

Patient and Caregiver Perspectives on Management of Crohn's-related Perianal Fistulas: Results of a US National Survey

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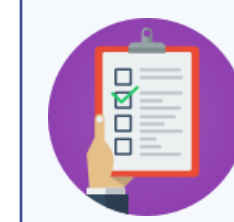
1. CE Outcomes, LLC 2. Takeda Pharmaceuticals USA, Inc

Introduction

Crohn's-related perianal fistulas (CPF) are major contributors to lowered quality of life for patients with Crohn's disease and are found in approximately 26% of patients with Crohn's disease (CD).¹ Previous studies have shown that patients experiencing CPF report a high level of disability and are generally seen by many different types of specialists.² Optimized current therapy has shown to achieve healing of fistulas in less than one third of all patients.³

This study aimed to identify the patient and caregiver perspectives and needs in CPF management in order to determine opportunities for clinician, patient, and caregiver education.

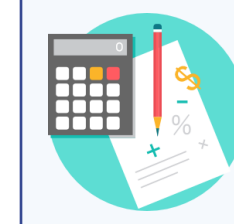
Methodology



To understand patient/caregiver perspectives and needs in CPF management, a survey instrument was developed and approved for exemption from IRB oversight by Western IRB (Puyallup, WA).



The web-based patient/caregiver survey was distributed in October 2020 through January 2021 through clinicians managing CPF and support groups. All patient/caregivers had to have Crohn's-related perianal fistulas or have a relationship with someone who does. 150 patient/caregiver responses were collected.



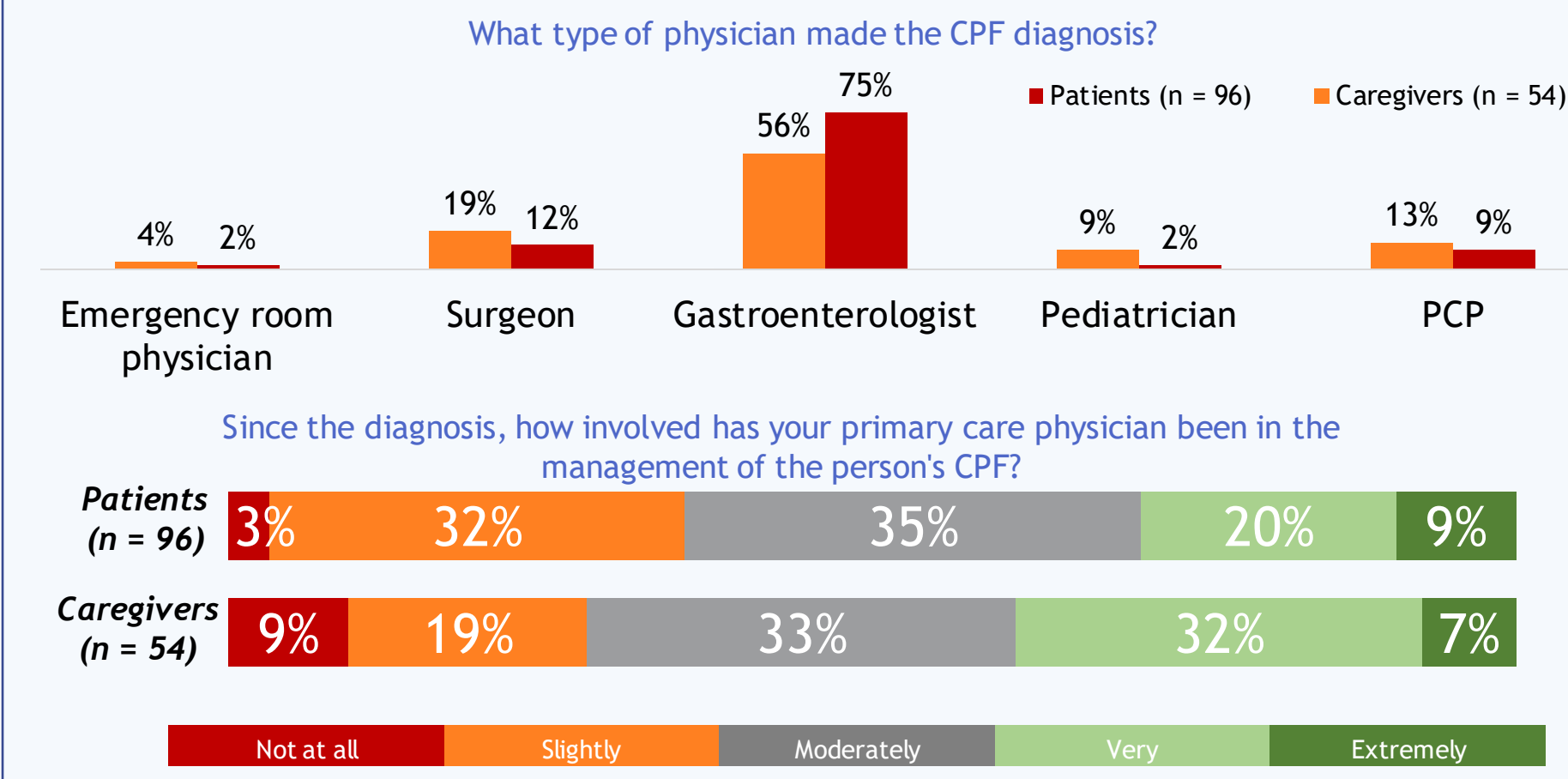
Analyses used a combination of quantitative methods with qualitative open-ended coding.

Demographics

	Patients (n = 96)	Caregivers (n = 54)
Patient age, mean (range)	33 (21-72)	37 (3-89)
Caregiver age, mean (range)	-	42 (22-73)
Relationship to person with CPF		
Self	100%	0%
Parent	0%	44%
Family caregiver	0%	56%
Received support to help pay for CPF care or medication?		
Yes	33%	32%
No	65%	63%
Unsure	2%	6%
Insurance status	(self)	(patient with CPF)
Yes, private	67%	39%
Yes, Medicare/Medicaid	30%	54%
No	3%	7%
Gender		
Male	63%	44%
Female	38%	54%
Non-binary, self-describe	0%	2%
Race/ethnicity		
White	67%	68%
Non-white (Black, Hispanic, Asian, Native American, Multiracial)	14%	32%

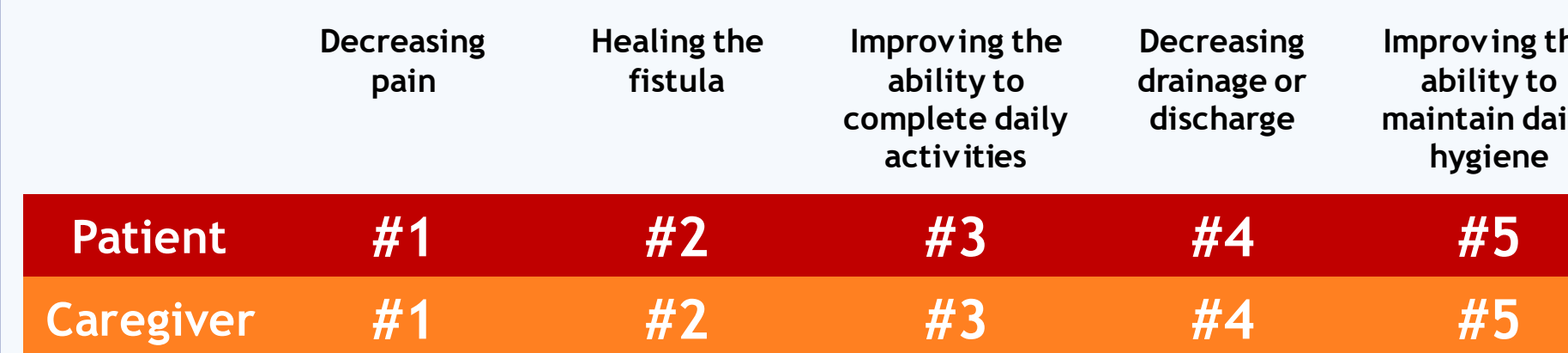
Diagnosis and PCP involvement

While the majority were diagnosed by gastroenterologists, other health care professionals (HCPs) also made diagnoses. Primary care physicians (PCPs) remained extremely or very involved with CPF management for 29% of patients and 39% of caregivers.



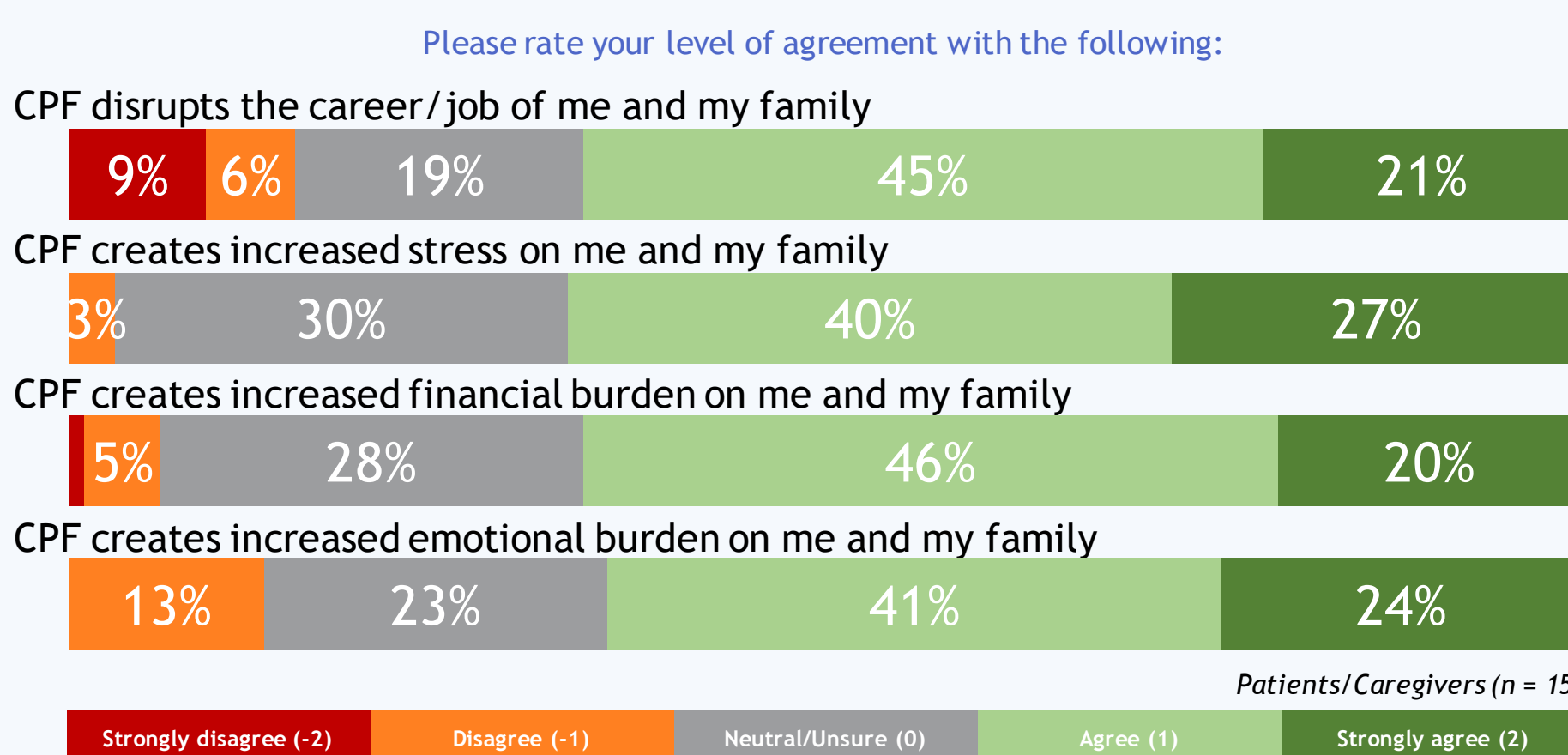
Goals of CPF Treatment

The top two patient and caregiver goals of CPF treatment were decreasing pain and healing the fistula.

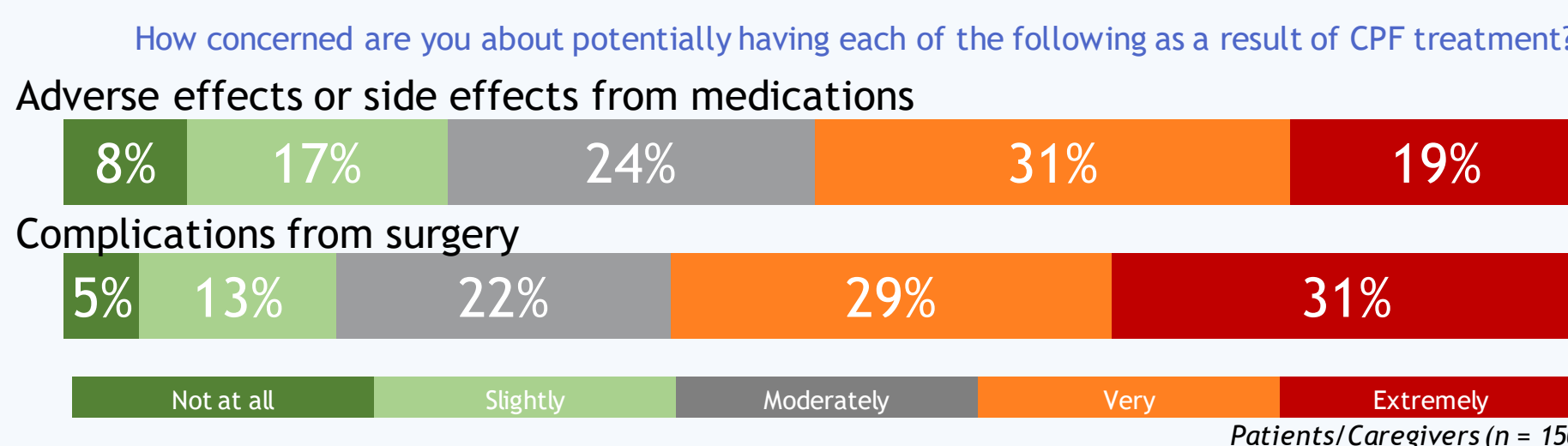


CPF burden and patient concerns

Respondents stated CPF increases stress, disrupts their job/career, increases their financial burden, and creates an increased emotional burden on patients and their families.

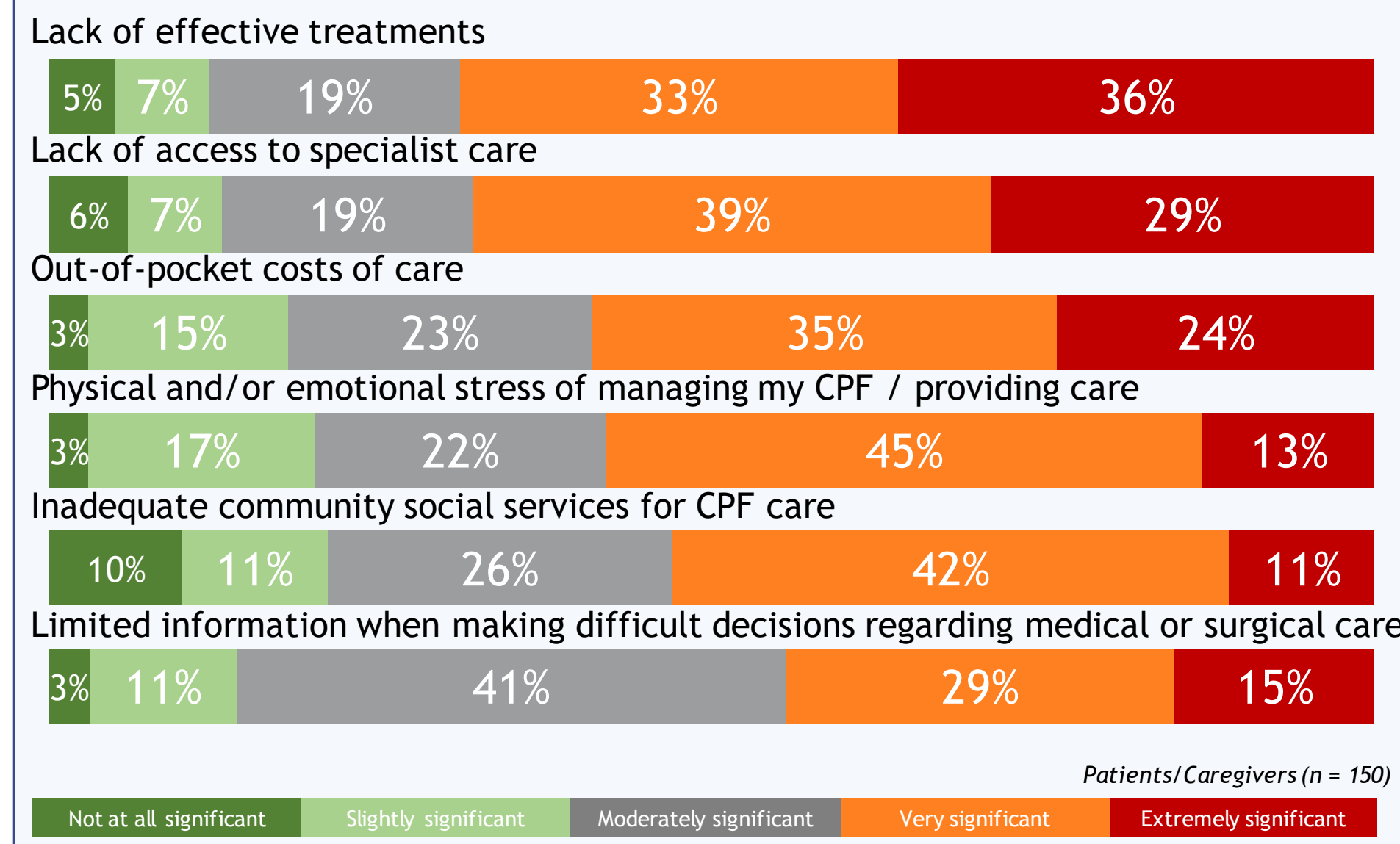


Many patients and caregivers were extremely or very concerned with surgical complications (60%) and medication side effects (50%).



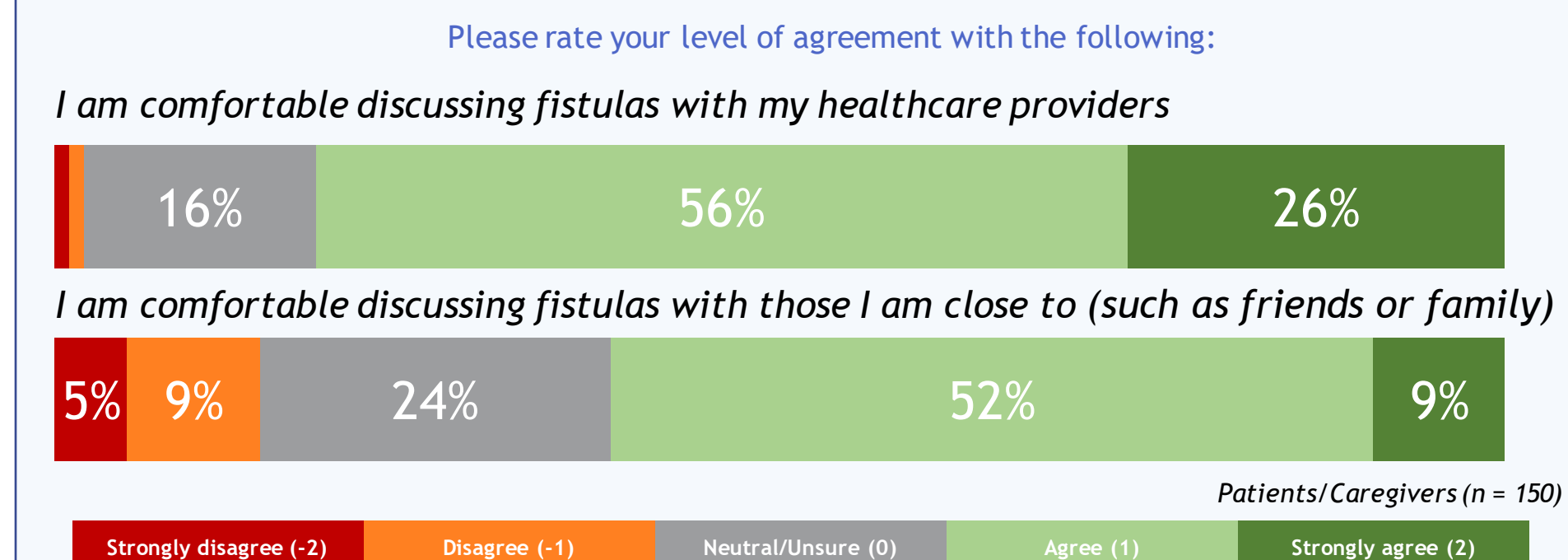
Barriers to optimal patient CPF management

How significant are each of the following problems or barriers to receiving the best possible CPF care?

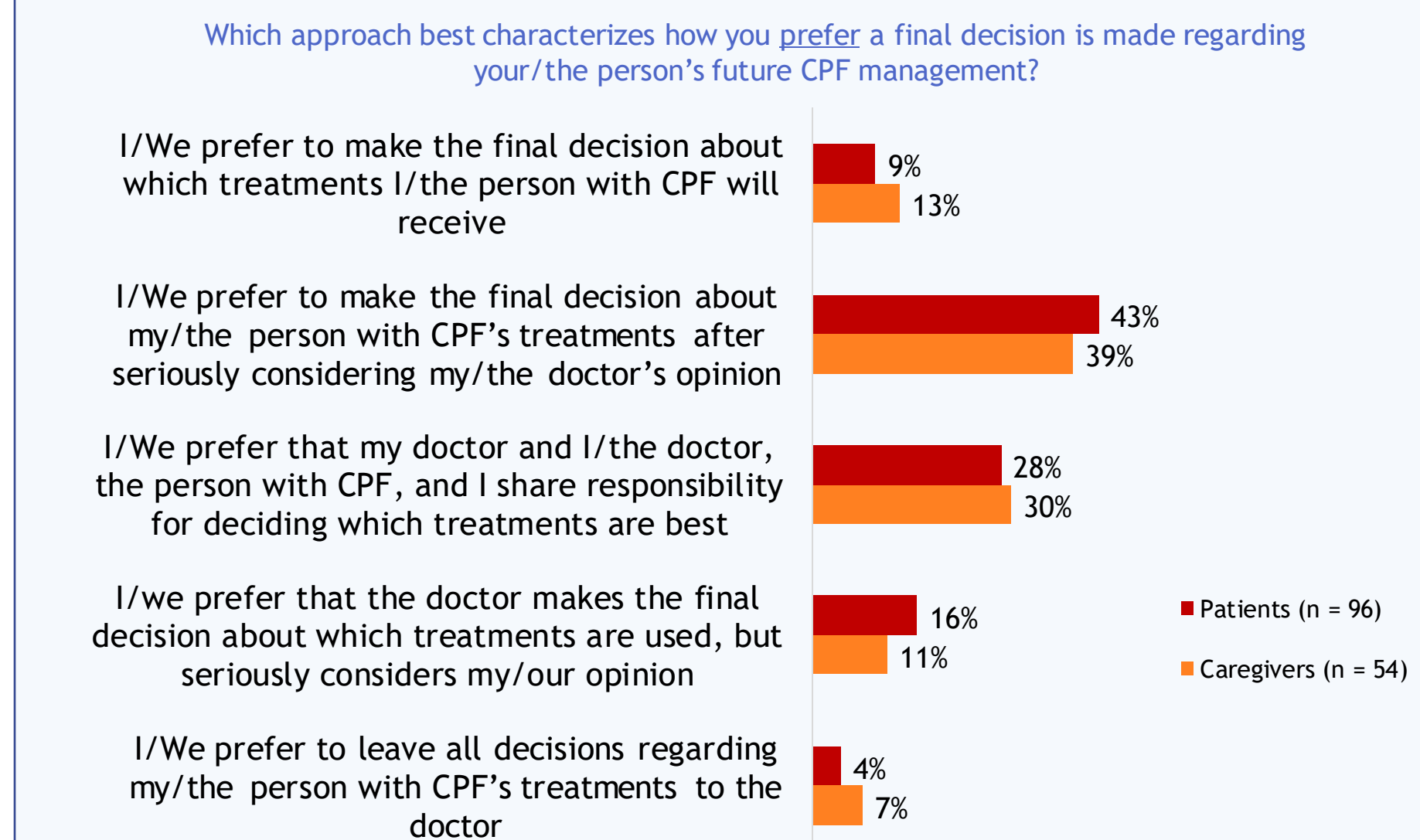


Attitudes on clinician discussions and shared decision-making preferences

Patients and caregivers are more comfortable discussing CPF with their HCPs than their friends or family members.

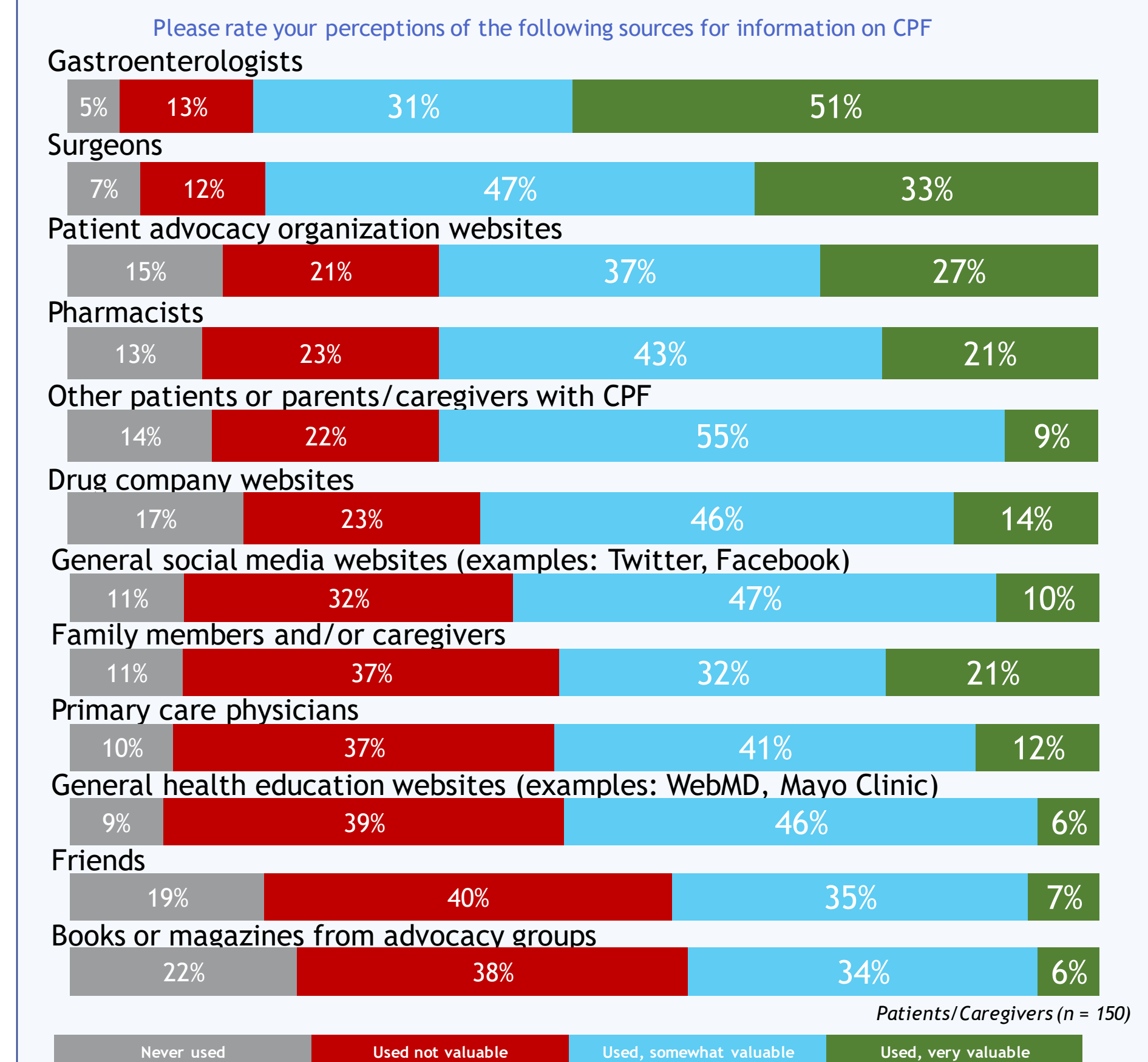


Patients and caregivers preferred to make the final decision on treatment after considering their doctor's opinion or prefer sharing decisions with their HCP.

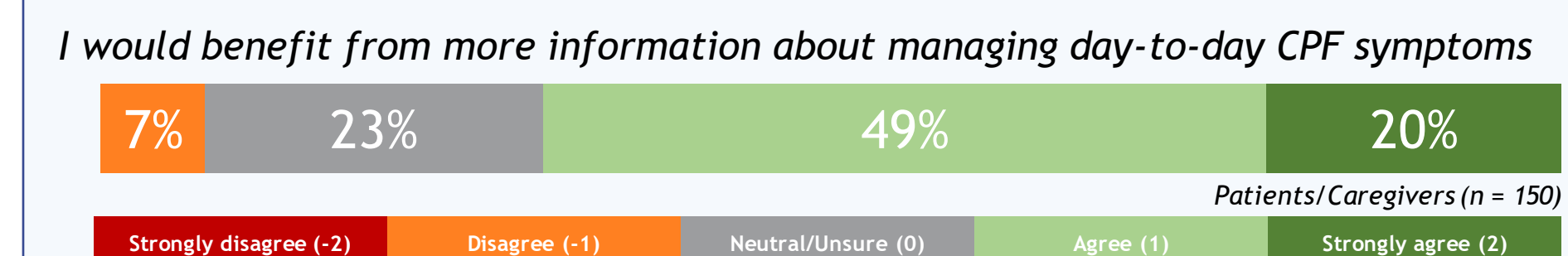


Patient and Caregiver Information Resources

Top sources of very valuable CPF information were gastroenterologists, surgeons, patient advocacy organizations, pharmacists, and family members/caregivers.



Most patients and caregivers stated they would benefit from more information on managing day-to-day CPF symptoms and would specifically find information on current and new/emerging medical/surgical treatments valuable.



What one informational or educational topic related to CPF would be most valuable to you/you or the person with CPF? [open-ended, classified by theme]

1. Current treatment options
2. New/emerging treatment
3. Surgery
4. Internet/app resources
5. Support groups

Conclusions

- CPF places physical, emotional, and financial burdens on patients and caregivers.
- Both patients and caregivers prefer to be involved in management decisions.
- Barriers to care were common, and patient/caregivers identified a need for more information on CPF.

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 2. McNair AGK, et al. Color Dis 2017; 19: 075-85
 3. Molendijk I. et al. Best Pract Res Clin Gastroenterol 2014; 28: 505-18.