

Addressing Barriers to Comprehensive Supportive Care for Patients with Head and Neck Cancer: A Mixed-Methods Study

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BACKGROUND


Patients with head and neck cancer (HNC) often face significant physical, emotional, and psychosocial challenges, compounded by barriers to comprehensive supportive care. This mixed-methods study, led by the Association of Cancer Care Centers (ACCC) in collaboration with the Head and Neck Cancer Alliance and American Society for Radiation Oncology, identified gaps in supportive care and care coordination for patients with HNC.

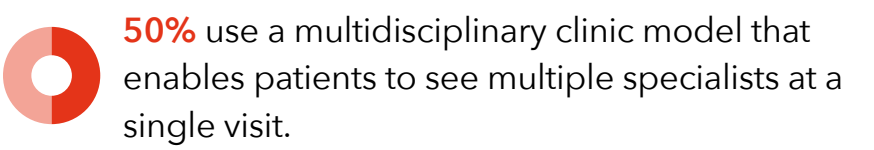
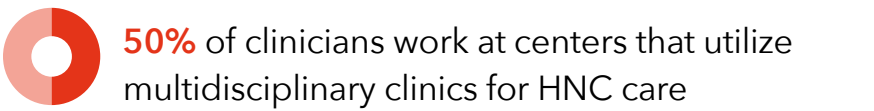
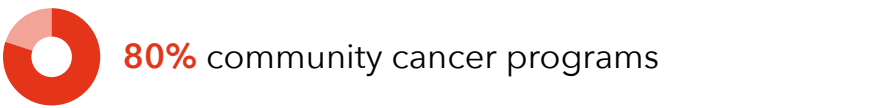
METHODS


Using an explanatory sequential design, data were collected from November 2023 to May 2024 to evaluate barriers to optimal HNC care. Likert-scale, multiple choice, and open-ended questions were used to assess gaps in supportive care services, disparities in access, and strategies to improve care delivery. Findings were analyzed and discussed at a multidisciplinary roundtable (n=24) to identify actionable interventions for enhancing supportive care in HNC management.

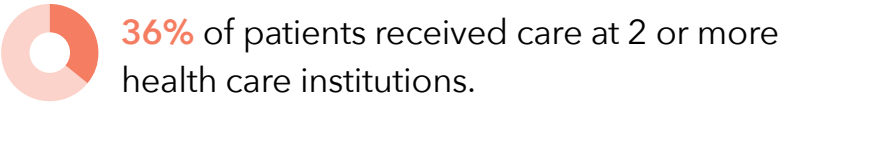
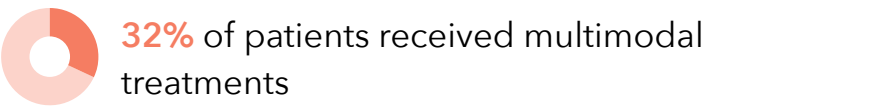
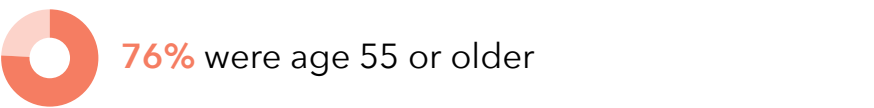
Methods Included:
Landscape Analysis
Patient-Facing Survey
Provider-Facing Survey
Focus Groups
Multistakeholder Roundtable

Who Completed the Surveys?

 **206 health care professionals**
from 42 states



 **247 patients and caregivers**
from 40 states



CONCLUSIONS

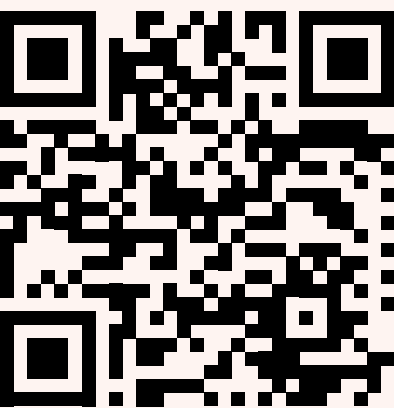
The study identified several key areas of opportunity for improving multidisciplinary HNC care:

- **Expand access to care** in rural and underserved areas through telehealth services, mobile clinics, and community health worker programs
- **Address travel and lodging needs** by connecting patients with available resources and support to ensure access to care
- **Enhance care coordination and communication** through collaborative care models and technology use
- **Ensure patient access to a HNC navigator**
- **Strengthen supportive care services** from diagnosis through survivorship
- **Address financial toxicity and disparities** in access to care
- **Educate health care providers and the public** by raising awareness about HNC symptoms, risk factors, and treatment options, with a focus on early detection.

Addressing these gaps requires targeted strategies by clinicians, patients, and patient advocacy groups. This research will be used to inform future educational programming and the development of interventions to improve care.

ACKNOWLEDGMENTS

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Explore additional resources on head and neck cancer by scanning the quick response (QR) code or visiting accc-cancer.org/headandneckcancer.

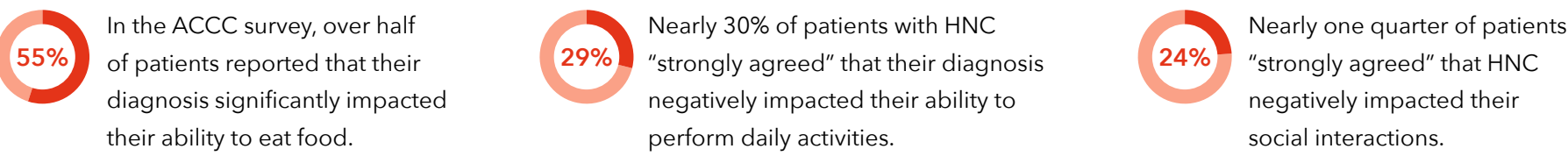
This project was made possible with support from EMD Serono.

RESULTS




“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

Supportive Care Needs




Challenge	Potential Solutions
Patients with HNC often experience significant physical and psychosocial challenges , including pain, scarring, disfigurement, difficulty swallowing, speech problems, and emotional distress. However, access to supportive care services (eg, mental health counseling, nutrition therapy, speech therapy) is not readily available for many patients.	 Integrated Care Teams: Integrate support staff into care teams, provide training for health care providers on identifying and addressing support needs, and schedule regular meetings to discuss specific patients who have complex care needs.
	 Support Groups: Connect patients and caregivers with advocacy organizations that offer local and/or virtual support groups.
	 Patient-Reported Outcomes: Establish a program to collect patient-reported outcomes and use this information to track symptoms, identify distress, and initiate early interventions or referrals.
	 Survivorship Clinics: Develop comprehensive, post-treatment survivorship clinics with mental health, nutrition, speech therapy, rehabilitation, and other supportive care services and ensure patients know how they can access these services.



Travel and Other Logistical Challenges

Challenge	Potential Solutions
Patients in rural areas or who live far from treatment centers face significant logistical and financial challenges related to travel , lodging, and being away from home. These obstacles can lead to treatment delays, interruptions, and increased stress for patients and caregivers.	 Transportation Assistance: Provide or subsidize transportation options, such as gas cards, ride-sharing services, or shuttle services to help patients access treatment.
	 Lodging Assistance: Partner with local organizations or establish dedicated facilities to provide affordable or subsidized lodging options for patients and caregivers during treatment.
	 Satellite Clinics and Telehealth: Establish satellite clinics to offer care in remote areas. Utilize telehealth for follow-up appointments and consultations, where appropriate.

Caregiver Support

Challenge	Potential Solutions
Caregivers may face their own challenges —including emotional distress, financial burden, and lack of support—while they play a crucial role in the patient’s care journey.	 Screening and Assessment: Train health care providers to assess caregiver needs and proactively offer support and resources.
	 Education on the Caregiving Role: Remind health care providers that caregivers often experience a lack of psychosocial support during their long journey of caregiving.
	 Caregiver Support Programs: Develop and implement programs for caregivers, including support groups, educational resources, and respite care.

“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