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The Oncology Nurse Navigator as "Gate Opener" to Interdisciplinary Supportive and Palliative Care for People with Head and Neck Cancer

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Abstract

Background: People living with head and neck cancer frequently encounter challenges in their treatment with multimodality therapy and risk of side effects. Ensuring access to and use of interdisciplinary supportive and palliative care is often challenging given the complex needs and unfamiliar treatment experiences.

Objectives: Describe the *CARE Clinic Plus ONN Gate Opener* as an approach to enhance access to and utilization of interdisciplinary supportive and palliative care for people living with head and neck cancer.

Discussion: The Cancer Appetite and Rehabilitation (CARE) Clinic model offers interdisciplinary supportive and palliative care to patients at risk, including those living with head and neck cancer. The oncology nurse navigator (ONN) serves as gate opener, ensuring that those individuals receive appropriate assessment with personalized education and referrals for timely prehabilitation, rehabilitation, and palliation.

Conclusions: The ONN, as a gate opener for people living with head and neck cancer, offers an innovative approach to elevate the patient experience and improve clinical outcomes through interdisciplinary supportive and palliative care when working in collaboration with the CARE Clinic. Guidance for other centers to adapt our model to meet their patient and family needs concludes our discussion.

People diagnosed with cancers of the head and neck benefit from rapidly advancing, multimodal therapeutic options.[1] Conversely, these individuals are likely to encounter personally and clinically significant side effects in addition to potential symptoms of their disease. Complex side effects and symptoms combine with prediagnosis health status, potentially altering capacity to complete cancer treatment and maintain functional status

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and quality of life. Declining functional status, escalating malnutrition, and uncontrolled side effects potentiate high healthcare utilization, making the patient experience more complicated.[2,3] Finally, latent long-term sequelae lead to the likelihood that health and functional status change permanently, limiting overall value of any success in cancer treatment.[4]

Access to and uptake of interdisciplinary supportive and palliative care promote optimal cancer care, patient experience, and clinical outcomes. Silos are common in the organization of head and neck cancer care. Recognition of these silos outlines opportunities to improve organization of care for these individuals who are often at high risk of complications and delayed transition to palliative care.[5] Standards for clinical oncology care support early integration of supportive and palliative care in cancer treatment. Most relevant standards similarly acknowledge that early assessment and intervention is critical for those with high-risk malignancies and advanced disease, such as those with squamous-cell malignancies of the head and neck, the most common pathology diagnosed in North America.[1,6,7] Persistent obstacles to early access and full utilization of supportive and palliative care remain a clinical challenge, despite acknowledgment of the critical role supportive and palliative care play in optimal patient experience and cancer care outcomes for people living with head and neck cancer.[2,5]

Oncology nurse navigators (ONNs), in an increasingly well-established role aimed at optimizing cancer care and patient experience, offer potential advantages in advancing interdisciplinary supportive and palliative care for those diagnosed with head and neck cancer. The ONN role is now nationally well accepted and widely disseminated throughout American cancer centers.[8,9] Although detailed studies of oncology nurse navigation in head and neck cancer care are only beginning to emerge, clinical experience implies that the role offers important value but that impact in interdisciplinary supportive and palliative care for these patients and their family members remains incompletely described.[10] Critically, the ONN role suggests a means to bridge silos, introduce supportive and palliative care early, and individualize head and neck cancer care with goals of improved patient experience, enhanced clinical care coordination, and favorable healthcare utilization.[5]

> Over the past decade, our model expanded from a focus on cancer cachexia to broad palliative and supportive care management for people living with and after a cancer diagnosis.

In this paper, we describe the innovation of introducing an ONN role into our interdisciplinary supportive and palliative care program to optimize access and utilization for people living with head and neck cancer. We first described our Cancer Appetite and Rehabilitation (CARE) Clinic almost a decade ago.[11] The clinic, part of our overarching supportive and palliative care program, aimed to improve nutrition and achieve rehabilitation for people at risk of cachexia, malnutrition, and deconditioning during and after cancer treatment. Now, with more than 10 years of clinical experience with this interdisciplinary program integral to supportive and palliative care provision in our center, we report our efforts to focus on the specific needs of people with head and neck cancer and the clinical advance of introducing an ONN to the interdisciplinary team.

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Methods

This paper uses clinical program description, supported by relevant clinical standards and current literature, to highlight the ONN role in our model of interdisciplinary supportive and palliative care for people living with head and neck cancer. We review the current CARE Clinic model and then outline each participating discipline's contribution to the model. We then delineate the ONN role, highlighting interactions with patient, family, and interdisciplinary team colleagues and calling out key supportive and palliative supportive care assessment and management strategies for people living with head and neck cancer across the cancer care continuum. Finally, the paper concludes with a summary of implications for practice and guidance for replication of the CARE *Clinic Plus ONN Gate Opener* model to enhance supportive and palliative care in other cancer care programs.

Findings

CARE Clinic Model

In 2007, the leadership team in supportive and palliative care for our cancer program established the Cancer Appetite and Rehabilitation (CARE) Clinic, a multidisciplinary cancer cachexia clinic.[11] The CARE Clinic was among the first to address cancer cachexia in a comprehensive and proactive fashion, using an interdisciplinary team. Over the past decade, our model expanded from a focus on cancer cachexia to broad palliative and supportive care management for people living with and after a cancer diagnosis. A follow-up paper described a gap analysis to evaluate and improve services specifically for those individuals living with and after head and neck cancer.[12] As a result, we redesigned the original model for the clinic we initially reported. The acronym remained the same, but the redesigned program represents an expanding focus, gap analysis, and development of the team needed to meet evolving patient and family needs. Thus, the program is now the Cancer Rehabilitation (CARE) Clinic.

With an original focus on comprehensive assessment and early intervention for cancer cachexia, our present multidisciplinary team is eminently able to care for people living with head and neck cancer. The team includes clinical experts in nutrition, physical therapy, speech and language pathology, and advanced practice nursing who—along with leadership from nursing administration—provide patients and their family caregivers with assessment, intervention, and education matched to the profile of needs commonly experienced by patients with head and neck cancer. Table 1 provides an overview of the role of each team member to deliver interdisciplinary supportive and palliative care to people living with and after head and neck cancer through the *CARE Clinic Plus ONN Gate Opener* model.

Oncology Nurse Navigator

Not surprisingly, because of the historical evolution of the CARE Clinic and the clinical needs of the population served by our cancer center, most people treated in the clinic are living with head and neck cancer. The complexity inherent in multimodality head and neck cancer treatment, including multiple appointments with a range of providers and clinicians, often leads to feelings of burden and confusion among patients and family members. The

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degree of complexity during treatment may breach thresholds of tolerance for some patients and their family caregivers. As a result, they may miss appointments with providers or for treatment. Critically, however, these individuals may feel overwhelmed to the extent that they reject outright appointments for supportive and palliative care services. They are then unable to explore potential benefits of these services. Thus, despite scientific evidence and best practices substantiating value in early interdisciplinary supportive and palliative care, patients in our program—as with many other programs—may not make use of the CARE Clinic and other supportive and palliative care services.[2,5,13] In contrast to the healthcare maxim of needing a gatekeeper to ensure optimal healthcare utilization, the people living with head and neck cancer whom we treat appear to need a "gate opener" to access care and avoid complications.[14,15]

Our cancer center provides ONN services to people diagnosed with a range of cancers, including head and neck cancer. The ONN role became part of our head and neck cancer team in 2016. Organically arising collaboration between the ONN and the CARE Clinic team emerged quickly after introduction of the ONN role. The collaboration logically connects 2 parallel efforts to reduce silos and enhance communication to improve patient experience, streamline processes, and advance quality outcomes. Simultaneously, the ONN team covering all patient populations completed a project to standardize initial patient assessment in relation to relevant standards for oncology navigation. As a result, the ONN role as gate opener for people living with head and neck cancer needing early supportive and palliative care was developed to include:

- Initial comprehensive assessment at time of diagnosis or at first meeting
- Early education needs assessment and foundational education
- Coordination between cancer care providers treating the patient and the CARE Clinic

By meeting individuals early in their treatment trajectory and often perioperatively, the ONN creates an early and trusting connection with patients and their family caregivers. The assessment, education, and referrals that follow through this connection represent gates to care opened.

> ONNs focus on personalizing the patient and family experience, avoiding delays and misuse of supportive and palliative care to reduce distress, improve self-care, and avoid complications.

The idea of the ONN opening gates entails the ONN improving accessibility and usability of health and social care services through a therapeutic relationship coupled with structured assessment, personalized education, and targeted referrals. Gate opening moves beyond the more common notion of gates being kept or managed to improve healthcare utilization. The familiar role of a gatekeeper, frequently used to optimize primary healthcare, is ill suited to the complex structure, multiple processes, and critical timing involved in cancer care. Conversely, in our model, the ONN metaphorically opens gates to care and encourages people living with head and neck cancer to pass through them, taking full advantage of supportive and palliative care services tailored to their needs.

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The ONN focuses on personalizing the patient and family experience, avoiding delays and misuse of supportive and palliative care to reduce distress, improve self care, and avoid complications. In parallel, the ONN becomes a communication director for patients and their caregivers, focused on building an ongoing trusting, therapeutic relationship. Trust, personalization, education, and relationship building aid in opening gates to healthcare. Simultaneously, the ONN aims to remove obstacles that may stand in the way of a patient being able to benefit from the full range of cancer care and supportive and palliative care services available. Quality care for people living with head and neck cancer mandates that both cancer and noncancer healthcare must be fully accessible and easily navigated to be used. Patients, who may frequently not feel well, along with family members and friends who support them, require dedicated support and guidance to access, navigate, and use the healthcare they need.

The rise and success of the ONN role in cancer care underscores that achieving accessible treatment and other services necessitates dedicated, knowledgeable navigation to ensure safe, high-quality care.[9,16] In our model, navigation goes beyond managing scheduling, insurance, transportation, and other logistical dimensions of cancer care. Importantly, our CARE Clinic model and our overarching approach to supportive and palliative care emphasize the role of administrative staff in ensuring accessible and navigable care. Well-informed administrative staff who effect timely clinical appointments and help resolve insurance and financial concerns become essential members of supportive and palliative care. Their actions reduce frustration and distress for patients and their family members when dealing with these matters. The distinction between the responsibilities of administrative staff and the ONN ensures that the ONN, who is most often masters prepared, is able to function at the top of their scope of practice and thus provide optimal care to our patients and their families.

Access to supportive and palliative care, including the CARE Clinic, typically requires education, explanation, and encouragement. We screen patients, including those with head and neck cancer, through our standardized ONN intake assessment for frailty and nutritional compromise. Screening positive for frailty, nutritional compromise, or both then prompts referral to the CARE Clinic for comprehensive assessment and planning intervention. Critically, the ONN opens the gate to supportive and palliative care by describing the CARE Clinic and introducing the team before cancer treatment commences or as soon as possible thereafter. The trusting ONN-patient-family relationship facilitates timeliness and clarity in communication over the course of treatment. Consequently, the ONN is more easily able to intervene and provide appropriate education and referrals to the CARE Clinic and other services should patients experience escalating side effects or worsening disease symptoms. Collaboration between the ONN and the multidisciplinary supportive and palliative care team in the CARE Clinic relies on application of available evidence coupled with relevant best practices to personalize care for each individual. In the CARE Clinic, the team focuses on appetite, nutrition, and functional status, relying on a set of measures drawn from the literature to gauge individual outcomes.[11]

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Dietitian

Nutrition care plays a pivotal role in supporting people with head and neck cancer and achieving optimal clinical outcomes.[17] The oncology specialist registered dietitian (ORD) aims for early intervention, relying on timely referral from the ONN for focused assessment. The ORD typically uses the Patient-Generated Subjective Global Assessment tool when approaching nutrition assessment,[18] an assessment for which the ONN is easily able to prepare patients. The ORD typically collaborates closely with the ONN and with the palliative care nurse practitioner (PCNP) to meet educational and medication needs.

Physical Therapist

The role of physical therapy in oncology rehabilitation is expanding rapidly, shifting toward prehabilitation to support both experience and outcomes for people living with head and neck as well as other cancers.[19–21] The ONN and the physical therapist (PT) work closely with patients and their family caregivers to ensure timely assessment and effective access to home and ambulatory therapy as well as to the CARE Clinic itself. The PT typically performs a baseline exam focusing on cervical spine, shoulder, and posture. The ONN and PT frequently expand their partnership to effect surveillance for those at risk of developing lymphedema, a sequela of treatment that is particularly functionally debilitating for many. Additionally, the focus on assessment and intervention for cancer-related fatigue becomes a priority for the PT and the ONN as a patient's treatment course advances.

Speech and Language Pathologist

The speech and language pathologist (SLP) is commonly among the disciplines best identified by patients and their caregivers as central to a successful experience of head and neck cancer treatment. The SLP addresses speech, voice, and swallowing function at baseline for prehabilitation and later in treatment, as changes in function arise and needs for rehabilitation grow. Assessment includes both clinical and instrumental domains to ensure comprehensive understanding of individual function, needs, and preferences. Nonetheless, the ONN typically needs to open gates for SLP assessment and intervention given that patients and their caregivers may initially be unfamiliar with these clinicians. The ONN and the SLP frequently collaborate to ensure optimal care for those individuals who may encounter barriers to adherence with recommended assessments and home exercises or other challenges. Critically, the ONN often collaborates closely with the ORD and the SLP when patients require enteral feeding or experience symptoms such as odynophagia or trismus, again with the aim of ensuring fully comprehensive care.

The SLP is commonly among the disciplines best identified by patients and their caregivers as central to a successful experience of head and neck cancer treatment.

Palliative Care Nurse Practitioner

The PCNP relies on application of key palliative care principles, supporting medical decision-making, and coordinating complex interdisciplinary care for people living with head and neck cancer. The ONN may arrange an initial visit with the PCNP when the goals of care for a patient are unclear after initial assessment. With that initial referral to the PCNP, the 2 colleagues can collaborate closely and work directly with the patient and

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their family to clarify goals and determine best actions. A joint decision for referral to the CARE Clinic with a focus on prehabilitation or rehabilitation as appropriate, as opposed to revisiting medical decision-making and reorienting the focus of care to be primarily palliative, generally results from such collaboration.

Administrative Leadership

The nursing administration led the development and implementation of the original CARE Clinic and the *CARE Clinic Plus ONN Gate Opener* model. Such leadership includes advocating for and securing funding through institutional budgeting processes and through philanthropic and scientific grant opportunities. Ensuring a sustainable and functional supportive and palliative care program is essential in an era where evidence to support such care accumulates more rapidly than institutional budgets may accommodate. Demonstrating economic benefit of the model further requires a sophisticated quality evaluation strategy, including mapping to avoid serial processes and create parallel processes in line with gate opening. Improvements are not exclusively clinical in nature. The most recent advent in the CARE Clinic is the addition of a dedicated administrative staff member to support the multidisciplinary team, along with clinic organization and growing visit volume.

Case Study – Mr Bearen

A case student best reflects the operation and effect of the CARE Clinic. Mr Bearen (a pseudonym) presented to our emergency department with a painful tongue lesion that he recalls bothering him starting about 4 weeks prior. A biopsy confirmed squamous-cell carcinoma of the oral tongue. CT scans of the face and neck showed an irregular, enhancing mass along the left aspect of the oral tongue with no evidence of lymphadenopathy or distant disease. The discharge instructions directed Mr Bearen to follow up with head and neck surgical oncology.

> The CARE Clinic model appears to make patients feel important, aligning strongly with national and international initiatives about addressing what matters to patients.

The ONN met with Mr Bearen in person 1 week later during his appointment in head and neck surgical oncology. The head and neck surgeon planned a composite resection, including total oral glossectomy and modified radical neck dissection with left anterolateral thigh free flap. Mr Bearen needed a tracheostomy and percutaneous endoscopy tube placed at the time of resection. Plans included discharge to a subacute rehabilitation facility after his inpatient postoperative recovery. Additional plans were for follow-up routine home care. His treatment plan also included concurrent chemotherapy and radiation after postoperative recovery. During their time together, Mr Bearen said he had pain, rated as 10 out of 10, at his tongue lesion. He had been using Vicodin several times each day since his emergency department admission and said he had difficulty swallowing and eating because of the pain. The ONN's assessment is presented in Table 2.

Mr Bearen's clinical situation and life circumstances illustrate how the ONN's initial assessment works to achieve early referral to the CARE Clinic. Without timely referral from the ONN, normative care processes too easily direct him to focus on completing surgical

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and postoperative care while neglecting supportive and palliative care. A potential delay in comprehensive ORD, PT, and PCNP assessments might then total weeks if not months under usual approaches to referrals for these services in healthcare systems around the country. Although SLP referral and assessment might occur at the surgical visit for preoperative assessment, the lag in the interdisciplinary bundle of services for conjoint assessment and planning represent a clinically significant gap in best practices. That gap increases the possibility of missed opportunities to intervene in prediagnosis morbidity consequential in cancer care. The ONN opens gates in cancer and healthcare, taking full opportunity to support prehabilitation and early rehabilitation.

Implications for Practice

The ONN gate opener role, combined with the CARE Clinic model, offers a feasible, innovative approach to improve patient experience and clinical outcomes through integrated interdisciplinary supportive and palliative care for people living with and after head and neck cancer. The ONN becomes the team member who opens gates to better cancer care and healthcare for people like Mr Bearen through a systematic approach to program development, clearly organized team structure, and established care processes, including ONN assessment. Assessing individual needs, establishing a trusting therapeutic relationship, and working directly with the interdisciplinary supportive and palliative care team appear essential to success from the clinicians' perspectives. Patient and family perspectives, garnered through quality improvement evaluations, suggest that the focus on the person and family in this model are key. The CARE Clinic model appears to make patients feel important, aligning strongly with national and international initiatives about addressing what matters to patients.

Other cancer centers may benefit from adapting our model of the *CARE Clinic Plus ONN Gate Opener* to their needs. Our experience in designing, developing, and sustaining this approach relies on strong nursing administration leadership and leverages an interdisciplinary model. The model itself is person- and family-centered. Engaging in a needs assessment to define need, identify barriers, and cultivate stakeholders creates a strong foundation. Our experience underscores that early conversations with colleagues in billing and electronic health records are fundamental to sustainability, focusing initially on documenting and billing for interdisciplinary team visits. Developing vision and mission statements supports clear communication with patients and family members and consistent messages to colleagues and the wider institution. The interdisciplinary care model mandates team members function at the top of their licensed scope. Thus, team members make timely, appropriate referrals to other supportive services, advanced practice providers, and physicians as necessary. For example, the SLP refers patients to gastroenterology directly, and the PT refers patients directly to the occupational therapist or to physiatry. Top of license function promotes parallel rather than serial clinical processes. Additionally, direct referrals from the ONN and care team builds collaboration with a wider network of specialists as well as primary care providers.

In summary, the *CARE Clinic Plus ONN Gate Opener* offers a novel means to marry oncology nurse navigation with nurse-led interdisciplinary supportive and palliative care.

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Our experience reflects high levels of patient and family satisfaction with the model and a decade of success in institutional terms, as we evolved this model from when we first reported it[11] to the present. We track patient satisfaction scores and conduct focus groups to assess the elements of this model, including the ONN role and the CARE Clinic. Those data, while unpublished, represent high patient and family satisfaction and qualitative expressions of valued experiences. Future clinical research, combined with ongoing quality improvement programming, is necessary to detail the effects of this model and to identify and define appropriate metrics necessary for further development and dissemination. We welcome colleagues interested in replicating our model to contact us by e-mail (Sarah Kagan, skagan@nursing.upenn.edu; Mary Pat Lynch, MaryPat.Lynch@PennMedicine.upenn.edu).

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Table 1

CARE Team Members and Core Role Elements in Care Provided to People Living with Head and Neck Cancer

Team Member	Core Role Elements
Oncology Registered Dietitian	• Assess nutritional status and establish nutritional goals • Education on management of nutrition-related symptoms with emphasis on mucositis, dysphagia, and xerostomia • Based on speech and language pathologist recommendations, provides options for texture modifications and nutritional supplements • Evaluation of current treatment plan and risk of needing a feeding tube • Assist patient in decision-making if tube feeding is recommended
Physical Therapist	• Education on strategies to manage cancer-related fatigue and sleep hygiene, including the use of energy-conservation techniques • Individualized exercise program to address weakness, balance deficits, shoulder dysfunction, range of motion impairments, and endurance • Referrals for outpatient physical therapy for lymphedema or cancer-related fatigue • Work and lifestyle modifications • Durable medical and adaptive equipment recommendations
Speech and Language Pathologist	• Assessment and treatment of voice and resonance disorders; articulation and speech intelligibility, including needs for compensatory strategy training or alternative/augmentative communication • Assessment and treatment of swallowing, including clinical and instrumental assessment via modified barium swallow study or fiber-optic endoscopic evaluation of swallowing • Treatment may include diet modification, prophylactic or rehabilitative swallowing exercises, compensatory swallowing strategies and maneuvers, and postural changes • Assessment and treatment of cognitive communication disorders • Measurement of patient- and clinician-reported outcomes for communication and swallowing function • Referrals to other healthcare providers as needed
Palliative Care Nurse Practitioner	• Assessment and management of symptoms related to cancer and cancer treatment • Assessment and management of emotional coping • Assistance with medical decision-making • Anticipatory guidance regarding expected treatment-related symptoms • Caregiver support • Coordination with oncology specialists and other healthcare providers
Nursing Administrative Leadership	• Ensuring appropriate staffing, multidisciplinary participation, and space • Advocating for and securing funding • Advocating for supportive care disciplines • Identifying key partnerships within healthcare system • Facilitating opportunities for nursing education

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Table 2

Oncology Nurse Navigator Assessment

Past Medical History	Seizures; chronic back pain; osteoporosis; chronic obstructive pulmonary disease; motor vehicle accident 4 years prior with right femur fracture; fall 2 years prior with humerus, shoulder, and elbow fractures.
Social History	20 pack-year history of smoking cigarettes. History of alcohol use greater than 35 drinks per week for several decades. Currently drinking 6 standard alcoholic drinks per day with occasional binge drinking of up to 20 drinks in a day. Currently disabled, having worked as a union carpenter with exposure to asbestos. Has received Social Security disability for decades.
Medication Review	Manages medications independently and does not identify barriers.
Gender, Cultural, and Religious Identification	Self-identifies as a man. Does not identify any religious affiliation.
Language and Learning Preferences	Reads and writes English. His preference is for pictures and reading. He is motivated to learn about his disease.
Home/Functional Assessment	Lives with his wife in a 3-story home with a bathroom and bedroom on the first floor. Requires minimal assistance with activities of daily living, using a cane for walking and a shower chair. Does not self-identify as a caregiver. He has limitations in shopping and cooking his own meals.
Support System	Wife is a nurse working 2 part-time jobs and is patient's primary caregiver. Three adult children and multiple siblings live nearby. No one residing with him has a history of drug misuse.
Nutrition	Five percent weight loss in 1 month and 14% weight loss in 6 months. Reduced oral intake due to pain and dysphagia.
Coping	States "Nothing I can really do. I just have to deal with it," becoming tearful and expressing concern about leaving his wife alone.
Finances	Currently able to meet financial obligations. His wife expresses concern about loss of income due to missing work for appointments and transportation.
Insurance	Adequately insured.
Transportation	Does not drive. His wife is available most days to drive him but is concerned about missing work.
Frailty Screening	Negative for frailty by Flemish version Triage Risk Screening Tool.[22] Reviewed summary of barriers to care, necessary initial education, and a plan for intervention with Mr Bearen.
Barriers	Physical disability from chronic back pain and history of syncope with seizures; fall risk; need for pain and symptom management; malnutrition; dysphagia; current tobacco use; current alcohol use; need for transportation assistance; need for emotional support; need for financial assistance.
Education	Smoking cessation, alcohol counseling, emotional support, and anticipatory guidance provided regarding expected treatment plan and transitions in care.
Intervention	CARE Clinic for nutrition, fall risk, dysphagia, and symptom management assessment. Transportation assistance provided through local charity organization. Refer to Social Services for emotional support and assessment and financial counseling.