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Abstract

Rationale: Hereditary angioedema (HAE) is a rare inherited disorder characterized by recurrent painful episodes of severe swelling in different parts of the body. The direct health care costs of HAE are significant but are little studied. We sought to understand the health care utilization of patients with HAE in Canada

Methods: In 2017 a comprehensive email survey was sent to all members of HAE Canada to gather information on multiple aspects of HAE. The data from respondents was collected and analysed as the percentage of respondents. Responses to questions on health care use were analysed for this report.

Results: The survey collected data from 113 respondent adults living with HAE. In the prior year, 11/79 (14%) reported <3 attacks while 34/79 (43%) reported ≥12. Routine HAE treatment was mainly performed at home (58/75, 77.3%) but some received treatment in a hospital (12.0%) or clinic (9.3%). In response to questions regarding health care use in the past year, most (43/71, 60.6%) saw a physician 1-3 times for HAE-related problems but 22% had 4-10 and 10% had >10 physician visits. Planned hospital visits were made 1-3 times by 32/69 (46.4%); 7.3% went >10 times and 33.3% not at all. Unplanned ER visits were made: never by 32/71 (45%), 1-6 times by 48%, and >7 times by 7%.

Conclusions: These findings suggest that having HAE leads to substantial health care costs which would be higher but for the high proportion of patients who receive treatment at home.

Introduction

Hereditary angioedema (HAE) is a rare inherited disorder characterized by recurrent painful episodes of severe swelling in different parts of the body. Abdominal attacks can be very painful and fatalities can result if the oropharynx is affected. The timing and severity of attacks are unpredictable potentially leading to a high use of emergency medical care.

Objective

The direct health care costs of HAE are significant but are little studied. We sought to understand the health care utilization of patients with HAE in Canada.

Methods

In 2017 a comprehensive email survey was sent to all members of HAE Canada to gather information on multiple aspects of HAE. The data from respondents was collected and analysed as the percentage of respondents. Responses to 5 questions on health care use were analysed for this report..

Results

The survey collected data from 113 respondent adults living with HAE. Of 104 respondents, 59.6% had Type I or Type II HAE, 26.0% had HAE with normal C1INH, 3.8% had acquired angioedema and 10.6% didn't know.

HAE Attacks in Prior Year

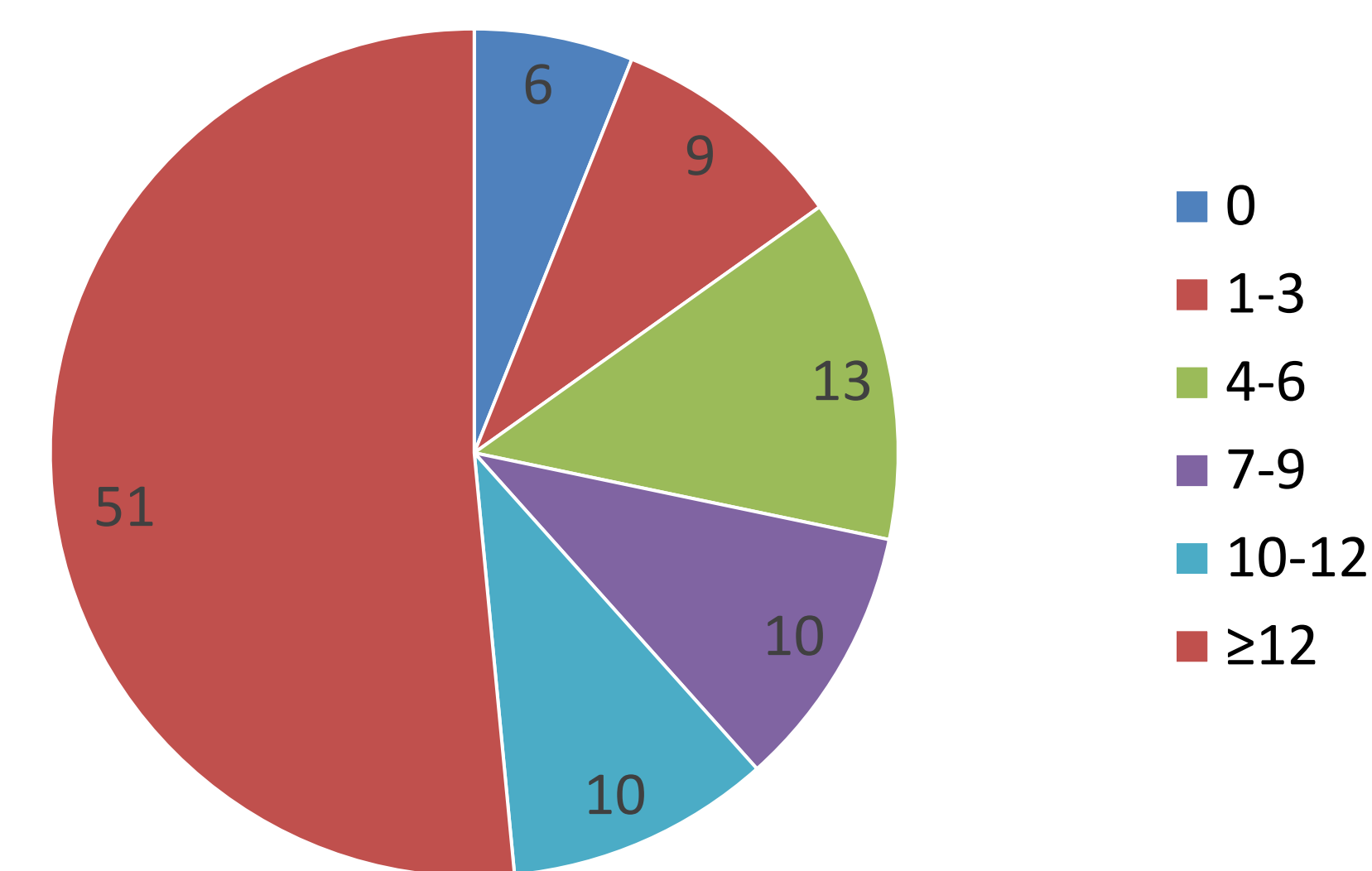


Figure 1. Many HAE patients had frequent attacks in the prior year; 51% had 12 or more attacks and 33% had between 4 and 11 attacks. Less frequent attacks (1-3) were reported by 9% of patients and 6% had no attacks at all. n=86

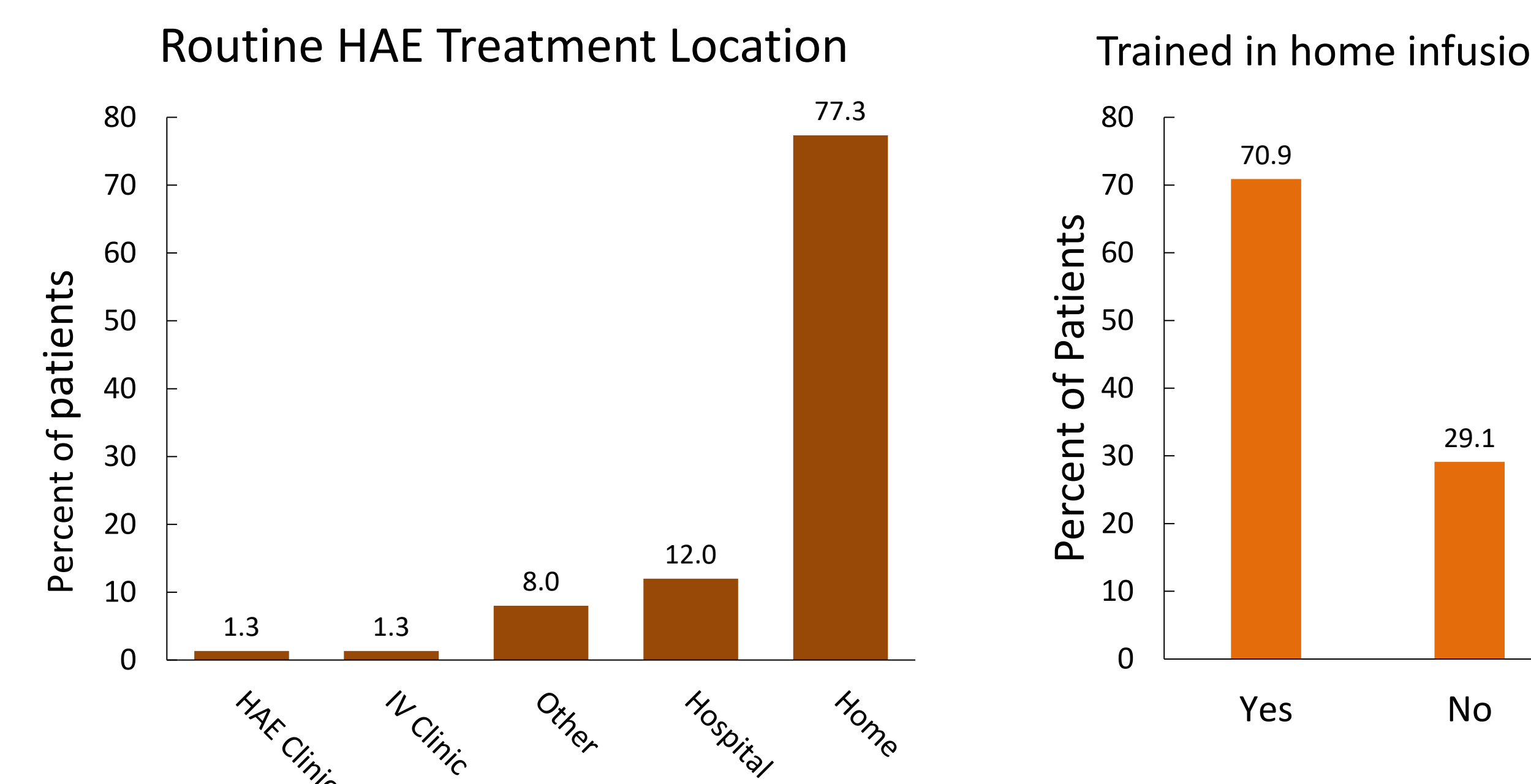


Figure 2. The majority of patients (58/75) received their regular HAE treatment at home, but some (17/75) used a clinic, hospital or other facility (Left Panel). Treatment at home was possible because many patients (56/79) are trained in home infusion (Right Panel).

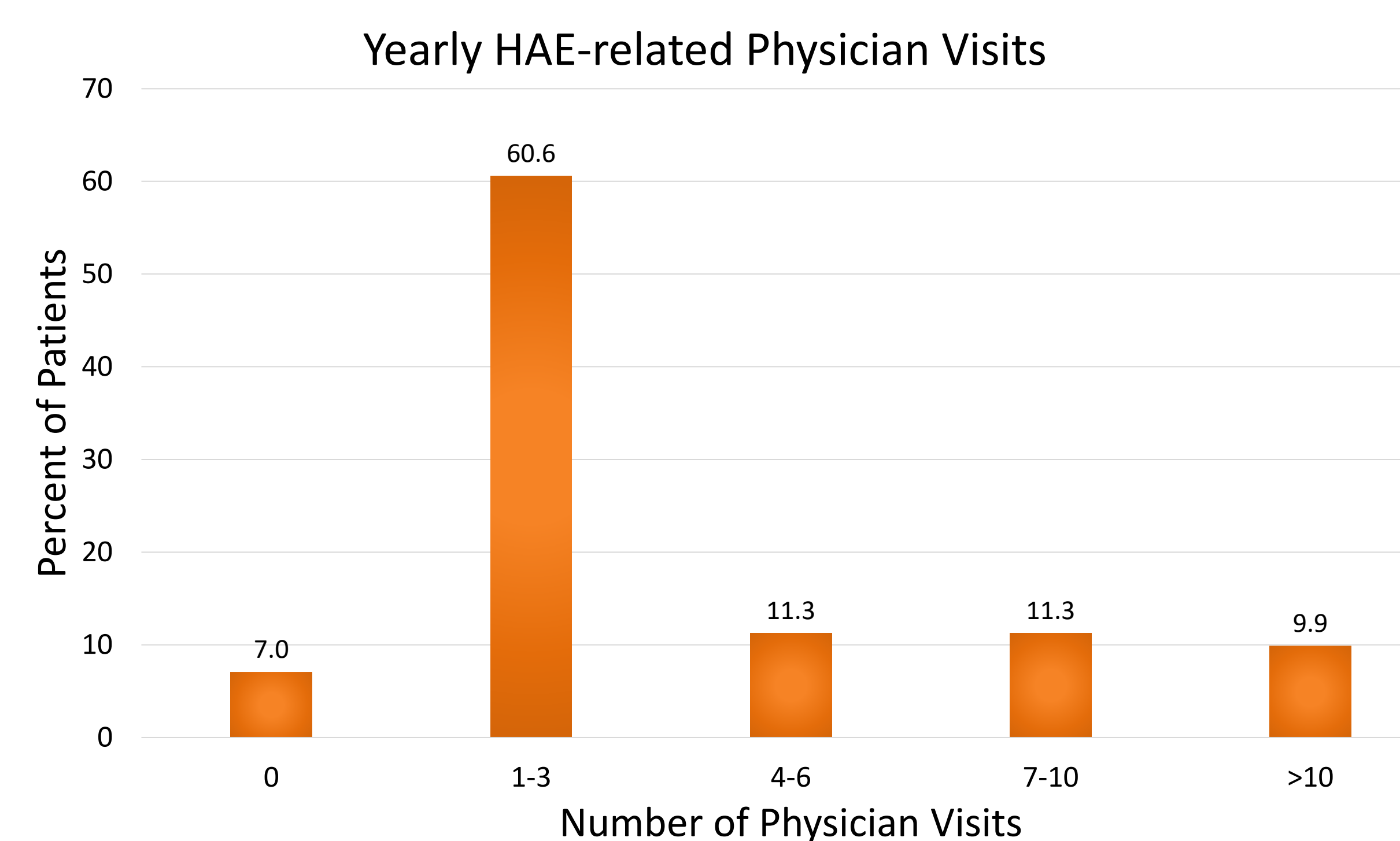


Figure 3. Most patients (60.6%) reported 1-3 physician visits for HAE per year but 33.5% reported 4 or more visits and 10% reported more than 10 visits per year. Seven percent of patients did not have a physician visit.

Results (continued)

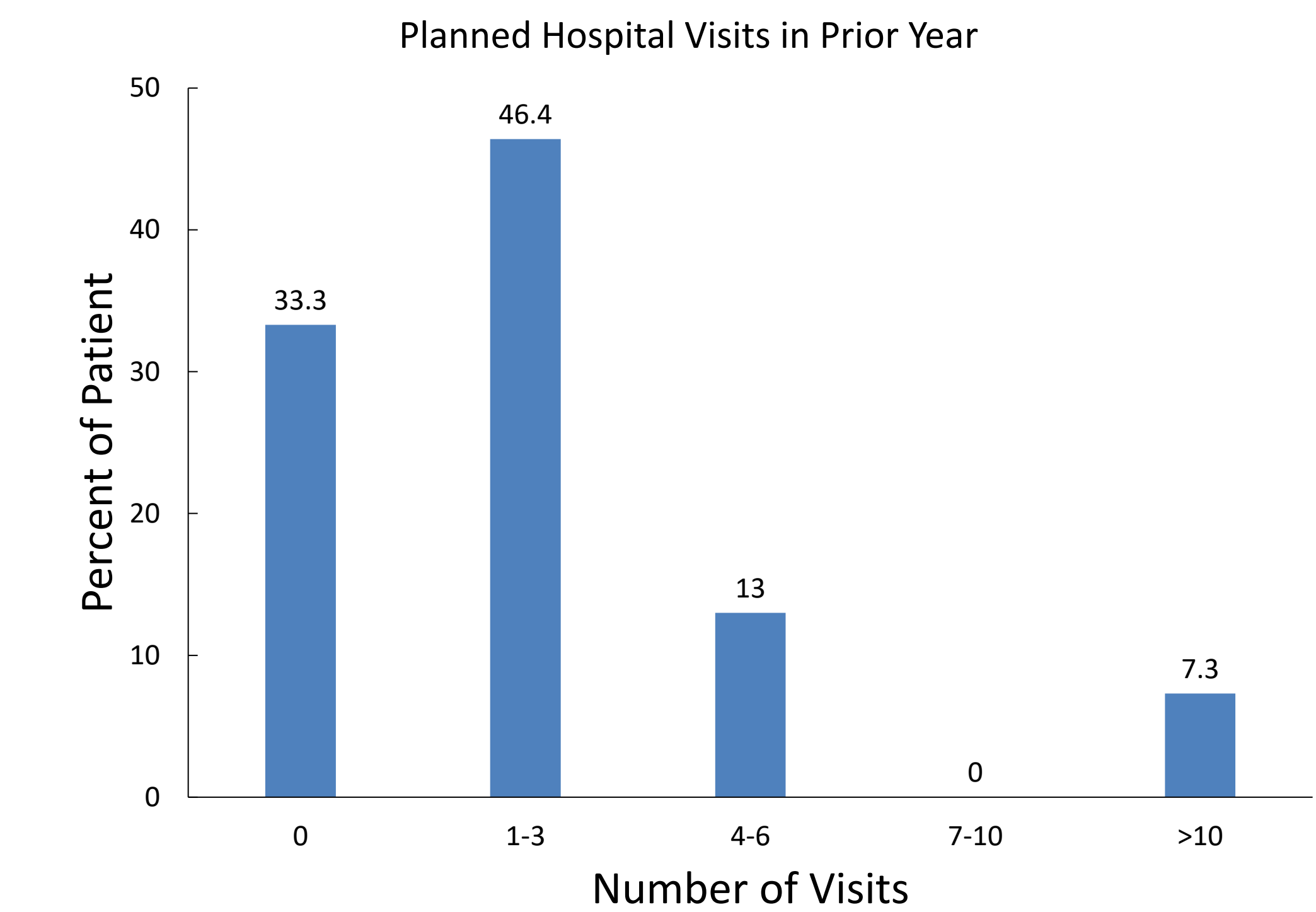


Figure 4 Planned hospital visits included but were not limited to pre-arranged surgery and visits to clinics for care or assessments. The majority of patients had none or only a few hospital visits; however, 20% had more than 4 in the prior year.

Emergency Room HAE-related Visits in Prior Year

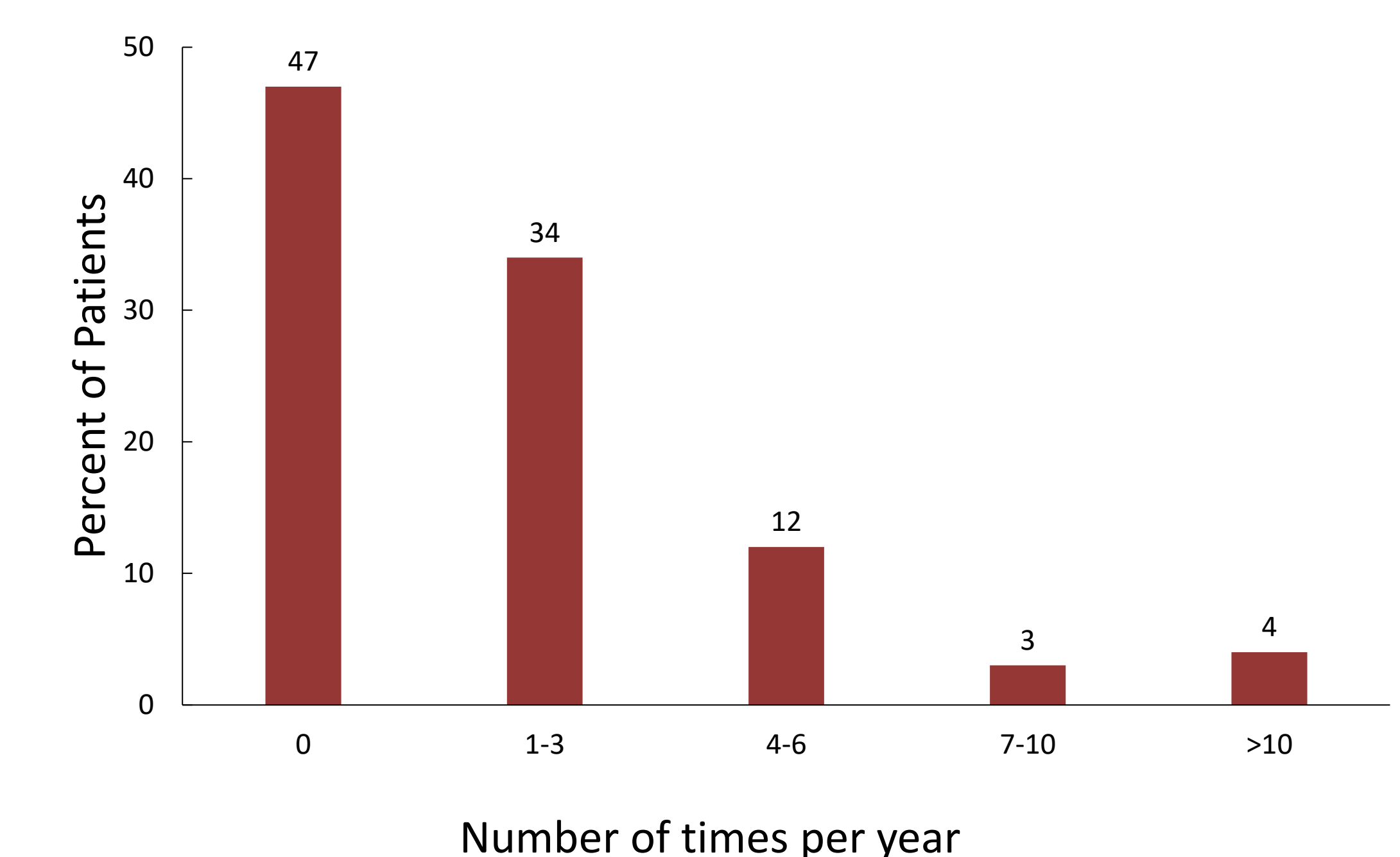


Figure 5. Emergency room visits were frequent (>4/year) in only 19% of respondents, 34% had 1-3 visits and 47% had none. n=76. Reasons for ER visits included laryngeal swelling, GI discomfort, and swelling of extremities or genitals.

Conclusions

- Health care costs incurred by HAE patients include treatment for HAE attacks mostly taken at home but requiring hospital or clinic visits for medication infusion.
- Hospital and ER visits are uncommon for the general public in any given year but amongst the HAE patients surveyed, 53% had at least one ER visit and 77% had a hospital visit indicating a greater health care burden.
- These findings suggest that having HAE leads to substantial health care costs. Costs would be even higher were it not for the high proportion of patients who receive treatment at home.