

MULTIDISCIPLINARY APPROACHES TO HEAD AND NECK CANCER CARE



Executive Summary



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Executive Summary

The Association of Cancer Care Centers (ACCC), in partnership with the Head and Neck Cancer Alliance (HNCA) and the American Society of Radiation Oncology, came together to identify and explore barriers to optimal care coordination for patients diagnosed with head and neck cancer to improve care delivery. Using a multifaceted approach—including a landscape analysis, surveys of 247 patients and 206 health care professionals, focus group discussions, and a multidisciplinary roundtable involving multiple stakeholders—ACCC examined clinical gaps and barriers in care delivery, unmet needs, timely cancer diagnosis and care, disparities impacting access to care, and strategies to mitigate the stigma of the disease.

Key findings from the program revealed significant barriers in the timely diagnosis of head and neck cancer; in particular, patients in rural areas face limited access to specialists, lower levels of health literacy, and other unique challenges. Delays in treatment were attributed to factors such as inadequate insurance coverage, lack of dental insurance, and scheduling difficulties. Communication between patients and clinicians and financial barriers were also identified as factors that impact how patients with head and neck cancer receive care.

The initiative highlights the essential role of nurse navigators in coordinating multimodal treatment and addressing the logistical, psychosocial, and financial needs of patients. Many cancer programs—especially in lower-volume settings—lack dedicated navigators for the management of head and neck cancer. Comprehensive supportive care services, including mental health, nutrition, speech and swallowing therapy, and post-treatment rehabilitation, were deemed critical to the provision of optimal care. Additionally, the program evaluated the importance of caregiver support since patients often experience a lengthy journey from treatment to recovery.

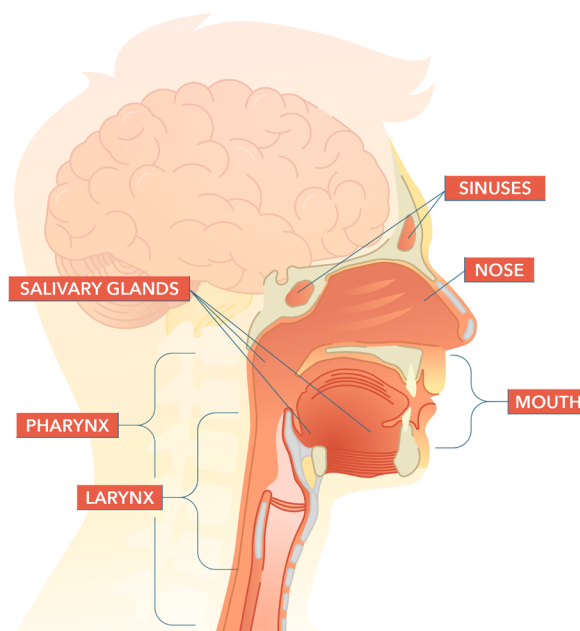
Key areas of opportunity were identified, including:

- Expanding access to care in rural and underserved areas
- Introducing mobile clinics, telehealth services, and community health workers to bridge gaps in care delivery
- Enhancing care coordination and communication
- Strengthening supportive care services
- Addressing financial toxicity
- And educating healthcare providers.

By advancing these opportunities, ACCC and its partners can work toward improving the quality of care delivered to patients with head and neck cancer across diverse practice settings.

Background

Head and neck cancer, a complex disease requiring a multidisciplinary approach to care, represents approximately 4% of all cancers in the United States.¹ **Tumors may occur in or around the mouth, throat (pharynx), voice box (larynx), nose, sinuses, and salivary glands.**² Advances in treatment and a multimodal approach (that may include surgery, radiation therapy, systemic medical therapy with chemotherapy, targeted therapy, and/or immunotherapy) are improving outcomes. However access to therapies and effective coordination of multidisciplinary care remain obstacles. Patients with head and neck cancer may also experience significant challenges and distress associated with disease symptoms: obstacles include difficulty eating and communicating, as well as other psychosocial factors that can reduce quality of life.³



Diagnosis of Head and Neck Cancers

Timely diagnosis of head and neck cancer remains a significant challenge due to several barriers. These include limited access to primary care providers, lack of local ear, nose, and throat (ENT) specialists, and patients' reluctance to seek care when symptoms arise. Long travel distances and lengthy wait times to see specialists further exacerbate these issues, particularly for patients in rural areas. Inadequate health and dental insurance coverage also contribute to delays in diagnosis.

Patients reported shock and anxiety upon receiving their diagnosis, highlighting the need for improved communication between patients and healthcare providers. In the ACCC survey, little more than half (56%) of patients *strongly agreed* that their clinicians explained their diagnosis in a way that they could understand, and nearly half (48%) of patients

believed that members of their treatment team communicated and coordinated care *very well*. Additionally, some patients reported feeling overwhelmed by the responsibility of making treatment decisions, indicating a need for improvements in shared decision-making processes.

"Access to dental care is so limited in our country. I think if everyone went to the dentist, we would see a lot of these things sooner. But [many people do not have] dental insurance, or they're scared..."

– Physician and Focus Group Participant

Multimodal Treatment Planning

Effective multimodal treatment planning for head and neck cancer involves coordination among various specialists including surgeons, medical oncologists, and radiation oncologists. High-volume centers typically have well-established multidisciplinary teams that meet regularly to discuss patient cases and coordinate treatment plans. **In the ACCC survey, 72% of respondents from high-volume cancer programs reported using a multidisciplinary clinic model in which patients may see multiple specialists during a single visit.** High-volume centers reported a strong sense of collaboration and frequent communication among team members at tumor boards and via electronic messaging. Members of the treatment team at these centers often include social workers, dietitians, speech and swallowing therapists, and mental health counselors, ensuring a comprehensive approach to patient care.

In contrast, lower-volume centers and those located in rural settings reported challenges in maintaining such coordination due to a lack of specialists and resources. In the ACCC survey,

50% of 39 patients living in rural areas reported needing to travel for treatment because there were no options close to home. In these situations, treatment plans may be fragmented, with medical or radiation oncologists taking ownership of the treatment plan while nurses or navigators coordinate care and make referrals. The absence of regular multidisciplinary meetings can lead to inconsistencies in care delivery. Moreover, patients may receive conflicting medical advice from different specialists who are not working collaboratively to coordinate care for the patient.

"I was very fortunate... my surgeon, medical oncologist, and radiation oncologist communicated so well that it was like a continuous river of information going back and forth between them."

– Patient and Focus Group Participant

Care Coordination and the Importance of Navigators

Care coordination is essential for providing optimal head and neck cancer treatment. Dedicated head and neck cancer navigators at high-volume centers are more efficient when coordinating multimodal treatment, arranging transportation, and making referrals for needed services. These navigators play a crucial role in ensuring that patients receive timely and coordinated care. **Yet in the ACCC survey, just 38% of cancer programs reported having dedicated navigators for patients with head and neck cancer.**

Navigators are vital members of the multidisciplinary care team, providing essential support to patients throughout the treatment journey. Clinical navigators, often with an education background and experience in nursing or nutrition, coordinate care across the team and serve as primary points of contact for patients. They assist with scheduling, referrals, and connection of patients with support services.

Many lower-volume settings lack such navigators, leading to gaps in care coordination. This issue is particularly pronounced in rural areas, where patients often need to travel long distances and stay in temporary housing to receive treatment. The need for improved care coordination in these areas is essential for addressing the unique challenges faced by patients living in rural areas.

Centers that lack navigators may consider training for and incorporation of community health workers (CHWs) as members of the care team. CHWs and lay patient navigators, who may not have clinical backgrounds, can help patients to navigate the health care system, access financial resources, and connect community members with health care resources. CHWs can help patients to navigate technology and access telehealth services, which is particularly important for those having limited digital literacy or access. The role for CHWs may be limited based on the extent of training and the scope of responsibilities defined by health care facilities. Opportunities may exist to expand these roles, providing more comprehensive training and measuring their impact in care delivery.

“Our nurse navigator is integral to taking care of our patients and making sure that they’re staying on track... they help our staff make sure that the patient gets scheduled and set up with the support services they need. We rely on them to help facilitate collaboration and communication with other members of the treatment team.”

– Physician and Focus Group Participant

Supportive Care Services

The initiative emphasized the need for comprehensive supportive care services for patients diagnosed with head and neck cancer and their caregivers. Psychosocial distress, including anxiety, depression, and adjustment challenges, is common among patients with head and neck cancer due to visible changes in appearance, communication difficulties, and treatment-related adverse effects. **In the ACCC survey, 55% of patients reported that their diagnosis had a large impact on their ability to eat food, 29% strongly agreed that their diagnosis negatively impacted their ability to perform daily activities, and 24% strongly agreed that their diagnosis negatively impacted their social interactions.**

These findings highlight the importance of tailored psychosocial distress screening protocols, support groups, counseling, patient and caregiver education, speech and swallowing therapy, body image and self-esteem workshops, mindfulness and relaxation techniques, and collaboration with mental health professionals for patients with head and neck cancer. Additionally, nutritional support and access to dietitians are critical components of supportive care.

Organizations like HNCA and Support for People with Oral and Head and Neck Cancer (SPOHNC) provide valuable resources, such as support groups, financial assistance, and educational materials for patients and caregivers.

Dental Insurance Gaps and Financial Toxicity

Many patients lack dental insurance or do not have adequate health insurance to meet all their care needs. According to the American Dental Association, nearly a quarter of adults aged 19 to 64 years lack dental insurance.⁴ **In the ACCC survey, only 35% of patients strongly agreed that their health insurance provided adequate coverage for all their medical needs.** The lack of dental insurance coverage may delay dental evaluation clearance before radiotherapy; impact how patients receive care for oral treatment-related complications; and delay treatment for issues such as radiation caries and osteoradionecrosis. Insurance coverage also must address nutritional needs such as tube feedings and referrals to dietitians. Study results show a correlation between overall survival and health insurance status among patients with head and neck cancer.⁵

Patients and cancer clinicians acknowledge that financial toxicity is a huge concern due to the out-of-pocket expenses for treatment, medical supplies, and logistics (eg, travel). **In the ACCC survey, 62% of clinicians reported that the top area to improve care delivery would be to provide patients with more financial resources.**

“We have a shortage of mental health professionals and many of them do not take health insurance. Patients can’t afford to pay out-of-pocket for therapy.”

– Nurse and Focus Group Participant

Care and Recovery After Treatment

Post-treatment care for patients with head and neck cancer involves the management of a range of issues including speech and swallowing therapy, nutrition, lymphedema, pain management, and mental health services. Navigators or survivorship care teams often coordinate this phase of care, emphasizing the importance of multidisciplinary collaboration and patient education.

Patients reported mixed experiences with post-treatment care, with some expressing gratitude for the support from family, friends, and peer networks. However, there is a need for better survivorship support and planning to address the emotional and mental health challenges that patients face after completing treatment.

The recovery phase is critical for patients with head and neck cancer, who often face ongoing medical and emotional challenges related to their treatment. Regular follow-up with multidisciplinary teams, including speech and swallowing therapists, dietitians, and mental health professionals, is essential for monitoring disease recurrence and managing long-term adverse effects. Support groups and peer networks

can also play a significant role in helping patients adjust to life after treatment.

The initiative also emphasized the need for continued support and resources for caregivers since the treatment journey may be lengthy and filled with emotional challenges as patients struggle to cope with their diagnosis and treatment. During the focus groups, several participants commented about the need for better support systems for family members and other caregivers who shoulder a significant burden and may experience emotional distress or be at risk of losing their jobs for taking multiple days away from work.

“Patients with head and neck cancer struggle the most after treatment is over... Some of them really struggle with mental and emotional health.”

– Social Worker and Focus Group Participant

Disparities in Care

Patients in rural areas face unique challenges accessing head and neck cancer care. Suicide rates, which are higher among patients with head and neck cancer, are particularly elevated for those living in rural areas.⁶ These individuals typically must travel long distances; in addition, they have limited access to specialists and inadequate transportation and lodging options. In particular, transportation is a significant barrier for those who require frequent visits for treatments like radiation therapy or access to mental health support services. Some patients may need to stay in temporary housing for extended periods while receiving treatment, which can be a significant burden. Solutions like telehealth and satellite clinics may help bridge some of these gaps. For instance, telehealth can provide behavioral

health support and follow-up consultations, reducing the need for travel. Satellite clinics staffed by visiting specialists can also improve access to care.

Social determinants of health (SDOH) have a profound impact on clinical outcomes, underscoring the need for targeted interventions and systemic changes to address these inequities. Diversifying the clinical workforce can enable better patient-clinician relationships, increase trust, and improve communication. Greater efforts are needed to ensure equitable access to high-quality care for all patients with head and neck cancer regardless of their geographic location, socioeconomic status, or cultural background.

Opportunities for the Future

The initiative identified several key areas of opportunities for improving multidisciplinary head and neck cancer care:

- **Expanding access to care in rural and underserved areas.** This includes exploring innovative models such as mobile clinics, telehealth services, and CHW programs. Access to specialists such as ENT surgeons and mental health professionals remains an ongoing challenge in remote areas.
- **Addressing travel and lodging needs.** Many patients travel considerable distances to receive some or all of their care for head and neck cancer. Ongoing efforts are needed to provide transportation and lodging support for patients who need to spend time away from home as they receive treatment.
- **Enhancing care coordination and communication.** This involves establishing or strengthening multidisciplinary teams, presenting patient cases at tumor boards, implementing care pathways, and using technology to facilitate communication among team members. Ensure that patients with head and neck cancer have access to a navigator. Cancer programs may explore ways to train and integrate CHWs into care teams.
- **Strengthening supportive care services.** This includes increasing access to mental health professionals, dietitians, speech and swallowing therapists, and other supportive care providers, as well as developing and implementing tailored psychosocial distress screening protocols. Additional resources and interventions are needed to meet the unique needs of caregivers.
- **Addressing financial toxicity and disparities in access to care.** This involves advocating for policy changes, expanding financial assistance programs, and addressing SDOH that impact access to care. Improving health and dental insurance coverage can reduce delays in diagnosis and treatment, ensuring that patients receive timely and appropriate care. Cancer programs can establish financial advocacy programs to help patients navigate the costs of care and access available resources. Clinician training programs can aim to increase the diversity of the health care workforce to better reflect the patient population and address disparities in care.

- **Educating healthcare providers and the public.** This involves raising awareness about head and neck cancer symptoms, risk factors, and treatment options as well as providing education to health care providers on the importance of early detection and referral to specialized care. Greater efforts with preventive measures such as providing human papillomavirus vaccinations, promoting smoking cessation, and limiting alcohol consumption may significantly decrease the incidence of head and neck cancer.⁷ Partnerships with local organizations, such as religious groups and community centers, may be effective ways to provide health education and support services.
- **Emerging cancer screening technologies.** Routine screening for head and neck cancer is not typically performed, but circulating tumor DNA tests and other innovations may detect head and neck cancer early.

This initiative underscores the need for enhanced care coordination and access to supportive services, and it highlights the crucial role of navigators and the importance of addressing financial barriers. By addressing these areas, ACCC and its partners can work towards improving the quality of care and outcomes for patients with head and neck cancer across diverse practice settings.

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