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Considerations for developing supportive care interventions for survivors of head and neck cancer: a qualitative study

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Abstract

Objective: This study aimed to describe considerations for developing supportive care interventions targeted to head and neck cancer (HNC) survivors.

Methods: One-time semi-structured interviews (N=33) were conducted with HNC survivors who had recently finished treatment (n=20) and HNC providers (e.g., physicians, nurses; n=13). Interviews were transcribed verbatim and coded using inductive applied thematic analysis techniques to identify themes.

Results: HNC survivors (75% male; M=61 years old) and providers (54% physicians; 62% female) were unanimously supportive of developing HNC-specific supportive care interventions. Participants described potential benefits of offering interventions at various points throughout the HNC treatment and survivorship trajectory rather than at a single critical time. Many participants preferred group-based interventions because of the high value of peer-support. Others described how group interventions may not be appropriate for all HNC survivors due to risks for negative social comparisons and exacerbated anxiety. Participants suggested topics that should be addressed in HNC-specific interventions including education about acute and long-term side effects, symptom management, nutritional support, relationship/social role changes, grief/loss, and fear of recurrence.

Conclusions: HNC-specific supportive care interventions are critically needed, as survivors experience persistent symptoms and distinct psychosocial concerns that impact quality of life.

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Conflicts of Interest: Dr. Gonzalez is a consultant for SureMed Compliance and KemPharm, and an advisory board member for Elly Health, Inc. Dr. Jim is a consultant for RedHill BioPharma, Janssen Scientific Affairs, and Merck and has grant funding from Kite Pharma. Dr. Kirtane owns stock in Seattle Genetics, Oncernal Therapeutics, and Veru. The other authors have no other relevant conflicts of interest to disclose.

Findings from this study can inform the development of supportive care interventions targeted to the unique psychosocial concerns of HNC survivors.

Keywords

cancer; head and neck neoplasms; oncology; palliative supportive care; psychosocial intervention; qualitative research

Head and neck cancers (HNC; e.g., cancers of the oral cavity, pharynx, larynx) will account for approximately 66,470 new cancer diagnoses and 15,050 deaths in the US in 2022 alone.¹ HNC is associated with significant symptom burden, as the location of tumors can interfere with vital functions including swallowing, breathing, and speaking. Treatments are associated with additional toxicities that can contribute to worse symptom burden, visible disfigurement, and often persist long after treatment.²⁻⁶ HNC survivors also have disproportionately high rates of mental illness,^{7,8} with rates of self-harm and suicide attempts three times higher vs. the general US population.⁹ In one study, HNC survivors described feeling like they were living “in captivity,” with existential concerns exacerbated by constant physical reminders of cancer.¹⁰ Collectively, the burden of acute and long-term symptoms, higher incidence of mental illness, and prevalence of existential concerns contribute to worse health-related quality of life (HRQOL) among HNC survivors relative to other cancer populations.^{6,8} In turn, worse HRQOL predicts increased odds of death.^{11,12} Thus, addressing HRQOL is critical to providing high-quality HNC care and may improve long-term outcomes.

Evidence-based supportive interventions, such as those grounded in cognitive-behavioral therapy and mindfulness, can improve HRQOL for various cancer populations.¹³⁻¹⁶ Yet, very few evidence-based interventions have been developed to address the unique supportive care needs of HNC survivors.¹⁷⁻¹⁹ An important step in developing supportive interventions for HNC survivors is to consider their lived experiences and preferences. This can be accomplished by engaging HNC survivors and other stakeholders in the intervention development process from the start.^{20,21} Thus, the purpose of this qualitative study was to describe considerations and preferences for designing supportive interventions for HNC survivors from the perspectives of HNC survivors and providers. Goals of this study were consistent with Phase 1a of the ORBIT model,²² which emphasizes a flexible approach to developing supportive interventions for new patient populations.

Methods

Participants

HNC survivors were 1) 18 years old; 2) diagnosed with locally advanced HNC; 3) finished chemotherapy (three weekly doses or one bolus dose) and radiation (six weeks) within the past year; 4) expected to survive >three months; and 5) able to speak/read English. Survivors with comorbid psychiatric or neurologic disorders that could interfere with participation were excluded (e.g., active psychosis, dementia). HNC providers were clinical team members that worked with HNC patients (e.g., nurses, physicians), excluding trainees and fellows.

Procedures

The study site's Institutional Review Board (Advarra, Inc.) determined this study was exempt from oversight (Pro00045231). From September 2020 to January 2021, a trained research coordinator worked with staff in Moffitt Cancer Center's Head and Neck-Endocrine Oncology Clinic to identify eligible HNC survivors using purposive and convenience sampling and approached the identified individuals by telephone or in-person. Interested survivors gave verbal consent to participate and have deidentified data published, completed a semi-structured interview from their home via telephone or videoconference, completed an online survey assessing their demographics (e.g., date of birth, gender), and were compensated with a \$50 gift card. Clinical data were collected from survivors' electronic health records (e.g., primary HNC site, treatment history). There were no *a priori* hypotheses regarding survivors' preferences for individual vs. group-based supportive interventions. Thus, individual interviews were conducted (vs. focus groups) to ensure participants' comfort.

Study investigators (LBO, KK) recruited a purposive sample of providers in Moffitt Cancer Center's Head and Neck-Endocrine Oncology Clinic via email. Participating providers nominated other providers as potential participants. Providers gave verbal consent to participate and have deidentified data published, completed a semi-structured interview from their home or office via videoconference, and completed an online survey to report their demographics (e.g., gender, race/ethnicity) and credentials (e.g., highest degree earned). Providers were not compensated. The data that support this study's findings are not publicly available, as they contain information that could compromise participant privacy.

Semi-Structured Interviews

Study investigators (LBO, KK) and a qualitative expert (BA) collaboratively developed semi-structured guides for the interviews with HNC survivors and providers (Supplemental Appendix 1 and 2). Interviews with survivors were conducted by two female post-baccalaureate study team members who were unknown to participants (CB, KS; staff research coordinators) after training from the qualitative expert. Training included conducting two pilot interviews (one per interviewer). The qualitative expert reviewed audio recordings of the pilot interviews, assessed their value and quality, and provided feedback to each interviewer. The pilot interviews were subsequently incorporated into the dataset. Interviews with providers were conducted by a female doctorate-level psychologist with extensive interviewing experience who was unknown to participants (LBO; faculty member). Only the interviewer and participant were present. Participants were informed of the study goals and that the interviewer was a member of the study team. They were provided a general description of a proposed evidence-based supportive intervention (i.e., "a program for people with HNC that will teach skills for managing stress and coping with side effects"), which was based on the efficacy of stress management interventions for improving HRQOL outcomes among cancer populations¹³⁻¹⁶ as well as acknowledgement that HNC and treatment-related side effects have significant negative effects on HRQOL.³ Participants were asked about the potential value of such an intervention and their preferences (e.g., for timing, format, mode of delivery, topics to address). Survivors were also asked about resources they had used to meet their supportive care needs (e.g., support groups, the

internet). Interviews were audio recorded, and no field notes were taken. Participants were continuously recruited and interviewed until no additional themes emerged with subsequent interviews (i.e., thematic saturation was reached) based on interviewer feedback. Twelve interviews are typically sufficient for saturation.²³ No interviews were repeated, and transcripts were not shared with participants for comment or interpretation.

Analyses

Participant characteristics were described with summary statistics using SAS version 9.4 (Cary, NC). Interviews were transcribed verbatim using NVivo's artificial intelligence-assisted software and analyzed for qualitative themes by two qualitative experts (BA, CG) using inductive applied thematic analysis techniques and Nvivo 12 Plus.²⁴ The coders read the interview transcripts, recorded their initial impressions, and developed a deductive preliminary codebook (i.e., codes and definitions), which was refined through multiple rounds of reiterative coding to achieve acceptable intercoder reliability ($Kappa=0.80$). Then, the coders conducted line-by-line coding of all transcripts. Emergent codes and subcodes were inductively identified and included in a second round of coding. Discrepancies were resolved through consensus, coded data were organized into major themes, and representative quotes were identified. Reporting was informed by CORE-Q guidelines.²⁵

Results

Participant Characteristics

We approached 26 eligible HNC survivors and $n=20$ (77%) consented to participate ($n=4$ unreachable/passively declined, $n=2$ too overwhelmed). We approached 13 HNC providers and all (100%) consented to participate. Interviews were 39–149 minutes for survivors and 29–60 minutes for providers. Tables 1 and 2 show the participants' characteristics. Survivors were an average of 61 years old and predominantly male, White, and non-Hispanic. Providers were mostly female, White or Asian, non-Hispanic, and included physicians, registered nurses, an advanced practice nurse practitioner, a registered dietician, and a speech-language pathologist.

Qualitative Themes

Four major themes were identified: 1) HNC survivors and providers were unanimously supportive of developing supportive interventions for HNC; 2) Supportive interventions are needed at multiple points throughout HNC treatment and survivorship; 3) There are benefits and drawbacks of group-based interventions; and 4) Different topics should be prioritized depending on the timing of interventions. Each theme is described next with representative quotes (see Supplemental Appendix 3 for additional quotes).

HNC survivors and providers were unanimously supportive of developing supportive interventions for HNC.

All survivors acknowledged a need to develop HNC-specific supportive interventions that focus on stress management, symptom management, and coping. They described how interventions could provide opportunities to express difficult emotions, provide and receive peer support, learn about what to expect at different stages of treatment and recovery, and

develop helpful coping strategies. Most survivors were enthusiastic about participating in supportive interventions:

“I wish it had been available to me. I would have volunteered for something like that.” (S001; male, HPV+ oropharynx cancer)

“It sounds really good, it really does, especially the managing stress part. That’s more universal.” (S005; female, HPV+ nasopharynx cancer)

A subset of survivors (n=5) indicated that they were supportive of developing HNC-specific interventions, but they would not personally participate due to preferences for keeping their challenges private or having an existing support network that met their needs:

“I think a lot of people would like a resource like that, and I think it would be very beneficial... I don’t really like to talk about my personal life at all, but I think it’s really necessary and helpful for someone else.” (S015; male, HPV+ oropharynx cancer)

Similarly, all providers indicated that HNC-specific interventions could provide a designated and safe space for survivors to offer and receive peer support, ask questions, and learn effective strategies for managing common anxieties and side effects. One provider cautioned that researchers and clinicians should have realistic expectations for survivors’ engagement, given other high priority demands on their time (e.g., financial stressors):

“I think that it is certainly needed and I think patients would benefit from [a supportive intervention] a lot... but on the flip side... typically HNC patients, they come from lower socioeconomic status... they may not have time... they’re struggling trying to make their ends meet or worried about their finances.” (P507; physician)

Supportive interventions are needed at multiple points throughout HNC treatment and survivorship.

There was no consensus regarding a single critical time to offer supportive interventions. Rather, participants suggested that interventions should be offered at multiple times, starting before treatment initiation and throughout the survivorship trajectory. Several survivors (n=7) and providers (n=6) described how interventions *before* treatment could proactively provide information and skills for managing common side effects that patients could then implement during treatment. However, providers cautioned that pre-treatment interventions must not add unnecessary burden during what is already an overwhelming time. A subset of survivors (n=4) noted that it would be beneficial to connect newly diagnosed patients with patients further along in their treatment:

“The minute the doctor says ‘cancer’ to you, they should be given a flyer that says, ‘here is your support group.’ ... If I had been able to sit down with an actual survivor right at the beginning and they told me, ‘Here’s what to expect’ ... that would have been hugely beneficial.” (S001; male, HPV+ oropharynx cancer)

A few survivors (n=4) and providers (n=2) described how interventions *during* treatment should focus on education about side effects and how to effectively manage them,

because this is likely when many patients experience their onset. Providers also noted that patients may be most receptive to interventions during treatment because the overwhelming treatment planning period has passed. A few survivors (n=3) and one provider described how interventions *after* treatment should focus on long-term side effects, social readjustment, and fear of cancer recurrence. The provider described how survivors have frequent interactions with their clinical teams during treatment, but interactions become less frequent post-treatment and may leave survivors at risk of feeling unsupported:

“Two or three months after they complete treatment, that’s when I think they need more of the support. Because when they’re going through treatment, we’re there every day for them. It’s after treatment finishes when I think they don’t want to be forgotten.” (P504; registered nurse)

Finally, several survivors (n=6) and providers (n=4) described how interventions at *multiple timepoints* as part of an ongoing program or based on treatment milestones could create opportunities to reinforce important information and skills over time. They emphasized that not all survivors will be able to engage with interventions at the same point in their care and stressed the importance of flexible options:

“Three times: before, during, and after [HNC treatment]... [HNC] affects different people differently... I think reinforcing things, that would be useful.” (S016; male, HPV+ oropharynx cancer)

“I think it will be different for different people... there isn’t a one-size-fits-all. There isn’t a moment in time that works for every single patient.” (P511; physician)

There are benefits and drawbacks of group-based interventions.

Most survivors (n=11) and providers (n=9) preferred interventions offered in a group or hybrid format (i.e., a mix of group and individual sessions). Survivors explained that the only way to truly understand what they endure is to experience it firsthand. Thus, peer support is highly valuable and could help survivors feel validated, encouraged, and not alone in their challenges. Providers agreed that survivors provide critical information and peer support to one another that others (e.g., providers, family) cannot. Thus, group interventions could help survivors develop accurate expectations for possible treatment-related challenges based on others’ lived experiences and aid in creating a sense of community:

“It’s comforting to know that there’s a group of people out there that have gone through the same thing that you’ve gone through... And one-on-one is great, but I think the group setting is more beneficial.” (S007; male, HPV+ oropharynx cancer)

“A lot of [patients’] symptoms as far as physical or the ways to eat and things like that, they really need each other’s support for that. And [providers] can only tell them. We have not experienced it ourselves.” (P503; advanced practice nurse practitioner)

However, survivors who had previously interacted with other HNC survivors described conflicting emotions; while some found comfort in talking to others about their shared experiences, others were frightened by other survivors’ stories, particularly when discussing

acute and long-term side effects. Some survivors actively avoided interacting with other HNC survivors:

“Depending on where you are in your treatment, you may not be physically in a good place... You look like you’re not well... And I try to steer clear of [support groups] for that purpose, not to have those images back in my head.” (S005; female, HPV+ nasopharynx cancer)

Participants also noted that survivors’ experiences can vary drastically, and a benefit of one-on-one interventions is that they can be tailored to a given survivor’s particular needs.

Different topics should be prioritized depending on the timing of interventions.

Participants strongly endorsed stress and symptom management as high-priority topics to address, with an emphasis on managing acute side effects, establishing realistic expectations for the resolution of side effects post-treatment, and managing late effects of treatment:

“What to expect along the lines of treatment and at the different stages of treatment. I find that the biggest feedback I get from patients is that it was very helpful to know that. They told me, ‘What you said was going to happen, when it was going to happen, happened.’ And that’s very helpful.” (P501; physician)

“Even though they’re done with their treatment... maybe they’re not done with being haunted by cancer... there are those lingering side effects that haunt patients well after their treatment is done.” (P513; speech-language pathologist)

Survivors expressed a need for high-quality HNC information. They reported most often using the internet to find information about their diagnosis, treatments, and side effects (e.g., websites, forums, podcasts). However, several survivors found that available resources were outdated, fear inducing, or inadequate to prepare them for the realities of treatment. One survivor described a discrepancy between the amount of information available about HNC relative to information available about other cancers (e.g., breast):

“When I was diagnosed with breast cancer 20 years ago, I mean, everybody supports breast cancer. Unfortunately, there wasn’t much out there on HNC.” (S013; female, HPV- nasopharynx cancer)

Participants also emphasized the importance of addressing social aspects of HNC, such as how relationships may change, strategies to improve communication, and approaches to re-socialization post-treatment. Several survivors shared how HNC negatively affected their intimate relationships and suggested that support for partners/caregivers would be valuable:

“Managing your relationships with your family and your friends, because I found it really, really easy to turn off the world when I was in the middle of all of this... I think managing relationships is a big challenge, especially your relationship with your spouse, because they’re going through it, too... You’re enduring [HNC], but they’ve got to sit there and watch you waste away.” (S001; male, HPV+ oropharynx cancer)

Several participants discussed the importance of nutritional education and support during and after treatment. Other suggested topics included establishing a “new normal” post-

treatment, addressing grief and loss (e.g., of functionality, relationships), and managing fear of cancer recurrence. Most participants reported there are no specific topics to avoid. However, providers cautioned that interventions should avoid directly comparing the experiences of one survivor to another, because experiences can vary drastically.

Discussion

Findings underscore a prevailing need for supportive interventions that target the unique experiences of HNC survivors. Participants emphasized that interventions should be available and targeted to survivors' changing needs at multiple timepoints across the HNC survivorship trajectory. For example, high-priority intervention targets before treatment may include fear of the unknown and what to expect with treatment. Post-treatment, high-priority targets include adjustment to a "new normal" and expectations for the resolution of lasting side effects. Across time, stress and symptom management were endorsed as highly important, and survivors unanimously identified HNC education as a top need.

Findings are consistent with recent systematic reviews, which concluded that the few existing supportive interventions for HNC survivors grounded in cognitive-behavioral therapy (e.g., stress and symptom management) and psychoeducation have the strongest empirical support for improving HRQOL.^{18,19} However, past studies are limited by low recruitment rates (e.g., <75%), small sample sizes, and limited dissemination beyond feasibility and single-arm pilot trials.¹⁸ Critically, HNC survivors in our study described a lack of reliable information about HNC on the internet, which was their main information source beyond the clinical team. This is consistent with a 2009 study, in which Ni Riordian and McCreary²⁶ found that, of the top websites related to HNC, less than half met all JAMA standards for evaluating websites (i.e., attribution, authorship, currency, disclosure).²⁷ Moreover, none achieved the highest score for quality of information according to the DISCERN instrument,²⁸ with information about HRQOL lacking from most websites.²⁶ A follow-up analysis found that the quality of internet HNC information had not improved.²⁹ Until more high-quality educational resources are developed and available publicly, the onus of HNC education falls largely on the clinical team. Supportive interventions with an emphasis on HNC education are one way in which to meet this need without adding additional burden to clinicians.¹⁸

Participants reported heterogeneous preferences for group-based vs. one-on-one supportive care. Many providers assumed that survivors would find comfort in hearing the stories of other survivors, and indeed some survivors highly valued peer support. Yet others expressed hesitations. The extant literature largely lacks attention to HNC survivor interactions, but according to social comparison theory,³⁰ people in ambiguous situations turn to peers for information by which to judge their own status. Depending on the target of comparison (e.g., someone perceived as better or worse-off) and the interpretation (i.e., similar or contrasting), social comparisons can negatively affect HRQOL.³¹ Thus, while group-based interventions could validate HNC survivors' lived experiences, they may also have inadvertent adverse effects for some. Future work should carefully consider the role of social comparisons in this population.

Researchers and clinicians must also consider the ongoing shift in HNC patients' sociodemographic characteristics. Historically, HNC was most prevalent among older males and associated with tobacco and alcohol use.³² However, as the incidence of HPV-related HNC has increased over the past several decades, so have cases among female and younger patients.^{33,34} Consequently, treatment paradigms and side effect profiles have shifted. Moreover, regardless of HPV status, HNC survivors may experience more feelings of self-blame and stigma than other cancer populations due to perceptions that lifestyle choices (e.g., substance use, sexual behaviors) are associated with HNC risk.³⁵ Stigma may be exacerbated by interactions between HNC survivors and others (e.g., family, friends, acquaintances) and also by interactions between survivors themselves. This adds additional complexity that must be considered in the context of intervention development.

Study Limitations

The HNC survivors were mostly male, White, non-Hispanic, diagnosed with oropharynx cancer, and had HPV+ disease. Survivors were identified using purposive and convenience sampling from a single comprehensive cancer center, and data on recruitment rates by HPV status were not available. Given these limitations, findings must be confirmed among more heterogeneous samples (e.g., by gender, race/ethnicity, HPV status) to ensure that themes generalize to diverse HNC subpopulations and individuals treated in other academic settings or community clinics.

Clinical Implications

Findings may guide the development of HNC-targeted supportive interventions. However, the clinical implications are challenging, as this study revealed heterogeneous preferences for the content and delivery of interventions across a wide trajectory of HNC treatment and survivorship milestones. Creative solutions may be needed for intervention development and implementation, such as delivering interventions using eHealth technologies³⁶ and/or using stepped-care approaches to funnel resources to patients most in need.³⁷ Studies will also benefit from leveraging dissemination and implementation frameworks during intervention testing and scale-up. For example, the RE-AIM framework assesses the reach, effectiveness, adoption, implementation, and maintenance of interventions via both qualitative and quantitative outcomes.^{38,39} Leveraging the RE-AIM framework may yield key insights into how to integrate multi-component interventions into clinical care with minimal disruption to existing workflows.

Conclusions

This study highlights the critical need for supportive interventions developed for and in collaboration with HNC survivors. Findings revealed heterogeneity of intervention preferences regarding timing, format, and high-priority topics, indicating a one-size-fits-all approach to HNC supportive interventions has the potential to leave many with unmet needs. Researchers and clinicians must adapt flexible approaches to intervention development and delivery.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

HNC survivors' demographic and clinical characteristics (n=20).

	Statistic
Age, years; M (SD)	60.6 (9.0)
Male; n (%)	15 (75)
White; n (%)	18 (90)
Non-Hispanic; n (%)	20 (100)
Married; n (%)	13 (65)
College graduate; n (%)	11 (55)
Employed full-time; n (%)	9 (45)
Annual household income; n (%)	
<\$20,000	3 (15)
\$20,000–\$39,999	3 (15)
\$40,000–\$59,999	1 (5)
\$60,000–\$100,000	4 (20)
>\$100,000	7 (35)
Did not answer	2 (10)
Smoking history; n (%)	
Previous smoker	7 (35)
Current smoker	1 (5)
Never smoker	12 (60)
Primary HNC site; n (%)	
Oropharynx	14 (70)
Nasopharynx	3 (15)
Oral cavity	1 (5)
Supraglottic larynx	1 (5)
Ethmoid sinus tumor	1 (5)
HPV+; n (%)	14 (70)
Months since diagnosis; M (SD)	9.1 (8.7)
Months since treatment completion; M (SD)	5.6 (4.0)
Surgery; n (%)	2 (10)
Chemotherapy regimen; n (%)	
Cisplatin	19 (95)
Carboplatin + Paclitaxel	1 (5)
Chemotherapy doses; M (SD)	5 (2)
Total dose of radiation therapy, gray; range	60–70
Interview length, minutes; M (SD)	75 (23)

Table 2.

HNC providers' demographic characteristics and credentials (n=13)

	Statistic
Female; n (%)	8 (62)
White; n (%)	6 (46)
Non-Hispanic; n (%)	11 (85)
Role on clinical team; n (%)	
Physician	7 (54)
Registered nurse	2 (23)
Advanced practice nurse practitioner	1 (8)
Speech-language pathologist	1 (8)
Registered dietician	1 (8)
Interview length, minutes; M (SD)	41 (9)

Note. Percentages may not sum to 100 due to rounding.

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