us to construct three thematic categories: the will to live; perceptions about improvement, delayed progression or worsening of the clinical condition resulting from the treatment; and perceptions about side effects of the drug and their repercussions on daily life.

## The will to live

IPF has a highly variable clinical course, usually with functional loss, progressive dyspnoea, and impaired quality of life. The interviewees indicated that they opted to start the antifibrotic because it could keep them alive and help them fight this Idiopathic Progressive Disease (IPF):

"It's the will to live" (I5, 60´s).

"The doctor explained to me that there is no cure for the disease, but we can stabilise it (...). Me using this stuff (the antifibrotic drug) will slow it (the progression of the disease) and will extend my life" (I6, 60´s).

Other attitudes that motivated starting treatment were based on the desire to intervene in the course of the disease and the fear of respiratory symptoms associated with its evolution.

"It was the only recommendation I had as a way to delay the progression of the disease" ( I16, 70´s).

"I only had to see the state in which my sister died of her lung disease" (I10, 60´s).

"(...) the doctor explained to me that this medicine isn't a cure, that it has contraindications (...) Then I said, 'but I'm okay, doctor, I'm okay with going through all that (...)' because I'm afraid of having shortness of breath on top of everything else" (I15, 80´s).

However, some interviewees reported that they started drug only because their physician had told them to do so.

"This antifibrotic medicine was prescribed to me by the doctor who was treating me" (I4, 80´s).

"I didn't want to use it because I left the decision up to the doctor" (I13, 60´s).

## Improvement, delayed progression or worsening of the clinical condition: Perceptions about the treatment

At the time of prescription, the doctors inform the patient that the antifibrotics are not curative, is not improve dyspnoea or quality of life. Perceptions regarding the clinical course of the disease after the initiation of therapy differed among the interviewees, with reports of improvement, delayed progression or worsening of the clinical condition.

"Things went great. It worked really well for me, now I can talk better (...), despite coughing and being tired at certain times of the day. I think I have to keep taking it, because my quality of life is better than it was before" (I7, 60´s).

"I have more energy now, and I've noticed an improvement in my condition, it's small but it's substantial. I practically stopped coughing" (I8, 70´s).

Other interviewees reported a delay in the progression of symptoms with the use of the drugs:

"I noticed that my ability was progressively decreasing, and with the drug, after that, I started to stabilise" (I2, 50´s)

"I feel like it's progressing much slower than before" (I16, 70´s).

"I'm really noticing that the disease is slowing down, braking. From the beginning, when I found out, until I started using the medicine, it was more accelerated (...) after I started taking it, I noticed a decrease in the progression of the disease" (I17, 50´s).

Progression of the disease and its symptoms, despite treatment, was also reported by some interviewees. Dyspnoea was the main complaint associated with clinical worsening:

"I didn't get tired walking on level ground, but now I am, a bit. (...) I'm getting more tired, even taking the medicine" (I9, 60´s).

"This shortness of breath (...) has not improved, lately it has got worse. (...) My breathing, it got a lot worse, even with this medicine" (I4, 80´s).

One of the interviewees, despite reporting a delay in the progression of the disease, remained highly symptomatic and began to hope for a lung transplant.

"(...) I don't feel like it has a good, active effect. For example, the medication is doing me good because it slowed down (the progression of the disease), not because it improved my breathing (...) my situation calls for a transplant, I can't see it any other way" (I1, 60´s).

## Adverse effects of the antifibrotics: Perceptions and repercussions for everyday life

In this thematic category, it was possible to identify individuals who experienced no side effects and those who experienced noticeable side effects that had negative repercussions for their lives. However, it is worth noting that, despite the adverse events, none of the participants discontinued the treatment.

"We did our research, talked about stomach problems, loss of appetite, etc. (...) The medicine didn't have any of those effects on me" (I16, 70´s).

"I feel good with the medicine. Thank God I don't have any side effects" (I6, 60´s).

"Side effects, no. It doesn't have a noticeable effect" (I1, 60´s).

However, side effects such as nausea, diarrhoea and abdominal pain were reported by some interviewees:

"The side effect is very aggressive. Diarrhoea, nausea, abdominal

pain (...). One of the reasons I don't work a lot (...) I have to take medicine for anxiety in the car. And diarrhoea too, that's why I'm limiting my hours" (I17, 50´s).

"This medication hinders you a bit" (I5, 60´s).

"The nausea with the medicine is very strong, to the point that I wonder if I should continue using it. Because when you're nauseated, you think about that, about the nausea, you don't think about the disease, you don't think about the quality that you've improved, how much you've improved" (I10, 60´s).

"Nausea, I vomited a lot" (I3, 70´s)

## DISCUSSION

It is quite challenging to deal with a fatal disease in which the progression is inevitable [3]. The main results of the present study show that, although antifibrotics does not provide the promise of a cure, complete interruption of the progression of the disease or reversal of symptoms already established, it can be seen as beneficial in that it can, in some cases, improve patient quality of life.

There are few data in the literature on the perceptions of patients with IPF regarding antifibrotics and their life priorities [13]. The present study brought a perspective, as evidenced by the interviewees' hope that antifibrotics would improve your condition. Although they were aware that drugs would not completely stop the progression of IPF, patients saw the treatment as giving them a chance to live longer. However, for some interviewees, the expectation placed on the treatment was based on the fear of physical suffering. Although the patients were aware that the treatment was unlikely to improve their symptoms, they saw it as an option to avoid the agony of not being able to breathe. At diagnosis, most individuals with IPF already have symptoms such as shortness of breath, cough and fatigue, which cause them to lose their independence as the disease progresses. The fear of such progression was seen mainly in the reports of the interviewees who had a familial pulmonary fibrosis and had witnessed very unfavourable outcomes in close relatives with IPF [8,20].

One relevant perception in the present study was the weight given to the opinion of the prescribing physician in the decisions made by the patients with IPF. Some interviewees stated that they were using the antifibrotic because their physician had recommended it, without citing any motivating expectation of their own. That underscores the importance of trust in the physician-patient relationship [13]. Knowing the expectations and needs of patients in relation to their own disease allows the physician to devise a tailored treatment plan that can address the life goals of each individual [4,13,16].

In the present study, patient reports differed with regard to perceptions of the effect that treatment had on the course of the disease and should be evaluated individually. Despite evidence indicating that antifibrotic do not have a positive effect on Health-Related Quality of Life (HRQoL) or dyspnoea, some of our interviewees reported a perception of improvement in their clinical condition after starting the treatment [1]. Others noted progression of the symptoms. Although antifibrotics can slow the progression of IPF, it is not possible to predict the course of the disease with accuracy in any given individual [21]. Various aspects of the disease and of the life of the patient are evaluated in order to determine HRQoL, and it is possible that new qualitative tools to explore the needs and expectations of patients with IPF could facilitate that evaluation [22].

In the present study, one respondent (I1, 60 years old) had accelerated progression of IPF before starting therapy, with rapid worsening of the clinical and pulmonary function. This patient maintained the treatment with the expectation of attenuating the progression of the disease while waiting for the transplant. Eight months after the interview he was successfully transplanted. It is noteworthy that patients on the waiting list for lung transplantation are facing a great impact on their daily activities, including reduced physical capacity and, in many cases, psychosocial impairment [23].

Although antifibrotics have proved safe, data related to patient tolerance of those drugs and the adverse events associated with their use must be disclosed to patients when they are prescribed [1]. In the present study, even the patients who reported limitations attributed to side effects continued the treatment, regardless of their perception regarding the improvement or stabilisation of their clinical condition. Burnett et al. reported that patients with IPF perceive significant adverse effects, including onerous effects such as weight loss [15]. Nevertheless, as in the present study, the participants in that study adhered to the management guidelines provided by the medical team, meaning that the treatment was maintained and that strategies such as dose reduction, ingestion with food, use of anti-diarrheal drugs and avoidance of exposure to sunlight were employed.

Unlike those in previous studies the interviewees in the present study demonstrated a high level of knowledge about IPF [13]. The desire for information beyond that transmitted in the physician consultation was common among our interviewees, who had a clear understanding of the progressive nature of the disease, the lack of any curative treatment and the potential side effects of the antifibrotics. Patient searches for information online were also reported by Maher et al. internet search platforms having been mentioned by 79% of the participants in their study [9]. These findings underscore the importance of approaching this complex disease at specialised referral centres, where encouraging self-education becomes part of the care plan, providing greater sharing of opinions between physicians and patients during the decision-making process [15].

One strength of the present study is that it reveals important aspects such as patient knowledge and understanding of the disease and its treatment, as well as the importance of trust in the physician-patient relationship, which may have contributed to the fact that none of the patients discontinued the treatment. In clinical practice, the assessment of patient desires and expectations, as well as the attempt to strike a balance between the response to treatment and the burden of side effects, should guide decisions about the introduction or continuation of antifibrotic. In the context of such a complex disease listening to patients regarding their preferences, risk tolerance and other life priorities allows the provision of humane care that is adapted to

the needs individual [12]. To our knowledge, this is the first study to show the perceptions of patients in Brazil, who have social, cultural and economic characteristics that differ from those of patients in other Latin American and countries in other parts of the world.

Our study has some limitations. The main limitation is that we did not interview the caregivers of the patients. It is well known that a caregiver plays an important role in the life of a patient with a progressive fibrosing disease [13]. Such caregivers provide fundamental support in the approach to IPF, often being the liaison between the physician and the patient [4].

## CONCLUSION

Studies involving caregivers are needed in order to devise approaches that also include these individuals who are so fundamental in the management of IPF. In conclusion, patients with IPF seem motivated to use antifibrotic therapy either by their will to live or by a desire to minimise their physical suffering. Having a treatment available, even one that does not provide the promise of a cure, appears to foster hope among such patients, as a means of extending their life or improving its quality.

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## AUTHOR CONTRIBUITIONS

EVM, MGA and LNG contributed to the study design. MGA, MBL, MPM, MLMS and PLB contacted and interviewed the participants. EVM, MGA and LNG analysed the qualitative data. All authors contributed to data interpretation, and drafted, revised and approved the manuscript for publication.

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## ETHICS APPROVAL

Ethics approval was obtained by the Research Ethics Committee of the Universidade Federal de Minas Gerais (Reference no. 3,342,556); operational approval from the provincial health authority. All participating patients gave written informed consent. All information obtained was considered confidential and the reports and results of this study were presented without any form of individual identification.

## AVAILABILITY OF DATA AND MATERIALS

The data that support the findings of this study are available on request from to the corresponding author on request.

## REFERENCES

1. Lederer DJ, Martinez FJ. Idiopathic pulmonary fibrosis. N Engl J Med. 2018;378(19):1811-1823.
2. Raghu G, Remy-Jardin M, Myers JL, Richeldi L, Ryerson CJ, Lederer DJ, et al. Diagnosis of idiopathic pulmonary fibrosis. An official ATS/ERS/JRS/ALAT clinical practice guideline. Am J Respir Crit Care Med. 2018;198(5):e44-68.
3. Kreuter M, Bendstrup E, Russell AM, Bajwah S, Lindell K, et al. Palliative care in interstitial lung disease: Living well. Lancet Respir Med. 2017;5(12):968-980.
4. Wijsenbeek MS, Bonella F, Orsatti L, Russell AM, Valenzuela C, Wuyts WA, et al. Communicating with patients with idiopathic pulmonary fibrosis: Can we do it better?. ERJ Open Res. 2022;8(1).
5. Raghu G, Rochwerg B, Zhang Y, Garcia CA, Azuma A, Behr J, et al. An official ATS/ERS/JRS/ALAT clinical practice guideline: treatment of idiopathic pulmonary fibrosis. An update of the 2011 clinical practice guideline. Am J Respir Crit Care Med. 2015;192(2):e3-19.
6. Richeldi L, Du Bois RM, Raghu G, Azuma A, Brown KK, Costabel U, et al. Efficacy and safety of nintedanib in idiopathic pulmonary fibrosis. N Engl J Med. 2014;370(22):2071-2082.
7. King Jr TE, Bradford WZ, Castro-Bernardini S, Fagan EA, Glaspole I, Glassberg MK, et al. A phase 3 trial of pirfenidone in patients with idiopathic pulmonary fibrosis. N Engl J Med. 2014;370(22):2083-2092.
8. Bridges JF, Paly VF, Barker E, Kervitsky D. Identifying the benefits and risks of emerging treatments for idiopathic pulmonary fibrosis: A qualitative study. Patient. 2015;8:85-92.
9. Maher TM, Swigris JJ, Kreuter M, Wijsenbeek M, Cassidy N, Ireland L, et al. Identifying barriers to idiopathic pulmonary fibrosis treatment: A survey of patient and physician views. Respiration. 2018;96(6):514-524.
10. Moor CC, Mostard RL, Grutters JC, Bresser P, Aerts JG, Dirksen CD, et al. Patient expectations, experiences and satisfaction with nintedanib and pirfenidone in idiopathic pulmonary fibrosis: A quantitative study. Respir Res. 2020;21(1):1-7.
11. Rajala K, Lehto JT, Sutinen E, Kautiainen H, Myllärniemi M, Saarto T. Marked deterioration in the quality of life of patients with idiopathic pulmonary fibrosis during the last two years of life. BMC Pulmonary Medicine. 20188(1):1-9.
12. Kalluri M, Younus S, Archibald N, Richman-Eisenstat J, Pooler C. Action plans in idiopathic pulmonary fibrosis: a qualitative study—'I do what I can do'. BMJ Support Palliat Care. 2021.
13. Lee JY, Tikellis G, Corte TJ, Goh NS, Keir GJ, Spencer L, et al. The supportive care needs of people living with pulmonary fibrosis and their caregivers: A systematic review. Eur Respir Rev. 2020;29(156).
14. 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(1):1-7.
15. Burnett K, Glaspole I, Holland AE. Understanding the patient's experience of care in idiopathic pulmonary fibrosis. Respirology. 2019;24(3):270-277.
16. Tikellis G, Tong A, Lee JY, Corte TJ, Hey-Cunningham AJ, Bartlett M, et al. Top 10 research priorities for people living with pulmonary fibrosis, their caregivers, healthcare professionals and researchers. Thorax. 2021;76(6):575-581.
17. Raghu G, Collard HR, Egan JJ, Martinez FJ, Behr J, Brown KK, et al. An official ATS/ERS/JRS/ALAT statement: idiopathic pulmonary fibrosis: evidence-based guidelines for diagnosis and management. Am J Respir Crit Care Med. 2011;183(6):788-824.
18. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101.

19. Rose J, Johnson CW. Contextualizing reliability and validity in qualitative research: Toward more rigorous and trustworthy qualitative social science in leisure research. J Leis Res. 2020;51(4):432-451.

20. Duck A, Spencer LG, Bailey S, Leonard C, Ormes J, Caress AL. Perceptions, experiences and needs of patients with idiopathic pulmonary fibrosis. J Adv Nurs. 2015;71(5):1055-1065.

21. 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(1):1-7.

22. Ramadurai D, Corder S, Churney T, Graney B, Harshman A, Meadows S, et al. 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?'. BMJ Open Quality. 2018;7(1):e000207.

23. Stubber C, Kirkman M. The experiences of adult heart, lung, and heart-lung transplantation recipients: A systematic review of qualitative research evidence. PloS one. 2020;15(11):e0241570.