


RESEARCH SUBMISSIONS

Patient experience of telemedicine for headache care during the COVID-19 pandemic: An American Migraine Foundation survey study

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Abstract

Objective: We sought to investigate the patient experience of telemedicine for headache care during the coronavirus disease 2019 (COVID-19) pandemic.

Background: The use of telemedicine has rapidly expanded and evolved since the beginning of the COVID-19 pandemic. Telemedicine eliminates the physical and geographic barriers to health care, preserves personal protective equipment, and prevents the spread of COVID-19 by allowing encounters to happen in a socially distanced way. However, few studies have assessed the patient perspective of telemedicine for headache care.

Methods: The American Migraine Foundation (AMF) designed a standardized electronic questionnaire to assess the patient experience of telemedicine for headache care between March and September 2020 to help inform future quality improvement as part of its patient advocacy initiative. The date parameters were identified as the emergence of severe acute respiratory syndrome coronavirus 2 disease and the declaration of a national emergency in the United States. The questionnaire was distributed electronically to more than 100,000 members of the AMF community through social media platforms and the AMF email database.

Results: A total of 1172 patients responded to our electronic questionnaire, with 1098 complete responses. The majority, 1081/1153 (93.8%) patients, had a previous headache diagnosis prior to the telemedicine encounter. A total of 648/1127 (57.5%) patients reported that they had used telemedicine for headache care during the study period. Among those who participated in telehealth visits, 553/647 (85.5%) patients used it for follow-up visits; 94/647 (14.5%) patients used it for new patient visits. During the telemedicine encounters, 282/645 (43.7%) patients were evaluated by headache specialists, 222/645 (34.4%) patients by general neurologists, 198/645 (30.7%) patients by primary care providers, 73/645 (11.3%) patients by headache nurse practitioners, and 21/645 (3.2%) patients by headache nurses. Only 47/633 (7.4%) patients received a new headache diagnosis from telemedicine evaluation,

whereas the other 586/633 (92.6%) patients did not have a change in their diagnoses. During these visits, a new treatment was prescribed for 358/636 (52.3%) patients, whereas 278/636 (43.7%) patients did not have changes made to their treatment plan. The number (%) of patients who rated the telemedicine headache care experience as “very good,” “good,” “fair,” “poor,” and “other” were 396/638 (62.1%), 132/638 (20.7%), 67/638 (10.5%), 23/638 (3.6%), and 20/638 (3.1%), respectively. Detailed reasons for “other” are listed in the manuscript. Most patients, 573/638 (89.8%), indicated that they would prefer to continue to use telemedicine for their headache care, 45/638 (7.1%) patients would not, and 20/638 (3.1%) patients were unsure.

Conclusions: Our study evaluating the patient perspective demonstrated that telemedicine facilitated headache care for many patients during the COVID-19 pandemic, resulting in high patient satisfaction rates, and a desire to continue to use telemedicine for future headache care among those who completed the online survey.

KEYWORDS

coronavirus disease 2019, migraine, patient perspective, patient satisfaction, telehealth, telemedicine

INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic has significantly affected the delivery of health care. In March 2020, many health-care institutions in the United States canceled elective, nonurgent clinics and procedures in response to this public health emergency. As a result, routine outpatient and procedural headache care were interrupted. Telemedicine, a real-time interactive video and audio remote communication between a patient and a clinician, was quickly implemented and rapidly evolved. Telemedicine has now become essential for health-care professionals and patients to deliver and receive care in a socially distanced way that minimizes the geographic and physical barriers, preserves personal protective equipment, and prevents the spread of COVID-19.

Even before the pandemic, there existed a need to expand telemedicine in neurology. In 2019, the American Academy of Neurology Telemedicine Work group provided an overview of the use of telemedicine among different subspecialties, including headache medicine, highlighting the growing evidence to support the use of telemedicine.¹ Indeed, prospective, randomized trials have demonstrated noninferiority, convenience, and patient satisfaction for the use of telemedicine in the evaluation and treatment of headache disorders compared with traditional in-person evaluations.² However, the studies were limited by small sample sizes, and only a few studies have directly assessed patient satisfaction in the clinical trials.³ Large-scale data evaluating the perspective of patients on their experience with and perceived value of telemedicine for headache care are lacking.

The American Migraine Foundation (AMF) is a nonprofit organization dedicated to the advancement of research and awareness surrounding migraine, a neurological disorder that affects 12% of Americans and is the second leading cause of years lived with disability worldwide and the first among young women.⁴ Migraine is also the

third most burdensome neurological disorder in terms of disability-adjusted life years in the United States.⁵ The organization was founded in 2010 to provide and increase global access to resources for individuals with migraine and other headache disorders. Given the significant disability and disease burden of headache disorders, every effort should be extended to improve access to care, especially in the context of a global pandemic. The purpose of this study was to present the patient perspective of telemedicine for headache care during the COVID-19 pandemic, and to report the patient preference to continue to use telemedicine by analyzing and summarizing the results of an online electronic survey conducted by the AMF as part of the quality improvement initiative to insure that patient advocacy needs are met.

METHODS

The AMF leadership designed an electronic questionnaire surveying patient experiences of telehealth for headache care during the COVID-19 pandemic to promote patient advocacy and quality improvement of headache care. The questionnaire included 15 standardized questions, two of which had logic applied for deeper answer identification. The questionnaire sought patient response for the details of telemedicine encounters and whether patients had used telemedicine for their headache care between March and September 2020. The date parameters were selected based on the emergence of severe acute respiratory syndrome coronavirus 2 disease and the emergency declaration made in the United States. Details of the telemedicine encounters asked included the provider types, whether new diagnosis or therapies were given, overall satisfaction, and the desire to use telemedicine going forward. A copy of the electronic questionnaire is included as Supporting Information.

The questionnaire was developed in and collected through SurveyMonkey, Inc. Respondents were not allowed to submit

multiple responses to avoid duplicate data entry. Participants were not required to enter their name, age, or any personal information to maintain anonymity. The survey was an open survey that did not require participants to enter any passwords. The survey was completed voluntarily and no incentives were offered.

The questionnaire was distributed electronically on AMF channels that were identified as having the largest potential reach. The channels included AMF's private patient support community of 26,000 patients (Facebook) and its email contact database of 80,000 contacts. The survey was open on these channels for 18 days and yielded 1172 responses.

After the results of the survey were collected by AMF, de-identified, aggregated results were sent to the researchers (CC and RHS) for further generalizable analysis. The data are not identifiable to an individual and provide no connection or access to any medical records or protected health information of any individual. Institutional Review Board (IRB) approval and informed consent were not required for analysis of aggregated results, as per discussion with Mayo Clinic IRB regarding study design and details.

Statistical analysis

Patient responses were entered directly into a SurveyMonkey electronic questionnaire. The different answers/checkboxes to each question were summed up automatically by the SurveyMonkey software and exported to Excel. Answers to each question in the survey were presented in percentage based on the number of participants who chose the particular answer divided by the total number of participants who answered the question. No additional statistical analysis was performed.

We did not perform power analysis to calculate sample size, but a target accrual of 1000 responses were felt to be sufficient by the authors to represent the experiences and opinion of patients active in the above mentioned social media channels. All results were primary analysis of the data obtained directly from the electronic questionnaire. No secondary or post hoc analyses were performed. The results of this manuscript have not been published elsewhere.

RESULTS

A total of 1172 participants responded to our questionnaire, with 1098 complete responses. As all the 1172 participants answered at least one question in the survey, we chose to include all the survey responses. Missing data to each question are outlined in Table 1. Among them, 1017/1172 (86.8%) were female, and 138/1172 (11.8%) were male, 7 patients chose "nonbinary," and 10 patients preferred not to disclose. The average age was 49.5 years old. A total of 1081/1153 (93.8%, missing data 19) patients were previously diagnosed with a headache disorder before the telemedicine encounter. Migraine, cluster headache, and tension-type headache were diagnosed in 1027/1074 (95.6%), 16/1074 (1.5%), and 7/1074 (0.7%)

TABLE 1 Baseline demographics and previous headache diagnosis

Total number of survey responses	1172	Missing data
Age	N = 1160	12
Mean 49.5 years old		
≤18 years old	12	
19–86 years old	1148	
Gender	N = 1172	0
Female	1017 (86.8%)	
Male	138 (11.8%)	
Nonbinary	7 (0.6%)	
Prefer not to disclose	10 (0.9%)	
Previous headache diagnosis	N = 1027	145
Migraine	1027 (95.6%)	
Cluster headache	16 (1.5%)	
Tension-type headache	7 (0.7%)	
Others	24 (2.2%)	
Two or all of the above headache diagnosis	9	
Headache after traumatic brain injury	4	
Spontaneous intracranial hypotension	1	
Idiopathic intracranial hypertension	1	
New daily persistent headache	3	
Occipital neuralgia	2	
Cervicogenic headache	1	
Unknown	2	
Headache associated with COVID-19	1	

patients, respectively. There were 98 missing data to this question. Other diagnoses were provided in 24/1074 (2.2%) patients as listed in Table 1. The diagnoses were made by general neurologists for 425/1073 (39.6%) patients, headache specialists for 364/1073 (33.9%) patients, primary care providers for 223/1073 (20.8%) patients, emergency room physicians or consultation for 12/1073 (1.12%) patients, and others for 49/1073 (4.57%) patients, with 99 missing data. For those whose diagnoses were made by "primary care providers," they referred to physicians for 209/225 (92.9%) patients, nurse practitioners for 10/225 (4.4%) patients, and physician assistants for 5/225 (2.2%) patients. The headache diagnosis was provided by OB/GYN for one patient.

When asked "Did you use telehealth/telemedicine visits for your headache disorder since March 2020 during COVID-19?" 1127 patients answered with 45 missing data. A total of 648/1127 (57.5%) patients answered "yes," and 479/1127 (42.5%) patients answered "no." Among the 479 patients who answered "no," 456 patients provided reasons for which they did not use telemedicine during the

COVID-19 pandemic, including "Had no need for a visit" in 256/456 (56.1%) patients, "I did not know it was an option" by 115/456 (25.2%) patients, "Wanted to but not offered by the doctor" in 59/456 (12.9%) patients, "Wanted to but not covered by insurance" in 16/456 (3.5%) patients, and "Wanted to but did not have technology to access telemedicine" in 10/456 (2.2%) patients.

Among the 648 patients who have used telemedicine, 94/647 (14.5%) patients used it for new patient visits, 553/647 (85.5%) patients used it for follow-up visits, and one patient did not answer this visit-type question. During telemedicine visits for headache care, 282/645 (43.7%) patients were evaluated by headache specialists, 222/645 (34.4%) patients were seen by general neurologists, 198/645 (30.7%) patients were seen by their primary care providers, 73/645 (11.3%) patients were evaluated by headache nurse practitioners, and 21/645 (3.2%) patients were evaluated by headache nurses. Three patients, among the 648 patients who have used telemedicine, did not answer this provider-type question. In terms of the frequency of telehealth/telemedicine utilization, 151/639 (23.6%) patients used it once in a month. Others have used it anywhere between one time and once in a week during the whole study period. Nine patients did not report the frequency of telemedicine utilization.

Among the 648 patients who have used telemedicine, 633 and 636 patients reported how telemedicine evaluation changed the evaluation and management of headache in terms of whether they received a new diagnosis, or were prescribed a new treatment through the telemedicine visit, with 15 and 12 missing data, respectively. A total of 586/633 (92.6%) patients reported that they did not receive a new headache diagnosis through the telemedicine visits, whereas 47/633 (7.4%) patients reported that they did. Of note, 358/636 (52.4%) patients were prescribed a new treatment through

the telemedicine visit, whereas 278/636 (43.7%) patients did not have changes made to their treatment plan.

In terms of patient satisfaction of the telemedicine visits, the number (%) of patients who rated the experience using telehealth/telemedicine for their headache disorder care "very good," "good," "fair," "poor," and "other" were 396/638 (62.1%), 132/638 (20.7%), 67/638 (10.5%), 23/638 (3.6%), and 20/638 (3.1%), respectively (Figure 1). Out of the 648 patients, 10 patients did not answer the question. Comments put in "other" included the following: "OnabotulinumtoxinA was not available due to no face-to-face visit," "Difficult, just got a referral and put on a wait list," "There were connectivity issues so ultimately had to do the visit by phone," "I'm hard of hearing, need to see provider face-to-face," and "The Doctor was very professional and attentive to concerns, but I think it's difficult to truly convey your true symptoms via a screen." When asked, "Would you continue to use telehealth/telemedicine visits for your headache disorder care and treatment?" 286/638 (44.8%) patients answered "yes," 287/638 (45.0%) patients indicated "yes, but not for all visits," 45/638 (7.1%) patients said "no," and 20/638 (3.1%) patients were unsure (Figure 1).

DISCUSSION

Telemedicine minimizes the physical and geographic barrier of patient care, and it became especially important during the COVID-19 pandemic to preserve personal protective equipment and reduce the risk of disease transmission, while maintaining headache care. Our study shows high patient satisfaction rate with the use of telemedicine for headache care between March and September 2020. Among the 1172 patients who responded to the survey, 648 (57.5%) patients

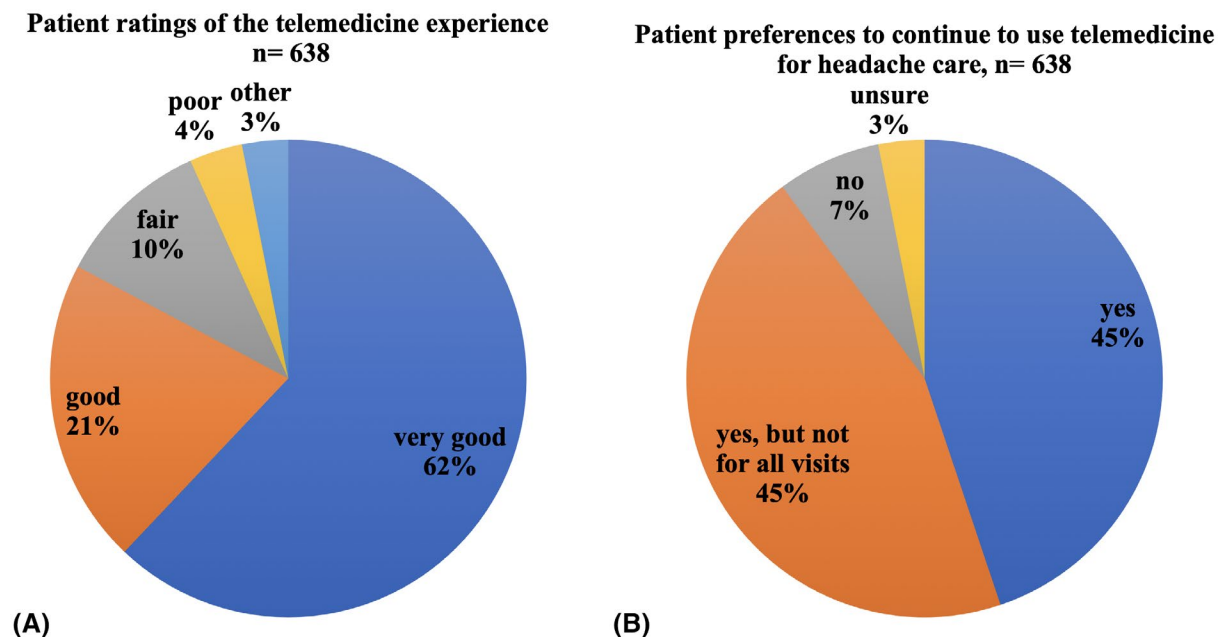


FIGURE 1 (A) Patient satisfaction/ratings of their telemedicine experience for headache care. (B) Patient preferences to continue to use telemedicine for headache care [Color figure can be viewed at wileyonlinelibrary.com]

had used telemedicine during the study period. The telemedicine experience was satisfactory for 528/638 (82.8%) patients who rated the experience as either “very good” or “good.” Furthermore, 573/638 (89.8%) patients would like to continue to have the option to use telemedicine for their ongoing headache care and treatment.

Overall, the results from this survey analysis were consistent with the data reported from previous randomized clinical trials.^{2,6} A study conducted in Norway randomized patients with nonacute headache to a one-time telemedicine ($n = 200$) or traditional in-person visit ($n = 202$). There was no difference in the efficacy end points (the difference in Headache Impact Test-6 score and visual analogue scale at 3–12 months compared with baseline). Only one secondary headache was identified in each group. At 1-year follow-up, among the 291 (72.4%) patients who responded, there was no difference in the satisfaction rate between the two groups (85.5% in the telemedicine group vs. 88.1% in the traditional group, $p = 0.653$), suggesting telemedicine as an effective, safe, and satisfactory alternative to in-person visits for patients with nonacute headaches.^{3,6} Similarly, another study conducted in the United States enrolled 45 patients who were diagnosed with migraine after the initial office consultation and randomized them to receive telemedicine or traditional in-person follow-ups at 1, 3, 6, 9, and 12 months. A total of 200 appointments were analyzed. The clinical outcomes, including Migraine Disability Assessment score, number of headache days, and average headache severity at 12 months, were not different between the two groups. However, patients in the telemedicine group reported significantly better convenience of visits and less time missed from work for visits. Additionally, the mean total time spent was shorter in the telemedicine group (25 min vs. 34 min, $p < 0.01$). Despite that, the patient perception regarding visit times was similar between the two groups.²

In our study, the majority of patients, 1081/1153 (93.8%), already had a headache diagnosis; similarly most patients, 553/647 (85.5%), also used telemedicine for follow-up visits. Although only 47/633 (7.4%) patients received a new headache diagnosis from the telemedicine visit, 358/636 (52.3%) patients were prescribed a new treatment through the telemedicine visit. Telemedicine appointments provides patients with opportunities to gain better control of their headache disorders and pain relief while not having to commit to the time to travel and risk of exposure to COVID-19.

Our study also showed the different levels of care involved in the real-life practice of headache medicine that used and benefited from telemedicine. Patients reported being seen by various providers through telemedicine, including headache specialists, general neurologists, primary care providers, gynecologists, nurse practitioners, physician assistants, and nurses for their headache care. Of note, among the patients who used telemedicine, 198/645 (30.7%) patients received headache care provided by their primary care provider. Telemedicine has become an essential tool for patients and a wide variety of providers. If the insurance coverage for telemedicine were to be rolled back, patients and multiple levels of health-care providers would be significantly affected.

Despite the many benefits of telemedicine, among the 1172 patients who responded to the survey, 479/1127 (42.5%) patients did

not use telemedicine during the study period. Although 256/456 (56.1%) patients reported that they did not have the need for a visit, 200/456 (43.9%) patients reported that they either did not know telemedicine was an option, or wanted to but it was not offered by the provider, not covered by insurance, or they did not have the necessary technology to access a clinician. These data highlight the need of clinicians, patient advocates, insurance providers for government agencies (Centers for Medicare and Medicaid Services), and licensing bodies to promote the knowledge, usage, accessibility, and reimbursement of telemedicine for headache care.

There are limitations to point out with this study. Ascertainment bias needs to be considered, given that our survey respondents were motivated individuals who were already engaged with AMF. As the survey was distributed electronically, both through Facebook and the AMF email database, participants were those who were comfortable with online services and had internet access. The COVID-19 pandemic has highlighted that reliable internet service has contributed to disparities in access in many ways, and health care via telemedicine has been one of those key areas that has been affected. Those who are not able to afford internet, lack proficiency in the use of technology, or have cognitive impairment might not be able to use telemedicine. Our study also had a comparatively small sample size—although a total of 106,000 individuals were invited to participate (26,000 from the Facebook group and 80,000 from the AMF email list), we received responses from 1172 people within 18 days, or 1.11% of the invited population. Although we heard from many patients, there are many more whose experiences were consequently not included.

Regardless, the importance from the patient viewpoint of having access to telemedicine services was made clear by our survey respondents, as the overwhelming majority of those who responded to the survey, over 89%, asserted they would like to have this option remain in place going forward. Our survey also revealed several barriers to care, which should be addressed to optimize the experience for patients. Out of the 44% of patients in our survey who did not use telemedicine services but did have a need to see a clinician, their reasons ranged from not knowing this was a choice, to not being offered a telemedicine appointment, to not having this option covered by insurance, or to not having adequate access to internet. We can address these challenges and improve our ability to provide care to patients by taking a few specific steps. First, by prioritizing the best interests of our patients, we need insurance companies to expand coverage and continue to reimburse telemedicine, even after the pandemic. This is a necessary measure to improve access to care. Second, as many patients in our study commented that they were unaware of this service, it is important to widely promote and broadcast the use of telemedicine as an established part of outpatient clinical medicine. Finally, this service is unfortunately limited to those who have reliable internet service. As we look at life beyond the COVID-19 pandemic and addressing disparities, it is important to consider internet access as a necessity. As a society, we should do what we can to help expand internet service more broadly across the United States with these perspectives in mind.

As a devoted patient advocacy group, the AMF also calls upon health-care insurance providers to continue the reimbursement

of telemedicine for headache care. We applaud the efforts implemented by many government and commercial insurance providers who facilitated the use of telemedicine in the beginning of the pandemic.⁷ Continued support of the use of telemedicine for headache care, and allowing providers to care for patients across state borders without having to be licensed in each state in which their patients may be located, is not only cost-effective but also beneficial to public health, especially during the ongoing pandemic, as it reduces visits to emergency departments and hospitals for headache care, lowers the probability of transmission of COVID-19, and improves the productivity and quality of life of those with headache disorders.

CONCLUSIONS

Telemedicine can expand and improve access to care, opening the opportunity for more patients to receive headache care from various levels of health-care professionals, including headache medicine specialists and primary care clinicians. Our patient perspective survey results showed that telemedicine facilitated headache care for many patients during the COVID-19 pandemic, resulting in high patient satisfaction rates, and a desire to continue to use telemedicine for future headache care for those who responded to the online survey. The voices of our patients are an important perspective to bring to the table as we look forward, even beyond the COVID-19 pandemic, to promote the best possible clinical care. We hope this study also serves as an appeal to insurers to continue to support telemedicine for headache care during, and after, the pandemic.

CONFLICT OF INTEREST

CC reports no financial disclosures. RHS has served on advisory boards for Impel and Teva. NL reports no financial disclosures. KSS reports no financial disclosures. DHL reports no financial disclosures. CL does ad board consulting work with Teva, Novartis, Eli Lilly, Aralez, and Allergan. DWD reports the following conflicts within the past 12 months: Consulting: AEON, Amgen, Clexio, Cerecin, Ctrl M, Allergan, Alder, Biohaven, Linpharma, Lundbeck, Promius, Eli Lilly, eNeura, Novartis, Impel, Satsuma, Theranica, WL Gore, Nocira, XoC, Zosano, Upjohn (Division of Pfizer), Pieris, Revance, Equinox. Honoraria: CME Outfitters, Curry Rockefeller Group, DeepBench, Global Access Meetings, KLJ Associates, Academy for Continued Healthcare Learning, Majallin LLC, Medlogix Communications, MJH Lifesciences, Miller Medical Communications, Southern Headache Society (MAHEC), WebMD Health/Medscape, Wolters Kluwer, Oxford University Press, Cambridge University Press. Research Support: Department of Defense, National Institutes of Health, Henry Jackson Foundation, Sperling Foundation, American Migraine Foundation, Patient Centered Outcomes Research Institute (PCORI). Stock Options/Shareholder/Patents/Board of Directors: Ctrl M (options), Aural analytics (options), ExSano (options), Palion (options), Healint (Options), Theranica (Options), Second Opinion/Mobile Health (Options), Epien (Options/Board), Nocira (options), Matterhorn (Shares/Board), Ontologics (Shares/Board), King-Devick Technologies (Options/Board), Precon Health (Options/Board).

Patent 17189376.1-1466:vTitle: Botulinum Toxin Dosage Regimen for Chronic Migraine Prophylaxis. LCN reports the following conflicts: Advisory boards: Amgen, Allergan, Biohaven, Lilly, Lundbeck, Supernus, Teva, and Theranica. Royalties: Oxford University Press. Stock Options: ControlM Health.

AUTHOR CONTRIBUTIONS

Study concept and design: Chia-Chun Chiang, Rashmi Halker Singh, Nim Lalvani, Lawrence C. Newman. *Acquisition of data:* Nim Lalvani, Lawrence C. Newman. *Analysis and interpretation of data:* Chia-Chun Chiang, Rashmi Halker Singh, Nim Lalvani, Lawrence C. Newman, Ken Shubin Stein, Deborah Henscheid Lorenz, Christine Lay, David W. Dodick. *Drafting of the manuscript:* Chia-Chun Chiang, Rashmi Halker Singh, Nim Lalvani, Lawrence C. Newman. *Revising it for intellectual content:* Chia-Chun Chiang, Rashmi Halker Singh, Nim Lalvani, Lawrence C. Newman, Ken Shubin Stein, Deborah Henscheid Lorenz, Christine Lay, David W. Dodick. *Final approval of the completed manuscript:* Chia-Chun Chiang, Rashmi Halker Singh, Nim Lalvani, Lawrence C. Newman, Ken Shubin Stein, Deborah Henscheid Lorenz, Christine Lay, David W. Dodick.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the Supporting Information section.

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