

Understanding intentional and non-intentional non-adherence in Pulmonary Fibrosis to antifibrotic treatment: a patient-led multivariate analysis

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Introduction

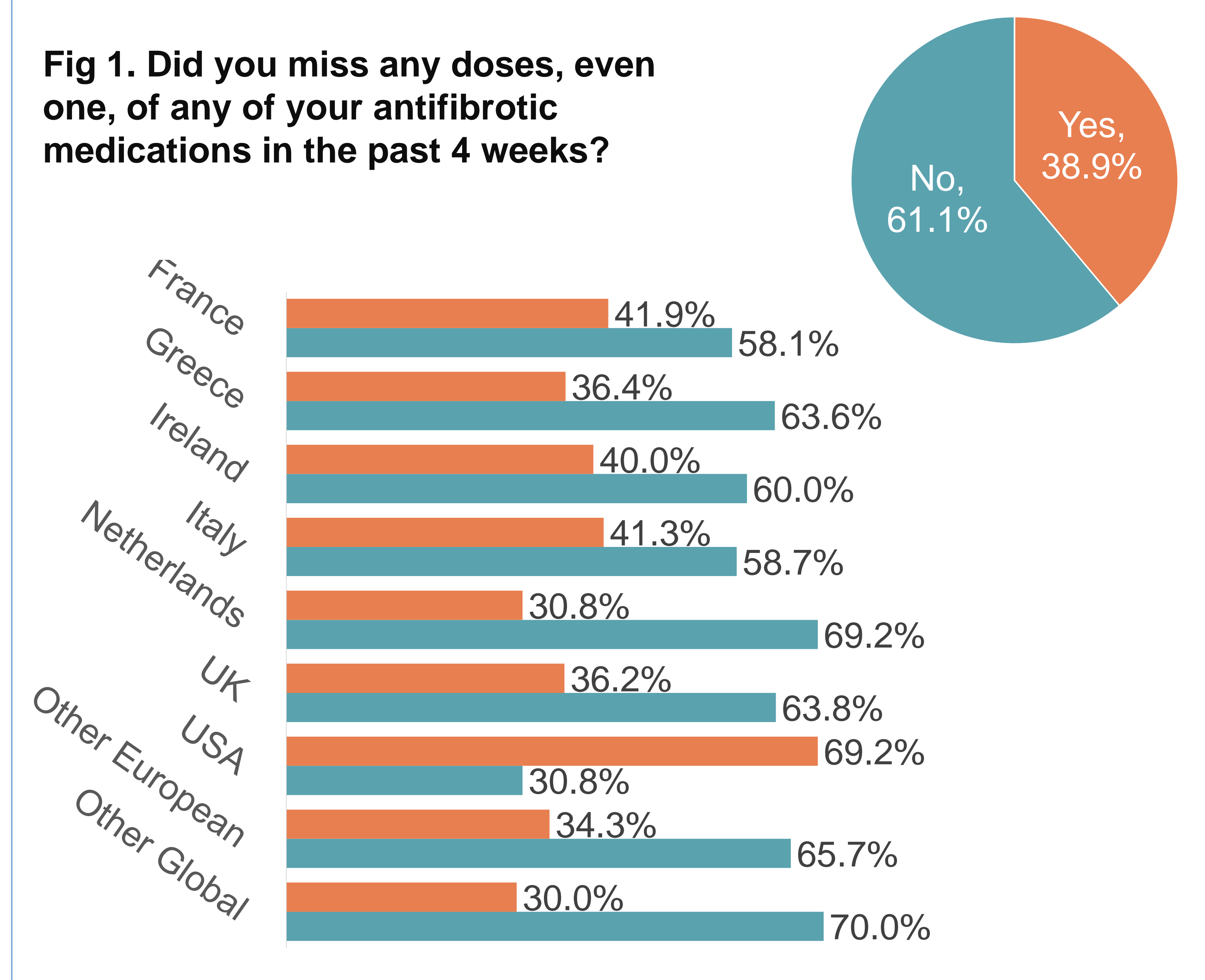
Pulmonary Fibrosis (PF), a devastating lung disease, affects 400,000 Europeans yearly, with 80,000 annual deaths. PF patients have a 3–7 years life expectancy after diagnosis. Two antifibrotic therapies are available, which slow progression and may extend life expectancy by 1-2 years, but both have side-effects. It is important to understand adherence to these medications so as to inform clinical practice and improve clinical outcomes and overall well-being.

Our study sought to evaluate the extent of non-adherence and the factors that influence it and gather evidence on the motives and beliefs in order to improve the adherence.

Objectives

1. To assess the extent of suboptimal adherence and to investigate associated motivations and behavioural patterns.
2. To identify factors increasing the probability of being in the high, medium or low adherence groups
3. To recommend how adherence within the patient population can be improved.

Fig 1. Did you miss any doses, even one, of any of your antifibrotic medications in the past 4 weeks?



Methods

An online web-based survey was developed to ask patients about their adherence to medications, targeting potential factors, reasons and/or motives. A total of 293 patients respond to the survey, 260 (89%) from Europe. Only patients who were currently on antifibrotic treatment were included in the survey.

The survey was separated into 5 group of questions and took approximately 15 minutes to complete:

- Demographics
- Diagnosis and treatment
- Treatment adherence
- Interaction with the PF pulmonologist treating you for PF
- BAASIS Adherence scale to gather validated data and be compared with other studies

The survey was translated to 7 languages: Greek, Italian, Spanish, French, German, Polish and Romanian and targeted pulmonary fibrosis patients who were currently undergoing antifibrotic treatment.

Fig 2. Why did you decide to miss a dose of your medication?

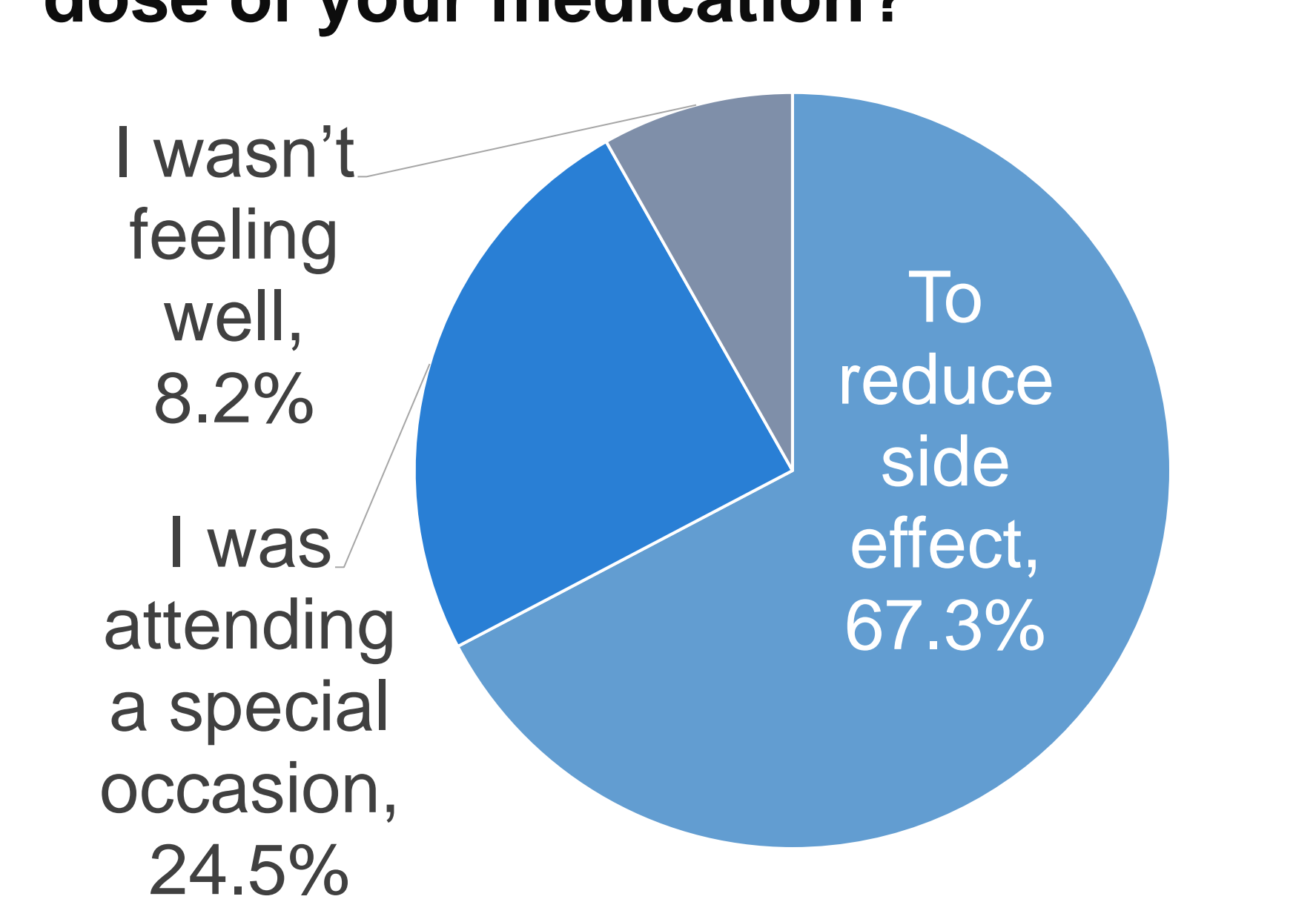


Fig 3. Have you taken a break from your PF medication without talking to your PF pulmonologist in the last year?

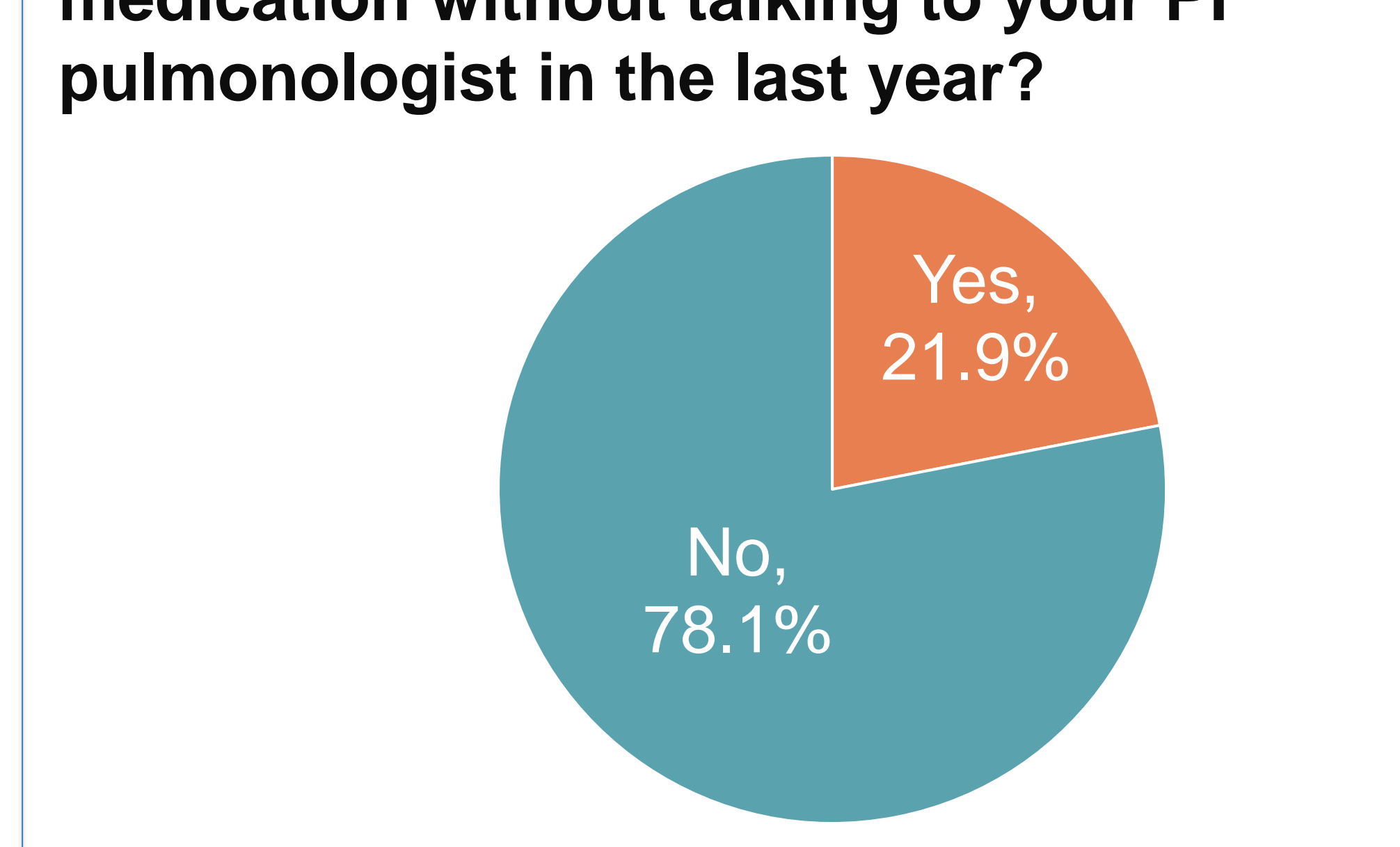
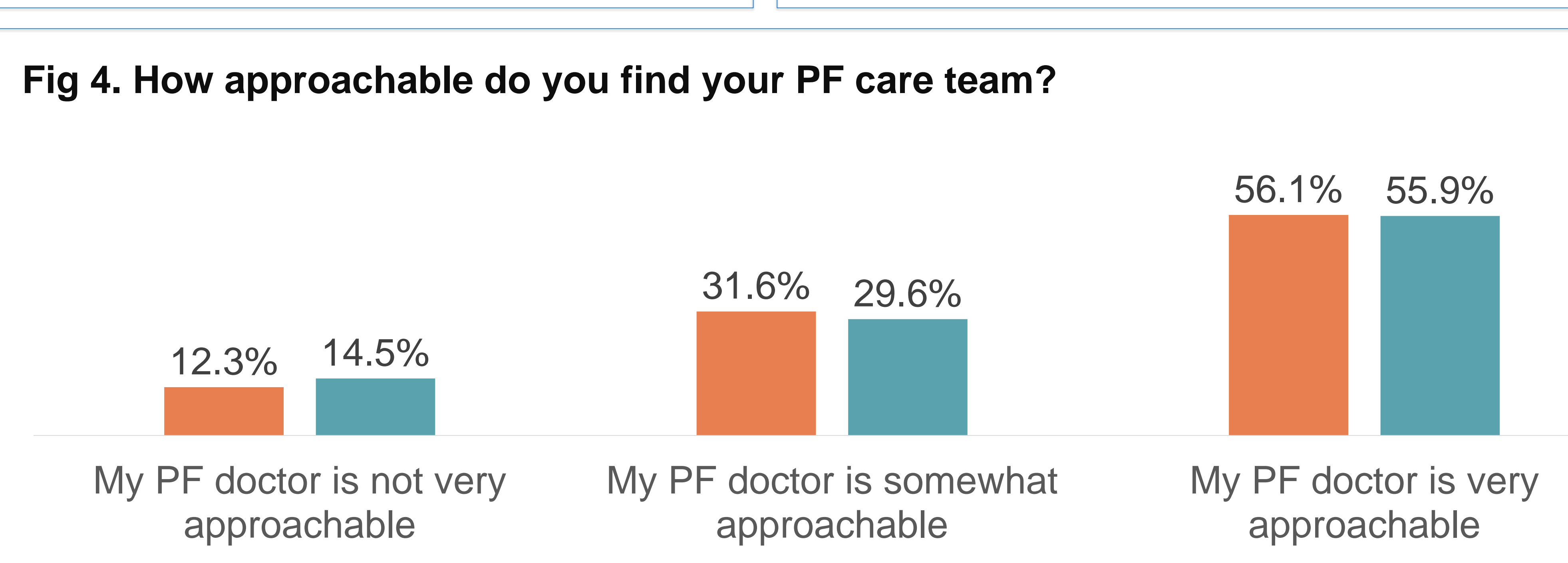


Fig 4. How approachable do you find your PF care team?



Results

1. Adherence Levels: The survey revealed poor adherence to antifibrotic treatment, with 39% of respondents missing one or more doses in the last 4 weeks. Most countries ranged between 30% and 42% but in the USA 69% of respondents had missed a dose in the last 4 weeks (Fig 1). When they took a break from medication, most respondents (75%) did so for 6 or more days.
2. The main reason people gave for missing a dose was to reduce side effects (67%), disruption of their normal schedule due to attending a special occasion (25%) and feeling unwell (8%) (Fig. 2).
3. Just under half of respondents missing doses discussed their decision with their pulmonologist but the remainder (22% of overall respondents) decided to take a medication break without discussing with their doctor (Fig. 3). This despite the fact that 85% report their pulmonologists and HCP team as 'approachable' or 'somewhat approachable' (Fig 4).
4. Positive Influences: Support from patient organizations and improved communication with healthcare providers were associated with better adherence.
5. Psychological and Social Factors: The survey highlighted a need for enhanced psychological support, as some patients expressed concerns about the medication's impact on their quality of life.

Conclusions

The PF Patient Adherence Survey provided critical insights into the adherence behaviours of PF patients. The findings suggest a need for targeted interventions, particularly in countries with higher non-adherence rates, to address psychological, social, and informational gaps that influence patient behaviour. Enhanced support systems, better communication, and tailored healthcare approaches are recommended to improve adherence and overall patient outcomes.

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