



BACKGROUND

Idiopathic Pulmonary Fibrosis (IPF) is a progressive, life-limiting disease requiring multidisciplinary, coordinated management. While referral to specialty centers is recommended, less is known about how patients define high-quality healthcare and how their experiences differ when seen by general pulmonologists and IPF specialists.¹

METHODS

A mixed-methods study was conducted with adults diagnosed with IPF who participated in:

- Quantitative surveys assessing healthcare experiences
- Semi-structured qualitative interviews exploring provider communication, access to care, care coordination, and support

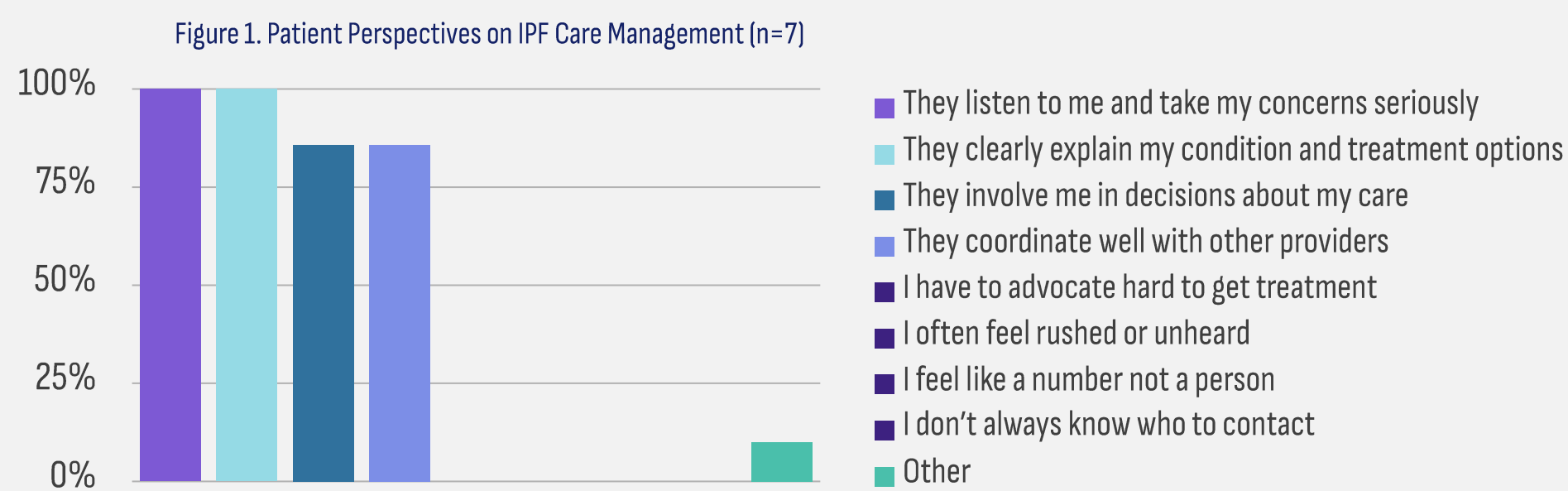
Quantitative data were summarized using descriptive statistics. Qualitative transcripts were analyzed thematically to identify recurrent patterns and patient-defined priorities. Data were anonymized and securely stored to protect participant confidentiality.*

RESULTS

Seven participants completed the quantitative surveys and qualitative interviews. Although the study sample was small, clear trends emerged from the collected data. Overall, participants emphasized that high-quality IPF care extends beyond clinical expertise to include timely access, strong communication, and partnership between the healthcare team, patients, and care partners.

Core Experience of Care

Patients reported high overall satisfaction with their healthcare teams (Figure 1).^{**}



These findings reflect a strong foundation of clinical competence and relational trust.

Attributes that Define High-Quality IPF Care

Patients emphasized that care excellence extends beyond provider expertise, highlighting the importance of:

- 1. Timely, Two-Way Communication**
 - Rapid responses via patient portals (e.g., MyChart), email, or phone reduced anxiety.
 - Proximity to care teams enhanced confidence and access.
- 2. Inclusion of Care Partners**
 - Care partners provide emotional grounding, advocacy, and improved information retention.
 - Care partners do not need to be family members. They may include spouses, friends, support group members, or others within a trusted circle.
- 3. Accurate Post-Visit Documentation**
 - Detailed, accessible visit summaries reinforced complex discussions.
 - Patients valued the ability to review notes and take proactive steps.

“A care partner can be the lead of a team you trust with your life.”

“Some people like to take charge. Some people just want to trust their doctors and don't want to feel that they have to be in charge... It's a difficult thing to nail down in terms of having one solution for all patient types.”

- 4. Flexible Shared Decision-Making**

While 88% reported active involvement in decision-making:

- Some patients embrace a “CEO of my healthcare team” philosophy.
- Others prefer to trust specialist expertise and not feel responsible for leading decisions.
- No single engagement model fits all patients.

- 5. Empowerment and Support Mechanisms**

Helpful elements reported by participants included:

- In-person healthcare visits
- Clinical trial and transplant coordinators
- Support groups (learning from others' lived experiences)
- Writing down questions before appointments
- Pulmonologist-approved educational websites
- Building reciprocal, respectful provider relationships

“Preparing questions in advance and asking all of them [has been helpful in my interactions with my healthcare team]. And establishing a relationship with the provider and showing care for them in return.”

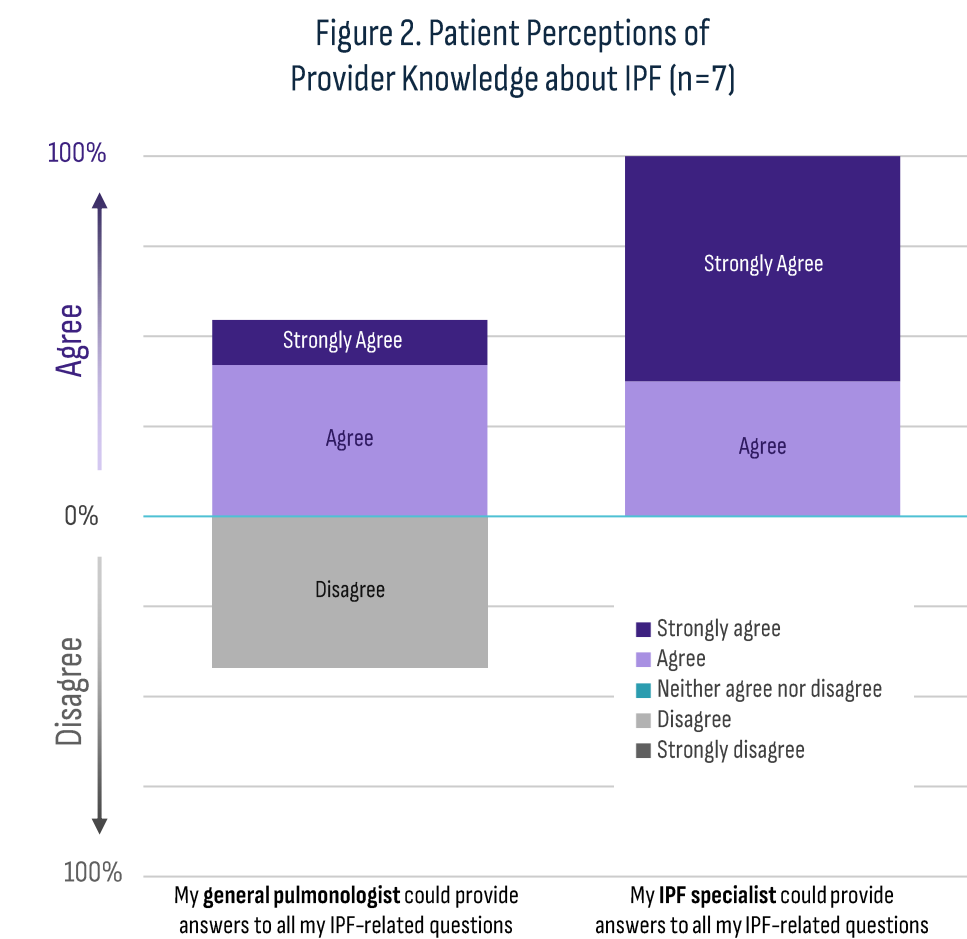
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General Pulmonologist vs. IPF Specialist

A gap emerged in perceived disease-specific expertise (Figure 2):

- 12.5% strongly agreed their general pulmonologist could answer all IPF-related questions
- 62.5% strongly agreed their IPF specialist could answer all IPF-related questions

Patients acknowledged that some general pulmonologists understand portions of the disease but expressed that specialized care is essential for comprehensive management and education.



CONCLUSIONS

Findings from this study indicate patients value care that is not only clinically competent but also responsive, accessible, and inclusive of care partners. IPF specialists are perceived as better equipped to address disease-specific needs, reinforcing the importance of referral to specialty centers. Flexible shared decision-making, care that is tailored to individual preferences, and timely communication are key to a truly patient-centered IPF care model.

Patients define high-quality IPF care as:

- Driven by a clinical expert
- Accessible and responsive
- Inclusive of care partners
- Adaptable to individual decision-making preferences
- Structured support and strong provider relationships

Although there is still much to learn about the lived experiences of individuals impacted by IPF, these findings can help to inform clinical, advocacy, and peer support models that better meet patients' needs.

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NOTES:
* This study was conducted in accordance with ethical research standards. All participants provided informed consent prior to participation. The protocol was reviewed and deemed exempt by an independent ethics committee. Data were anonymized and securely stored to protect participant confidentiality. Interviews and surveys focused on non-interventional, experiential insights from individuals diagnosed with IPF.

** The Pulmonary Fibrosis Foundation recommends that multidisciplinary teams at PFF Care Centers include a board-certified center director and associate director, a lead site coordinator, a pulmonary hypertension specialist, a rheumatologist, and additional specialty providers available for consultation.

REFERENCES:
1) Raghu G, Remy-Jardin M, Richeldi L, et al. Idiopathic Pulmonary Fibrosis (an Update) and Progressive Pulmonary Fibrosis in Adults: An Official ATS/ERS/JRS/ALAT Clinical Practice Guideline. Am J Respir Crit Care Med. 2022 May 1;205(9):e18–e47.

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