

Head and Neck Cancer Online Support Groups: Disparities in Participation and Impact on Patients

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Abstract

Objective. To characterize the users of the head and neck cancer (HNC) online support group (OSG) and describe the perceived benefits of membership.

Study Design. Cross-sectional.

Setting. Online.

Methods. An administered survey with questions asking about demographics, cancer history, treatment choices, and feelings about OSGs was posted on the 5 largest HNC OSGs on Facebook.

Results. A total of 97 participants completed the survey. Mean age was 57.8 years old (standard deviation = 10.7 years). Most participants were female (50.5%) and Caucasian (92.8%). This cohort was well educated with 65.5% holding at least a college degree. Annual income was high with 41.8% reporting annual income of \$100,000 or greater. The most common treatment modality was radiation (88.7%). The most common surgery was neck dissection (46.4%). Most participants preferred OSGs (70.8%) over other support group types. OSGs were heavily utilized with our cohort reporting using the OSG at least several times a week (80.0%). The top reasons for joining the OSG were sharing one's experience of HNC (76.3%) and gaining support from others with HNC (85.6%). OSGs were ranked as the #3 source of medical information for HNC behind otolaryngologists and oncologists. Membership in a HNC OSG had a minimal impact on decision-making.

Conclusion. HNC OSGs appear to provide a beneficial community for HNC patients. Otolaryngologists should consider incorporating HNC OSG as a possible supplemental resource for their HNC patients.

Keywords

head and neck cancer, online support community, support group

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Given the increasing survival rates of head and neck cancer (HNC) patients over time,^{1,2} an increased emphasis has been placed on HNC survivorship and quality of life (QoL) following primary treatment.^{3,4} These efforts can be especially difficult given the functional and cosmetic side effects patients experience following surgery, the burden of coordinating multidisciplinary postoperative care, and struggling to maintain proper home care due to 1-time instruction during follow-up appointments.³⁻⁷ Coupled with feelings of isolation due to the unique challenges of HNC survivorship, HNC patients often feel overwhelmed and endorse higher rates of depression and suicide relative to other cancer patients.^{3,4} Given the impact of patient mental health on postoperative outcomes and patient QoL in other surgical specialties,⁸⁻¹¹ interventions such as physical rehabilitation, patient body image disturbances, conservative surgical techniques, and psychotherapy have been suggested to improve patient QoL and psychosocial health following primary treatment. Yet, current interventions are inadequate, as up to 70% of HNC patients endorse unmet psychosocial and other needs after treatment.¹²

Support groups have been suggested as a method of improving HNC patient psychosocial support and health education. Though their benefits have been primarily elucidated in the breast cancer literature,^{13,14} online support groups (OSGs) have also been suggested as beneficial to HNC patients.¹⁵ OSGs, which exist on

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social media websites like Facebook, may further reduce patient isolation and improve support and education by removing geographic barriers to support group participation. Given the relative rarity of HNC, OSGs may provide HNC patients with a significantly larger community and increased access to information compared to what is readily available to patients locally.

Despite the promise and benefit OSGs can offer HNC patients, this psychosocial intervention has been poorly characterized in the otolaryngology literature. We sought to better understand the impact HNC OSGs have on patients as well as to characterize who participates in these groups.

Methods

This study received approval from the University of Southern California Institutional Review Board (UP-22-00183).

OSG Distribution

Given the high prevalence of support group activity on Facebook relative to other social media platforms, as previously demonstrated in the literature, HNC OSGs were identified on the platform using the search terms “head and neck,” “head and neck cancer,” and “HNC” to identify all major HNC OSGs, defined as those with over 900 members.¹⁶ No other social media platforms were assessed for the purposes of this study.

Survey Development and Distribution

The anonymous survey used was modeled after a previous study that examined the impact of OSGs on those with vestibular dysfunction.¹⁶ A literature review was performed to understand the most relevant topics and questions to include in the survey in addition to the best verbiage to use for readability and accuracy. This survey was reviewed by a team of fellowship-trained head and neck surgeons.

The final 44-question survey created in the RedCap electronic data tool queried topics such as demographic and clinical information, reasons for joining and benefits derived from OSGs, level of participation in OSGs, perception of OSGs, and impact on medical decision-making.

In descending order of membership count measured at the time of manuscript writing, this survey was distributed to the 5 largest HNC OSGs on Facebook: Head and Neck Cancer Survivors (6096); Head And Neck/Oral Cancer Chat And Support (6032); Head and Neck Cancer Support Group (4500); Survivors of Head and Neck Cancer (3751); Cancer/Head and Neck (967). Following group administrator approval, a post requesting responses was created and posted with a link to the anonymous survey. Survey responses were collected over

a 3-month period with occasional reminder posts to continue survey participation. A \$50 gift card raffle was offered for compensation.

Statistical Analysis

Responses of participants who completed the survey were included in the final data analysis. Outcomes of interest included participant demographics, OSG usage, benefits of OSGs, and OSGs' impact on patient decision-making. Descriptive statistics were performed in Microsoft Excel (2022, Version 16.69.1) and R (2022, Version 4.2.2) to characterize responses.

Results

Demographics and Clinical Characteristics

A total of 97 participants completed the survey. The participants had a mean age of 57.8 years old (SD = 10.7 years) (**Table 1**). About half of the participants (50.5%) were female and 92.8% were Caucasian. Most participants obtained a college degree (42.2%) or completed graduate school training (23.3%). Among US geographic regions, Southern states were predominantly represented (35.5%); 15.5% of respondents resided outside the United States. Most participants (60.9%) had private insurance while 31.7% reported an annual income between \$55,000 and \$99,999. The tongue was the most common primary site of HNC (32.2%). Most of the participants (48.1%) reported a clinical diagnosis of stage IV malignancy. On average, patients had seen more than 1 physician (2.4) prior to receiving a diagnosis of HNC. Radiation was the most common treatment among participants (88.7%). Of the 62.9% of patients who underwent surgery, 29.9% underwent tumor resection without other surgical intervention, and 46.4% required neck dissection. Many participants (40.2%) responded to the survey between 1 and 5 years after treatment. Self-reported recurrence rate among participants was 20.8%.

Patient Participation

Most participants (70.8%) reported regularly interacting with an online community exclusively (**Table 2**). 45.3% of patients reported reading and commenting on what others posted. 29.5% of respondents reported engaging their support platform of choice multiple times a week with many (44.1%) spending 1 hour or less per week. The most cited OSG membership length was 1 to 5 years (41.5%); 69.1% joined an OSG within 6 months of their HNC diagnosis.

Patient Perceptions

Patient perceptions and expectations from their OSG participation are outlined in **Figure 1**. Most patients (n = 83, 85.6%) reported joining the OSG to gain support from others and (n = 74, 76.3%) to share their experience with others. Respondents primarily

Table 1. Demographic Characteristics

Characteristic	n (%)
Age (mean, SD)	57.80 (10.65)
Gender	
Male	48 (49.47)
Race/ethnicity	
Caucasian	90 (92.78)
Black	2 (2.06)
Hispanic	1 (1.03)
Asian American/Pacific Islander	3 (3.09)
Other	2 (2.06)
Geographic region	
Northeast	13 (13.40)
Midwest	15 (15.46)
West	17 (17.53)
South	34 (35.05)
Outside United States	15 (15.46)
Other	2 (2.06)
Education	
Grade school	0 (0.00)
High school	12 (13.33)
Some college	19 (21.11)
College	38 (42.22)
Graduate school	21 (23.33)
Insurance	
Private	56 (60.87)
Medicare	21 (22.83)
Medicaid	3 (3.26)
Uninsured	4 (4.35)
Other	8 (8.70)
Annual income	
<\$20,000	9 (11.39)
\$20,000-\$49,999	12 (15.19)
\$50,000-\$99,999	25 (31.65)
\$100,000-\$199,999	22 (27.85)
>\$200,000	11 (13.92)

Abbreviation: SD, standard deviation.

reported that they shared their experience with others (n = 89, 91.6%) and supported others (n = 85, 87.6%). Thirty-six (37.1%) of participants cited the opportunity to hear from others with similar experiences as the most important benefit provided by the OSG.

Treatment Decision-Making

Figure 2 outlines the impact of OSG engagement on treatment decision-making. Prior to cancer diagnosis, 49 (57.7%) patients reported accessing the internet for health information less than once a month. In terms of the sources of information patients most relied on for medical decision-making, 80 (82.5%) patients reported their Oncologist as a source of information, followed by their Otolaryngologist (n = 75, 77.3%) and their OSG (n = 31, 32.0%).

Table 2. Clinical Characteristics

Characteristic	n (%)
HNC primary site	
Tongue	28 (32.18)
Oral cavity	7 (8.05)
Tonsil	18 (20.69)
Throat	10 (11.49)
Thyroid	1 (1.15)
Larynx	2 (2.30)
Nose	2 (2.30)
Upper jaw	3 (3.45)
Lower jaw	2 (2.30)
Parotid	2 (2.30)
Skin	2 (2.30)
Other	10 (11.49)
Stage at diagnosis	
I	17 (21.52)
II	16 (20.25)
III	25 (31.65)
IV	38 (48.10)
Number of physicians seen before diagnosis (average, SD)	2.40 (1.30)
Treatments undergone	
Surgery	61 (62.89)
Radiation	86 (88.66)
Chemotherapy	62 (63.92)
Immunotherapy	11 (11.34)
Other	2 (2.06)
Type of surgery	
Tumor resection	29 (29.90)
Rotational flap	4 (4.12)
Free flap	24 (24.74)
TORS	9 (9.28)
Neck dissection	45 (46.39)
Other	23 (23.71)
Time since diagnosis	
<3 mo	5 (5.43)
3 mo to 1 y	25 (27.17)
1-5 y	37 (40.22)
>5 y	25 (27.17)
Recurrence	20 (20.83)

Abbreviations: HNC, head and neck cancer; SD, standard deviation; TORS, transoral robotic surgery.

There were high levels of respondent agreement to the following survey questions, as measured on a 5-point Likert scale: “It (OSG) provides a safe place where I can share my experiences without my friends/family reading everything” (4.5), “Based on your experiences, would you recommend that other people with head and neck cancer join your main online support group?” (4.6). Most patients report rarely finding inaccurate medical information shared in their OSG (n = 61, 67.0%).

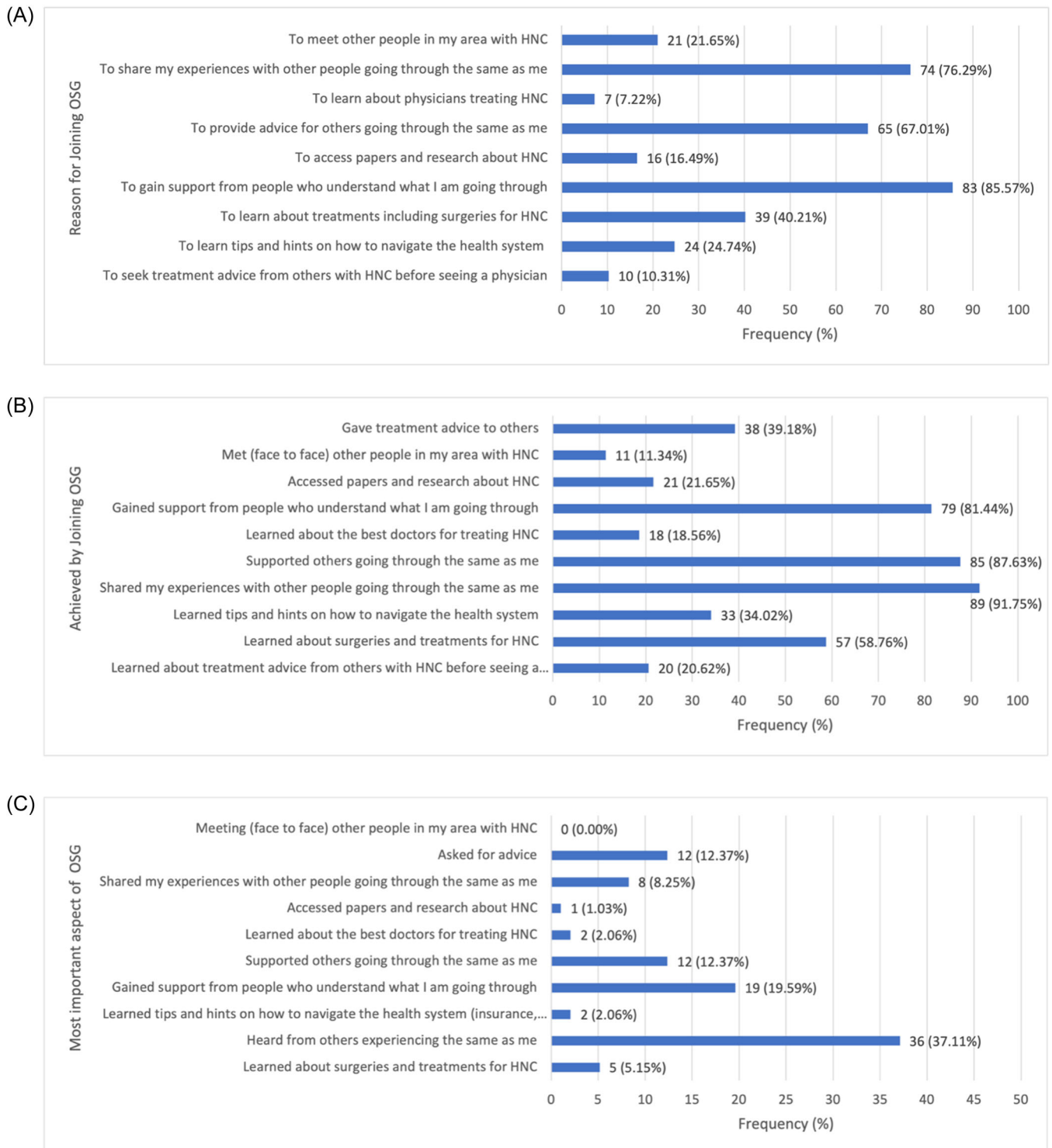


Figure 1. Benefits of online support groups (OSG). (A) Reason for joining OSG. (B) Achieved by joining OSG. (C) The most important aspect of OSG. HNC, head and neck cancer.

Discussion

Our study on HNC OSGs demonstrated interesting findings that can be categorized into these categories: participant demographics, members' OSG usage, benefits of OSGs, and OSGs' impact on patient decision-making.

To the author's knowledge, many of these questions have not yet been explored. There exists a single study exploring the psychosocial impact of HNC OSGs on its users which found longer use of OSGs was associated with higher health-related QoL but did not explore the impact of HNC

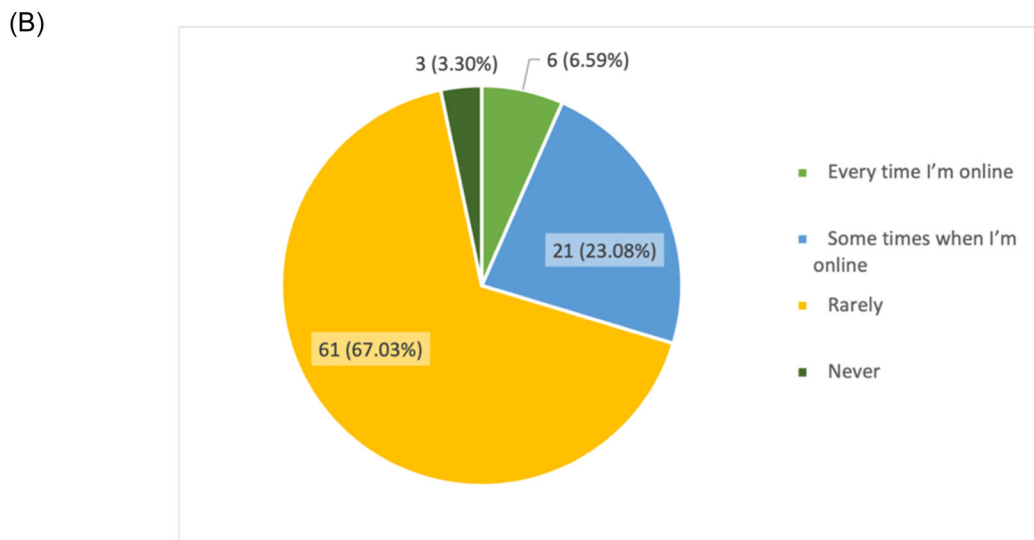
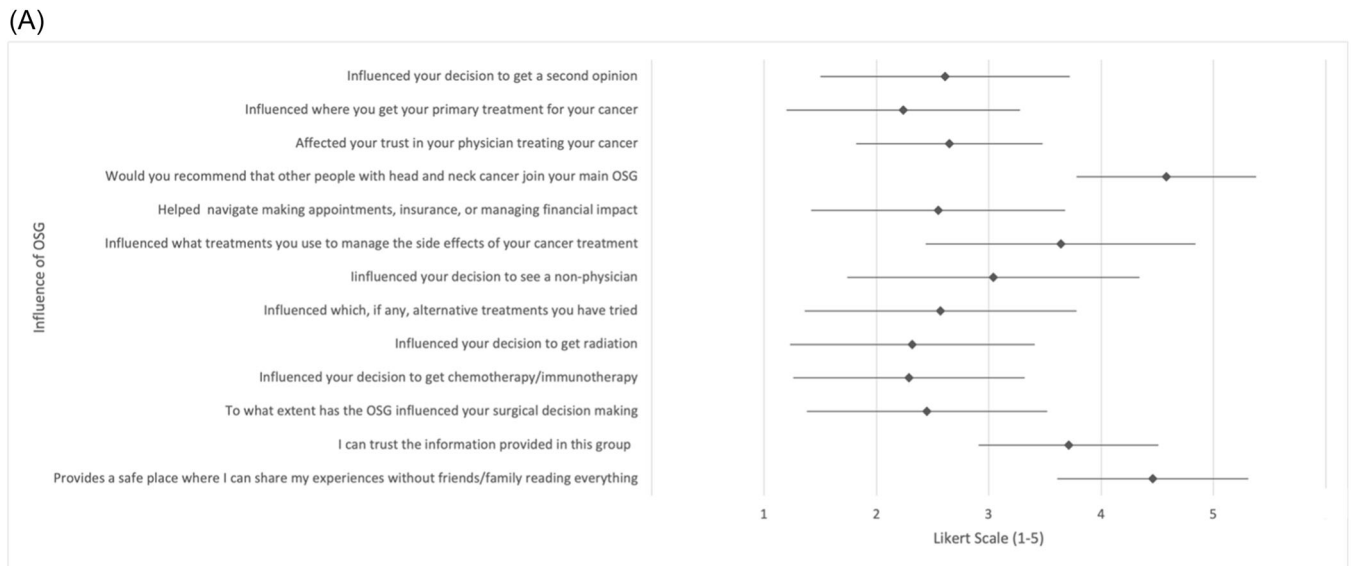


Figure 2. Impacts of OSG. (A) Aspects of impact. (B) Frequency of incorrect medical information on OSG. 1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree. OSG, online support group.

OSGs on patient decision-making and the self-perceived benefits of membership.¹⁵ A study in Korea showed that users of a single thyroid cancer OSG were more likely to have a college education and to have higher levels of depression and anxiety compared to nonusers.¹⁶ Our study significantly expands on what is currently known about HNC OSGs by further investigating user demographics, impact on decision-making, and perceived benefits.

Demographics

In this study, most participants identified as white, a finding previously seen in studies examining OSGs for patients with other conditions.¹⁷⁻¹⁹ Although the non-Hispanic white population is a patient demographic frequently affected by HNC, making up 75.2% of new oral cavity, pharyngeal, thyroid, and laryngeal cancer

diagnoses in the United States in 2019, this population is overrepresented in our study which is 92.8% white.²⁰ These findings suggest there may be easier accessibility or an increased awareness of the benefits of OSGs among white HNC patients relative to racial and ethnic groups. Combined with the high level of education (65.6% with at least a college degree) and relatively high income (41.8% with at least \$100,000 annual household income) reported by our cohort, our findings suggest that despite these OSGs being free to use, minority and disadvantaged populations may not participate in OSGs. Prior studies have indicated certain sociodemographic groups may be more likely to have lower health literacy, which may serve not only as an obstacle to treatment adherence but also as a deterrent to using health resources such as online health portals.²¹⁻²³ This may also be one of the causes of the demographic disparities in OSG usage in our cohort.

Given the ability of OSGs to remove geographic barriers to possible psychosocial benefits, improving awareness and accessibility of these groups may benefit HNC patients. It should be noted that it is possible our study was subject to selection bias, with white participants more likely to complete the survey. Two prior studies on OSGs for idiopathic subglottic stenosis and vestibular disorders also demonstrated a significant white predominance and a prior study on OSGs for breast cancer found white race was associated with higher engagement.²⁴ As such, further evaluation of participation levels of members in HNC OSGs is required to better understand what demographic factors, if any, are associated with high engagement. It is possible that there is higher engagement among white participants in these HNC OSGs. Furthermore, our cohort was small relative to the membership of the OSGs surveyed, making it challenging to draw conclusions about general membership characteristics.

OSG Usage

Our cohort preferred OSGs relative to in-person support groups or hybrid options. While the COVID-19 pandemic and subsequent mandatory self-isolation may have influenced this preference for OSGs, this phenomenon fails to explain why patients did not prefer a videoconference-based alternative, which would have maintained physical distance while allowing for some degree of natural human interaction. As opposed to these other digital offerings, OSGs offer a degree of anonymity which some patients may prefer as they learn to cope with their new lives as HNC survivors. OSGs also allow participants to access them at any time and from any location, reducing the need to make specific meeting times or travel to receive social support. However, solely distributing our survey in OSGs may have biased our results, as a previous national survey conducted among in-person cancer support group participants demonstrated that 75.0% of participants had never used an OSG.²⁵ This difference suggests different personalities may prefer one form of support group over the other. Therefore, the relative novelty of OSGs—with only 1 of the 5 OSGs in our study created prior to the time of the aforementioned publication—may also influence these previously reported results.

When assessing how participants utilize OSGs, few (20%) reported mostly reading other posts, while the rest reported some combination of reading posts, commenting, and asking questions of others. The subgroup of participants who read without active engagement have been referred to as “lurkers” in previous literature²⁶; our 20% lurker rate lies in the middle of the 15.6% to 32% rate reported across previous studies of other OSGs.²⁷ Our participants endorsed a high frequency of engagement,

Table 3. OSG Participation

Characteristic	n (%)
Preferred form of OSG	
Face-to-face, in-person, or over video	4 (4.21)
Online community on social media	67 (70.75)
Both	11 (11.58)
Neither	13 (13.68)
Participation level	
I mostly read what others post	19 (20.00)
I read and comment on what others post	43 (45.26)
I read and comment on others' posts and ask questions of others equally	33 (33.74)
I mostly ask questions of others	0 (0.00)
Frequency of engagement	
Several times a day	23 (24.21)
Once a day	25 (26.32)
Multiple times a week	28 (29.47)
Multiple times a month	11 (11.58)
Once a month	5 (5.26)
Every 2-3 months	1 (1.05)
A few times a year	2 (2.11)
Hours spent on OSG per week	
1 or fewer	41 (44.09)
Between 1 and 3	32 (34.41)
Between 3 and 5	12 (12.90)
Between 5 and 10	4 (4.30)
More than 10	4 (4.30)
Length of membership in OSG	
<1 mo	3 (3.19)
1-3 mo	9 (9.57)
3 mo to 1 y	26 (27.66)
1-5 y	39 (41.49)
>5 y	17 (18.09)
Time from diagnosis to joining OSG	
<1 wk	18 (22.22)
1 wk to 1 mo	14 (17.28)
1-3 mo	12 (14.81)
3-6 mo	12 (14.81)
>6 mo	25 (30.86)

Abbreviation: OSG, online support group.

with 50.5% reporting using OSGs at least daily (**Table 3**). Despite frequent use, the most selected time spent on OSGs per week was under 1 hour (44.1%) with most users spending fewer than 3 hours per week on OSGs (78.5%). This amount of time is roughly consistent with the weekly time requirements of an in-person support group, which may meet for an hour or 2 per week.²⁸ As such, our reported high frequency of engagement coupled with relatively low overall time spent on OSGs further suggests patients may prefer the accessibility and availability that OSGs offer over the rigid schedules and time commitment that in-person support groups require.

Benefits of OSGs

The top 3 reasons for joining an OSG were to receive support from others (85.6%), to share one's experience dealing with HNC (76.3%), and to provide advice for others going through a similar experience (67.0%). These represent the core benefits support groups often provide²⁹ and as expected, participants reported these goals were the 3 most achieved after joining the OSG. Interestingly, while 40.2% of participants reported joining in part to learn about treatments for HNC, 58.8% reported actually learning about these treatments. As the largest net difference among all reasons for joining OSG, this finding indicates that OSGs may serve as a resource for treatment information that may offer supplemental insight when health care providers are not readily available.

When allowed to select only 1 answer choice regarding the most important aspect of an OSG, participants voted "heard from others experiencing the same as me" most often (37.1%). Given the relative rarity and lack of public awareness of HNC in comparison to other common malignancies such as breast cancer and lung cancer, HNC patients may feel a sense of isolation and desire membership in a community of people who understand and even share their experiences as HNC survivors.¹² Patients may want to learn about others' personal experiences more so than receiving support, which was the second most common answer selected because the treatments for HNC often impair critical functions such as smelling, eating, swallowing, speaking, and breathing. The major changes in a patient's life postdiagnosis cannot be understated and hearing from other individual experiences can help assuage anxieties and alleviate concern.

Notably, participants rarely reported joining the OSG primarily to learn about treatments, doctors, hospitals, or research on HNC. Although participants ranked the OSG as an important source of information, the need to gain knowledge did not appear to be the main driver of OSG membership and may serve a more adjunctive role behind the information provided by health care professionals.

Treatment Decision-Making

An interesting finding in our study is that prior to HNC diagnosis, over half (57.7%) of participants reported using the internet for health information less than monthly, which is understandable given the older demographic we captured and the expected lower electronic and internet literacy among this patient group. Despite this general lack of internet usage, most of the cohort (78.4%) reported using the OSG at least several times a week. This finding suggests the benefits OSGs provided outweighed our cohort's lack of dependence on online health information and they adjusted their personal behavior in search of psychosocial benefit. The online interface likely reduces barriers to access by eliminating the need for transportation or physical contact, both of which can be

barriers for the elderly due to lack of reliable transportation or fear of exposure to infectious diseases.^{28,30}

In our survey, OSGs were ranked as the third most important source of health information behind only otolaryngologists and oncologists. OSGs outpaced other professional sources such as primary care physicians, professional medical associations, and medical articles. Users appear to value and trust the information they find on the OSG; however, given the lack of medical professionals on these sites, the factual accuracy may not be high relative to other sources. OSGs could be improved by actively involving physicians to educate patients and disprove false information, but doing so may run counter to a key benefit of the OSG—serving as a safe space removed from clinicians and other health care professionals. In terms of medical decision-making, participants did not rate the OSG as particularly influential on their decision-making regarding chemotherapy, radiation, surgery alternative treatments, nonphysician care (ie, dietician, speech-language pathologist), location of HNC treatment or decision to seek a second opinion. A modest effect on HNC treatment side effect management was noted. While it appears users trust the information on the OSG, it does not change their overall reliance on health care professionals to help them make medical decisions and to use the OSG for emotional support instead.

HNC OSGs provide information and support within the HNC community but information posted in these groups is not vetted by medical professionals. Further research into the accuracy of posted information is necessary. However, OSGs do appear to successfully provide psychosocial support to its members who may have anxiety associated with their diagnosis of HNC. The authors recommend otolaryngologists consider sharing HNC OSGs as a supplemental resource to their HNC patients given the possible educational and likely psychosocial benefits that an office visit cannot always achieve. While HNC OSGs cannot replace the professional counseling of an otolaryngologist, they may serve as a useful adjunct for patients desiring to hear the personal perspective of patients with similar experiences and join a community that can provide emotional support.

Limitations

This study has several limitations. Although our survey was distributed to the largest HNC OSGs on Facebook, there are smaller ones that were not reached so this cohort may not describe all OSG users. The survey was posted using an anonymous link that could have been filled out multiple times by accident or intentionally, though all responses were screened for duplicates. By relying on self-completion, there is a high risk of response bias with active and engaged users more likely to respond and given our estimated response rate of less than 5%, response bias may create the false appearance of a predominately white

membership. The low response rate is a significant limitation and is common among survey-based studies. Future studies delineating specific demographics of these OSGs may yield different results. Additional research on factors associated with engagement level is also necessary.

Conclusion

There may be socioeconomic disparities in participation in the largest HNC OSGs with most members self-identifying as white and reporting high income and education levels. Users of HNC OSGs are highly engaged and frequent users who endorse emotional and educational benefits from membership. Otolaryngologists should consider incorporating HNC OSG as a possible supplemental resource in the multidisciplinary care needed for HNC patients.

Author Contributions

Benjamin Tam, survey development, data analysis, manuscript writing, revision, and approval; **Matthew Lin**, survey development, data analysis, manuscript writing, revision, and approval; **Carlos Castellanos**, survey development, manuscript writing, revision, and approval; **Ruben Ulloa**, survey development, manuscript writing, revision, and approval; **Niels Kokot**, conception and design of work, interpretation of data, revision, and approval; **Kevin Hur**, conception and design of work, interpretation of data, revision, and approval.


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