

# Disparities in Diagnosis and Management of Patients with Crohn's Perianal Fistulas

## Results of a US National Patient and Caregiver Survey

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### Introduction

Crohn's-related perianal fistulas (CPF) are found in approximately 26% of patients with Crohn's disease (CD) and are major contributors to lowered quality of life.<sup>1</sup> Previous studies have shown that there may be racial and ethnic disparities in CPF presentation and/or care.<sup>2-6</sup> Awareness of these issues is important for clinicians managing patients with CD and fistulas.

A survey was conducted to understand CPF patient and caregiver perspectives and needs.<sup>7</sup> A post-hoc analysis was conducted to identify potential disparities in care.

### Methodology

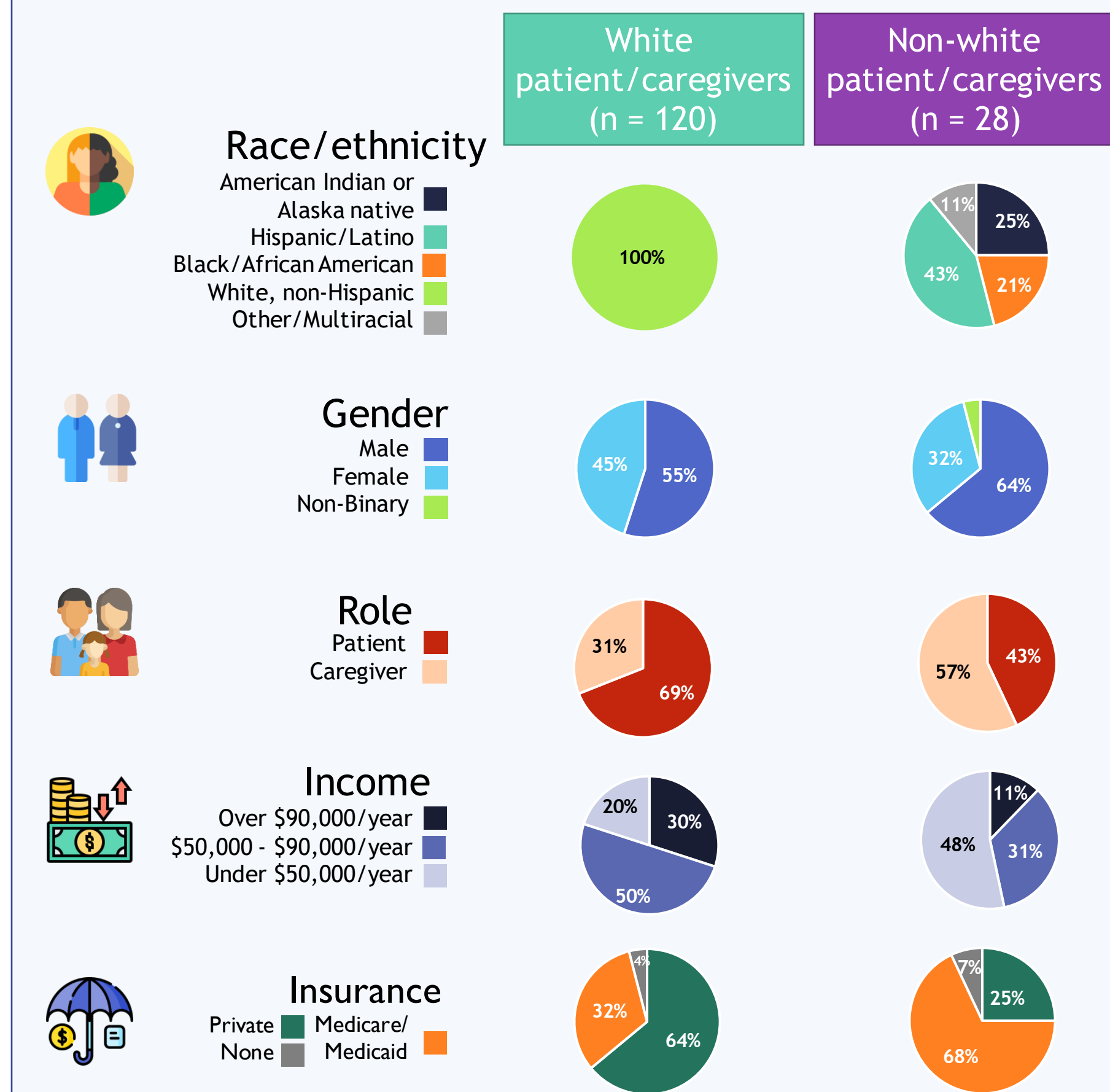
A survey instrument was developed to understand patient/caregiver perspectives and needs in CPF management and was approved for exemption from IRB oversight by Western IRB (Puyallup, WA). The survey was programmed for Web-based distribution through Qualtrics, an online survey platform.

150 responses from patients and caregivers were collected between October 2020 and January 2021, through clinicians managing CPF and patient support groups. Respondents had to either have CPF or a relationship with someone who does. Two responses were removed from this analysis due to no race/ethnicity indicated.

Analyses used a combination of quantitative methods with qualitative open-ended coding. Subanalysis and inferential statistics were used to segment the patient/caregiver sample by race and ethnicity and determine potential areas of care disparities.

### Demographics

Of 148 patient/caregiver responses analyzed, 28 were non-white. Average age of patient with CPF was 35 amongst white patient/caregivers and 38 amongst non-white patient/caregiver respondents.

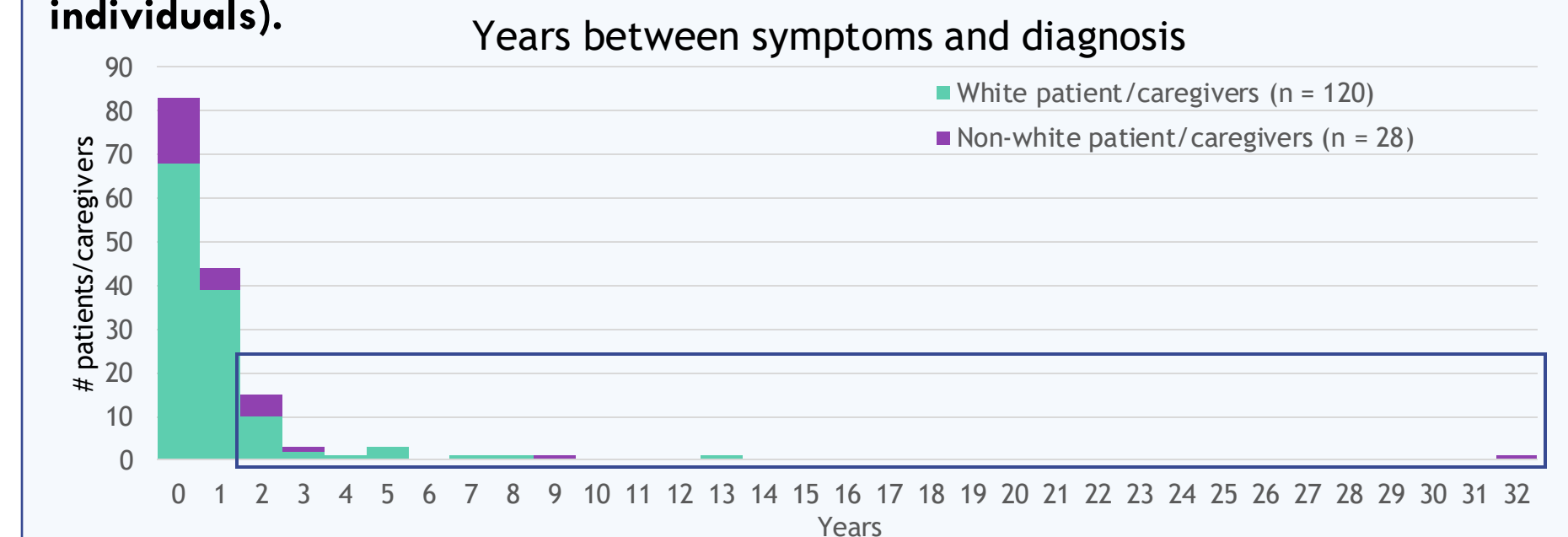


### Time between first symptoms and diagnosis

Non-white patient/caregivers reported a longer mean time between symptoms and diagnosis (over 2 years) than white patients/caregivers (mean of <1 year). While demographics such as gender, role, income, or insurance status differ between these groups, in regression analyses only race/ethnicity predicted the differences in diagnostic delay.

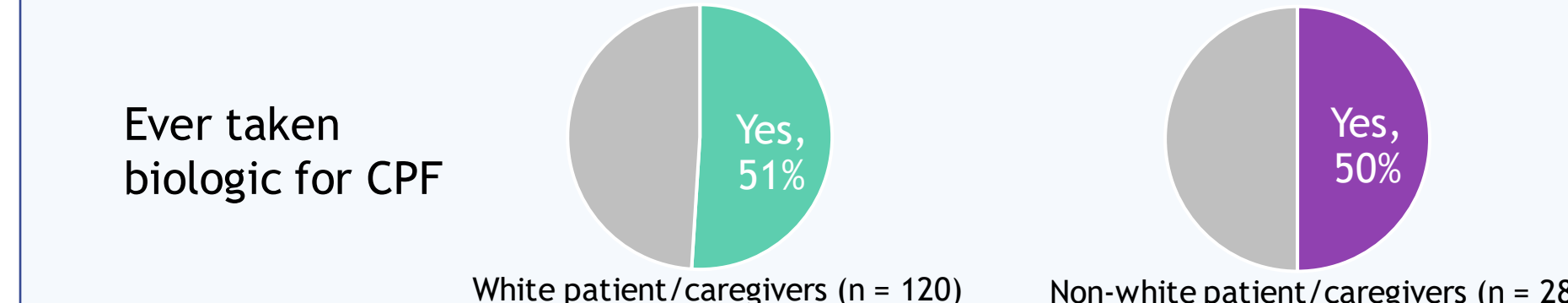
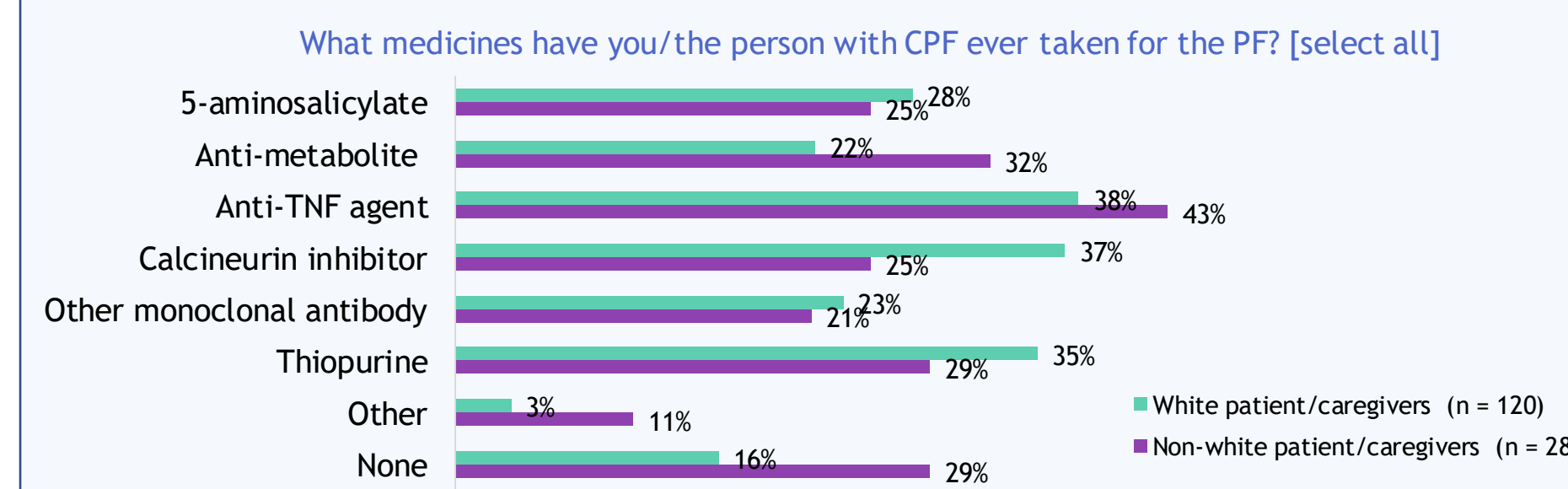
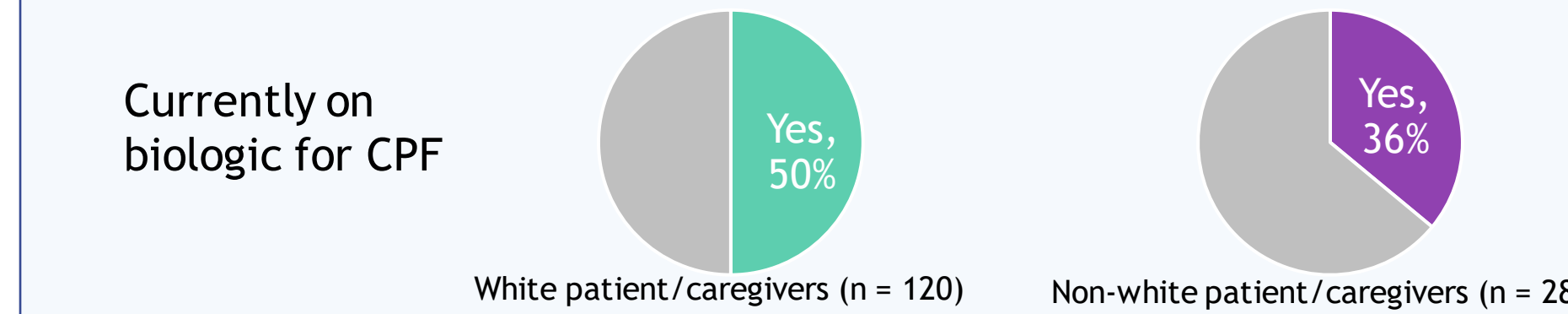
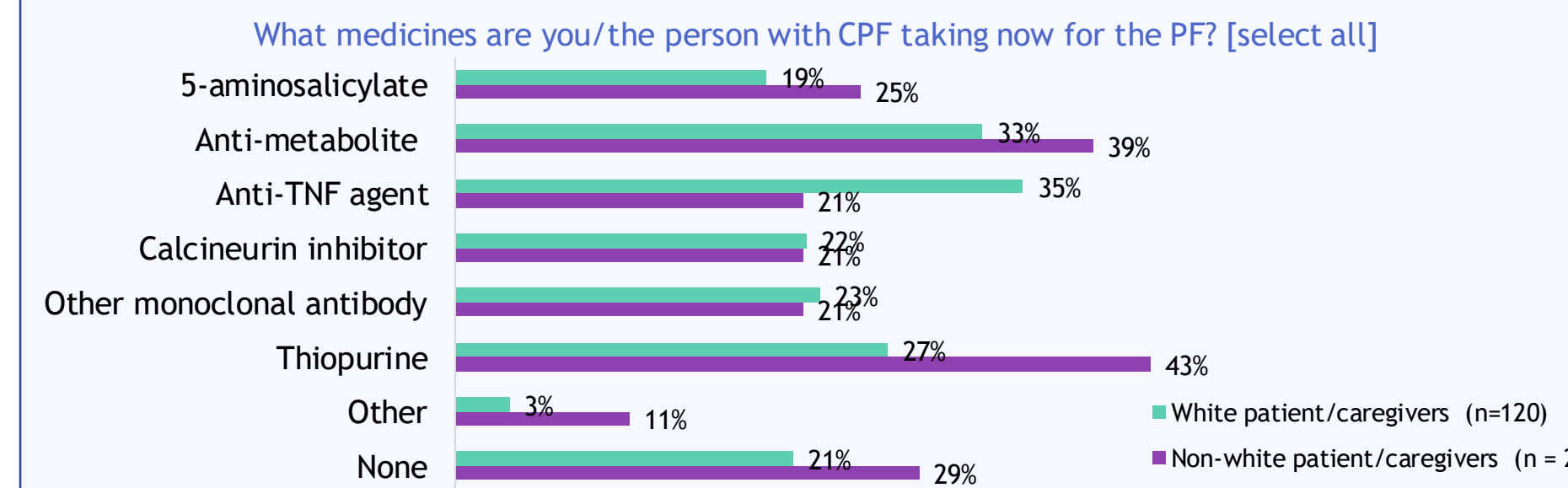
	White patient/caregivers (n = 120)	Non-white patient/caregivers (n = 28)
Years since CPF symptom onset, mean	4.05	5.32
Years since formal CPF diagnosis, mean	3.26	3.21
Years difference between symptoms and diagnosis, mean	0.79	2.11

14% (21 individuals) indicated that the process took 2 years or more between symptoms and a formal diagnosis. Of those 21, 38% identified as non-white (8 individuals).



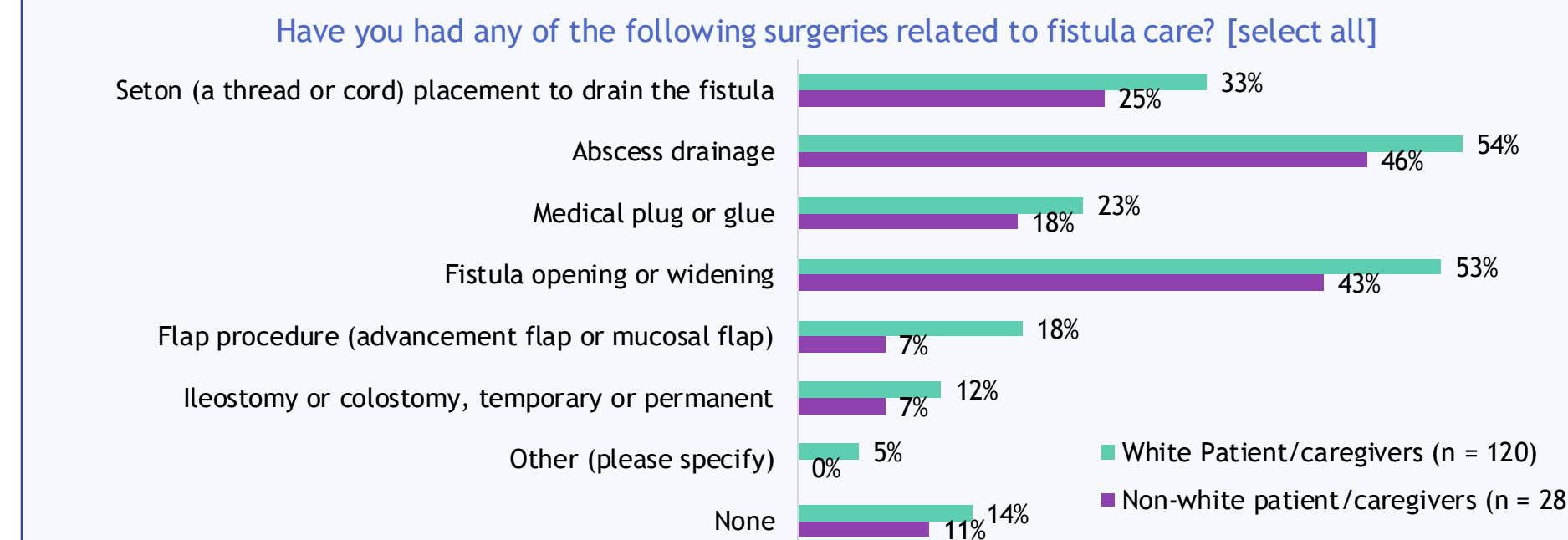
### Current and past medical management of CPF

White patients/caregivers reported higher (50%) current use of biologics than non-whites (36%); however, past use of biologics was almost equal for both groups.



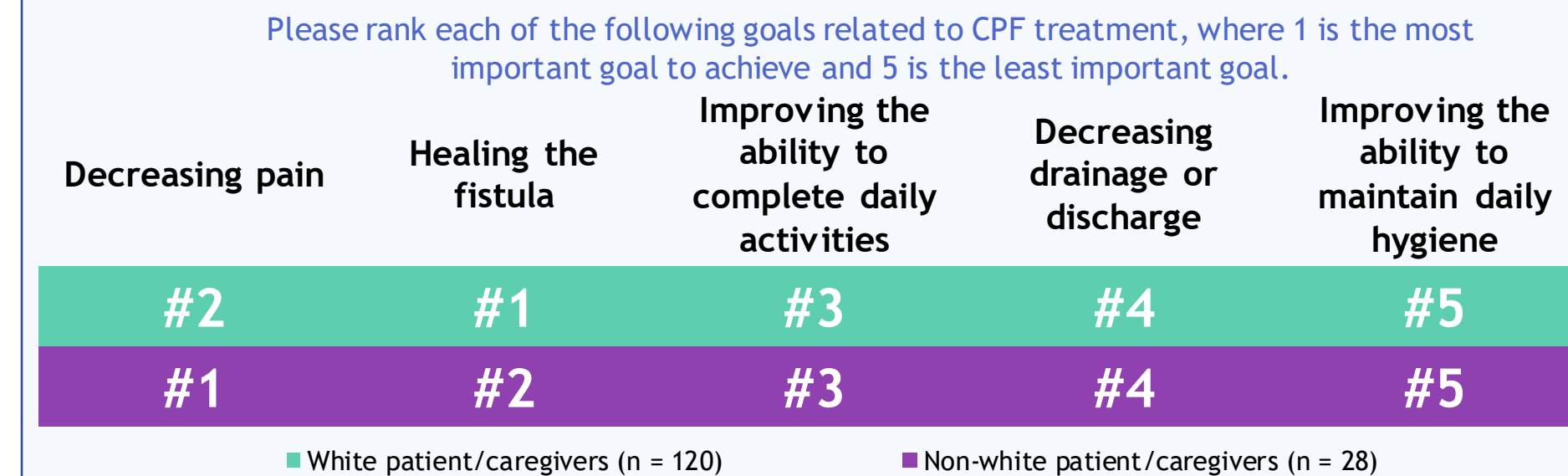
### Surgical management of CPF

Of patients who had undergone surgical procedures (86.5%), non-white patients/caregivers had a lower average number of different surgery types (1.64) than white patient/caregivers (2.31).



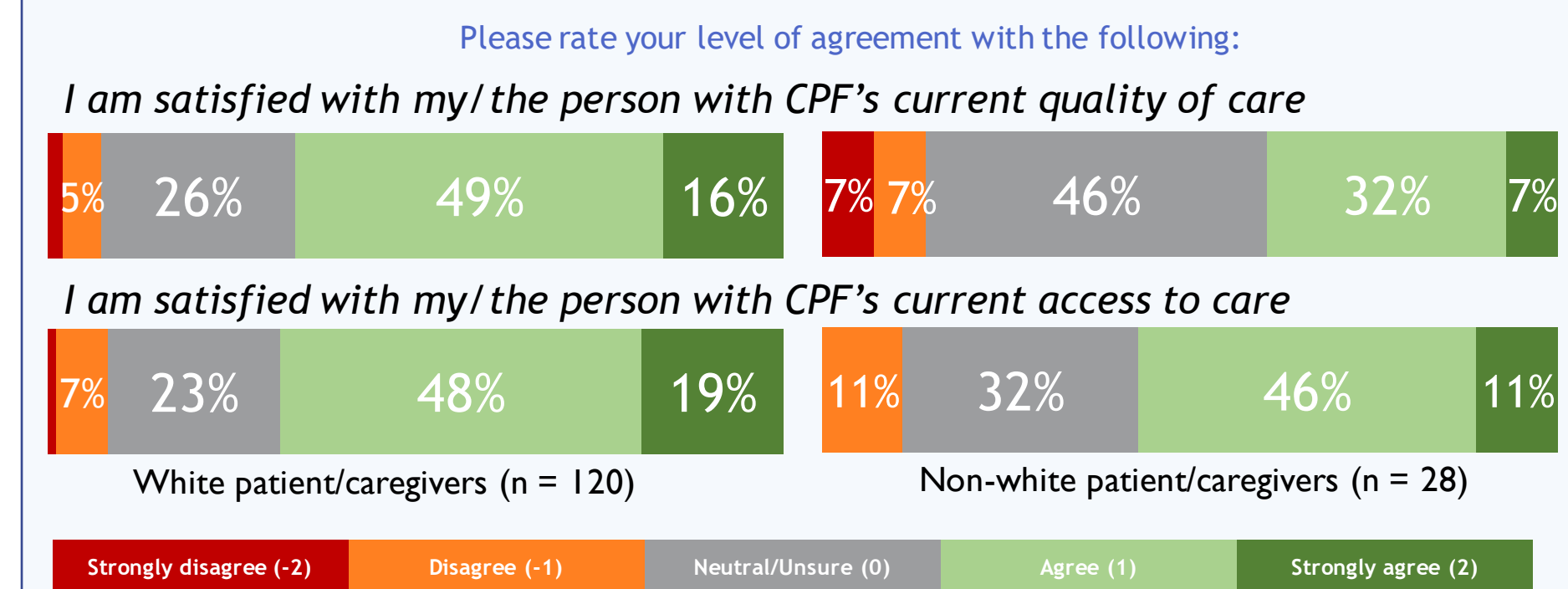
### Goals of CPF treatment

The top two reported goals of treatment for both groups were decreasing pain and healing the fistula.

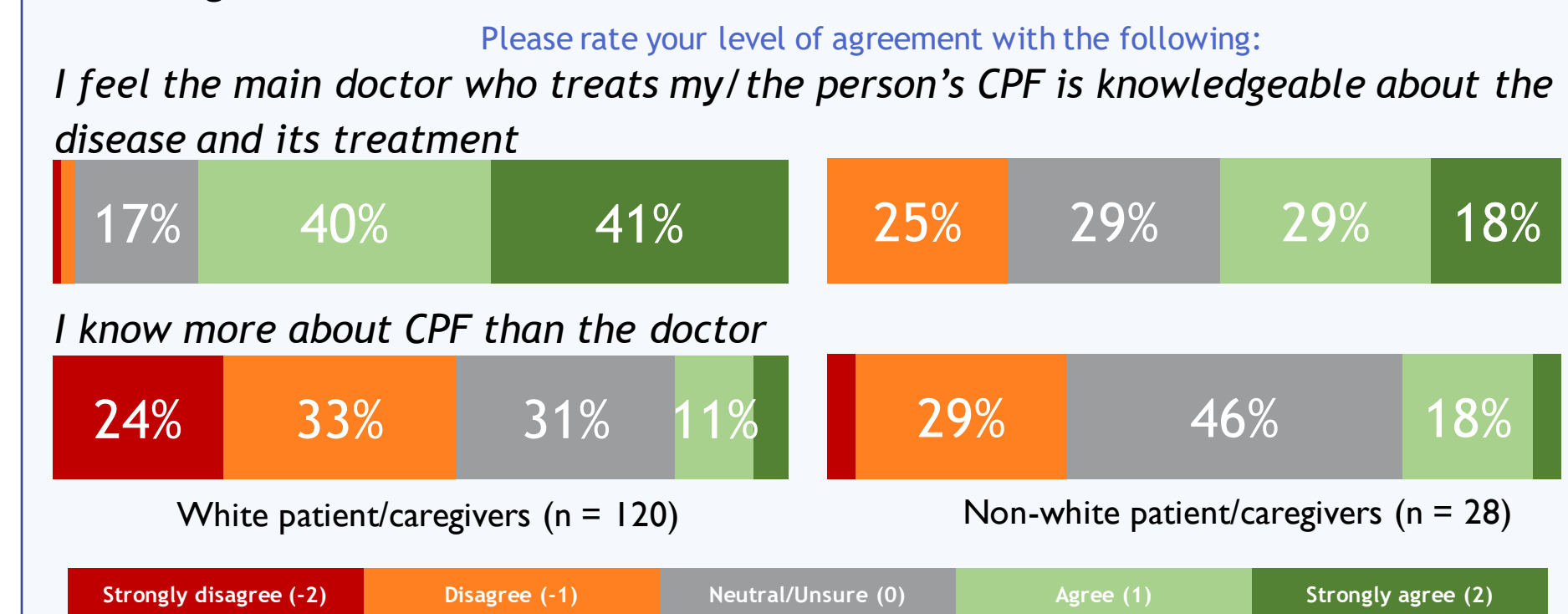


### Perception of clinician management

Fewer non-white patients/caregivers agreed or strongly agreed they were satisfied with their current quality and access of care.

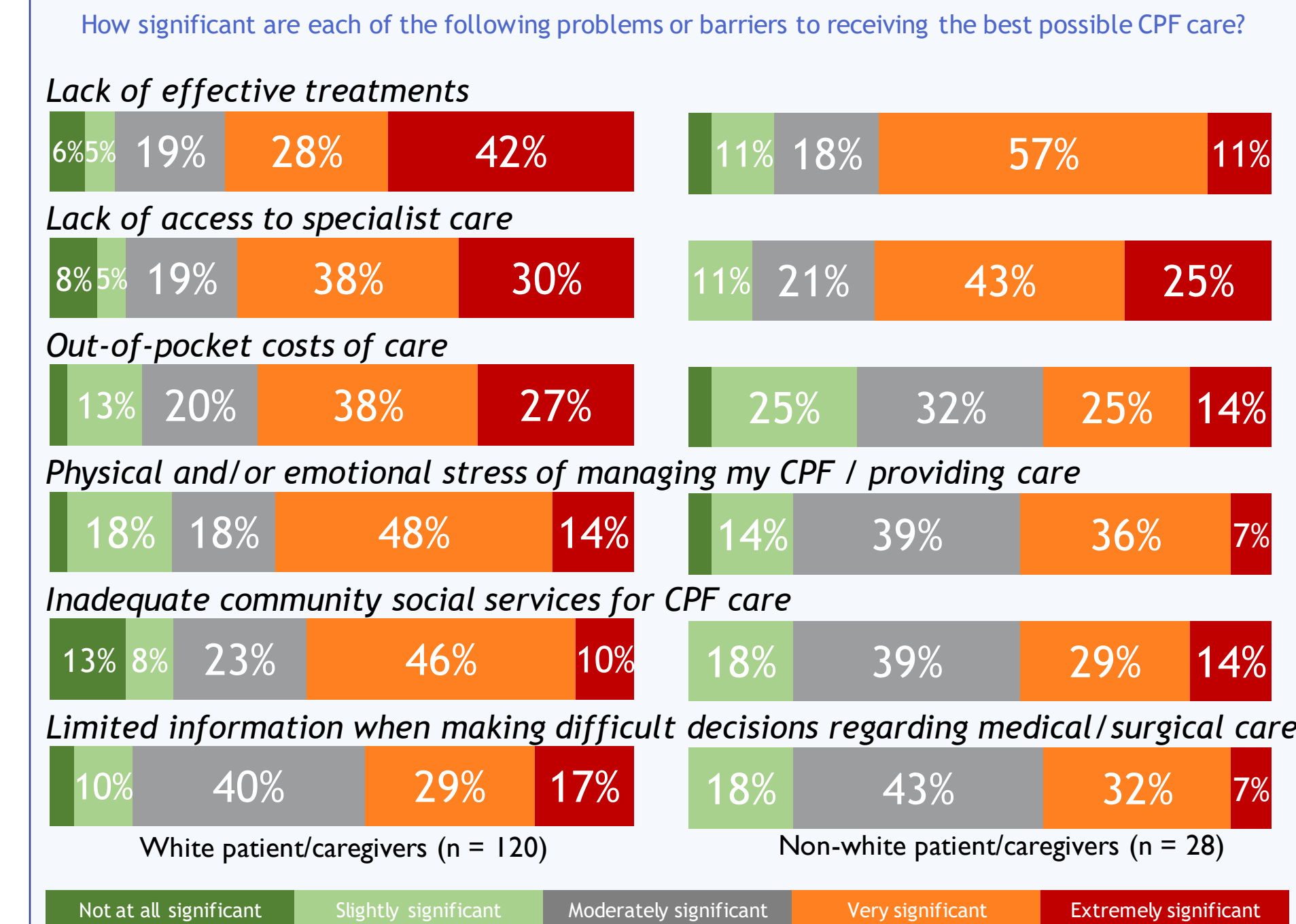


White patients/caregivers had more positive attitudes towards their doctor's knowledge about CPF and its treatments.

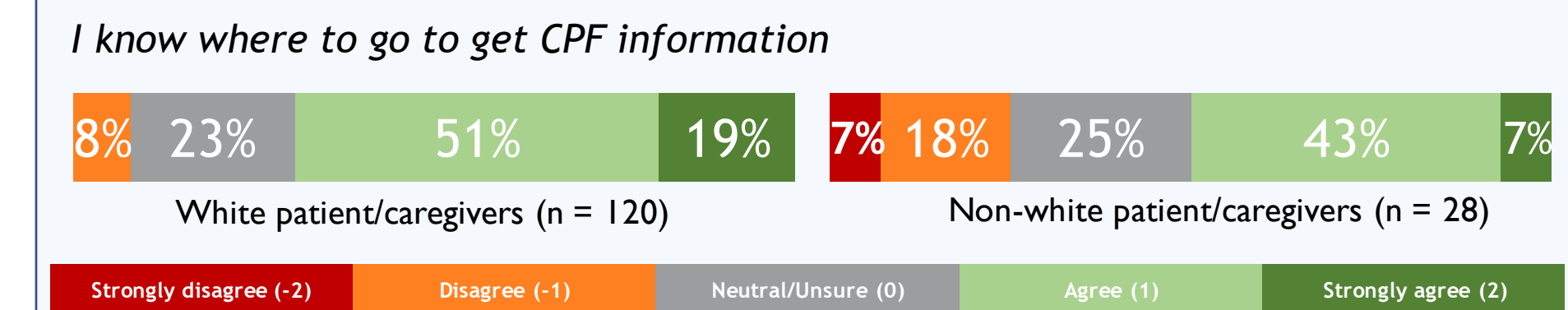


### Barriers to optimal patient CPF management

Both white and non-white patient/caregivers indicated similar significance levels of barriers to receiving the best possible CPF care. Top barriers included lack of effective treatments and lack of access to specialist care.



Only 50% of non-white patients/caregivers versus 69% of white patients/caregivers agreed or strongly agreed that they know where to go to get CPF information.



### Conclusions

Disparities in diagnosis and management of CPF exist between non-white and white patients/caregivers, including length of time to diagnosis, perceptions of quality of care and barriers to treatment. Further research into disparities in the management of CPF is needed, as is CPF education for patients/caregivers and HCP education on managing CPF in minority populations.

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