European Journal of Cancer Care

WILEY

RESEARCH ARTICLE OPEN ACCESS

Beyond the Clinic: A Netnographic Analysis of Head and Neck Cancer Survivors on Instagram

Wilfredo Alejandro González-Arriagada[1,2,3,4] | Monserrat Soto[5] | Cynthia Cantarutti[5] | Felipe Rodríguez-Oria[1] | Carolina Masson[4] | Catalina Troncoso[1]

[1]Facultad de Odontología, Universidad de los Andes, Santiago, Chile | [2]Centro de Investigación e Innovación Biomédica, Universidad de los Andes, Santiago, Chile | [3]Patología Oral y Maxilofacial, Servicio de Odontología, Hospital El Carmen Dr. Luis Valentín Ferrada de Maipú, Servicio de Salud Metropolitano Central, Santiago, Chile | [4]Clínica Universidad de los Andes, Universidad de los Andes, Las Condes, Santiago, Chile | [5]Facultad de Medicina, Escuela de Odontología, Pontificia Universidad Católica de Chile, Santiago, Chile

Correspondence: Wilfredo Alejandro González-Arriagada (wgonzalez@uandes.cl)

Received: 12 September 2025 | **Revised:** 15 January 2026 | **Accepted:** 21 January 2026

Academic Editor: Tarcilia Silva

Keywords: head and neck cancer | Instagram | netnography | patient experience | social media | social support | survivors

ABSTRACT

Background: Head and neck cancer (HNC) represents a global health issue with significant physical, psychological, and social implications for patients. Netnography, an online research method, offers a unique opportunity to explore the experiences of HNC survivors in the digital age. This study analyzes the Instagram posts of HNC survivors to understand their lived experiences, coping mechanisms, and support networks.

Materials and Methods: A netnographic content analysis was conducted on Instagram posts from 29 HNC survivor users. A mixed qualitative and quantitative approach was used to identify and interpret patterns and meanings within the textual data.

Results: The analysis revealed 11 key themes. These individuals used their platforms to educate about HNC, sharing personal experiences to raise awareness of early detection and support newly diagnosed patients. They documented the multifaceted impact of treatment, including physical and emotional challenges such as pain, disfigurement, and loss of voice. Despite these difficulties, they emphasized the importance of social support networks, including family, friends, and healthcare providers, in their recovery process. Their posts expressed a range of emotions, from fear and anxiety to resilience and hope, reflecting the emotional struggle inherent in survivorship. They also shared experiences adapting to post-treatment life, including the use of medical devices, managing physical limitations, and economic difficulties. They celebrated small victories and offered practical advice and emotional support to others.

Conclusion: HNC survivors use social media to share their experiences, provide support, and advocate for themselves and others. Their stories highlight the multifaceted challenges of cancer and the importance of resilience, social support, and adaptation in the recovery process. These findings underscore the potential of netnography to provide valuable insights into the lived experiences of HNC survivors, which can inform healthcare practices and support programs.

1 | Introduction

Head and neck cancer (HNC) is a heterogeneous group of malignancies that includes cancers of the lip, oral cavity, oropharynx, nasopharynx, hypopharynx, and larynx [1]. It is a prevalent disease and ranks as the seventh most common cancer worldwide [1]. Its incidence continues to rise, and it is estimated to cause approximately 325,000 deaths annually [2, 3].

Although HNC predominantly affects individuals over 50 years old, recent decades have shown a concerning increase in younger populations [1]. Historically, tobacco, alcohol, and betel nut consumption were the major etiological factors [4]. However, even in regions where tobacco use has declined, HNC incidence continues to rise, partly due to the growing contribution of human papillomavirus (HPV), particularly in oropharyngeal cancers [5, 6]. Treatment for HNC typically involves a combination of surgery, radiotherapy, and chemotherapy, all of which are associated with substantial adverse effects. Patients undergoing radiation therapy for HNC experience early and long-term side effects including mucositis, odynophagia, dysphagia, dermatitis, xerostomia, osteoradionecrosis, dental caries and pharyngoesophageal stenosis, among others [7, 8]. Surgical interventions in the head and neck region are frequently invasive and may be disfiguring, leaving lifelong functional and cosmetic sequelae. These can include altered facial appearance, altered voice, trismus, impaired chewing and swallowing, and reduced smell and taste perception [9]. In addition to these physical burdens, patients commonly experience psychological distress, including anxiety, depression, and fears related to treatment and prognosis [10–12]. Collectively, these factors profoundly affect patients' quality of life (QoL) [13, 14]. Once treatment begins, patients face new challenges beyond the immediate effects of therapy, as they must adapt to significant changes in the way they eat, communicate, and participate in their daily lives. They also face significant financial toxicity, characterized by high out-of-pocket expenses, fragmented insurance coverage, loss of productivity, and difficulty returning to work. These financial pressures further exacerbate psychological distress and worsen overall QoL [15, 16]. The impact of these challenges extends to the family environment, influencing caregivers and household functioning [17].

In this context, peer support networks have been shown to improve well-being among patients with HNC, but literature remains scarce [18]. Connecting with others who have faced similar experiences provides social, emotional, and practical support to help them to cope with their own situations [19]. However, practical barriers, such as the physical location of meetings and discomfort with group-based settings, often limit patient participation in traditional peer support programs [20]. In this context, social media has emerged as an important alternative platform, providing a virtual meeting space where HNC patients and survivors can access support and information regardless of geographical or logistical constraints [21, 22]. HNC peer support groups, such as Young Tongues Global, use social media to share personal experiences and offer coping strategies and practical advice for managing treatment-related toxicities [23]. This content is also valuable for healthcare professionals and researchers, who can better understand patients' needs and concerns. Given the expanding role of these platforms, there is a growing need to understand the type of information shared by these channels and how HNC influencers and followers interact, including their experiences and knowledge, particularly about oral toxicities of cancer therapy.

Digital platforms have evolved into vital ecosystems for patient interaction [24]. Social networks have become key spaces for the creation of educational and emotionally meaningful content, where survivors act as influencers, guiding peers through the physical and emotional challenges of treatment [25]. Within this context, analyzing digital interactions offers a unique lens to understand how patients communicate their experiences and share management strategies for oral toxicities. Therefore, this research aims to analyze the Instagram posts of HNC survivors to understand their lived experiences, coping mechanisms, and support networks via a netnographic approach.

2 | Methods

2.1 | Study Design

This study employed a qualitative approach to explore the lived experiences, coping strategies, and digital peer support networks among HNC survivors. A descriptive netnographic approach was used to analyze content shared by HNC survivors–influencers on Instagram. Netnography is a qualitative research methodology adapted from traditional ethnography, designed for the systematic study of cultures, communities, and experiences emerging from digital-mediated communication [24]. The decision to conduct this netnography on Instagram was based on its active HNC survivor community. Instagram was identified as the primary platform hosting the most influential and engaging profiles dedicated to sharing detailed HNC survival narratives. Furthermore, the platform's robust reliance on public hashtags allowed us to implement a systematic protocol for identifying and searching for relevant profiles. The qualitative component was grounded in a naturalistic and interpretive-constructivist paradigm, acknowledging the subjective nature of participants' narratives [26]. Data interpretation remained close to participants' original expressions [27, 28].

2.2 | Participants and Setting

The dataset included publicly accessible content retrieved from Instagram posts, reels, and associated comment threads authored by self-identified cancer survivors. These individuals were recognized as HNC survivor influencers due to their sustained engagement in HNC-related advocacy and storytelling on social media platforms.

Profiles were included based on the following criteria:

- Posts written in English.
- Public Instagram accounts with $\geq$ 1000 followers.
- A minimum of 50 posts.
- At least one post using the hashtags: #headandneckcancer, #oralcancer, #tonguecancer, or #laryngealcancer.

Profiles or content originating from healthcare professionals, organizations, or institutional accounts were excluded.

2.3 | Data Collection

Data were collected by two female researchers through non-participant observation and transcription of posts, reels, and associated comment threads shared by the included profiles. The time frame spanned from each user's first post up to March 2024. Additionally, quantitative descriptors were extracted and tabulated to describe the sample, including (i) number of posts per user, (ii) number of followers, (iii) self-reported demographic information (age andd gender), and (iv) self-reported oncological history (type of cancer, treatment modalities, and year of

diagnosis). We followed the standards for reporting qualitative research, adapting the COREQ checklist criteria where applicable to our netnographic design (Supporting File 1) [29].

2.4 | Data Analysis

The qualitative data were analyzed using thematic analysis. The analysis process began with thoroughly reading all data to ensure deep familiarization with the content. Our approach was inductive, meaning the themes and patterns were generated directly from the collected narratives and not predetermined by existing theory. In the first stage, two researchers without prior expertise in oncology or netnographic studies collected all posts, reels, and comments, systematically registering them in Excel and assigning preliminary codes as they progressed through the material. Subsequently, one male and two female researchers, all with experience in qualitative research, but not involved in the data collection and with no prior knowledge of the participants, conducted a line-by-line reading and refined the coding. Initial codes were then organized into broader categories, which were iteratively refined into overarching themes. This process included continuous comparisons and peer review among the researchers to ensure internal coherence within each theme and clear distinction between them. Thematic frequencies were calculated to explore the prevalence of patterns across influencers and to assess thematic saturation. Documentation of coding decisions was maintained throughout. Credibility was enhanced by including verbatim examples that illustrate each theme.

For quantitative analysis, numeric and categorical variables were extracted to examine sociodemographic characteristics, diagnoses, treatments, reported toxicities, and thematic content. Descriptive statistics summarize continuous variables (total posts, active time, and followers) using means, ranges, and categorical variables (age group, gender, cancer type, treatment, and toxicities) with absolute and relative frequencies.

2.5 | Ethical Considerations

This study was conducted in accordance with ethical guidelines for Internet-based research and the principles outlined in the Declaration of Helsinki [30]. As the research was based solely on publicly accessible content from Instagram, without any interaction or direct engagement with users, this study did not require informed consent from participants, nor formal ethical approval under institutional guidelines. To ensure confidentiality and respect for participant privacy, no real names, usernames, or identifying details were disclosed in the publication. The focus remained on thematic patterns rather than on individual narratives.

3 | Results

A total of 29 profiles met the inclusion criteria and were analyzed. Demographic and clinical characteristics are described in Table 1. Most participants identified as males (51.7%), followed by females (44.8%). Nearly half (48.2%) were aged 45 years or less. The most frequently reported cancer type was tongue cancer (41.3%) followed by laryngeal (31.0%) and other oral cavity sites (20.6%). Regarding treatment, most of them underwent a combination of surgery and radiotherapy/chemotherapy (68.9%).

TABLE 1 | Demographics of head and neck cancer Instagram influencers ($n = 29$).

Category	*n* (%)
Gender	
Males	15 (51.7)
Females	13 (44.8)
LGBTQ+	1 (3.4)
Country	
United States	17 (58.6)
United Kingdom	7 (24.1)
Australia	2 (6.8)
Canada	1 (3.4)
Thailand	1 (3.4)
United Arab Emirates	1 (3.4)
Age	
≤ 45 years	14 (48.2)
> 45 years	12 (41.3)
No information	3 (10.3)
Type of Cancer	
Tongue	12 (41.3)
Larynx	9 (31.0)
Other Oral Cavity Cancers	6 (20.6)
Oropharynx	1 (3.4)
Other	1 (3.4)
Treatment	
Surgery + RT/QT	20 (68.9)
Surgery only	5 (17.2)
RT/QT	2 (6.9)
No information	2 (6.9)

Note: RT/QT, radiotherapy and chemotherapy.

The frequency of all treatment-related complications and symptoms reported is presented in Figure 1. The most frequently mentioned symptoms were dysphagia and pain, each reported by over 70% of the accounts analyzed. These were followed by phonological complications (65.5%), dermatitis (41.3%), nausea (34.4%), oral mucositis (31.0%), xerostomia (31.0%), and alopecia (31.0%). Other symptoms such as dysgeusia (27.5%), coughing (17.2%), and hearing loss (17.2%) appeared with lower frequency. While some profiles described multiple concurrent complications, others focused on one or two specific adverse effects of cancer treatment.

3.1 | Qualitative Data Analysis

Data analysis resulted in the identification of 11 main themes (see Supporting Table 1): (i) The Journey Through the Struggle: Navigating Treatment Experiences, (ii) Reinventing Eating: Nutritional Adaptation as a Form of Survival, (iii) The Transformed Body: Loss of Identity, (iv) Reconstructing the Self: Transformation of Identity and Self-Image, (v) Day-to-Day During Cancer Treatment: Resources and Strategies for Oral Toxicities, (vi) The Emotional Landscape: Navigating Psychological Complexity, (vii) The Importance of Family Support and

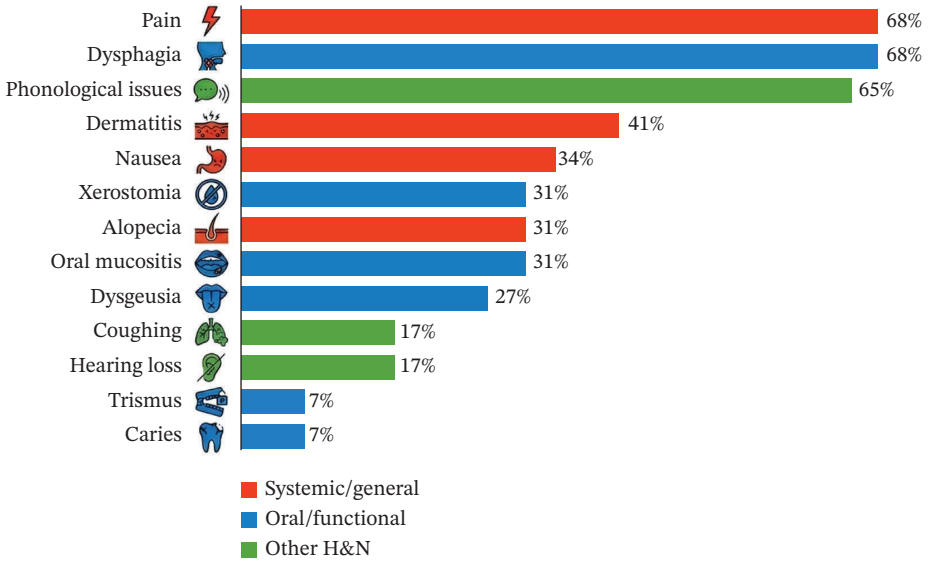

FIGURE 1 | Distribution of symptoms among head and neck cancer patients ($n = 29$). The chart highlights the variability in the prevalence of these complications within the sample population.

Caregivers During Cancer Treatment, (viii) Long-Term Follow-Up: Navigating Ongoing Medical Surveillance, (ix) Financial Burden of Oral Cancer Treatment: Between the Disease and the Healthcare System, (x) Networks of Connection and the Transformative Power of Social Support, and (xi) Turning Cancer suffering into an Educational Mission: Advocacy and Awareness.

3.1.1 | Theme 1. The Journey Through the Struggle: Navigating Treatment Experiences

Patients documented their experiences with a wide range of treatments, including complex surgeries such as hemiglossectomies and mandibulectomies, as well as radiotherapy, chemotherapy, and immunotherapy. The narratives revealed a deep technical understanding of their conditions and treatments, often including detailed descriptions of medical procedures and side effects. Immunotherapy emerged as particularly significant for patients with advanced diseases. These individuals shared their physical struggles transparently, using their posts to chronicle their journey and mark clear turning points in their recovery narratives:

> *"Half of my tongue had been surgically removed, and I had fewer teeth in the back of my mouth" (P1, Female, tongue cancer, Surgery + RT/QT).*

Others celebrated treatment milestones with optimism and joy:

> *"Today is my 40th spa treatment which makes it my Ruby Anniversary! Immunotherapy is keeping me alive and kicking" (P2, male, > 45, oral cancer, immunotherapy).*

3.1.2 | Theme 2. Reinventing Eating: Nutritional Adaptation as a Form of Survival

The transformation of the relationship with food emerged as a universal theme. Users described major challenges in chewing and swallowing, which required the adoption of new nutritional strategies. Feeding tubes were frequently mentioned as a temporary necessity, especially when solid or liquid intake was not possible. They recognized this support as vital for maintaining adequate nutrition during the most painful stages of radiotherapy. Pain management was also essential during this time, with analgesics frequently administered through feeding tubes due to severe throat pain and difficulties swallowing:

> *"After my oral cancer treatment, chewing and swallowing became much more difficult. Nutrition was of primary importance, but my ability to eat was compromised" (P1).*

Gradual recovery of the ability to eat orally was celebrated as a major milestone and often shared with enthusiasm. Transitioning to solid foods and varied textures was seen as a meaningful step toward normal eating:

> *"Yesterday I ate a small jelly; it may seem insignificant, but for me it was a big victory." (P3, < 45, Male, tongue cancer, Surgery)*

> *"Been unable to eat so have been given food via tube (which on many days I didn't want)" (P4, > 45, Male, tongue cancer, Surgery).*

Many also reported the use of nutritional supplements to meet their needs when eating normally was not feasible, especially during periods of pain or swallowing difficulty. Diet was adapted for swallowing difficulties with nutritious smoothies combining fruit, greens, protein powders, and supplements:

> *"I drink a 'yummy tummy green drink' every day: avocado, banana, greens, lemon, ginger, and protein powder—it's so much better than soda and easier to swallow" (P1).*

During the recovery period, several patients recommended avoiding irritating or difficult-to-swallow foods, opting instead for soft and easy-to-digest options. Chemosensory changes caused adverse reactions to intense flavors such as spices or mint,

leading to a preference for bland foods and increased sensitivity to the temperature of food and drinks. Even common products like mint toothpaste became intolerable:

> *"Chemosensory changes, this could be a strong reaction to intense flavors such as spices or mint. after my treatment i prefer to go with lower or no spice options and very very careful about the temperature of my foods and drinks even regular mint toothpaste" (P5, < 45, female, larynx, Surgery + RT/QT).*

3.1.3 | Theme 3. The Transformed Body: Loss of Identity

Individuals described multiple forms of physical impact, including speech difficulties, xerostomia, facial appearance changes, and hair loss. Their narratives reflected complex adaptation processes to functional limitations:

> *"Used some of my scar tissue to build a z-flap under the front of my tongue, essentially loosening its tether, improving my speech, and making my lip and jaw more symmetrical in appearance" (P1).*

> *"Chemo didn't take my hair, but radiation took some of it-a two-inch-wide strip across the naped of my neck" (P5).*

Voice was portrayed as an integral part of identity. Its loss was associated with significant communication challenges and a sense of identity disruption. Written expression through posts was seen to reclaim lost aspects of the self and reaffirm identity:

> *"My voice may be gone, but my words are still here" (P6, > 45, Male, larynx, RT/QT).*

> *"Losing one of your 5 senses has to be one of the scariest things, especially when you can't explain why" (P7 > 45, Male, tongue cancer, Surgery).*

Following laryngectomy, the body undergoes profound changes that affect personal identity. Daily routines include caring for a voice prosthesis and stoma, tasks usually taught by nursing staff but described by users as painful and challenging. The difficulty of changing the prosthesis, along with the slow and frustrating process of relearning speech through assistive devices, highlights the physical and emotional struggle involved. Speech therapy, combined with breathing and relaxation techniques, provides some support for restoring vocal function, yet the overall experience reflects a significant transformation in the user's sense of self and bodily integrity.

3.1.4 | Theme 4. Reconstructing the Self: Transformation of Identity and Self-Image

Participants described complex processes of personal reconstruction following significant physical changes. Narratives included negotiating altered appearances, using wigs as coping strategies, rebuilding self-esteem, and integrating the identity of "cancer survivor":

> *"The thought of being ´normal` wearing lipstick and looking nice for my love was such a distant thought" (P8, < 45, Female, oral cancer, Surgery + RT/QT).*

> *"I`m beginning a new season of ´mostly wigs, most of the time AND I AM SO EXITED! It`s like discovering a new way to change up my look every single day" (P1).*

The use of medical devices and adaptation to physical limitations were common experiences. Nevertheless, users sought meaning in this "new normal" and worked to reclaim autonomy:

> *"I graduated as competent to change my speaking valve—it's a small victory" (P3).*

> *"A celebratory walk post feeding tube removal and I`m feeling great. What a blessed relief it is not to have a foot length of plastic sticking out of my tummy" (P5).*

3.1.5 | Theme 5. Day-to-Day During Cancer Treatment: Resources and Strategies for Oral Toxicities

Patients used their social media to share the side effects of oral cancer therapy and how they managed them, offering practical tips for coping. They described multiple complex side effects impacting their physical health and QoL. Xerostomia (dry mouth) was common, making speaking and swallowing difficult and increasing the risk of tooth decay. Good oral hygiene and fluoride treatments were essential:

> *"Small sips of water and moisture-mimicking products really help" (P1).*

> *"Radiation affects my mouth: sores, dryness, and risk of tooth decay. I do fluoride treatments, brush, and rinse with baking soda and salt frequently" (P9, < 45, Female, Tongue Cancer, Surgery + RT/QT).*

Dysphagia and muscle spasms were frequent, occurring not only in the legs but also in the neck. Massage and exercise helped relieve symptoms. Trismus was another common challenge, requiring daily exercises and devices to maintain jaw mobility:

> *"After surgery, I had muscle spasms not just in my leg, but in my neck too. Massages and exercise made a big difference" (P9).*

> *"Trismus is tough — my jaw wanted to stay closed after radiation, so daily exercises and my appliance are a must to keep it open" (P1).*

> *"My tongue depressors and TheraBite after my first round of radiation in 2018. You'll notice my face, teeth, and voice look and sound different. This is a year and a half before my second surgery! ... I could open my mouth MUCH" (P8).*

Radiation burns on the neck required hypoallergenic soaps and moisturizers:

> *"Radiation burn on my neck looked like a bad sunburn — gentle hypoallergenic soap and Aquaphor kept it soft and soothed" (P1).*

> *"My skincare routine became more important than ever after treatment" (P9).*

"I researched some natural vegan products I could use to care for my skin... I have been using both daily for the last 3 months leading up to radiotherapy, during, and beyond. My skin looked a bit irritated in some photos, but within just under 3 weeks my skin pretty much completely healed" (P5).

Lymphedema management involved lymphatic massages and daily exercises to reduce swelling:

"I'm doing daily neck and shoulder exercises to help get things moving and reduce the fluid buildup" (P9).

Other recommendations included staying active in the hospital, using exercise rooms even when fitted with drains, and seeking emotional or psychological support during treatment and recovery phases.

3.1.6 | Theme 6. The Emotional Landscape: Navigating Psychological Complexity

The emotional landscape described was multifaceted, marked by the coexistence of fear of recurrence and deep gratitude for life. Users portrayed resilience as a defining trait, often finding humor and joy even in difficult circumstances. They did not limit their narratives to physical suffering, but included the full spectrum of emotional experience:

"I still get scared that my cancer will come back. Sometimes it takes a while to fall asleep" (P1).

"I have had some struggles and I still have sometimes when I break down and lose it. I don't ever want an 'I'm sorry for you' or any pity... I just want to be looked at for what I have inside" (P8).

While many embraced humor, they did not deny or minimize suffering. They openly acknowledged difficult emotions and resisted oversimplified narratives of constant positivity:

"It's bloody tough, scary, so much fear, you feel weak, and the thought of death may be running through your mind 24/7... I felt so depressed, weak, embarrassed ..." (P10, > 45, male, oral cancer, RT/QT).

Both large and small achievements were celebrated as meaningful steps toward recovery and a return to ordinary life:

"After months without being able to speak, I had my first real conversation. It was exhausting, but incredible" (P5).

3.1.7 | Theme 7. The Importance of Family Support and Caregivers During Cancer Treatment

Participants reported that the journey through cancer treatment represented not only a battle against the disease itself but also an emotional and physical challenge that tested the resilience of both them and their loved ones. They emphasized that the unconditional support of family, friends, and caregivers helped them cope with the pain, fear, and uncertainty that accompanied the diagnosis and the therapy process. This support network was frequently described as fundamental for managing the emotional burden of treatment.

"Me and my nurses had a little fun and me and my family and friends cried and was emotional because they knew the pain, suffering, hard days, wanting to give up, sickness, weakness, weight loss, and depression I went through just trying to fight through cancer and these treatments... thanks to all who pray for me and I LOVE MY SUPPORT SYSTEM" (P12 , < 45, Male, larynx, Surgery + RT/QT).

"Not only was today my last radiation treatment (#30), but I had the most beautiful surprise when I came out and saw my mom, dad, and brother had traveled all the way to Orlando to congratulate me ... Thank you to everyone who has supported me along this journey..." (P13, > 45, female, tongue cancer, surgery + RT/QT).

Additionally, the importance of caregivers was highlighted during stages when patients need more assistance or are unable to perform certain tasks, leading other family members to take on greater responsibilities to support them:

"Amid the pain, uncertainty, and fear, her love and dedication hold me up. In the fight against cancer, it's not just the disease we battle, but also the unwavering care and patience of those who stand by our side, loving us without giving up" (P7).

3.1.8 | Theme 8. Long-Term Follow-Up: Navigating Ongoing Medical Surveillance

Follow-up appointments emerged as significant events shaping life after treatment, as they represented not only routine medical check-ups but also moments filled with uncertainty and fear about the possible return of cancer. Participants developed specific routines around this medical surveillance and shared strategies to manage anticipatory anxiety, often referred to as "scanxiety." The celebration of "clean" results was described as a ritual of emotional renewal, temporarily easing the worry about a potential recurrence:

"This morning's mission is Operation Top Cat. Yes, it's time for my scan" (P2).

"CT scan result today shows no evidence of cancer which means immunotherapy continues to work wonders for me" (P7).

"Too many routine doctor appointments this month. Happy to report all is good ... still kick' in the 'big C's' ass" (P11, NI, Female, tongue cancer, surgery + RT/QT).

"To make a long story short, I had a biopsy done on Tuesday, and I found out on Friday that I HAVE TONGUE CANCER AGAIN" (P4).

Medical follow-up was framed as an active responsibility. This included not only attending medical visits but also adopting lifestyle changes, managing symptoms, and engaging in personal monitoring for physical changes.

3.1.9 | Theme 9. Financial Burden of Oral Cancer Treatment: Between the Disease and the Healthcare System

Participants reported that oral cancer treatment represents not only a physical and emotional challenge but also a significant financial burden for themselves and their families. They noted that they face a healthcare system that lacks the support and flexibility needed to cover all treatment and rehabilitation needs, such as disability benefits, specialized equipment, therapies, and prosthetics essential for basic functions and QoL. This lack of coverage increases the economic and emotional strain, forcing them to seek solutions on their own. According to the participants, this reveals a serious flaw in the healthcare system, which neglects the continuous care required, putting the QoL of people with HNC at risk:

> *"This last time has been a nightmare; I have been trying to talk to social security to be able to get benefits for treatment for the disability this disease has caused me" (P5).*

> *"But this is just one of many stories I have regarding the lack of insurance coverage for head and neck cancer rehabilitative equipment and therapies and required prosthetics for both quality of life and life in general" (P8).*

3.1.10 | Theme 10. Networks of Connection and the Transformative Power of Social Support

Connection with other cancer survivors was described as especially meaningful, providing unique validation and understanding. Online communities on Instagram became vital spaces for mutual support, transcending geographic limitations:

> *"The best thing you can do after a diagnosis is GET CONNECTED. Find the people who have shared experiences" (P1).*

Emotional bonds and expressions of vulnerability were shared in posts:

> *"There's not a day that doesn't go by that I don't thank God, The Universe, the doctors, nurses, my husband, kids, family, friends, and all of social media ... I had no idea at the time, but I can tell you that your prayers lifted me through the ordeal. They were and still are so powerful" (P13).*

> *"The supportive comments from you all have truly inspired me to keep it together ..." (P11).*

3.1.11 | Theme 11. Turning Cancer Suffering Into an Educational Mission: Advocacy and Awareness

Most influencers turned their painful experiences into platforms for education and advocacy. Their narratives revealed a commitment to cancer prevention, early detection, demystification of oral and pharyngeal cancers, and promotion of patient resources and research. Social media was used strategically to amplify these messages. For many, cancer became an opportunity to educate others on symptom recognition and early diagnosis. They also guided newly diagnosed patients by sharing what to expect in future stages:

> *"I hope that by sharing my journals and photos, I can help at least one person who is just beginning this journey" (P10).*

> *"Never ever stop asking questions about your health — you don't have to stay with local providers or accept their diagnoses. No one knows your body like you. Keep fighting" (P7).*

Their personal pain was transformed into a tool for preventing similar experiences in others:

> *"I hope that by sharing my story, I can help someone not ignore the signs" (P14, > 45, Male, Oropharynx, NI).*

Influencers recognized the unique reach of digital platforms and used them intentionally:

> *"When I make funny videos on Facebook, millions and billions of people listen—and some of them hear my voice or see my scars, and they want to know what happened—so they Google me and get to know my cancer story" (P1).*

4 | Discussion

This netnographic analysis of Instagram posts by HNC survivors offers a broad view that incorporates patient experience beyond the clinical setting. The 11 themes identified demonstrate that digital platforms function not only as spaces for sharing experiences but also as powerful tools for dissemination, peer support, and health education. By observing these interactions, researchers and advocacy groups can identify unmet needs that often go unnoticed during in-person consultations, as social networks provide an environment where survivors freely express concerns and coping strategies.

The findings reflect that the impact of HNC transcends clinical symptoms and extends multidimensionally into daily life, affecting relationships, emotional well-being, and QoL. This aligns with recent meta-analyses describing how swallowing problems, voice alterations, psychological distress, and nutritional repercussions significantly compromise health-related QoL in this population [31, 32]. Narratives about the treatment process reported invasive procedures—hemiglossectomies, mandibulectomies, and laryngectomies—experienced as deeply transformative changes. However, the specific functional impact varied among HNC subtypes. While complex adaptations were required across the board, survivors of tongue and oral cavity cancer primarily described severe limitations in chewing and swallowing mechanics, whereas laryngeal cancer survivors focused on the profound challenge of vocal restoration and stoma care. Consistent with previous studies, dysphagia and pain were the most frequently mentioned toxicities, followed by mucositis and xerostomia, complications widely documented in the literature [33–35].

The analysis identified financial burden as a significant challenge in survivors' narratives including lack of insurance coverage for HNC patient rehabilitation and out-of-pocket expenses. These results are consistent with prior research that has highlighted this concern as one of the main worries among HNC patients, even surpassing fear of death [15, 36–38]. However, these financial strains are not always adequately addressed in current

care models, which reinforces the need to design specific support systems that integrate this dimension alongside physical and emotional sequelae.

Another central aspect was nutritional adaptation as a survival strategy. As reported in the literature, persistent xerostomia can affect more than 80% of survivors and often coexists with dysphagia and taste alterations [39]. In line with Crowder et al., posts showed how supplementation, frequent hydration, and avoidance of certain foods are part of a long-term routine [40]. Eating was not presented as a return to pre-illness normality but as a redefined experience, where small advances such as swallowing gelatin or drinking without pain were celebrated as significant achievements.

On the psychosocial level, physical sequelae such as facial disfigurement, alopecia, and voice loss were described. Interestingly, distinct patterns emerged based on the tumor location: survivors treated for oral cancer often centered their narratives on the visible stigma of facial disfigurement and scarring, while those with laryngeal cancer narrated the social isolation resulting from the loss of natural voice. This is consistent with studies linking these sequelae with social isolation, depression, and impaired QoL [41, 42]. While much of the literature analyzes these consequences from a clinical perspective, our analysis reveals how survivors narrate and resignify them in open digital spaces.

This process of self-reconstruction, also described in another studies, manifested in actions such as the use of wigs, makeup routines, prostheses, or deliberate exposure of scars, practices presented as expressions of identity and resilience [43]. Emotions —such as fear of recurrence, anxiety, or grief—coexisted with humor, gratitude, and joy, demonstrating that survivorship is not a linear path to well-being but a dynamic process of adjustment. Reintegration into daily life, including returning to work and recovering social roles, aligned with prior findings that emphasize the need for sustained psychosocial support [44–46].

Family support and the role of caregivers emerged as essential pillars for coping during and after treatment, reinforcing prior studies on the importance of close support in this context [47, 48]. Concurrently, many survivors transformed their experience into an educational and advocacy mission, actively participating in raising awareness about diagnosis and early prevention, even supporting peers who may begin their journey. The analyzed profiles demonstrated sustained involvement with established HNC advocacy organizations, including Young Tongues (which also inspired the conceptual focus of the present study), as well as the HNC Living Foundation, Support for People with Oral and Head and Neck Cancer (SPOHNC), the Head and Neck Cancer Alliance, and the Oral Cancer Foundation. This transition from patient to advocate, supported by evidence, showing the value of peer support in reducing psychological distress, is especially relevant in the context of HNC, where visible and functional sequelae heighten the need for empathy and connection [18, 49].

Prolonged medical and dental follow-up, a transversal element in the narratives, reinforced the perception of cancer as a chronic condition and highlighted the need for regular fluoride application to prevent dental caries, as well as routine dental checkups for oral rehabilitation following HNC treatment sequelae [50]. Consistent with another study, surveillance for recurrences was experienced as a constant priority but accompanied by significant emotional burden, exemplified by "scanxiety"—a term describing the anxiety occurring before, during, and after cancer-related imaging, particularly high during the waiting period between scan and results [51, 52]. Receiving a "clean" result was celebrated as a temporary relief, though with awareness that the threat persists. Nonetheless, such emotional support is often underrepresented in clinical practice, especially during extended follow-up, highlighting opportunities to improve care models and psychological support [53].

Moreover, this study provides important clinical insights by identifying patient-reported strategies for managing treatment-related side effects that complement or extend beyond traditional interventions. Several strategies discussed by patients, such as dietary modifications including smoothies or texture-adapted foods, and the use of portable devices for mandibular rehabilitation, are supported by prior clinical literature and received collective validation through repeated endorsement within online communities [54–56]. In contrast, other strategies, including frequent rinsing with sodium bicarbonate and salt for mucositis, the use of natural or vegan topical products for dermatitis, and the preparation of homemade beverages incorporating fruits, vegetables, and plants as nutritional supplements, were primarily anecdotal and not consistently grounded in clinical evidence [57]. Recognition and validation of these practices in clinical settings may empower patients, strengthen the therapeutic alliance, and promote active participation in health management, which are key factors for improving outcomes and QoL during cancer survivorship [58, 59]. However, some practices reported by patients are not consistently integrated into conventional clinical protocols, largely due to limited evidence regarding their effectiveness.

In summary, this study shows that the experience of HNC survivorship is a complex process involving physical adaptation, identity reconstruction, family and social support, management of emotional and functional sequelae, and active participation in digital networks as spaces of support and advocacy. Rather than replicating prior findings, this analysis highlights how cancer survivors narrate and share their experiences in public online environments, enabling the identification of unmet needs and the exploration of patient-generated strategies to alleviate symptoms and improve QoL, which could be systematically evaluated through future research.

Despite its valuable contributions, this study has several limitations that should be acknowledged. First, the analysis relied exclusively on publicly available content from a single social media platform, which may limit the diversity of perspectives captured. The absence of direct interaction with participants precluded opportunities to clarify context or explore underlying meanings; therefore, future studies could incorporate qualitative methods such as interviews or focus groups to deepen interpretation. In addition, the sample size and its representativeness across different HNC types and their relative prevalences could not be fully assessed, potentially affecting the generalizability of the findings. Participants were predominantly from the United States and the United Kingdom, with limited representation from other countries. Differences in healthcare systems, access to services, and supportive care practices across countries may therefore have influenced patient experiences and the

strategies reported. Future research should address these limitations by including multiple platforms, larger and more diverse samples, and contextual clinical and geographic data.

Likewise, investigating how to effectively incorporate patient-reported practices and resources into integrated, personalized HNC clinical care models would be relevant; a growing body of research demonstrates that systematic collection and integration of patient-reported outcomes can improve symptom management, care personalization, and patient–clinician communication [60–62]. The results also highlight the need to strengthen healthcare professional training and awareness in the comprehensive management of patients with HNC, encompassing emotional, social, and economic dimensions of care, a need that has been reported in previous studies highlighting substantial psychosocial and supportive care gaps among survivors [63–65]. The growing use of digital platforms—including social media communities (e.g., Facebook groups, Instagram, Twitter) and other online forums—as spaces for support, information-seeking, and self-management among cancer survivors suggests that collaboration between researchers, clinicians, and virtual communities is particularly critical in HNC care [66, 67]. Unlike other malignancies, HNC survivors often face speech impairments and facial disfigurement that create barriers to traditional in-person or synchronous support [22, 68–70]. Digital platforms, therefore, are not merely convenient alternatives but critical spaces that allow these patients to communicate without the pressure of verbal articulation or real-time visual exposure, facilitating social reintegration in ways that clinical settings often cannot.

5 | Conclusion

This netnographic study examined how HNC survivors use Instagram to narrate their lived experiences, share coping strategies, and build peer support networks beyond the clinical setting. The findings demonstrate that survivorship is experienced as a multidimensional process involving physical adaptation, identity reconstruction, emotional regulation, and sustained social engagement. Survivors used digital platforms not only to document treatment-related toxicities, such as dysphagia, xerostomia, voice loss, and facial disfigurement, but also to exchange practical self-management strategies, including dietary modifications, oral hygiene routines, rehabilitation devices, and approaches to managing anxiety and social reintegration. These patient-generated practices, together with peer-led emotional support and advocacy efforts, highlight the value of digital spaces as complementary environments where experiential knowledge is produced and shared. By making visible the everyday challenges and resources used by survivors, this study contributes to a deeper understanding of HNC survivorship and identifies areas where future research may systematically evaluate patient-informed strategies to better support QoL after treatment.

Funding

This study has been supported by Bidirectional Commitment In Innovation—UANDES (BiCI23I-21).

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

References

1. H. Sun, M. Yu, Z. An, et al., "Global Burden of Head and Neck Cancer: Epidemiological Transitions, Inequities, and Projections to 2050," *Frontiers Oncology* 15 (2025): 1665019, https://doi.org/10.3389/fonc.2025.1665019.

2. F. Bray, M. Laversanne, H. Sung, et al., "Global Cancer Statistics 2022: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries," *CA: A Cancer Journal for Clinicians* 74, no. 3 (2024): 229–263, https://doi.org/10.3322/caac.21834.

3. D. E. Johnson, B. Burtness, C. R. Leemans, V. W. Y. Lui, J. E. Bauman, and J. R. Grandis, "Head and Neck Squamous Cell Carcinoma," *Nature Reviews Disease Primers* 6, no. 1 (2020): 92, https://doi.org/10.1038/s41572-020-00224-3.

4. D. C. Whiteman and L. F. Wilson, "The Fractions of Cancer Attributable to Modifiable Factors: a Global Review," *Cancer Epidemiology* 44 (2016): 203–221, https://doi.org/10.1016/j.canep.2016.06.013.

5. E. Kaminagakura, L. L. Villa, M. A. Andreoli, et al., "High-Risk Human Papillomavirus in Oral Squamous Cell Carcinoma of Young Patients," *International Journal of Cancer* 130, no. 8 (2012): 1726–1732, https://doi.org/10.1002/ijc.26185.

6. X. Meng, B. Yang, H. Yin, et al., "Global Burden and Incidence Trends in Cancers Associated with Human Papillomavirus Infection: a Population-Based Systematic Study," *Pathogens* 14, no. 9 (2025): 880, https://doi.org/10.3390/pathogens14090880.

7. I. Brook, "Early Side Effects of Radiation Treatment for Head and Neck Cancer," *Cancer Radiotherapie* 25, no. 5 (2021): 507–513, https://doi.org/10.1016/j.canrad.2021.02.001.

8. I. Brook, "Late Side Effects of Radiation Treatment for Head and Neck Cancer," *Radiation Oncology Journal* 38, no. 2 (2020): 84–92, https://doi.org/10.3857/roj.2020.00213.

9. S. Orozco-Núñez, N. Oishi, J. Izquierdo, F. Martínez-Expósito, A. García-Lliberós, and E. Zapater, "Postoperative Evolution of Health-Related Quality of Life in Patients with Head and Neck Cancer," *Journal of Surgical Oncology* 132 (2025): 480–488, https://doi.org/10.1002/jso.70022.

10. H. Lang, E. France, B. Williams, G. Humphris, and M. Wells, "The Psychological Experience of Living with Head and Neck Cancer: a Systematic Review and meta-synthesis," *Psycho-Oncology* 22, no. 12 (2013): 2648–2663, https://doi.org/10.1002/pon.3343.

11. A. A. Mäkitie, R. O. Alabi, L. Pulkki-Råback, et al., "Psychological Factors Related to Treatment Outcomes in Head and Neck Cancer," *Advances in Therapy* 41 (2024): 3489–3519, https://doi.org/10.1007/s12325-024-02945-3.

12. J. Thirupathi, V. Keluskar, R. D. Sagar, et al., "Psychological Distress of Patients with Head and Neck Cancer Following Various Oncologic treatments-A Longitudinal study," *Supportive Care in Cancer* 33, no. 7 (2025): 553, https://doi.org/10.1007/s00520-025-09604-5.

13. C. Hammermüller, A. Hinz, A. Dietz, et al., "Depression, Anxiety, Fatigue, and Quality of Life in a Large Sample of Patients Suffering from Head and Neck Cancer in Comparison with the General Population," *BMC Cancer* 21 (2021): 94, https://doi.org/10.1186/s12885-020-07773-6.

14. K. J. Taylor, C. D. Amdal, K. Bjordal, et al., "Long-Term health-related Quality of Life in Head and Neck Cancer Survivors: a Large Multinational Study," *International Journal of Cancer* 154, no. 10 (2024): 1772–1785, https://doi.org/10.1002/ijc.34861.

15. A. S. Dhane, "Financial Toxicity in Head and Neck Cancer Care: Current Issues and Future Directions," *Oral Oncology Reports* 11 (2024): 100580, https://doi.org/10.1016/j.oor.2024.100580.

16. J. Yu, J. Smith, R. Marwah, and O. Edkins, "Return to Work in Patients with Head and Neck Cancer: Systematic Review and Meta-Analysis," *Head & Neck* 44, no. 12 (2022): 2904–2924, https://doi.org/10.1002/hed.27197.

17. A. E. Richardson, R. Morton, and E. Broadbent, "Psychological Support Needs of Patients with Head and Neck Cancer and Their Caregivers: a Qualitative Study," *Psychology and Health* 30, no. 11 (2015): 1288–1305, https://doi.org/10.1080/08870446.2015.1045512.

18. R. A. Hatton, J. Crane, S. N. Rogers, and J. Patterson, "Head and Neck Cancer peer-to-peer Support and Quality of Life: Systematic Scoping Review," *British Journal of Nursing* 31, no. 5 (2022): S30–S36, https://doi.org/10.12968/bjon.2022.31.5.S30.

19. H. Y. Park, M. J. Kim, J. Y. Kim, et al., "Could Peer Support Programs Be a Good Resource for Managing the Unmet Needs of Cancer Patients?" *J Canc Educ* 34, no. 5 (2019): 950–957, https://doi.org/10.1007/s13187-018-1399-4.

20. K. A. Pateman, P. J. Ford, M. D. Batstone, and C. S. Farah, "Coping with an Altered Mouth and Perceived Supportive Care Needs Following Head and Neck Cancer Treatment," *Supportive Care in Cancer* 23, no. 8 (2015): 2365–2373, https://doi.org/10.1007/s00520-015-2607-y.

21. J. Zhou and C. Wang, "Improving Cancer Survivors' e-health Literacy via Online Health Communities (OHCs): a Social Support Perspective," *Journal Cancer Survivour* 14, no. 2 (2020): 244–252, https://doi.org/10.1007/s11764-019-00833-2.

22. A. J. Lazard, M. K. R. Collins, A. Hedrick, et al., "Using Social Media for Peer-to-Peer Cancer Support: Interviews with Young Adults with Cancer," *JMIR Cancer* 7, no. 3 (2021): e28234, https://doi.org/10.2196/28234.

23. "About Us," (2023), https://youngtonguesglobal.com/about-us.

24. R. V. Kozinets, *Netnography. the International Encyclopedia of Digital Communication and Society* (John Wiley & Sons, Ltd, 2015).

25. M. T. Argan, M. Argan, and A. Özer, "A Netnographic Study on Virtual Community of Patients with Spinal Cord Injury (SCI) in Turkey," *Iuyd* 7 (2016): 31–43, https://doi.org/10.5505/iuyd.2016.66588.

26. B. R. Ferrell, M. L. Twaddle, A. Melnick, and D. E. Meier, "National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines," *Journal of Palliative Medicine* 21, no. 12 (2018): 1684–1689, https://doi.org/10.1089/jpm.2018.0431.

27. D. G. Willis, S. Sullivan-Bolyai, K. Knafl, and M. Z. Cohen, "Distinguishing Features and Similarities Between Descriptive Phenomenological and Qualitative Description Research," *Western Journal of Nursing Research* 38, no. 9 (2016): 1185–1204, https://doi.org/10.1177/0193945916645499.

28. C. Bradshaw, S. Atkinson, and O. Doody, "Employing a Qualitative Description Approach in Health Care Research," *Global Qualitative Nursing Research* 4 (2017): 2333393617742282, https://doi.org/10.1177/2333393617742282.

29. A. Tong, P. Sainsbury, and J. Craig, "Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item Checklist for Interviews and Focus Groups," *International Journal for Quality in Health Care* 19, no. 6 (2007): 349–357, https://doi.org/10.1093/intqhc/mzm042.

30. M. A. Moreno, N. Goniu, P. S. Moreno, and D. Diekema, "Ethics of Social Media Research: Common Concerns and Practical Considerations," *Cyberpsychology, Behavior, and Social Networking* 16, no. 9 (2013): 708–713, https://doi.org/10.1089/cyber.2012.0334.

31. M. Yuwanati, S. Gondivkar, S. C. Sarode, et al., "Oral health-related Quality of Life in Oral Cancer Patients: Systematic Review and meta-analysis," *Future Oncology* 17, no. 8 (2021): 979–990, https://doi.org/10.2217/fon-2020-0881.

32. R. Grigore, P. L. Bejenaru, G. S. Berteşteanu, et al., "Impact of Oncological Treatment on Quality of Life in Patients with Head and Neck Malignancies: a Systematic Literature Review (2020–2025)," *Current Oncology* 32, no. 7 (2025): 379, https://doi.org/10.3390/curroncol32070379.

33. W. Gao, Z. Xia, T. Zhou, and Y. Dong, "Adverse Event Profile of Five Anti Head and Neck Squamous Cell Carcinoma Drugs: a Descriptive Analysis from WHO-VigiAccess," *Frontiers in Pharmacology* 16 (2025): 1602276, https://doi.org/10.3389/fphar.2025.1602276.

34. P. H. P. Rocha, R. M. Reali, M. Decnop, et al., "Adverse Radiation Therapy Effects in the Treatment of Head and Neck Tumors," *RadioGraphics* 42, no. 3 (2022): 806–821, https://doi.org/10.1148/rg.210150.

35. Oral complications from head and neck cancer therapy, *Head and Neck Cancer Rehabilitation* (Elsevier, 2025).

36. E. Raggini, D. Mattavelli, G. Zigliani, P. Bossi, and C. Piazza, "Measuring Financial Toxicity in Head and Neck Cancer: a Systematic Review," *Acta Otorhinolaryngologica Italica* 44 (2024): 1–12, https://doi.org/10.14639/0392-100X-N2762.

37. J. Rast, V. Zebralla, A. Dietz, G. Wichmann, and S. Wiegand, "Cancer-Associated Financial Burden in German Head and Neck Cancer Patients," *Frontiers Oncology* 14 (2024): 1329242, https://doi.org/10.3389/fonc.2024.1329242.

38. S. J. Ma, A. J. Iovoli, K. Attwood, et al., "Association of Significant Financial Burden with Survival for Head and Neck Cancer Patients Treated with Radiation Therapy," *Oral Oncology* 115 (2021): 105196, https://doi.org/10.1016/j.oraloncology.2021.105196.

39. M. M. Alnaeem, S. K. Darwish, and A. J. Nashwan, "Radiation-Induced Xerostomia in Head and Neck Cancers: a Comprehensive Review for Burden and Impact on Nutrition, Sleep, and Quality of Life," *Discovery Medicine* 2, no. 1 (2025): 143, https://doi.org/10.1007/s44337-025-00362-1.

40. S. L. Crowder, N. Najam, K. P. Sarma, B. H. Fiese, and A. E. Arthur, "Head and Neck Cancer Survivors' Experiences with Chronic Nutrition Impact Symptom Burden After Radiation: a Qualitative Study," *Journal of the Academy of Nutrition and Dietetics* 120, no. 10 (2020): 1643–1653, https://doi.org/10.1016/j.jand.2020.04.016.

41. S. Bhandari, R. Singh, S. Mehndiratta, and M. Dadhich, "The Impact of Facial Disfigurement and self-image Anxiety on the Quality of Life of Head and Neck Cancer Patients," *Oral Oncology Reports* 10 (2024): 100518, https://doi.org/10.1016/j.oor.2024.100518.

42. V. Zebralla, G. Wichmann, M. Pirlich, et al., "Dysphagia, Voice Problems, and Pain in Head and Neck Cancer Patients," *European Archives of Oto-Rhino-Laryngology* 278, no. 10 (2021): 3985–3994, https://doi.org/10.1007/s00405-020-06584-6.

43. C. Vandamme, S. Cremades, S. Testelin, and S. Lelorain, "Women's Experiences of Head and Neck Cancer: an Interpretative Phenomenological Analysis," *BMC Women's Health* 25, no. 1 (2025): 145, https://doi.org/10.1186/s12905-025-03671-w.

44. S. L. Crowder, N. Najam, K. P. Sarma, B. H. Fiese, and A. E. Arthur, "Quality of Life, Coping Strategies, and Supportive Care Needs in Head and Neck Cancer Survivors: a Qualitative Study," *Supportive Care in Cancer* 29, no. 8 (2021): 4349–4356, https://doi.org/10.1007/s00520-020-05981-1.

45. Y. Yang, L. Hou, W. Zeng, X. Gan, Z. Qian, and X. Zhao, "Emotions and Experiences of Head and Neck Cancer Survivors Returning to Work: a meta-synthesis of Qualitative Studies," *Journal of Psychosocial Oncology* 43, no. 6 (2025): 855–874, https://doi.org/10.1080/07347332.2025.2496642.

46. L. Lin, H. Lin, R. Zhou, B. Liu, K. Liu, and R. Jiang, "Surviving and Thriving: Assessing Quality of Life and Psychosocial Interventions in Mental Health of Head and Neck Cancer Patients," *Asian Journal of Surgery* no. 24 (2024): 02651–02654, https://doi.org/10.1016/j.asjsur.2024.11.048.

47. H. Ullgren, T. Tsitsi, E. Papastavrou, and A. Charalambous, "How Family Caregivers of Cancer Patients Manage Symptoms at Home:

a Systematic Review," *International Journal of Nursing Studies* 85 (2018): 68–79, https://doi.org/10.1016/j.ijnurstu.2018.05.004.

48. M. Pasek, A. Goździalska, M. Jochymek, and R. Caruso, "Social Support in a Cancer Patient-Informal Caregiver Dyad: a Scoping Review," *Cancers (Basel)* 15, no. 6 (2023): 1754, https://doi.org/10.3390/cancers15061754.

49. A. Kiemen, M. Czornik, and J. Weis, "How Effective is peer-to-peer Support in Cancer Patients and Survivors? A Systematic Review," *Journal of Cancer Research and Clinical Oncology* 149, no. 11 (2023): 9461–9485, https://doi.org/10.1007/s00432-023-04753-8.

50. E. Pituskin, "Cancer as a New Chronic Disease: Oncology Nursing in the 21st Century," *Canadian Oncology Nursing Journal* 32, no. 1 (2022): 87–92.

51. N. A. Pagedar, N. Kendell, A. J. Christensen, T. A. Thomsen, M. Gist, and A. T. Seaman, "Head and Neck Cancer Survivorship from the Patient Perspective," *Head & Neck* 42 (2020): 2431–2439, https://doi.org/10.1002/hed.26265.

52. H. M. Derry-Vick, L. C. Heathcote, N. Glesby, et al., "Scanxiety Among Adults with Cancer: a Scoping Review to Guide Research and Interventions," *Cancers (Basel)* 15, no. 5 (2023): 1381, https://doi.org/10.3390/cancers15051381.

53. F. Boele, C. Harley, S. Pini, L. Kenyon, A. Daffu-O'Reilly, and G. Velikova, "Cancer as a Chronic Illness: Support Needs and Experiences," *BMJ Supportive & Palliative Care* 14, no. e1 (2019): e710–e718, https://doi.org/10.1136/bmjspcare-2019-001882.

54. S. J. van der Geer, H. Reintsema, J. I. Kamstra, J. L. N. Roodenburg, and P. U. Dijkstra, "The Use of Stretching Devices for Treatment of Trismus in Head and Neck Cancer Patients: a Randomized Controlled Trial," *Supportive Care in Cancer* 28, no. 1 (2020): 9–11, https://doi.org/10.1007/s00520-019-05075-7.

55. B. Talwar, R. Donnelly, R. Skelly, and M. Donaldson, "Nutritional Management in Head and Neck Cancer: United Kingdom National Multidisciplinary Guidelines," *Journal of Laryngology & Otology* 130, no. S2 (2016): S32–S40, https://doi.org/10.1017/S0022215116000402.

56. A. Surwiłło-Snarska, A. Kapała, and D. Szostak-Węgierek, "Assessment of the Dietary Intake Changes in Patients with Head and Neck Cancer Treated with Radical Radiotherapy," *Nutrients* 16, no. 13 (2024): 2093, https://doi.org/10.3390/nu16132093.

57. O. Di Fede, F. Canepa, L. Maniscalco, P. Tozzo, D. Matranga, and G. Giuliana, "Prevention and the Treatment of Oral Mucositis: the Efficacy of Sodium Bicarbonate vs Other Agents: a Systematic Review," *BMC Oral Health* 23, no. 1 (2023): 4, https://doi.org/10.1186/s12903-022-02586-4.

58. J. H. Hibbard and J. Greene, "What the Evidence Shows About Patient Activation: Better Health Outcomes and Care Experiences; Fewer Data on Costs," *Health Affairs* 32, no. 2 (2013): 207–214, https://doi.org/10.1377/hlthaff.2012.1061.

59. R. L. Street, G. Makoul, N. K. Arora, and R. M. Epstein, "How Does Communication Heal? Pathways Linking clinician-patient Communication to Health Outcomes," *Patient Education Counselling* 74, no. 3 (2009): 295–301, https://doi.org/10.1016/j.pec.2008.11.015.

60. D. Howell, Z. Rosberger, C. Mayer, et al., "Personalized Symptom Management: a Quality Improvement Collaborative for Implementation of Patient Reported Outcomes (PROs) in "real-world" Oncology Multisite Practices," *Journal of Patient-Reported Outcomes* 4, no. 1 (2020): 47, https://doi.org/10.1186/s41687-020-00212-x.

61. J. Lai-Kwon, E. Thorner, C. Rutherford, N. Crossnohere, and M. Brundage, "Integrating Patient-Reported Outcomes into the Care of People with Advanced Cancer-A Practical Guide," *American Social Clinical Oncology Education Book* 44, no. 3 (2024): e438512, https://doi.org/10.1200/EDBK_438512.

62. N. L. Crossnohere, N. Anderson, J. Baumhauer, et al., "A Framework for Implementing patient-reported Outcomes in Clinical Care: the PROTEUS-Practice Guide," *Nature Medicine* 30, no. 6 (2024): 1519–1520, https://doi.org/10.1038/s41591-024-02909-8.

63. N. Thome, N. Garcia, and K. Clark, "Psychosocial Needs of Head and Neck Cancer Patients and the Role of the Clinical Social Worker," *Cancer Treatment and Research* 174 (2018): 237–248, https://doi.org/10.1007/978-3-319-65421-8_14.

64. S. Li, Z. Gao, Y. Xu, M. Zhang, J. Wang, and X. Bai, "Social Participation and Its Associated Factors Among Head and Neck Cancer Patients: a cross-sectional Study," *BMC Palliative Care* 24, no. 1 (2025): 231, https://doi.org/10.1186/s12904-025-01875-3.

65. P. Pradhan, A. R. Sharman, J. Lacey, et al., "Health Care Utilisation and Unmet Needs in Survivors of Head and Neck Cancer in Regional Australia: a Cross-Sectional Survey," *Psycho-Oncology* 34, no. 1 (2025): e70056, https://doi.org/10.1002/pon.70056.

66. R. W. Gao, J. D. Smith, and K. M. Malloy, "Head and Neck Cancer and Social Media: the Patient Experience and Cancer Survivorship," *The Laryngoscope* 131, no. 4 (2021): E1214–E1219, https://doi.org/10.1002/lary.29074.

67. B. M. Stiles and J. N. Mynard, "Social Media and Your Cancer Patient," *Seminars in Thoracic and Cardiovascular Surgery* 33, no. 2 (2021): 517–521, https://doi.org/10.1053/j.semtcvs.2020.12.014.

68. R. M. Benzo, M. K. Tetrick, J. L. Krok-Schoen, et al., "Digital information-seeking Behaviors Among Cancer Survivors: Associations with Sociodemographic Determinants, Cancer History, and Perceived Health," *J Cancer Surviv* (2025): https://doi.org/10.1007/s11764-025-01927-w.

69. J. O. Atarere, H. K. Onyeaka, O. G. Chido-Amajuoyi, et al., "Social Media Use and Health Promotion Among Cancer Survivors," *Psycho-Oncology* 33, no. 1 (2024): e6299, https://doi.org/10.1002/pon.6299.

70. H. K. Onyeaka, J. Zambrano, R. M. Longley, C. M. Celano, J. A. Naslund, and H. L. Amonoo, "Use of Digital Health Tools for Health Promotion in Cancer Survivors," *Psycho-Oncology* 30, no. 8 (2021): 1302–1310, https://doi.org/10.1002/pon.5677.

Supporting Information

Additional supporting information can be found online in the Supporting Information section.

Supporting Information 1. Supporting File 1: Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist criteria.

Supporting Information 2. Supporting Table 1: Summary table of the 11 identified themes: (i) The Journey Through the Struggle: Navigating Treatment Experiences, (ii) Reinventing Eating: Nutritional Adaptation as a Form of Survival, (iii) The Transformed Body: Loss of Identity, (iv) Reconstructing the Self: Transformation of Identity and Self-Image, (v) Day-to-Day During Cancer Treatment: Resources and Strategies for Oral Toxicities, (vi) The Emotional Landscape: Navigating Psychological Complexity, (vii) The Importance of Family Support and Caregivers During Cancer Treatment, (viii) Long-Term Follow-Up: Navigating Ongoing Medical Surveillance, (ix) Financial Burden of Oral Cancer Treatment: Between the Disease and the Healthcare System, (x) Networks of Connection and the Transformative Power of Social Support, and (xi) Turning Cancer suffering into an Educational Mission: Advocacy and Awareness.