



# Communicating with patients with idiopathic pulmonary fibrosis: can we do it better?

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Communication from clinicians to patients with idiopathic pulmonary fibrosis should be empathetic, and take account of the patient's perceptions and concerns. Tools are available to help clinicians improve their interactions with patients with IPF. <https://bit.ly/3BWjA7h>

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## Abstract

Communications between clinicians and patients with idiopathic pulmonary fibrosis (IPF) have the potential to be challenging. The variable course and poor prognosis of IPF complicate discussions around life expectancy but should not prevent clinicians from having meaningful conversations about patients' fears and needs, while acknowledging uncertainties. Patients want information about the course of their disease and management options, but the provision of information needs to be individualised to the needs and preferences of the patient. Communication from clinicians should be empathetic and take account of the patient's perceptions and concerns. Models, tools and protocols are available that can help clinicians to improve their interactions with patients. In this article, we consider the difficulties inherent in discussions with patients with IPF and their loved ones, and how clinicians might communicate with patients more effectively, from breaking the news about the diagnosis to providing support throughout the course of the disease.

## Introduction

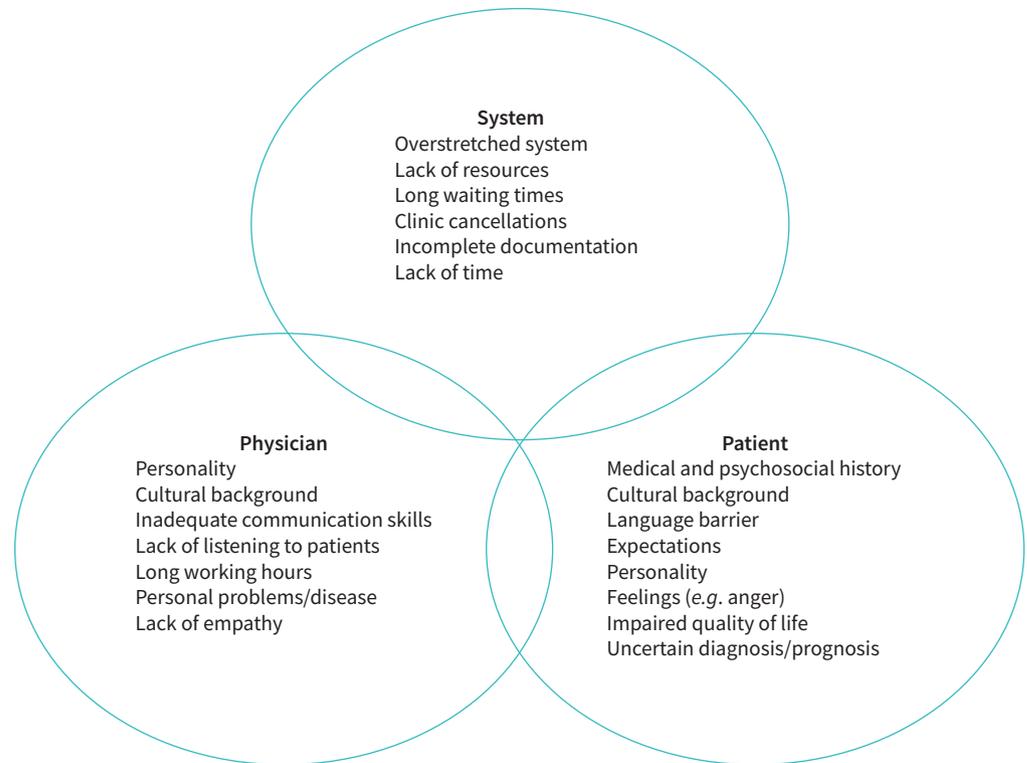
Idiopathic pulmonary fibrosis (IPF) is a diagnosis with devastating consequences for the patient. Receiving a diagnosis of IPF may evoke a range of emotions, including sadness, fear, confusion and denial [1–3]. Patients look to their clinicians as a source of information about their disease, its prognosis and how they can lessen its impact on their lives [4–6], and should be supported to take an active role in their care [7]. Patients may benefit from both emotional support and practical advice as they adapt to the impact of IPF on their lives and relationships, and contemplate the shortening of their lives [2, 3, 8, 9].

Conversations between a clinician and a patient have the potential to be challenging, for reasons related to the patient, the clinician and the healthcare system (figure 1) [10]. The variable course, risk of acute exacerbations and poor prognosis associated with IPF cause uncertainty both for patients and clinicians. However, this uncertainty should not lead to “prognostic paralysis” and prevent clinicians from having meaningful conversations about patients' fears and needs, while acknowledging uncertainties. In this article, we consider the difficulties in communicating with patients with IPF and their loved ones, and how clinicians might communicate with patients more effectively, from breaking the news about the diagnosis to providing support throughout the course of the disease.

## What are the challenges in communicating with patients with IPF?

Most people diagnosed with IPF have never heard of IPF and nor have their families or friends. Patients have often taken some time to receive their diagnosis, seen a number of specialists, and received





**FIGURE 1** Factors that contribute to challenging interactions between physicians and patients. Reproduced and modified from [10] with permission.

conflicting information about their likely diagnosis and prognosis [11, 12]. A diagnosis of IPF may leave patients feeling confused and misunderstood [1, 2, 4, 9]. Not all centres are set up to provide adequate information and support [13, 14]. Time constraints in busy clinics pose challenges to providing adequate patient support. Many patients find information online that is inaccurate, outdated or misleading [15, 16], or would have been better understood if communicated by a clinician than read by the patient alone. A significant proportion of patients trying to cope with IPF suffer from anxiety or depression [17–19] or other forms of psychological distress. Multiple factors may contribute to this, including breathlessness and cough, a loss of ability to perform daily activities, and fears around how progression of their disease will affect them and their families. Although awareness has increased, clinicians may not be willing to initiate a discussion about mental health with their patients.

The fear of destroying patients' hopes leaves many physicians reluctant to have conversations about life expectancy with their patients [20]. The unpredictable course of disease and risk of acute exacerbations of IPF, which are associated with very high mortality, make discussions about prognosis even more challenging. An online survey of 287 European pulmonologists found that only 28% rated themselves as comfortable when discussing the typical prognosis of IPF with a newly diagnosed patient and only 54% typically communicated the typical prognosis to a patient at diagnosis [5]. Only 31% of respondents said that they typically provided facts about average life expectancy if a patient asked them how long they had left to live. The reasons for this are likely multifactorial and reflect the difficulty of "putting a number on" life expectancy when the course of IPF is variable. In clinical practice, clinicians must balance the uncertainties of prognostic estimates with the need (and, in some countries, the legal requirement) to provide patients with all necessary information.

#### Could communication skills training help?

Communication is a skill that must be learnt and practised. The importance of training should not be underestimated: research has demonstrated that clinicians' empathy and communication skills, including in breaking bad news, can be improved through well-designed training programmes [21, 22]. Discussions between clinicians and patients require a structured, relationship-centred approach, in which patients not only are given information with compassion and kindness but also have their most important concerns addressed [10, 23–25]. Patient-reported outcome measures, such as questionnaires assessing symptoms and specific impacts of the disease on quality of life, may be useful to identify issues that need to be discussed

[26] but they need to be implemented appropriately [27]. The use of a simple supportive care decision aid tool, completed by the clinician and designed to highlight poor prognostic factors, symptoms of concern and changes in functional status, has been shown to result in increases in end-of-life discussions with the patient and in referrals to palliative care [28]. Tools have also been developed to measure patients' perceptions of empathy during a consultation and so provide clinicians with feedback for self-evaluation [29].

### **What can be learnt from research in patients with cancer?**

IPF has some parallels with life-limiting cancers in the fear that it generates among patients and their families, and the communication challenges that it presents to clinicians. Research conducted into optimising communication between clinicians and patients with cancer may have implications for the care of patients with IPF. The US National Cancer Institute has published a model for patient-centred communication in cancer care, which stresses that communication is a learnt skill, and describes verbal and nonverbal behaviours that clinicians can use to build a strong patient–doctor relationship [23]. The American Society of Clinical Oncology has published a consensus guideline, developed by a multidisciplinary panel, on how to optimise the patient–clinician relationship [30]. Key recommendations focus on core communication skills; how best to discuss care and prognosis, treatment options and end-of-life care; how to facilitate family involvement in care; how to manage barriers to communication; and the role of training in improving communication skills. A systematic review and meta-analysis suggested that communication skills training among clinicians who care for patients with cancer improves empathy, encourages use of more open questions and reduces the likelihood that the clinician states facts without tailoring the response to the patient's emotions or offering support [31]. An evidence-based model known as the “Four Habits Model” provides a simple approach to training on fundamental clinician–patient communication skills [32, 33]. This model focuses on four key habits required by clinicians and the skills associated with them, as well as providing techniques and examples (table 1).

Communication skills guidelines recognise that breaking bad news is a complex communication that is easily affected by emotions (both the patient's and the clinician's) and for which many clinicians feel unprepared [34]. It is important that clinicians resist the temptation to reduce the patient's immediate distress by downplaying the serious nature of the disease, deflecting difficult questions or rushing through the conversation; rather, the patients' questions and emotions should be addressed with empathy [35]. The SPIKES (Setting, Perception, Invitation for information, Knowledge, Empathy, Strategy and Summary) protocol is a skills-based, patient-centred process for breaking bad news [36], which has been shown to reflect the perspectives of patients with several life-changing diseases, including cancer [37]. Emphasis is given to getting the setting right, understanding the patient's perception of their illness, providing knowledge and support, responding to the patient's emotions with empathy, and providing a strategy for the future (figure 2). A series of videos explaining the SPIKES protocol is available at [www.pulmonaryfibrosis360.com](http://www.pulmonaryfibrosis360.com). In addition to aiding communications around diagnosis and prognosis, the SPIKES framework may be used to guide other discussions that require an empathetic approach, for example, those around disease progression [38]. A survey of 226 patients in whom the SPIKES protocol had been used during disclosure of a malignant neoplasm diagnosis found that while the protocol was applied well, the Perception and Invitation steps, which allow the clinician to recognise the patient's viewpoint and adjust their approach, were applied less well than the other steps [39]; this may indicate the areas that present the greatest challenges to clinicians and that require most training.

It should be acknowledged that while the oncology field has prioritised communication and advanced care planning, implementation in practice remains suboptimal [40].

### **What steps can clinicians take to improve communications with patients with IPF?**

Clinicians should plan in advance how they will deliver the necessary information to the patient, being aware of the temptation to down-play the seriousness of the situation, while also taking care not to convey only the worst-case scenario. While some information should be given at diagnosis, given the wealth of information that needs to be conveyed and the variable evolution of IPF and comorbidities, there may be value in pacing additional information as the disease progresses, in line with the preferences of the patient [25, 41]. Studies in a range of diseases have shown that patients are unable to recall several pieces of information provided at the same time and that recall may be worse in patients with a poorer prognosis [42–44]. A study based on focus groups with patients with IPF and their carers concluded that at the point of diagnosis, the key messages that should be communicated are 1) what IPF is, 2) that there is no cure, 3) that IPF is chronic and progressive, and 4) that there are effective treatments to slow progression and manage symptoms [25]. A follow-up appointment 1–4 weeks later may be a better time to have a lengthy discussion about prognosis and treatment options [25]. Important information should be repeated at

TABLE 1 The Four Habits Model for clinician–patient communication

Habit	Skills	Techniques and examples
Invest in the beginning	Create rapport quickly	Introduce yourself to everyone in the room Make a social comment or ask a nonmedical question to put the patient at ease Convey knowledge of the patient’s history by commenting on a prior visit or problem Consider the patient’s cultural background and use appropriate eye contact and body language
	Elicit the patient’s concerns	Start with open-ended questions: “I understand that you’re here for... Could you tell me more about that?”
	Plan the visit with the patient	Repeat concerns back to check understanding Let the patient know what to expect: “How about if we start with talking about..., then I’ll do an exam, and then we’ll go over possible tests/ways to treat this. Sound OK?” Prioritise when necessary: “Let’s make sure we talk about x and y. It sounds like you also want to make sure we cover z. If we can’t get to the other concerns, let’s...”
Elicit the patient’s perspective	Ask for the patient’s ideas	Assess the patient’s point of view: “What concerns you most about this problem?” “What have you done to treat your illness so far?” Ask about ideas from loved ones or the community
	Elicit specific request	Determine the patient’s goal in seeking care: “How were you hoping I could help?”
	Explore the impact on the patient’s life	Check context: “How has the illness affected your daily activities/work/family?”
Demonstrate empathy	Be open to the patient’s emotions	Respond in a culturally appropriate manner to changes in body language or voice tone
	Make an empathetic statement	Look for opportunities to use brief empathic comments: “You seem really worried.” Compliment the patient on their efforts to address the problem
	Convey empathy nonverbally	Use a pause, touch or facial expression
Invest in the end	Deliver diagnostic information	Frame the diagnosis in terms of the patient’s original concerns
	Provide education	Explain the rationale for tests Explain treatments and possible side-effects of therapy Discuss options that are consistent with the patient’s lifestyle, cultural values and beliefs Provide resources in the patient’s preferred language when possible
	Involve the patient in making decisions	Discuss treatment goals Assess the patient’s ability and motivation to carry out the proposed plan Explore barriers: “What do you think we could do to help overcome any problems you might have with the treatment plan?” Test comprehension by asking the patient to repeat instructions Set limits respectfully: “I can understand how getting that test makes sense to you. From my point of view, since the results won’t help us treat your condition, I suggest we consider this instead.”
	Complete the visit	Summarise the visit and review next steps Ask for additional questions Close the visit in a positive way: “It’s been nice meeting you.”

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multiple visits and the patient’s understanding confirmed; this not only ensures that the patient understands the information provided but may also help to improve their recall of it [45].

Provision of information should be individualised at every stage, taking account of the patient’s preferences and priorities. Not all patients want to know everything and patients’ consent to receive more information should be solicited. Most patients want to know their test results, such as spirometry, but these need to be explained in a way that ensures that patients can understand them in the context of having a progressive disease; other patients find that receiving “too much” information increases their anxiety. Prognostication not only plays a role when discussing diagnosis but also during follow-up, when response to therapy and events such as exacerbations, increasing frailty or comorbidities may affect prognosis. The availability of new treatments, participation in research or treatment of comorbidities may provide hope or setbacks for patients.

Clinicians need to be prepared to manage psychological issues as needed over the course of the disease and encourage use of counselling services where these are available. Specific events, such as the initiation of supplemental oxygen, may have a particular impact on the patient and require specific counselling [46].



**FIGURE 2** The six steps of SPIKES for breaking bad news [36]. A series of videos explaining the SPIKES protocol in more detail is available at [www.pulmonaryfibrosis360.com](http://www.pulmonaryfibrosis360.com)

Questions about the side-effects of medications should be answered in a prompt and practical manner. Palliative and supportive care should be provided as needed and not restricted to end-of-life care [47, 48].

The patient's partner, family member or carer should not just be viewed as a source of support for the patient but as a person who may have questions and worries of their own [2]. During a consultation, it may be valuable to repeat a comment or question back to the patient or caregiver, perhaps using different phrasing, to reassure them that you understand what they are saying and see them as a partner in shared decision-making. Where there is disagreement, or simply a number of options, this should be clearly explained to avoid miscommunication.

Conversations with patients should be ended in a way that does not leave the patient feeling "dismissed". A question such as "Tell me what you are going to tell your loved ones about what we discussed today" can be valuable to bring closure to the discussion and provide an opportunity to clarify any points that have been missed. Acknowledging that questions that the patient thinks of following the consultation can be answered later can be reassuring. Following a consultation, clinicians should take time to reflect on how the conversation went and what they might wish to change or add next time.

**TABLE 2** Actions that specialist physicians can take to improve communication with patients with idiopathic pulmonary fibrosis (IPF) (proposed by focus groups of patients and carers)

Use plain language, and be honest and empathetic
Allow adequate time for questions
Ensure there is a follow-up appointment (or telephone/e-mail contact) 1–4 weeks after diagnosis, when the patient has had time to digest their diagnosis and to formulate questions
Tailor information to the individual; the needs of each patient will be different and will change over time
Explain all treatment options to a patient, even those that are not an option for them (and explain why)
Encourage patients to keep a health diary and to report any changes in their health at each appointment
Explain the importance of remaining physically active
Address any concerns with treatments for IPF or comorbidities
Arrange a point of contact for the patient who can be contacted outside of scheduled appointments
Raise the issue of end-of-life planning with the patient when it is a medical imperative or the patient requests information
Provide prompt access to a team trained in dealing with end-of-life issues

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A summary of actions that physicians can take to improve communication with patients with IPF (based on the feedback from focus groups of patients and carers) is given in table 2 [25].

### Conclusions

Patients with IPF see their clinicians as a source of support and information about their disease. The variable course and poor prognosis of IPF should not prevent clinicians from having meaningful conversations with patients about their fears and needs, while acknowledging uncertainties. Effective, empathetic communication is a skill that clinicians can learn and practise. Models, tools and protocols are available that can help clinicians to improve their communication skills, including those needed in breaking bad news. More effective communication, taking into account the individual needs and preferences of the patient, can help to lessen the impact that IPF has on the lives of patients and their loved ones.

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