

# An Exploratory Analysis of the Chronic Rhinosinusitis Online Support Community

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## Abstract

**Objective.** To characterize the users of the largest chronic rhinosinusitis (CRS) online support communities (OSCs), describe the perceived benefits of OSCs for their users, and understand how patient medical decision making is affected by membership in OSCs.

**Study Design.** Cross-sectional online survey.

**Setting.** Online.

**Methods.** A cross-sectional online survey was adapted from the existing literature on patient support groups and modified for CRS patients. The survey was posted on multiple Facebook/Reddit groups aimed at providing support toward patients with CRS. Survey data was collected over 3 months and analyzed thereafter.

**Results.** There were 127 total participants. The majority were female (65.35%), white (76.98%), and the median age was 38 years. Just under half of patients had nasal polyps (48.67%) and 54.54% had undergone surgery. Many participants (69.42%) reported engaging in the OSC at least multiple times per month. The most common reason for joining an OSC was to learn tips on how to manage CRS (89.7%) and the most achieved goal from membership was hearing from others undergoing a similar experience (79.5%). Involvement in an OSC impacted knowledge of CRS in 87.41% of participants. Most users (81.1%) would recommend membership in an OSC and 54.33% reported the OSC influenced their medical decision-making.

**Conclusion.** A majority of patients with CRS who frequently engage in an OSC for CRS have a positive experience. OSCs are a resource that CRS patients utilize to manage their disease.

## Keywords

chronic rhinosinusitis, online support community, support group

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The Internet can serve as an important source of health information and an avenue of support for patients. One study found that, in 2010, 80% of individuals used the Internet to search for health-related information.<sup>1</sup> Medical online support communities (OSCs), found primarily on social media platforms such as Facebook and Twitter, are online resources that patients engage in. Previous studies have suggested that the benefit OSCs provide is mainly psychosocial and facilitate group interactions that aid in disseminating medical information.<sup>2,3</sup> Despite OSC's psychosocial importance, there is a paucity of literature examining their impact on disease perception and medical decision making.

Chronic rhinosinusitis (CRS) affects 4.8% to 12% of adults in the United States and results in over \$5 billion in associated health care expenditures and \$12.8 billion lost in productivity annually.<sup>4-6</sup> There are several medical and surgical treatment options for those with CRS including: nasal saline rinses, nasal corticosteroids, and endoscopic sinus surgery.<sup>4</sup> In addition, CRS can considerably affect a patient's quality of life by impacting social, physical, and mental health.<sup>7,8</sup> Results from a national database suggest that those with CRS have a higher incidence of psychiatric diagnoses such as anxiety and depression.<sup>9</sup> In this population, it is possible that participation in OSCs could help with the psychosocial and medical effects of CRS as well as the overall management of their

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disease. However, there is a lack of research assessing how those with CRS benefit from participating in OSCs. The purpose of this study was to assess OSC use in those with CRS and quantify how they impact psychosocial factors and treatment decision-making.

## Methods

This study was approved by the institutional review board at the University of Southern California (UP-22-00183).

### OSC Distribution

Prior research on OSCs suggests that Facebook is the social media platform with the greatest amount of support group activity.<sup>10</sup> Therefore, the Facebook search function was combined with the search terms “chronic rhinosinusitis” and “chronic sinusitis” to systematically examine all of its major CRS OSCs. The social media platform Reddit was also queried using similar methods. Reddit is a social discussion forum that hosts communities dedicated to specific topics, such as CRS, with a voting system that helps users identify and highlight relevant information. The social media site has over 50 million daily active users as of 2022.<sup>11</sup> All OSCs surveyed had a minimum of 1000 members. No other social media platforms were examined.

### Survey Development and Distribution

The survey was modeled after a previously published questionnaire used to study characteristics and participants' perception of benefits in vestibular dysfunction OSCs.<sup>10</sup> The survey was created after an extensive literature review to determine the best language possible for the desired content. A team of patient advocates, CRS patients, and clinicians designed the survey.

The anonymous survey assessed basic demographic and clinical information as well as participation measures, self-perceived benefits from participation in the OSC, and influences on medical decision-making. The survey (see supplement) was distributed using REDCap electronic data capture tools at the University of Southern California as described below.

The survey was distributed to the 4 largest CRS OSCs on Facebook which are, in descending order of membership count as of December 2022, Sinusitis/Rhinitis/Hayfever Support Group (18,000), Chronic Sinusitis Sufferers (14,800), Chronic Sinusitis With Nasal Polyp (CRSwNP) Support & Discussion Group (9500), and Chronic Sinusitis Support Group (8800). The survey was also distributed on the Reddit groups r/Sinusitis (7500), r/NasalPolyps (1900), and r/Allergies (30,700). Upon receiving approval from the group administrators for survey distribution, a single post requesting survey participation was made containing the anonymous survey link and responses were collected over 3 months. Reminder posts were made

periodically throughout the 3-month interval to encourage participant engagement with the survey. All collected participant data were self-reported. No compensation was provided for participation. Given that many members of these groups, particularly r/Allergies, likely did not meet diagnostic criteria for CRS, we screened completed surveys and excluded those who did not meet diagnostic criteria for CRS or indicate which OSC they were a member of. Despite its popularity, Twitter was not included because it does not utilize a “Group” or “SubReddit” function which makes it less comparable to a support group.

### Statistical Analysis

Participants who completed the entire survey were included in the final dataset for analysis. Outcomes of interest included CRS treatment plans, OSC participation, and perceived benefits of the OSC. Pearson's chi-squared test or Fisher's exact test was used to evaluate differences between categorical variables and descriptive statistics were obtained using SPSS 27 (IBM Corp). Significance was defined as a *P* value less than .05.

## Results

### Demographics and Clinical Characteristics

A total of 127 participants completed the survey. Of the total number of participants, 71 participants (55.9%) were recruited from Reddit, and 56 (44.1%) were recruited from Facebook. The overall median age of participants was 38.0 years old (interquartile range [IQR]=20 years), 65.4% were female, and 77.0% identified as white (**Table 1**). We did not observe a statistically significant difference with respect to race and gender between participants recruited through Reddit compared to Facebook. The median age reported by participants recruited from Reddit was 34 years, while participants recruited from Facebook reported a median age of 46 years, which was statistically significant ( $P < .001$ ). A diagnosis of CRS with nasal polyps was reported by slightly less than half of all participants (48.7%) with no significant difference between Reddit and Facebook users. Most participants either had a college degree (43.3%) or graduate school training (28.4%). Geographically, 60.3% of participants lived in the United States and 37.3% lived outside the United States. Many patients ( $n = 96$ , 75.6%) had seen more than 1 physician for their CRS, and 29.2% had seen 4 or more. Otolaryngologists (62.6%) were the most common group of physicians to make the initial diagnosis of CRS, followed by Allergy and Immunology specialists at 17.3%. Nasal congestion (84.3%) and facial pain/pressure (74.8%) were the top 2 symptoms reported by patients.

**Table 1.** Demographics and Clinical Characteristics

| Characteristic             | Overall, n (%) | Facebook, n (%) | Reddit, n (%) | P value <sup>1</sup> |
|----------------------------|----------------|-----------------|---------------|----------------------|
| CRS phenotype              |                |                 |               | .16                  |
| CRSwNP                     | 55 (48.67%)    | 29 (55.77%)     | 26 (42.62%)   |                      |
| CRSsNP                     | 58 (51.33%)    | 23 (44.23%)     | 35 (57.38%)   |                      |
| Sex                        |                |                 |               | .10                  |
| Male                       | 44 (34.65%)    | 15 (26.79%)     | 29 (40.85%)   |                      |
| Female                     | 83 (65.35%)    | 41 (73.21%)     | 42 (59.15%)   |                      |
| Age (median, IQR)          | 38 (30, 50)    | 46 (36, 58)     | 34 (27, 42)   | <.01                 |
| Race                       |                |                 |               | .88                  |
| Asian/Pacific Islander     | 8 (6.35%)      | 4 (7.27%)       | 4 (5.63%)     |                      |
| Black                      | 3 (2.38%)      | 1 (1.82%)       | 2 (2.82%)     |                      |
| Caucasian                  | 97 (76.98%)    | 44 (80.00%)     | 53 (74.65%)   |                      |
| Hispanic/Latino            | 3 (2.38%)      | 1 (1.82%)       | 2 (2.82%)     |                      |
| Other                      | 15 (11.90%)    | 5 (9.09%)       | 10 (14.08%)   |                      |
| Geographic location        |                |                 |               | .02                  |
| East                       | 31 (24.60%)    | 14 (25.45%)     | 17 (23.94%)   |                      |
| Midwest                    | 13 (10.32%)    | 2 (3.64%)       | 11 (15.49%)   |                      |
| West                       | 17 (13.49%)    | 6 (10.91%)      | 11 (15.49%)   |                      |
| South                      | 15 (11.90%)    | 4 (7.27%)       | 11 (15.49%)   |                      |
| Outside the United States  | 47 (37.30%)    | 26 (47.27%)     | 21 (29.58%)   |                      |
| Other                      | 3 (2.38%)      | 3 (5.45%)       | 0 (0.00%)     |                      |
| Highest level of education |                |                 |               | .05                  |
| Grade school               | 2 (1.57%)      | 2 (3.57%)       | 0 (0.00%)     |                      |
| High school                | 13 (10.24%)    | 10 (17.86%)     | 3 (4.23%)     |                      |
| Some college               | 21 (16.54%)    | 8 (14.29%)      | 13 (18.31%)   |                      |
| College                    | 55 (43.31%)    | 21 (37.50%)     | 34 (47.89%)   |                      |
| Graduate school            | 36 (28.35%)    | 15 (26.79%)     | 21 (29.58%)   |                      |
| Number of physicians       |                |                 |               | .94                  |
| 1                          | 24 (20.00%)    | 12 (22.64%)     | 12 (17.91%)   |                      |
| 2                          | 33 (27.50%)    | 14 (26.42%)     | 19 (28.36%)   |                      |
| 3                          | 28 (23.33%)    | 12 (22.64%)     | 16 (23.88%)   |                      |
| 4+                         | 35 (29.17%)    | 15 (28.30%)     | 20 (29.85%)   |                      |
| Diagnosing physician       |                |                 |               | .57                  |
| Primary care               | 16 (13.91%)    | 8 (16.00%)      | 8 (12.31%)    |                      |
| Otolaryngology             | 72 (62.61%)    | 33 (66.00%)     | 39 (60.00%)   |                      |
| Rhinology                  | 2 (1.74%)      | 0 (0.00%)       | 2 (3.08%)     |                      |
| Allergy and immunology     | 20 (17.39%)    | 6 (12.00%)      | 14 (21.54%)   |                      |
| APP                        | 2 (1.74%)      | 1 (2.00%)       | 1 (1.54%)     |                      |
| Other                      | 3 (2.61%)      | 2 (4.00%)       | 1 (1.54%)     |                      |
| Nasal congestion           | 107 (84.25%)   | 46 (82.14%)     | 61 (85.92%)   | .56                  |
| Facial pain/pressure       | 95 (74.80%)    | 40 (71.43%)     | 55 (77.46%)   | .44                  |
| Nasal drainage             | 92 (72.44%)    | 39 (69.64%)     | 53 (74.65%)   | .53                  |
| Hyposmia/anosmia           | 66 (51.97%)    | 32 (57.14%)     | 34 (47.89%)   | .30                  |

Bolded values indicate statistical significance ( $p < .05$ ).

Abbreviations: APP, advanced practice provider; CRS, chronic rhinosinusitis; CRSsNP, CRS without nasal polyps; CRSwNP, CRS with nasal polyp; IQR, interquartile range.

<sup>1</sup>Pearson's  $\chi^2$  test; Wilcoxon rank sum test; Fisher's exact test.

### Prior Treatment

**Table 2** describes the characteristics of prior treatment undergone by study participants. The most common treatment modality was combined medical and surgical therapy (50.4%). Among these medical therapies, steroid

rinses (64.6%) and oral steroids (61.4%) were the most common treatments. Over half of the participants ( $n = 66$ , 54.5%) had undergone surgical treatment for CRS. Out of those who reported having surgery, slightly over half reported undergoing 1 surgery (54.6%) for CRS and

**Table 2.** Treatment Characteristics

| Characteristic           | Overall, n (%) | Facebook, n (%) | Reddit, n (%) | P value <sup>1</sup> |
|--------------------------|----------------|-----------------|---------------|----------------------|
| Biologic therapy         | 26 (20.47%)    | 10 (17.86%)     | 16 (22.54%)   | .52                  |
| Oral steroids            | 78 (61.42%)    | 36 (64.29%)     | 42 (59.15%)   | .56                  |
| Steroid saline rinses    | 82 (64.57%)    | 36 (64.29%)     | 46 (64.79%)   | .95                  |
| Xhance                   | 12 (9.45%)     | 6 (10.71%)      | 6 (8.45%)     | .67                  |
| Other                    | 28 (22.05%)    | 14 (25.00%)     | 14 (19.72%)   | .48                  |
| Antibiotics              | 11 (8.66%)     | 6 (10.71%)      | 5 (7.04%)     | .53                  |
| Antihistamines           | 14 (11.02%)    | 6 (10.71%)      | 8 (11.27%)    | .92                  |
| Endoscopic sinus surgery | 48 (37.80%)    | 23 (41.07%)     | 25 (35.21%)   | .50                  |
| Balloon sinus dilation   | 14 (11.02%)    | 4 (7.14%)       | 10 (14.08%)   | .21                  |
| Turbinate reduction      | 32 (25.20%)    | 14 (25.00%)     | 18 (25.35%)   | .96                  |
| Septoplasty              | 34 (26.77%)    | 15 (26.79%)     | 19 (26.76%)   | >.99                 |
| Treatment type           |                |                 |               | .81                  |
| Medication only          | 55 (45.45%)    | 24 (44.44%)     | 31 (46.27%)   |                      |
| Surgery only             | 5 (4.13%)      | 3 (5.56%)       | 2 (2.99%)     |                      |
| Both                     | 61 (50.41%)    | 27 (50.00%)     | 34 (50.75%)   |                      |
| Number of surgeries      |                |                 |               | .09                  |
| 1                        | 36 (54.55%)    | 13 (41.94%)     | 23 (65.71%)   |                      |
| 2+                       | 28 (42.42%)    | 16 (51.62%)     | 12 (34.29%)   |                      |
| Missing                  | 2 (3.03%)      | 2 (6.45%)       | 0 (0.00%)     |                      |

<sup>1</sup>Pearson's  $\chi^2$  test; Fisher's exact test.

slightly less than half of those participants had 2 or more surgeries (42.4%). Of those 66 participants who reported having surgery, 2 (3.03%) participants did not disclose how many times they underwent surgery. The most common surgical treatments were endoscopic sinus surgery (37.8%), septoplasty (26.8%), turbinate reduction (25.2%), and balloon sinuplasty (11.0%).

### CRS OSC Patient Experience

The initial motivations for joining and achievements gained from CRS OSC participation are outlined in **Figure 1**. The majority of patients (89.7%) reported joining the OSC “to learn tips and hints on how to deal with CRS” and “to hear from others with the same condition” (76.7%). Respondents primarily reported that they gained insight “from others with the same condition as me” (79.5%) and “learned tips and hints to deal with CRS” (69.9%). There were significant differences between initial motivation in joining the OSC and goals achieved from membership in the OSC in the following categories: gaining support from others, learning about treatments, hints and tricks for dealing with CRS, learning about doctors treating CRS and papers/research about CRS ( $P < .05$ .) **Table 3** outlines patient behavior in engaging with the OSG platform. The most cited frequency of engagement was multiple times a month (28.1%) with a median participation time of 1 hour per week. The most common length of membership was 1 to 5 years (30.3%).

### CRS OSC Perceptions

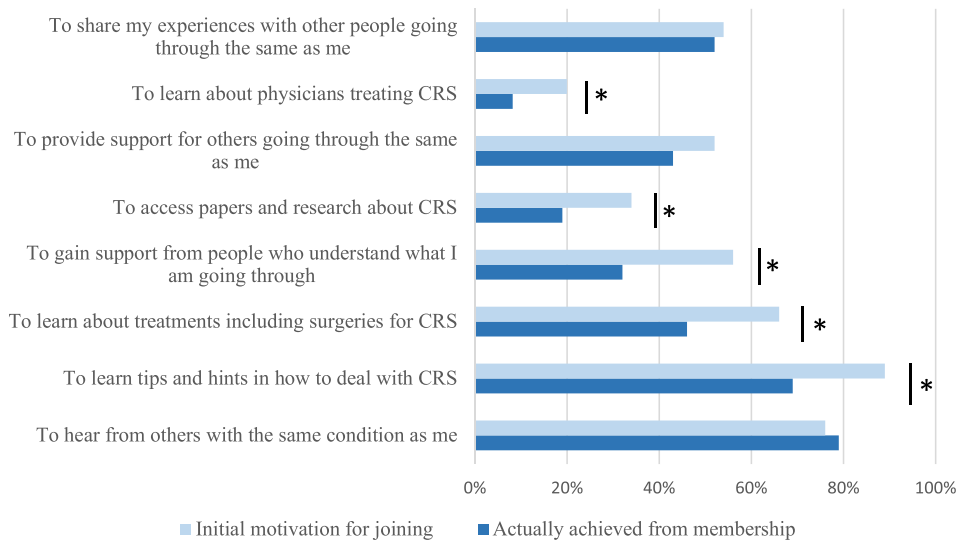
**Table 4** outlines participant perceptions of the CRS OSC platform. A majority of participants (55.1%) believed that their privacy was protected on the OSC platform. Participants were mostly “Neutral” to “Positive” (87.4%) regarding their level of trust in the information shared in the OSC. Most believed that the CRS OSC was a safe place where they could share their experiences (73.2%) and recommend the platform to other CRS patients (81.1%).

### Impact on Medical Decision Making

**Table 5** summarizes the role of the CRS OSC in medical decision-making among users. More than half of patients reported that OSC influenced their medical decision-making (54.3%). By extension, the support group also influenced the treatments requested by many participants (49.6%). However, 67 patients (52.8%) were not influenced by the support group regarding which doctor they ultimately sought for treatment. Many patients (50.4%) felt the OSC influenced the alternative treatments they requested from their physician. On average, members from the Facebook cohort felt more strongly influenced by their OSC when requesting what type of alternative treatment they sought from their physicians than the Reddit members ( $P = .001$ , **Table 6**).

### Perceived Psychosocial Benefit

Most patients reported that engagement with the CRS OSG expanded their knowledge of CRS (87.4%),



**Figure 1.** Participant's initial motivations for joining a CRS OSC compared to their achievements from membership. CRS, chronic rhinosinusitis; OSC, online support community. \* $P < .05$ .

**Table 3.** Online Behavior

| Characteristic                             | Overall, n (%)    | Facebook, n (%)   | Reddit, n (%)     | P value <sup>1</sup> |
|--|-------------------|-------------------|-------------------|----------------------|
| Frequency of engagement                    |                   |                   |                   | .31                  |
| More than once a day                       | 7 (5.79%)         | 4 (7.69%)         | 3 (4.35%)         |                      |
| Once a day                                 | 19 (15.70%)       | 10 (19.23%)       | 9 (13.04%)        |                      |
| Multiple times a week                      | 24 (19.83%)       | 14 (26.92%)       | 10 (14.49%)       |                      |
| Multiple times a month                     | 34 (28.10%)       | 12 (23.08%)       | 22 (31.88%)       |                      |
| Once a month                               | 22 (18.18%)       | 6 (11.54%)        | 16 (23.19%)       |                      |
| Every 2-3 mo                               | 9 (7.44%)         | 3 (5.77%)         | 6 (8.70%)         |                      |
| Once a year                                | 6 (4.96%)         | 3 (5.77%)         | 3 (4.35%)         |                      |
| Online participation (hours per week, IQR) | 1.00 (1.00, 2.00) | 1.00 (1.00, 2.00) | 1.00 (1.00, 2.00) | .84                  |
| Length of membership                       |                   |                   |                   | .08                  |
| <1 mo                                      | 24 (19.67%)       | 11 (21.15%)       | 13 (18.57%)       |                      |
| 1-3 mo                                     | 20 (16.39%)       | 6 (11.54%)        | 14 (20.00%)       |                      |
| 3 mo to 1 y                                | 36 (29.51%)       | 14 (26.92%)       | 22 (31.43%)       |                      |
| 1-5 y                                      | 37 (30.33%)       | 16 (30.77%)       | 21 (30.00%)       |                      |
| >5 y                                       | 5 (4.10%)         | 5 (9.62%)         | 0 (0.00%)         |                      |

Abbreviation: IQR, interquartile range.

<sup>1</sup>Fisher's exact test; Wilcoxon rank sum test

**Table 4.** Perceptions of Online Support Group

| Questions, n (%)   | Definitely not | Probably not | Neutral     | Probably    | Definitely  |
|--|----------------|--------------|-------------|-------------|-------------|
| I feel my privacy is protected   | 10 (7.87%)     | 23 (18.11%)  | 22 (17.32%) | 41 (32.28%) | 29 (22.83%) |
| I can trust the information within the group   | 3 (2.36%)      | 11 (8.66%)   | 36 (28.35%) | 54 (42.52%) | 21 (16.54%) |
| It provides me a safe place where I can share my experiences without my friends/family reading everything      | 2 (1.57%)      | 3 (2.36%)    | 27 (21.26%) | 51 (40.16%) | 42 (33.07%) |
| Based on your experiences, would you recommend that other people with CRS join your main online support group? | 2 (1.57%)      | 2 (1.57%)    | 18 (14.17%) | 45 (35.43%) | 58 (45.67%) |

Abbreviation: CRS, chronic rhinosinusitis.

**Table 5.** Influence on Medical Decision-Making

| Questions, n (%)  | Definitely not | Probably not | Neutral     | Probably    | Definitely  |
|---|----------------|--------------|-------------|-------------|-------------|
| To what extent has the social media support group influenced your medical decision-making?  | 9 (7.09%)      | 16 (12.60%)  | 31 (24.41%) | 45 (35.43%) | 24 (18.90%) |
| To what extent has the social media support group influenced what treatments you have requested from your doctor?                   | 7 (5.51%)      | 19 (14.96%)  | 36 (28.35%) | 39 (30.71%) | 24 (18.90%) |
| To what extent has the social media support group influenced what doctor to see?  | 45 (35.43%)    | 22 (17.32%)  | 31 (24.41%) | 15 (11.81%) | 12 (9.45%)  |
| To what extent has the social media support group influenced what alternative treatments you have tried (ie, CBD oil, acupuncture)? | 20 (15.75%)    | 14 (11.02%)  | 27 (21.26%) | 38 (29.92%) | 26 (20.47%) |

Abbreviation: CBD, cannabidiol.

**Table 6.** Differences in Perceptions of Online Support Groups, Influence on Medical Decision-Making, and Psychosocial Benefits Between Facebook and Reddit

| Questions   | Overall mean | SD   | Facebook |      | Reddit |      | P value        |
|---|--------------|------|----------|------|--------|------|----------------|
|   |              |      | Mean     | SD   | Mean   | SD   |                |
| I feel my privacy is protected  | 3.45         | 1.25 | 3.33     | 1.35 | 3.54   | 1.18 | .38            |
| I can trust the information within the group  | 3.63         | 0.95 | 3.67     | 0.93 | 3.61   | 0.96 | .72            |
| It provides me a safe place where I can share my experiences without my friends/family reading everything                           | 4.02         | 0.89 | 3.98     | 0.92 | 4.06   | 0.88 | .64            |
| Based on your experiences, would you recommend that other people with CRS join your main online support group?                      | 4.24         | 0.87 | 4.35     | 0.87 | 4.15   | 0.87 | .21            |
| To what extent has the social media group influenced your medical decision-making?  | 3.47         | 1.15 | 3.39     | 1.25 | 3.54   | 1.08 | .49            |
| To what extent has the social media support group influenced what treatments you have requested from your doctor?                   | 3.43         | 1.13 | 3.46     | 1.16 | 3.41   | 1.12 | .79            |
| To what extent has the social media support group influenced what doctor to see?  | 2.42         | 1.34 | 2.57     | 1.38 | 2.3    | 1.30 | .25            |
| To what extent has the social media support group influenced what alternative treatments you have tried (ie, CBD oil, acupuncture)? | 3.29         | 1.35 | 3.72     | 1.19 | 2.96   | 1.38 | <b>&lt;.01</b> |
| Knowledge of CRS  | 4.22         | 0.69 | 4.19     | 0.75 | 4.25   | 0.65 | .59            |
| Social support  | 4.09         | 0.78 | 4.20     | 0.68 | 4.00   | 0.85 | .15            |
| Practical coping skills   | 3.82         | 0.77 | 3.93     | 0.70 | 3.73   | 0.81 | .15            |
| Anxious feelings  | 3.58         | 0.82 | 3.63     | 0.83 | 3.55   | 0.81 | .59            |
| Depressed feelings  | 3.5          | 0.79 | 3.67     | 0.78 | 3.38   | 0.78 | <b>.04</b>     |
| Relationships with family or friends  | 3.34         | 0.71 | 3.54     | 0.84 | 3.18   | 0.54 | <b>.01</b>     |
| Hope for the future   | 3.64         | 0.88 | 3.83     | 0.89 | 3.49   | 0.86 | <b>.03</b>     |

Bolded values indicate statistical significance ( $p < .05$ ).

Abbreviations: CBD, cannabidiol; CRS, chronic rhinosinusitis.

provided a platform for social support (75.6%), and encouraged practical coping skills (63.8%). Support group members reported “No impact” or “Slightly positive” impacts by the OSG on their anxious feelings (79.5%), depressed feelings (80.3%), relationships with their family or friends (86.6%), and their hope for the future (73.2%) (Table 7). Facebook members reported significantly more positive benefits regarding feelings of depression ( $P = .044$ ), interpersonal relationships ( $P = .008$ ), and hope for the future ( $P = .032$ ) than Reddit members (Table 6).

## Discussion

This cross-sectional study describes the characteristics of participants in CRS OSCs as well as the impact of CRS OSCs on participants. Prior studies have characterized the demographics and investigated the impact of OSCs on otolaryngologic diagnoses and treatments such as idiopathic subglottic stenosis, vestibular disorders, and bone-anchored hearing aids but this has yet to be done in a CRS OSC.<sup>10,12,13</sup> The prior studies showed similar results

**Table 7.** Psychosocial Benefits—How Has Your Involvement in the Support Groups Impacted Each of the Following?

| Questions, n (%)                     | Very negative | Slightly negative | No impact   | Slightly positive | Very positive |
|--------------------------------------|---------------|-------------------|-------------|-------------------|---------------|
| Knowledge of CRS                     | 1 (0.79%)     | 0 (0.00%)         | 13 (10.24%) | 67 (52.76%)       | 44 (34.65%)   |
| Social support                       | 0 (0.00%)     | 2 (1.57%)         | 27 (21.26%) | 54 (42.52%)       | 42 (33.07%)   |
| Practical coping skills              | 0 (0.00%)     | 3 (2.36%)         | 41 (32.28%) | 57 (44.88%)       | 24 (18.90%)   |
| Anxious feelings                     | 1 (0.79%)     | 5 (3.94%)         | 57 (44.88%) | 44 (34.65%)       | 18 (14.17%)   |
| Depressed feelings                   | 0 (0.00%)     | 5 (5.51%)         | 64 (50.39%) | 38 (29.92%)       | 16 (12.60%)   |
| Relationships with family or friends | 2 (0.79%)     | 3 (2.36%)         | 85 (66.93%) | 25 (19.69%)       | 11 (8.66%)    |
| Hope for the future                  | 1 (0.79%)     | 9 (7.09%)         | 46 (36.22%) | 47 (37.01%)       | 22 (17.32%)   |

Abbreviation: CRS, chronic rhinosinusitis.

with otolaryngologic OSCs being utilized by a predominantly white, female, young to middle-aged, and highly educated audience and revealed similar positive psychosocial and knowledge benefits.<sup>14,15</sup>

Our racial and gender demographics are comparable to prior literature on CRS with our cohort predominantly identifying as white and female. It should be noted that minority groups, particularly Hispanic and African American patients, are likely underrepresented in CRS research and that we may not have an accurate demographic assessment of all CRS patients.<sup>16-18</sup> Our cohort was highly educated with nearly a third of participants holding a graduate degree and over two-thirds having at least a college degree. This may suggest a heightened awareness of the existence and benefits of an OSC in patients who are more educated as well as an increased ease of use of digital resources. Studies have shown that higher education and income levels are associated with increased utilization of the Internet for health information.<sup>19-21</sup>

Our study population differed from previous studies in the distribution between those with CRSwNP and those with CRS without nasal polyps (CRSsNP).<sup>22</sup> In the general population, CRSsNP is more prevalent than CRSwNP by a 2-to-3-fold ratio.<sup>9,22,23</sup> Compared to patients without nasal polyposis, those with nasal polyposis report significantly higher SNOT-22 scores and decreased health-related quality of life scores.<sup>9,24,25</sup> The high proportion of patients with nasal polyps in our study may be due to the fact that CRSwNP carries a more severe symptom and quality of life burden compared to CRSsNP, causing some selection bias.

Obtaining a CRS diagnosis from a physician appeared to be elusive for many patients with about half of patients seeing at least 3 physicians before being formally diagnosed. CRS symptoms overlap with other common upper airway conditions such as allergic rhinitis and viral/bacterial infections which can lead to misdiagnosis. A prior study of primary care and emergency physicians revealed only 1 out of 114 patients diagnosed with CRS actually met diagnostic criteria for CRS.<sup>26</sup> Further education of front-line physicians who typically see the patient before the otolaryngologist can reduce the time to diagnosis and treatment.

Among the initial reasons for joining the OSC, learning about treatments and hearing from others were 2 of the most cited. Interestingly, participants did not gain support or learn about treatments, hints and tricks, doctors, and papers/research for CRS to the extent they had hoped for when initially joining. Possible explanations for the failure to achieve these goals include off-topic discussions, advertisements, and spam posts on the OSCs which were observed by the authors during the study. This may be alleviated by tighter moderation by the group administrators or by providing physicians or other highly knowledgeable professionals to make the OSC a better source of information.

The majority of participants (>50%) had positive perceptions of the OSC in regard to privacy, trust in the information provided, and safety of the online space and would recommend that others with CRS join their OSC. These OSCs were all moderated by patients and each had clear guidelines that broadly required users to be supportive, empathetic, and positive to others. This likely fostered the development of a safe space that members could feel comfortable expressing themselves in.

OSCs had an impact on decision making with over 60% of users reporting the OSC having probably or definitely influenced their medical decision making. A little less than half of users also reported OSCs influenced what treatments they requested from their physician as well as what alternative treatments they tried to treat their CRS. It is unclear why Facebook users were more likely to be influenced in their alternative treatment decisions but it may relate to the higher proportion of female users amongst the Facebook cohort as female CRS patients have been found to be more likely to utilize alternative therapies.<sup>27</sup> The members of the CRS OSCs appear to trust the information on the OSC enough that it informs their medical decision-making and affects the conversations they have with their physicians about how to manage CRS. Physicians should be aware that membership in a CRS OSC may guide a patient toward certain treatment modalities such as alternatives to conventional Western medicine. In our increasingly digital world, OSCs act as another medium for health literacy though the accuracy of health information on these websites is likely highly variable based on previous

studies of other otolaryngology disease content on social media.<sup>28,29</sup> Otolaryngologists should be aware of the possible influence of CRS OSCs on patient decision making and further research is needed to investigate the quality and accuracy of content posted on CRS OSCs.

Our results indicate users are receiving psychosocial support from membership. These overall positive findings are important as CRS is known to cause significant impairments to quality of life and is associated with higher rates of depression as well as self-reported sleep and sexual dysfunction.<sup>30-32</sup> While our results are only self-perceived impacts and do not necessarily prove a truly beneficial effect on mental health in CRS patients, they indicate that a negative effect on psychosocial well-being is less likely. Facebook users reported greater benefits to depressed feelings, relationships with family or friends, and hope for the future when compared to Reddit users. This may be due to Facebook more closely simulating real-world interactions with real names and profile pictures compared to Reddit where usernames and avatars are used, thus making Reddit feel like less of a community.

This pilot study on CRS OSCs has several limitations. First, there exists more OSCs than those evaluated in our study so many users were not reached and the generalizability of this study to all CRS OSC users is uncertain, particularly given the skewed demographics of the cohort which is not necessarily representative of CRS OSC users, or CRS patients. Second, the anonymous survey link could have been accessed by anyone, including those not in a CRS OSC. Third, there is likely some selection bias given our cohort disproportionately suffered from CRSwNP. Finally, all medical information including the diagnosis of CRS was self-reported and could not be independently verified given the anonymous nature of this study. Additionally, the survey developed by our research team is not validated, precluding our ability to collect standardized data and compare it across existing studies. However, there currently are no validated questionnaires that focus on online communities.

## Conclusion

The CRS OSC is generally perceived positively by its users, has several psychosocial benefits, and impacts medical decision-making in a proportion of its users. There remains room for improvement as certain informational and support needs were not met for many users. Also, the accuracy of posted medical content is unverified and may misinform patients. Otolaryngologists should be aware of the existence of CRS OSCs and the possible impact they have on CRS patients who participate in them.

## Author Contributions

**Ruben Ulloa**, Study design, data analysis, interpretation of data, manuscript writing and approval; **Benjamin Tam**, data analysis, interpretation of data, manuscript writing,

revision, and approval; **Francis Reyes Orozco**, interpretation of data, manuscript writing, revision and approval; **Carlos X. Castellanos**, study design, interpretation of data; **Michael T. Chang**, manuscript writing, revision and approval; **Kevin Hur**, study design, data analysis, interpretation of data, manuscript writing, revision and approval.

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## Supplemental Material

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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