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Oncology Nutrition Connection

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Message from the Chair

Greetings ON DPG members. New members, welcome. Existing members, glad you choose to renew your ON DPG membership. We are here only because of the dedication and passion of our members. The pandemic sure presented us with unforeseen challenges, and I commend you for your fortitude and diligence in making sure the needs of your patients/clients were met. YOU ROCK!

I am excited to introduce myself to you as your 2021-2022 Chair. I am an academician, oncology researcher, a champion for diversity, equity and inclusion, and student engagement. I am excited to be working with a phenomenal group of dedicated oncology dietitians and a student member on the Executive Committee. There are some new names on the Executive Committee and some familiar names in new position. The 2021-22 Leadership directory is included in this newsletter for your reference. Do check it out.

Other great news - The second edition of the *Oncology Nutrition for Clinical Practice* book is now available in the Academy bookstore. This is a comprehensive and must-have resource for clinicians, providing both evidence- and experience-based information. Special thanks go out to Anne Voss and Valaree Williams who served as editors for this edition.

I am providing you with an update on a few projects in progress:

FNCE® - FNCE® is virtual again this year and a group of members are hard at work planning your FNCE® activities. More will be shared later. For now, do note that the ON Spotlight session will be held on October 17, 2021 at 11:30 AM-12:30 PM and the topic is "Integrative Practices in Oncology: State of the Science." Dr. Heather Greenlee of Fred Hutchinson Cancer Center, WA and ON DPG member Dr. Mara Vitolins of Wake Forest School of Medicine, NC will be the featured speakers.

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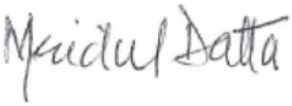
Patient Resources – ***Cholangiocarcinoma Foundation patient resource*** under the leadership of Chair-elect Erin Gurd is well on its way to completion. A new patient resource that was recently approved for development is on ***Nutrition and Stomach Cancer*** and is being led by Caitlin Benda and is planned in conjunction with the Hope for Stomach Cancer organization.

Student Engagement and Research – Student engagement is an initiative near and dear to my heart, not just because I am an academician, but also because I remember the difficulty I had as a student trying to get into the field of oncology. This is a sentiment echoed by our new student coordinator Jamie Baham, who is actively working on developing plans for increasing student engagement in the DPG. Additionally, with lack of travel and significantly reduced expenses due to COVID, the Executive Committee has approved increasing student scholarships to the Academy Foundation from one to five. We are also investing in funding more student and clinician research by creating undergraduate, graduate, clinician and post-graduate research award categories. You will hear more on these from our new Awards Coordinator, Paula Macris.

Symposium Update – The Symposium will be returning in June 2022 and will be held in Rosemont, IL (a suburb outside of Chicago). Details are being finalized and will be shared via e-blast soon.

I welcome your suggestions and ideas on how the Executive Committee can better meet the needs of its members. Please do not hesitate to reach out to me or other members of the Executive Committee if we can be of assistance to you.

Take care,



Mridul Datta, PhD, RD, LD, FAND
Chair, ON DPG

PS — Don't forget to follow us on Facebook, Instagram, Twitter, and LinkedIn

Monitoring Rates of Malnutrition Risk in Outpatient Cancer Centers Utilizing the Malnutrition Screening Tool Embedded into the Electronic Health Record

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Abstract

Background

The risk of malnutrition in patients with cancer is well documented. However, screening to identify patients at risk in ambulatory cancer centers is not standardized nor uniform. The 2-question Malnutrition Screening Tool (MST) is validated in the ambulatory oncology setting and endorsed by the Academy of Nutrition and Dietetics.

Objective

To test the feasibility of operationalizing and standardizing malnutrition risk assessment across 2 large ambulatory cancer centers by embedding the MST into the electronic health record (EHR) with the goal of identifying and quantifying the prevalence of malnutrition risk in outpatient settings.

Design

A Quality Assurance Performance Improvement project was conducted to evaluate malnutrition screening practices by leveraging the EHR. Work standards were developed, implemented, and evaluated to assess the feasibility of utilizing de- identified MST data, entered as discrete variables in an EHR flowsheet, to track monthly MST completion rates and to identify and quantify patients being treated for cancer scoring at risk for impaired nutritional status.

Participants/setting

Data from 2 large adult ambulatory community cancer centers in the upper Midwest were collected between April 2017 and December 2018.

Results Over a 20-month period, the average monthly MST completion rate was 74%. Of those with completed MST screens, the average percentage of patients identified at nutritional risk (MST score !2) was 5% in medical oncology and 12% in radiation oncology.

Conclusion

It is feasible to (1) integrate and standardize data collection of the MST into existing EHR flowsheets and (2) identify and quantify patients at risk for malnutrition on a consistent basis.

Malnutrition screening has been identified as a major limitation to assessing nutrition care in outpatient oncology centers (1), and it is the position of the Academy of Nutrition and Dietetics that, based upon current evidence, the Malnutrition Screening Tool (MST) should be used to screen adults for malnutrition (undernutrition) regardless of their age, medical history, or setting (2). Patients with cancer are among the most malnourished of all patient groups, with up to 80% receiving multimodal therapy experiencing unintentional weight loss (3). In outpatient settings, more than half of patients being treated for cancer exhibit nutritional impairment at their first oncology visit (4). The etiology of weight loss and malnutrition of the patient with cancer is often multifactorial and compounded by the toxic effects of treatments, physiological changes from the tumor, and/or the patient's response to the tumor (5). Malnutrition correlates with a reduced tolerance and efficacy of treatment, increased risk for clinical and surgical complications, reduced quality of life, lower survival rates, longer hospital stays, and a concomitant increase in health care costs (5,6).

Despite the negative health effects of malnutrition on patients with cancer, many patients at nutritional risk go unscreened and, therefore, undetected. In a study of patients with different types of cancer in which there was a 39% prevalence of malnutrition, 42% of patients who were malnourished received no nutrition counseling or interventions (5). Many cancer centers (CCs) provide insufficient, if any, nutritional services to patients with cancer. We recently reported that ambulatory CCs have a registered dietitian nutritionist (RDN)-to-patient ratio of 1:2308, well below an adequate ratio of 1:120.7 Furthermore, only 50% of these CCs consistently screened for malnutrition.

Standardized and systematic nutritional screening is the first step in the early identification and treatment of patients who are malnourished or are at risk for malnutrition (8) Once identified, at-risk individuals should receive a comprehensive and focused nutritional assessment by a trained nutritional professional, such as an RDN (9). Without early and consistent malnutrition screening, the window to detect and favorably change the trajectory of a patient's nutritional care is lost (7).

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Although consistent malnutrition screening is recommended by many US oncology organizations, such as the American College of Surgeons' Commission on Cancer and the Association of Community Cancer Centers (10,11) it is not a standardized component of oncology care in the United States. Yet mandatory nutritional screening has been established in some countries (12). For instance, the European Society of Clinical Nutrition and Metabolism Expert Guidelines recommend regular evaluation of nutritional intake, weight changes, and body mass index beginning at cancer diagnosis and repeated as indicated by the stability of the clinical situation (12).

Nutrition screening tools generally include dietary intake, anthropometrics, comorbid disease state, and subjective assessment of body composition (13). These methodologies require variable time commitments by nurses, physicians, RDNs, or other hospital staff (13). To be efficient, screening must be brief, inexpensive, and highly sensitive and have good specificity (12).

Although several validated tools for screening for malnutrition exist, there is no universal, standardized approach for screening ambulatory patients with cancer. Adult patients being treated for cancer should be screened using a screening tool validated in the setting in which the tool is intended for use (14,15). The MST is one such tool. It is a quick and easy screening tool, requiring no blood samples, anthropometric measurements, or clinical examinations (16). The MST has also been validated in the ambulatory oncology setting against the Patient-Generated Subjective Global Assessment as well as against computed tomography assessment of body composition (17,18). The MST consists of 2 questions—one regarding appetite and one prompting for recent unintentional weight loss (Figure 1). A summative score is assigned to each question. Subjects who score 2 to 5 are at risk of malnutrition (19).

At many institutions, information from a patient's electronic health record (EHR) is downloaded regularly and stored in a "data warehouse," which is a large database where EHR data are stored in a standardized format and accessed by data analysts. These data can be extracted for analyses by various statistical programs. Data warehouses allow deidentified data to be analyzed to query patients' EHR and track specific information over time. Structured data elements, such as vital signs, weight, and height, are "machine interpretable," meaning these are discrete variables for which computer logic can be applied (13). These types of data offer potential for electronic surveillance, because they can be analyzed using algorithms applied to data located in the EHR reporting tables or in the research data warehouse. Because MST scores are structured data elements, they can be easily and fully integrated in the EHR in a flowsheet (Figure 1). By leveraging automated data collection with EHR data, real-time reports can be obtained and evaluated to rapidly identify at-risk patients.

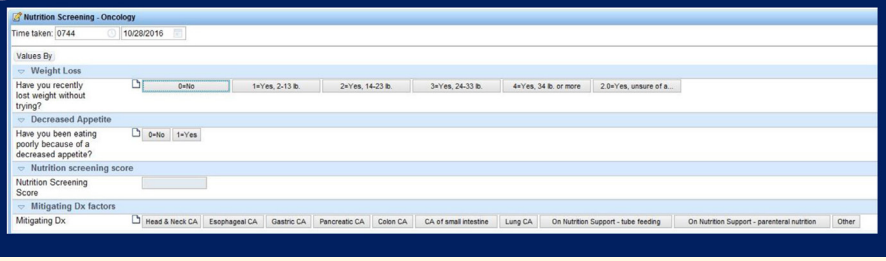
The purpose of this Quality Assurance Performance Improvement (QAPI) project was to test the feasibility of (1) standardizing malnutrition risk assessment across 2 large CCs using the MST embedded in a common EHR and (2) utilizing MST aggregate data reports to quantify the prevalence of patients at risk of malnutrition. Here we report data on 2 of the largest CCs in the HealthPartners (HP) health care system located in the upper Midwest of the United States.

Figure 1. Malnutrition Screening Tool (MST). (A) MST; a cumulative score of 2 or more indicates patient at risk of malnutrition. (B) Screenshot of the MST questions embedded in an Electronic Health Record. Adapted with permission from: Ferguson M, Capra S, Bauer J, Banks M. Development of a valid and reliable malnutrition screening tool for adult acute hospital patients. Nutrition. 1999;15:458-464.

A

Have you lost weight recently without trying?	
No	0
Unsure	2
If yes, how much weight (kilograms) have you lost?	
1-5	1
6-10	2
11-15	3
>15	4
Unsure	2
Have you been eating poorly because of a decreased appetite?	
No	0
Yes	1
Total	

B



Methods

This QAPI project integrated the MST into the EHR system (EPIC Systems Corporation, Verona, Wisconsin) at the 2 largest community CCs in the HP system. HP is the largest consumer-governed nonprofit health care organization in the country, providing care, coverage, research, and education to its members, patients, and the community. HP serves more than 1.8 million medical and dental health plan members and more than 1.2 million patients. Deidentified data from unique monthly visits by outpatient adult patients being treated for cancer by either the medical or radiation oncology departments between April 2017 to December 2018 were collected using automated reports within the EHR data warehouse. This project was

Table. Average MSTa completion rates and malnutrition risk rates in 2 large ambulatory cancer centers: Data results over a 20-month period.

Variables	All patients	Medical oncology	Radiation oncology
	←——— *n* ———→		
Unique patients	68,119	63,108	5011
	←——— *n (%)* ———→		
Completed MST screen	50,672 (74)	47,165 (75)	3507 (70)
MST ≥2	2752 (5)	2333 (5)	419 (12)
	←——— *n* ———→		
Mean MST ≥2/mo	131	111	20

[a]MST = Malnutrition Screening Tool.

determined to be a quality assurance project by the Health Partners Institutional Review Board and did not require human subjects review oversight.

MST work standards were developed by the oncology RDNs and approved by nursing and medical staff for MST administration at every oncology provider visit with a medical doctor (MD) or nurse practitioner. Registered nurses (RNs) or medical assistants (MAs) verbally administered the MST to patients during their intake assessment in the examination room at each clinic visit. Patient responses were entered into the vital sign data collection flowsheet in the EHR. If the patient scored ≥2 on the MST, an automated Best Practice Alert was generated to initiate an approved standing MD order for a nutrition consultation with the oncology RDN. This order was automatically signed by the MD and sent to the RDN work queue. In addition, all patients who screened at risk (≥2) were provided approved oncology nutrition educational materials by the RN/MA, which was documented in the flowsheet.

Content was developed to implement MST work standard into the CCs orientation process for all staff responsible for completing patient visit intakes in the EHR. During this 20-month project, 10% of all provider visits were audited 2 days per week to evaluate if the MST was administered per the work standard (at every provider visit). If MST work standards were not met, MA and RN staff meetings were held to determine barriers to implementation and provide retraining. Reports on MST completion rates and the data on prevalence of patients identified as at risk for malnutrition were shared at multidisciplinary cancer care team meetings and nursing quality care committee meetings.

Monthly EHR data extraction was conducted by the HP programmers from the research data warehouse. Variables of interest included (1) CC clinic, (2) patient's medical record number (MRN), and (3) MST questions with the total MST score. After extraction, data were sorted by MRN and MST cumulative score from high to low. Duplicate MRNs were deleted from the data set to identify unique provider encounters for each month. If a patient had multiple visits with an MD or nurse practitioner during a 1-month period, the visit with highest MST score was included. Cumulative MST scores were assessed to identify rates of malnutrition risk across the 2 CCs. The percentage of MST completion was calculated by dividing the unique number of patients with a completed MST (defined as 2 MST questions asked and answered plus a total MST score generated) divided by all unique outpatients who had a provider visit within each monthly increment. The case mix of oncology diagnoses were obtained through the Cancer Registrar for the corresponding 20-month data collection period.

These data were securely e-mailed from the data ware- houses to the lead project RDN. The RDN sorted these data using the custom data option, sorted by MRN, then ranked the MST score from high to low. The sorted data were simplified using the data tab and duplicated MRNs were removed.

Results

Data are presented for the 20-month study period. The cancer site case mix was 22% breast, 16% gastrointestinal, 11% prostate, 10% lung and bronchus, 10% hematology, 9% skin, 7% genitourinary, 6% head and neck, 6% gynecological, and 3% other. Over the 20-month period, the average monthly MST completion rate was 74% (range = 60%-80%) (Table and Figure 2). Overall, 5% of the patients screened scored ≥2 on MST. Specifically, 5% of patients treated in medical oncology departments and 12% of patients treated in radiation oncology departments scored ≥2 on MST (Table and Figure 3).

The trends over time for MST completion rate and number of patients with MST ≥2 also are reflected in Figures 2 and 3, respectively. A linear rise in MST completion rate was noted over the 20-month period, beginning with a 60% completion rate in April 2017 and concluding with a 78% completion rate in December 2018 (Figure 2).

Discussion

The Academy of Nutrition and Dietetics supports the use of a single, validated tool, the MST, to screen adults for malnutrition (2). This QAPI found that incorporating the MST into the EHRs to standardize malnutrition screening is feasible across 2 community CCs. Additionally, the high MST completion rates of

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almost 75% over a 20-month period indicates that once embedded in the EHR, completion of this tool is sustainable in outpatient CCs.

Following administrative and medical staff approval, the integration of the MST into the EHR patient intake assessment was easily accomplished by the EHR team and provided the opportunity to examine the need and capacity for full integration of nutritional care into ambulatory CCs. Based on the high MST completion rate, 131 patients per month were identified as at risk for malnutrition in these 2 large CCs. Extrapolated to an ideal setting in which 100% of the patients obtained MST screening, approximately 175 patients per month (or 8.7 patients per day based on a 5-day workweek) would be at risk for malnutrition. Based on our previous findings that oncology RDNs evaluate or counsel an average of 7.4 patients in an 8-hour workday (7), 1.2 RDN full-time equivalents would be required to provide proactive nutritional counseling to those patients identified at risk for malnutrition. Note this conservative estimate does not account for ongoing or follow-up nutritional services.

In this project, we found the average rate of malnutrition risk was 5% in patients treated in medical oncology departments and 12% of patients treated in radiation oncology departments. These rates differ from other data reported in the literature. In adult outpatient settings receiving oncology-specific treatment for malignant neoplasms, the MST detected 28% of patients to be at risk of malnutrition (6). The prevalence of malnutrition is associated with tumor type, and the documented range is 62% in upper gastrointestinal cancer to 13% in breast cancer. The cancer types with the highest prevalence of malnutrition are of the upper gastrointestinal, head and neck, lung, hematological, gynecological, and colorectal (20). The lower rates of malnutrition risk in our population may be due to the diverse oncology populations, including more tumor types that typically do not develop malnutrition, such as breast, prostate, skin, genitourinary, and others, which represented 52% of our population case mix.

Although consistent nutritional screening is critical for the early identification and treatment of patients who are at risk for malnutrition or who are already malnourished, a recent national survey indicated that only 53% of CCs routinely screened for malnutrition; of the 53% who screened, approximately 35% used unvalidated tools (7). The Academy of Nutrition and Dietetics advocates abandoning all unvalidated MSTs, including tools that were validated, then modified without rigorous validation against a standard definition of malnutrition (2).

The MST has demonstrated good validity and reliability in identifying patients at risk of malnutrition in the oncology setting (17). Other MSTs validated in the outpatient cancer setting include Patient-Generated Subjective

Figure 2. Malnutrition Screening Tool (MST) completed screening trends over a 20-month period. The average monthly MST completion rate was 74%, and the range was 60% to 80%.

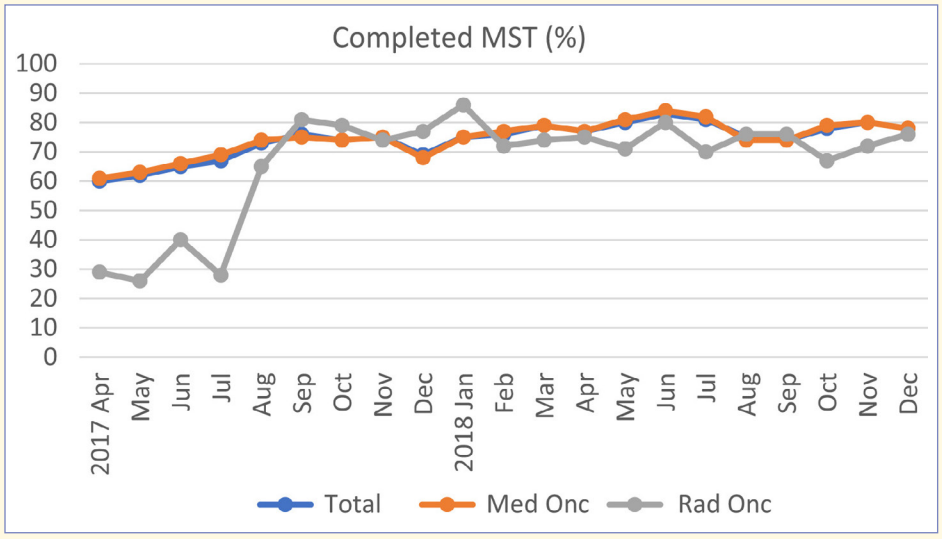
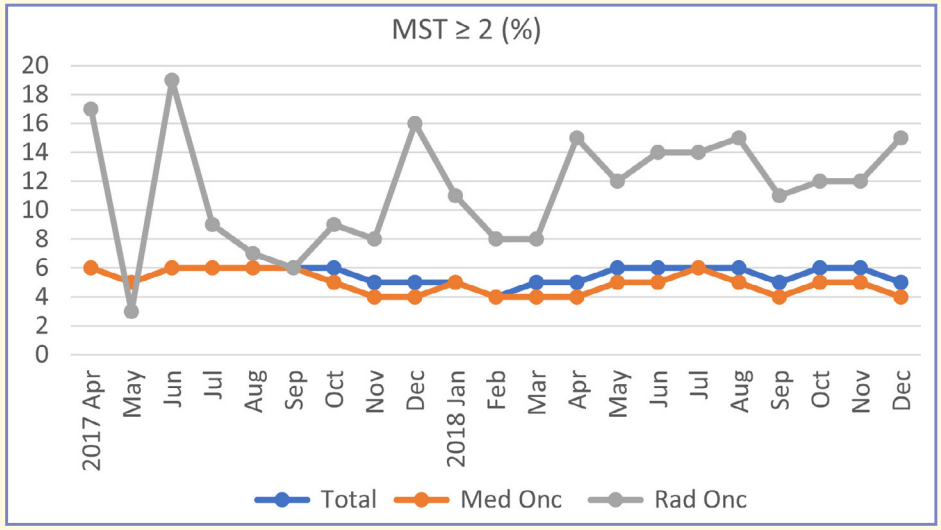


Figure 3. Trend of percentage of patients scoring ≥2 on the Malnutrition Screening Tool (MST) over a 20-month period. On average, 5% of the total patient population scored ≥2 on MST; 5% of patients treated in medical oncology (Med onc) departments and 12% of patients treated in radiation oncology (Rad onc) departments scored ≥2 on MST.



Global Assessment Short Form, NUTRISCORE, Nutrition Risk Index, and Short Nutritional Assessment Questionnaire (6,14,18,21-23). Of these tools, the MST is the quickest and easiest (16). The MST requires a clinician to interview the patient without altering the verbiage of the 2 questions nor the scoring system for referrals as originally presented. Adding items, modifying questions, or interpreting scores differently must be avoided, as any changes invalidate the MST tool (2).

Despite the MST's ability to quickly and easily identify high-risk patients with cancer for subsequent referrals to trained clinicians, nutrition screening is often not prioritized in outpatient settings. Barriers to implementing nutritional screening practices include non-standardized referral processes, limited administrative support, inadequate staffing or competing time constraints, lack of consensus on screening tool implementation, and limited frontline or nursing support. This results in late identification and referral delays that impact health outcomes (7). In a study of patients with cancer in which half were being treated as an outpatient, 70% of patients had more than 2 nutritional barriers, screening was used in 35% of patients, nutrition referrals should have occurred sooner in nearly half of the patients, and significantly more outpatients were more likely to have missed earlier referral opportunities (24).

In the absence of nutritional screening, malnutrition may be neglected, particularly in patients who are overweight or obese, in which the excess body fat may mask loss of weight and lean body mass and malnutrition (25). As mentioned previously, more than 50% of patients with cancer exhibit signs of malnutrition at their initial oncology visit, even prior to initiation of cancer treatment (4). Thus, screening should be performed early in the treatment regimen and repeated at regular intervals to identify high-risk patients needing subsequent referrals for a more comprehensive nutritional assessment and management plan (25). There is consensus that nutritional intervention should be introduced at a point when the aim is maintenance or improvement in nutritional status. Full nutritional assessments for every patient with cancer is

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ONC Feature
ON DPG Member Spotlight

The Oncology Nutrition Connection's Member Spotlight will feature a new member each quarter, highlighting how they are making a difference and how they have benefited from ON DPG membership. It offers you an opportunity to share your story with your colleagues, inspire future oncology nutrition professionals, and strengthen awareness of the profession and DPG.

Go to the ON DPG newsletter page to find the Member Spotlight Questionnaire.

not realistic due to constraints on resources. Thus, screening is recommended to identify people at nutritional risk who need further assessment (24).

The reimbursement structure for oncology nutrition counseling by RDNs varies widely across outpatient CCs. Although screening may trigger an MD order for a nutrition consultation, the Center for Medicare and Medicaid Services and many other insurers do not reimburse for medical nutrition therapy and thus, although screening may be successfully implemented, many patients decline nutrition consultations due to lack of insurance coverage.

The strengths of this study are the relatively large sample size, successful implementation of the MST work standards, support from RN and MD CC leadership, and ongoing evaluation of adherence to MST administration. Additionally, there were excellent participant response rates.
There were certain limitations of this study. The MST is a screening tool and is only the initial step in identifying patients that require a more thorough nutritional assessment. The MST is not intended, in isolation, to diagnose malnutrition, hence our results reflect this fact. Although patients scoring ≥2 on MST automatically triggered a standing MD order for a nutrition consultation, it was beyond the scope of this project to follow up on completion of nutritional consultations. Other limitations include generalizability to oncology clinics in other geographic locations and to other CCs with more acute cancer case mix that includes patients at greater risk for malnutrition. Additionally, there is a lack of knowledge related to the patients' physical, mental, and social characteristics.

It is recommended that clinics that implement and utilize the MST should consistently monitor data to compare patient populations, predict adequate clinic resources for screening and subsequent treatment, and support ongoing research to inform future studies.

Conclusions

Standardized malnutrition risk screening is feasible by embedding the MST into a common EHR across ambulatory CCs. Once implemented, malnutrition screening using the MST can be completed on a high percentage of patients. Furthermore, the aggregate data can be utilized to identify the prevalence of malnutrition risk. Future considerations may be how the consistent use of the MST in the EHR and leveraging data on MST completion rates may be used to inform staff adherence to MST work standards, consistency in care, RDN staffing needs and patterns, cost-benefit analysis, and health outcomes for patients being treated for cancer.

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Evaluation of the Impact of Cyproheptadine Hydrochloride on Weight Status and Nutrition Diagnosis in Pediatric Oncology Patients

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Abstract

Children with cancer frequently develop anorexia, cancer cachexia, and malnutrition related to cancer-directed therapies. Increasing appetite and food intake is the preferred nutrition intervention in pediatric populations. Appetite stimulants are used to promote oral intake and act as a possible alternative to nutrition support. This retrospective study evaluated the effectiveness of Cyproheptadine hydrochloride in 139 patients based on overall weight change, change in body mass index (BMI) z-score, and change in nutrition diagnosis in pediatric oncology patients.

Nutrition diagnosis (severely malnourished, moderately malnourished, mildly malnourished, normal, or overweight) was determined based on BMI z-score at the first and last cycle of Cyproheptadine hydrochloride. Participants in this study showed a +3% change in overall body weight while prescribed Cyproheptadine hydrochloride however, overall change in weight and BMI was statistically insignificant (% change in weight p=0.058; change in BMI z-score p=0.137).

Introduction

Children with cancer frequently develop anorexia and malnutrition (1-3). The prevalence of malnutrition identified in pediatric cancer patients has been reported to range from 10 to 50% and may vary based on disease type and treatment modality (2,3). Malnutrition and weight loss in pediatric oncology patients has been associated with negative therapeutic outcomes including increased risk of infection, decreased tolerance of medical procedures, and increased mortality (4-8).

Oncology protocols which may include invasive surgery, radiation, and polypharmacy, can have a drastic impact on the ability and desire for children to eat while undergoing cancer therapy. Many drugs used in therapy have negative side effects including decreased appetite, altered taste, nausea, vomiting, diarrhea, and stomach pain (9-11). Additionally, the combination of drug-induced side effects and an altered metabolic state can result in cancer cachexia (10,12). Complications associated with cancer cachexia include negative changes in functional status such as loss of strength, decreased immune function, and negative changes in pulmonary function (13,14). Impaired nutrition status may result in lower tolerance of chemotherapy, psychological stress, impaired cognitive function, and reduced quality of life (9,15).

Overview of Nutrition Interventions in Pediatric Oncology

Nutrition interventions for cancer therapy include use of oral supplements, enteral or parenteral feeding, and appetite stimulants. Appetite stimulants are used to promote oral intake and act as a possible alternative to nutrition support. Appetite stimulants initially demonstrated effectiveness in weight gain for adults with cystic fibrosis and Human Immunodeficiency Virus (HIV) in the chronic disease setting (16-18). An appetite stimulant commonly utilized in adult and pediatric populations is Cyproheptadine hydrochloride. Cyproheptadine hydrochloride is a serotonin and histamine antagonist that is commonly used for seasonal allergies but can also be utilized as an appetite stimulant. It has been positively associated with increased appetite and weight gain for children with cystic fibrosis, feeding difficulties, and undernutrition (18-20). Some studies have demonstrated that Cyproheptadine hydrochloride may be a viable intervention for pediatric oncology patients by effectively improving appetite; however, further research is necessary. The purpose of this retrospective study was to evaluate the impact of Cyproheptadine hydrochloride usage on the nutrition status of children actively receiving cancer treatments (21,22).

Materials And Methods

This Institutional Review Board (IRB)-approved analysis was conducted at St. Jude Children's Research Hospital in Memphis, TN. Medical records of pediatric oncology patients between the ages of 2 to 20 years of age and who were prescribed Cyproheptadine hydrochloride as an intervention for weight loss between January 1, 2000 and December 31, 2009 were included in the analysis. Patients were not included in this study if they were undergoing steroid treatment or receiving additional nutrition support (parenteral nutrition, enteral nutrition, or a different appetite stimulant) in addition to receiving Cyproheptadine hydrochloride. The hospital's formulary recommends weight-directed dosing for

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Table 1. Cutoffs for Nutrition Diagnosis using BMI Z Score[a]

Mildly malnourished	BMI z-score between -1 to -1.99
Moderately malnourished	BMI z-score of -2 to -2.99
Severe malnourished	BMI z-score -3 and lower
Normal nutrition status	BMI z-score of - .99 to 1.04
Overweight	BMI z-score of 1.05 to 1.63
Obese	BMI z-score of 1.64 and above

[a] *Adapted from the Pediatric Nutrition Focused Physical Exam Pocket Guide, Academy of Nutrition and Dietetics 2015*

appetite stimulants in children ≥2 years and adolescents as such: oral: 0.25 mg/kg/day divided twice daily; age-dependent maximum daily dose: ≤6 years: 12 mg/day; 7 to 14 years: 16 mg/day; ≥15 years: 32 mg/day.

The impact of Cyproheptadine hydrochloride on nutrition status was evaluated based on the following criteria:

A. Overall weight change at the start of the first cycle of Cyproheptadine hydrochloride to the end of the last cycle. Cycle refers to the time that the patient was prescribed Cyproheptadine hydrochloride; some of the patients were prescribed Cyproheptadine hydrochloride multiple times during the time of this analysis. Starting and stopping of the Cyproheptadine hydrochloride occurred for several reasons such as treatment conflicts or chemotherapy restrictions.
   As a resulted of these conflicts, some of the patients had multiple cycles of Cyproheptadine hydrochloride.
B. Change in body mass index (BMI) z-score at the start of the first cycle of Cyproheptadine hydrochloride to the end of the last cycle.
C. Change in nutrition diagnosis, based on BMI z-scores (Table 1), from the beginning of the first cycle Cyproheptadine hydrochloride to the end of the last cycle.

Additionally, overall average percent body weight change was compared with average cumulative dose of Cyproheptadine hydrochloride in order to evaluate the impact of dosing on weight change.

Statistical Analysis

Demographic characteristics of pediatric oncology patients who received Cyproheptadine hydrochloride were summarized using descriptive statistics (Table 2). The overall change in body weight, measured in kilograms, was calculated as the product of all the relative body weights measured at each time point minus the initial body weight. The cumulative dosage of Cyproheptadine hydrochloride was calculated. The total amount of dosage received was calculated as the prescription amount time the frequency times number of days in the corresponding treatment period. The correlation between overall change of body weight and cumulative dosage of Cyproheptadine hydrochloride was evaluated using rank correlations (Spearman's Rho). Given that the distribution of cumulative dosage of Cyproheptadine hydrochloride was highly skewed, a logarithmic transformation was applied to the original cumulative dosage of Cyproheptadine hydrochloride. The association between overall change of body weight and log-transformed cumulative dosage was examined using a linear regression model. The BMI z-scores were calculated with CDC reference data (2000 CDC Growth Charts, ages 2 to <20 years) and categorized based on the Nutrition Diagnosis Classification table (shown in Table 1). The difference between z-scores at the beginning and the end of the study were examined using Wilcoxon Signed Rank test. The overall change in nutrition diagnosis from the beginning of the first cycle to the end of the last cycle were evaluated using the Bhapkar's test for homogeneity. Two-sided significance of $p<0.05$ was employed for statistical methods, and all analyses were performed using SAS software version 9.4.

Results

Description of Patient Population

A total of 139 patients were included in this retrospective study. Demographic and clinical characteristics of participants are summarized in Table 2. Of those included, 61 (43.9%) were female and 78 (56.1%) were male. Median age of participants at the beginning of their Cyproheptadine hydrochloride cycle was 7.17 years (range of 2-19 years) with the primary diagnosis being brain tumor (43.2%). Most participants (47.5%) had normal nutrition diagnosis and were not categorized as malnourished, overweight, or obese at the start of their first Cyproheptadine hydrochloride cycle.

Overall Weight Change at the Start of the First Cycle of Cyproheptadine Hydrochloride to the End of the Last Cycle

Cumulative dosing information and change of body weight are demonstrated in Table 3. One hundred and thirty-one of the participants had evaluable records of change in body weight with an average overall body weight change of 3%. The average cumulative dosage of Cyproheptadine hydrochloride was 555.98 mg over the entire course of treatment. The association coefficient between the overall change of body weight and cumulative dosage was 2.05 (SE=1.07, p=0.058), which suggested no positive association was indicated.

Change in the BMI z-score at the Start of the First Cycle of Cyproheptadine Hydrochloride to the End of the Last Cycle

There was a slight improvement of 0.17 in BMI z-score, but there was no significant evidence that BMI was positively affected by using Cyproheptadine Hydrochloride (p=0.137) (Table 4).

Change in Nutrition Diagnosis Based on BMI z-scores from the Beginning of the First Cycle of Cyproheptadine Hydrochloride to the End of the Last Cycle

Nutrition diagnosis based on BMI z-score and change in BMI z-score are summarized in Table 4 and Table 5. A majority of patients (81%) maintained their nutrition diagnosis or moved positively to a different nutrition category. Of the 139 patients, five moved into an overweight diagnosis and one maintained their diagnosis as obese. Bhapkar's test supports a significant difference between nutrition diagnosis at the beginning of the first cycle and the end of the last cycle (p=0.029).

Discussion

Many cancer therapies have shown increased risk of malnutrition and cancer cachexia. Both conditions can affect a patient's nutritional status and treatment outcomes. Early recognition of individuals at risk of treatment-related complications such as nausea, vomiting, inadequate intake, or decreased appetite is essential in the care of patients (9-11).

This retrospective analysis demonstrated that nutrition status was not adequately affected by use of Cyproheptadine hydrochloride in our subset of patients. There were several limitations including inconsistencies associated with a retrospective design such as initiating appetite stimulant therapy as well as monitoring, follow-up, and possible escalation in daily dosages. Additionally, a referral to the registered dietitian did not happen at the time of the initiation of the medication and therefore a full nutrition assessment including nutrient analysis and evaluation of side effects, disease status, and progression of disease were not fully explored.

Insufficient monitoring, including energy requirements and nutrient analysis, and follow-up by healthcare professionals could be related to the ineffectiveness of Cyproheptadine hydrochloride in this study. In comparison to other medications, Cyproheptadine hydrochloride is associated to less severe side effects; however, it is important for healthcare professionals to continue to monitor the effectiveness and benefits of the drug regularly. Adequate monitoring of effectiveness could promote appropriate dose escalation, weight gain, and change in nutrition status.

Cyproheptadine hydrochloride has shown to be an effective intervention for nutritional status in other pediatric populations (17-19). Further research is needed to address the limitations of this study, evaluate the effectiveness of nutrition assessment and monitoring of Cyproheptadine hydrochloride, and determine the impact of dose escalation and increased duration in the pediatric oncology population. Cyproheptadine hydrochloride should be closely monitored by all medical staff but may also be used to improve nutrition and treatment outcomes. Therefore, we recommend conducting a complete medical nutrition evaluation with a RDN and development of an individualized care plan for each patient when Cyproheptadine hydrochloride is prescribed. We also recommend that weekly follow-up evaluations be conducted by staff to help determine dose changes needed to promote adequate growth and development.

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Table 2. Description of Patient Population

Characteristics		Result (N=139)
Age at start (years)	Mean (SD)	7.35 (3.69)
	Median (Range)	7.17 (2.00 - 19.00)
Age at end (years)	Mean (SD)	7.54 (3.67)
	Median (Range)	7.33 (2.17 - 19.08)
Initial weight (kg)	Mean (SD)	23.85 (11.60)
	Median (Range)	21.50 (9.70 - 76.30)
End weight (kg)	Mean (SD)	24.18 (11.10)
	Median (Range)	21.50 (10.80 - 73.20)
Initial height (cm)	Mean (SD)	120.54 (20.90)
	Median (Range)	119.60 (83.30 - 180.70)
End height (cm)	Mean (SD)	119.98 (22.94)
	Median (Range)	119.90 (34.40 - 181.60)
Initial BMI (kg/m2)	N	138
	Mean (SD)	15.54 (2.55)
	Median (Range)	15.00 (11.70 - 27.60)
End BMI (kg/m2)	Mean (SD)	15.64 (2.29)
	Median (Range)	15.10 (11.90 – 26.30)
Gender	Female	61 (43.9%)
	Male	78 (56.1%)
Disease code	Brain Tumor	60 (43.2%)
	Solid Tumor	50 (36%)
	AML/CML	18 (12.9%)
	Lymphoma	11 (7.9%)
Initial nutrition diagnosis	Severely Malnourished	10 (7.2%)
	Moderately Malnourished	22 (15.8%)
	Mildly Malnourished	28 (20.1%)
	Normal Nutrition Status	66 (47.5%)
	Overweight	10 (7.2%)
	Obese	3 (2.2%)
End nutrition diagnosis	Severely Malnourished	7 (5%)
	Moderately Malnourished	10 (7.2%)
	Mildly Malnourished	37 (26.6%)
	Normal Nutrition Status	71 (51.1%)
	Overweight	13 (9.4%)

Table 3. Overall Change of Body Weight and Cumulative Dosage of Cyproheptadine Hydrochloride

Characteristics	Result
	Change of body weight (%)
N	131
Mean (SD)	3.01 (9.96)
Median (Range)	2.20 (-18.43 - 35.57)
Cumulative dosage of cyproheptadine hydrochloride (mg)	
N	129
Mean (SD)	5.97 (0.81)
Median (Range)	5.86 (4.03 – 8.02)

The value was applied a logarithmic transformation to the original values.

Table 4. Initial and End BMI z-scores

	At Start	At End	Difference	p
BMI z-Score				0.1366
N	139	139	139	·
Mean (SD)	-0.85 (1.42)	- 0.68 (1.26)	0.17 (1.05)	·
Median (Range)	-0.74 (-4.98 – 2.56)	-0.68 (-4.23 – 1.82)	0.02 (-3.02 – 3.30)	·

Table 5. Change in Nutrition Diagnosis Following Cyproheptadine Hydrochloride Prescription

Initial Nutrition Diagnosis (# in category)	# of patients who maintained their initial nutrition diagnosis (% compared to initial diagnosis)	# of patients who moved positively to different nutrition diagnosis (% compared to initial diagnosis)	Total # of patients who maintained or moved positively to a different nutrition diagnosis (% compared to initial diagnosis)
Severely Malnourished (10)	2 (20%)	8 (80%)	10 (100%)
Moderately Malnourished (28)	5 (17.9%)	13 (46.4%)	18 (64.3%)
Mildly Malnourished (28)	16 (57.1%)	11 (39.3%)	27 (96.4%)
Normal Nutrition Status (66)	50 (75.8%)	0	50 (75.8%)
Overweight/Obese (13)	7 (53.9%)	0	7 (53.9%)

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Event Summary - Academy of Nutrition and Dietetics' Leadership Institute Report Out

Kristin D. Cuculovski, MS, RDN, CSO, LD/N

Program Organizer

Academy of Nutrition and Dietetics offers the Leadership Institute to its members.

Venue

The Leadership Institute utilized multiple virtual platforms due to COVID-19 preventing in-person learning.

Funding Support

I was awarded the ON DPG Education Grant of $500 toward attendance at the ON DPG Symposium in 2020. Due to COVID-19 and the cancellation of the symposium, I was allowed to use the award to partially fund my participation in the Leadership Institute.

Registration

Any Academy member is eligible to apply to the Leadership Institute. There are two opportunities for participating 1) state affiliates, Dietetic Practice Groups and Member Interest Groups can nominate and send one member or 2) individuals can apply through the open application process.

Number of Attendees

93 participants participated in the Leadership Institute during the 2020-2021 session.

Overview

Over the course of 11 months, September 2020 – July 2021, the Academy brought together top nutrition leaders from across the country to participate in the new Leadership Institute. The Leadership Institute was designed as the ultimate professional development program for nutrition professionals seeking to enhance their leadership skills, network with top leaders in dietetics, and take on future leadership positions. Due to COVID-19, the program was redesigned to a virtual learning experience. The program included self-directed study modules, virtual live learning experiences, and hands-on experience working in small cohort groups.

Event Format

The Leadership Institute invited and accepted leader participants of all experience levels; therefore, the program started with two Certificate of Training programs to provide a foundation for essential leadership skills. These were *Certificate of Training #1: Developing Your Role as Leader*, and *Certificate of Training #2: Advancing Your Role as Leader*. The Leadership Institute fee also included complimentary registration to FNCE 2020 to enhance education and networking opportunities.

The next portion of the Leadership Institute focused on engaging workshops to build knowledge, network with other participants in various breakout sessions, and to lay the foundation for our future project work. There was also an optional book club to dive even deeper into each of the workshop topics.

- Workshop #1: Harnessing the Power of Emotional Intelligence
- Workshop #2: Permission Granted to Build an Inclusive Culture
- Workshop #3: Leading with Disruptive Innovation

After finishing the workshop sessions as a full Leadership Institute group in December 2020, we were then divided into smaller cohort groups based on the preferred topic we selected during the application process. The remaining months of the Leadership Institute were dedicated to cohort group work. Group work concluded with presentations on our innovative solutions.

Leadership Institute Themes

Each stage of the Leadership Institute was designed to guide participants to develop an innovative solution to a variety of issues facing the dietetics profession. The cohort group themes included:

1. Professional Development
2. Marketing and Promotion of the Self and the Profession
3. Global Malnutrition
4. Evidenced-Based Practice
5. Competition in the Market Place
6. Policy and Advocacy
7. Diversity, Equity, and Inclusion

The Academy was looking for bold and innovative solutions to influence the profession for decades to come. It was not a small task to think in such grand terms but using the framework provided during workshop #3, each group worked meticulously to frame out these big ideas. Each cohort group worked with a variety of mentors to shape their solutions into real possibilities. After months of dedicated work, each group was able to present their innovative solution in a thirty minute presentation to the Academy Board of Directors, Academy Foundation Board of Directors, Nominating Committee members, Leadership Institute Mentors, CDR Leaders, ACEND Leaders, Academy Executive Team and Academy Staff.

As a graduate of the Leadership Institute, participants received complimentary registration to FNCE 2021, access to a Leadership Institute graduate community within the Academy networking system, potential opportunities to mentor future Leadership Institute participants, a digital badge and certificate designating each graduate of the program, and an invitation to attend FNCE 2022 for onsite recognition.

Personal Reflection

My overall experience as an attendee of the Leadership Institute was very positive. It was

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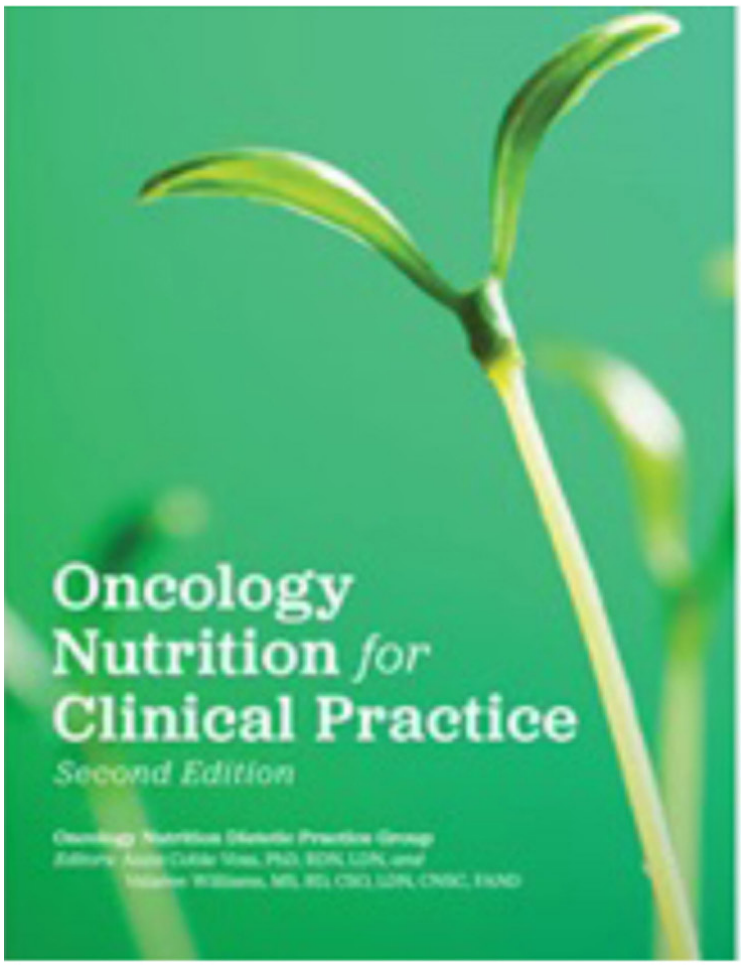
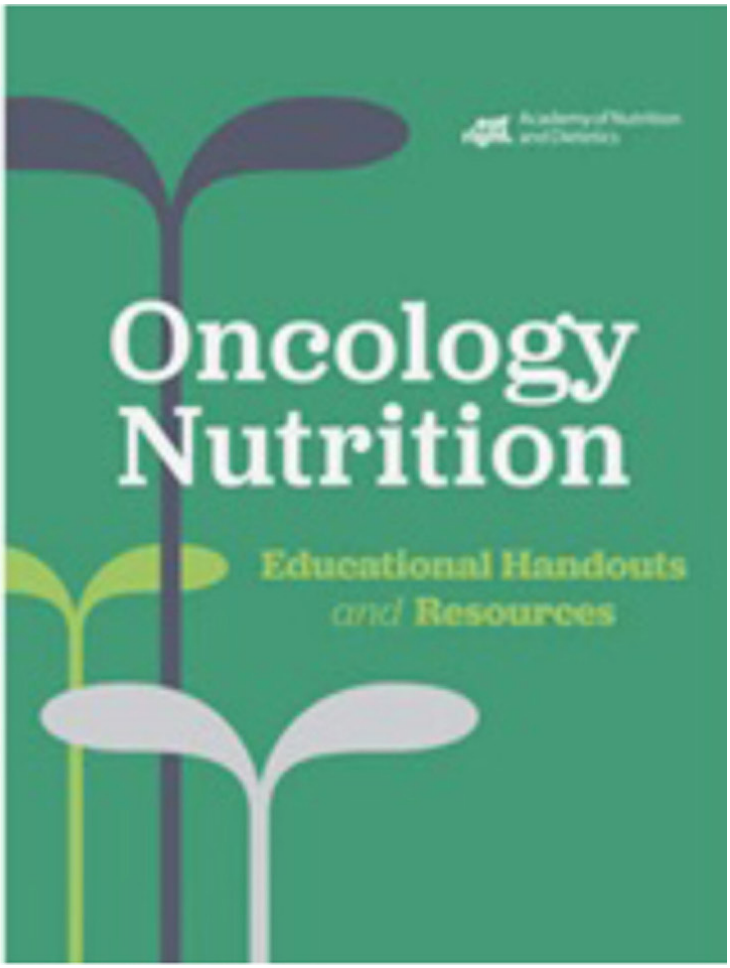
an honor to be accepted as a participant and to work with such high-quality leaders from across the country. I wish that the program could have been a hybrid mix of in person and virtual events as originally designed, but due to COVID-19 that was not possible. The virtual experience was still great. My cohort group is looking forward to meeting in person at FNCE 2022.

As oncology dietitians, we have many opportunities to display our leadership skills whether it is an official job title or specific to situations like advocating for a patient or heading a committee to make a change. The Leadership Institute is a program designed to enhance your leadership skills and to provide you with a foundation and resources to work with a team successfully and effectively. If you are seeking to build your leadership skills or confidence as a leader this program is a great place to start – leadership development is a lifelong commitment.

The Leadership Institute pushed me professionally to think on a much grander scale when it comes to solutions. It showed me that the seemingly impossible idea you want is possible with the right planning, framework, and support. Learning the framework and putting it into practice immediately was key for this skill development. As the Clinical Nutrition Coordinator for a very robust cancer institute, I am required to work with a variety of professionals on a multitude of projects and the Leadership Institute provided new skills and practice to build confidence to keep working towards big ideas and out of the box solutions to any opportunity that presents itself!

Kristin Cuculovski is a Registered Dietitian and a Board Certified Specialist in Oncology Nutrition. She works as the Clinical Nutrition Coordinator for the Oncology and General Outpatient Nutrition Services department at Northside Hospital in Atlanta, GA. Kristin has been able to combine her two passions, leadership and oncology, in one dream job. She applied to the Leadership Institute to enhance her leadership skills to better serve her team and department. Kristin completed her Masters of Science in Clinical Nutrition at East Tennessee State University and her Bachelor of Science at Middle Tennessee State University and has been practicing as a dietitian for over 11 years.





The highly anticipated release of Oncology Nutrition for Clinical Practice is here! This comprehensive resource from the ON DPG provides both evidence-and experience-based information for application in clinical practice.

Head and Neck Cancer Survivors' Experiences with Chronic Nutrition Impact Symptom Burden after Radiation: A Qualitative Study

Sylvia L. Crowder, MS, RD; Natasha Najam; Kalika P. Sarma, MD; Barbara H. Fiese, PhD; Anna E. Arthur, PhD, MPH, RD

Abstract

Background

Head and neck cancer (HNC) survivors may face an array of nutrition impact symptoms (NIS), including dysphagia, xerostomia, taste alterations, and difficulty chewing, which occur as a result of tumor location and treatment with radiation. Few qualitative studies have assessed the chronic impact of NIS on everyday life.

Objective

The aim of this study was to obtain a comprehensive understanding of the lived experience of chronic NIS burden on HNC survivors.

Design and participants

Semi-structured, face-to-face interviews were conducted with 31 HNC survivors to address the research aims and objectives. An interview guide was utilized to consider themes that had been generated through the review of literature and through the researchers' clinical experience within the field. There were probes within the interview for participants to raise unanticipated issues and flexibility to follow such leads. Interviews were conducted between March 2018 and May 2019.

Analysis

A single researcher conducted the interviews to maintain consistency in data collection. Interviews lasted approximately 1 hour and were audio-recorded. All inter- view transcripts were professionally transcribed verbatim and checked for accuracy to ensure a complete account of participants' responses. Two researchers applied qualitative thematic content analysis to identify major themes.

Results

The following 4 major thematic categories emerged from the interview data: symptom presence, dietary preferences, eating adjustments, and addressing symptoms. The most common symptoms were dysphagia, xerostomia, taste alterations, and bothered chewing. As a result of dietary preferences, survivors avoided citrus fruits, dry foods, raw vegetables, sweets, and meats. Survivors preferred soft and moist foods, spices or seasonings, and sauces or gravies. Eating adjustments were described as increased time to consume meals, cutting food into smaller pieces, consuming less food, and consuming more fluid. As a result of food preference changes and eating adjustments, survivors reported dietary pattern changes from pre to post treatment. All survivors experienced 1 or more chronic NIS, yet nearly 40% were unaware before treatment that NIS had the potential to persist chronically.

Conclusions

The results of this study provide unique qualitative insight into the lived experience of chronic NIS burden on HNC survivors. By recognizing the daily challenges, health care team members can better support HNC survivors in the transition from active treatment to follow-up care.

It is estimated that 90% of head and neck cancer (HNC) survivors experience exceptionally high rates of nutrition impact symptoms (NIS) in survivorship as a result of tumor location and aggressive treatment with radiation to the head and neck region (1,2) Although there are notable improvements in survival with high-dose radiation treatment (3). These protocols contribute to significant NIS burden during and after treatment.4 NIS refers to any adverse effects or symptoms that compromise the ability and/or the desire to eat and drink, including but not limited to dysphagia, trismus, xerostomia, difficulty chewing, mucositis, and taste alterations (2). Although it is possible for acute NIS to resolve after treatment, NIS can continue for months or even years after treatment completion and become a chronic health problem (2,5). Chronic NIS can have potentially devastating effects on survivors' overall well-being, as eating ability might never return to normal, forcing survivors to make adaptations and relearn how to eat (5). In addition to physical eating difficulty, psychological and social challenges can also exist, given the significance of food in day-to-day life (4).

Despite the impact of radiation-and tumor-induced NIS, most of the knowledge related to NIS burden is based on quantitative studies (6-9). This constitutes an important knowledge gap, as quantitative research is unable to explore, in-depth, how HNC survivors live with NIS burden (7,10). Through qualitative research, it is possible to explore survivors' perceptions of NIS burden in the way they interpret and perceive them. To date, only 5 solely qualitative studies have examined the effects of radiation-induced NIS on patient outcomes, and all of these studies examined NIS in the early survivorship phase only

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(maximum of 18 months post radiation) (4,11-14). In addition, the 2 qualitative studies that examined survivors more than 1 year post radiation assessed dysphagia only, compared to a more robust NIS list (12,13).

The primary aim of this study was to obtain a comprehensive understanding of the lived experience of chronic NIS in HNC survivors who were 6 months to 9 years post radiation. Outcomes, including symptom presence, dietary preferences, eating adjustments, and addressing symptoms, were explored. Qualitative methodology was appropriate to address our exploratory, patient-centered research aims, exploring survivors' own descriptions of how they lived and managed their everyday NIS. A semi-structured interview guide was used to consider main themes from the literature and the researchers' experience in the field. The results of this study might raise awareness of chronic NIS in HNC survivors and encourages health care providers to inform patients of potential NIS risks and consequences. This work also highlights the need for more effective NIS prevention and management in this population.

Methods

Ethical Approval

The protocol was approved by the Institutional Review Boards of Carle Foundation Hospital and the University of Illinois at Urbana-Champaign and adhered to the principles of the Declaration of Helsinki. All participants were informed of the purpose and procedures of the study and informed written consent was obtained from all participants before data collection. Participation in the study was voluntary and participants retained the right to withdraw at any time without explanation. To ensure confidentiality, patient health information was anonymized and assigned a number code. No individuals are identifiable in any presentations of results.

Study Population

Screening and recruitment occurred between March 2018 and May 2019. Eligibility criteria included previously diagnosed stage I to IV primary cancer of the oral cavity, oropharynx, hypopharynx, nasopharynx, or larynx; within 6 months to 10 years post treatment with radiation or chemoradiation; currently deemed by their oncologist and/or surgeon as having no evidence of disease; able to consume food orally; 18 years or older; and English-speaking. In the last decade, HNC survivors experienced a change in treatment modalities from conventional radiotherapy to parotid- sparing intensity-modulated radiotherapy. Therefore, those HNC survivors who were treated with radiation within the past 10 years were identified via the Hospital Cancer Registry to ensure homogeneity in the type of radiation received. In summary, 265 HNC survivors were screened for the study, 79 were deemed eligible, and 31 signed letters of consent and completed the interview. All participants were disease-free at the time of the interview. Mean (standard deviation) length of interviews was 50 (26) minutes (range=35-73 minutes). We aimed to recruit until saturation had been reached, anticipating approximately 15 to 20 participants. However, due to high participant response, we recruited beyond our initial goal.

Data Collection

Demographic and Clinical Characteristics

Participants completed a health survey that included self-reported data on demographic and behavioral characteristics, including age, race, ethnicity, sex, marital status, income, smoking, and alcohol status. An electronic medical record review was conducted to collect clinical data on cancer stage, treatment type, and time since diagnosis.

Qualitative Phase

Semi-structured, face-to-face interviews were conducted to address the research objectives. Interviews were chosen over focus groups, as we were interested in learning about survivors' individual beliefs and experiences as compared to a group consensus. A qualitative methodology was chosen because we were not seeking to test a hypothesis, rather we wanted to obtain a better understanding of the lived experience of chronic NIS post radiation. The first author (S.L.C.) conducted interviews in a private room at a midwestern cancer center. An interview guide was utilized to consider themes that had been generated through the review of literature, a team of experts, and the researchers' clinical experience with HNC survivors. There were probes within the interview for participants to raise unanticipated issues and flexibility to follow such leads. One trained researcher conducted the interviews to ensure consistency in data collection. The researcher was trained to have minimal verbal input and prompt only when appropriate.15 Interviews lasted approximately 1 hour and were audio-recorded. All interview transcripts were professionally transcribed verbatim and checked for accuracy to ensure a complete account of participants' responses. Interview transcripts and audio files were stored on a password-protected flash drive in a locked filing cabinet.

Data Analysis

Data were analyzed using a 6-step thematic analysis approach, as outlined by Braun and Clarke (16). A qualitative method for identifying, analyzing, and reporting themes. Thematic analysis was chosen to provide a rich description of the data and to identify themes at an explicit level using a realistic approach (16). The first author who conducted all face-to-face interviews, first re-familiarized herself with the data by reading all verbatim transcripts several times. Starting with line-by-line coding, statements thought to be related to NIS, eating adjustments, and dietary preferences were coded and categorized. These codes were then amended and refined through discussion between the first author and the second author until a single list was agreed. The first author entered the list of codes into Dedoose (SocioCultural Research Consultants [SCRC]), a web application used for qualitative data analysis, and coded all the transcripts, with codes added to the list where necessary. The second author then coded all transcripts to check for reliability and any discrepancies were discussed and resolved in discussion. Once the coding had been agreed upon, the 2 researchers reviewed the coded transcripts to search for common themes. These themes were reviewed, refined, and named and each was given a written description.

Results

The Table displays the demographic and clinical characteristics of the study population. All survivors were non-Hispanic. Slightly more than one-half of survivors were male and most

were diagnosed with stage IV cancer. More than one-half of survivors were married. One-half of survivors were current drinkers and former smokers. The findings of the study are presented under the headings "nutrition impact symptom presence," "dietary preferences," "eating adjustments," and "addressing symptoms." These themes were identified in HNC survivors' reflections on their experiences with, and perceptions of, NIS, eating, and coping considerations (Figures 1 and 2).

Qualitative Results

NIS Presence. Survivors experienced a variety of tumor- and radiation-related adverse NIS, including dysphagia, trismus, xerostomia, difficulty chewing, mucositis, thickened saliva, coughing/choking, and taste and smell alterations. Other symptom burden included voice changes (eg, tone, clarity, and voice tiring easily); pain, inflammation, or tightness in the neck or shoulder; and nasal blockage or secretions. Among these, the 4 most frequently reported NIS were xerostomia (n=30), taste alterations (n=29), dysphagia (n=22), and bothered chewing (n=20).

Xerostomia. Of the 31 survivors, 30 experienced xerostomia. The only survivor who did not report xerostomia stated he had "too much" and a "white and thick" saliva consistency. Xerostomia was the most distressing NIS for 8 survivors and was described it as "terrible," "cotton-like," and as if their "mouth is stuck together." Twelve survivors reported that xerostomia interrupted the quality of their sleep, as they were awakened with dry mouth. One survivor described this experience by stating the following:

> *"Because like when I wake up during the night because of my dry mouth, I gotta reach over and get a drink. So I always have water at the bed now. I never used to have water at my bed before." (study ID 1015, female)*

In addition, 8 survivors declared xerostomia was the easiest NIS to manage and developed various coping mechanisms, including carrying portable water bottles to increase fluid intake and using specialty products, including mouthwashes, lozenges, and

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Table. Demographic and clinical characteristics of 31 head and neck cancer survivors participating in semi-structured interview data collection on post-treatment nutrition impact symptoms.

Characteristic	Data
Age, y, mean±SD (range)	63.2±12.0 (32-81)
BMI,	
a **mean±SD (range)**	25.7±4.8 (16.5-38.3)
Under/normal weight	17 (54.8)
Overweight/obese	14 (45.2)
Sex, n (%)	
Male	18 (58.1)
Female	13 (41.9)
Ethnicity, n (%)	
Non-Hispanic	31 (100)
Race, n (%)	
European American/white	29 (93.5)
Other	2 (6.5)
Education, n (%)	
High school/GED[b] or more	14 (45.2)
Some college or more	17 (54.8)
Annual household income, n (%)	
≤$54,999/y	18 (58.1)
≥$55,000/y	13 (41.9)
Marital status, n (%)	
Married	19 (61.3)
Not married	12 (38.7)
Smoking status, n (%)	
Current	2 (6.5)
Former	16 (51.6)
Never	13 (41.9)
Alcohol status, n (%)	
Current	17 (54.8)
Former	12 (38.7)
Never	2 (6.5)
Time since diagnosis, n (%)	
≤6 mo to 2 y	9 (29.0)
≤2 to 5 y	14 (45.2)
≤5 to 9 y	8 (25.8)
Tumor site, n (%)	
Oral cavity	16 (51.6)
Oropharynx	11 (35.5)
Hypopharynx	1 (3.2)
Nasopharynx	1 (3.2)
Cancer stage, n (%)	
I	2 (6.5)
II	9 (29.0)
III	3 (9.7)
IV	17 (54.8)
Treatment, n (%)	
Concurrent chemoradiation	18 (58.0)
Radiation only	13 (42.0)

a BMI=body mass index; calculated as kg/m^2.
b GED=General Educational Development.

chewing gum, to stimulate saliva production. One survivor described the use of products by stating the following:

"I put two sticks of gum in my mouth sometimes and a week later it deteriorates, and I stick in two more sticks of gum. I just chew the gum as long as it'll go. I mean there's no flavor to it but it's not the flavor. It's just—stimulating the saliva glands." (study ID 1018, male)

Taste alterations. The majority of survivors (n=29) reported being bothered by taste alterations, describing it as "frustrating," "troublesome," "disappointing," and "aggravating." Three survivors described taste alterations as the most distressing NIS. One survivor stated they had "no taste" and are "not interested in eating" and "all my favorite foods, since I can't taste, I don't wanna ruin the way I remember them tasting." Another survivor described her frustrations with taste alterations by stating the following:

"There's just no flavor. The thing of it is it's really frustrating to be able to smell food cooking and think, 'Oh, wow. I'm excited to eat,' but then it doesn't taste the way it should. It doesn't have any particular—it's just that there's no flavor." (study ID 1034, female)

Taste alterations were most commonly reported in sweets, specifically chocolate and ice cream; meats; and fruit. Meanwhile, others stated seasonings, such as salt and garlic, and other sweets, such as cakes and cookies, were foods that they could taste but not to the pretreatment intensity. One male survivor described taste alterations by stating the following:

"I usually drink chocolate milk. I have to make it really strong so I can taste it. Everybody else thinks it's yucky. It just tastes normal to me. What's sweet to everybody else isn't sweet to me. I take a sweet tea, and I have to add sugar to it. Nothing is ever actually sweet anymore. What used to be sweet isn't sweet." (study ID 1037, male)

Dysphagia. The majority of survivors reported dysphagia (n=22), describing it as "bothersome," an "annoyance," and stating food "catches." Nine survivors declared no issues with dysphagia, however, as the interview continued these survivors went on to discuss eating modifications made to food, including consuming small bites, chewing foods excessively, and tilting their head to assist with swallowing as a result of dysphagia:

"When I swallow, I try to put my head back and make sure it all goes." (study ID 1033, female)

Three survivors described dysphagia as the most distressing NIS. One stated the following:

"Swallowing food I would say bothers me the most. I can deal with everything else, but like I say, it'd be nice to be able to eat something and not have to have a glass of water there to wash it down. It probably really doesn't take away from the flavors and that, but psychologically, it's like I just wanna eat something." (study ID 1002, male)

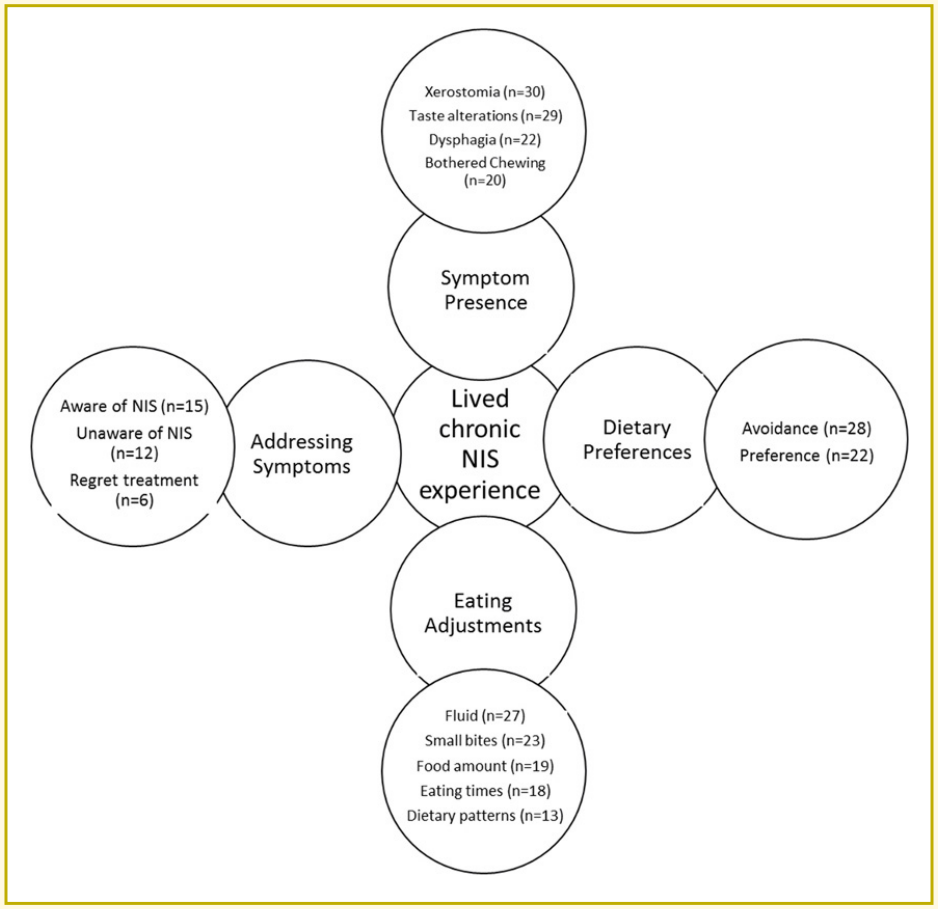
A few survivors stated dysphagia was the most manageable NIS, as they adapted through consuming more fluids and selectively choosing moist or soft foods. One male participant stated how he coped with dysphagia as follows:

"Probably the swallowing [is most manageable]. I just make sure I know don't eat a real dry, pastry type food unless I got water. Or if I order something, make sure it's more liquid and moist. And then after that, no problem." (study ID 1014, male)

Survivors reported having to swallow multiple times before food would "go down," taking sips of water between bites to assist with swallowing, and having to "re-learn" how to swallow. One male participant shared the following:

"I had to learn how to swallow all over again. You just take everything for granted. You just put something in your mouth, chew it, and swallow it. You've gotta totally rethink things. If you don't have something to drink, I constantly go back to get something to drink because it's impossible to swallow." (study ID 1037, male)

Figure 1.



Bothered chewing. Chewing difficulties were common in slightly more than one-half of survivors, who described it as "uncomfortable," "troublesome," and "inconvenient." Eleven survivors declared no chewing issues; however, as the interview continued, these survivors discussed eating adjustments as coping mechanisms. A male participant shared the following:

"Sometimes I can do roast, stuff like that, you know like in crock pots and stuff like that, if it gets very, very soft and it's cut up fine, to where it's more or less I really don't chew it, I just swallow it." (study ID 1032, male)

One survivor stated bothered chewing was the most manageable NIS and adapted by choosing moist or soft foods. A few survivors stated they preferred to swallow foods instead of chew them, as they felt it was too much effort to chew, and by the time they finished chewing their jaws were tired before they were full.

"Well, I do a lot of juices and smoothies, just because it's a lot less effort. Since it does take me so long to eat, and chew, a lot of times, I won't get full, so having a smoothie or something will actually make me feel full." (study ID 1041, female)

Survivors reported avoiding foods they knew would take a long time to chew, including rice, raw vegetables, pastries, and meats.

Dietary Preferences. Food avoidance. As a result of NIS, there was a heightened awareness of what survivors "could no longer eat." Nearly all survivors reported food avoidance, describing it as "depressing," "disappointing," and a "struggle." One survivor stated the following:

"There's lots [I avoid], and I couldn't even name them all honestly, because there's just so much stuff I just don't even attempt to eat it, or I'll try and be like, eh." (study ID 1015, female)

Nineteen survivors stated they avoided meat, most commonly red meat, as it was "a drier meat."

"I avoid them [meats]. I just have avoided them because they were difficult to eat, and if I was going to eat, I was going to have something that was not difficult—didn't cause me problems." (study ID 1009, female)

The majority of survivors avoided soft breads and starches for reasons including: "they dry me up quicker," "I'm chewing on it a long time after I've really finished the bulk of it," and "it'll literally stick in the back of my throat and just stay there." Survivors also avoided fruit, most commonly citrus fruits and "fruit with skin," including apples and grapes. One female survivor shared the following:

"Some fruit—I eat bananas every day, but fruit with skin I can't eat. I love strawberries and grapes, but I have to be able to mash the strawberries and I have to take the skin off the grape; I can't manage that." (study ID 1024, female)

One-third of survivors avoided raw vegetables. Other common food avoidances included sweets/cakes/pastries, chocolate, potato chips, crackers, and carbonated beverages. One female participant described her avoidance of raw vegetables as follows:

I used to really like raw carrots. I can't eat a raw carrot at all, now. So, I'll steam it and make it fairly soft, versus the broccoli I used to like it kind of a little crunchy, but still soft. Now, I just make it completely soft." (study ID 1041, female)

Foods preferred. In addition to food avoidances, survivors reported several food preferences. The majority of survivors reported a preference for soft foods, including applesauce, yogurt, eggs, pasta noodles, and cottage cheese. Twenty-one survivors reported a preference for adding sauces, gravies, jams, and butters to food to make them easier to chew and swallow. One survivor described adding moisture to her food as follows:

"I add gravy, those cans of [store-bought] gravy, chicken, beef, pork. Those are my friend. Like I say, butters and jellies and even a little bit of cream cheese I discovered with jelly work okay." (study ID 1034, female)

Survivors reported adding spice, salts, and seasonings to their food as a way to increase taste and promote saliva production. In addition, survivors reported a preference for cooked vegetables, bananas, canned peaches, and blending or mashing foods to make them easier to chew and swallow. One-third of survivors reported cooking modifications, including cooking meats for less time. One survivor described this rationale as follows:

"So now, I have to, like, back off heating-cooking [meats] all the way, so it's a little juicier, a little more pinker, so. But, normally [before treatment], I would prefer it cooked all the way through." (study ID 1015, female)

Eating Adjustments. Food amount, dietary patterns, fluid intake, time to consume meals, and size of bites. The majority of survivors reported consuming less food and remained at a lower weight than before treatment. They also reported a change in dietary patterns from pre- to post treatment. Survivors believed their diet had improved and stated they were making a conscious effort to include more cooked vegetables and fruits in their meals. One survivor shared increasing their vegetable intake, as follows:

"Yeah, I eat—I wanna try to eat stuff that I can get the most out of. Vegetables, because I do—I like eating, so I'm gonna try to get the most out of the healthiest food that I can get down in me." (study ID 1026, male)

Nearly all survivors increased their overall fluid intake. Survivors reported "always having a water bottle" and stated they are "constantly drinking water, coffee, or pop." The majority of survivors were unable to eat without fluids. One survivor described their increased fluid requirement during meals as follows:

"I have to have something to drink constantly, especially if I'm eating. I can't eat unless I have something to drink." (study ID 1037, male)

Slightly more than one-half of survivors reported increased eating times. One survivor shared the following:

"It just seems like it takes longer for all of the crumbs, pieces, particles, to go down. All of it. So, I feel like I'm chewing on it a long time after I've really finished the bulk of it. Because chewing is awkward, and it takes me longer to finish. I just don't want to inflict how I have to do things—when you're eating it's gross if people can't just talk and swallow normally, and I have to slow down and certain things." (study ID 1028, female)

The majority of survivors cut food into smaller more "manageable" bites. One survivor

(Continued on page 22)

Figure 2. Themes and subthemes from semi-structured interviews of long-term head and neck cancer survivors' chronic nutrition impact symptom experience.

Code	Description	Study ID, Patient's Sex: Example Quote
Theme 1: Nutrition Impact Symptoms		
Xerostomia	Also referred to as xerostomia Any report of a decreased production of saliva, cotton mouth, and increased fluid intake	1018, male: *"Yes, okay dry mouth. That's why I chew gum 24 hours a day, 7 days a week whenever I can. I do have a major problem."* *1019, female: "I have no saliva."* 1030, male: *"I get up two or three times, my mouth is very, very dry. I keep a bottle of water right there."*
Taste dysfunction	Any report of the ability or inability to taste	1023, female: *"I think it's the taste buds. I think I was surprised about how much they've changed."* 1020, female: *"I have some taste on some things, it depends."*
Dysphagia	Report of the ability or inability to swallow foods and liquids	1002, male: *"I would say my swallowing ability would be at about 60% of what it initially was."* 1025, male: *"I have no problems with eating. No swallowing problems, no nothing."*
Bothered chewing	Report of the ability or inability to chew food	1019, female: *"I don't have the power in my jaws to chew, it's very hard to grind."* 1020, female: *"I have to chew a little more than say, if I hadn't had the cancer."*
Theme 2: Dietary Preferences		
Food avoidance	Any report or instance of avoiding foods ate before treatment for any reason	1002, male: *"A lot of spices I can actually taste . . . I like to eat stuff that's got a little bit of spice to it because it's a little more enjoyable."*
Sweets	Preference/no preference consuming sugar, sugar-sweetened beverages, and cakes/candies	1012, male: *"I don't eat hardly any sweets—sugar, chocolate, things like that they just don't—and I used to love those things, cookies, pies cakes . . ."*
Breads/ starches	Preference/no preference consuming breads, pastries, toast, and rolls	1002, male: *"I try not eat bread because bread takes a lot of fluid to get down . . . it sticks to the back of my throat and just stays there."*
Meat	Preference/no preference consuming meats (eg, chicken, pork, and beef)	1020, female: *"But as far as the meats, well like I said no. I haven't had meat in 7 years."* 1041, female: *"Well, meat in particular is very difficult to eat."*
Vegetables	Preference/no preference consuming raw, hard, or uncooked vegetables	1005, female: *"I can eat vegetables, cook them and steam them (to make softer)."*
Fruits	Preference/no preference consuming fruit	1024, female: *"Some fruit—I eat bananas every day, but fruit that's stringy I can't eat. I love grapes but I have to take the skin off the grape; I can't manage that."* 1033, female: *"I can't think right now, but different things, like apples, fruit-type things that are hard I don't eat anymore."*
Spice/salt/ seasoning	Any report or instance of adding spices, salts, and seasonings to food	1002, male: *"A lot of spices I can actually taste . . . I like to eat stuff that's got a little bit of spice to it because it's a little more enjoyable."*
Sauces/ gravies/ jams	Any report or instance of adding moisture to foods to make easier to eat	034, female: *"If the food is saucy or has gravy on it or moist, it goes down better than dry things."*
Soft food preference	Any report or instance of choosing soft/ mashed consistencies	1019, female: *"Squish it, or run it through the blender."* 1020, female: *"Well, I blend the soup even the cream of chicken or cream of potato, because they have things in them and I have to blend that up so I can (eat) it."*
Cooking modifications	Any report or instance of cooking foods differently (eg, cook veggies longer to make softer, cooking meats less to have more juice/remain tender/ preference for more "fatty" foods)	1023, female: *"I cook (meats) a little more to the medium rare side versus the well-done side."* 1002, male: *". . . (meats) get cooked less because I order it medium-rare because I wanna keep it softer."* 1033, female: *"Absolutely. Totally different. I mean I eat the same things at night that I used to, but I cook them different, and I ate heavier foods before, I guess you would say. And I snacked a lot more than I do now."*

Figure 2. Themes and subthemes from semi-structured interviews of long-term head and neck cancer survivors' chronic nutrition impact symptom experience.

Code	Description	Study ID, Patient's Sex: Example Quote
Theme 3: Eating Adjustments		
Food amount	Any report or instance of changing the size of the meal (eg, eat more or eat less) than before treatment	1009, female: *"I don't eat as much because I have to eat slow. I mean, I guess your stomach must fill or something because it doesn't take as much for me to feel full."*
Dietary patterns	Any report or instance of dietary changes occurring from pretreatment to post treatment (eg, eating more fruits/ veggies now than before treatment)	1023, female: *"So, like avocados. I didn't like the taste of avocados before cancer, and now I can stand them. Like sushi, I didn't like sushi before, and now I eat it all the time."* 1027, male: *"And I used to love watermelon and muskmelon. But they're just not the same, really. So, I don't eat as much of those anymore."*
Size of bites	Any report or instance of changing the size of bites from pre- to post treatment (eg, cutting food into smaller pieces, using a fork/knife to eat vs biting into a sandwich)	1019, female: *"I have to take tiny bites. Very little bites-of anything."*
Time to consume meals	Any report or instance of the time to consume a meal change from pre- to post treatment/chewing thoroughly or excessively while eating meals	1028, female: *"Because chewing is awkward, and it takes me longer to finish. I just don't want to inflict how I have to do things—when you're eating it's gross if people can't just talk and swallow normally, and I have to slow down and certain things."*
Fluid intake	Increased fluid intake due to dry mouth and/or swallowing fluid with every bite of food	1019, female: *"Every bite's swallowed with water."* 1023, female: *"I just make sure I have something to drink at every meal."*
Theme 4: Addressing Symptoms		
Not aware of NIS	Being unaware of NIS before receiving treatment	1005, female: *"No. No. No, I did not know I would lose my taste or have dry mouth or choke."* 1029, male: *"No, I had no idea. I know the surgery would've had some side effects, but that—what is it—radiation. You'd almost think I would go through that surgery again before I go through that radiation. That thing gives you a lot of side effects. They're no fun."*
Aware of NIS	Being aware of NIS before receiving treatment	1017, male: *"Symptom management, again, they let me know what to expect. If anything, I felt like maybe I didn't—they had me a little more frightened about symptoms than it turned out in my case I needed to be . . ."*
How learned NIS	Internet, speaking with doctor, health care team, friends, or family	1008, male: *"I know Dr. XX did tell me that I would probably lose most of my saliva glands. They would be burnt up. And how much they came back he didn't know. I was also aware of the taste factor, how much come back, and then he said a lot of that would come back. Some people with a year, some people it was 5 years. So, I was aware of that. I don't—I wasn't really aware how much of this tightness that I'd feel."*
Who talk to	Who survivor confides symptom concerns with (eg, family, spouse, friends, doctor, and health care team)	1027, male: *"Well, I probably talk to my wife some and my primary physician."*
Keep to self	Independent, no concern, prefer not to talk about symptoms/cancer	1019, female: *"I don't—friends-wise—because at our age, we've kind of drifted away, so I can't say friends. Family, I don't have much family."*
Regret treatment	Survivor's negative perception of recovery, treatment, and NIS	1032, male: *"You know, I don't know. I don't know. I never—I guess I really thought about it. But I can tell you this, I sure wouldn't want to go through it again to be here, all of this stuff [symptoms]."* 1037, male: *"That's right I wouldn't have done the radiation. I don't want anybody to go through what I'm going through."*

described their frustrations regarding the size of bites as follows:

"It's like I have to take little tiny little bites around to eat a corndog, or I just cut it up and eat it with a fork. There's lots of stuff I eat cut up with a fork now because I can't eat it like I used to eat it." (study ID 1015, female)

Addressing Symptoms. Symptom awareness. Of the 31 survivors, 15 were aware of at least 1 NIS and 2 survivors stated they were "prepared well." Survivors learned of NIS through discussions with their oncologists, nurses, and other HNC survivors. Survivors described the challenges of not knowing how long NIS would persist or if they would be permanent. One survivor described being aware of NIS while hoping for the return of normal function as follows:

"Yes and no. They kind of talk about the symptoms before you go in, but they're usually like well, on average it comes back in six months or something like that, and I always seem to be on the very end side, the longer side coming back." (study ID 1041, female)

Nearly 40% of survivors were unaware of the potential for lingering side effects from radiation and would have preferred to have been made aware before treatment. Survivors developed coping mechanisms, including avoiding talking about NIS and keeping NIS problems to themselves, and others preferred sharing concerns with members of their social support, primarily spouses or partners, children, parents, or oncologists. A few survivors stated that if they were aware of the severity of chronic NIS they would have refused treatment. One male survivor shared the following:

"I think people should know what they're getting into before they do it. If it was me, I wouldn't do this again. I wouldn't have done it the first time if I knew what I was getting into." (study ID 1037, male)

A female survivor shared the following:

"… well, I'm thinking if they would've told me up front that I was gonna lose my taste, I don't know if I would've went through the radiation or not because a lot of people don't realize how important taste is. Some of my friends will say, 'Here, taste this. Do you like it?' And I just look at them like haven't they heard me say every day that I can't taste it, I can't taste it? But that's the only thing I regret." (study ID 1005, female)

Discussion

This qualitative study provided insight into the long-term experience of living with chronic NIS after HNC treatment. Thematic analyses suggest NIS burden persisted in all survivors post treatment, despite many survivors adapting to these long-term challenges through the development of coping mechanisms, such as cutting food into smaller bites and selectively choosing foods. Furthermore, findings suggest a large proportion of the HNC survivors in this study were not fully aware of the breadth of NIS and the potential for NIS to persist and impact their lives chronically. Survivors received symptom education primarily from their oncologist, nurse, or other HNC survivors. Survivors who were unaware of NIS would have preferred to receive symptom information before treatment to better prepare for life after radiation and/or guide their decision making regarding their cancer treatment.

Our findings are similar to those of earlier studies exploring dietary consumption after treatment for HNC survivors. Survivors in our study adapted to eating adjustments by selectively choosing foods, changing dietary patterns, performing cooking modifications, cutting food into smaller bites, increasing fluid intake, and mashing/ blending foods into soft consistencies. Similar, Patterson, Nund, and their colleagues (12,13) recognized that survivors modified food preparation methods and limited overall dietary intake as a result of NIS. Furthermore, McQuestion, Patterson, and their colleagues (4,12) also reported that time to consume meals increased substantially after radiation. Contradictory to prior research, the addition of spices and seasonings was viewed favorably in our survivor population, but was reported as bothersome and avoided in previous HNC populations as a result of mucosal sensitivity and xerostomia (4,12,17). Prior studies were conducted with patients during or immediately after treatment. It is more likely that the oral mucosa was still sensitive in comparison to our study population, which included survivors up to 9 years post radiation.

Food avoidance related to chronic NIS was common in our population. Perhaps one of the most surprising findings was that many survivors reported dietary pattern improvements from diagnosis to post treatment as a result of food avoidance. Survivors reported higher consumption of cooked and soft plant-based foods compared to meat proteins that are chewier and challenging to swallow. Survivors complained of taste alterations and believed if everything tasted bland they might as well try to eat "food that is better for their bodies" and "more fruits and more vegetables." Survivors also reported avoiding "junk foods," including sweets, pastries, candies, and chocolates because they no longer tasted the same or were too drying to consume. Despite many survivors reporting dietary improvements, some reported an avoidance of citrus fruits, "fruits with skin," and raw vegetables. Avoidance of these food groups over time may result in vitamin and mineral deficiencies (5). In addition, these food groups are abundant in antioxidants and phytochemicals that might offer a promising strategy for reducing treatment- related NIS burden (9). while improving overall survival in this population (18,19). Without the regular consumption of these food groups, survivors might miss out on their potential benefits (20-22). Nutrition intervention studies are needed that focus on educating survivors on the importance of fruit and vegetable intake and teaching them the skills needed to prepare fruits and vegetables in a way that is easy for this population to chew and swallow. Although HNC survivors might employ eating adjustments to cope with chronic NIS, health care professionals should not assume survivors have fully adapted to their new life after treatment (23).

An unexpected finding from the study was that many survivors were unaware of the NIS consequences of radiation to the head and neck, and nearly 20% of survivors stated that if they had been made aware, they would have refused treatment. HNC patients should be made aware of potential chronic symptom burden and functional problems to help guide

their decision making regarding cancer treatment and to better prepare them for life after treatment (4,11,12,24). Oncology registered dietitian nutritionists are uniquely poised to tackle NIS issues, as they have appropriate training in nutrition and dietetics therapeutic counseling and might be able to effectively manage patients' nutritional challenges (25). Currently, Medicare coverage only includes outpatient medical nutrition therapy provided by a registered dietitian nutritionist for beneficiaries with diabetes or kidney disease, but health care spending for cancer equals or exceeds these costs (25). According to the National Comprehensive Cancer Network guidelines, all HNC patients should receive dietary counseling with the initiation of treatment and regular registered dietitian nutritionist follow-up should continue until the patient has achieved a nutritionally stable baseline after treatment (26). To meet cancer survivors' need for nutritional services across the cancer continuum and improve symptom management, changes in plan benefit design and insurance coverage policies are warranted to encourage access to cost-effective comprehensive care (25).

Although oncologists were the main source of NIS information, prior HNC research has revealed that patients who receive verbal information only from their oncologist do not retain as much, are confused, and express dissatisfaction in their plan of care (23). In an effort to help HNC survivors prepare for treatment, information should be tailored using a variety of different learning modules, such as visual and audio, as a means of simplifying complex information and retaining the quality and quantity of content (23). The treatment care plan should consider quality of life in addition to quantity of life, highlighting coping considerations for adapting to life after cancer, as HNC survivors might require additional symptom monitoring and management beyond the termination of therapy (2).

A large and consecutive group of HNC survivors with repeated thematic interviews is warranted to explore the presence of chronic NIS from diagnosis to several years post treatment. It is also important to identify predictive factors that might place survivors at greater risk for developing severe eating challenges and food aversions related to NIS. Emphasis should be placed on educating and preparing HNC patients before treatment to better guide their treatment decision-making process. In addition, intervention studies employing symptom education via multimedia methods are encouraged to address potential physical NIS burden and the associated psychological consequences of treatment-related toxicities.

A strength of the present study is that it included long-term HNC survivors, which allowed for the exploration of the lived experiences of chronic NIS after treatment. The same researcher performed all face-to-face interviews, allowing for consistency in data collection. In the analysis process, the first and second authors coded all interviews until complete agreement was reached. The interviews took place in a neutral and familiar environment, allowing survivors to feel comfortable sharing their NIS experiences. Finally, the most notable strength of this study is that these findings are based on the HNC survivors' own voices as they articulate their experiences with NIS in the context of their own lives.

Study findings should be considered in light of the following limitations. It is important to note that this study reflects the lived experiences of a small sample of individuals from the Midwest and, therefore, it is possible our observations are not generalizable to all HNC survivors. We were unable to blind the study participants to our research question, therefore, it is possible that survivors who were interested in the study and completed the interview were also the ones who were most bothered by NIS post treatment. Another potential weakness is the condensation of the huge amount of data into short case narratives. This is a process of reduction and it is difficult to ensure that this reduction takes all relevant contextual factors into consideration (24). However, we performed combined analysis with independent categorization and joint discussions as a means of highlighting main themes and subthemes.

Conclusions

The current study highlighted the high prevalence and complex consequences of radiation-induced NIS on long- term HNC survivors. As a result of NIS, survivors reported modifications made to foods and changes in food preferences and dietary patterns. The current study confirms that the wide-ranging consequences of NIS are not confined to the early post-treatment period. Additional qualitative research is needed to identify the lived experience of chronic NIS across various time points and implications on quality of life.

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Suddenly a Virtual RD: My Reflection on Transitioning to Telenutrition during the COVID-19 Pandemic

Whitney Christie, MS, RD, CSO, CNSC

When the COVID-19 pandemic hit, I knew I had to do something to continue to provide services to patients with cancer. Like many outpatient oncology dietitians, I transitioned to working remotely and started seeing patients virtually. In early 2020, I remember my manager asking what I was going to do. I have wanted to offer telenutrition services to my patients for a long time, so this was an excellent opportunity and seemed like the right format to meeting cancer patients' needs during the pandemic and even beyond.

Photo of Whitney Christie at work.

Services to cancer patients prior to transition

Nutrition services in my health system are provided free of charge to patients with cancer. We are located in Fredericksburg, VA, which is between Washington, DC and Richmond, Virginia. I cover three hospital-based radiation oncology facilities and a small infusion center associated with our hospital's cancer program. Most of my patients receive their cancer treatments at their local oncologists' offices which are privately owned. These providers also refer to me for Medical Nutrition Therapy services. Referrals also are generated through surgeons, advanced practice providers, nurses, dietitians, patients and other providers in the area.

I began to offer nutrition service via Microsoft Teams in April of 2020 and continue to do so today. My telehealth services offer many forms of electronic communications and telecommunications including video, telephone and email.

Positive aspects of telenutrition

Telenutrition offers flexibility to the patient and the dietitian. Patients are often running to various appointments, tests, and procedures which makes it difficult for them to schedule with many supportive services including dietitians.

One big change is that I am able to see patients prior to the initiation of their cancer treatments. Prior to the pandemic, patients would see me when they started treatment because of their busy schedules. That never seemed right to me. I felt like they should get information before they started treatment. No-shows have not been significant for my telenutrition appointments; outpatients tell me that they appreciate the ease and convenience of the tele format. Some breathe a sigh of relief during our scheduling phone call when I tell them they don't have to come to the hospital for an appointment.

I've also educated myself on telehealth as my journey has continued to take shape. Think about the time we have given back to patients and their families. One thing that really stuck is that individuals with cancer do not want to spend their extra time in doctor's offices. Loved ones don't have to take a day off work to bring their family member to an hour long visit with the dietitian.

Some think telehealth isn't as personal as an in-person visit. I disagree. I've made connections with patients using video and telephone counseling. Cancer patients are resilient. Telehealth is evidence of that. Throughout this pandemic, lots of people have learned how to video conference because they want or need to stay connected with family and friends, church, work or other events in a safe way. I have had some very memorable video visits with patients. I had daughters from three different states on a video with their mother. I also was able to use the hospital's interpreter services to provide sign language and Spanish interpreter services to several patients. Care providers dial in and will sit next to the patient who is in their bed resting. The sessions were not only remarkable but also pretty touching. It really showed how our hospital could work together to do anything to meet our patients' needs. I feel privileged to be the one to start this service in our cancer program.

With video visits, the dietitian has the ability to share your screen and show education materials as you teach. Patients are often more prepared and relaxed than the scheduled or impromptu services that I had provided pre-pandemic at the radiation center. Patients will setup for the appointments and be ready to take notes. I feel more efficient and effective because of the change too.

Negative aspects of telenutrition

As with all things, there are some negatives of telenutrition. One such con was poor internet connection or lack of availability. In that case, those patients receive telephone counseling. In addition, it can be challenging to reach certain subsets of patients; in particular, those who may not realize the importance of nutrition in their cancer journey.

I continue to go onsite a few times a week to check in with the team and do miss the daily interactions with coworkers whom I have worked with for over 10 years.

Patient satisfaction, patient volumes

Through telenutrition, I was not only able to initiate a new service (video visits) with patients, but I was able to increase my unique and total encounters with patients. The most common patients I counsel are those with head and neck, esophageal, pancreatic, lung, colorectal and breast cancers. I may visit with a patient one time or follow some patients over the course of their cancer treatments.

Patients received consistent and valuable nutrition counseling time in the virtual format. Timing was a big challenge with in-person visits. Often times, I would be given a few minutes prior to the doctor entering the room or someone needed the patient for radiation treatments, which led to interrupted (and ineffective) counseling. I'd often run around from room to room and travel to various clinics to have a short moment to talk to a patient about nutrition. Sometimes patients don't feel well enough to see me for follow-up or have other appointments to go to. I'd also have to schedule other patients not on radiation that would come in for in-person appointments and visit two satellite centers. I know my services are important but that was a lot to manage.

Advice to RDs considering telenutrition

My advice to other oncology dietitians is to consider it as a useful tool to add to your practice. Push through the challenges that come with starting it and see how great it is. I also think that those of us who are doing telenutrition need to talk about it and our experiences with it to other oncology dietitians.

Other services offered virtually

I have always enjoyed educating the public and healthcare professionals on various topics related to cancer and nutrition. Last year was busy with virtual presentations. As part of the prevention portion of Mary Washington Regional Cancer Center's (Fredericksburg, VA) Commission on Cancer accreditation, I helped organize and provide education to the public through virtual grocery store tours. We partnered with a dietitian at a local Giant supermarket to provide dynamic presentations geared towards reducing the risk of cancer through nutrition.

Going forward, future plans

I have always loved research and the wheels are already turning for a research project with a focus on telenutrition services.

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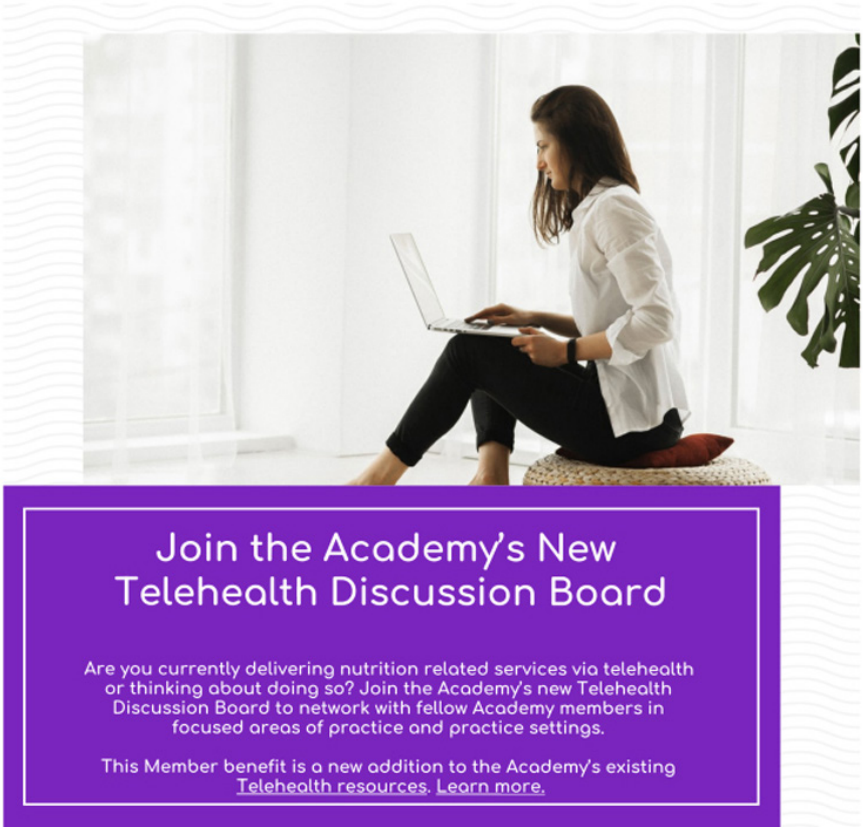

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