Title Page

**Head and Neck Cancer Survivorship Care in the United States: Existing Programs and Future Directions**

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Abstract

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University of Pittsburgh, 2019

**Abstract**

Cancer survivorship begins at the time of a cancer diagnosis launching an extremely complex journey of acute therapies, treatment-related toxicities and financial hardship. Currently, the United States has no formalized system to aid patients as they transition from active treatment to long-term recovery. This fragmented system forces patients to navigate a confusing array of survivorship programs, if one is even available in their community, making cancer survivorship of great public health significance. Head and neck cancer patients have unique treatment-related toxicities that can be challenging for primary care providers to address on their own. There must be a new focus on care that responds to the changing needs of the head and neck cancer population. This paper reviews cancer survivorship programs across the country and highlights the experience of the UPMC Head and Neck Cancer Survivorship Clinic. There are some early changes in the payment structures of health insurance programs, including Medicare and Medicaid, that are opening the path forward for increased access to new forms of survivorship care, but more progress is needed. Health policy changes mirrored after chronic care management may incentivize providers to offer the coordinated-care these patients desperately need. Further study is required to truly understand the clinical and financial benefits of a robust head and neck cancer survivorship program.

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# Introduction

The 2006 publication *From Cancer Patient to Cancer Survivor: Lost In Transition* by the Institute of Medicine (IOM) suggests that significant gaps exist in the care cancer patients receive after the acute phase of their treatment has concluded. (1) This seminal report outlines how patients are currently getting lost as they transition from acute cancer treatment to life after cancer. The National Coalition for Cancer Survivorship recognizes cancer survivorship starting at the time of cancer diagnosis and continuing through the remainder of the patient’s life. (2) Unfortunately, the existing fee-for-service structure of the United States (US) healthcare system does not incentivize providers to coordinate care at this critical time of transition away from acute treatment, leaving much of the burden on the patients and their caregivers. The lack of coordination by providers as the patient transitions creates a “non-system” made up of distinct silos rather than a well-developed, interdependent system.

The 2006 IOM report provides ten recommendations for improving cancer care, most of which are common-sense but often lost in practice. The more patient-facing recommendations included; (a) raising awareness for the needs of cancer survivors and associated programing, (b) developing comprehensive survivorship care plan summaries with established follow-up plans, (c) use of evidence-based medicine to manage the late effects of treatments, and (e) quality assurance programs to evaluate the efficacy of the these survivorship programs. (1) Survivorship programs have been developed at many large National Cancer Institute (NCI) designated comprehensive cancer centers, including in head and neck cancer. (1,3–7) The format and structure of these programs vary significantly, but they all primarily focus around survivorship care plans and surveillance recommendations. Only a select few focus on other aspects of a patient’s quality of life such as health promotion and well-being. Unfortunately, many centers do not have formalized program of survivorship services.

This paper aims to review cancer survivorship care in the United States with a specific focus on head and neck cancer (HNC). The UPMC Head and Neck Cancer Survivorship Clinic will be specifically featured and explored. Finally, policy changes and directions for next steps in academic investigations will be discussed.

# Current Landscape of Cancer Survivorship Care in United States

The thesis of the Institute of Medicine Report *From Cancer Patient to Cancer Survivor: Lost In Transition* outlines how the American healthcare system consistently fails patients after their primary or acute treatment of cancer concludes. (1) With few incentives for coordination of care outside of specialized programs from private third-party payors or Centers for Medicare and Medicaid Services (CMS) programs, the fragmented nature of the US healthcare system creates a “non-system” of care delivery, a series of silos without meaningful interactions to support patients. (1) The typical post-cancer patient experience starts at follow-up with their oncologist with a primary focus of surveillance for recurrence. Consensus guidelines, such as those developed by the National Comprehensive Cancer Network (NCCN), provide a framework for cancer surveillance by cancer type, but often do not specify the type of provider. (8) For example, NCCN guidelines recommend 5 years of active, frequent surveillance for head and neck cancer patients. (9) Little consideration is given for treatment-related toxicities, health promotion and other well-being related concerns when cancer surveillance or treatment is the primary focus. (10,11) Often, there is only passing thought given to a care plan after the formal cancer treatment has concluded, despite numerous recommendations by national organization promoting development of survivorship care plans. (1,12–14) Busy oncology practices have patients lost to follow-up, or they provide sporadic or episodic care that does not provide a meaningful, value-added experience. (11)

Survivorship care in a more formalized way generally takes the form of three different versions; (a) primary care based with specialty care collaboration, (b) disease-specific survivorship clinics, or (c) comprehensive, non-disease specific clinics. (10) While each type has their benefits, no one program type has been demonstrated to be the most effective for cancer survivors.

## Primary Care Focused

Primary care-centered survivorship care models work in coordination with specialist services such as surgeons and oncologists to incorporate the ongoing cancer survivorship and surveillance care into existing chronic disease management. Often, there is a transition from the oncologist to the primary care physician (PCP) at some arbitrary point in the patient’s care. Some oncology practices may continue to follow the patients for longer periods of time, but eventually, a transition becomes necessary. Ideally, the PCP is operating in collaboration with the other specialists involved in the patient’s care. (14)

This model fits best into the existing fee-for-service framework without significant modification or novel reimbursement methods. However, primary care physicians are already burdened with extensive preventative medicine tasks and chronic care management. (15) Without guidance in the form of a survivorship care plan, these physicians may be ill-equipped to manage surveillance for new or recurrent cancers or late-term toxicities that can be expected after treatment. (10) Further, these PCPs would be expected address survivorship for all cancer types with patients within the already time-limited clinic visits. This model also requires the oncologists to prepare survivorship care plans for the PCPs to reference. The survivorship care plans do require a significant investment of resources to produce in order to be clinically useful. (16) Oncology practices would have to devote time and resources to develop the plans and communicate with PCPs, all of which may not be a reimbursable clinical encounter.

Primary care-based follow-up does have the advantage of starting with an established provider-patient relationship, presumably in the patient’s local community. PCPs are also aware of other medical conditions outside of the patient’s cancer care and are equipped to coordinate the care of the patient with other local providers. PCPs may also have a better understand of local support structures and resources that would directly benefit patients and caregivers.

## Comprehensive and Disease-Specific Survivorship Clinics

Disease-specific clinics offer an array of services tailored to a patient’s particular cancer type. These types of clinics are typically offered by larger academic institutions or comprehensive cancer centers. An example of this approach is the UPMC Head and Neck Cancer Survivorship Clinic. (17) Disease-specific clinics can develop very detailed survivorship care plans because of their in-depth knowledge of one specific disease processes and the various treatment-related toxicities. Because they focus on a narrow set of diseases, survivorship plan development may be less resource intensive for each patient. These clinics can be structured as a one-time visit to develop a comprehensive survivorship care plan, or they may follow patients over a longer period of time. The former approach is largely oncologist-staffed clinics while the latter type is typically staffed by advanced practice providers (APP) such as nurse practitioner or physician assistant. (11)

Unfortunately, the majority of cancer care in the United States occurs outside of large academic centers or comprehensive cancer centers which leads to a significant disparity in survivorship care. When specialty survivorship clinics do exist, they often do not address issues outside of cancer. They may not be integrated with care options outside of their home institution to allow them to facilitate additional follow-up care in the patient’s own community, as a local PCP may be able to do.

Multi-disciplinary, comprehensive survivorship clinics are very similar to the disease specific clinics but do not focus on a specific cancer type. These clinics can also function as a one-time consultation resource or as a longer-term, follow-up clinic with the same types of providers available. There is no general consensus regarding the types of providers that should be established in either comprehensive or disease-specific clinics. Most of the established clinics are staffed most commonly with APPs. (10,11)

## Cost of Cancer Care

A diagnosis of cancer is not only physically and mentally punishing, but it can also be financially devastating for the patient. Even with increasing insurance coverage, a cancer diagnosis can result in significant financial hardship. Davidoff et al. reported that Medicare enrollees with cancer had 47% higher out-of-pocket expenses when compared to enrollees without cancer. (18) One retrospective study of patients in Washington state found that patients with cancer were 2.65 times more likely to file for bankruptcy than those without cancer. (19) This effect was worse in the younger population when the average debt-to-income ratios are higher when compared to older, Medicare-eligible patients. In fact, a systematic review in 2016 found a significant portion of cancer survivors experience some sort of financial toxicity, 28-48% when using monetary measures or 16-73% when using subjective measures. (20) Worse yet, the financial burden of cancer is significantly associated with a lower health-related quality of life. (21,22) Patients experiencing a financial burden are more likely to forgo continuing medical care which can affect overall survival and quality of life.

Comparing patients with all types of cancer to those with head and neck cancers, non-head and neck cancer patients have a 23% higher median income than those with head and neck cancer. Yet, HNC patients have significantly higher medical expenditures. (23) Much of these findings are likely attributable to the lower socioeconomic status and reduced access to care of the HNC population. Reduced access alone may not explain the higher expenditures. A study examining medical expenditures of head and neck cancer patients in the Surveillance Epidemiology and End Results (SEER) database found that mean cost per patient ranged from $51,857 to $82,181 without any significant change in median survival suggesting that more care does not change the outcome of for HNC patients. (24)

While it may seem obvious that patients with cancer have higher healthcare expenditures, a Canadian study demonstrated that only half of HNC patients were able to return to their previous employment status while one third did not return to work at all. (25) In contrast to the US, Canada does provide universal health insurance coverage. However, the Canadian study does demonstrate the scope of employment status changes that occur with HNC patients. The majority of Americans receive employer-sponsored health insurance, so changes in employment status represent a significant burden from treatment. This may lead to even higher financial toxicity as a direct result from cancer care. Short et al. interviewed nearly 1,500 cancer survivors regarding changes in the employment status and found that 13% of patients quit working due to cancer within the first four years after diagnosis. (26) The authors examined a wide breadth of cancer types and found that HNC patients were particularly at risk for a change in employment status.

# Head and Neck Cancer Survivorship Care

## Overview of Head and Neck Cancer and Survivorship

Head and neck cancer has shown an increased incidence as well as an increase in 5-year overall survival from 52.7% in the 1980s to 65.9% in the 2000s with HNC patients now representing 4% of all cancer survivors. (27,28) HNC refers to an array of cancers found in the beginning of the aerodigestive tract with 90% of them occurring on the mucosal surface of ﻿oral cavity, oropharynx, and larynx with a squamous cell carcinoma histology. (29) Treatment for HNC has also been changing in recent years as there has been a shift away from surgical intervention after the Department of Veterans Affairs (VA) study indicated that chemotherapy followed by radiation vs. surgery plus adjuvant radiation demonstrated similar tumor control rates. (30) After the VA study, the Intergroup Radiation Therapy Oncology Group 91-11 trial demonstrated that patients with stage III or IV glottic or supraglottic squamous cell cancer had no difference in laryngectomy-free survival when comparing induction chemotherapy followed by radiation treatment, chemoradiation or radiation therapy alone. (31) The study further demonstrated increased local control and organ preservation in the chemoradiation arm. Chemoradiation has now emerged as the primary treatment for nasopharynx, oropharynx, and hypopharynx. (32) Human papillomavirus (HPV) related HNC is also on the rise in the US which may have significant impact on the treatment course for patients as they are more sensitive to current non-surgical treatment modalities than non-HPV related cancers. (33) With a transition to chemoradiation and organ preservation, treatment-related toxicities in both the acute and long term are increasing. (34) In fact, survivors have higher death rates from noncancer causes than the head and neck cancer itself. (27,35)

There is a growing need to create a multidisciplinary approach to all cancer survivorship but specifically head and neck cancer due to the delayed treatment toxicities. (1,35,36) Unfortunately, HNC survivorship care in the US is primarily limited to major cancer care centers and may not be meeting the complete needs of the patients and their families. (36)

## Treatment-Related Toxicities

### Long-Term Toxicities

Head and neck cancers often present at an advanced stage and are typically treated with surgery, chemotherapy or chemoradiation. The most common toxicity found in patient-reported outcomes (PRO) were difficulties or changes in swallowing function during and after treatment. (37) Xerostomia, stomatitis, candidiasis, and dental caries are all both long- and short-term treatment-related toxicities seen in the HNC population. (38) Long-term dysphagia is also a significant concern; however, the mechanism for this dysphagia may not the same as short-term dysphagia. (32) Fibrosis of the soft tissues over time may lead to a more chronic, insidious dysphagia resulting in silent aspiration or other related complications. In a study from our institution, survivors 6 years or more from last treatment showed an increase in dysphagia on patient-reported outcomes. (32) Additionally, the same study showed patients 15 years or more had similar swallowing dysfunction as those patients undergoing acute treatment. HNC survivors are at an increased risk of major depressive disorder which can affect treatment compliance. Misono and colleagues found that cancer patients are a higher risk of suicide with oral cavity, oropharynx and larynx cancers among the top 4 disease sites for suicide rates. (39) A SEER registry study demonstrated that despite improvements in overall survival, head and neck cancer patients experienced a 27% increase in risk of suicide over the past decade. The authors noted HNC patients are twice as likely to die from suicide than patients with other types of cancers, likely due to unique treatment needs and treatment-related toxicities. (39)

A study in the Netherlands examined the cause-specific excess mortality in head and neck cancer patients after treatment, and while their study found the highest non-cancer deaths were related to cardiovascular disease, they found that alcohol- and tobacco-related conditions contributed to significantly to excess mortality. (40) This demonstrates the need for survivorship care to focus on health promotion in addition to oncology specific concerns. Additionally, patients with cancer of the oropharynx were at two times higher risk of dying of pneumonia compared to ones with oral cavity cancer. (40) This finding may be related to swallowing dysfunction and subsequent aspiration leading to pneumonia. However, comprehensive data on the long-term toxicities are largely lacking for head and neck cancer patients.

## Unmet Needs of Head and Neck Cancer Patients

Head and neck cancer patients are living longer which may result in an increase in treatment-related toxicities or other needs not previously recognized. A Canadian comprehensive interview study by Giuliani et al. found that 45% of survivors felt they needed additional assistance to help coordinate their overall cancer care. (25) This study found that the needs for HNC patients differed from other cancer types suggesting the exigency for disease-specific survivorship programs. Henry et al. used self-reported outcomes on validated questionnaires to demonstrate 68% of head and neck cancer survivor patients have unmet needs; the majority of these unmet needs are psychological in nature. (41) However, the survey instruments used did not specifically include an option for coordination of care as a potential unmet need. It is reasonable to surmise, however, that some of the 68% of the patients’ psychological unmet needs were actually related to care coordination concerns. As providers, it is critical to consider all factors of patient needs, even non-clinical ones.

## Current Head and Neck Cancer Survivorship Care in US

There are several survivorship programs at major academic institutions across the country that focus on head and neck cancer. These programs have a variety of approaches from disease-specific clinics utilizing complex treatment algorithms to general survivorship clinics providing one-time consultations for cancer survivors.

### Memorial Sloan Kettering Cancer Center

Memorial Sloan Kettering has an established institution-wide survivorship initiative to monitor recurrence or new cancers and manage treatment-related toxicities. (4) The institution offers a nurse practitioner-based disease-specific clinic that provides recurrence screening, behavior modifications, new cancer screening, and identification and management of long-term effects of cancer treatment. The clinic also provides treatment summaries and survivorship care plans for patients and as a reference for primary care physicians. This clinic follows patients on a regularly-scheduled basis and offers transition procedures to non-survivorship specific providers as needs decrease. No additional providers are present in the clinic, so referrals are made to other providers if and when necessary.

### The University of Texas MD Anderson Cancer Center

The University of Texas MD Anderson Cancer Center (MD Anderson) provides an array of disease-specific evidence-based survivorship algorithms which are made publicly available. In Houston, they provide a nurse practitioner-based survivorship clinic for patients who completed their treatment course with MD Anderson. (42) For HNC, patients can enter the survivorship program, generally 30 months after treatment for cancer, if post-treatment imaging shows no evidence of disease. Patients are evaluated by an HNC nurse practitioner with referrals or consults, as necessary, for late-treatment effects, risk reduction, early detection of other cancers or evaluation of psychosocial functioning. MD Anderson publicly states that the algorithms are made available so patients can discuss the implications with their primary care providers. (6)

### Dana-Farber Cancer Institute - Dana–Farber/Harvard Cancer Center

Dana-Farber Cancer Institute, in Boston, has both an adult and child survivorship program that consists of multi-disciplinary providers who develop individual survivorship care plans in collaboration with primary care providers. (7,43) Patients are not required to have received their original treatment at Dana-Farber. A comprehensive care plan is prepared for all patients which is then used by the patient and primary care physicians to guide future care. The clinic is a one-time consultation visit. Unlike at their the Head and Neck Cancer Treatment Center which follows HNC patients in active treatment, the Dana-Farber survivorship clinic is not disease-specific.

### The Ohio State University Cancer Care Center – James

OSUCCC – James has a general survivorship clinic focused on providing services ranging from supportive counseling and genetic counseling to nutrition education or symptom management. (5) The institution also provides survivorship clinics in a select few disease-specific areas including head and neck cancer (additional referral is required). These advance practice provider-based clinics develop survivorship care plans at the end of the clinic visit. These care plans outline course of action without any follow-up within the survivorship clinic (a one-time, consultation approach). OSUCCC – James also provides online caregiver and survivor support groups ranging in topics from infertility to quality of life issues. (44)

# UPMC Head and Neck Cancer Survivorship Clinic

## Clinic Overview

The UPMC Head and Neck Cancer Survivorship clinic (the clinic) is a comprehensive clinic that utilizes patient-reported outcomes to drive individualized care administered by an array of providers in a single clinic visit. The clinic is located in the third floor of the Eye and Ear Institute Building on the campus of UPMC Presbyterian Hospital. It opened in December 2016 and serves approximately 600-700 patients per year from throughout the region. This is a unique clinic compared to peer institutions because the multi-disciplinary staff offers a multitude of screenings, therapies and education, all completed during one visit. This clinic is open to all individuals with head and neck cancer regardless of whether they are pre-treatment or decades post-treatment. The clinic is open one day each week, 48 weeks per year. It shares a clinic space with two other sub-specialty otolaryngology clinics, which allows for shared administrative and operational staff.

During a typical visit, patients begin by answering several patient-reported outcome (PRO) instruments to assess the degree of symptoms over a wide range of topics. These are validated instruments used for head and neck-specific patients including the E. All patients receive a head and neck cancer screening examination by an otolaryngologist followed by a need-specific evaluation or educational sessions from a specialized provider. Visits are tailored to each specific patient based on their current course in treatment and details reported on PRO instruments. The otolaryngologist can perform a fiberoptic endoscopic evaluation of swallowing (FEES) in conjunction with a speech-language pathologist. Other providers available in the clinic include audiology, physical therapy, speech-language pathology, geriatric medicine and dentistry.

## Clinic Providers

### Head and Neck Oncology Nurses

The care of enrolled patients begins well before the arrival at the clinic door. The oncology nurses work with the otolaryngologist to create a treatment history report from the patient’s electronic medical record. This includes compiling information from the inpatient, outpatient and oncology-specific electronic medical records from the UPMC system. This information is critical for the development of a survivorship care plan. The nurses also review responses from the PRO instruments to guide providers seen during each visit.

### Audiology

All patients have a hearing screening performed by an audiology assistant regardless of their reported hearing ability. This screening allows the head and neck oncology nurses to review PROs without interruption of the clinic’s work flow. Any abnormalities found during the hearing screening will result in a referral to an audiologist for a formal audiogram conducted the same day. Given the co-location of the clinic with an otology clinic, specialized otology nurses are also available to address any cerumen impactions at the same time. The clinic can also service and clean existing hearing aids, on-site at no cost.

### Speech-Language Pathology

Speech-language pathologists (SLPs) provide dysphagia screening for at-risk patients based on responses to the EAT-10 or if concerns are otherwise identified during the course of the visit. SLPs also perform a FEES with the otolaryngologist when a formal assessment of swallowing function is warranted. SLPs provide patient education on exercises to maintain swallowing function during the course of cancer treatment. Ideally, patients are evaluated prior to initiation of any chemotherapy or chemoradiation to establish baseline characteristics. Therapy can then target perseveration of function rather than recovery. If ongoing regular services are needed, a referral is made to a provider in the community with experience treating head and neck cancer patients. Staff selects the appropriate community provider and schedules an appointment on behalf of the patient, obviating the need for the patient to locate a suitable SLP on their own.

### Physical Therapists

Physical therapists provide screenings for mobility problems or musculoskeletal dysfunction during their evaluation, specifically evaluating the neck, shoulders, jaw and nearby structures. Given the incidence of neck pain, neck disability and soft tissue fibrosis in the head and neck cancer patients, some patients require a referral to a UPMC Centers for Rehab Services (CRS) location for ongoing physical therapy outside of the clinic. CRS providers are also certified in lymphedema management and can develop treatment regimens as necessary. Patients are contacted by CRS within 24 – 48 hours to schedule an appointment.

### Dentist

A licensed dentist provides routine dental screenings for patients, particularly those peri- or post-treatment. The dentist provides patient education on ways to address common complications after treatment such as xerostomia willy apply a fluoride varnish when indicated. Patients with immediate dental health needs are referred to a clinic at the University of Pittsburgh School of Dental Medicine with some same-day appointments available.

### Medical Consultant

The medical consultant is a board-certified internal medicine physician who reviews responses to the PHQ-8 and GAD-7, assessing for depression and anxiety. The physician also reviews the patient’s medication list to provide education about indications, side-effects and how to best take the medications. Special attention is made to polypharmacy issues and mitigation of possible adverse outcomes. Based on the consultation, the physician may elect to initiate new medications, particularly for depression or anxiety, based on the consultation. This information is also actively relayed to the primary care provider to ensure continuity of care.

### Future Providers

Given the prevalence of behavioral health pathologies within the head and neck cancer population, a behavioral health specialist will be brought into the team to address patient-raised issues or concerns identified on the PRO including the PH Q-8 and GAD-7. The behavioral health provider is able to expand the services already provided by the medical physician allowing him or her to focus on medication management, reducing polypharmacy and offering education.

## Survivorship Care Plans and Treatment Summaries

Survivorship care plans are the core function of the UPMC clinic. These plans are comprised of various documents which are started prior to the patient’s visit and updated with their current, past and future treatment plans. Survivorship care plans serve as the foundation of the treatment summaries that are generated after every patient visit to the clinic. These summaries include all specialist-specific instructions for the patient. Contact information for all providers seen, all patient education materials written by a provider, and information on external referrals are given to the patients at discharge. These documents together, in aggregate, fulfill the mission of survivorship care plans and coordination of follow-up care recommended by the 2006 Institute of Medicine report and the American College of Surgeons Commission on Cancer Standards. (1,13)

## Financial Structure

The survivorship clinic is largely supported financially and administratively by the UPMC Department of Otolaryngology with additional support from the Eye and Ear Foundation, UPMC Health Plan and some other foundational grants. Net patient revenue does not currently support the operational expenses of the clinic as the patients routinely only receive one invoice. Revenue is generated from evaluation and management (E&M) services plus from procedures performed by the staff otolaryngologist, including FEES procedures. During a FEES, a speech-language pathologist also interprets the results of the study, which is a separately billable encounter. Evaluations by the physical therapist, dentist and audiology assistant do not rise to the criteria required for a third-party reimbursement including Medicare. Therefore, they are non-revenue generating activities. It should be noted that other than the audiology assistant and SLPs, these employees’ salaries and benefits are not directly paid from the budget of the Department of Otolaryngology. The operating expenses including both direct and indirect costs routinely exceed patient revenue by nearly $200,000 per year. This number excludes the effort of the staff otolaryngologist and downstream revenue from referral to outside services. (Unpublished Data) The clinic’s billing currently functions by having the providers incorporate the clinic hours into their existing job description. Given the multiple layers of support from a variety sources including the effort of the staff otolaryngologist, the real total costs to replicate this clinic in another setting would likely be far greater.

## Benefits of the UPMC Head and Neck Cancer Survivorship Clinic

The strengths of the UPMC Head and Neck Cancer Clinic lie within the coordination of care among the specialty providers. A collaborative environment has been established to ensure patients are referred to providers experienced in head and neck cancer patients, designed to avoid non-value-added services. Appointments are arranged on behalf of patients at experienced speech-language pathologists who can provide evidence-based treatments. These providers provide feedback to the clinic to allow for additional referrals or re-evaluation in the clinic to avoid unnecessary unplanned care. Today, patients are now often referred to the clinic at the time of diagnosis to identify critical points of intervention and prevention before, during and after their acute cancer treatment.

Demonstrating a quantifiable benefit to the patients has been an operational challenge. As with any patient intervention, establishing an appropriate control group to demonstrate effectiveness without bias can be difficult. The anecdotal experience in the clinic is providing the treatment summaries to the patients with contact information of each provider results in patients turning to less expensive care settings for unexpected issues, such as worsening dysphagia or feeding tube malfunctions. Reducing unplanned care, such as emergency department visits or inpatient hospitalizations, is an important and future investigational topic for the clinic.

# Future Directions and Policy Recommendations

## Future Directions

Recommendation five from the IOM *Lost in Transition* report states federal agencies should support demonstration programs aimed to “test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care” with the three primary models of care highlighted by the authors: (a) a “shared care” model with collaborations between primary care and specialists, (b) a nurse-led model to offset the responsibility of physicians, or (c) a multidisciplinary approach with all services offered at one site. (1) Survivorship programs in all forms must robustly collect data on clinical outcomes, patient-reported outcomes and patient-perceived benefits. Further research into the economic models behind survivorship care can provide significant credibility to calls for improved survivorship programs. Patient-reported outcomes should be collected by survivorship programs as providers may not always ask or be in tune with the true needs of the cancer patient. (32,37) Once all information is collected by the programs, action plans in the form of survivorship care plans must be created from this information and implemented.

There is some controversy over the development of survivorship care plans as described in the IOM report because there is no clear outline of essential components. (11) Additionally, the care plans may not have great utility for lower-risk patients or those with indolent cancer types which will be discussed later. If these lower risk patients can be identified, automated systems such as OncoLink (Philadelphia, PA) could serve important a role. OncoLink is a publicly available website from the University of Pennsylvania that generates a survivorship care plan based on patient-entered information. (37,45) This type of system can provide patient guidance, expectation management and surveillance recommendations specific to a cancer type and to patient-reported symptoms with minimal resources. Comprehensive care plans developed by survivorship programs could then be reserved for complex patients who do not fit squarely within the boxes of automated systems. In fact, the United Kingdom has been rolling out The National Cancer Survivorship Initiative now known as The Recovery Package, which includes a risk-stratified approach in order to address expanded patient concern. (46) The National Health Service (NHS) believes it can improve the patient experience and patient-reported outcomes while decreasing outpatient visits and unplanned hospital admissions with this approach. These programs have shown to result in improved patient-reported outcomes with reasonably low cost interventions. (47)

### Economic Evaluations of Survivorship Care

Survivorship care should not be viewed as simply a revenue negative intervention for health care systems. While the acute phase of treatment is a high-cost portion of the care, follow-up care alone is unlikely to represent a comparably high-resource utilization phase of care. However, patients with short- and long-term treatment-related toxicities may experience symptoms that drive them to high-cost unplanned care such as emergency department and urgent care without sufficient support. Additionally, end of life care with low-value treatment can also be a driver of overall patient cost. (29) Economic evaluations of the survivorship care programs may help drive awareness to the patient’s clinical outcomes of the patient as was as the psychosocial benefits. Coyle at al. recently published a cost-effectiveness analysis of survivorship care plans for patients with breast cancer and concluded development of these plans may not be a cost-effective endeavor. (16) However, the patients and their data were derived from a randomized clinical trial of early stage breast cancer patients having transitioned to primary care for their remaining survivorship care. These patients may not represent the best population which to intervene upon because of their already positive prognosis. Evaluations of the head and neck cancer population or similar higher risk patients may yield different results. Further, an alternative approach may be identifying the higher risk patients that would benefit from the development of survivorship care plans or referral to a survivorship clinic. (11,48) The NHS has evaluated its own Recovery Package programs and found the survivorship care interventions provided in the United Kingdom are reasonably priced, but they could not make a formal assessment of cost-effectiveness due to limited cost data. (47)

## Policy Recommendations

There is some precedent for a primary care-based survivorship model with the development of patient-centered medical home (PCMH) as defined by The Agency for Healthcare Research and Quality (AHRQ) which aims to coordinate care of chronic conditions. (49) The PCMH concept is best defined by a patient-centered approach with “care coordinated across all the elements of the health system.” (50) A better comparison is the “medical neighborhood” concept developed by AHRQ in a recent white paper in which primary care physicians (PCP) are surrounded by a network of specialist physicians working together to provide coordinated effort of care. (50) This type of model is expanding in healthcare systems across the United States and could represent a model for developing survivorship services.

 In 2015, the Centers for Medicare & Medicaid Services (CMS) began to separately pay providers for chronic care management under CPT 99490. (51) CMS recognized that patients with two or more chronic conditions are resource-intensive from the provider perspective because of medication refill requests, correspondence to/from other providers, written or verbal patient communication and more. Much of this care occurs outside of a standard reimbursable clinic visit which disincentivizes providers from participating in these care-coordination activities. While these non-face-to-face encounters have several technical requirements for the providers and may result in a copayment for patients, these programs are highly-received by patients with high perceived benefits. (52–54) Using a difference-in-differences analysis, a 2017 CMS commissioned report found that the CCM enrollment resulted in decreased per-beneficiary per-month spending driven by decreases in inpatient, hospital outpatient, and skilled nursing facility expenditures. (55) CCM resulted in less emergency department visits and hospitalizations amid increased primary care and home health services utilization. The authors found that the most significant reductions in spending were for patients nearing the end of life. The CCM model of care coordination by a primary care physician demonstrates that such a program can be successful if implemented correctly.

There are currently no established billing codes specifically for survivorship services. (12) Although there are temporary Healthcare Common Procedure Coding System codes for “treatment planning and care coordination management for cancer,” but these are not recognized by Medicare and Medicaid. Development of reimbursable visits by third-parties could expand access to survivorship. In addition, a reimbursement program that identifies cancer patients undergoing complex treatments needing long-term follow-up and provides additional payments for care coordination may incentivize institutions to expand access to survivorship services. A new reimbursement method for cancer survivorship could support a primary care-based care model or nurse-driven coordination of care program, with the PCPs employing the nurses, similar to what is in place for the chronic care management. (54)

CMS has also experimented with similar ventures such as the Oncology Care Model currently housed within the CMS Innovation Center. This program provides a monthly payment per beneficiary to help providers in “effectively managing and coordinating care for oncology patients” while patients undergo chemotherapy treatments. (56) This program is easier to administer since patients must be undergoing active chemotherapy treatments, and it is structured under episode-based payments through the Affordable Care Act. However, if successful during the pilot phase, this program represents another model for coordinating survivorship benefits in the long term. Episodes of care can be defined by survivorship diagnosis codes based on the types of cancer and any expected follow-up, much like the oncology care model or other bundled payment structures.

Provider and payer partnerships are not confined to federally funded programs. Premera Blue Cross and Cancer Care Northwest entered into a contract that created a pay-for-performance model with quality and performance metrics that resulted in improved outcomes and reduced cost savings. (57) This type of private partnerships could work in parallel to any CMS funded programs.

The challenge to using primary care as the hub of survivorship care is that PCPs are already overburdened with other types of care coordination. Only 3% of small- to medium-sized primary care practices employ care managers despite the fact that the average PCP is coordinating the care of their patient panel with an average of 229 different physicians. (58,59) Even with financial incentives for establishing chronic care management billing, there are still many barriers to adoption across the country. Physicians unwilling to establish these types of programs within their practices cite fear of financial liability from documentation errors, upfront implementation costs and the time burden associated with the additional patient care responsibilities. (52,54) And like all physicians, theses coordination of care efforts pile upon the ever-expanding nonvisit tasks that already present significant burdens to the physician’s workday. (15)

# Conclusion

Survivorship care fits perfectly within the Institute of Healthcare Improvement’s Triple Aim to improve patient care experience, improve the health of populations and reduce the per capita cost of healthcare. (60) All survivorship care programs, by design, recognize that a cancer diagnosis can be truly overwhelming for the patient and require careful monitoring by a provider using evidence-based guidelines. Head and neck cancer patients face unique long-term need that are best addressed by disease-specific survivorship programs. However, the fractured structure of today’s US healthcare system often leaves cancer patients to fend for themselves after their acute treatment has concluded. In response, several institutions around the country are creating programs for survivorship with positive results including the UPMC Head and Neck Cancer Survivorship Clinic, but these currently only exist in urban centers or at academic institutions. There are some programs within some private and public third-party payer systems to incentivize the coordination of needed care, but many are still in the early stages as the system slowly shifts from a fee-for-service to a value-based or population health centered model. Further work is needed to bring comprehensive cancer survivorship care into the 21st century.

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