Raising awareness on physician–patient communication in IPF: an Italian multicenter study exploring the pulmonologist’s perspective

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Abstract. Background: Idiopathic pulmonary fibrosis (IPF) remains a debilitating, poor prognosis disease requiring a patient-centered approach. Objectives: To explore the pulmonologist’s perspective on physician–patient communication. Methods: A faculty of psychologists and pulmonologists organized a training course consisting of two workshops 12 months apart. Self-assessment questionnaires (pre- and post-course), role play (RP) simulations (during both workshops) and clinical consultation observations followed by semi-structured interviews (during the 12 months) were employed to evaluate the pulmonologists’ knowledge of patient-centered medicine and communication/relational skills (questionnaires), their communication style (RP) and possible communication/relational difficulties (semi-structured interviews). Results: Twenty-three pulmonologists attended the first workshop and 14 the second one; 10 attended both. The questionnaires revealed the interest in patient-centered medicine and communication but also the need for deeper knowledge and improved skills. From the RP sessions performed during the first workshop, a disease-oriented approach emerged; notably, after the training, some improvements suggested a more patient-centered approach, e.g., a more frequent exploration of the patient agenda. Finally, the semi-structured interviews allowed to identify the low patients’ cultural level and the poor general knowledge of IPF among the barriers hampering an effective communication with the clinician, who, however, is responsible for overcoming these obstacles. Conclusions: Despite the overall disease-prone approach to IPF patients, there was room for improvement through adequate training, which, in practice, may ameliorate communication and drive towards patient-centeredness. Exploring the pulmonologists’ needs may help tailoring training interventions. Raising awareness on these topics is crucial to ensure IPF patients optimal care.

Keywords: Communication, Idiopathic pulmonary fibrosis, Questionnaire, Patient-centeredness, Role play, Semi-structured interviews, Training.

Introduction

Idiopathic pulmonary fibrosis (IPF) is a chronic progressive lung disease characterized by a highly variable clinical course and dismal prognosis, with a median survival of 3 years (1–3). Albeit new antifibrotic drugs may delay progression (4,5) and prolong
survival (4,6), IPF remains an extremely debilitating disease, with a considerable personal, social and economic burden imposed on both patients and caregivers (7–12). The current goal of management is to promptly diagnose IPF and commence therapy, in the attempt to improve the clinical outcomes as well as the quality of life (QoL) (7,13). Accordingly, as with other chronic diseases, the need for a holistic patient-centered approach is emerging also in the setting of IPF (14–17). Such an approach comprehensively accounts for the patients’ psychological status besides physical conditions, being tailored on individual preferences, needs and values; moreover, it tries to enhance patients’ engagement, involve them actively in shared decision-making, and integrate caregivers as well in the process of care (18,19). Patient-centered medicine is based on the creation of a strong therapeutic alliance between physicians and patients, which, over time, can contribute to reduce physicians’ stress and burnout and increase patients’ compliance to therapy (20–22). A good alliance, in turn, relies on effective physician-patient communication (23,24), which correlates with improved patient health outcomes (25). This is particularly important when treatment is associated to adverse events that may lead to discontinuation: in this case, educating patients on how to promptly recognize and manage such events can improve symptoms and increase treatment persistence (22,26). Notably, several studies assessing the feasibility and efficacy of training programs on physicians’ emotions and attitudes towards communication have demonstrated that good communication skills can be taught and learned (20,27–31).

In the context of IPF, exploration of the patients’ views of disease management has unveiled several unmet needs, including the need for better communication with the physician, for more and high-quality information, and for psychological support at all stages of patient journey (12,32–40). In contrast, the pulmonologists’ perspective has been poorly documented; yet, this is crucial to identify possible areas of improvement in physician-patient communication, particularly in such complex patients.

Here, we report the main findings of a training course held for Italian pulmonologists and focused on physician-patient communication. It aimed to assess and possibly improve the communication knowledge and skills of specialists, and to raise awareness on the importance of communication and patient-centeredness in the challenging setting of IPF.

**Methods**

**Study design**

The training course took place between April 2017 and April 2018 and was organized by a multidisciplinary faculty composed of psychologists (directed by MM), all MDs specialized in psychotherapy and working as researchers and trainers at the University of Milan, with extensive experience in physician-patient communication, patient-centered medicine and qualitative research; and of pulmonologists (who, together with MM, are authors of this paper) actively involved in the care of patients with IPF. Before the course, the psychologists and the pulmonologists collaborated to identify key topics to focus the course on. The pulmonologists then participated as trainees in the course activities.

This is a mixed-method study structured on two components: quantitative, based on a self-assessment questionnaire, and qualitative, based on role play (RP) and semi-structured interviews.

The data were collected during the training course, that was structured as follows:

- **First workshop (21st April 2017).** The psychologists and all trainees first met on this day. The psychologists introduced themselves, illustrating their activities and interests, and presented the techniques that they were going to employ during the course. Then, the faculty provided lectures covering the following aspects of patient-centered medicine: the counseling of IPF patients from the specialist’s point of view; how to give and collect information during a clinical consultation; exploring the patient’s agenda, that is the patient’s background (with feelings, ideas, expectations and context linked to the disease) he/she brings to the consultation; specific techniques of communication and the logic of communication.

At the beginning of the workshop, a self-assessment questionnaire on the knowledge of patient-centered medicine and on communication and relational skills was administered to participants.

During the workshop, the pulmonologists were involved in RP sessions with the aim to analyze their communication style.
- 12-month period, during which the psychologists of the faculty participated as observers in the clinical consultations, spending an entire day in the clinic for 8 non-consecutive days at each site.

After every consultation, the psychologists discussed with each pulmonologist about his/her communication style and, at the end of the 8 days, conducted face-to-face, semi-structured interviews to collect qualitative data on the pulmonologist’s perspective.

- Second workshop (13th April 2018), during which the same activities performed in the first workshop (i.e. self-assessment questionnaire [at the end of the workshop] and RP [during the workshop]) were repeated and new topics were discussed, such as breaking bad news and patient education. Moreover, the psychologists of the faculty shared and discussed with the participants the results of the interviews.

Participants

In all, 10 Centers were selected (4 in Northern, 4 in Central and 2 in Southern Italy).

For the present study, no Ethics approval had to be requested according to our current National legislation, as no patient data are involved. All pulmonologists participating in the initiative were volunteers and signed an informed consent.

Data collection

Self-assessment questionnaire

Before the start of the first workshop and at the end of the second one, participants completed a self-assessment questionnaire composed of 8 questions aimed at evaluating their knowledge of patient-centered medicine and their communication and relational skills. Questions were formulated by the psychologists and pulmonologists of the faculty; they are reported in Figure 1. A 5-point scale was chosen to quantitatively rate each answer.

Role-play simulations

Among the variety of interactive and engaging educational techniques available, RP is a simulation method frequently employed in medical education to practice and improve clinical and conversational skills (41). The RP usually simulates challenging situations encountered by physicians in their daily practice such as difficult conversations with seriously ill patients (20,40,41) – indeed, it is widely used in oncology and palliative care settings.

Before the course, the psychologists consulted the pulmonologists of the faculty to appropriately plan the RP script. They decided to simulate a 4-minute consultation during which a pulmonologist had to communicate the diagnosis of IPF to a 51-year-old woman. In the simulation, the pulmonologist had to replace the colleague in charge of the patient; the patient role was simulated by an actress, trained and rehearsed by the faculty to follow a detailed script.

Each session was video-recorded. The RP method was employed in both workshops.

Semi-structured in-depth interviews

In-depth interviewing is a qualitative research technique relying on the conduction of intensive one-to-one interviews to explore the respondent’s perspectives on a particular idea or situation, for instance collecting experiences and meanings of a disease (44).

At each site, after observing the clinical consultations, the psychologists of the faculty conducted face-to-face semi-structured in-depth interviews using a guide with 4 mandatory open questions (Q) that they had developed with the pulmonologists of the faculty to capture the difficulties encountered during the clinical consultations with IPF patients:

Q1. What are the main communicative-relational difficulties encountered when dealing with patients affected by IPF?

Q2. What are the main communicative-relational difficulties encountered when communicating the therapeutic plan?

Q3. What mechanisms come into play in the therapeutic decision-making process?

Q4. What are the main communicative-relational difficulties when evaluating IPF patients and their treatment adherence during therapy?

Based on the answers, the interviewer could decide to go more in depth into the pulmonologist’s perspective. Each interview was audio-recorded, transcribed verbatim and anonymized in accordance with local data protection laws.
Data analysis

Self-assessment questionnaire

For each question, the proportion of responders indicating any of the 5-point scale scores was calculated. Due to the limited number of participants, analyses are descriptive only.

Role-play simulations

Each video-recorded consultation was independently analyzed by two psychologists, who employed an ad-hoc 20-item grid to evaluate the communication and relational style of the pulmonologist using the following interventions:

Physician’s presentation to the patient: scored as complete if the doctor stood up, shook the patient’s hand and introduced him/herself; incomplete, if he/she did not stand up or did not shake the patient’s hand or did not introduce him/herself; absent, if he/she did not stand up, shake the patient’s hand and introduced him/herself

First question: it could be open (e.g., how are you?), closed or absent (i.e. when the patient starts talking even if the physician has asked no question) in case the patient started talking without waiting for the doctor’s question

Multiple/linked closed questions, which may limit the communication in any consultation

Other techniques of communication: silence, paraverbal communication, categorization (i.e., the physician anticipates what he/she is going to tell or do with the patient), focusing (i.e., strategies to focus the patient’s attention), warning shot (i.e., a statement used to alert the patient to the seriousness of what is about to be said), brief recap (of what the physician said) and feedback (i.e., the physician verifies that the patient has understood the most important information imparted during the consultation)

Exploration of the patient agenda: it includes feelings, ideas, expectations and context (all detailed in the simulation’s script).

Cut-off, that is when the physician prefers to cut out the patient cues that refer to his/her agenda rather than acknowledging and spending time on them – as he/she believes that the information is of no clinical interest (45)

Results were expressed as frequencies of participants (N [%]) using each item. The psychologists developed a patient-centeredness score, which was calculated by a rating scale ranging from -1 to +1, where -1 refers to a completely disease-centered intervention, and +1 to a completely patient-centered one: thus, the total score ranged between -20 and +20.

To compare the results of the RP sessions simulated before and after the training (by the same specialist [N=9] and overall [pre: N=22; post: N=12]), we calculated the median (range) patient-centeredness score.

Some weeks after the end of the course, each trainee received via email the results and debriefing of each RP session he/she had participated in.

Semi-structured in-depth interviews

After checking the transcription of each interview (N=15) individually, the psychologists shared and discussed the results, and then organized the key concepts into themes and subthemes, illustrating them by representative quotes.

Results

Participants

Overall, 23 pulmonologists attended the first workshop (females: 60.9% [N=14]) and 14 (females: 50% [N=7]) the second one; 10 specialists (females: 50% [N=5]) participated in both. The median age of participants was 34 years (range: 26-63) in the first workshop and 39.5 years (range: 28-64) in the second one.

At the 10 Centers involved in the initiative, 49 pulmonologists (37 attending specialists and 12 residents) had a psychologist present in the clinic for an entire day, for 8 non-consecutive days.

Self-assessment questionnaire

All participants in the first workshop filled in the questionnaire (N=23) aimed at evaluating their knowledge of patient-centered medicine and communication/relational skills. Results are shown in Figure 1.
Figure 1. Results of the 8-question self-assessment survey completed by pulmonologists before the start of the first workshop (pre; N=23) and after the end of second one (post; N=11).
Overall, the interest towards the topics of patient-centered medicine and communication was accompanied by the awareness of poor knowledge and inadequate skills. Briefly, the expertise in the field of patient-centered medicine (question 1) was self-rated as satisfying by 40.3% of responders and good or excellent by 30.4%; only 4% deemed it as insufficient. While the responders were rather attentive to the area of communication and relationship during clinical consultations (86.9% and 73.9% of responders declared to have thought frequently/very frequently to their own or their colleagues’ style, respectively – questions 2 and 3), this attention did not translate into good knowledge and scientific update on the literature concerning important aspects of patient-centered medicine (breaking bad news [question 4], patient’s cues and prompts [i.e. hints and suggestions in the form of single words that patients, not fully conscious, provide during the consultation about their view of the disease and that refer to an area of their agenda, question 5] and the physician-patient relationship [question 6]). Interestingly, 65.2% of responders thought that the physician-patient communication can be taught (question 7). Finally, 43.5% declared to be unable to explain the limits and principles of doctor-centered medicine (question 8).

During the second workshop, 11 of 14 (78.6%) participants completed the questionnaire. Despite the limited number of responders and the fact that the answers were anonymous, an improvement was observed with regard to the following issues: more responders declared to feel able to explain the meaning of cues and prompts (73% vs 9%, question 5), to consider teachable the physician-patient communication (100% vs 65.2%, question 7) and to feel able to explain the meaning and limits of disease-centered method (81% vs 22%, question 8) (Figure 1).

Role-play simulations

This interactive method was used to test the physician’s communication and relational style (Table 1). The actual aim of the simulated consultation was to communicate the diagnosis of IPF. During the first workshop, the majority of participants did communicate the diagnosis (N=19, 86.4%). Physician’s presentation was complete in 12 (54.6%) consultations and the techniques more frequently used were silence and paraverbal communication in 19 cases/each (86.4%). The patient agenda was explored in 2 cases only in which, however, just 1 of the 4 components (i.e. ideas) was taken into account. The cut-off intervention was used in 12 (54.6%) consultations, for a total of 16 times (up to 3 times in the same session).

During the second workshop, 12/14 (85.7%) specialists participated in RP, 9 of whom had already participated in the first workshop. Results of the ad-hoc 20-item grid completion in the 12 cases are reported in Table 1. When the median patient-centeredness score was compared between all pre-(N=22) and post-training (N=12) simulations, an increase was observed from 2 (range: -1, 6) to 5 (range: 2, 8). This depended mainly on the higher proportion of specialists who explored the patient agenda (from 9.1% to 66.7%), with an effort to explore not only ideas but also feelings and expectations (for a total number of 11 times), and to avoid the use of cut-off (decreased from 54.5% to 8.3%). Moreover, there was a more frequent use of complete physician’s presentation to the patient (from 54.6% to 88.9%), a first question open (from 27.3% to 50.0%) and of a reduced use of multiple/linked close questions (from 45.5% to 25.0%).

Semi-structured in-depth interviews

Overall, 173 consultations were conducted with patients diagnosed with IPF (74.6% [N=129] men; mean duration: 45 minutes, range: 15-120 minutes): of these, 21 (12.1%) were first visits; 15 of the 37 pulmonologists who had a psychologist present in the clinic accepted to undergo semi-structured interviews. After listening to the transcription of the interviews, based on the answers to 4 mandatory questions and other possible questions formulated to go more in depth into the pulmonologist’s perspective, the psychologists organized the key concepts into themes and subthemes supporting them through quotes (Table 2). Some communication and relational difficulties emerged in different moment of the process of care.

When dealing with patients affected by IPF (Q1), the pulmonologists acknowledged the following difficulties: breaking bad news; ensuring patient’s deep understanding of disease severity, treatment features and their impact on the patient’s lifestyle, which is frequently due to the patient’s low
Table 1. Overall results of the RP sessions taking place before (pre, N=22) and after (post, N=12) the workshop, during which a pneumologist had to replace a colleague and communicate the diagnosis of IPF to a patient simulated by an actress. Each video-recorded consultation was analyzed by two psychologists, who scored in an ad-hoc 20-item grid whether the diagnosis of IPF had been fully communicated, along with the use of the communication interventions reported in the table to define whether the approach adopted was more oriented towards patient-centered medicine or disease-centered medicine. For each item, the number (%) of specialists employing it during the simulation is reported.

| Item                        | Pre N=22 | Post N=12 |
|-----------------------------|----------|-----------|
| Communication of the diagnosis of IPF | 19 (86.4) | 11 (91.7) |
| Physician’ presentation     |          |           |
| Complete                    | 12 (54.6) | 11 (91.7) |
| Incomplete                  | 9 (40.9)  | 0 (0)     |
| Absent                      | 1 (4.5)   | 1 (8.3)   |
| First question              |          |           |
| Open                        | 6 (27.3)  | 6 (50.0)  |
| Close                       | 9 (40.9)  | 3 (25.0)  |
| None                        | 7 (31.8)  | 3 (25.0)  |
| Multiple/linked close questions | 10 (45.5) | 3 (25.0)  |
| Other techniques of communication |      |           |
| Silence                     | 19 (86.4) | 9 (75.0)  |
| Paraverbal communication    | 19 (86.4) | 9 (75.0)  |
| Categorization              | 9 (40.9)  | 3 (25.0)  |
| Focusing                    | 6 (27.3)  | 2 (16.7)  |
| Warning shot                | 1 (4.5)   | 1 (8.3)   |
| Brief recap                  | 1 (4.5)   | 3 (25.0)  |
| Feedback                    | 0 (0)     | 1 (8.3)   |
| Agenda exploration          |          |           |
| Feelings                    | 2 (9.1)   | 8 (66.7)  |
| Ideas                       | 0 (0)     | 2 (16.7)  |
| Expectations                | 2 (9.1)   | 8 (66.7)  |
| Context                     | 0 (0)     | 0 (0)     |
| Cut-off                     | 12 (54.5) | 1 (8.3)   |

education and poor knowledge of the disease; delivering information about the lack of therapies able to cure IPF; the presence of caregivers. Making the patient fully understand the importance of therapy and the mental and physical commitment it requires was reported as the main obstacle when communicating the therapeutic plan (Q2). The lack of full comprehension of patient’s needs and expectations and the lack of a strong therapeutic alliance by the pulmonologist, together with the patient’s young age and asymptomatic or paucisymptomatic disease contributed to this difficulty. In the therapeutic decision-making process (Q3), it emerged the importance of tailoring treatment to each patient’s clinical and psychological characteristics, preferences and social life, without overlooking the adverse events associated to treatment. Finally, during the follow-up, treatment adherence did not seem to be a source of concern (Q4) if the patient understood the severity of IPF and the importance of therapy. However, in this phase of the patient’s journey, lies and complaints may represent obstacles to the correct evaluation of the patient’s status.

**Discussion**

To our knowledge, this is the first study comprehensively evaluating the training needs of pulmonologists caring for IPF patients and their view on the management of these complex patients. While several
Table 2. Results of the semi-structured interviews (N=15) conducted by the psychologist team at the end of the 8 days of on-site clinical consultations. After listening to the transcription of the interviews, the psychologists organized the key concepts into themes and subthemes.

| Questions                                                                 | Themes and subthemes                                                                 | Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|---------------------------------------------------------------------------|--------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| **Q1. What are the main communicative-relational difficulties encountered when dealing with patients affected by IPF?** | *Breaking bad news and emotional burden (not for all specialists)*<br>*Ensuring deep understanding of disease severity and treatment features by patients, and of their impact on the subject’s lifestyle*<br>- Patients’ cultural level (frequently low)<br>- Poor (general) knowledge of the disease: when the patient finds out that IPF is not a cancer, he/she is relieved<br>*Communicating the lack of an effective therapy to cure IPF, which, conversely, is important to prevent or delay progression*<br>- Lifelong<br>- Adverse events may impair QoL and limit daily activities<br>*The presence of caregivers*<br>- Their presence may hamper communication during the consultation; conversely, engaging caregivers may facilitate patient commitment and adherence | *“The first difficulty is to inform on a disabling disease with a dismal prognosis”; “the main emotional difficulty is to cope with disease denial and silent patients”*<br>*“The difficulty of communicating depends on the cultural background of the patient; it may be required to use simple words to convey complex messages”*<br>*“When the diagnosis is communicated, patients and their families are relieved as IPF is not a cancer”; “in contrast to cancer, IPF is poorly known”; “some patients say they would prefer to be diagnosed with cancer (as it is a well-known disease), but IPF prognosis is poor as well”*<br>*“The main difficulties are actually linked to the communication of the diagnosis: what IPF is, what clinical evolution implies and what the limitations in daily activities are”; “It is tough to communicate that IPF cannot be cured but at least progression can be slowed down”; “sometimes it is difficult to convince a patient in good conditions to take a therapy that will make him/her feel bad because of adverse events”*<br>*“Sometimes communication is complicated by the presence of the family, who may talk over to the patient and try to get all the physician’s attention and drive the consultation”; “it is important to have the collaboration of the person close to the patient”*<br>*“Patients are scared; if the physician can establish an alliance, then reaching the goal (i.e. having him/her on therapy) gets easier”*<br>*“As efficacy data in asymptomatic patients are scarce, making a therapeutic decision in these patients, who resist to therapy just because of their health conditions, is more difficult”*<br>*“The available therapies require multiple administrations, regular visits over the year and impose limitations, so that the patient must be mentally and physically committed”*<br>*“Patients are scared; if the physician can establish an alliance, then reaching the goal (i.e. having him/her on therapy) gets easier”*<br>*“As efficacy data in asymptomatic patients are scarce, making a therapeutic decision in those patients, who resist to therapy just because of their health conditions, is more difficult”*<br>*“The choice depends on each patient’s age, needs, expectations and, lifestyle, clinical situation, comorbidities and polypharmacy and on the drug’s adverse events as well”*<br>*“There are no many tools to monitor adherence to therapy besides patient’s integrity: he/she knows that IPF is a severe disease and that therapy is expensive and has to be picked-up at the hospital’s pharmacy once a month; we perform blood tests monthly and visit patients every 4 weeks, and evaluate disease progression and therapy efficacy every 6 months”; “There is a very strict control of prescriptions”; “We perform functional tests every three months and blood tests every month; patients have to pick-up the drug every month, this helps compliance”; “the hardest part is to have therapy started: once it is commenced, compliance is high”*<br>*“I found out that patients lie, and it has been a surprise; it may happen even after years; more honesty would help to establish a better process of care”*<br>|
| **Q2. What are the main communicative-relational difficulties encountered when communicating the therapeutic plan?** | *Making the patient fully understand the importance of therapy, which requires both mental and physical commitment*<br>- Lack of full comprehension of patient’s needs and expectations by the pulmonologist<br>- Lack of an established therapeutic alliance<br>- Young patient’s age<br>- Asymptomatic or paucisymptomatic patients | *“The choice depends on each patient’s age, needs, expectations and, lifestyle, clinical situation, comorbidities and polypharmacy and on the drug’s adverse events as well”*<br>*“The available therapies require multiple administrations, regular visits over the year and impose limitations, so that the patient must be mentally and physically committed”*<br>*“Patients are scared; if the physician can establish an alliance, then reaching the goal (i.e. having him/her on therapy) gets easier”*<br>*“As efficacy data in asymptomatic patients are scarce, making a therapeutic decision in those patients, who resist to therapy just because of their health conditions, is more difficult”*<br>*“The choice depends on each patient’s age, needs, expectations and, lifestyle, clinical situation, comorbidities and polypharmacy and on the drug’s adverse events as well”*<br>*“There are no many tools to monitor adherence to therapy besides patient’s integrity: he/she knows that IPF is a severe disease and that therapy is expensive and has to be picked-up at the hospital’s pharmacy once a month; we perform blood tests monthly and visit patients every 4 weeks, and evaluate disease progression and therapy efficacy every 6 months”; “There is a very strict control of prescriptions”; “We perform functional tests every three months and blood tests every month; patients have to pick-up the drug every month, this helps compliance”; “the hardest part is to have therapy started: once it is commenced, compliance is high”*<br>*“I found out that patients lie, and it has been a surprise; it may happen even after years; more honesty would help to establish a better process of care”*<br>|
| **Q3. What mechanisms come into play in the therapeutic decision-making process?** | *Accounting for both clinical parameters, psychological status and social life (therapy is not for everyone and must be tailored on the candidate’s features)*<br>- Accounting for the changes and AEs caused by therapy, which may affect QoL (e.g. photosensitivity)<br>- Accounting for the patients’ preferences | *“The choice depends on each patient’s age, needs, expectations and, lifestyle, clinical situation, comorbidities and polypharmacy and on the drug’s adverse events as well”*<br>*“The available therapies require multiple administrations, regular visits over the year and impose limitations, so that the patient must be mentally and physically committed”*<br>*“Patients are scared; if the physician can establish an alliance, then reaching the goal (i.e. having him/her on therapy) gets easier”*<br>*“As efficacy data in asymptomatic patients are scarce, making a therapeutic decision in those patients, who resist to therapy just because of their health conditions, is more difficult”*<br>*“The choice depends on each patient’s age, needs, expectations and, lifestyle, clinical situation, comorbidities and polypharmacy and on the drug’s adverse events as well”*<br>*“There are no many tools to monitor adherence to therapy besides patient’s integrity: he/she knows that IPF is a severe disease and that therapy is expensive and has to be picked-up at the hospital’s pharmacy once a month; we perform blood tests monthly and visit patients every 4 weeks, and evaluate disease progression and therapy efficacy every 6 months”; “There is a very strict control of prescriptions”; “We perform functional tests every three months and blood tests every month; patients have to pick-up the drug every month, this helps compliance”; “the hardest part is to have therapy started: once it is commenced, compliance is high”*<br>*“I found out that patients lie, and it has been a surprise; it may happen even after years; more honesty would help to establish a better process of care”*<br>|
| **Q4. What are the main communicative-relational difficulties when evaluating IPF patients and their treatment adherence during therapy?** | *Adherence is not such a big deal, unlike for other chronic diseases, if the patient has clearly understood the severity of IPF*<br>- Regular monthly visits<br>- Regular drug pick-up<br>- Importance of therapy<br>- Cost of therapy<br>- Awareness of disease severity<br>- An effective physician-patient relationship<br>*Understanding when patients lie*<br>*Interpreting patients’ complaints and if they really depend on IPF therapy* | *“The choice depends on each patient’s age, needs, expectations and, lifestyle, clinical situation, comorbidities and polypharmacy and on the drug’s adverse events as well”*<br>*“The available therapies require multiple administrations, regular visits over the year and impose limitations, so that the patient must be mentally and physically committed”*<br>*“Patients are scared; if the physician can establish an alliance, then reaching the goal (i.e. having him/her on therapy) gets easier”*<br>*“As efficacy data in asymptomatic patients are scarce, making a therapeutic decision in those patients, who resist to therapy just because of their health conditions, is more difficult”*<br>*“The choice depends on each patient’s age, needs, expectations and, lifestyle, clinical situation, comorbidities and polypharmacy and on the drug’s adverse events as well”*<br>*“There are no many tools to monitor adherence to therapy besides patient’s integrity: he/she knows that IPF is a severe disease and that therapy is expensive and has to be picked-up at the hospital’s pharmacy once a month; we perform blood tests monthly and visit patients every 4 weeks, and evaluate disease progression and therapy efficacy every 6 months”; “There is a very strict control of prescriptions”; “We perform functional tests every three months and blood tests every month; patients have to pick-up the drug every month, this helps compliance”; “the hardest part is to have therapy started: once it is commenced, compliance is high”*<br>*“I found out that patients lie, and it has been a surprise; it may happen even after years; more honesty would help to establish a better process of care”*
studies have explored the perspective of IPF patients, little is known on the perspective of specialists.

The main finding of our work is that an adequate training may ameliorate communication and drive towards patient-centeredness, in line with previous studies demonstrating that communication skills can be taught and learned (20,27–31). This is important, given that the social and emotional burden of IPF is leading to shift from a disease-centered to a patient-centered approach.

The self-assessment questionnaire offered the unique opportunity to explore the knowledge and skills of pulmonologists about communication and patient-centered medicine. Results show that even in the case of pulmonologists interested in these topics, knowledge gaps remain to be filled and skills to be improved. Before the first workshop, most responders self-rated as satisfying to excellent their expertise in patient-centered medicine and declared to have paid attention to the communication style during clinical consultations; however, these elements did not translate into good knowledge and scientific update on the literature concerning important aspects of patient-centered medicine. Thus, our results shed some light on the educational needs (not just in terms of disease-related information) of physicians managing IPF patients, which have been poorly explored so far (40). Interestingly, following the training course, an effort emerged to pay even more attention to the style of communication and to increase knowledge, for example, on the available literature regarding “breaking bad news” in medicine. This topic has been extensively investigated in several life-changing diseases but not in IPF. Furthermore, in line with the main message emerged from RP, more participants declared to believe that training can improve the physician-patient relationship. Through the course, pulmonologists focused more attention on patient-centeredness and their attitude was more prone to meet the needs of patients and caregivers, especially with regard to the emotional support (12,32–40). It is worth mentioning that, although data on the actual length of participants’ practice were not collected, their age suggests that younger physicians have a great sensitivity towards the issue of physician-patient communication. This is potentially an aspect deserving better training in all university and post-graduate medical training courses.

From the RP sessions performed before the training course, an approach more prone to disease-centered medicine surfaced, as shown, in particular, by the following elements: i) underuse of many communication techniques besides silence and open questions; ii) almost complete lack of exploration of the patient’s agenda (performed only by two specialists who limited to explore the area of ideas) which, instead, should be the basis of the consultation; iii) frequent use of cut-offs, employed by more than half of specialists. Nonetheless, the same activities performed after the course demonstrate that an adequate training can improve certain skills typical of patient-centered medicine.

Finally, the semi-structured interviews, frequently used to gain insight into the perspective of the interviewees on a specific topic (46), show that several barriers hinder an effective communication with the patient in clinical practice. When dealing with patients affected by IPF, the difficulty in making the patient clearly understand the severity of the disease as a life-threatening condition and the burden of treatment was mainly attributable to the low cultural level of patients and the poor general knowledge of IPF. These factors are common to other scarcely understood, yet severe, diseases such as chronic obstructive pulmonary disease; as a result, patients tend to feel relieved when they realize to have a non-malignant disease (47). Regardless of the underlying causes, it is certainly responsibility of the clinician to find a way to make patients unequivocally understand the meaning of a complex diagnosis. This further supports the importance of planning ad-hoc interventions focused on physician-patient communication and relation in any complex setting.

With regard to therapy, antifibrotics currently represent the standard of care for the treatment of IPF. Still, a subset of patients undergo dose reduction and temporary or permanent therapy discontinuation because of the adverse events (48). Thus, educating them on how to recognize and manage such events can favor treatment persistence and increase the clinical benefit (26,49,50). Notably, the interviews allowed to identify the lack of a therapeutic alliance as a barrier to the full comprehension of the importance of treatment when communicating the therapeutic plan, which once more underlies the value of training the specialists.
In our study, two factors deserve particular attention: first, the mean duration of a consultation (i.e. 45 minutes) is a rather long time especially if compared to the average time generally available in clinics, that, in the authors’ experience, is about 20 minutes. This further highlights the complexity of IPF patients, and the commitment required to ensure adequate management. The second element is that, unexpectedly, adherence did not rise concerns among specialists: indeed, it was favored by the fact that if the patient clearly understands the severity of IPF, he/she is motivated to take therapy, and by the modalities of therapy administration. Although this does not necessarily mean that patients do actually take medicines, previous reports have confirmed high adherence on antifibrotic drugs (51,52). This also suggests that the hardest part, for a pulmonologist dealing with a patient diagnosed with IPF, is to accompany him/her up to this point of the process of care.

The main limitation of the study relies on the limited number of specialists participating in the activities of both workshops, which permitted only descriptive analyses and did not allow to draw any definitive conclusion on the effectiveness of the training course. In particular, the fact that different pulmonologists completed the survey before and after the course hampers a direct comparison Moreover, we acknowledge a possible selection bias: it is likely that physicians participating in a communication course are interested in this topic and more prone to feel inadequately skilled, as documented by the results of the pre-course questionnaire. The main strength is represented by the comprehensive approach, set-up by a team of psychologists experienced in physician-patient communication, patient-centered medicine, and qualitative research, to explore the training needs as well as the perspective of specialists managing IPF patients in their clinical practice.

Despite the recent advances in understanding IPF pathogenesis and treatment, it remains a debilitating, poor prognosis disease. Thus, managing these complex patients requires to shift from a disease-centered to a patient-centered approach. Our results showed that participants adopted a disease-prone approach to IPF patients, but also that there was room for improvement through adequate training.

As the physician-patient communication is a pillar of patient-centered medicine, providing adequate education and training to specialists is of the utmost importance to improve their communication and relational skills, ultimately ensuring patients optimal care. In this context, the pulmonologists’ needs described here may help to plan such training interventions. Raising awareness on these topics remains crucial.

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