

# Concerns and Needs of Patients With Head and Neck Cancer in the COVID-19 Era

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## Abstract

**Objective.** To evaluate the concerns and needs of patients and survivors of head and neck cancer (HNC) in the COVID-19 era.

**Study Design.** Prospective cross-sectional survey.

**Setting.** Contact lists of 5 North American HNC advocacy groups.

**Methods.** A 14-question survey was distributed to the contact lists of 5 HNC advocacy groups evaluating patient and survivor needs and concerns related to their cancer care and COVID-19.

**Results.** There were 171 respondents, with 75% in the post-treatment period. The most common concern was contraction of COVID-19 (49%). More patients in active treatment preferred in-person visits than those in the early ( $\leq 5$  years) and late ( $> 5$ ) survivorship period (72% vs 61% vs 40%,  $P < .001$ ). A higher percentage of late survivors preferred virtual visits (38% vs 28%,  $P = .001$ ). In total, 91 (53.2%) respondents sought emotional support outside of immediate family and friends. This included cancer support groups (36.2%), the medical team (29.7%), and other sources outside of these (34.1%), including faith-based organizations and online communities. A higher proportion of women than men (62% vs 41%,  $P = .001$ ) were seeking emotional support outside of immediate family and friends.

**Conclusions.** During the early stages of the COVID-19 pandemic, patients with HNC who were actively undergoing treatment had increased need for support resources and preferred in-person provider visits. Alternatively, a higher percentage of patients  $> 5$  years from treatment preferred virtual visits. Emotional support outside of family and friends was sought out by a majority of respondents. Further research is needed to determine what support and educational resources are needed to best aid these various populations.

## Keywords

COVID-19, head and neck cancer support

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Coronavirus disease 2019 (COVID-19) was announced as a global pandemic on March 11, 2020.<sup>1</sup> Since then, COVID-19 has imposed enormous psychosocial, financial, and health constraints on the global population. In fact, the American Cancer Society (ACS) demonstrated that 50% of patients with cancer had their health care affected by the pandemic, with 27% in active treatment reporting a delay of care secondary to the pandemic.<sup>2</sup> Patients with head and neck cancer (HNC) may be particularly vulnerable to these effects, given their associated chronic disease burden, physical duress, and increased risk of psychosocial distress.<sup>3,4</sup>

The management of patients with HNC generally involves multimodality treatment and necessitates a close interplay with many members of the multidisciplinary team. In addition,

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when compared with cancers of other regions, the unique anatomic location of HNC can greatly affect a patient's ability to speak, swallow, and eat and requires multiple visits to rehabilitate these important functions in the posttreatment period. As a result, the collision of COVID-19 and cancer care has created numerous logistical challenges for patients with HNC. The social distancing restrictions of COVID-19 and the impact on health care, including delays in treatment and cancellations of routine clinic visits, may also affect patients with HNC and have long-lasting consequences on psychosocial and physical health.<sup>5-8</sup> Yet, these precautionary measures may be especially prudent to follow as providers may be more at risk for infection and patients may be more at risk of severe sequelae from COVID-19.

HNC advocacy groups have played an instrumental role in providing support for patients with HNC.<sup>9</sup> These organizations, though each with its own focus, collectively serve to raise awareness regarding prevention, detection, and treatment of HNC. They also support research in HNC and offer needed aid for patients with HNC through promotion of emotional and physical health as well as provision of financial assistance. For example, the HNC Living Foundation offers individual grants to fund approved expenses such as copays and travel costs. The Head and Neck Cancer Alliance (HNCA) similarly offers gift cards to pay for gas to travel to appointments. With the COVID-19 pandemic, these groups have adapted in providing a variety of support platforms, with an emphasis on virtual care and correspondence. Previous work has demonstrated the role of these advocacy groups in promptly responding to the increased needs of patients with HNC during the COVID-19 era, with directed efforts at providing dependable information through articles, webinars, and podcasts and for specific HNC populations such as those with tracheostomy or laryngectomy.<sup>9-12</sup> However, recognizable needs can differ at an individual patient level based on where one is within the continuum of care. A newly diagnosed patient versus one in the posttreatment survivorship period may have different concerns and unmet needs during this COVID-19 era.

In an effort to ensure that the work of advocacy organizations is most supportive of patients with HNC, we assessed the needs and concerns of patients, survivors and caregivers. The secondary objective of this study is to identify methods through which patients with HNC derive psychosocial, physical, and emotional support, to identify gaps that may be filled by different support organizations.

## Methods

After Institutional Research Board approval was obtained from Indiana University (Pro 2005819510A002), an invitation to complete a 14-question online survey was administered to contact email mailing lists and/or social media followers of 5 well-known North American HNC advocacy groups (HNCA, HNC Living Foundation, SPOHNC [Support for People With Oral and Head and Neck Cancer], and the THANC Foundation) through social media postings

(ie, Facebook), online community forums (ie, Inspire and HNCA), and email newsletters and during SPOHNC support group meetings. This was sent on July 17, 2020, at a time during which protective personal equipment was still in short stock and COVID-19 vaccinations were not yet fully developed and implemented. Our patient cohort included anyone who responded to the request asking for participation in our study via completion of the 14-question online survey. Each advocacy organization sent out a standardized request for participation stating that the survey was a part of a multiorganizational study to describe the concerns and needs of the respondents during COVID-19. No compensation, financial or otherwise, was offered or provided for participation in the study. Since the survey was voluntary, completion indicated a willingness to participate. The following inclusion criteria were used: a personal history of HNC or being a caregiver of a patient with HNC, the ability to complete a web-based survey, and patient age  $\geq 18$  years. If a patient was unable to complete the web-based survey him- or herself, a caregiver or social worker was allowed to fill out the survey on behalf of the patient. The 14-question survey obtained basic demographic and clinical information of the responder and characterized patient-specific concerns (Supplemental Table S1, available online). The option for free-text responses allowed for elucidation of subjective patient-level concerns. Survey outcomes were stored in a password-protected REDCap data center to ensure privacy of participants. All survey responses were collected 1 month from the initial survey invitation.

## Data Reporting and Statistical Analysis

Survey data were qualitatively and statistically interpreted to describe the impact of COVID-19 on patient concerns and needs. Categorical variables were summarized by frequency and percentage. Analyzed variables included demographic variables (age, sex, and race), region, survey responder, and treatment. Age was split into 4 categories: <40 years, 40 to 55 years, 56 to 70 years, and >70 years. Four regions were defined: Northeast (ME, NH, CT, RI, MA, NY, NJ, PA, VT, MD, DE; Washington, DC), South (WV, VA, NC, SC, KY, TN, GA, FL, AL, MS, AR, LA, TX, OK), Midwest (OH, IN, IL, MI, MO, KN, IA, WI, MN, ND, SD, NE), and West (MT, WY, CO, NM, ID, UT, AZ, WA, OR, NV, CA, AK, HI). The status of the survey responder was defined as a patient undergoing active treatment, a caregiver of a patient speaking on behalf of the patient, or a patient in the survivorship period (<2, 2-5, or >5 years from the end of treatment). Pearson's chi-square analysis was performed to delineate differences in survey responses based on demographic and clinical characteristics. Due to limitations in statistical power based on responses, a multivariate analysis could not be performed. Based on a regression model with a small effect size at 0.02, a probability level at 0.05, and a desired statistical power level of 0.80, the minimum required sample size is 193 for 2 predictors (sex) and 242 for 4 predictors (age, region). A  $P$  value <.05 was considered statistically significant. All statistical analysis was performed with SPSS version 25.0 (IBM Corporation).

## Results

Between July 17, 2020, and August 16, 2020, 171 individuals responded to the survey (male,  $n = 58$ , 33.9%; Caucasian,  $n = 150$ , 87.7%) (see **Table 1**). Given that the route of administration was via social media posts and email mailing lists, a response rate could not be determined as it was not possible to establish the number of individuals who viewed the survey during the study period (some individuals may not have accessed their social media accounts or email addresses used during the study window). However, we estimated 13,505 potential respondents based on the collective number of each organization's followers on social media. Of the respondents, most were between 56 and 70 years old ( $n = 88$ , 51.5%), followed by  $>70$  years old ( $n = 32$ , 18.7%). The majority of responders were HNC survivors in the posttreatment period ( $n = 128$ , 74.9%), followed by those in active treatment ( $n = 25$ , 14.6%) and caregivers ( $n = 12$ , 7.0%).

The survey aimed to first identify the largest concern of patients with HNC (**Table 2**). Survey responders were most concerned about the increased risk of contracting COVID-19 infection due to their general medical condition or cancer ( $n = 83$ , 48.5%), followed by delays in care due to COVID-19 ( $n = 26$ , 15.2%) and ability to afford medication and medical supplies/care ( $n = 14$ , 8.2%), food and daily essentials ( $n = 4$ , 2.3%), or other nonmedical expenses ( $n = 7$ , 4.1%). Many responders also expressed financial support as an unaddressed need, with multiple free-text answers asking for help with hospital bills, utilities and food, tracheostomy supplies, mortgage payments, and medical disability (Supplemental Table S2, available online).

Respondents were asked where they may seek out emotional support. In total, 91 (53.2%) respondents sought emotional support outside of immediate family and friends. Of these, support was derived from cancer support groups ( $n = 33$ , 36.2%), the medical team ( $n = 27$ , 29.7%), or other sources outside of these ( $n = 31$ , 34%). Free-text responses characterizing other sources of emotional support demonstrated many responders finding support from faith-based organizations (church family, religion, faith), online communities (support group online, social media, Twitter), other health care practitioners (therapists, practitioners), and personal volunteer efforts. Additionally, respondents were asked where they sought out information regarding HNC care during the COVID-19 pandemic. This included the medical team ( $n = 84$ , 49.1%), the hospital system ( $n = 11$ , 6.4%), social media ( $n = 33$ , 19.3%), online blogs and chat rooms ( $n = 12$ , 7.0%), and other ( $n = 25$ , 14.6%), such as various medical websites and news sources (Supplemental Table S1, available online).

Last, the survey assessed preferred alterations of care to accommodate risk of COVID-19 transmission as well as resources that may be most useful. More than half of survey respondents (56.7%) preferred to keep in-person visits without delay, whereas 28.1% preferred to have a telemedicine or virtual visit. When stratified by their status in treatment, however, patients undergoing active treatment and patient

**Table 1.** Characterization of Survey Respondents.

	No. (%)
<b>Age, y</b>	
<40	17 (9.9)
40-55	28 (16.4)
56-70	88 (51.5)
>70	32 (18.7)
<b>Sex</b>	
Male	58 (33.9)
Female	106 (62.0)
<b>Race</b>	
Caucasian	150 (87.7)
African American	3 (1.8)
Hispanic/Latino of any race	7 (4.1)
Asian/Asian American	2 (1.2)
American Indian/Alaskan Native	0 (0)
Asian Indian	3 (1.8)
<b>Region</b>	
Northeast	48 (28.1)
South	39 (22.8)
Midwest	54 (31.6)
West	23 (13.5)
<b>Survey responder</b>	
Patient with head and neck cancer	25 (14.6)
Caregiver	12 (7.0)
Survivor of head and neck cancer, years from treatment	
<2	64 (37.4)
2-5	24 (14.0)
>5	40 (23.4)
<b>Treatment</b>	
Surgery	121 (70.8)
Radiation	144 (84.2)
Chemotherapy	88 (51.5)
Immunotherapy	16 (9.4)
Other	8 (4.7)
<b>Tracheostomy/feeding tube status</b>	
Tracheostomy	8 (4.7)
Laryngectomy stoma	28 (16.4)
Feeding tube	26 (15.2)
I don't have a tracheostomy/stoma or feeding tube	114 (66.7)

caregivers were most likely to prefer to keep in-person visits (72% and 75%) over survivors  $\leq 5$  and  $> 5$  years after treatment (61.4% and 40%,  $P = .001$ ). Yet, HNC survivors  $> 5$  years from treatment had the highest proportion of respondents preferring telemedicine visits (37.5%) over patients  $\leq 5$  years from treatment (26.1%) and patients in active treatment (28.0%,  $P = .001$ ). In total, 56.7% responders found educational materials on HNC and COVID-19 to be the most useful, followed by information regarding financial support (19.3%) and emotional support groups (14.0%).

Univariate analysis demonstrated variations in survey responses based on sex and responder status. A higher proportion of women versus men (62% vs 41%,  $P = .001$ ) were

**Table 2.** Characterization of COVID-19–Related Concerns.

Survey question	No. (%)
<b>Which of the following choices is MOST concerning to you?</b>	
Delays in my care due to precautions related to COVID-19	26 (15.2)
The risk of contracting COVID-19 by going to a health care facility	19 (11.1)
My increased risk of contracting COVID-19 due to my cancer or general medical condition	83 (48.5)
My inability to get medications and/or medical supplies	5 (2.9)
My inability to get food or other daily essentials	4 (2.3)
My inability to get emotional or psychological support	4 (2.3)
My inability to pay for medical care	9 (5.3)
My inability to pay for nonmedical expenses	7 (4.1)
Other	8 (4.7)
<b>During the current COVID-19 pandemic, how would you like your doctor's office visits addressed?</b>	
Keep in-person visits	97 (56.7)
Delay your in-person outpatient visit by 6 weeks	10 (5.8)
Have a telemedicine/virtual visit	48 (28.1)
I am no longer going to doctor's visits	10 (5.8)
<b>Other than your immediate family and friends, where do you go for emotional support?</b>	
My medical team	27 (15.8)
A cancer support group organized by your hospital	12 (7.0)
A local cancer support group (not hospital affiliated)	13 (7.6)
A national cancer support group	8 (4.7)
Other	31 (18.1)
I don't seek emotional support	74 (43.3)
<b>Where do you go for information related to COVID-19 and head and neck cancer?</b>	
My medical team	84 (49.1)
My hospital system	11 (6.4)
Social media	33 (19.3)
On-line blogs or chat rooms	12 (7.0)
Other	25 (14.6)
<b>Which of the following resources would you find MOST useful?</b>	
Educational materials related to COVID-19	10 (5.8)
Educational materials on head and neck cancer and COVID-19	97 (56.7)
Links to financial support	33 (19.3)
Support groups aimed at providing emotional support	24 (14.0)
<b>Are there any resources you need but have not been able to find?</b>	
Yes	26 (15.2)
No	139 (81.3)

seeking emotional support outside of immediate family and friends. Additionally, those requiring outside emotional support more often depended on other outside resources for information, over those not requiring emotional support (20% vs 10%,  $P = .049$ ). Last, patients undergoing active treatment more frequently required additional resources not readily available to them (40%) over patients in the survivorship period (12.5%,  $P = .001$ ). No other differences were seen by demographic variables such as age, financial status, or education.

## Discussion

Over the past year, COVID-19 has had a profound impact on our society. Here we demonstrate that there is a wide spectrum of needs among patients with HNC, and the specifics of

their needs depend greatly on demographics and where patients fall on the continuum of care. We identified the major concerns of patients with HNC during this COVID-19 era, as well as preferred alterations to care and areas of support that were lacking (psychosocial and financial). Our findings similarly aligned with a survey distributed by the ACS to a national representative group of patients with cancer, which highlighted challenges such as delays in health care services and financial uncertainty to afford health care, medical supplies, as well as basic household necessities.<sup>13</sup> Results of our study may offer insight regarding the experiences of patients with HNC that will allow for targeted efforts on behalf of advocacy organizations and the health care team alike to alleviate these concerns.

## Alterations to Care

Many aspects of care have been altered, such as the increased use of virtual telehealth visits and a reduction of in-office procedures, including fiberoptic laryngoscopy. While the majority of patients with HNC preferred to keep in-person visits, this depended on where they were in the continuum of care. For individuals in active treatment, 72% still preferred an in-person encounter, as compared with 61% of those  $\leq 5$  years posttreatment and 40% of those  $> 5$  years from treatment. A higher percentage of those in late survivorship ( $> 5$  years from treatment) preferred a virtual encounter than those in active treatment. This supports that patients far out from treatment may be willing to undergo a less rigorous assessment in an effort to minimize their risk for COVID-19 infection. While a transition to virtual visits effectively reduces the risk of COVID-19 transmission, this may lead to enhanced uncertainty for patients and caregivers; it also may be less accessible to certain underserved populations.<sup>14-16</sup>

## Psychosocial Impact

Fear of infection and mandates for social distancing have resulted in increased isolation and psychological strain on many. This is evident by the 56.7% of our respondents seeking emotional support outside of immediate family and friends. Likewise, the aforementioned ACS survey found that 48% of respondents reported declining emotional well-being by their experiences as a cancer survivor in the COVID-19 era.<sup>13</sup> Due to the nature of COVID-19 transmission, these individuals are at increased risk for delays in care, often leading to anxiety, confusion, and, in some cases, progression of their disease. For those who may benefit most from advocacy and support groups, respondents seeking information from outside sources separate from the medical team were more likely to pursue outside emotional support. This may emphasize that emotional support may be an overlooked concern. Given the social distancing challenges at the time, HNC advocacy organizations can serve as valuable support systems for patients. The role of these groups may be especially noted, as 36.2% of respondents seeking outside emotional support have turned toward these advocacy organizations.

The growing field of telemedicine may provide a platform for solutions to combat growing unmet needs for patients with HNC. For example, increased virtual communication may supplant the less frequent in-person contact with medical providers. This may broaden to other areas by incorporating aspects such as palliative care, social work, psycho-oncologic counseling, and other disciplines in an effort to leverage hospital system resources and community treatment and support. In fact, multiple institutions have found outreach telehealth counseling services to be feasible and beneficial for cancer patients.<sup>17-19</sup>

## Financial Concerns

COVID-19 and social distancing protocols have imparted a large economic burden of which self-employed and lower-wage individuals may be most affected. This may be

especially felt by patients with HNC, who have been traditionally more disadvantaged. Specifically, patients with HNC are often of lower socioeconomic status, publicly insured, less educated, and of lower general health, and they are more likely to experience severe financial toxicity compared to the general population and other patients with cancer.<sup>20-23</sup> Our results have demonstrated that financial concerns have persisted, given the 14.6% of patients expressing concern regarding financial distress, the 19.3% finding links to financial support most useful, and the additional abundance of free-text responses regarding need for financial help. In the aforementioned ACS survey, patients of other cancer subsites had the same sentiment, with 30% of responders having concerns about their ability to afford care and 46% reporting changes to their financial situations since the COVID-19 pandemic.<sup>13</sup>

The resulting health repercussions from financial concerns experienced by patients with HNC are multifaceted. Inability to afford medical care coupled with the evolving risk-stratified treatment paradigm set in place during this COVID-19 can make routine care less accessible. Additionally, financial concerns may be more pronounced, such as affording basic life necessities, including rent/mortgage, utilities, and groceries. In an already financially vulnerable population, efforts to identify and provide resources to lessen this financial burden may be especially relevant during this era.<sup>23</sup> It is clear that many of the advocacy organizations' pursuits in alleviating these concerns have focused on addressing this (gas card provided by HNCA, grants given by the HNC Living Foundation).

## Limitations

There are many limitations of our study. First, 87% of our respondents characterized themselves as Caucasian and 62% were female, which is not representative of the general HNC population. Moreover, as this was a voluntary survey administered through HNC support and advocacy group contacts and social media followers, selection bias was likely for not only those on the lists but also those who completed the survey. For example, lack of access to the internet or an electronic device on which to fill out the survey may have precluded participation of a number of potential respondents. Participants who are usually not well represented, such as those of minority race/ethnicity, the elderly, and those of low socioeconomic status, may be even more affected by the digital divide, which may be exacerbated in the current times.<sup>24</sup>

Our estimation of 13,505 potential participants may be an overestimation, because the survey was disseminated via social media postings and email lists; also, many followers may not have been aware of the survey, depending on the frequency that they check their social media newsfeeds or email accounts. Additionally, our survey divided responders based on different time points of cancer care treatment (ie, undergoing active treatment vs in the survivorship period). As the degree of symptomatic sequelae from disease burden and following treatment may differ, stratification based on symptom burden may be explored in future studies to assess how this may influence the concerns and needs of patients with HNC.

Last, the survey was created and distributed in a rapidly changing landscape during the COVID-19 pandemic, and there is no prior analogous study before COVID-19 to use as a control to evaluate the specific impact of the pandemic on these responses. For example, the time point during the COVID-19 pandemic during which our survey was administered may affect the degree of concern regarding contracting COVID-19 versus cancer care. In the future, a follow-up survey may allow for further characterization of concerns and needs as they evolved throughout the pandemic.

## Conclusions

Patients and survivors of HNC have significant concerns and unmet needs with regard to the impact of COVID-19 on their health and cancer care, with those receiving active treatment being disproportionately affected. While contraction of COVID-19 was the greatest concern of surveyed patients with HNC, a higher percentage of patients in active treatment and in the first 5 years of survivorship still preferred an in-person visit. Further research is needed to determine what support and educational resources are needed to best aid these various populations.

## Author Contributions

**Flora Yan**, conception and design, analysis and interpretation of data, drafting the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Erika Rauscher**, conception and design, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Amanda Hollinger**, conception and design, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Mary Ann Caputo**, conception and design, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **John Ready**, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Shaun A. Nguyen**, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Carole Fakhry**, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Cherie-Ann O. Nathan**, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Chris Leonardis**, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Danielle Yearout**, conception and design, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Terry A. Day**, analysis and interpretation of data, critical revision of the article, final approval of the version to be published, agreement to be accountable for all aspects of the work; **Michael G. Moore**, conception and design, critical revision of the article, final approval of the version

to be published, agreement to be accountable for all aspects of the work.

## Disclosures

**Competing interests:** Erika Rauscher receives salary support for her executive director position of the THANC Foundation. Amanda Hollinger receives salary support for her position as executive director of the HNCA. Mary Ann Caputo receives salary support as the executive director of SPOHNC. John Ready receives salary support as the executive director of the Foundation for Voice Restoration. Carole Fakhry is a volunteer board member of the HNCA. Cherie-Ann O. Nathan is a volunteer board member of the HNCA. Chris Leonardis receives salary support for employment with SPOHNC. Danielle Yearout receives salary support as the executive director of the HNCLF. Terry A. Day is a volunteer board member of the HNCA. Michael G. Moore is a volunteer board member of the HNCA.

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## Supplemental Material

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