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# Patient-Centered Dosing Initiative (PCDI)

## MBC Patient-Centered Dosing Survey Results, 08/20

“Designed by Patients, for Patients”

*\*\*\* With Appreciation from the PCDI Team! \*\*\**



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# Patient-Centered Dosing Initiative (PCDI) Introduction

LAUNCHED BY A TEAM OF METASTATIC BREAST CANCER (MBC) PATIENT ADVOCATES WORKING WITH HEALTHCARE PROFESSIONALS TO IMPROVE PATIENTS' QUALITY OF LIFE VIA TREATMENT-RELATED ADAPTATIONS

## Rationale:

- While MBC is considered incurable, it can be treatable for years, or in rare cases, decades
- Cancer drug development normally focuses on the maximum tolerated dose (MTD), even though patients can rarely tolerate the MTD for extended periods
- As a consequence of toxicity-related side effects, patients with MBC have been known to require emergency medical assistance, stop a working treatment prematurely, or be rendered incapable of receiving their treatment on schedule
- Although more data is needed, recent evidence suggests that approved lower doses of some MBC cancer therapies may be just as effective as the MTD with less severe side effects, and may allow patients to remain on therapy for a longer period of time

**Mission:** To enhance quality of life, while maintaining therapy effectiveness, by enabling patients with MBC and their physicians to identify the optimal approved dosage of treatment based upon each patient's unique physical, circumstantial, and psychological factors. Learn more at [www.therightdose.org](http://www.therightdose.org)

***Patients should never reduce their dosage or change anything regarding their treatment without speaking with their doctor!***

# Meet the PCDI Team!



Lesley Glenn



Flori Hendron



Julia Maues



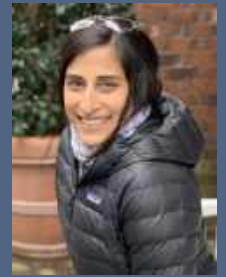
Natalia Padron



Anne Loeser, Founder



Sheila McGlown



Kimberly Parekh



Chawnte Randall



Sandra (Sandi) Spivey



## PCDI Advisory Board Members



Aditya Bardia, M.D., MPH

Kevin Kalinsky, M.D., M.S.



Mark E. Burkard, M.D., PhD

Erin Nelli, D.O.



Hope Rugo, M.D.



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To the 1,221 People Who Took the Survey...





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## About the MBC Patient-Centered Dosing Survey

The PCDI sought to obtain a greater understanding about MBC treatment-related side effects and the approaches used to manage them - in lieu of making assumptions

- ✓ Questions pertained to treatment-related experiences, quality of patient-physician communication, and level of support provided by physicians whose patients experience treatment-related side effects
- ✓ Responses are enabling the 9-member PCDI patient advocate team and the medical professionals supporting this initiative to identify opportunities for future improvements regarding side effect mitigation



# Survey Methods

Previously launched a limited “Beta Pilot Survey” to obtain key learnings

Reviewed the survey with the PCDI’s Advisory Board of Medical Oncologists

Attempted via Voluntary Consent verbiage to restrict responses to US-only due to varying data privacy and protection laws

Advertised participation via social media, online support groups, email lists, and organizational newsletters

Encouraged participation from minority groups via photos of African-American and Hispanic-American PCDI members accompanying the flyers; translated into Spanish







## Similarities to Results from Other Studies

Most common side effects were fatigue (78%), nausea (53%), and low blood counts (53%). (*The MBCA Landscape Analysis reported fatigue as the most common side effect at 80%*)

All 7 males reported having hormone receptor (HR) positive disease - consistent with the 97% HR+ rate reported for male breast cancer

62% of survey respondents reported having recurrent breast cancer; 38% presented as de novo

- de novo disease normally represents 6% of all MBC cases
- The MBC Project indicated that 36% of patients reported de novo disease

7% of respondents were diagnosed > 10 years ago, similar to the MBC Project's 6%

Disease by subtype reporting is likewise consistent with that of the MBC Project

	PCDI	MBC Project
Hormone Receptor Positive	77%	81%
HER2 Positive	30%	32%
TNBC	10%	11%



## Surprises and Key Learnings

22% of patients reported being diagnosed with MBC more than 5 years ago. (Normally the > 5 year survival rate is 27%).

16% of participants had 5 or more lines of treatment

86% reported experiencing one or more bad side effects from treatment

- 20% visited the Emergency Room/hospital
- More than 2 of 5 patients (43%) missed at least one treatment
- 98% reported discussing their side effects with their physician (*in contrast to a study mentioned in the MBCA Landscape Analysis whereby only 65% of patients seen in comprehensive cancer centers and 50% of patients seen in community oncology practices told their physicians of these issues*)
- 82% of these patients received assistance from their doctors



## Surprises and Key Learnings, (Cont'd)

Of the patients who experienced treatment-related side effects and reported these to their physicians, 66% were prescribed a reduced treatment dosage

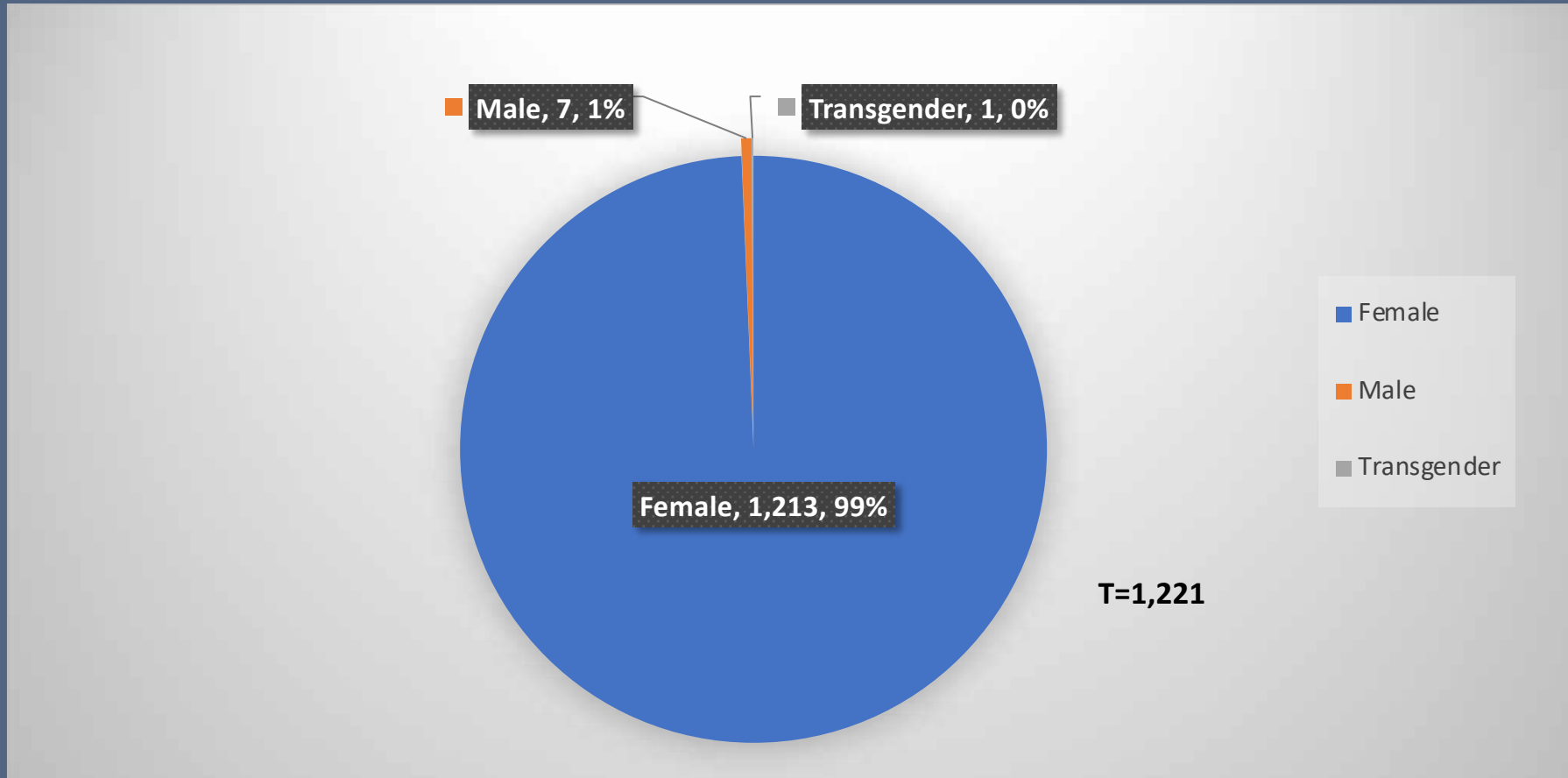
- 83% of patients whose dosage was reduced reported feeling better, at least initially
- 64% of these patients required only one dosage reduction to feel better
- 28% needed two dosage reductions
- 8% required 3 dosage reductions

80% of patients reported being aware that most MBC therapies are available in multiple approved dosages

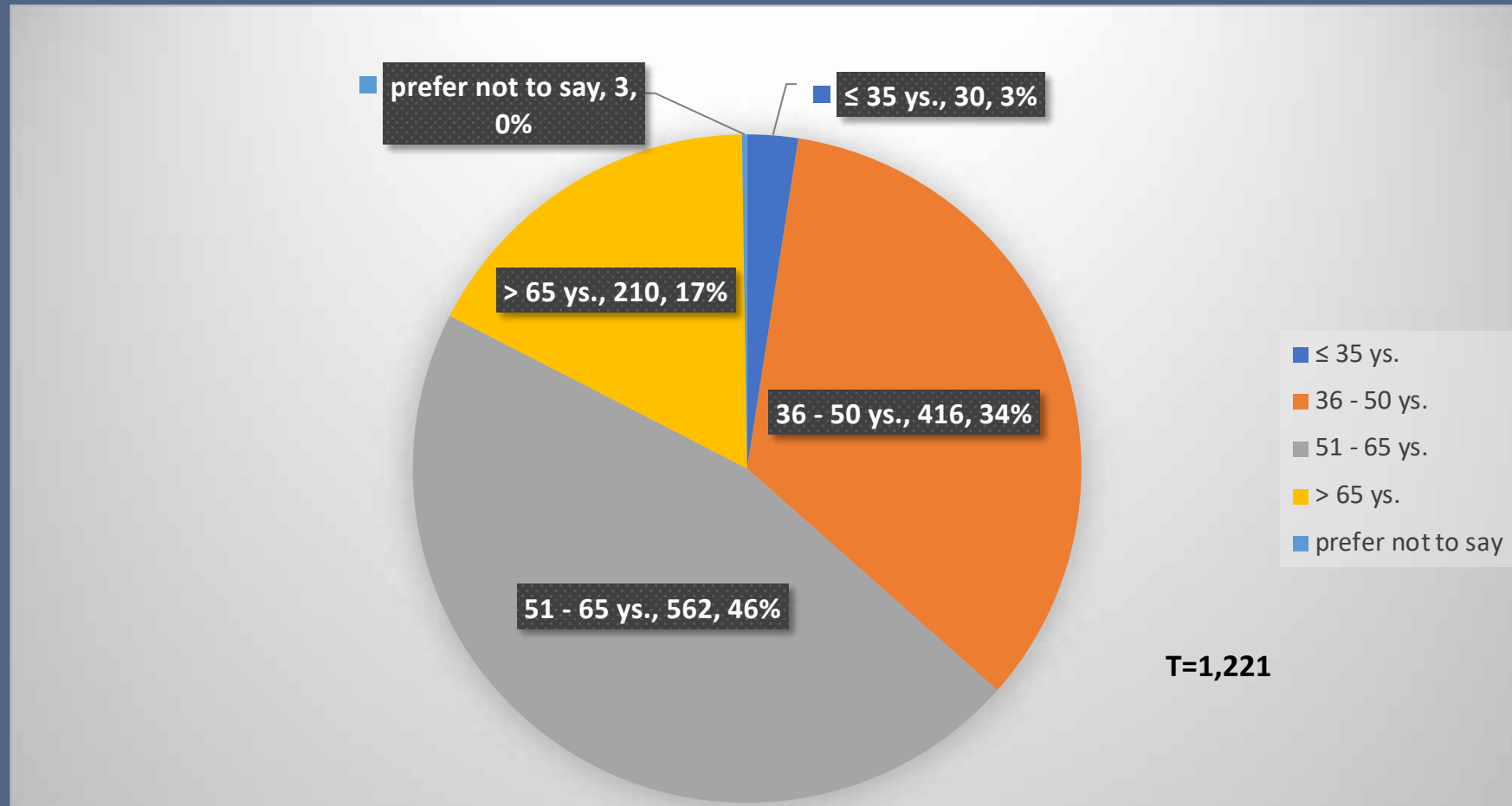
53% of patients felt that a higher dose of a cancer drug is not necessarily more effective than a lower dose, whereas 20% hold the opposite belief (27% were undecided)

The vast majority of patients (92%) would be willing to discuss approved MBC drug dosing options with their physician based upon their unique characteristics

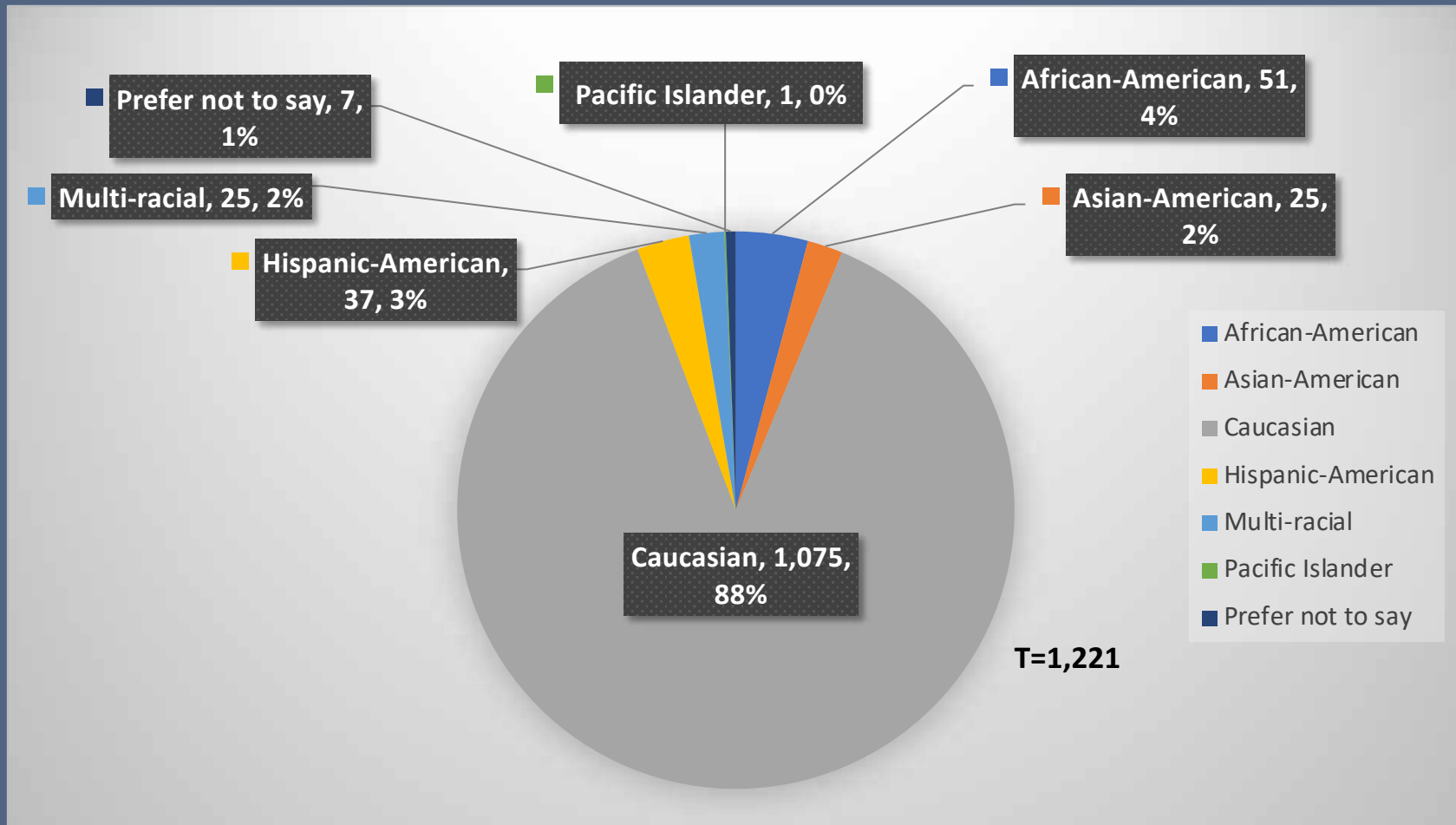
# Gender Identification



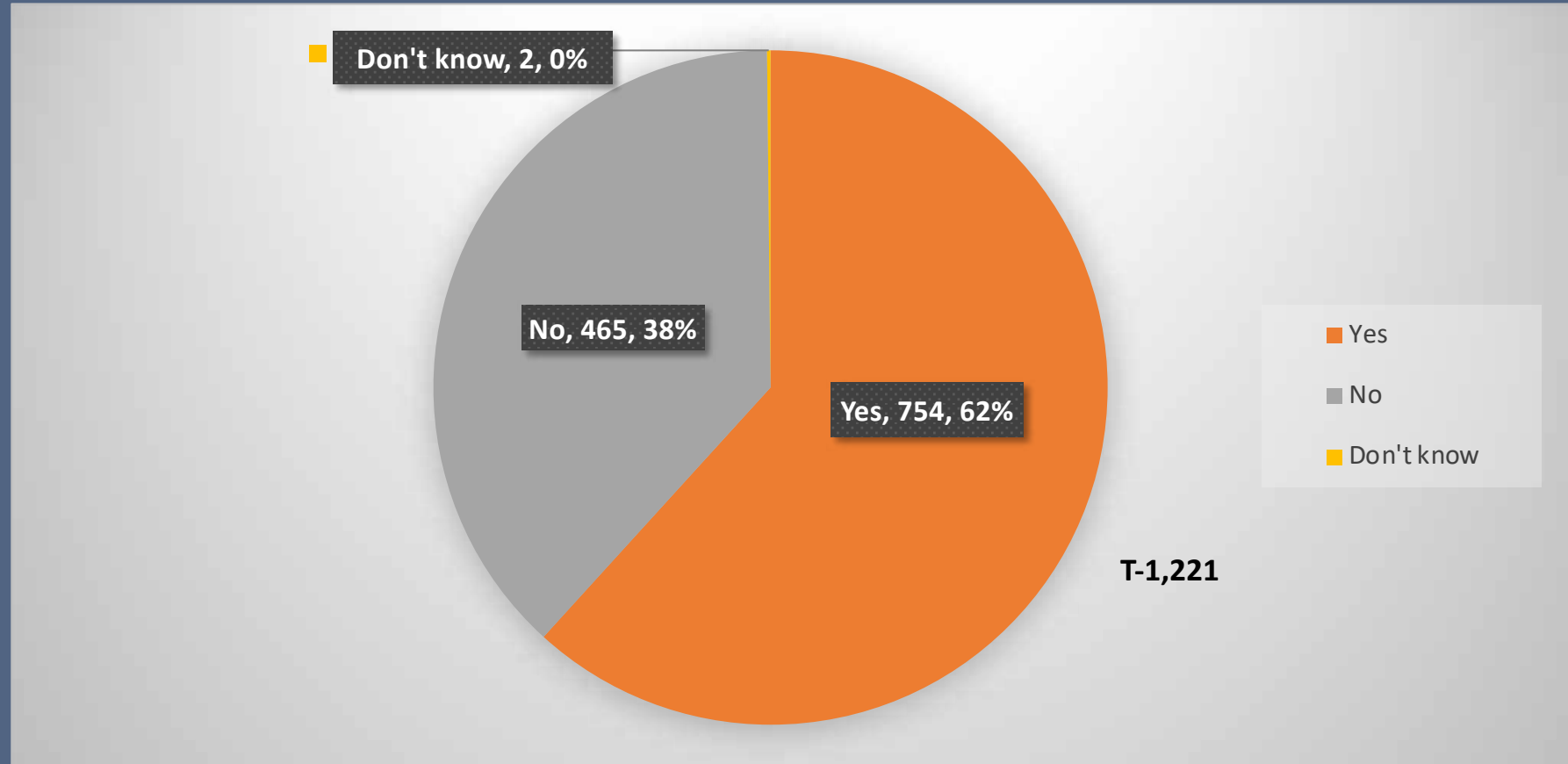
# Age Group



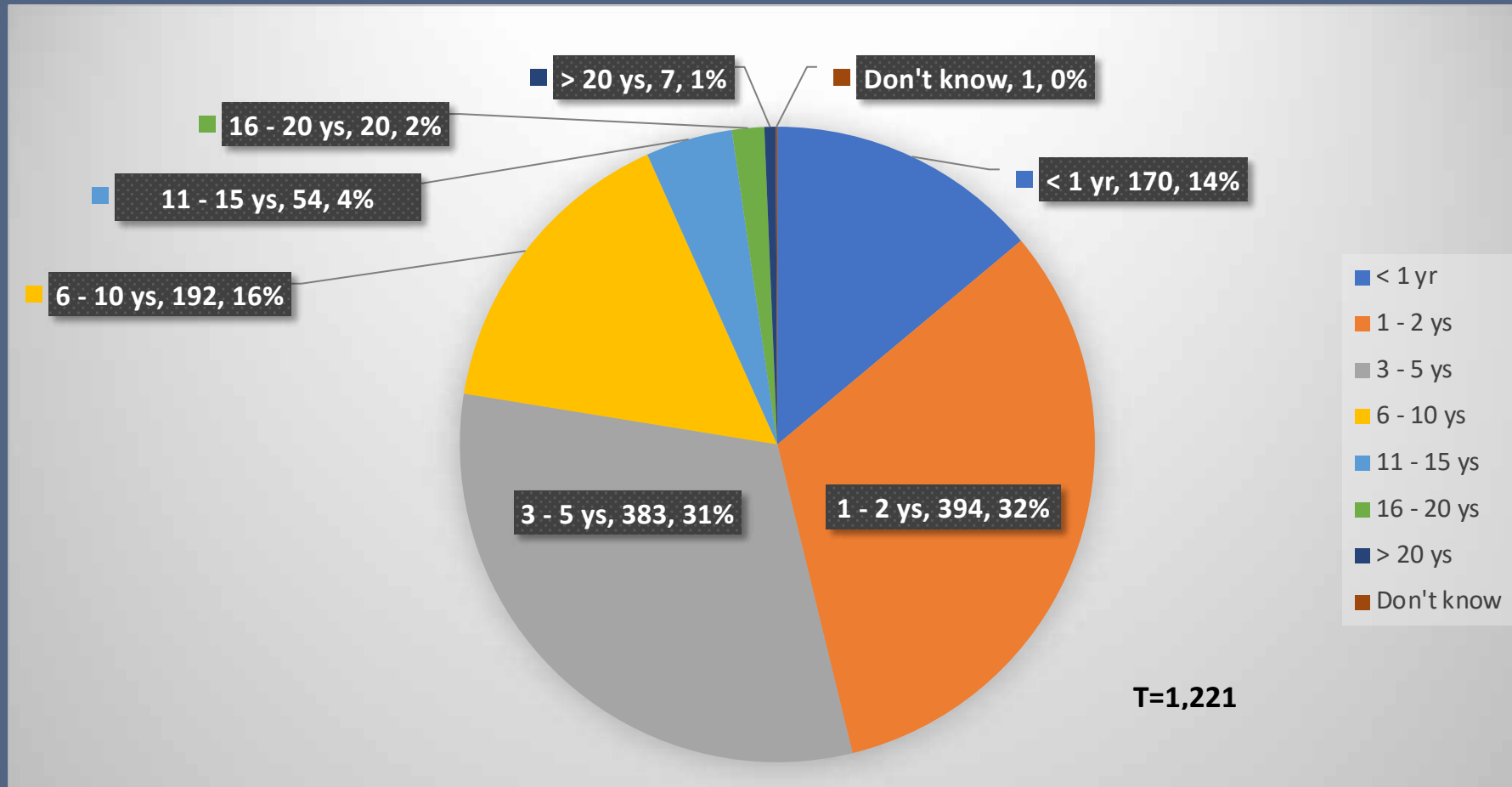
# Racial Group



## Was Patient Previously Diagnosed with Early Stage BC?

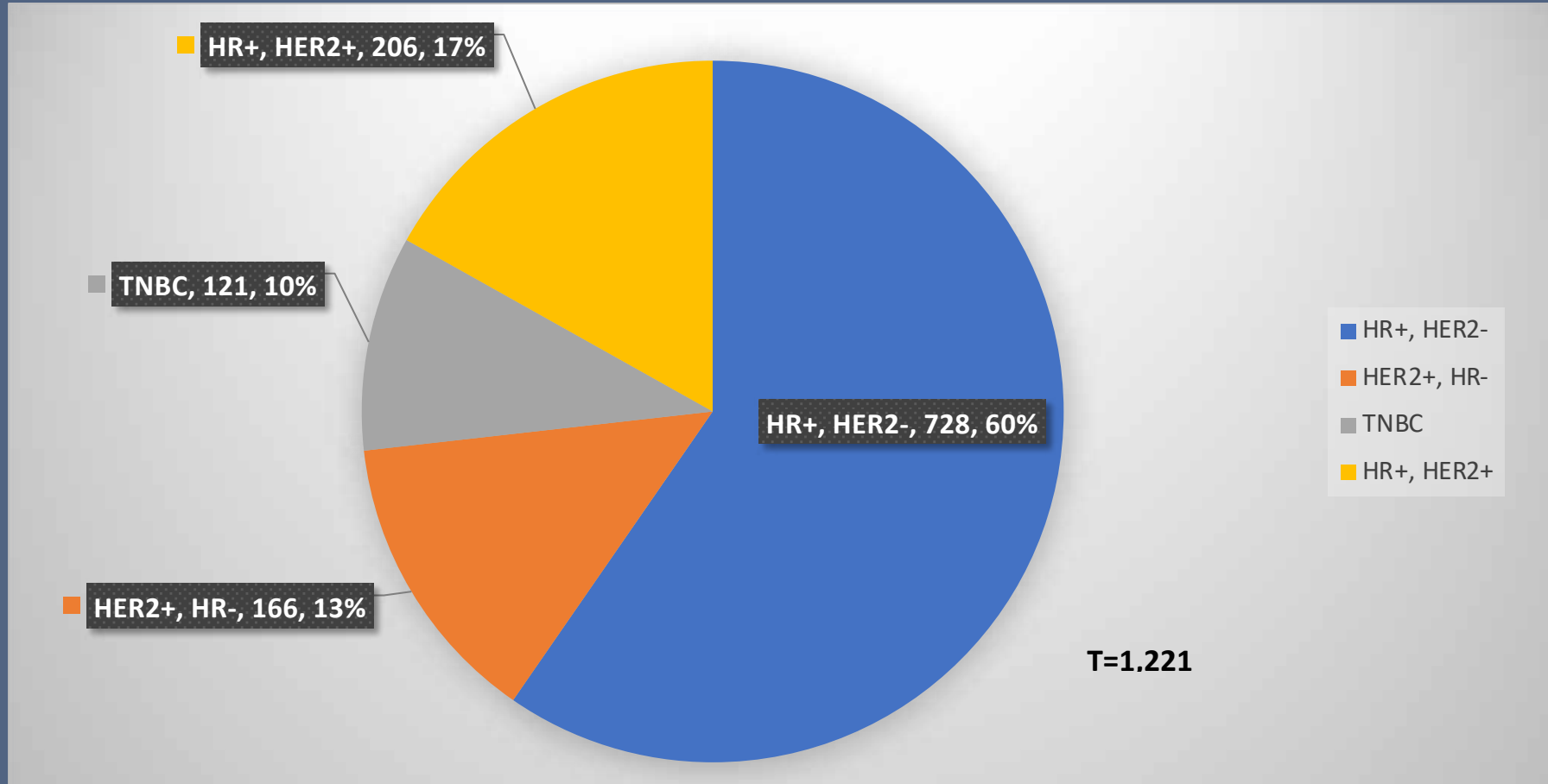


## Years Since MBC Diagnosis

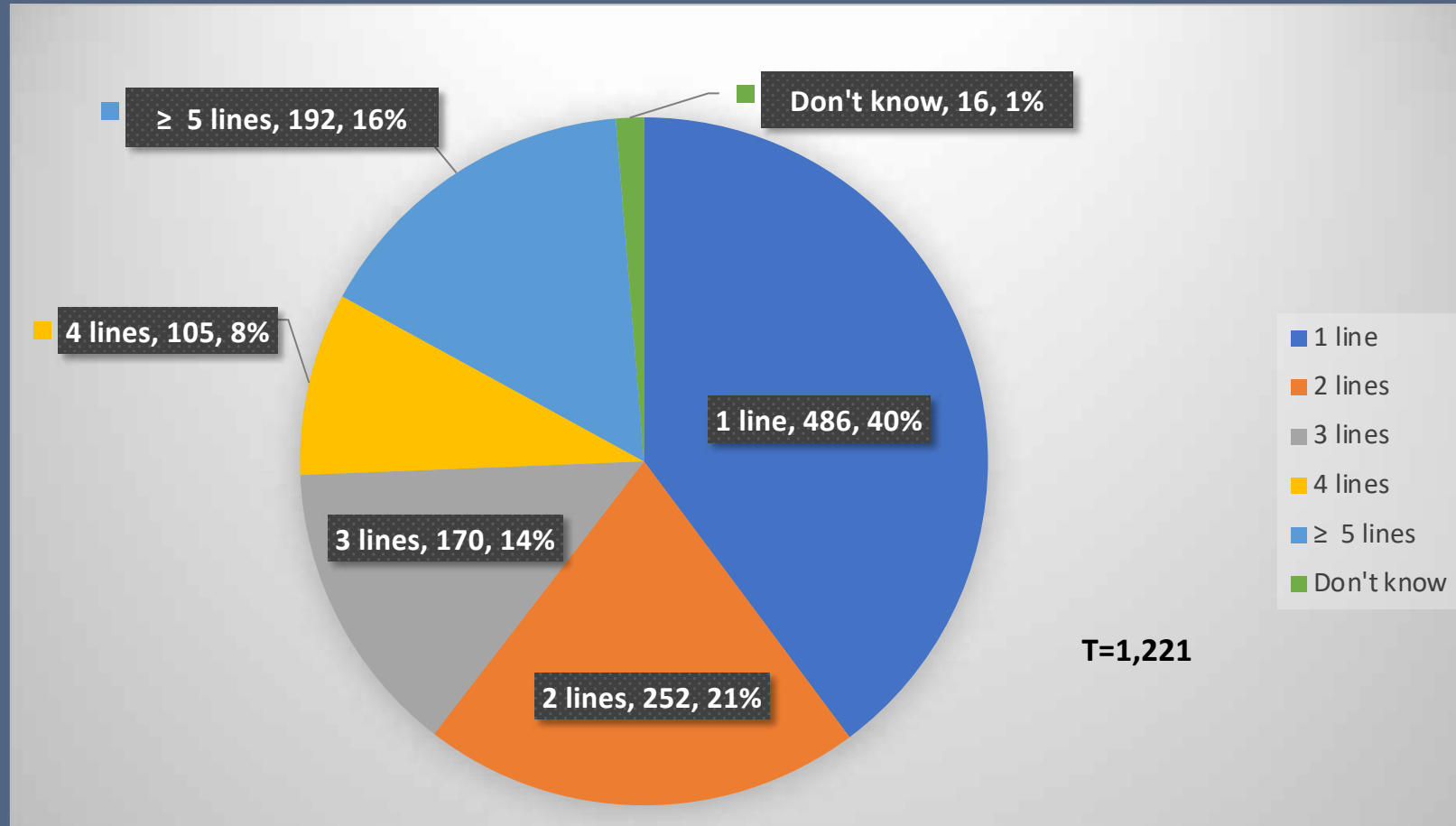




# MBC Subtype

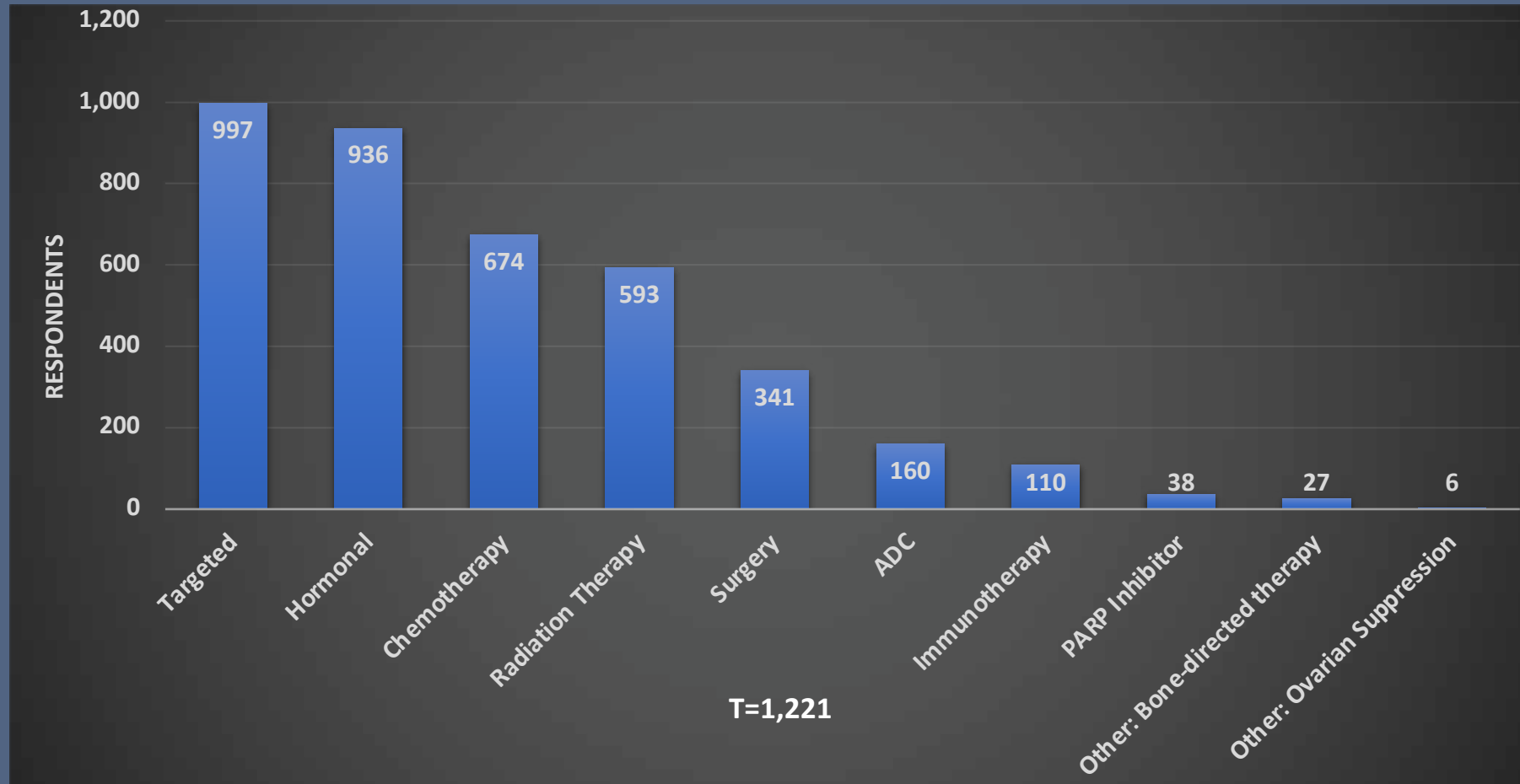


## Nr. Sequential Treatments/Lines of Therapy

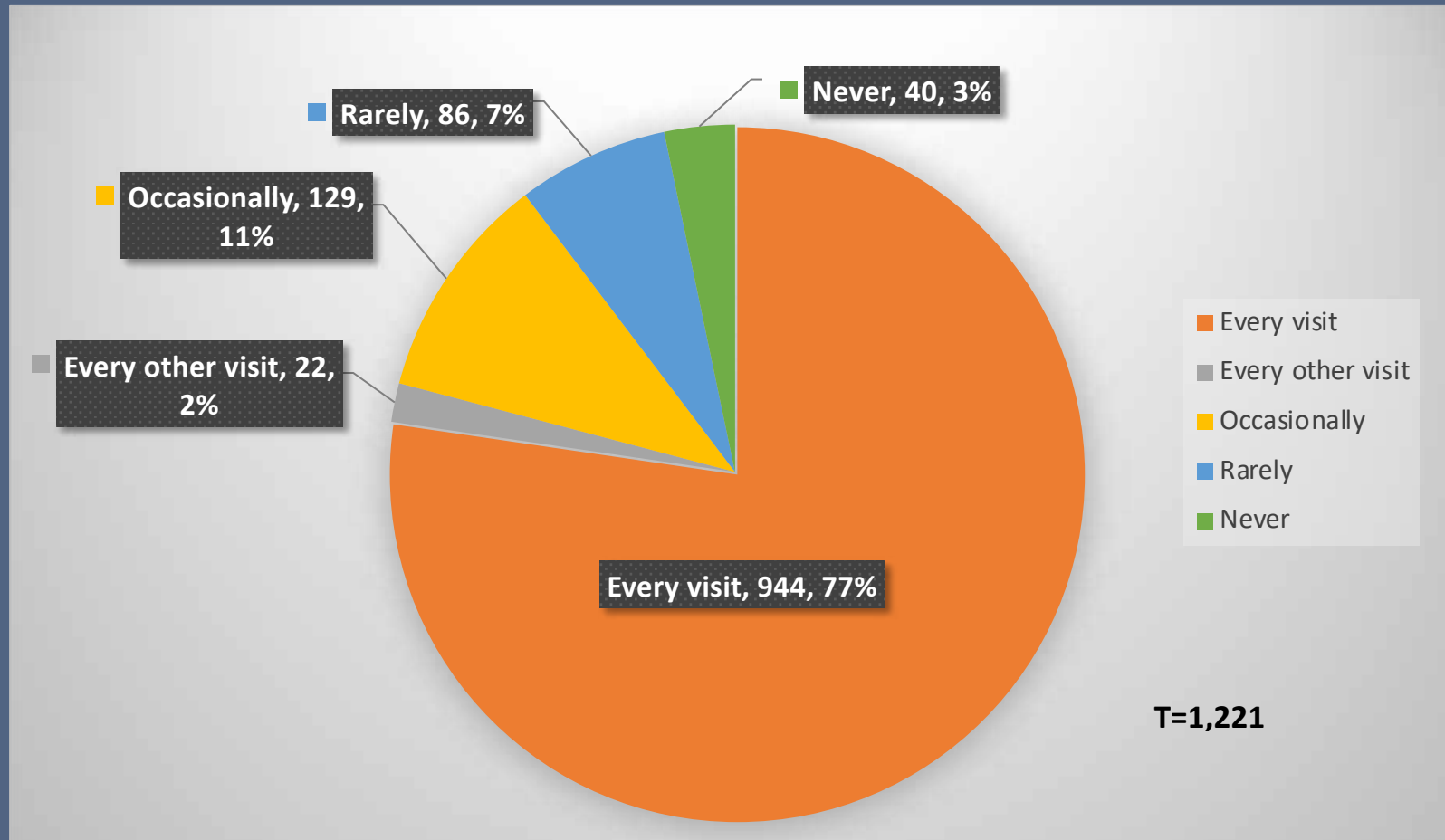




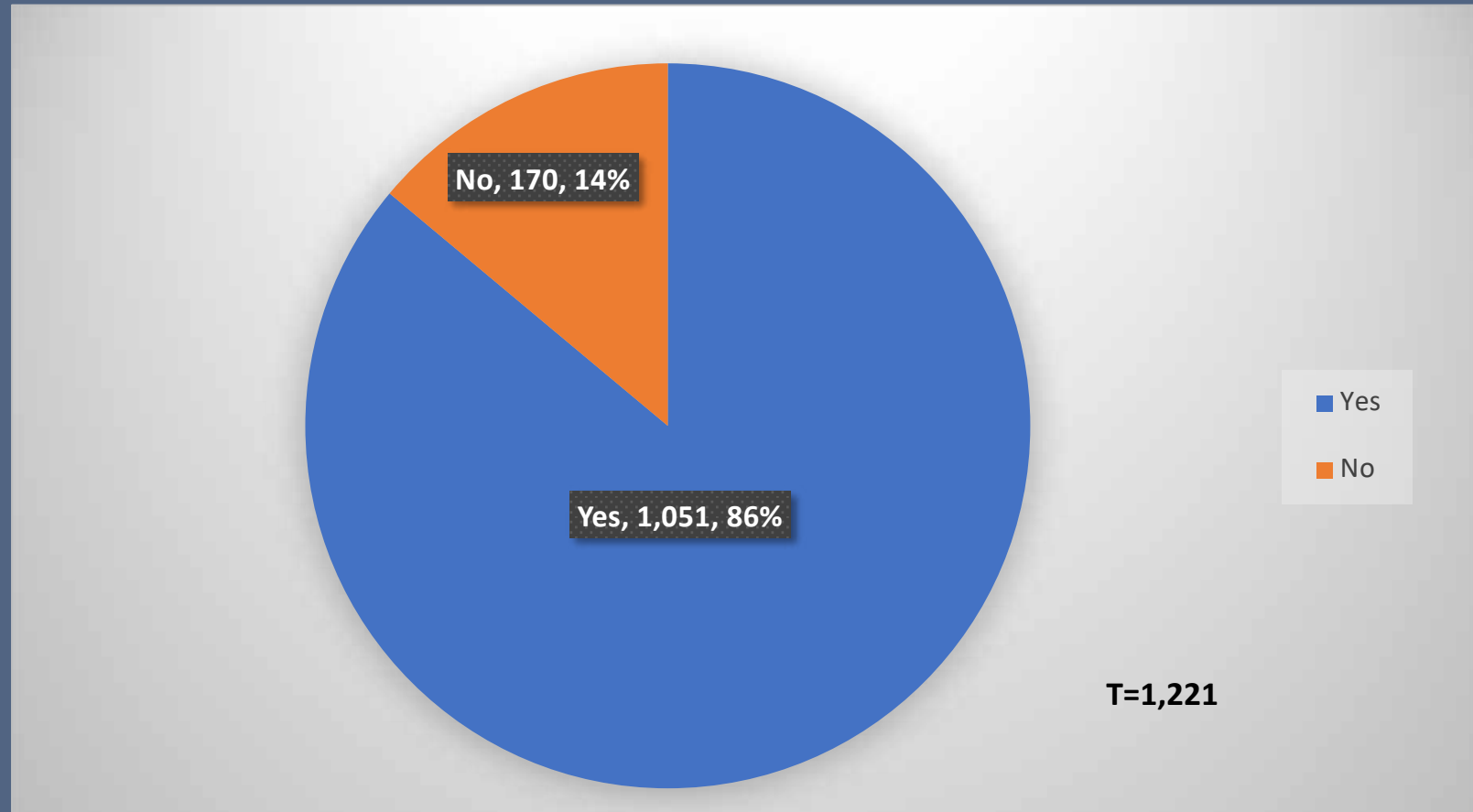
# Types of Treatment (check all that apply, add other)



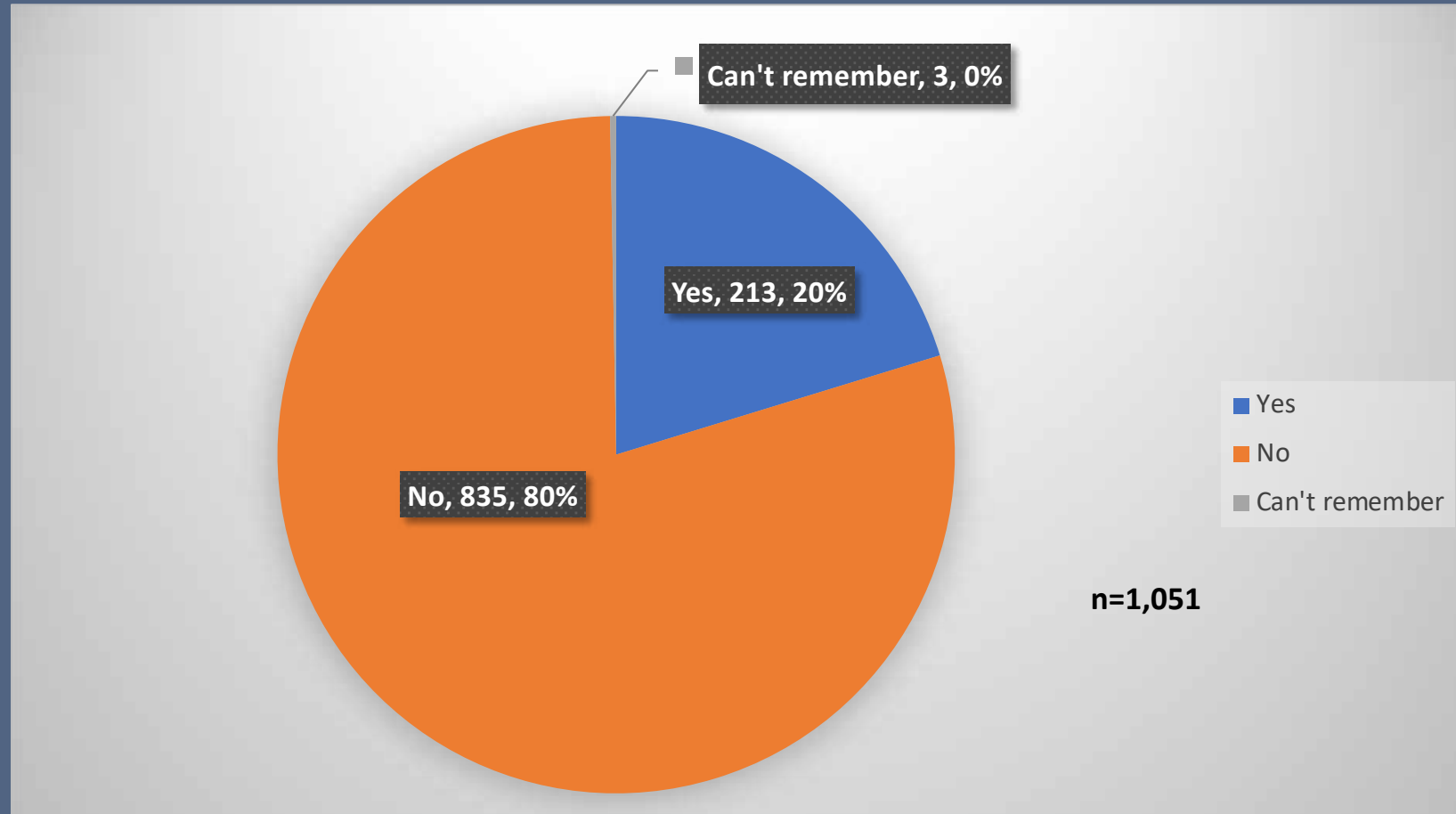
## Frequency of Physician Inquiry Regarding Side Effects



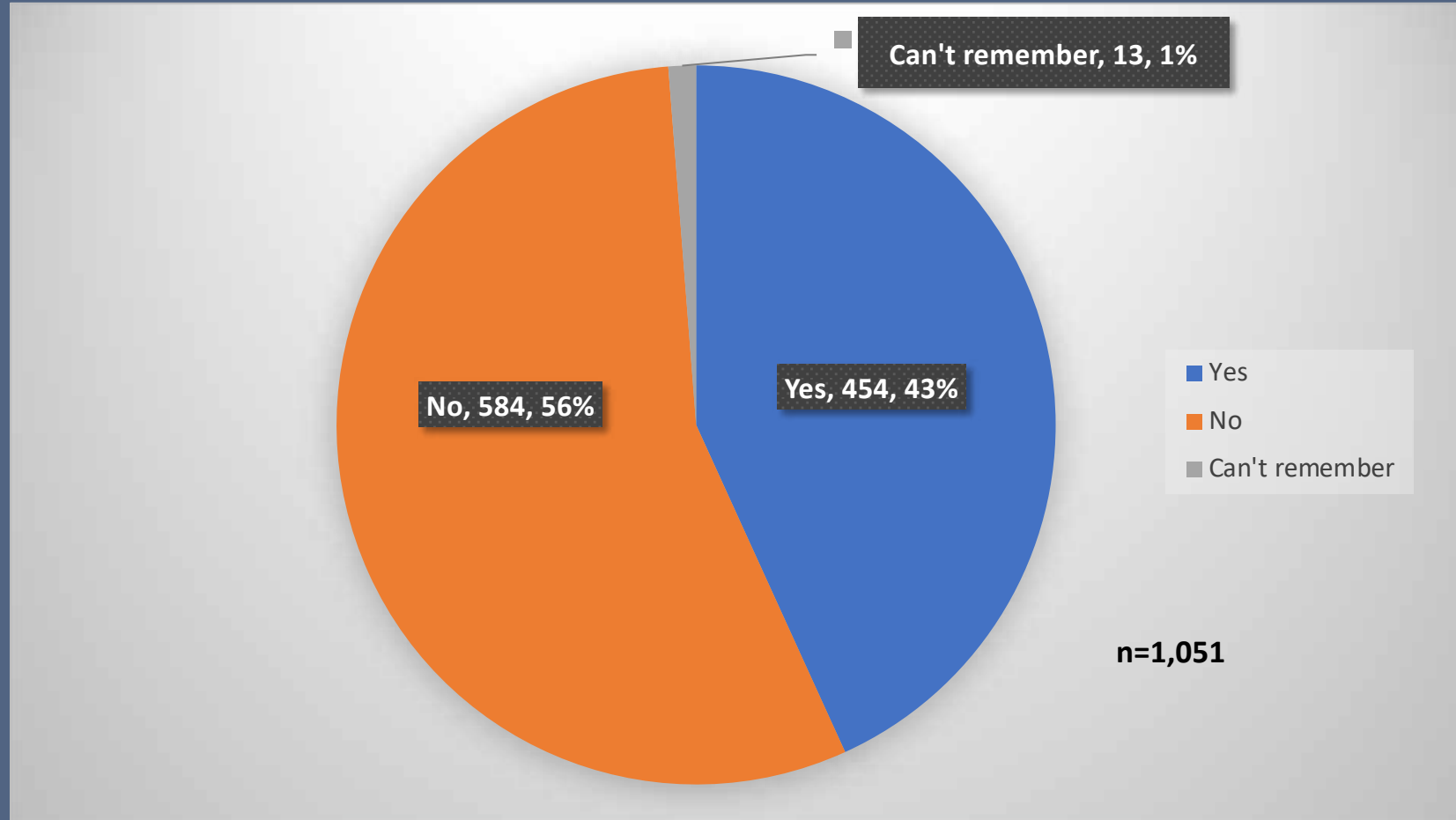
## Has Patient Experienced a Bad Treatment-Related Side Effect?



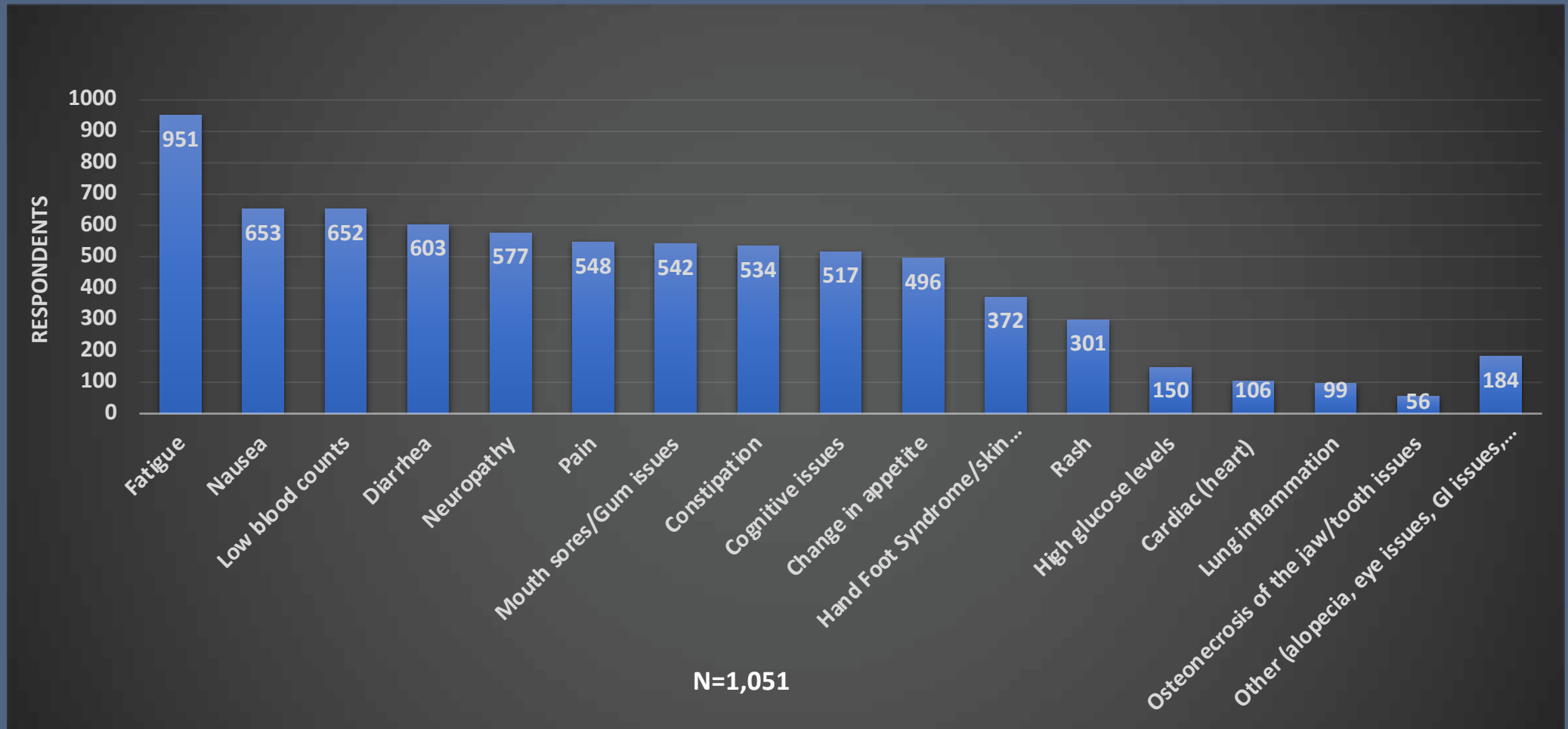
## Did Side Effect Result in Emergency Room/Hospital Visit?



## Did Patient Miss Treatment Due to Side Effect?

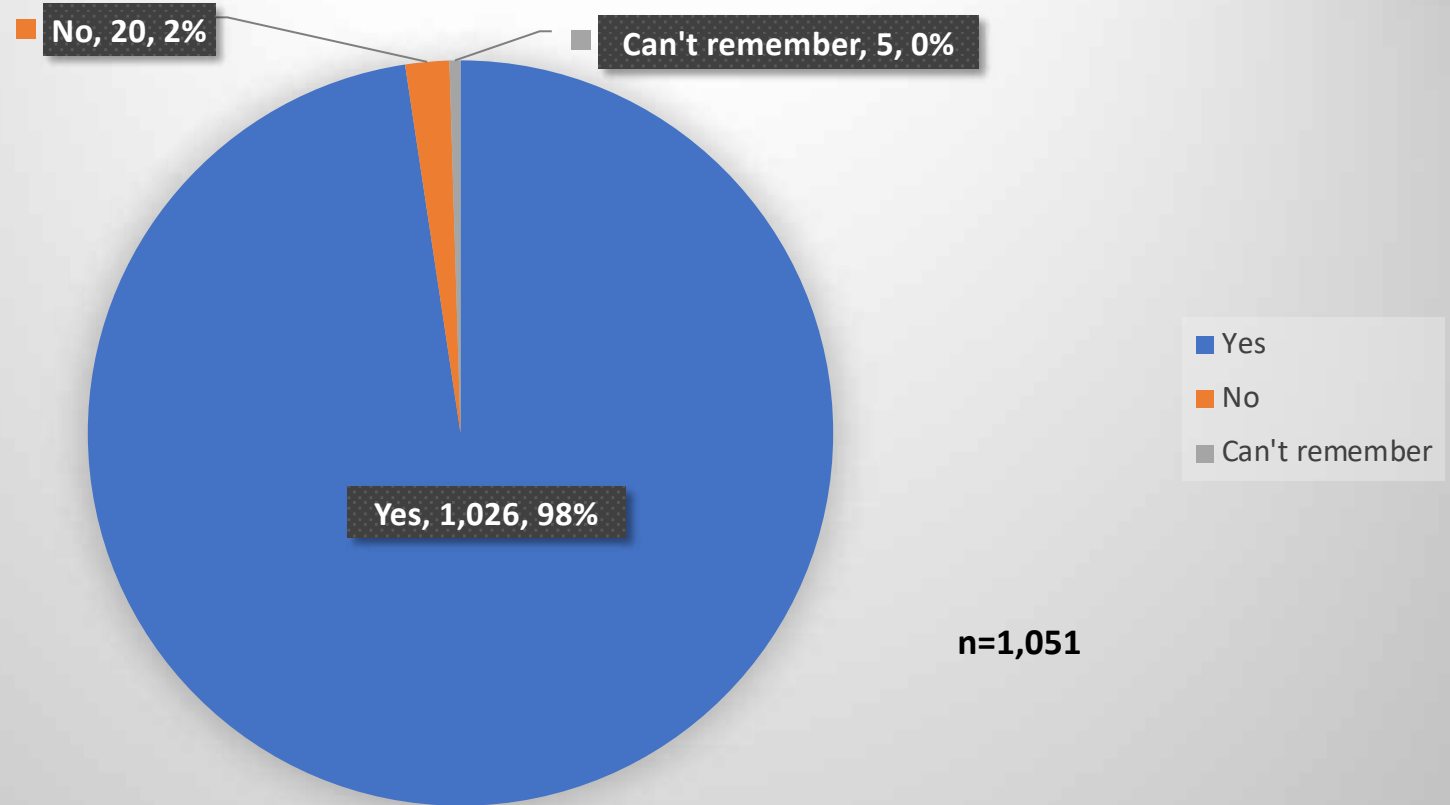


# Treatment-Related Side Effects (check all that apply, add other)

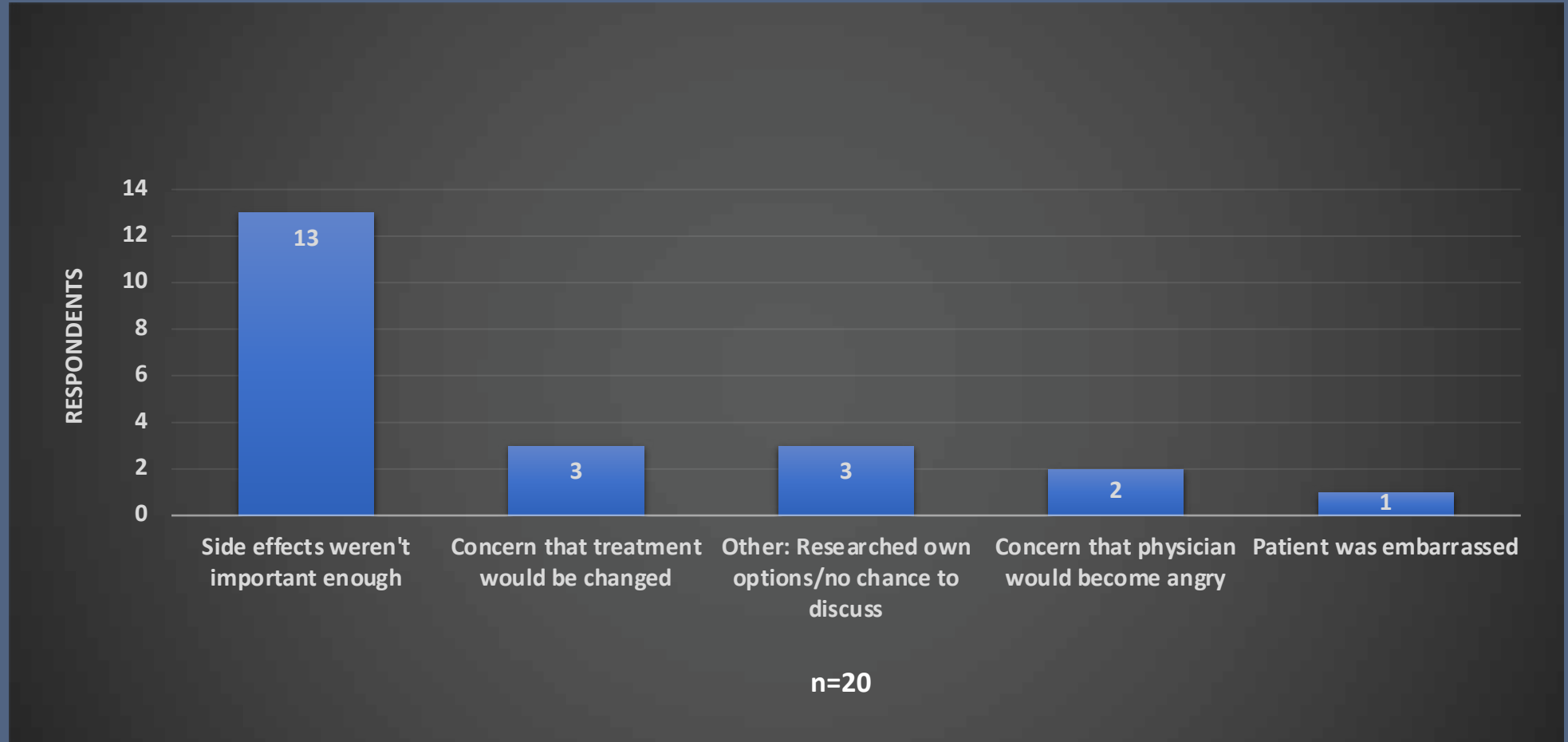




# Did Patient Inform Physician About Side Effects?

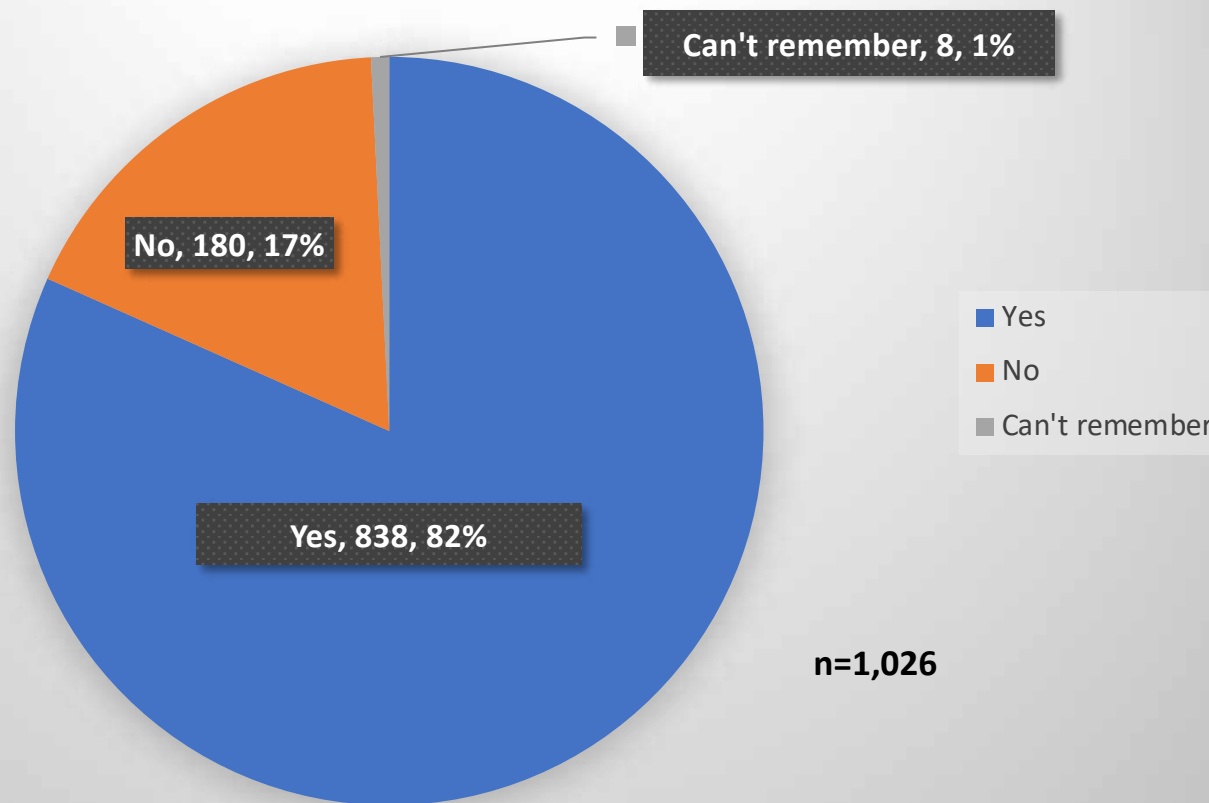


## Why Didn't Patient Inform Physician About Side Effects? (check all that apply, add other)





# Did Physician Assist Patient With Side Effects?



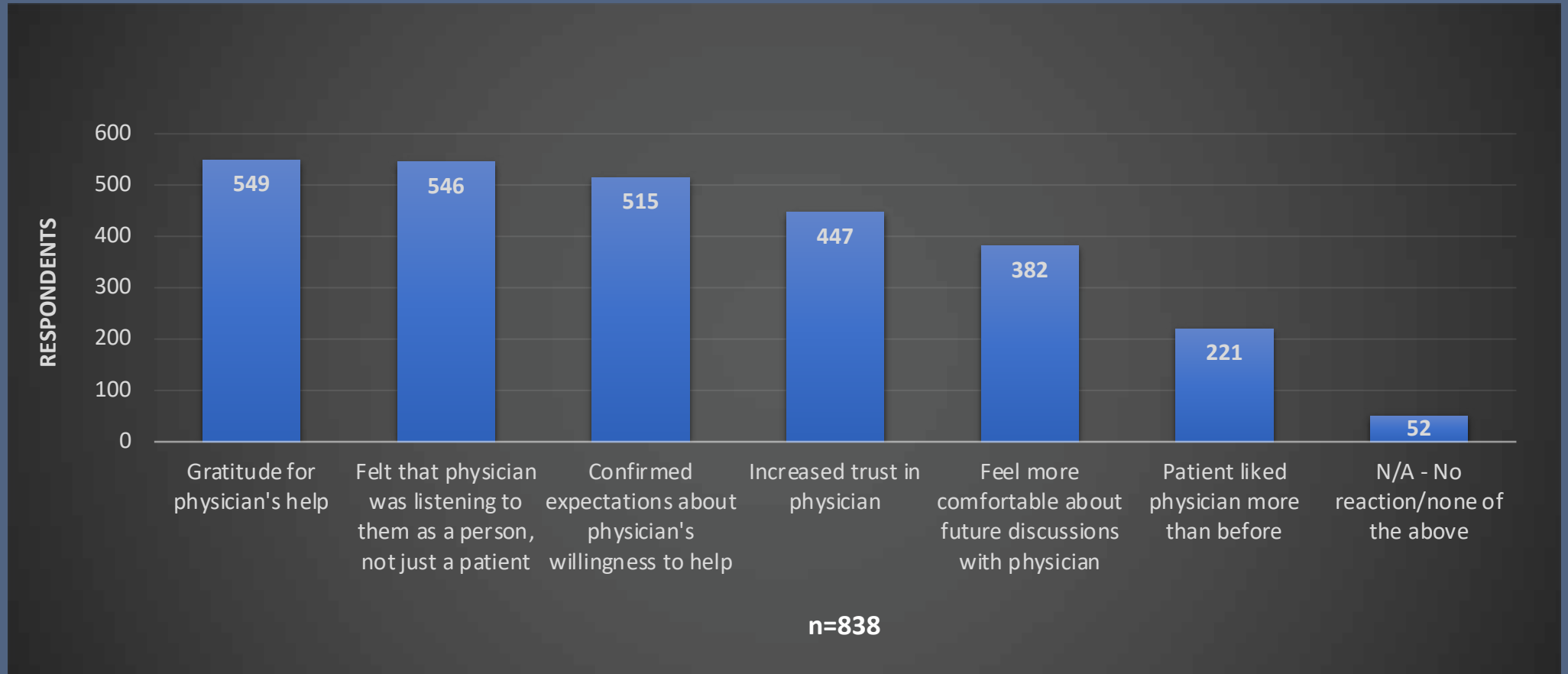
T=1,221

Pts. w side effects: 1,051

Pts. who informed physician about side effects: 1,026



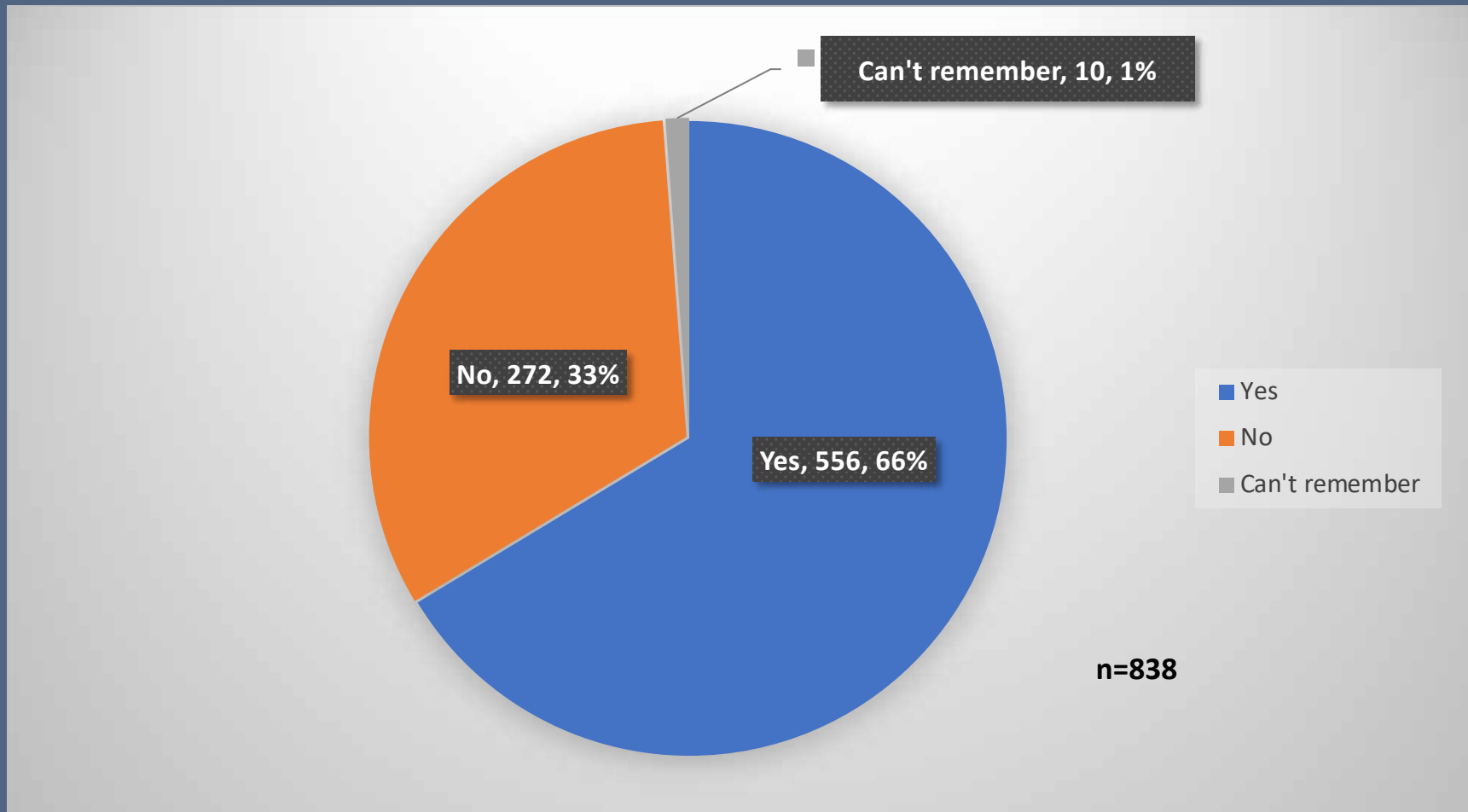
## Patients' Reactions When Physician Helped with Side Effects (check all that apply)



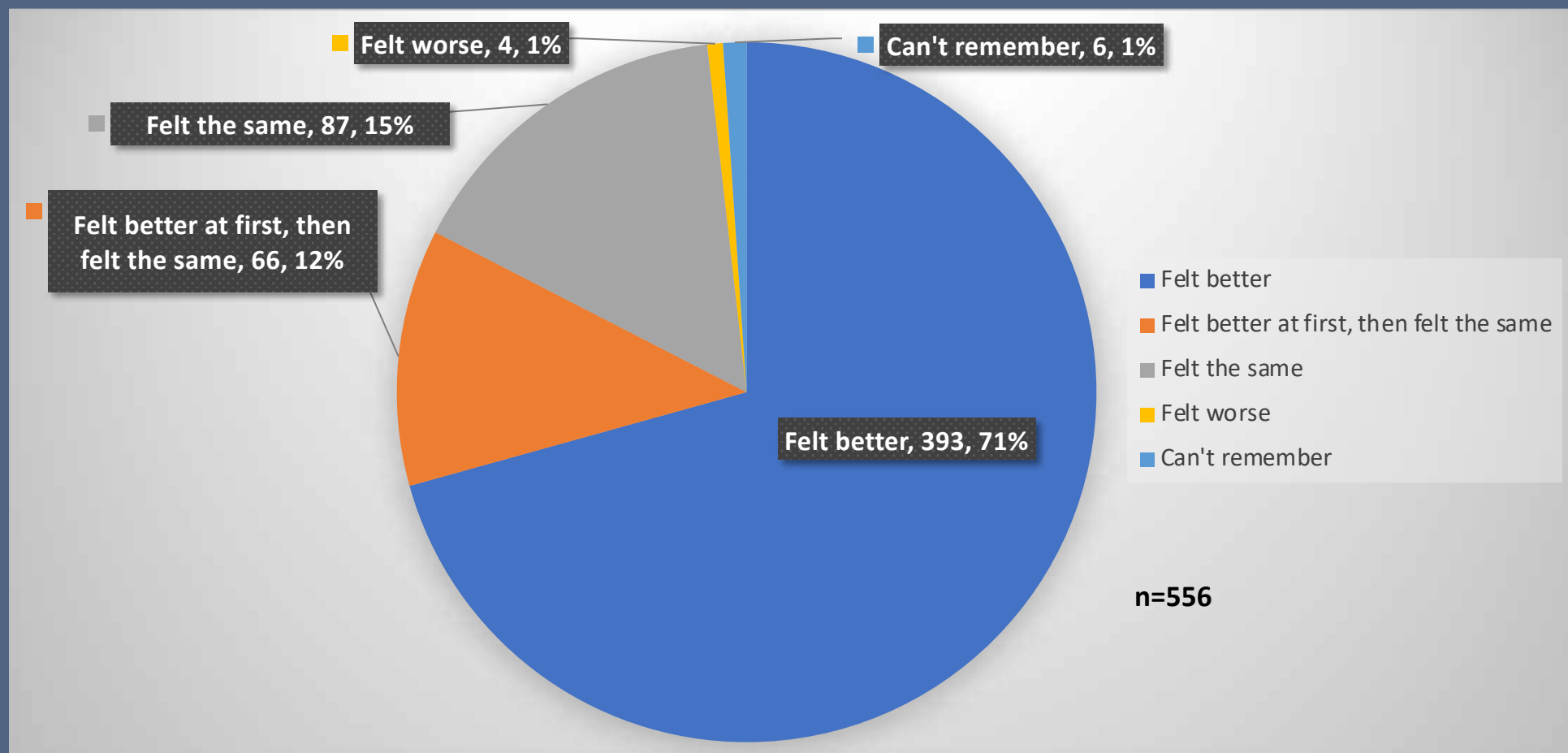
Pts. who informed physician about side effects: 1,026

Pts. whose physicians tried to help: 838

## Did Physician Lower the Dosage?



## Patients' Responses to Lower Dosage

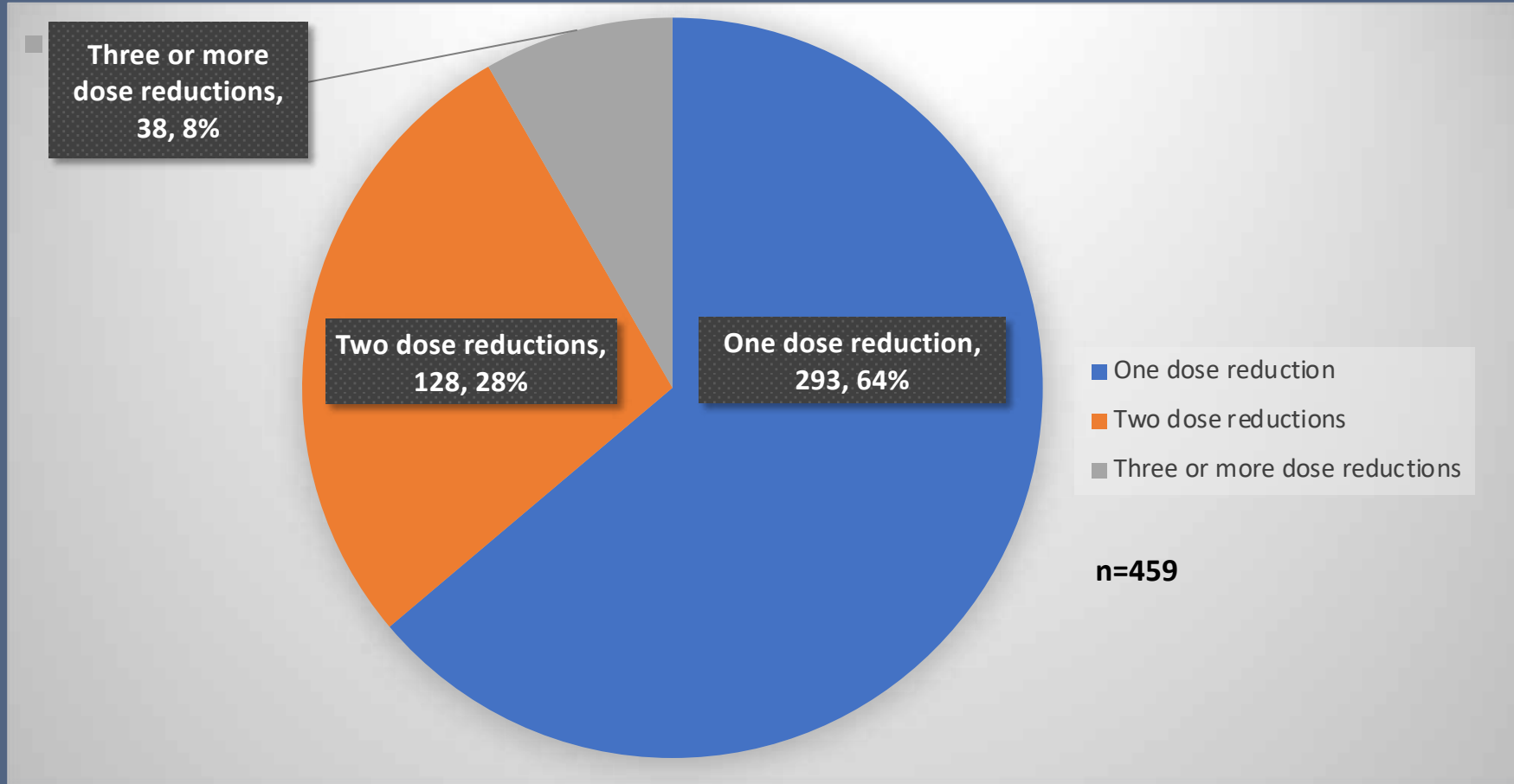


Pts. whose  
physicians tried  
to help: 838

Pts. given a  
lower  
dosage: 556



# Number of Dose Reductions Required to Feel Better

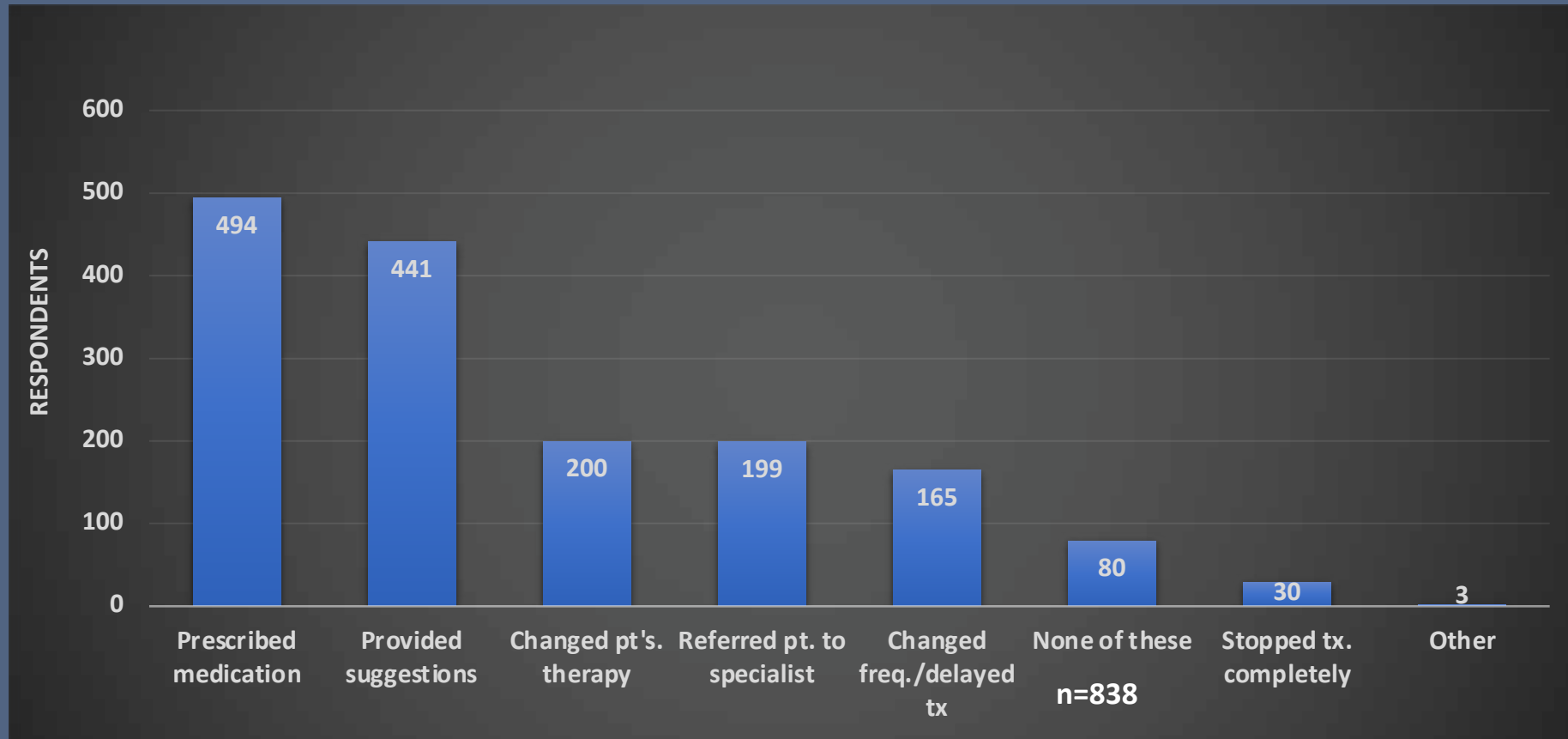


Pts. given a lower dosage: 556

Pts. who felt better on a lower dosage: 393+66 = 459



## Other Measures Taken by Physician to Alleviate Patients' Side Effects (check all that apply, add other)



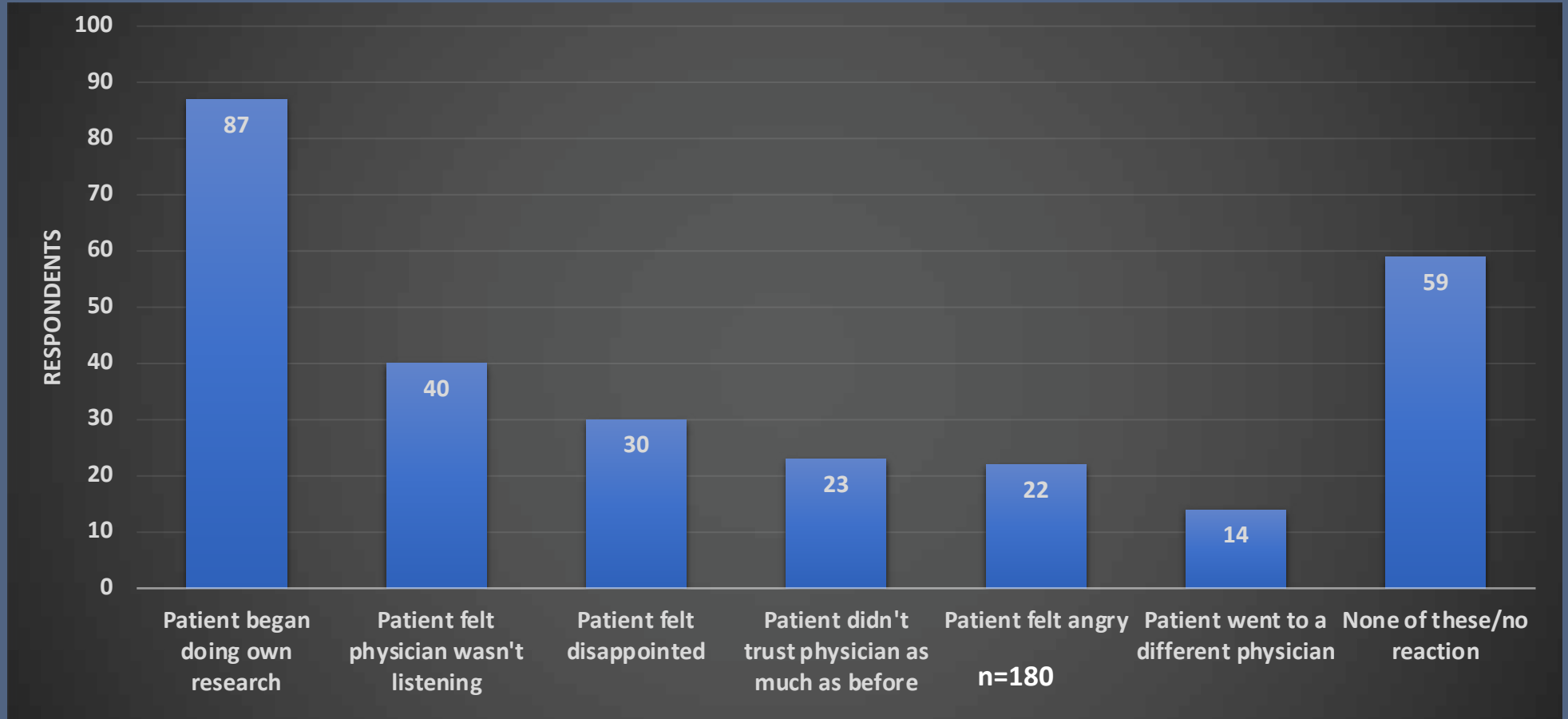
Pts. who informed physician about side effects: 1,026

Pts. whose physicians tried to help: 838





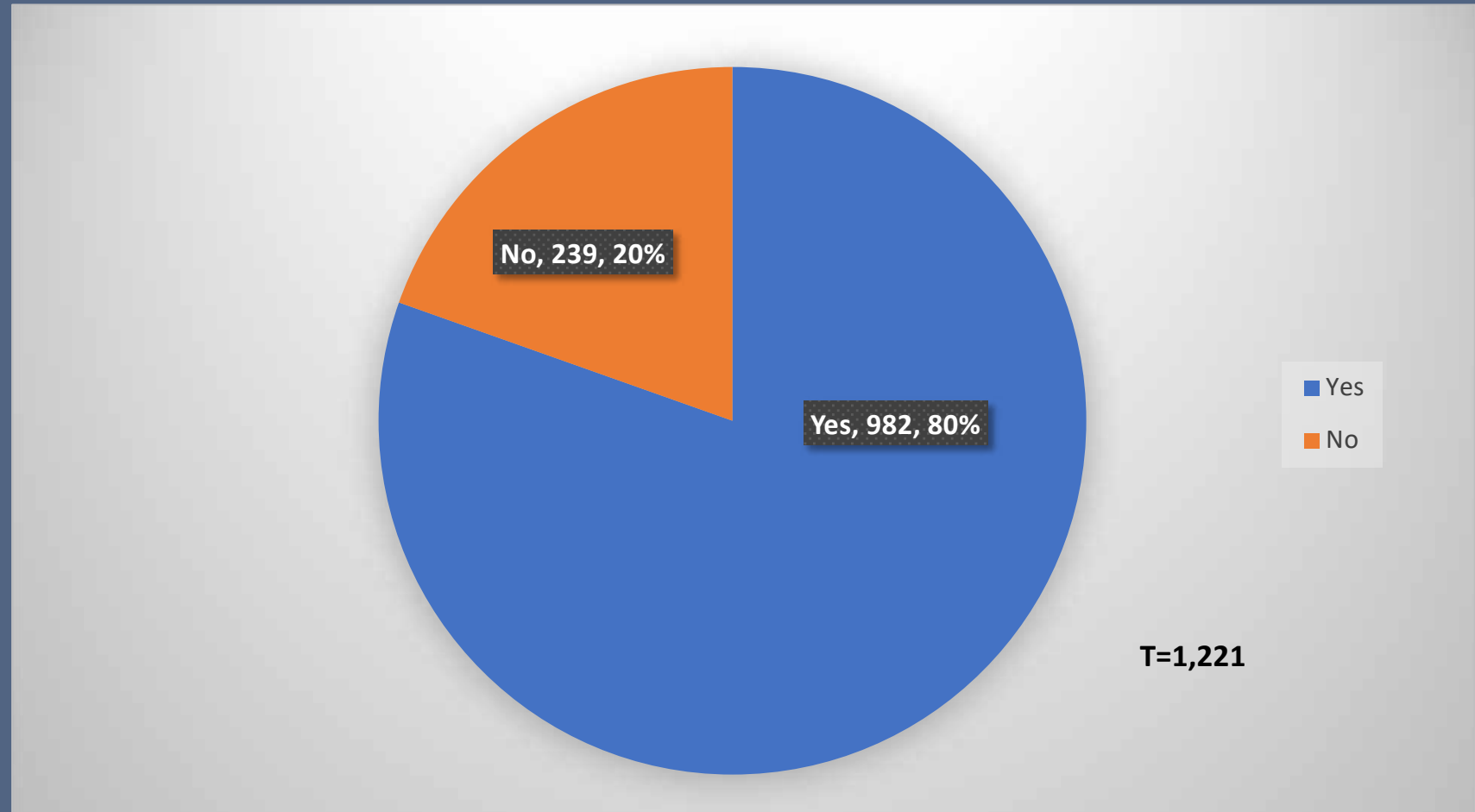
## Patients' Reactions When Physician Didn't Try to Relieve Side Effects (check all that apply)



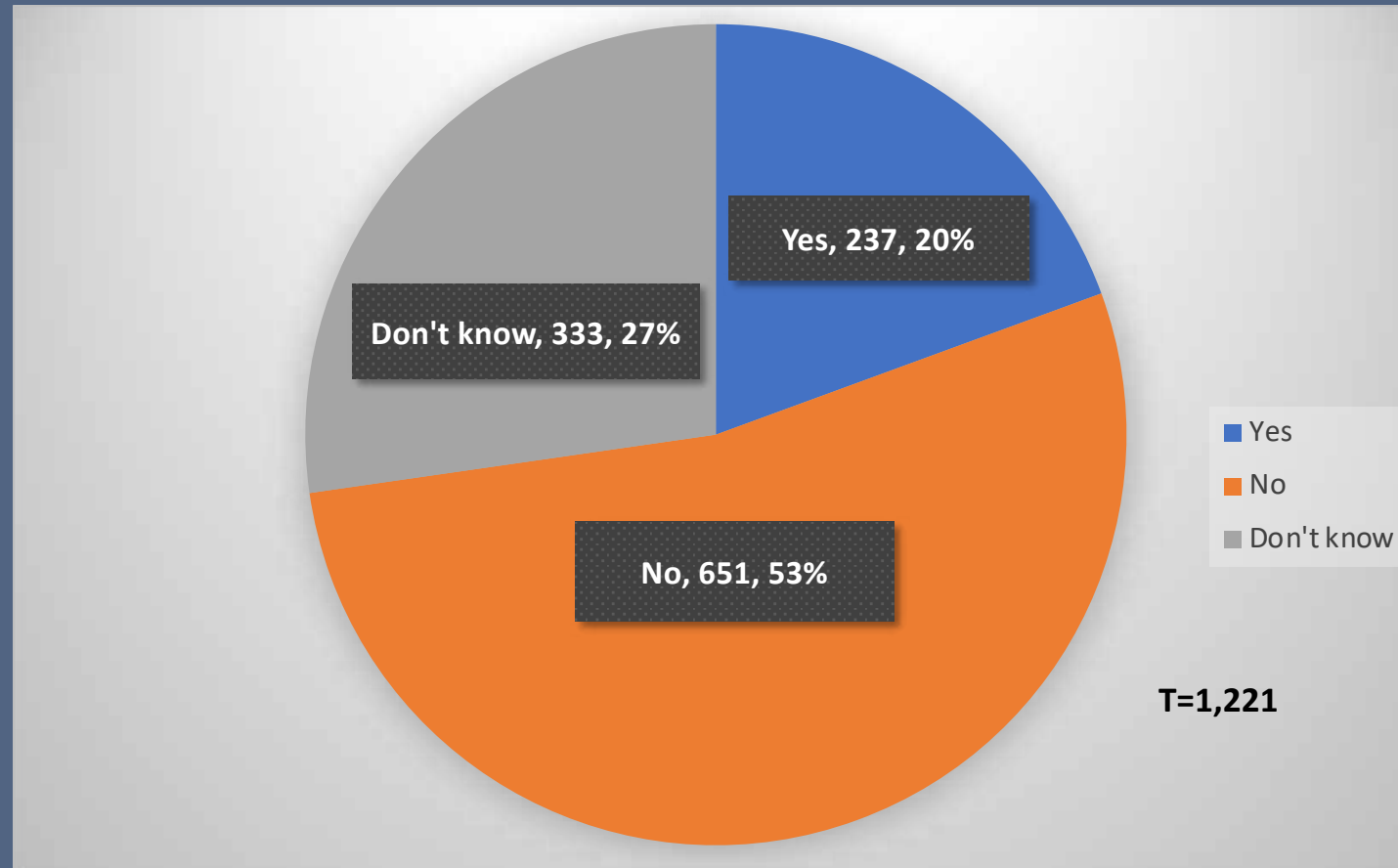
Pts. who informed physician about side effects: 1,026

Pts. whose physician didn't try to help: 180

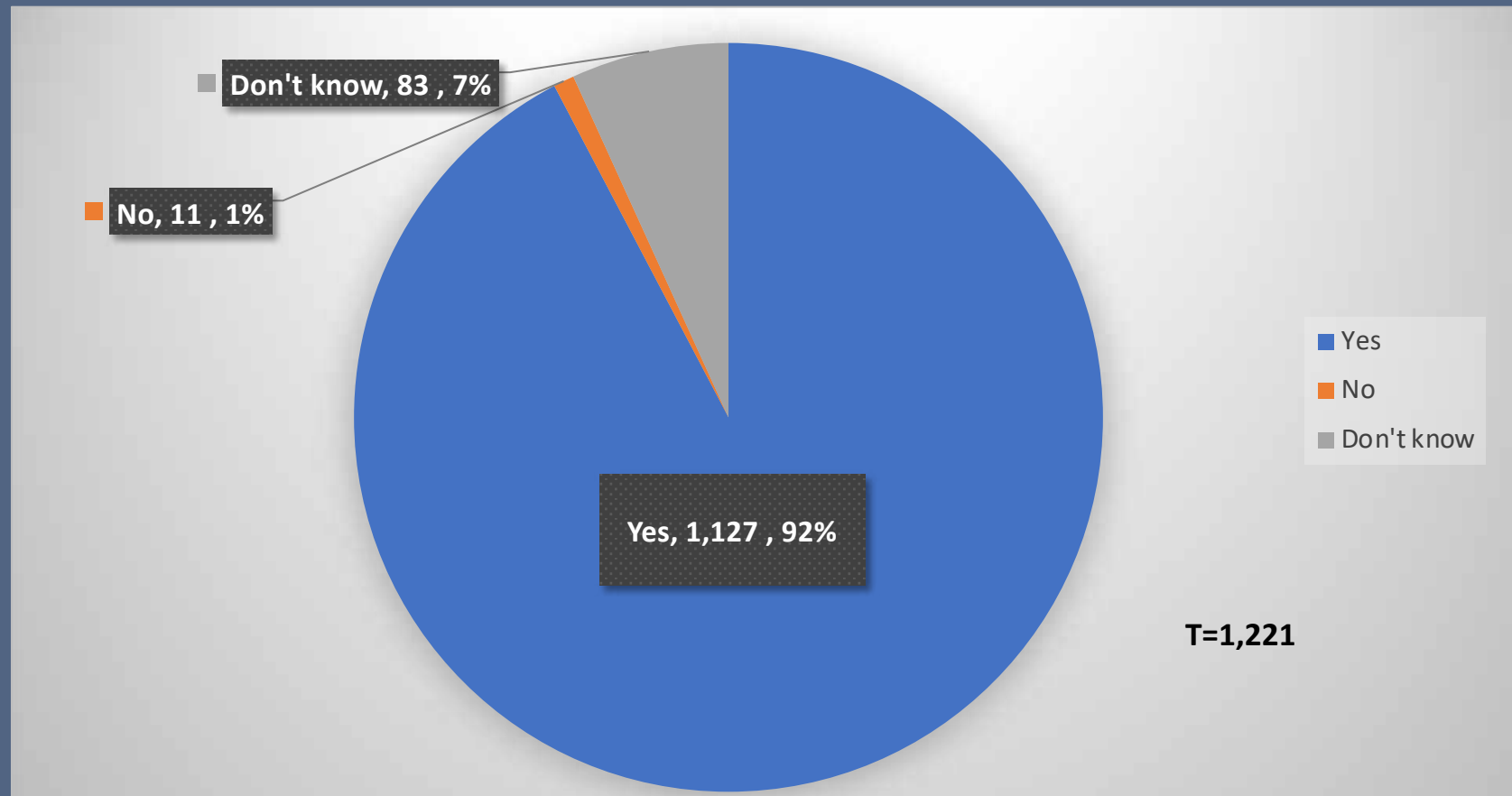
## Patient Aware that Lower Doses May be an Option to Relieve Side Effects?



## Patient Believes the Highest Approved Drug Dose is Always More Effective than a Lower Approved Drug Dose?



## Patient Willing to Discuss Approved Drug Dosing Options with Physician Based on Patient's Unique Characteristics?



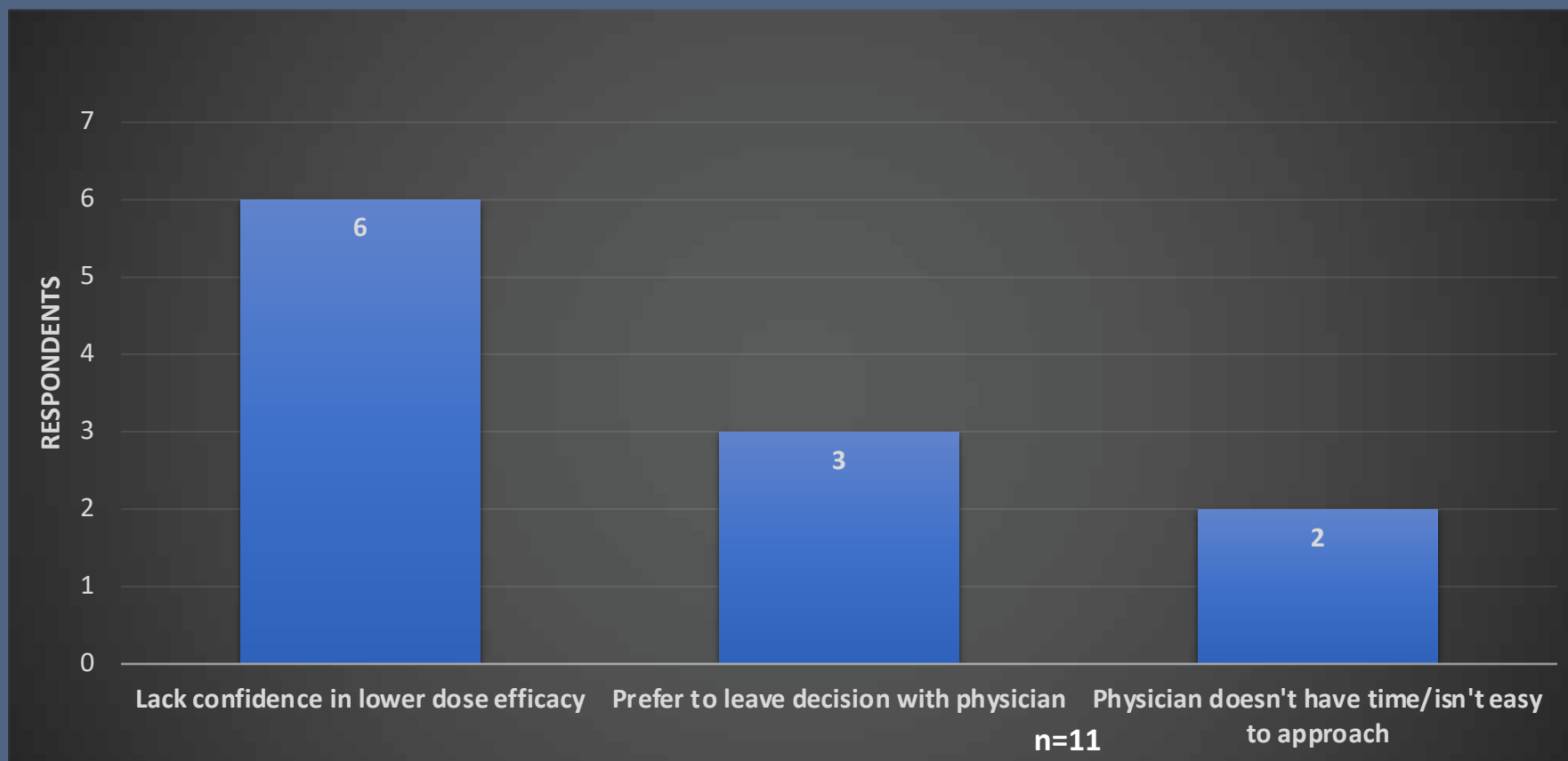


PATIENT  
CENTERED  
DOSING  
INITIATIVE

#TheRightDose

## Reason Patient is Unwilling to Discuss Approved Drug Dosing Options with Physician Based on Patient's Unique Characteristics

(check all that apply, add other)





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## Summary

- ✓ Most patients (86%) experienced a bad treatment-related side effect
- ✓ 1 out of 5 (20%) patients visited the Emergency Room/hospital due to side effects
- ✓ 2 out of 5 (43%) patients missed treatment due to side effects
- ✓ 83% of patients given a lower dose reported feeling better
- ✓ **Vast majority of patients (92%) would be willing to discuss dosage options with their physicians based on their unique characteristics**



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Find out more at [www.therightdose.org](http://www.therightdose.org)

Email: [info@therightdose.org](mailto:info@therightdose.org)