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

Marlies S. Wijsenbeek1, Francesco Bonella2, Leticia Orsatti3, Anne-Marie Russell4, Claudia Valenzuela5, Wim A. Wuyts6 and Walter F. Baile7

1Dept of Respiratory Medicine, Erasmus MC, University Medical Centre, Rotterdam, The Netherlands. 2Center for Interstitial and Rare Lung Disease, Ruhrlandklinik, University Hospital, Duisburg-Essen University, Essen, Germany. 3Boehringer Ingelheim International GmbH, Ingelheim, Germany. 4College of Medicine and Health University of Exeter, Exeter, UK. 5Pulmonology Dept, Hospital Universitario de la Princesa, Universidad Autonoma de Madrid, Madrid, Spain. 6Unit for Interstitial Lung Diseases, Dept of Pulmonary Medicine, University Hospitals Leuven, Leuven, Belgium. 7University of Texas M.D. Anderson Cancer Center, Houston, TX, USA.

Corresponding author: Marlies S. Wijsenbeek (m.wijsenbeek-lourens@erasmusmc.nl)

Shareable abstract (@ERSpublications)
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

Cite this article as: Wijsenbeek MS, Bonella F, Orsatti L, et al. Communicating with patients with idiopathic pulmonary fibrosis: can we do it better? ERJ Open Res 2022; 8: 00422-2021 [DOI: 10.1183/23120541.00422-2021].

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...
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.
ERJ OPEN RESEARCH REVIEW | M.S. WIJSENBEEK ET AL.

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. 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   | Start with open-ended questions: “I understand that you’re here for… Could you tell me   |
| concerns               |                               | more about that?”                                                                       |
|                         |                               | Repeat concerns back to check understanding                                             |
| Plan the visit with the|                               | Let the patient know what to expect: “How about if we start with talking about…, then I’ll  |
| patient                 |                               | 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   | Ask for the patient’s ideas   | Assess the patient’s point of view: “What concerns you most about this problem?”        |
| perspective             |                               | “What have you done to treat your illness so far?”                                      |
|                         | Elicit specific request       | Ask about ideas from loved ones or the community                                         |
|                         | Explore the impact on the    | Determine the patient’s goal in seeking care: “How were you hoping I could help?”      |
| patient’s life          | patient’s life                | Check context: “How has the illness affected your daily activities/work/family?”         |
| Demonstrate empathy     | Be open to the patient’s      | Respond in a culturally appropriate manner to changes in body language or voice tone    |
|                         | emotions                     | Look for opportunities to use brief empathic comments: “You seem really worried.”       |
|                         | Make an empathetic           | Compliment the patient on their efforts to address the problem                          |
|                         | statement                    | Use a pause, touch or facial expression                                                 |
|                         | Convey empathy nonverbally   |                                                                                         |

| Habit                   | Deliver diagnostic           | Frame the diagnosis in terms of the patient’s original concerns                          |
|                         | information                  | Explain the rationale for tests                                                         |
|                         | Provide education            | Explain treatments and possible side-effects of therapy                                 |
|                         | Involve the patient in       | Discuss options that are consistent with the patient’s lifestyle, cultural values and    |
|                         | making decisions             | beliefs                                                                                  |
|                         |                               | Provide resources in the patient’s preferred language when possible                      |
|                         |                               | 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      | It sounds like you also want to make sure we cover z. If we can’t get to the other      |
|                         | review next steps            | concerns, let’s…”                                                                       |
|                         | Ask for additional questions |                                                                                         |
|                         | Close the visit in a positive way: “It’s been nice meeting you.”                        |

Reproduced and modified from [33] with permission.

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].

https://doi.org/10.1183/23120541.00422-2021
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.
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.

References
1 Senanayake S, Harrison K, Lewis M, et al. Patients’ experiences of coping with idiopathic pulmonary fibrosis and their recommendations for its clinical management. *PLoS One* 2018; 13: e0197660.
2 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: 00065-2016.
3 Ramadurai D, Corder S, Churney T, 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 Qual* 2018; 7: e000207.

---

**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)

| Action                                                                                                                                 |
|-------------------------------------------------------------------------------------------------------------------------------------|
| 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                                                      |

Reproduced and modified from [25] with permission.
4 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.
5 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: 514–524.
6 Moor CC, Wijsenbeek MS, Balestro E, et al. Gaps in care of patients living with pulmonary fibrosis: a joint patient and expert statement on the results of a Europe-wide survey. *ERJ Open Res* 2019; 5: 00124-2019.
7 Lee JS, McLaughlin S, Collard HR. Comprehensive care of the patient with idiopathic pulmonary fibrosis. *Curr Opin Pulm Med* 2011; 17: 348–354.
8 Bajwah S, Koffman J, Higginson IJ, et al. “I wish I knew more…” The end-of-life planning and information needs for end-stage fibrotic interstitial lung disease: views of patients, carers and health professionals. *BMJ Support Palliat Care* 2013; 3: 84–90.
9 Giot C, Maronati M, Becattelli I, et al. Idiopathic pulmonary fibrosis: an EU patient survey. *Curr Res Med Rev* 2013; 9: 112–119.
10 Hardavella G, Aamlí-Gaagnat A, Frille A, et al. Top tips to deal with challenging situations: doctor–patient interactions. *Breathe* 2017; 13: 129–135.
11 Cosgrove GP, Bianchi P, Danese S, et al. Barriers to timely diagnosis of interstitial lung disease in the real world: the INTENSITY survey. *BMJ Pulm Med* 2018; 18: 9.
12 Hoyer N, Prior TS, Bendstrup E, et al. Risk factors for diagnostic delay in idiopathic pulmonary fibrosis. *Respir Res* 2019; 20: 103.
13 Bonella F, Wijsenbeek M, Molina-Molina M, et al. European IPF patient charter: unmet needs and a call to action for healthcare policymakers. *Eur Respir J* 2016; 47: 597–606.
14 The European Federation on Idiopathic Pulmonary Fibrosis and Related Disorders Federation. A snapshot of patient and expert statement on the results of a Europe-wide survey. *ERJ Open Res* 2019; 5: 00124-2019.
15 Fisher JH, O’Connor D, Flexman AM, et al. Accuracy and reliability of internet resources for information on idiopathic pulmonary fibrosis. *Am J Respir Crit Care Med* 2016; 194: 218–225.
16 Lashari BH, Chan V, Shoukat U, et al. YouTube as a source of patient education in idiopathic pulmonary fibrosis: a media content analysis. *J Community Hosp Intern Med Perspect* 2019; 9: 98–102.
17 Ryerson CJ, Berkley J, Carrieri-Kohlman L, et al. Depression and functional status are strongly associated with dyspnea in interstitial lung disease. *Chest* 2011; 139: 609–616.
18 Holland AE, Fiore JF Jr, Bell EC, et al. Dyspnoea and comorbidity contribute to anxiety and depression in interstitial lung disease. *Respirology* 2014; 19: 1215–1221.
19 Gaspole IN, Chapman SA, Cooper WA, et al. Health-related quality of life in idiopathic pulmonary fibrosis: data from the Australian IPF Registry. *Respirology* 2017; 22: 950–956.
20 Brown CE, Jecker NS, Curtis JR. Inadequate palliative care in chronic lung disease. An issue of health care inequality. *Ann Am Thorac Soc* 2016; 13: 311–316.
21 Back AL, Arnold RM, Baile WF, et al. Efficacy of communication skills training for giving bad news and discussions transitioning to palliative care. *Arch Intern Med* 2007; 167: 453–460.
22 Poissy A, Windover AK, Bokar D, et al. Communication skills training for physicians improves patient satisfaction. *J Gen Intern Med* 2016; 31: 755–761.
23 Epstein RM, Street RL Jr. Patient-centered communication in cancer care. Promoting healing and reducing suffering. *NIH Publication No. 07-6225. Bethesda, National Cancer Institute, 2007. Available from: https://cancercontrol.cancer.gov/ 316.
24 Wuyts WA, Peccatori FA, Russell A-M. Patient-centred management in idiopathic pulmonary fibrosis: similar themes in three communication models. *Eur Respir Rev* 2014; 23: 231–238.
25 Masefield S, Cassidy N, Ross D, et al. Communication difficulties reported by patients diagnosed with idiopathic pulmonary fibrosis and their carers: a European focus group study. *ERJ Open Res* 2019; 5: 00055-2019.
26 Swigris JJ, Brown KK, Abdulgawi R, et al. Patients’ perceptions and patient-reported outcomes in progressive fibrosing interstitial lung diseases. *Eur Respir Rev* 2018; 27: 180075.
27 Aaronson N, Elliott T, Greenhalgh J, et al. User’s guide to implementing patient-reported outcomes assessment in clinical practice. *www.isoqol.org/wp-content/uploads/2019/09/2015UsersGuide-Version2.pdf. Date last accessed: 25 January 2021. Date last updated: January 2015.
28 Sharp C, Lamb H, Jordan N, et al. Development of tools to facilitate palliative and supportive care referral for patients with idiopathic pulmonary fibrosis. *BMJ Support Palliat Care* 2018; 8: 340–346.
29 Mercer SW, Maxwell M, Heaney D, et al. The consultation and relational empathy (CARE) measure: development and preliminary validation and reliability of an empathy-based consultation process measure. *Fam Pract* 2004; 21: 699–705.
30 Gilligan T, Coyle N, Frankel RM, et al. Patient-clinician communication: American Society of Clinical Oncology consensus guideline. *J Clin Oncol* 2017; 35: 3618–3632.
31 Moore PM, Rivera S, Bravo-Soto GA, et al. Communication skills training for healthcare professionals working with people who have cancer. Cochrane Database Syst Rev 2018; 7: CD003751.
32 Frankel RM, Stein T. The Four Habits Model. J Pract Manage 2001; 16: 184–191.
33 Stein T, Frankel RM, Krupat E. Enhancing clinician communication skills in a large healthcare organization: a longitudinal case study. Patient Educ Couns 2005; 58: 4–12.
34 Monden KR, Gentry L, Cox TR. Delivering bad news to patients. Proc (Bayl Univ Med Cent) 2016; 29: 101–102.
35 Back A, Arnold R, Tolsky J. Mastering communication with seriously ill patients. New York, Cambridge University Press, 2009.
36 Baile WF, Buckman R, Lenzl R, et al. SPIKES – a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist 2000; 5: 302–311.
37 Mirza RD, Ren M, Agarwal A, et al. Assessing patient perspectives on receiving bad news: a survey of 1337 patients with life-changing diagnoses. AJOB Empir Bioeth 2019; 10: 36–43.
38 Baile WF. Giving bad news. Oncologist 2015; 20: 852–853.
39 Marschollek P, Bąkowska K, Bąkowski W, et al. Oncologists and breaking bad news - from the informed patients’ point of view. The evaluation of the SPIKES protocol implementation. J Cancer Educ 2019; 34: 375–380.
40 Bestvina CM, Polite BN. Implementation of advance care planning in oncology: a review of the literature. J Oncol Pract 2017; 13: 657–662.
41 Overgaard D, Kaldan G, Marsaa K, et al. The lived experience with idiopathic pulmonary fibrosis: a qualitative study. Eur Respir J 2016; 47: 1472–1480.
42 Jansen J, Butow PN, van Weert JC, et al. Does age really matter? Recall of information presented to newly referred patients with cancer. J Clin Oncol 2008; 26: 5450–5457.
43 Selic P, Svab I, Repolusk M, et al. What factors affect patients’ recall of general practitioners’ advice? BMC Fam Pract 2011; 12: 141.
44 McCarthy DM, Waite KR, Curtis LM, et al. What did the doctor say? Health literacy and recall of medical instructions. Med Care 2012; 50: 277–282.
45 Bravo BN, Postigo JML, Segura LR, et al. Effect of the evaluation of recall on the rate of information recalled by patients in primary care. Patient Educ Couns 2010; 81: 272–274.
46 Swigris JJ. Transitions and touchpoints in idiopathic pulmonary fibrosis. BMJ Open Respir Res 2018; 5: e000317.
47 Kreuter M, Bendstrup E, Russell AM, et al. Palliative care in interstitial lung disease: living well. Lancet Respir Med 2017; 5: 968–980.
48 Kalluri M, Claveria F, Ainsley E, et al. Beyond idiopathic pulmonary fibrosis diagnosis: multidisciplinary care with an early integrated palliative approach is associated with a decrease in acute care utilization and hospital deaths. J Pain Symptom Manage 2018; 55: 420–426.