

Real-World Survey Assessing Pruritus in PSC in France, Germany, Italy and the United States: Results From a Matched Patient and Their Treating Physician Cohort

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Introduction

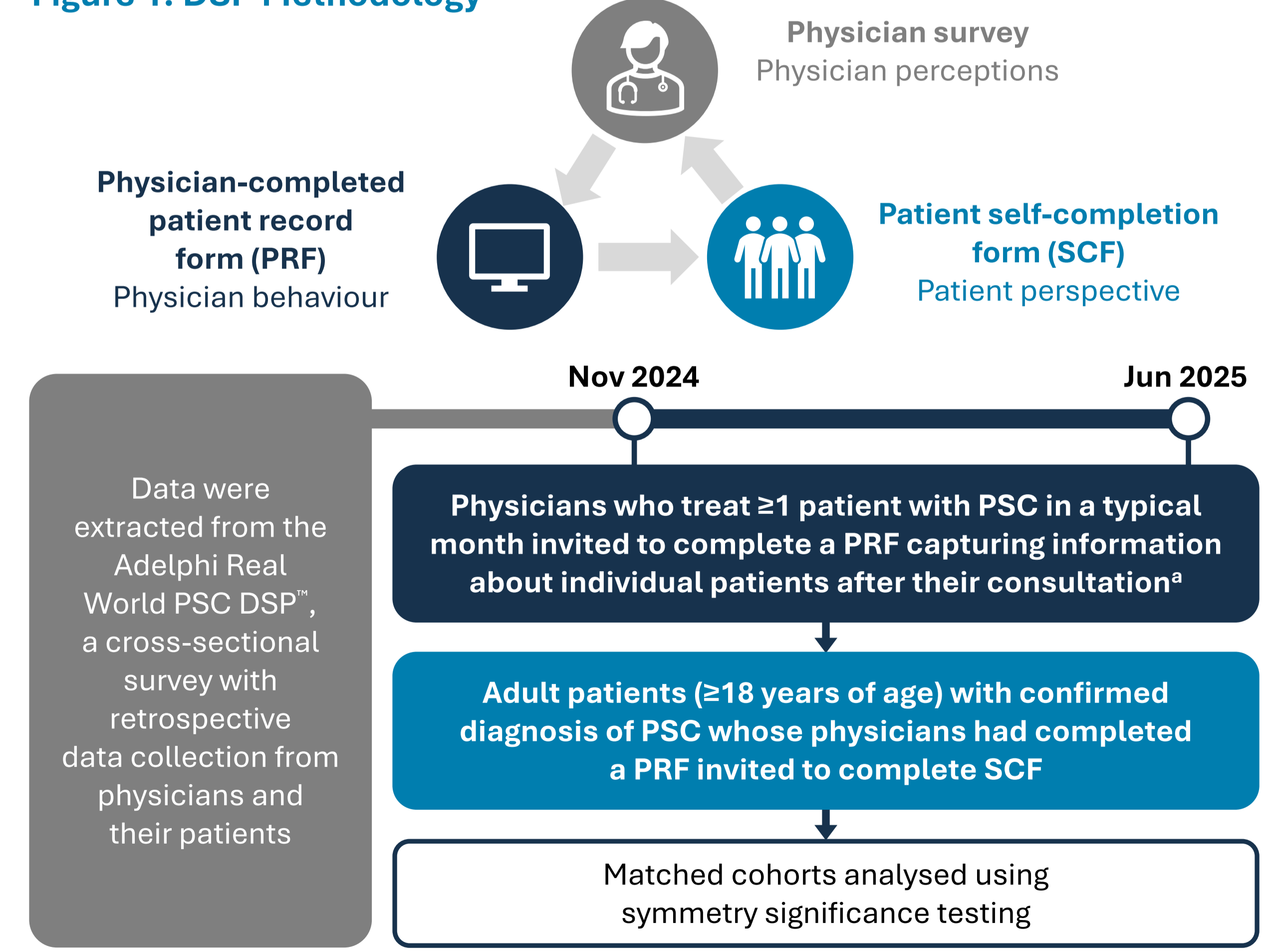
- Primary sclerosing cholangitis (PSC) is a progressive, autoimmune, cholestatic liver disease characterised by scarring and destruction of intrahepatic and extrahepatic bile ducts that can lead to fibrosis, cirrhosis, hepatocellular carcinoma, or bile duct cancer.¹⁻³
 - Key clinical manifestations include fatigue, pruritus, difficulty sleeping, brain fog, anxiety, pain, and jaundice.^{1,2,4,5}
- Pruritus is experienced by up to 91% of patients with PSC and can be severe and debilitating, leading to reduced quality of life (QoL).^{1,4,6}
- In a recent survey, physicians reported that 42% of their patients with PSC had pruritus, and 90% of physicians believe that pruritus has a profound impact on a patient's QoL.⁷
- More data are needed to understand the alignment between physician and patient perceptions of symptoms, such as pruritus, fatigue, and sleep disturbance, and management of PSC.
- The Adelphi Real World PSC Disease Specific Programme (DSP)[™] is a multinational, cross-sectional survey with retrospective data collection from physicians and their patients with PSC in the United States, France, Germany and Italy, providing a view of the entire patient journey.⁸⁻¹⁰

Objective

- To describe the similarities and differences between physicians' and patients' perceptions of PSC-related symptoms and treatments using matched cohort data from a cross-sectional survey.

Methods

Figure 1. DSP Methodology



[†]Recruited physicians included hepatologists and gastroenterologists with or without hepatology sub-specialisation in the United States, internists and hepato-gastroenterologists in France, and gastroenterologists with or without hepatology sub-specialisation in Germany and Italy.

Abbreviations
 DSP, Disease Specific Programme; PRF, patient record form; PSC, primary sclerosing cholangitis; SCF, self-completion form; QoL, quality of life.

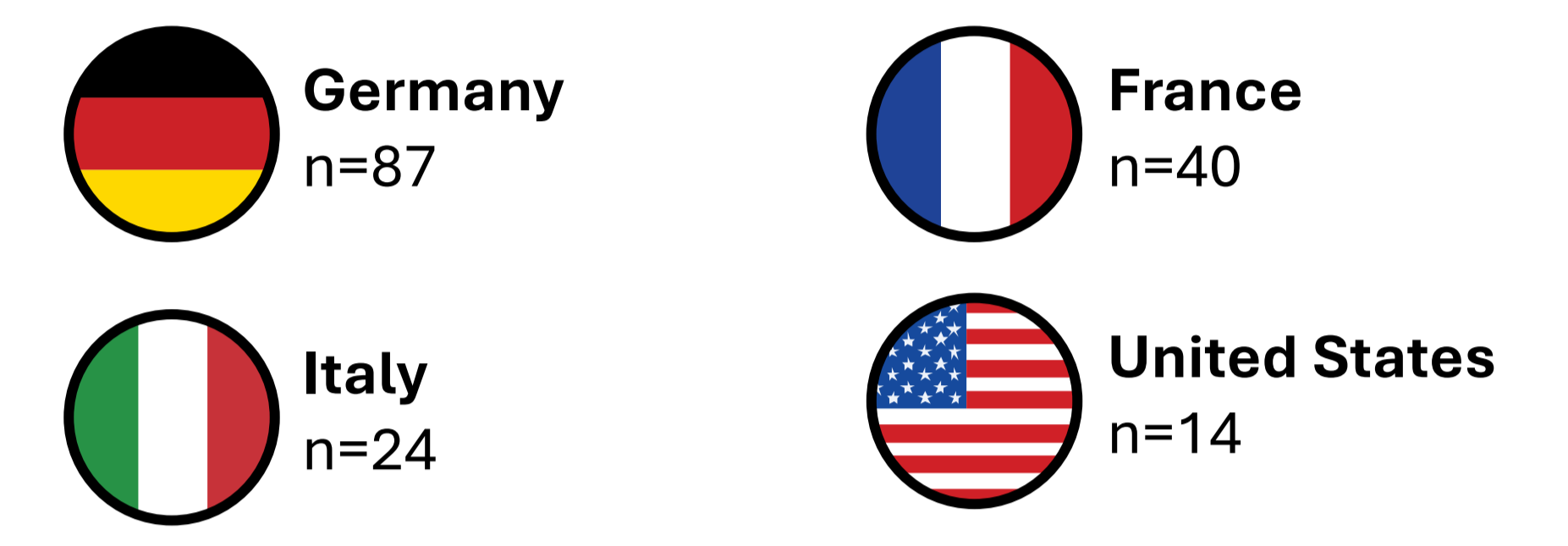
Disclosures
 MJM is a consultant for CymaBay, Gilead, Intercept, Ironwood, Ipsen, Kezar, and Mirum Pharmaceuticals, Inc., and has received research funding from CymaBay, Gilead, GSK, Ipsen, and Mirum Pharmaceuticals, Inc. MC is a consultant for and advisory board member of Advanz, CymaBay, Echovion, Falk, GSK, Ipsen, Mayoly, Mirum Pharmaceuticals, Inc., and Zydus. WJ and LA are employees of Adelphi Real World. GL, JT-R, LQ, and RH are employees of and shareholders in Mirum Pharmaceuticals, Inc. VK-A is an advisory board member of AstraZeneca, Falk, and Mirum Pharmaceuticals, Inc., and has received honoraria from Albireo/Ipsen, Falk, Mirum Pharmaceuticals, Inc., AbbVie, Intercept, CSL, Gilead, and Sanofi for speaking engagements.

Results

Physician and Patient Characteristics

Data From 165 Linked Physician and Patient-Reported Records Were Included

Physicians and Patients With PSC From Four Countries Participated in the Survey[†]:



[†]The n values represent the number of linked physician and patient-reported records.

Table 1. Characteristics of Patients With PSC

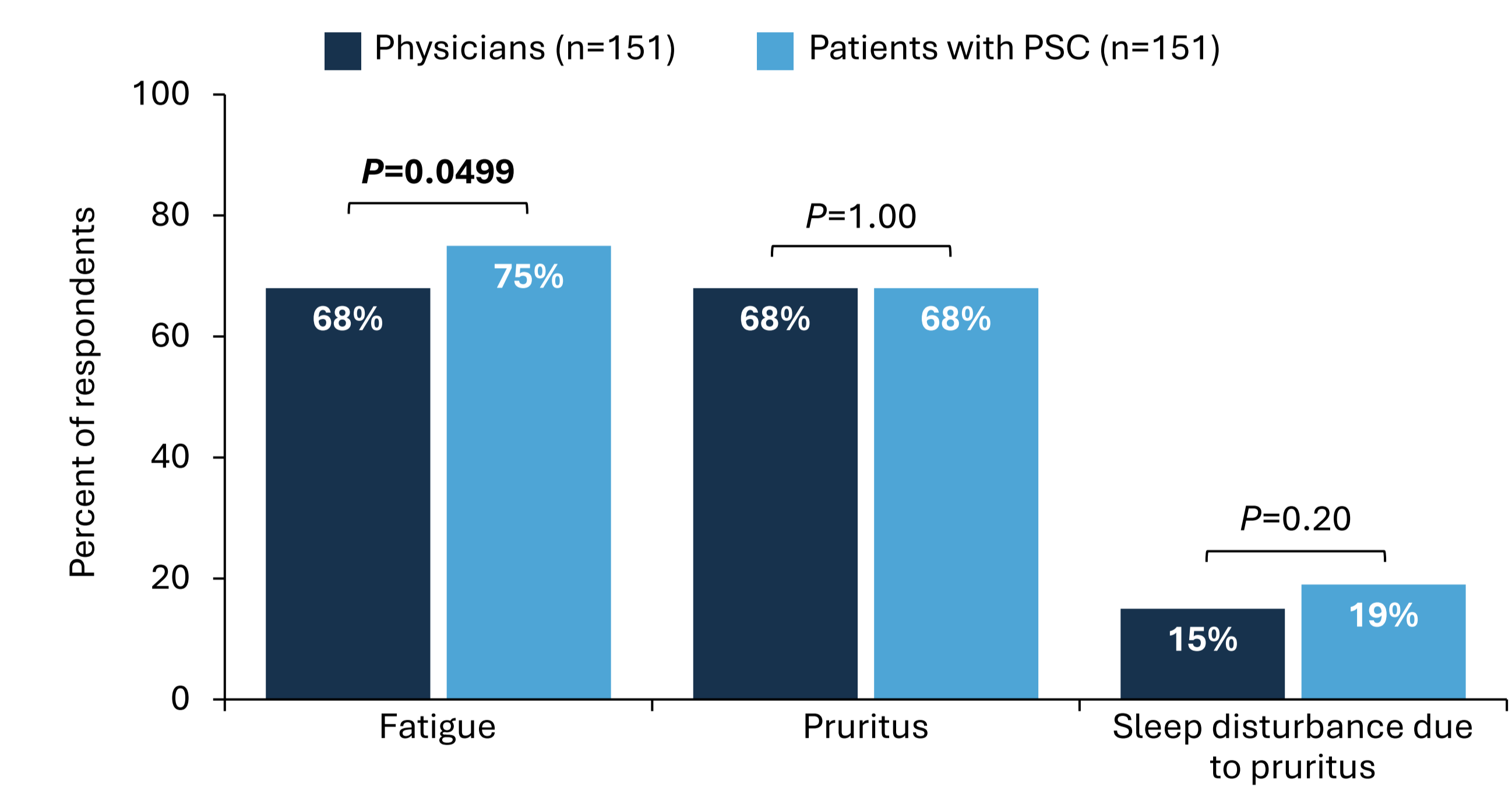
Demographics	Patients With PSC (SCF) N=165
Age, years, mean (SD)	44.5 (13.4)
Sex, female, n (%)	113 (68)
Race, White, n (%) ^c	123 (98)
Time since diagnosis, years, mean (SD)	2.7 (3.3)
Employment status, full/part-time, n (%)	117 (71)

^cRace was not collected in France.

Assessment of Symptoms

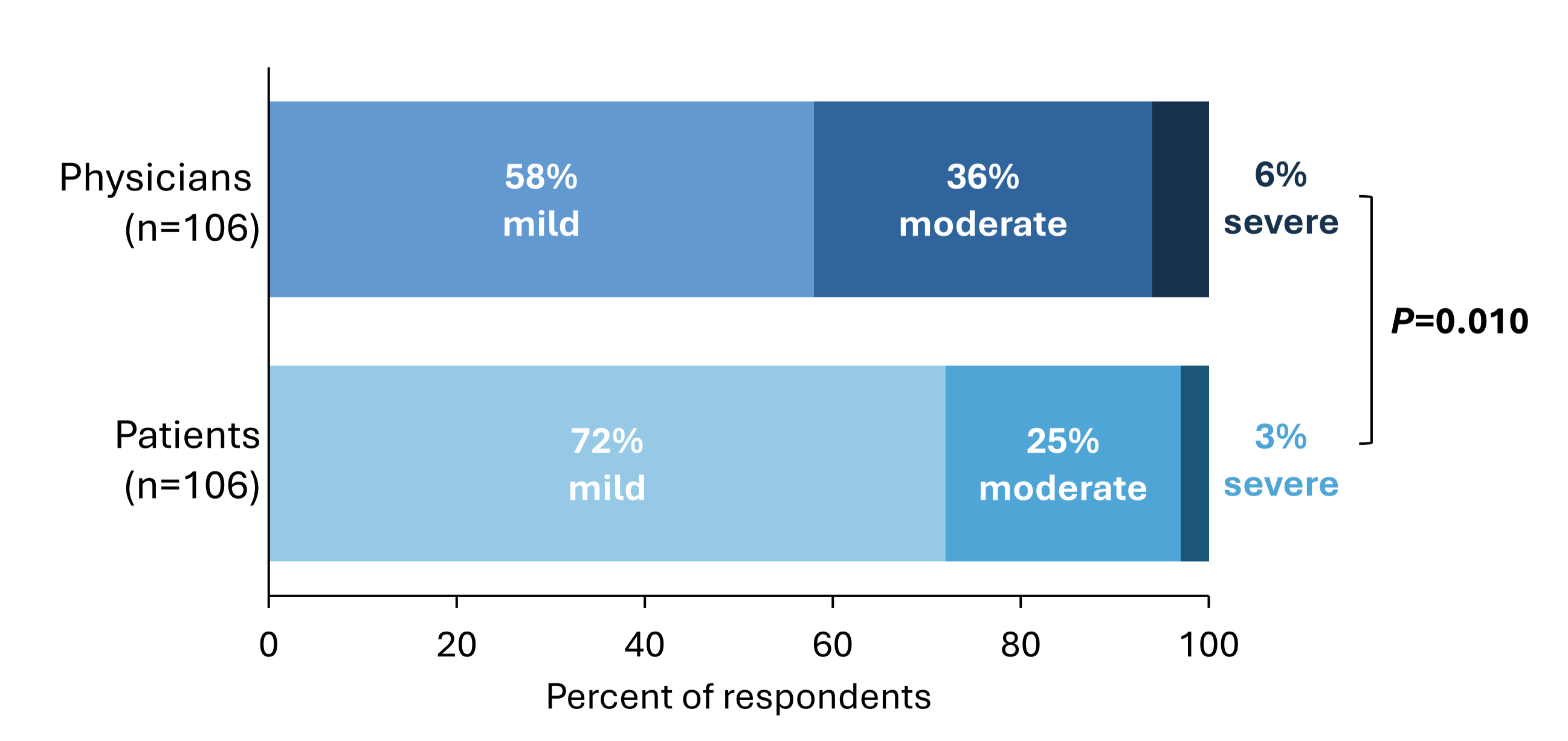
Both Physicians and Patients Reported Fatigue and Pruritus Were Highly Prevalent Symptoms

Figure 2. Current Symptoms



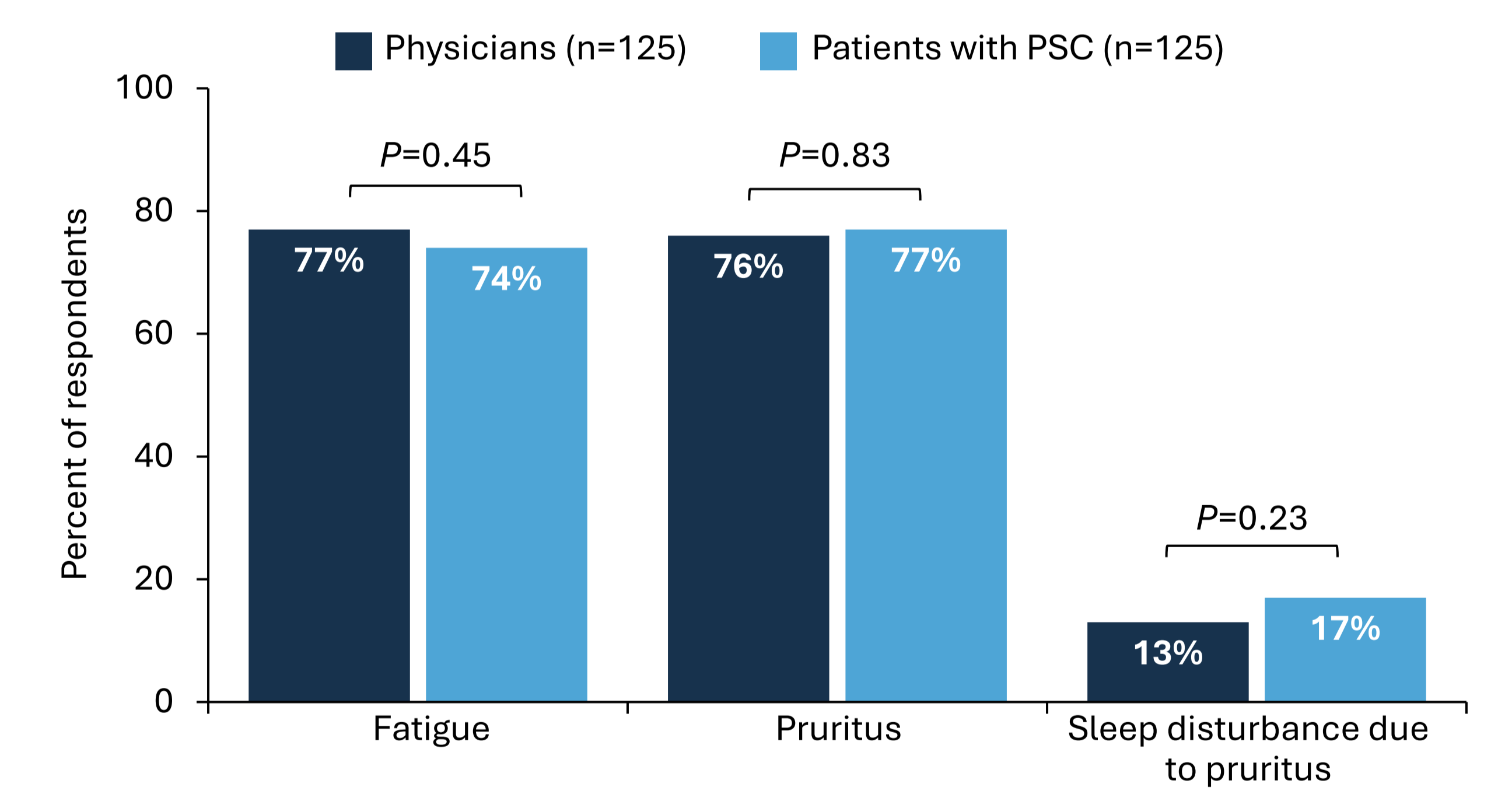
Physicians' and Patients' Perceptions of Pruritus Severity Were Significantly Different, With Physicians Being More Likely to Perceive Pruritus as More Severe Compared to Patients

Figure 4. Current Pruritus Severity



Both Physicians and Patients Reported Fatigue and Pruritus as the Most Bothersome Symptoms

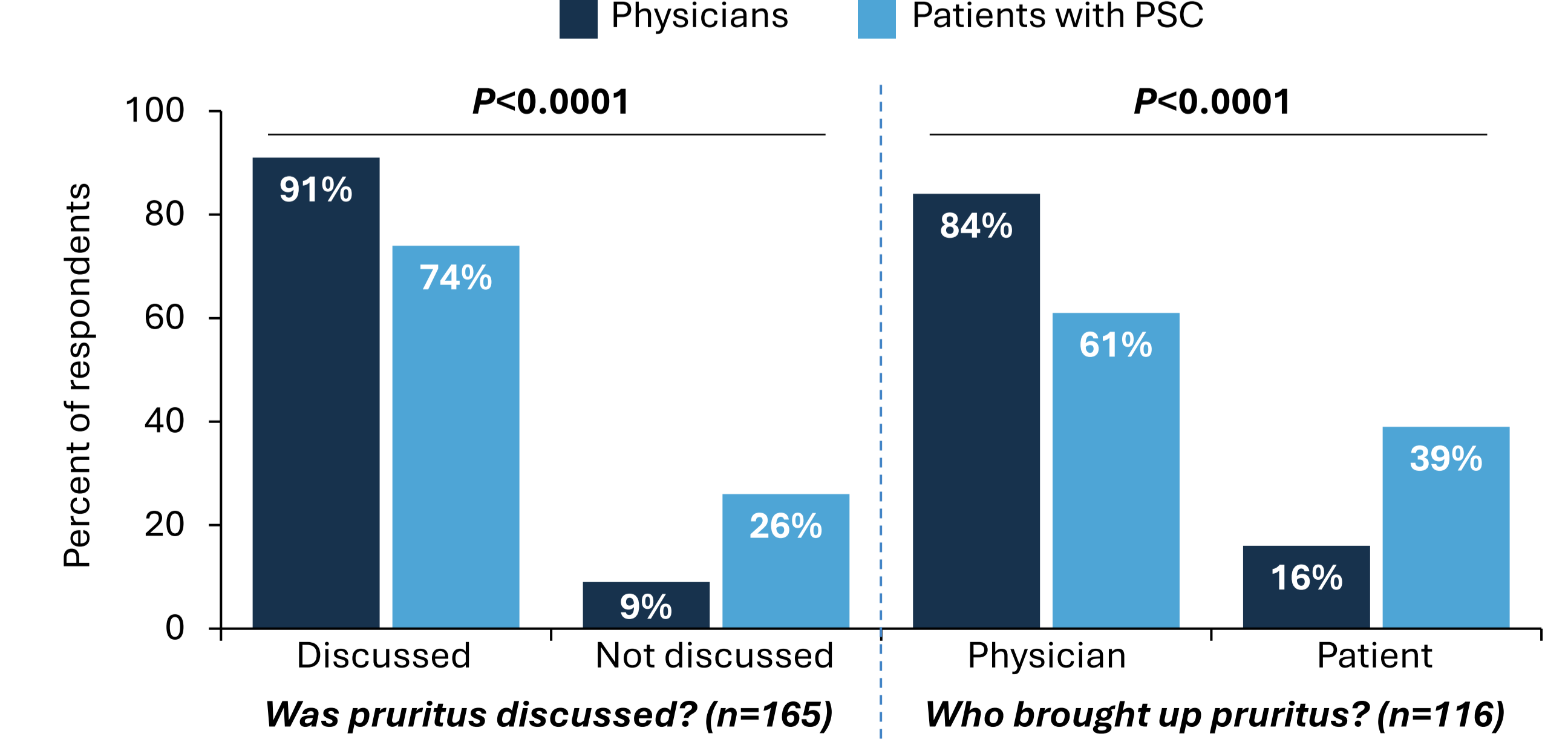
Figure 3. Most Bothersome Symptoms^d



^dPercentage who included the symptom as one of the three most bothersome symptoms.

Physicians' and Patients' Perceptions of Pruritus Discussions Were Significantly Different, With More Physicians Reporting Pruritus Was Discussed and That They Initiated the Discussion

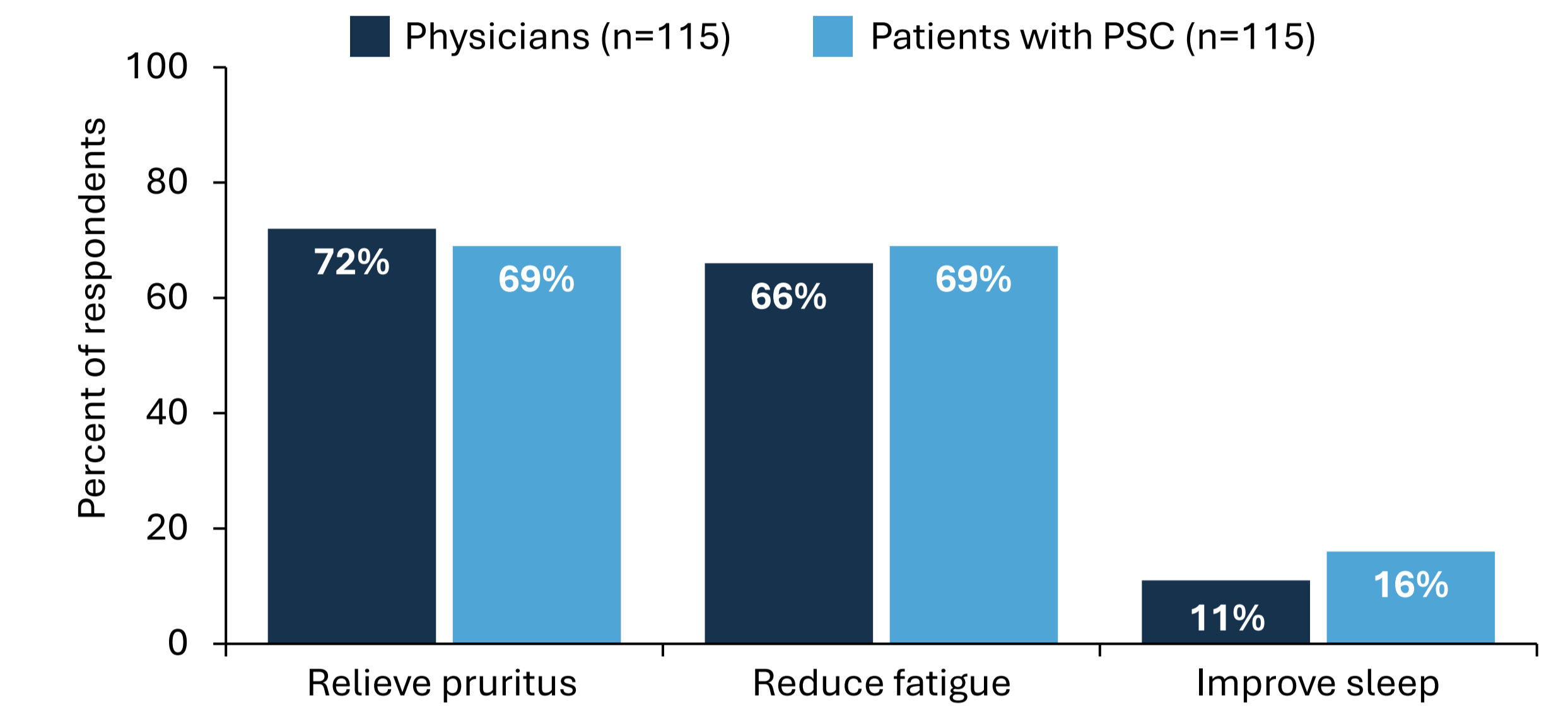
Figure 5. Discussion of Pruritus



Attitudes Toward Treatments

For Both Physicians and Patients, Improving Pruritus Was a Key Treatment Goal

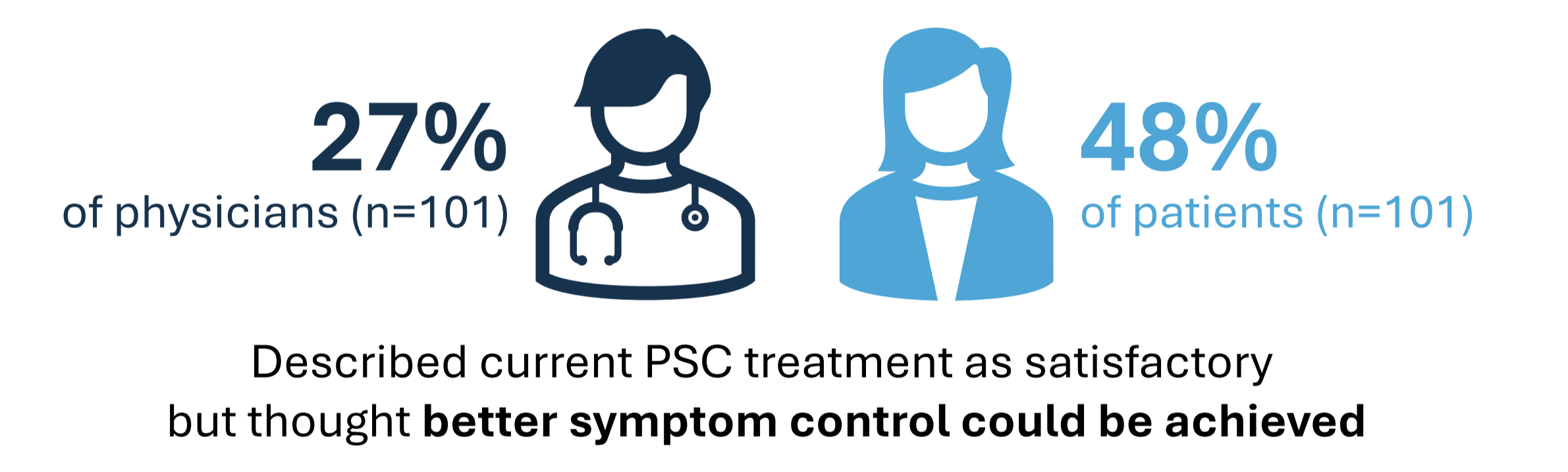
Figure 6. Treatment Goals^e



^ePercentage who included the treatment goal as one of the three most important goals.

- Perceptions of current treatment performance differed between physicians and patients, with physicians being significantly more likely to report poorer results in relation to liver function ($P=0.029$).

Fewer Physicians Believed Better Symptom Control Could Be Achieved



Conclusions

- Physicians and patients concurred that the most common current symptoms and most bothersome symptoms in PSC were fatigue and pruritus.
- Perspectives on the burden of symptoms appeared to differ, with physicians being more likely to perceive patients' pruritus as more severe.
- While physicians and patients generally agreed on treatment goals, including relieving pruritus, physicians were less likely to believe that better symptom control was possible.
- These initial data highlight the different perspectives of physicians and patients and indicate there is a need for more consistent assessment and discussion of pruritus during clinical encounters to bridge perceptual differences.

Acknowledgements

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