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Abstract

Background

Hereditary angioedema (HAE) is a chronic spontaneous life-threatening disease. Due to the unpredictable nature associated with the disease it can have a significant impact on a patient's quality of life. We sought to better understand the overall satisfaction of treatments from a patient perspective.

Method

In 2017-2018, data was collected through voluntary online surveys of children, youth, and adults who live with HAE and their caregivers in Canada. The following data was based solely on adult participants.

Results

Once a proper diagnosis was obtained following patient navigation and treatments were established the annual number of days missed from work or school decreased by an average of 48%, the amount of phone calls to Doctor's offices decreased 60%, the occurrence of unscheduled visits to health care professionals decreased 75%, the frequency of Emergency room visits decreased 50%, and the number of hospitalizations decreased 67%. Most patients reported they were satisfied with the frequency they must use their HAE treatments (31%) and satisfied with the effectiveness of their current treatments to prevent attacks (40%). Overall patients were satisfied (39%) and very satisfied (24%) with their current HAE treatment.

Conclusion

Results show patients are generally satisfied with the treatments they are currently receiving; however, there are still necessary improvements that will enhance a patient's quality of life. All results are limited to the respondents and may not represent the broader Canadian HAE population.

Introduction

- Swellings are typically of slow onset over several hours and can last 1-5 days, although some patients may also experience rapid onset swellings
- During an attack and for days subsequent to an attack, patients with hereditary angioedema may be unable to partake in their normal daily activities due to the pain, fatigue, and disfigurement associated with the edema.
- The disease places extraordinary strain on patients emotionally, physically, and psychologically.
- It is common for patients to miss many days of school and/or work during an attack.

Methods

In October 2017, the first National Canadian HAE survey was electronically distributed to all HAE Canada members. The data was collected for the purpose of gaining insight into the treatment satisfaction and the quality of life of Canadians living with HAE.

Results

BEFORE Access To Treatment	Average	Total
Approximate number of unscheduled missed work or school days due to HAE-related issues per year.	40	2330
Approximate number of unscheduled visits to see your doctor or nurse due to HAE-related issues per quarter.	4	229
Approximate number of unscheduled HAE-related telephone calls to your doctor or nurse per year.	5	277
Approximate number of unscheduled Emergency room visits due to HAE-related issues per year.	10	582
Approximate number of unscheduled hospitalisations due to HAE-related issues per year.	3	146

Figure 1: N=59

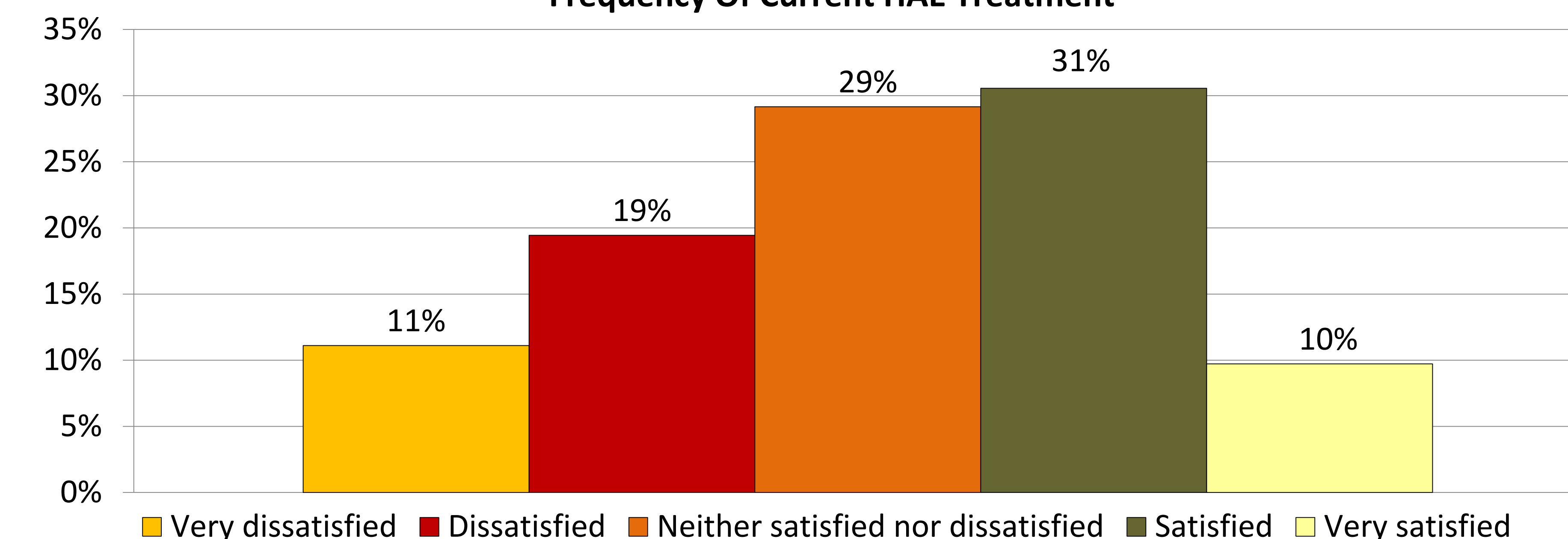
AFTER Access To Treatment	Average	Total
Approximate number of unscheduled missed work or school days due to HAE-related issues per year.	21	1173
Approximate number of unscheduled visits to see your doctor or nurse due to HAE-related issues per quarter.	1	76
Approximate number of unscheduled HAE-related telephone calls to your doctor or nurse per year.	2	133
Approximate number of unscheduled Emergency room visits due to HAE-related issues per year.	5	293
Approximate number of unscheduled hospitalisations due to HAE-related issues per year.	1	56

Figure 2: N=58

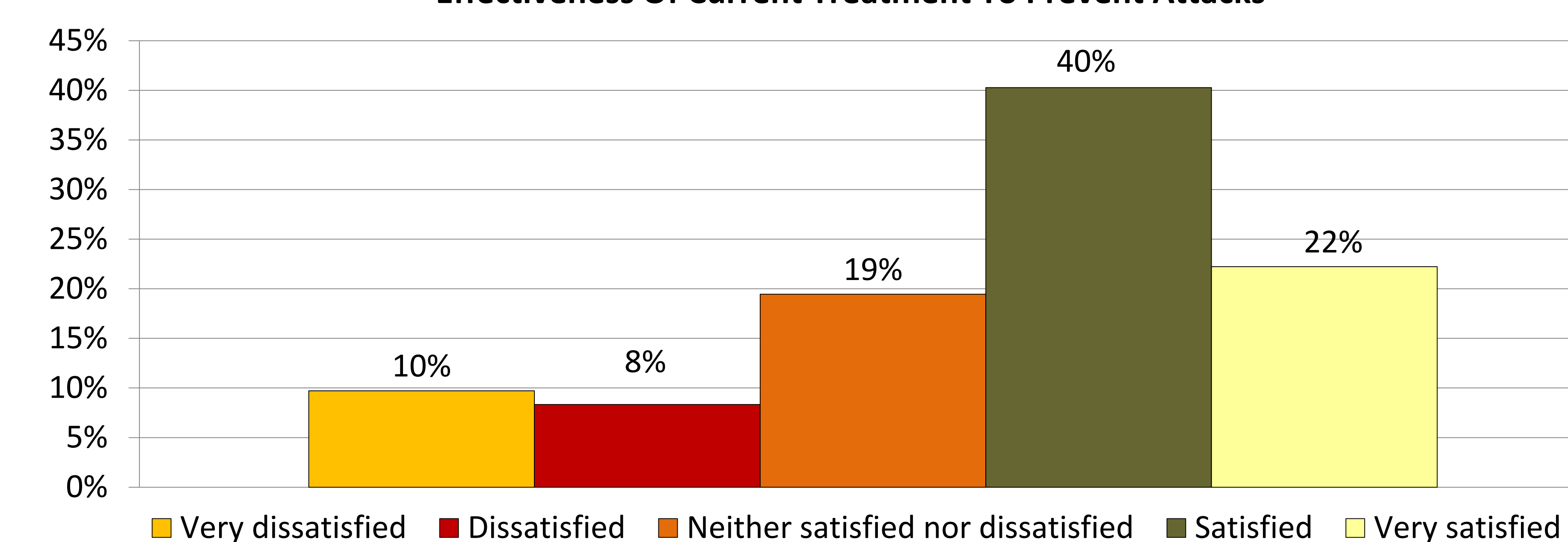
AFTER Access To Treatment	Average	Total
Approximate number of unscheduled missed work or school days due to HAE-related issues per year.	-48%	-50%
Approximate number of unscheduled visits to see your doctor or nurse due to HAE-related issues per quarter.	-75%	-67%
Approximate number of unscheduled HAE-related telephone calls to your doctor or nurse per year.	-60%	-52
Approximate number of unscheduled Emergency room visits due to HAE-related issues per year.	-50%	-49%
Approximate number of unscheduled hospitalisations due to HAE-related issues per year.	-67%	-62%

Figure 3

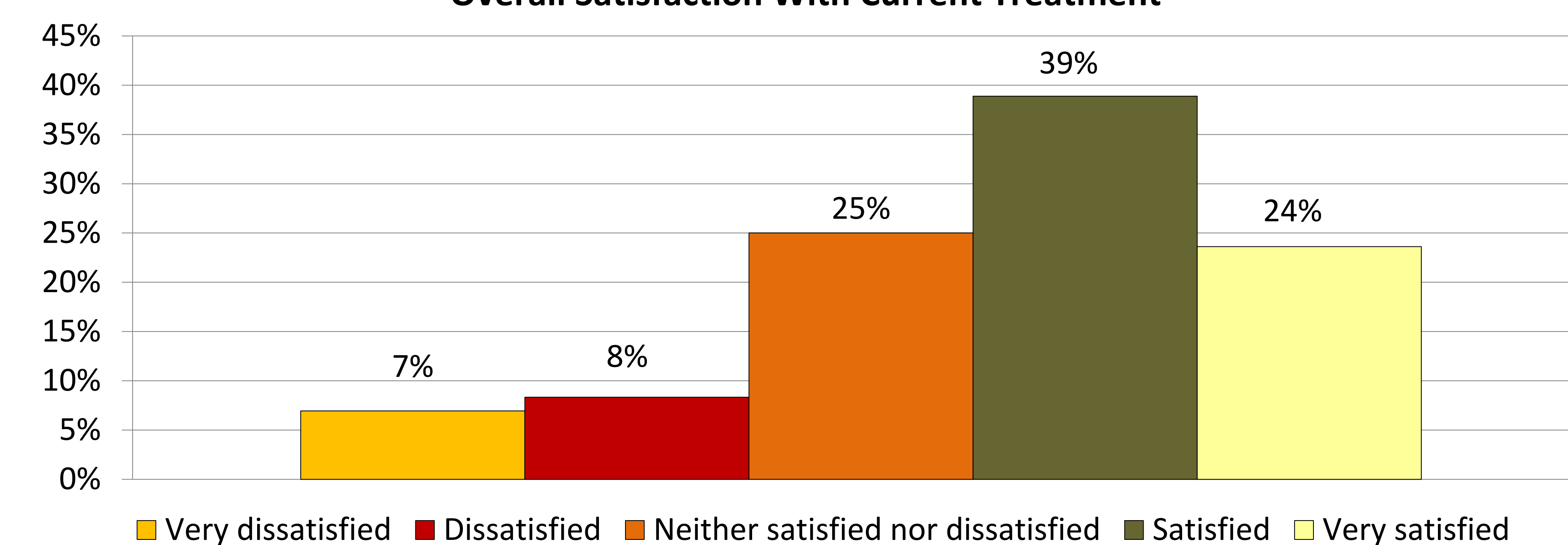
Frequency Of Current HAE Treatment



Effectiveness Of Current Treatment To Prevent Attacks



Overall Satisfaction With Current Treatment



Conclusion

Results show patients are generally satisfied with the treatments they are currently receiving. We believe improvements such as financial coverage, frequency and method of administration, reduction of attack frequency/severity as well as improved awareness of the disease, both medical and psycho-social aspects, will enhance a patient's overall treatment satisfaction and quality of life. All results are limited to the respondents and may not represent the broader Canadian HAE population

References

<https://www.haecanada.org/>
 Longhurst, H. J., Farkas, H., Craig, T., Aygoren-Pursun, E., Bethune, C., Bjorkander, J., et al. (2010). HAE international home therapy consensus document. *Allergy, Asthma & Clinical Immunology*, 6(22). Retrieved October 13, 2011, from www.aacjournal.com/content/6/1/22

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