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Introduction

The US prevalence of multiple myeloma (MM) is 83,367 as of January 1, 2011 (SEER, 2014), and an estimated 24,050 new MM cases will be diagnosed in 2014 (American Cancer Society, 2014).

With advances in treatment, MM patients are living longer, but are often confronted with complex treatment decisions.

Many patients are not fully prepared to discuss their treatment options with healthcare providers.

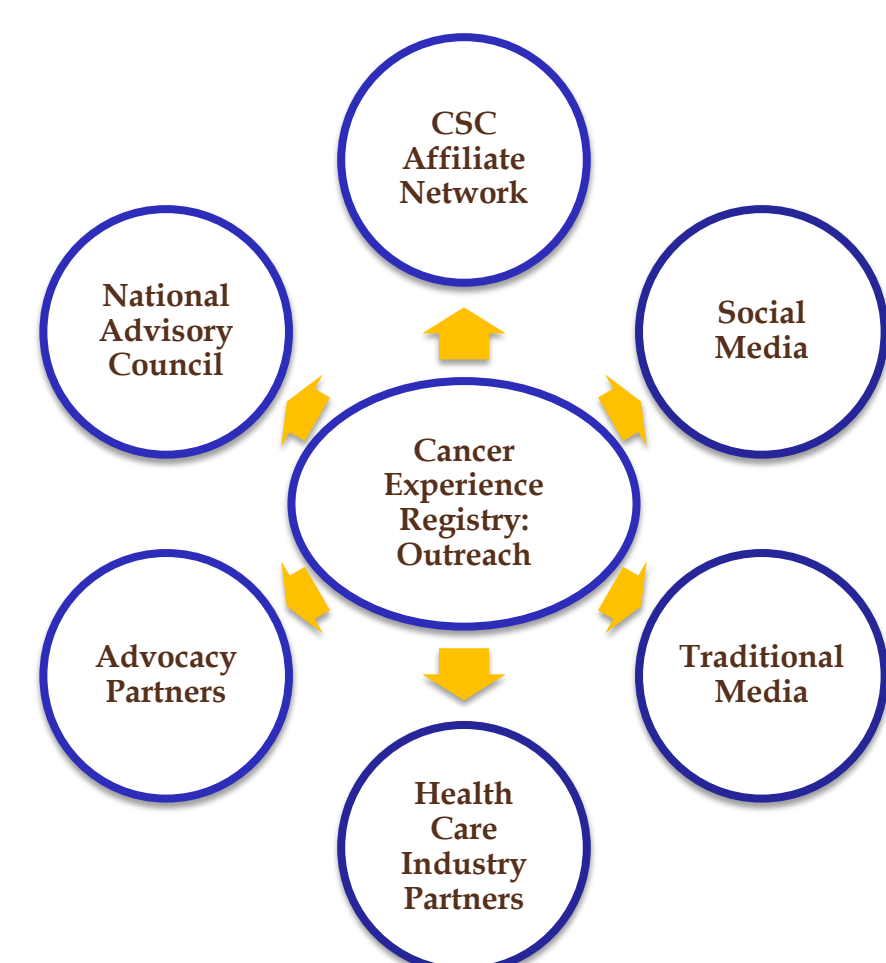
Aim

The purpose was to investigate and raise awareness about the MM patient experience with treatment decision making.

Method

The Cancer Experience Registry

Collecting, analyzing and sharing information about the experience and needs of patients and their families throughout the cancer journey.



- From July 2013 to July 2014, the Cancer Support Community (CSC) registered 495 people living with MM to the Cancer Experience Registry.
- 387 (78%) registrants responded to the questionnaire.
- The present analysis is limited to 280 US based registrants who answered on treatment decision making.

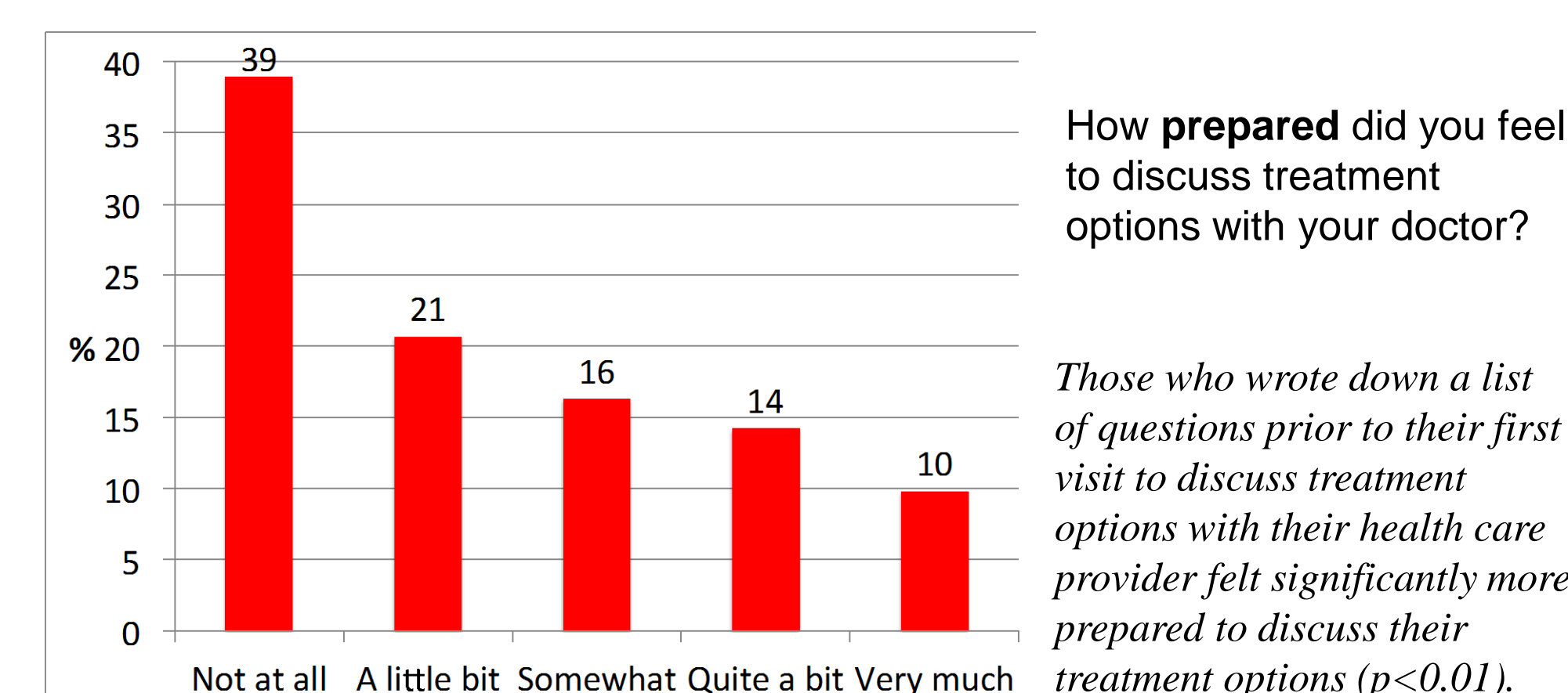
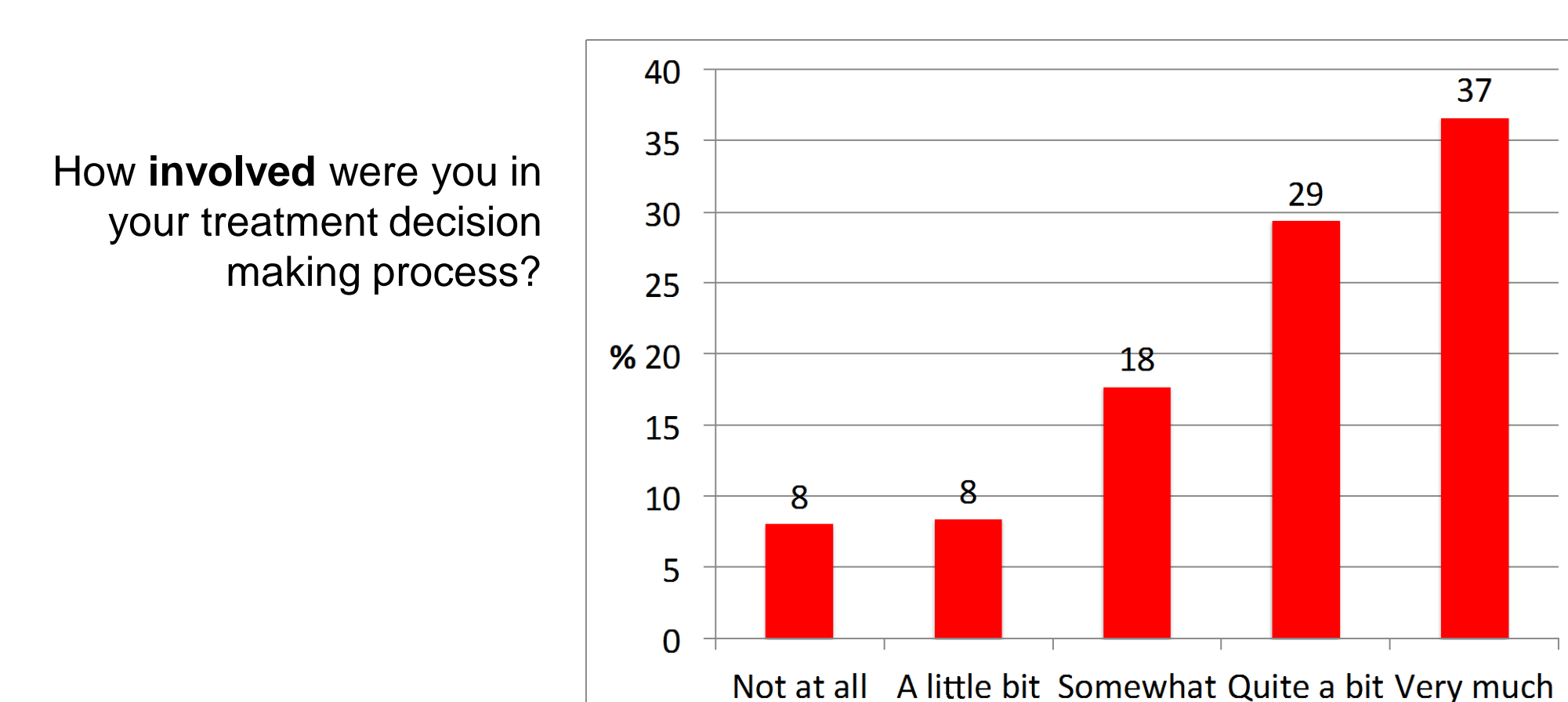
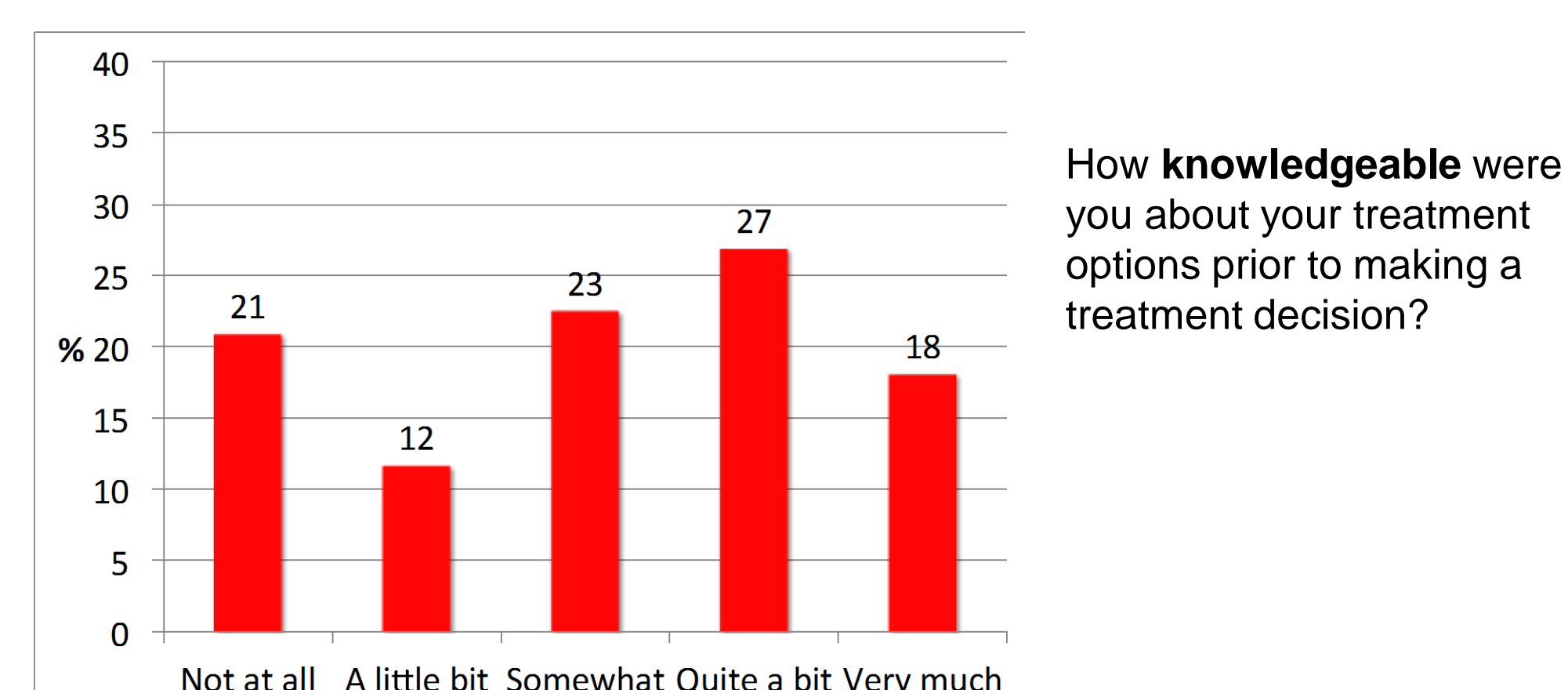
Results

Sample Characteristics	
Median age	64 years
Female	54%
Caucasian	87%
Black or African American	10%
Hispanic	2%
College degree or higher	56%
Median time since MM diagnosis	4.5 years

Treatment Decision Making

Prior to making a treatment decision:

- 94% received information about their diagnosis
- 80% about their treatment options
- 52% about clinical trials



Results

Relationship between knowledgeable, involved and prepared

	Knowledgeable	Involved
Involved	0.62*	---
Prepared	0.44*	0.36*

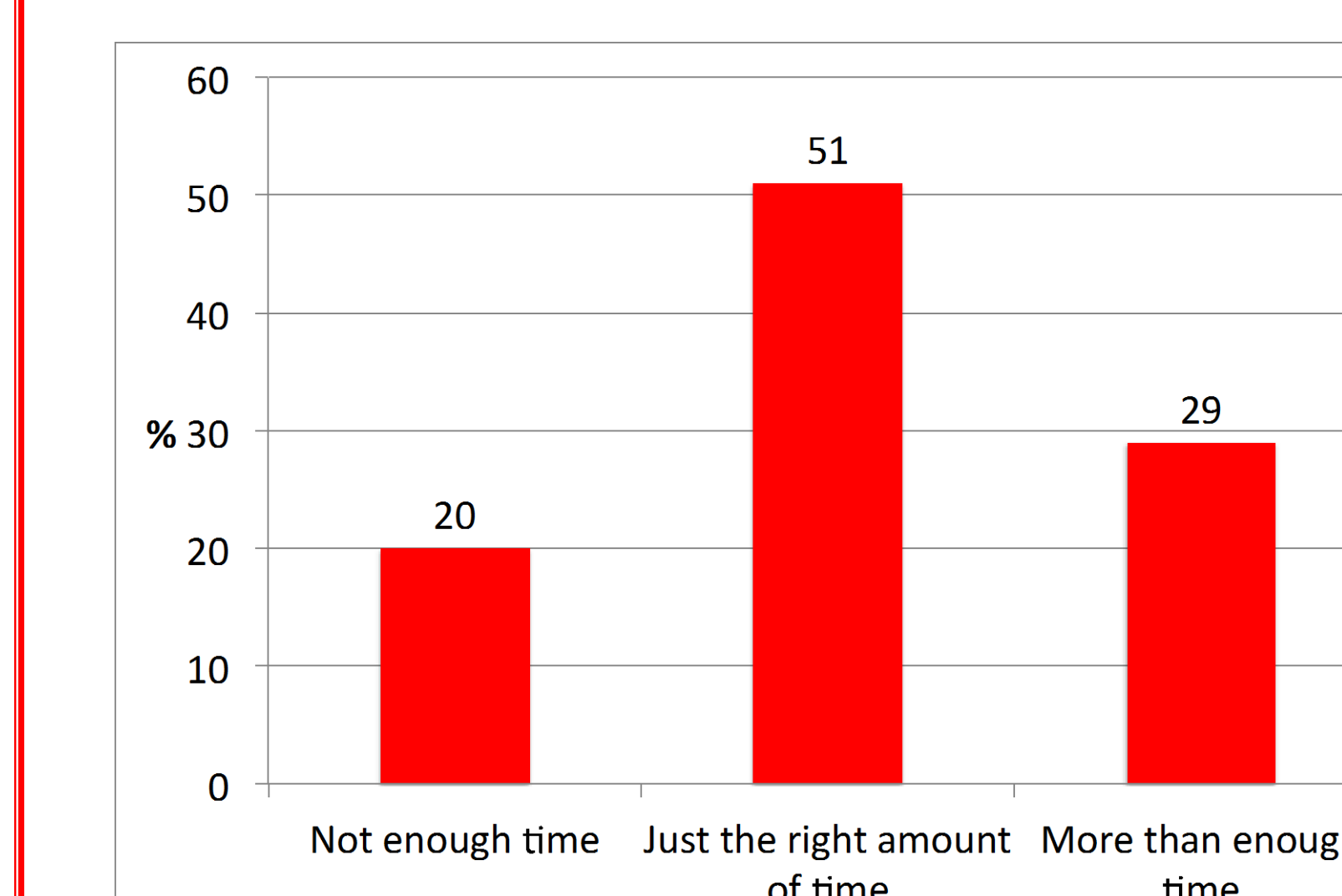
- 40% received treatment decision support prior to therapy.
- 36% would have liked more support.
- 25% did not feel they had a treatment choice.
- 20% reported they did not have enough time to make a treatment decision.
- 64% of registrants reported that a member of their health care team spoke to them about cancer clinical trials, and 29% participated in a clinical trial.

Patient Satisfaction and Empowerment

Knowing what you know today, how satisfied are you with:	Satisfied (%)	Dissatisfied (%)
The outcome of the treatment(s) you received	82	6
Your doctor's explanation of the benefits of each treatment option	74	10
How you arrived at a decision	71	13
How much you participated in making the treatment decision	68	17
Your doctor's explanation of the risks and side effects of each treatment option	67	14

66% received a **second opinion** about medical treatment. Those who got a second opinion were slightly more satisfied with how they arrived at their treatment decision (OR=1.61; 95% CI=0.90, 2.88; p=0.11), but getting a second opinion did not affect patient's satisfaction with treatment outcomes.

Results



How much time do you feel you had to make a treatment decision?

Conclusion

Although 84% of MM patients reported being involved in making treatment decisions, only 40% felt prepared to discuss treatment options with their doctor, and 39% said they were not a bit prepared. The data indicate those who prepared a list of questions prior to a consultation with the doctor felt significantly more prepared to make appropriate decisions compared to those who did not.

Additionally, while most patients reported receiving information about their treatment options, less than half reported being knowledgeable about treatment options, and a substantial proportion reported not having enough knowledge or support to fully engage in treatment decisions. Further efforts are needed to address gaps in the delivery of treatment decision preparedness support to MM patients.

Acknowledgements

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