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TITLE PAGE:

Title:

Head and Neck Cancer and Social Media: The Patient Experience and Cancer Survivorship

Running Title: Social media and cancer survivorship

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Social media, cancer survivorship

LEVEL OF EVIDENCE

Level 4 - Non-randomized descriptive study

FINANCIAL DISCLOSURE

None.

ABSTRACT:

Objectives:

To characterize the head and neck cancer patients' lived experiences with survivorship through Instagram and examine opportunities for health professionals to provide support and outreach specifically targeting these needs.

Methods

We analyzed key head and neck cancer related hashtags by querying medical and layman terminology. The top English-language posts for #headandneckcancer underwent further content examination using thematic analysis based in grounded theory for categorization for user engagement (determined by likes and comments), type of content, and category of account which created the post. Of the survivorship posts by patients, the content of posts in top user accounts was further analyzed.

Results

There were 11,600 Instagram posts on #headandneckcancer; 1,300 posts on #headandneckcancerawareness; 1,100 posts on #headandneckcancersurvivor, and several thousand posts for additional layman terms. The majority of posts were from patients (65%), with few from head and neck surgeons or medical organizations (26%). User engagement was primarily by non-medical accounts (95%). Posts by patients discussed medical appointments and treatments (81%), managing treatment effects and symptoms (66%), and cancer screening and

prevention (23%). Specific concerns include fatigue (53%), post-surgical cosmetic appearance (27%), and weight and nutrition (34%).

Conclusions

Our study suggests that Instagram accounts can be intimate records of the patient experience, and gaining a better understanding of the daily experience of survivorship may be critical for head and neck surgeons and other oncology providers to provide truly comprehensive cancer care.

INTRODUCTION

As cancer treatments have improved over time, increased attention has been given to issues of symptom management and longer-term survivorship considerations.[1,2] The most inclusive definition of "survivorship" provided by the National Coalition for Cancer Survivorship and the Office of Cancer Survivorship and the National Cancer Institute includes both the patient and their families who are "living with, through and beyond a cancer diagnosis."[3,4]

Head and neck cancer (HNC) treatment and survivorship presents many uniquely difficult and socially isolating challenges.[5-8] Difficulties with nutrition and eating, changes in speech and articulation, surgical scarring in highly visible and cosmetically sensitive areas, and social and financial stressors all contribute to survivorship experience. Some patients may have additional risk factors such as alcohol and tobacco use which can be addressed.

Head and neck surgeons, radiation oncologists, medical oncologists, and other health care professionals involved in a patient's oncologic connect with patients for brief clinic visits, once every few weeks or months initially, to every few years in the longer term. The lived experience

of patient survivorship, however, includes every single day between these intermittent visits as well – a time which is not as easily characterized or studied.

With the advent and rise of social media, these lived patient experiences have gradually become more available and gained greater visibility. Patients and caregivers have increasingly turned to social media to document their cancer survivorship journey, seek social support and community, and obtain medical information.[9-14] Social media platforms have the potential to offer a more intimate, nuanced view of the day-to-day of cancer of survivorship.

Instagram is the third most commonly used social media network behind only Facebook and YouTube and has emerged as a popular platform for building online communities through sharing photos and short videos.[15] This media-centric model has led to the increased popularity of Instagram by cancer survivors, with previous research showing substantial utilization by breast, prostate, and skin cancer survivors.[16-20]

To date, however, there is still very limited understanding of how HNC patients utilize social media, including Instagram, for their documentation of their daily lived experiences with survivorship. No previous research was addressing this deficiency was identified. As such, our study's objective was to better characterize the content and user engagement on Instagram related to HNC patient experiences and survivorship.

We hypothesized that analyzing Instagram posts by patients will provide greater insight into the daily patient experience of survivorship, offering both opportunities for further research and for health professionals to provide support, education, and outreach on Instagram specifically targeting these needs.

MATERIALS AND METHODS

Study Design

We performed a descriptive study using both qualitative and quantitative methods. We analyzed the publicly-available, English-language hashtags by querying HNC-related topics from Instagram (www.instagram.com, Facebook, Menlo Park, California, USA). With review by an otolaryngology-specific academic librarian, we developed a systematic search methodology for hashtags and utilized grounded theory-based qualitative thematic analysis for post content. Posts are images or videos with captions posted by users on a social media site. Data was obtained September 2019 to May 2020.

Hashtag Prevalence

We queried both medical and lay person terminology for HNC content via hashtag analysis. Hashtags are words or phrases used commonly in social media to label content, such as #cancer or #cancersurvivor. The queries we used were based on American Joint Committee on Cancer 8th Edition HNC staging categories, such as #oralcavitycancer, #oralcancer, #oropharyngealcancer, #nasopharyngealcancer, #laryngealcancer, #supraglotticcancer, #salivaryglandcancer. Within each category, recognized anatomic subsites were also included, such as lip, tongue, floor of mouth, gingiva, buccal mucosa, retromolar trigone, and hard palate for oral cavity. For each anatomic site, the lay person equivalent was also included (e.g. #nosecancer for #nasopharyngealcancer or #nasopharynxcancer, #gumcancer for gingiva). To account for more specific pathology-based diagnoses, the World Health Organization Classification of Tumors was used to query specific HNC pathological types, such as #squamouscellcarcinoma.[21]

The total number of posts using each hashtag was recorded. When tags with only minor grammatical differences were encountered, such as #headandneckcancer, #headandneckcancers, #headneckcancer, and #headneckcancers, the hashtag with the larger number of posts was

recorded. Hashtags which resulted in less than 200 posts were excluded. Hashtags with more than half of the top 10 posts referring to an unrelated topic were excluded (e.g. #earcancer referring colloquially to music tastes).

Types of Accounts Active with #Headandneckcancer

We then analyzed the type of account which created the top 200 posts for #headandneckcancer. The accounts were categorized as belonging to a head and neck surgeon/otolaryngologist, other health professionals (e.g. speech-language pathologist, dermatologists, oral surgeons, dentists), patients, or other. Accounts which were unable to be identified or were assigned as "private with content withheld" were excluded.

We subsequently focused in on a further subset and analyzed the "top posts" for #headandneckcancer. "Top posts" on Instagram are the first posts to be featured as results for any given hashtag and are determined by Instagram's internal algorithm that ranks post popularity by user engagement. This internal algorithm also determines granularity of the number of "hits" on a hashtag.

We analyzed the user engagement (defined as "likes" or "comments") for #headandneckcancer posts to determine what type of accounts (and thus individuals or groups) interact with HNC posts. The accounts which commented on the selected top posts were then categorized as belonging to head and neck surgeons, other health professionals, the general public (i.e. accounts from users who do not appear to work in the healthcare field), and other.

Thematic Analysis of Post Content by Patients

A preliminary qualitative thematic analysis evaluation was undertaken using methodology based in grounded theory via an iterative approach. Grounded theory is a methodology commonly used

in the social sciences for qualitative research that is "grounded in data systematically gathered and analyzed." [22]

There was an initial content analysis review of 25 posts to draw and code themes via an inductive approach. Using this open coding analysis, specific categories such as were refined. Then, a subsequent iterative review of another 25 posts was performed to verify saturation of the coding categories, such as "social support." Then the 200 posts in the paper's dataset were analyzed using the code book. The formal content analysis was then performed on the top 200 publicly available "top posts" for quantitative analysis. Based on the thematic analysis, each post by patients was quantitatively categorized as primarily discussing a medical appointment or procedure, a cancer milestone, social support, or cancer screening and prevention. The classification of the 200 posts was then repeated for verification for test-retest reliability was performed using Cohen's Kappa.

To explore specific patient concerns and challenges with survivorship, the patient-created posts from the top 200 posts for #headandneckcancer, #thyroidcancer, #oralcancer were separately analyzed. These three hashtags were selected since they were the most popular hashtags identified and had the possibility of representing different unique subpopulations. #basalcellcarcinoma was not used due to the inclusion of possible non-head and neck locations.

A similar iterative post based in grounded theory as discussed previously was utilized in order to systematically gather qualitative information. The posts were categorized as discussing issues with pain, speech changes, surgical scars, facial and neck deformities, weight and nutrition challenges, fatigue, social stress, financial challenges, and psychological stress.

How Often Cancer Patients Post Regarding Their Diagnosis

Then, to determine how often HNC patients post about their cancer diagnosis and symptoms, 50 patient accounts from the top 50 patient-created posts for #headandneck were examined further. The most recent 20 posts for each account were examined to determine if it contained content directly related to cancer treatment or symptoms, and the average percentage of posts was determined.

Statistical Analysis

The statistics and data analysis were performed using Microsoft Excel 2017 (Microsoft Corporation, Redmond, Washington, USA) and GraphPad Prism (GraphPad Software Incorporated, Irvine, California, USA).

RESULTS

Popularity of Head and Neck Cancer Hashtags

A total of 11,600 posts were tagged #headandneckcancer (Table 1). The most popular type of head and neck cancer was #thyroidcancer at 115,000, #oralcancer at 22,500, and #basalcellcarcinoma at 13,400 (with some overlap with non-head and neck regions). Additional laymen hashtags such as #nosecancer, #neckcancer, and #tonguecancer also returned several hundred posts (345, 836, and 2100 respectively). The most common pathology-based cancer diagnoses were #basalcellcarcinoma with 13,400 posts, #squamouscellcarcinoma with 10,800 posts, and #ameloblastoma with 2,500 posts. A notable subset which was not further analyzed due to the significant cross-over with non-head and neck regions were the cutaneous malignancies such as melanoma or basal cell carcinomas.

Accounts Involved

Of the top 200 posts tagged #headandneckcancer, 128 posts (64%) were created by accounts of patients and/or their families (Figure 1A). Only 14 (7%) were posted by head and neck surgeons or other otolaryngologists, and 38 (19%) were posted by other health care professionals (e.g. oral surgeons, dentists, speech-language pathologists, etc.). Most of the remaining 10% were posted by medical content pages which featured different diseases.

The types of accounts which engaged with the top posts tagged #headandneckcancer were primarily from the general public (95%), which were categorized as personal accounts of individuals who did not appear to work in healthcare (Figure 1B). Only 4% of engagement was by head and neck surgeons or other health care professionals.

Content of Patient Posts
Of the 128 "top posts" made by patients, 104 posts (81%) referenced medical appointments or treatments they recently underwent or have planned (Table 2). 85 posts (66%) discussed managing treatment-related symptoms and side effects such as mucositis, weight loss, fatigue, etc. 24 posts (19%) mentioned their social support networks, and 44 (34%) discussed a cancer milestone (e.g. 5 years cancer-free). 29 posts (23%) touched on the importance of cancer screening, early symptoms, or cancer prevention (e.g. wearing sunscreen). Cohen's kappa for was 0.86 on average, indicating very high agreement.

Patient Survivorship Challenges
The three most popular hashtags #headandneckcancer, #thyroidcancer, and #oral cancer were independently analyzed for specific patient experiences and challenges of survivorship. Of the 200 top posts for each, 128 were posted by patients for #headandneckcancer, 144 for #thyroidcance, and 61 for #oralcancer (Figure 2). 112 posts (88%) of #headandneckcancer tagged patient posts, 121 (84%) of #thyroidcancer, and 43 (70%) of #oralcancer posts discussed at least one cancer survivorship challenge or concern.

Concerns which were mentioned more commonly included general tiredness and fatigue (53% for both) (Figure 2). The care of surgical scars was mentioned in 34 posts (27%) for #headandneckcancer, 44 posts (31%) for #thyroidcancer, and none for #oralcancer. Other cosmetic concerns included facial and neck deformities in 25 posts (19%) which related to "overly thin" necks post neck dissection, radiation fibrosis, and other skin discoloration which seen in the #headandneck tagged population at 19% and 3% for #oralcancer. Difficulty with weight and nutrition were prominent in all groups at 44 posts (34%) for #headandneckcancer, 61 posts (42%) for #thyroidcancer, and 22 posts (36%) for thyroid cancer. 16 posts (12%) and 29 posts (20%) respectively described social or financial hardships directly or indirectly caused by their cancer diagnosis and treatment. Psychological stress or mental health challenges were mentioned in 62 posts (48%) of #headandneckcancer patient posts and 104 (72%) of #thyroidcancer posts.

How Often Cancer Patients Post Regarding Their Diagnosis
On average, 5.4 out of 20 (27%) of the most recent posts on an HNC patient's Instagram account discussed cancer diagnosis, treatment, or symptoms. Standard deviation was high at 5.64 with some accounts posting predominantly on a patient's cancer course and other's only incidentally as part of an Instagram account with a different primary focus (e.g. paintings done by the patient).

DISCUSSION

With the rise of social media, cancer patients have increasingly turned to online platforms such as Instagram for community, medical information, and outreach. Analyzing Instagram posts by patients may thus give greater insight into the daily head and neck cancer patients' experience of

survivorship and explore opportunities for health professionals to provide more tailored support and outreach specifically targeting these needs.

Our study examined the utilization of Instagram by HNC patients and their documented survivorship experiences on the platform. HNC posts had thousands to tens of thousands of Instagram posts with high user engagement of "likes" and "comments." Our study showed that the majority of the posts (64%) were created by patients, and the vast majority of engagement with these posts (95%) was by the general public. Our studied also suggested that patients with HNC frequently posted about their cancer diagnosis, with potentially a quarter of all posts on their accounts relating to cancer-related issues.

Of these patient-created posts, the majority (81%) discussed the patients' cancer treatment course, a finding also seen in previous studies on social media posts by cancer survivors.[23] Many of these posts also describe the challenges managing treatment effects and symptoms and other survivorship concerns (66%), the most common of which were fatigue (53%), psychological stress (48%), weight and nutrition (34%), and surgical scars (27%).

There were some differences noted between patient concerns in the subpopulations using the hashtags #thyroidcancer, #oralcancer, and #headandneckcancer. These HNC subcommunities reflect the diversity of malignancies which affect the head and neck region, and further research may be able to provide a more nuanced understanding of how their different needs are expressed on social media. The thyroid cancer population in particular is a distinct subpopulation from the more traditional HNC squamous cell carcinoma population, but we chose to include this data because we believe that it would be remiss to exclude this large population of patients who are operated on by head and neck surgeons and identify as cancer survivors. We do, however, recognize that the thyroid cancer patient population is distinctive, so we excluded this subpopulation from the primary analysis of the hashtag #headandneckcancer, and we analyzed

the thyroid data separately for Figure 2. We believe that this should remove the potential for confounding the thyroid data with the squamous cell carcinoma data while still respecting the value of the experiences of thyroid cancer patients.

However, it is notable that at least 70% of all patient posts expressed some type of challenge or difficulty the patient and his/her loved ones have faced or are preparing to face. As such, there remains significant opportunity for support and outreach via Instagram by oncology providers, including otolaryngologists. The #headandneckcancer tag has thousands of posts and tens of thousands of marks of user engagement primarily by patients and the general public, demonstrating that there is an engaged audience with interest in outreach efforts. These issues may not always be fully explored or addressed during brief clinic visits but are critical for providing truly comprehensive cancer care.

Education and outreach may be tailored to address the survivorship challenges shown in our study. Our findings and future research may present opportunities to provide care that is more targeted towards these specific needs. Although the most commonly reported patient concerns in our study, acute and chronic fatigue and psychological stress are often not fully addressed by oncology providers.[24,25] Also, head and neck surgeons may be able to address concerns on weight and nutrition with the help of dietician and speech-language pathology colleagues.

These efforts may be in the form of increased support efforts in the clinical setting or online social media campaigns and education. For example, our study showed that over a quarter of posts were regarding surgical scarring, and thus, further education on scar and wound care may be helpful. Patients and the general public have increasingly turned to online resources to obtain medical information and support, and there are already opportunities collaborate with other health care professionals on existing and new campaigns for survivorship education on social

media, such as sun protection and continued skin checks, mental health, and tobacco and alcohol cessation.

However, our study was limited in only presenting a snapshot of the current status of HNC content. We did not analyze dynamic changes in content and engagement over time. Our study also focused on Instagram and did not include additional social media sites such as Facebook or Twitter. We chose to examine Instagram because their media-centric model has shown broad appeal and substantial utilization by cancer survivors in previous research.[16-20] While Facebook is a larger social media platform than Instagram and has a higher percentage of older users (65% vs. 23% of adults in the United States over age 50), it is less image-centric than Instagram.[26-27] Twitter has a similar age distribution as Instagram but is a less popular platform and lacks the image and video-centric model which as an additional dimension of information sharing.[15, 26]

Instagram also allows for accounts to make private posts, and our study could only examine publicly available posts, thus missing individual patients' private posts to close friends and family. Additionally, since we only analyzed "top posts," it may not be a full reflection of post diversity, as less popular posts may have different content and characteristics. HNCs may have bimodal age distributions (such as for HPV-positive vs. HPV-negative squamous cell carcinoma), and the older patient population's experience may be less well-represented since they are less likely to use social media. However, colon cancer and prostate cancer also have an older distribution but still have robust communities with several hundred thousand posts.

While our study was a limited descriptive study broadly characterizing the documentation of the head and neck cancer patient experience and survivorship on Instagram. Based on our preliminary results, further research may include a larger sample size for more nuanced analysis and improved understanding of the day-to-day patient experience and needs. Future studies may

also address how social media use affects mental health for HNC patients and how effective education and outreach methods through social media may be.

Additionally, as with all social media-related content, patient privacy and the ethics of use within health care must be carefully considered in all future research and outreach efforts.

CONCLUSIONS

Our study suggests that Instagram accounts can be intimate records of the patient experience, and gaining a better understanding of the daily experience of survivorship may be critical for head and neck surgeons and other oncology providers to provide truly comprehensive cancer care.

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TABLES AND FIGURES

Table 1: Hashtags related to head and neck cancers queried for number of posts. Hashtags resulting in less than 200 posts were not included.

Figure 1: A) Types of Instagram accounts which create posts tagged #headandneckcancer. B) Type of Instagram accounts which engage in posts ("likes" or "comments") on posts tagged #headandneckcancer.

Table 2: Thematic analysis of categories of patient posts tagged #headandneckcancer.

Figure 2: Symptoms and concerns reported in posts by patients or patient families in posts tagged #headandneckcancer compared to #thyroidcancer. *Percentages may not add up to 100% as a single post may contain content from several categories.

Hashtag	Number of Posts
#thyroidcancer	115,000
#oralcancer	22,500
#basalcellcarcinoma	13,400
#headandneckcancer	11,600
#squamouscellcarcinoma	10,900
#throatcancer	7,600
#papillarythyroidcancer	3,400
#ameloblastoma	2,500
#tonguecancer	2,100
#adenoidcysticcarcinoma	1,700
#medullarythyroidcancer	672
#nasopharyngealcancer	670
#pleomorphicadenoma	569
#salivaryglandcancer	534
#nasalcancer	470
#larynxcancer	450
#lipcancer	445
#mucoepidemoidcarcinoma	410
#follicularthyroidcancer	362
#mucosalmelanoma	345
#nosecancer	344
#merkelcellcarcinoma	317
#tonsilcancer	301

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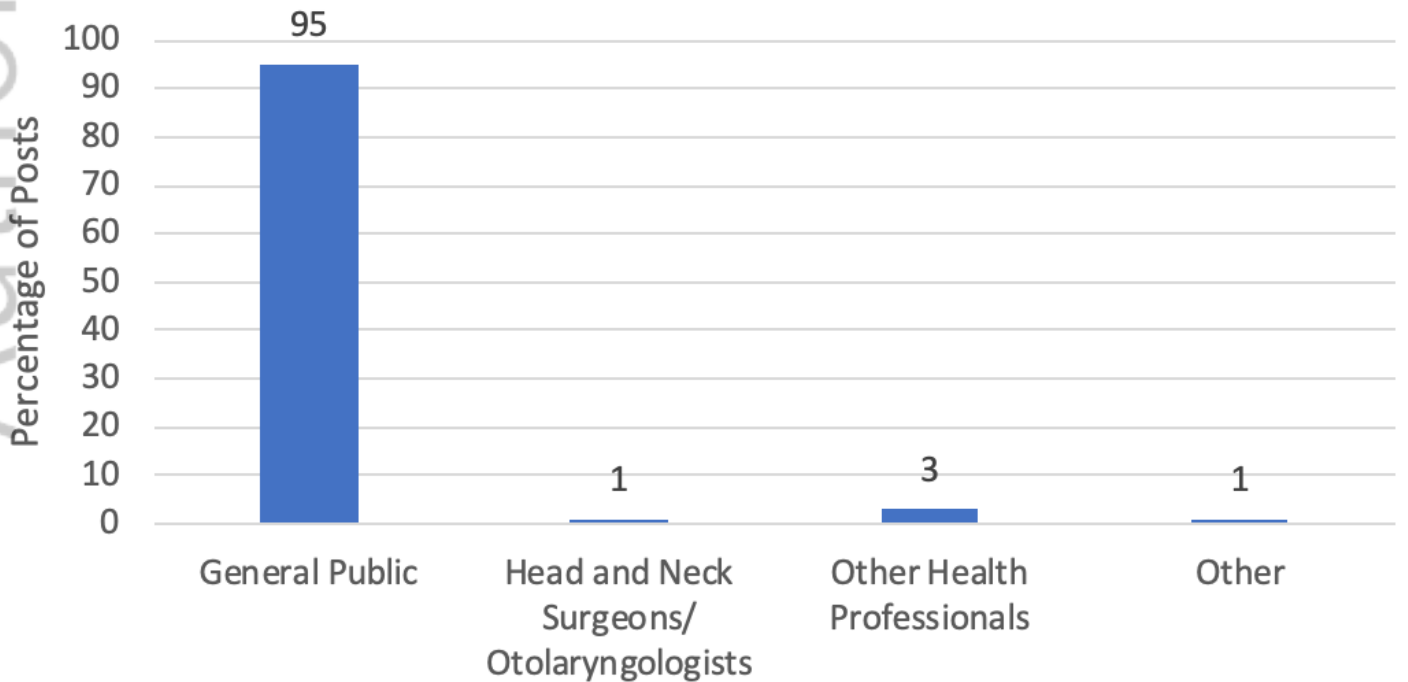| Theme	Number of Occurrences (%)	Example of Post	Cohen's kappa
Medical appointments and procedures	104 (81.3%)	"Day 5 radiation in the books. 25 more to go. Chemo/radiation tomorrow."	0.92
Managing treatment effects and symptoms	85 (66.4%)	"Today is the first day I've felt human in a long while! Eating is getting easier (would be even better if this…sore on the roof of my mouth would go away) and I haven't lost weight for the first time in like a month. Cut my fentanyl dose in half and only taking oxy at night now. Skin is dry but healed around my neck."	0.83
Social support	24 (18.8%)	"It's been a very long year and I've met many amazing people who were/are going through the same thing. I couldn't have done it without the support of my wife, family & amazing crazy…friends."	0.78
Cancer milestones	44 (34.4%)	"Second PET scan done, second NED results! Almost six months since by last treatment, and a little over 2 months from now will be my first Cancerversary. I can't believe it."	0.84
Cancer screening and prevention	29 (22.7%)	"I've now had my carcinoma removed from my nose now….I'm posting this as I really want to make people aware that if you don't protect your skin from the sun you may get skin cancer….I also used sun beds when I was younger…don't do it"	0.92

A

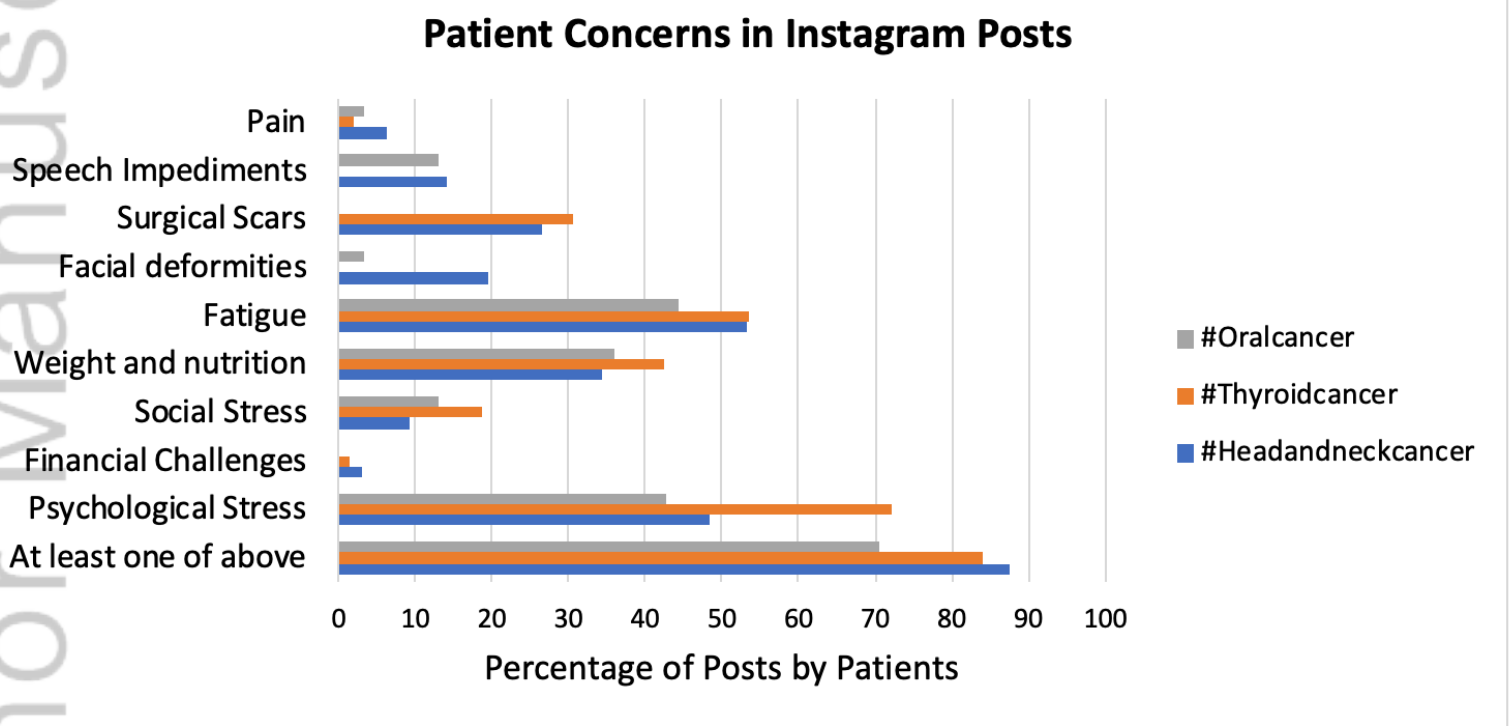**ACCOUNTS CREATING HEAD AND NECK CANCER POSTS**
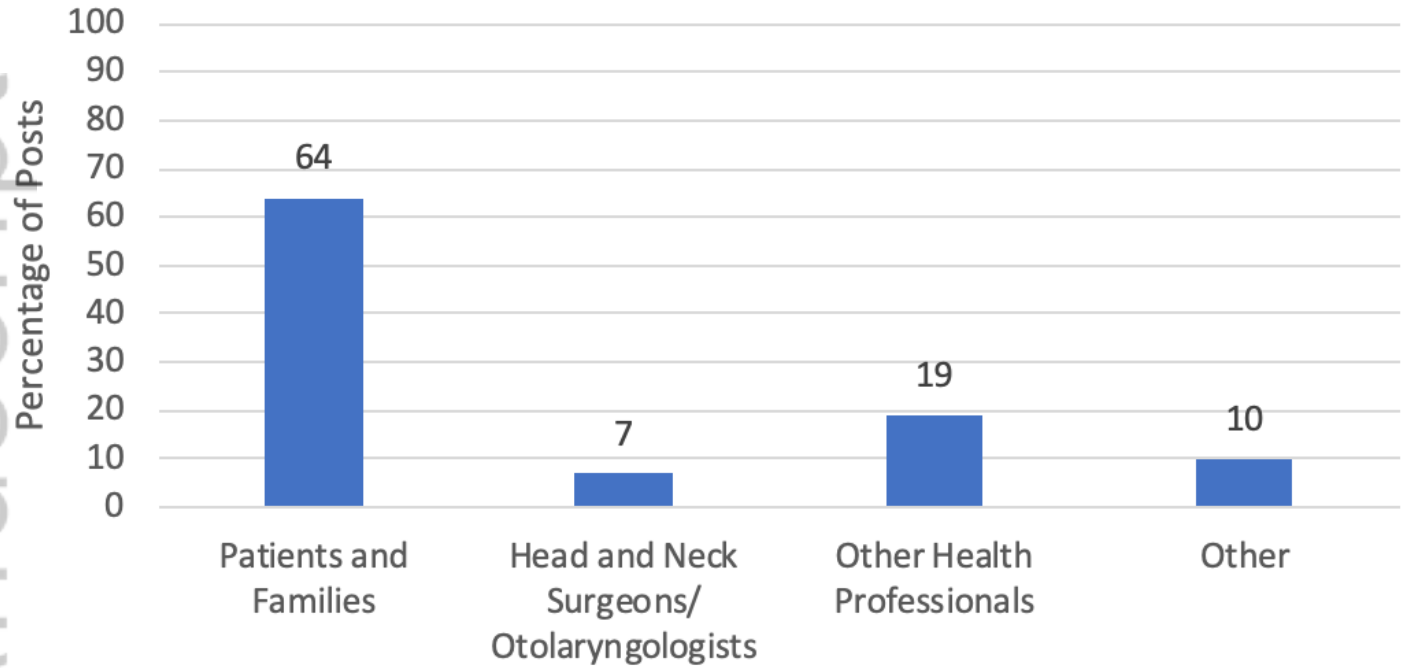
B

ACCOUNTS ENGAGING WITH HEAD AND NECK CANCER POSTS

LARY_29074_HN Cancer Survivorship - Figure 1.png

Patient Concerns in Instagram Posts

Legend:
- #Oralcancer (gray)
- #Thyroidcancer (orange)
- #Headandneckcancer (blue)

Categories (top to bottom):
- Pain
- Speech Impediments
- Surgical Scars
- Facial deformities
- Fatigue
- Weight and nutrition
- Social Stress
- Financial Challenges
- Psychological Stress
- At least one of above

X-axis: Percentage of Posts by Patients (0–100)

LARY_29074_HN Cancer Survivorship - Figure 2.png

Hashtag	Number of Posts
#thyroidcancer	115,000
#oralcancer	22,500
#basalcellcarcinoma	13,400
#headandneckcancer	11,600
#squamouscellcarcinoma	10,900
#throatcancer	7,600
#papillarythyroidcancer	3,400
#ameloblastoma	2,500
#tonguecancer	2,100
#adenoidcysticcarcinoma	1,700
#medullarythyroidcancer	672
#nasopharyngealcancer	670
#pleomorphicadenoma	569
#salivaryglandcancer	534
#nasalcancer	470
#larynxcancer	450
#lipcancer	445
#mucoepidemoidcarcinoma	410
#follicularthyroidcancer	362
#mucosalmelanoma	345
#nosecancer	344
#merkelcellcarcinoma	317
#tonsilcancer	301

Theme	Number of Occurrences (%)	Example of Post	Cohen's kappa
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Social support	24 (18.8%)	"It's been a very long year and I've met many amazing people who were/are going through the same thing. I couldn't have done it without the support of my wife, family & amazing crazy…friends."	0.78
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