2 7 ANNUAL O MEETING BOSTON, MASSACHUSETTS OCTOBER 7-11 2017

A Survey on Disease Experiences of Meningioma Patients

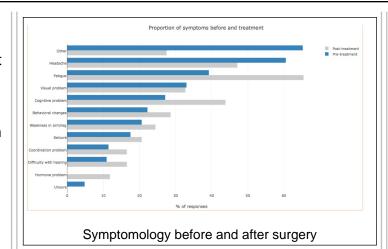
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Introduction

Patient experiences and perceptions with respect to the management of their meningiomas is poorly understood. We report the results of an international survey conducted with the American Brain Tumor Association (ABTA) to describe the disease-related experiences of patients with meningiomas and their caregivers.

Methods

A 26-item questionnaire was prepared with items regarding demographics, symptoms, treatment, support systems, involvement in clinical trials and effect on work/school. The survey was performed using SurveyMonkey® between May 11 and June 2, 2016 and distributed by the ABTA through social media channels, email, and via the ABTA website. Statistical analysis was performed in SPSS 24 using Pearson Chi-square tests, the Mann-Whitney U test, and cumulative-odds ordinal logistic regression with proportional odds.



Results

1852 usable responses representing of the responses of 1542 meningioma patients (83.3%), 270 caregivers (14.5%), and 40 other respondents (2.2%) were analysed. The majority of patients were female (86.8%). Notably, female sex was associated with increased time to diagnosis (OR = 1.708, 95% CI 1.255 to 2.325, X2(1)=11.595, p=0.001). 96% of respondents stated the patient did not participate in a clinical trial, with only 3.6% stating they would not be interested in participating, if offered. Furthermore, 33% of patients felt they didn't receive adequate information and 34.6% stated their primary source of information about their disease was the internet. Patients who reported a post treatment side effect were also more likely to have had the same symptoms preoperatively (p<0.001), suggesting that there was a high rate of persistent neurological deficits after successful treatment.

Conclusions

This is the first large scale study to report the perceptions of patients and their families around their diagnosis of a meningioma. Notably, females were more likely to respond to the survey and had a significantly longer time to diagnosis compared to males. Further in-depth studies are necessary to elucidate any gender differences in meningioma disease and management. Most importantly, this study shows that patients and their families lack information regarding the diagnosis, treatment and available clinical trials for their meningioma. Most meningioma patients need more accurate and reliable, easily accessible information and are open to participation in clinical trials.

Learning Objectives

By the conclusion of this session, participants should be able to: 1) discuss the importance of effective communication with patients regarding disease 2) discuss possible factors leading to gender differences in meningioma management and 3) discuss the chronic nature of meningioma disease and effects on patients