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Symptom Importance, Patient Expectations, and Satisfaction in Chronic Rhinosinusitis

Jose L. Mattos, MD,MPH¹, Luke Rudmik, MD,MSc², Rodney J. Schlosser, MD^{3,4}, Timothy L. Smith, MD,MPH⁵, Jess C. Mace, MPH⁵, Jeremiah Alt, MD,PhD⁶, and Zachary M. Soler, MD,MSc³

¹Department of Otolaryngology – Head and Neck Surgery, Division of Rhinology and Sinus Surgery, University of Virginia, Charlottesville, VA

²Department of Surgery, Division of Otolaryngology–Head and Neck Surgery, University of Calgary, Calgary, AB, Canada

³Department of Otolaryngology – Head and Neck Surgery, Division of Rhinology and Sinus Surgery, Medical University of South Carolina, 135 Rutledge Ave, MSC 550, Charleston, SC 29425, USA

⁴Department of Surgery, Ralph H. Johnson VA Medical Center, 109 Bee St, Charleston, SC, 29401, USA

⁵Department of Otolaryngology-Head and Neck Surgery, Oregon Health & Science University, Portland, OR, USA

⁶Department of Surgery, Division of Otolaryngology-Head and Neck Surgery, University of Utah School of Medicine, Salt Lake City, UT, USA

Abstract

Introduction: Sinonasal symptoms and poor quality of life (QOL) prompt chronic rhinosinusitis (CRS) patients to undergo sinus surgery (ESS). However, little is known regarding the symptoms most important to patients and how these impact expectations and post-operative satisfaction.

Methods: A prospective, multi-institutional cohort study of 100 CRS patients undergoing ESS completed a novel adaptation of the SNOT-22 wherein they rated how important it was for specific symptoms to improve after surgery, along with pre-operative expectations and post-operative satisfaction. The primary satisfaction measure was whether a patient would choose to undergo ESS again. A multivariate, logistic regression model was built using demographics, objective measures, and the adapted SNOT-22 data. Spearman correlation analysis was also performed.

Correspondence to be sent to: Jose L. Mattos, Division of Rhinology and Sinus Surgery, Department of Otolaryngology – Head and Neck Surgery, University of Virginia, Charlottesville, VA. Phone: 434-924-5934. jm6cb@virginia.edu. Mail: PO Box 800713, Charlottesville, VA 22908.

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Results: Nasal obstruction was rated as “extremely or very” important by 93% of patients, followed by smell/taste, thick nasal discharge, need to blow nose, post-nasal discharge, and sleep symptoms (range 61–72%). Symptoms like sadness and embarrassment were not considered important by preoperative patients (28%). In multivariate logistic regression, postoperative satisfaction depended on pre-operative expectations being met and ESS improving their most important symptoms (OR 19.6, 27.5; $p < 0.005$). Post-operative satisfaction was not correlated with achieving a minimal clinically important difference, however it was correlated with magnitude of change in SNOT-22 ($r = 0.35$, $p < 0.05$).

Conclusions: Nasal, smell, and sleep-related symptoms were deemed most important by this cohort. Meeting of pre-operative expectations, improvement of most important symptoms, and the magnitude of change in the SNOT-22 may drive post-operative satisfaction.

Keywords

Chronic sinusitis; sinus surgery; expectations; satisfaction; patient reported outcomes

INTRODUCTION

Outcome measures in patients undergoing endoscopic sinus surgery (ESS) for chronic rhinosinusitis (CRS) have recently received significant attention in the rhinologic literature. Outcomes-centered research in rhinology has progressively increased in methodological rigor and several prospective studies have attempted to determine which factors impact patient outcomes after ESS. In 2010, a multi-institutional prospective cohort study showed that 20% to 30% of patients who undergo ESS do not experience clinically significant improvement as measured by disease-specific instruments,¹ and the only significant predictor of clinical outcomes was having undergone prior ESS, despite studying multiple clinical, demographic, and radiologic factors.

Since then, further attempts have been made to establish which patient factors might influence outcomes after ESS by several well-designed studies, and a large multi-institutional prospective cohort has been established to attempt to answer this question. One study analyzed factors that influence a patient's choice to pursue sinus surgery.² Despite examining multiple factors like demographics, clinical measures, social support, personality type, and physician patient-relationships, only pre-operative 22-item Sinonasal Outcome Test (SNOT-22 © 2006, Washington University, St. Louis, MO) survey scores were predictive of treatment selection. Furthermore, in some patients there may be a disconnect between pre-operative pathology and post-operative outcomes.^{3,4–6} Little is known about the relative importance that different patients place on the different symptoms and QOL disturbances of CRS, and perhaps there is a yet unidentified measure that contributes to post-operative patient outcomes that may relate to patient expectations. The relative valuation of symptoms, pre-treatment patient expectations, and the fulfillment of those expectations have been shown to impact outcomes measures in multiple areas of medicine.⁷ However, the effect of patient expectations on ESS outcomes remains unexplored. Additionally, the concept of patient satisfaction after ESS is largely unexplored in CRS, and the relationship between satisfaction, symptom improvement, and disease-specific QOL remains poorly understood.

Our objective was to study: 1) The relative importance that patients place on symptoms as measured by the SNOT-22; 2) How improvement in the most important symptoms and the fulfillment of pre-operative expectations correlate with patient outcomes and satisfaction; 3) The intersection between improvement in symptom severity, patient expectations, and patient satisfaction after ESS.

MATERIALS and METHODS

Study Population and Inclusion Criteria

Adult (≥ 18 years) patients were prospectively enrolled from academic, tertiary care centers in North America (Medical University of South Carolina, Oregon Health Sciences University, and the University of Calgary) with medically refractory symptoms of CRS. Confirmed diagnosis of CRS was provided using criteria provided by the American Academy of Otolaryngology.⁸ Study participants provided written informed consent in English during initial enrollment meetings. The Institutional Review Board at each enrollment site provided annual review and safety monitoring with central regulatory study oversight.

Patients who opted to pursue ESS were enrolled into this study after appropriate medical management failed to provide adequate symptom resolution. Surgical intervention was not randomized or assigned for study purposes. Surgical approach was formulated by each enrolling surgeon. Surgery was either primary or revision ESS and conducted under general anesthesia for all cases. Procedures consisted of unilateral or bilateral maxillary antrostomy, partial or total ethmoidectomy, sphenoidotomy, and/or Draf (type: 2a, 2b, or 3) frontal sinusotomy as needed. Anatomic ventilation was further maximized by incorporating either inferior turbinate reduction and/or septoplasty if indicated. Postoperative management included continued nasal saline irrigations (QD) and topical corticosteroid sprays/rinses to facilitate optimal postoperative healing. Study participants were followed through the postoperative standard of care up to 3 months. CT score were obtained using the Lund-Mackay scoring system⁹, and endoscopy scores using the Lund-Kennedy scoring system.¹⁰ Follow-up evaluations occurred during routine clinical appointments or phone call evaluations, and these occurred no sooner than 3 months post-operatively. Patient demographics, comorbidities, and disease-specific metrics that were collected are listed in Table 1.

Primary Patient Reported Outcome Measures (PROMs)

Disease-specific QOL Instrument: CRS-specific QOL was assessed using the SNOT-22 instrument, which includes 22 questions designed to capture QOL deficits related to CRS. The SNOT-22 has been found to have high internal consistency (Cronbach's alpha=0.91), test-retest reliability (coefficient=0.93), and discriminatory ability, and is among the most robust instruments available for CRS disease-specific QOL measurement. The minimal clinically important difference (MCID) for the SNOT-22 has been previously reported to be 8.9 points.^{11,12}

Importance of SNOT-22 Symptoms: The symptoms listed in the SNOT-22 were assessed for their importance to individual patients. We measured importance using a 5-point Likert scale. Since no validated instrument to assess symptom importance for CRS exists, we based the wording and format of our questionnaire based on an extensive literature review. The literature review focused on publications focusing on patient preferences, expectations, and symptoms importance. Multiple wording choices were identified in the literature, ranging from those assessing a patient's feelings, needs, importance, expectations, confidence, beliefs, desires, etc. Additionally, multiple grading scales were identified which were almost exclusively Likert scales. A consensus was reached by the authors that the most appropriate term, or the concept we are attempting to capture, is "importance". We wished to know how important certain symptoms were to individual patients, and whether the improvement in those most important symptoms impacted outcomes and satisfaction. Consequently, previously used importance Likert scales were adopted for this instrument.^{13–15} Table 2 contains the importance questionnaire completed by the patients in this study.

Patient expectation and satisfaction: While there is no CRS or ESS specific expectation and satisfaction tool, there are several well validated tools assessing patient expectations and satisfaction in other medical specialties. We therefore adapted questions from five previously published tools: The SNOT-22¹⁶, the Pittsburgh Sleep Quality Index (PSQI)¹⁷, The Stanford Expectations of Treatment Scale (SETS)⁷, the Allergic Rhinitis Patient Benefit Index (AR-PBI)¹⁸, and the Surgical Satisfaction Questionnaire (SSQ8)¹⁹. Table 3 lists the final questions used to assess patient expectations and satisfaction.

Statistical Analysis—Descriptive statistics for baseline and demographic factors were performed. Descriptive analysis and student's t-test were performed on the expectation and satisfaction questionnaires. The primary satisfaction metric was chosen to be whether a patient would choose to undergo surgery again, as measured by question 7 in Table 3. Correlation analyses were performed with the satisfaction metric. Finally, logistic regression analysis was performed on the primary satisfaction metric (question 7 in Table 3), which was collapsed into a binary variable, where "yes" was indicated by a response of agree or strongly agree, and "no" by a response of neutral, disagree, or strongly disagree. Univariate logistic regression was performed with multiple predictors of: age, race, gender, polyp status, aspirin sensitivity, self-reported allergy status, self-reported asthma status, CT score using Lund-Mackay scoring system⁹, endoscopy score using the Lund-Kennedy scoring system¹⁰, achieving MCID, change in SNOT 22 total score, resolution of expectations (see Table 3, question 3), and improvement of most important symptoms (see Table 3, question 4). The items which were significant in univariate analysis were carried forward into a multivariate regression, from which a stepwise backward modeling approach was used.

RESULTS

Baseline Characteristics

In this prospective longitudinal study, we enrolled 100 subjects who were undergoing ESS and completed both the SNOT-22 and the symptom importance instrument at baseline. A total of 80 patients completed follow-up SNOT 22 scores, and 66 of these completed the

satisfaction and expectations questionnaire. Table 1 details these characteristics. We examined those patients with and without follow-up to assess potential biases between these groups, and we found only minimal differences between them. The participant group with follow-up had a lower prevalence of both comorbid allergy (37% vs. 58%; $p=0.040$) and AERD (8% vs. 24%; $p=0.040$). The average improvement in SNOT-22 score was 39 points (Standard deviation = 25), with 71 (89%) achieving MCID.

Importance Ratings

For baseline importance ratings of SNOT-22 symptoms, there was a wide range of ratings, with 14 of 22 symptoms being ranked as at least “somewhat important” to patients. Furthermore, even the symptoms with low mean importance ratings were ranked as important or very important by 25% to 42% of patients. The top five most important symptoms for patients were blockage/congestion of nose, sense of smell/taste, thick nasal discharge, need to blow nose, and post-nasal discharge. Waking up tired, fatigue, lack of a good night’s sleep, and fatigue were the next three most important symptoms. Table 4 details the importance ratings for the SNOT-22 symptoms.

Expectation and Satisfaction Ratings

The responses to the expectations and satisfaction questions in Table 3 were collapsed into binary ratings. The “agree” rating include the agree and strongly agree responses. The “disagree” rating include all other responses. A total of 65% of patients expected surgery to completely resolve their symptoms, but overall 73% of patients felt that the outcome of surgery matched their pre-operative expectations. Most patients were satisfied with surgery, 83% felt surgery improved those symptoms most important to them, 98% felt adequately informed before surgery, 86% would do the surgery again, and 94% would recommend ESS to others. The results of these ratings are detailed in Table 5 and 7.

Predictors of Patient Satisfaction

There was no correlation between improvement in individual symptoms of the SNOT-22 and satisfaction. However, satisfaction did show a weak correlation between improvement in overall SNOT-22 scores ($r=0.38$, $p<0.05$) and the achievement of MCID on SNOT-22 scores ($r=0.26$, $p>0.05$). Interestingly, even the majority of patients who did not achieve MCIDs reported high levels of satisfaction with the outcomes of ESS. Patients who did not achieve MCIDs were still highly likely to pursue sinus surgery again, recommend surgery to others, and had high ratings on the majority of the satisfaction questions (see Table 6).

On multivariate logistic regression analysis, however, we found no significantly different odds of election for ESS again and average post-operative changes in SNOT-22 scores. In fact, the only significant predictors of our primary satisfaction metric were whether the resolution of symptoms matched pre-operative expectations ($OR=27.5$, $p=0.002$) and whether surgery improved the symptoms most important to patients ($OR=19.6$, $p=0.001$). Table 7 details the findings of our univariate and multivariate models.

DISCUSSION

Patient-centered care is healthcare that is respectful of and responsive to individual patient preferences, needs, and values. In fact these values of care are considered by the Institute of Medicine to be one of the six pillars of high-quality healthcare delivery.²⁰ In order to deliver patient-centered care, we must first understand the relative values and areas of importance for individual patients, their expectations, and how the fulfillment of expectations (or lack thereof) impacts outcomes and satisfaction. The current study shows that patients undergoing ESS place different levels of importance on CRS-specific symptoms. In this study, nasal, smell, and sleep-related symptoms seem to dominate in importance, over other symptoms like ear symptoms, embarrassment and sadness. Understanding what symptoms matter most to patients can then help us tailor our counseling and treatment approaches, and can guide the exploration of pre-treatment expectations.

Pre-treatment patient expectations, and the fulfillment of those expectations, have been shown to impact outcomes measures in multiple areas of medicine.⁷ However, relative valuation of symptoms by patients and the effect of patient expectations on ESS outcomes and satisfaction have remained unexplored until now. In the orthopedic literature, patients undergoing total knee arthroplasty who had high pre-operative expectations experienced improved post-operative pain, stiffness, knee function, and overall QOL.¹³ Importantly, the patients who had high fulfillment of their expectations also had increased improvement in the above outcomes, compared to those who did not.¹³ Similar findings have been reported in many other scenarios including, but not limited to, physical therapy, interventional pain control, pharmaceutical intervention, psychotherapy, and nausea after chemotherapy.^{21–25} Furthermore, the expectancy effect in some instances may be a better predictor of outcomes than the actual treatment condition (active vs. sham).²⁶ Our data suggest that only the fulfillment of patient expectations and the improvement of those symptoms was deemed most important to predict satisfaction, and as such the impact of expectancy on CRS and ESS outcomes deserve further study.

Furthermore, our current study suggests that there may be an intriguing intersection between patient satisfaction, symptom improvement, disease-specific QOL, and patient expectations. Overall, our cohort had very high satisfaction rates, even in those patients who did not achieved MCID in the SNOT-22 total scores. Only 8 patients did not achieve MCID, but of these 63% of them would undergo ESS again, 75% felt that surgery improved the symptoms most important to them, 86% felt overall satisfaction with their outcomes, and 87% of them would recommend sinus surgery to others. While there was a correlation between the magnitude of change in the SNOT-22 and whether someone would choose surgery again, in our multivariate model, only the fulfillment of pre-operative expectations and the resolution of the symptoms most important to patients were associated with satisfaction. This would suggest that measuring success after sinus surgery solely with disease-specific QOL instruments, or with arbitrary cut-offs like an MCID, may be failing to capture patients who are indeed satisfied with their outcomes.

The finding that patients are satisfied when we improve their most important symptoms, but also when we meet their pre-operative expectations may have important implications as we

move forward in our determination of success in the treatment of CRS. Recently, a core outcomes set (COS) has been suggested for CRS and ESS.²⁷ A COS is an agreed standard collection of outcomes for a specific disease area, and it serves to decrease the heterogeneity of published outcomes data, and improve the ability to pool together data from multiple studies in meta-analyses.²⁷ The wide-spread adoption of a COS in CRS and ESS would signify a major advancement in our field, but the precise contents of the COS are not yet fully determined. One item that the CRS COS does not presently contain is a measure of patient satisfaction or expectation fulfillment. Our findings suggest that expectancy and satisfaction should be given consideration for COS adoption, or at least studied further as to whether it would be appropriate and feasible to do so. After all, if a patient is not satisfied with the outcome of elective surgery, does it really matter what the other outcomes metrics show us? Furthermore, since satisfaction seems to be strongly related to the meeting of pre-operative expectations, should we not be systematically evaluating this and tracking post-operative expectancy fulfillment? As our field moves forward and tries to establish a COS, patient expectations and satisfaction should be considered as part of this core set of metrics.

While this study was performed prospectively, across multiple institutions, and recorded demographics, comorbidities, and CRS-specific disease severity measures it does have limitations. This is a cohort recruited from tertiary rhinology practices with a high burden of disease, so the results may not be generalizable to other patient populations. Furthermore, our cohort experienced a larger than expected improvement in the SNOT-22, and had very high levels of satisfaction. This limits the subset of the cohort which was not satisfied or had sub-optimal outcomes and so this may skew our results. Larger, comprehensive prospective investigations into this subject are warranted to overcome these limitations and further understand the role of expectations and satisfaction on ESS outcomes.

CONCLUSION

The nasal and smell related symptoms captured by the SNOT-22 were deemed most important by this cohort of CRS, closely followed by sleep disturbance and fatigue. The majority of patients were satisfied with the outcomes of ESS, including most of the patients who did not achieve MCID on the SNOT-22. Achieving MCID on the SNOT-22 did not correlate with satisfaction. Only the fulfillment of pre-operative expectations, and the improvement of symptoms most important to patients were associated with our primary satisfaction metric.

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Table 1:
Demographics and Baseline Characteristics

Variable		Mean/Count ¹
Demographics		
Age		45.7
Sex	Female	46
	Male	54
Race	White	81
	African American	14
	Asian	2
	Other	3
Ethnicity	Non-Hispanic / Latino	100
Comorbidities		
Asthma		32
AERD ²		11
Allergy		43
CRS characteristics		
CRSwNP ³		59
Endoscopy Score		9.1
CT Score ⁴		14.7
SNOT-22 ⁵		61.8

¹ Sample size is 100 subjects, so count = percentage

² AERD = Aspiring Exacerbated Respiratory Disease

³ CRSwNP = Chronic Rhinosinusitis with Nasal Polyps

⁴ CT = Computed Tomography

⁵ SNOT-22 = 22-item Sinonasal Outcome Test

Table 2:
Symptom Importance Instrument*

Below you will find a list of symptoms and social/emotional consequences of your rhinosinusitis. We are interested in knowing how IMPORTANT it is for you to have improvement in the items listed below following treatment. As a result of treatment, how IMPORTANT is it to have improvement in your...						
	Not relevant	Relevant	Less important	Somewhat Important	Important	Very important
SNOT-22 symptoms	0	1	2	3	4	5

* This is an example of the instrument used. In the real data-collection instrument, every symptom of the SNOT-22 was included in the instrument, and subjects rated the importance of each of the symptoms.

Table 3:
Expectation and Satisfaction Questionnaire

1. Before you had sinus surgery, did you believe this treatment would completely resolve your sinus condition related symptoms?
2. Prior to sinus surgery, were you worried or did you have fears about the surgery?
3. The resolution of my symptoms following sinus surgery matched my expectations that I had prior to surgery.
4. Sinus surgery improved the symptoms most important to me.
5. Following sinus surgery, I was satisfied with the time it took to return to daily activities.
6. I was satisfied that I was adequately informed about the issues important to my decision to receive sinus surgery.
7. If you had to do it again, would you pursue sinus surgery?
8. I would recommend sinus surgery to someone else who needed it.

Likert scale response: 1= strongly disagree, 2=disagree 3=neither agree nor disagree 4=agree 5=strongly agree

Table 4:**Median and Mean Scores of Symptom Rating**

Symptom	Median	Mean	SD	Very important or important (%)
blockage/congestion of nose	5	4.6	0.7	93
sense of smell/taste	5	4	1.3	72
thick nasal discharge	4	3.9	1.3	71
need to blow nose	4	3.8	1.3	77
postnasal discharge	4	3.8	1.3	70
waking up tired	4	3.6	1.6	50
lack of good night's sleep	4	3.5	1.7	61
fatigue	4	3.5	1.7	60
frustrated/restless/irritable	4	3.5	1.7	59
runny nose	4	3.4	1.4	57
facial pain/pressure	4	3.4	1.7	56
reduced productivity	4	3.4	1.7	60
reduced concentration	4	3.3	1.8	53
waking up at night	3.5	3.1	1.8	50
ear fullness	3	2.9	1.7	42
sneezing	3	2.7	1.5	35
difficulty falling asleep	3	2.7	1.9	42
cough	3	2.6	1.8	38
dizziness	2	2.3	1.8	31
ear pain	2	2.2	1.8	28
sad	2	2	1.8	27
embarrassed	1	1.8	1.8	25

SD = standard deviation

5 = Very important; 4 = Important; 3 = Somewhat Important; 2 = Less Important; 1 = Relevant; 0 = Not Relevant

Table 5:
Expectation Responses (converted to agree / disagree) – stratified by MCID¹ yes/no

Expectation Questions	Response	Overall	MCID = No	MCID = Yes	p-value
Before you had sinus surgery, did you believe this treatment would completely resolve your sinus condition related symptoms?	agree	43 (65%)	3 (37.5%)	40 (69%)	0.115
	disagree	23 (35%)	5 (62.5%)	18 (31%)	
Prior to sinus surgery, were you worried or did you have fears about the surgery?	agree	21 (32%)	2 (25%)	19 (32.8%)	>0.999
	disagree	45 (68%)	6 (75%)	39 (67.2%)	
The resolution of my symptoms following sinus surgery matched my expectations that I had prior to surgery.	agree	48 (73%)	5 (62.5%)	43 (74.1%)	0.673
	disagree	18 (27%)	3 (37.5%)	15 (25.9%)	

¹MCID = Minimal Clinically Important Difference on the 22-item Sinonasal Outcomes Test

Table 6:
Satisfaction Responses (converted to agree / disagree) – stratified by MCID¹ yes/no

Satisfaction Questions	Response	Overall	MCID = No	MCID = Yes	p-value
Sinus surgery improved the symptoms most important to me.	agree	55(83%)	6(75%)	49(84.5%)	0.6114
	disagree	11(17%)	2(25%)	9(15.5%)	
Following sinus surgery, I was satisfied with the time it took to return to daily activities.	agree	62(94%)	8(100%)	54(93.1%)	>0.999
	disagree	4(6.9%)	0	4(6.9%)	
I was satisfied that I was adequately informed about the issues important to my decision to receive sinus surgery.	agree	65(98%)	8(100%)	57(98.3%)	>0.999
	disagree	1(1.7%)	0	1(1.7%)	
If you had to do it again, would you pursue sinus surgery?	agree	57(86%)	5(62.5%)	52(89.7%)	0.0706
	disagree	9(14%)	3(37.5%)	6(10.3%)	
I would recommend sinus surgery to someone else who needed it.	agree	62(94%)	7(87.5%)	55(94.8%)	0.4113
	disagree	4(6%)	1(12.5%)	3(5.2%)	
Overall satisfaction	yes	52(82%)	6(85.7%)	48(85.7%)	1.000
	no	9(13%)	1(14.3%)	8(14.3%)	

¹MCID = Minimal Clinically Important Difference on the 22-item Sinonasal Outcomes Test

Table 7:
Logistic Regression Analysis of Patient Satisfaction Predictors

Would choose surgery again	Odds Ratio	Std. Err.	P-Value	95% Confidence Interval
Resolution of symptoms matched expectations	85.7	68.42	<0.001*	17.9 – 409.7
Surgery improved the most important symptoms	82.9	56.33	<0.001	21.9 – 314.0
Change in SNOT-22 total score ¹	1.0	0.01	0.012*	1.0 – 1.1
Allergies	0.4	0.16	0.019*	0.2 – 0.9
Age	1.0	0.01	0.45	0.9 – 1.0
Achieved MCID ²	2.2	1.58	0.28	0.5 – 9.0
Race	0.9	0.32	0.84	0.5 – 1.8
Polyp status	0.9	0.37	0.79	0.4 – 2.0
Aspirin sensitivity	0.3	0.20	0.08	0.1 – 1.1
Asthma status	0.9	0.39	0.79	0.4 – 2.1
CT score ³	1.0	0.05	0.46	0.9 – 1.1
Endoscopy score	1.1	0.07	0.15	0.9 – 1.2
Would choose surgery again	Odds Ratio	Std. Err.	P-Value	95% Confidence Interval
Resolution of symptoms matched expectations	27.5	28.94	0.002*	3.5 – 216.0
Surgery improved the most important symptoms	19.6	18.24	0.001*	3.2 – 121.4
Change in SNOT-22 score	1.0	0.02	0.08	0.9 – 1.1
Allergies	0.2	0.15	0.051	0.02 – 1.1

¹ SNOT-22: 22-item Sinonasal Outcome Test

² MCID: Minimal Clinically Important Difference

³ CT: Computed Tomography