

# Patient-reported outcomes in head and neck cancer: prospective multi-institutional patient-reported toxicity

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**Purpose:** Head and neck cancer is occurring in an increasingly younger patient population, with treatment toxicity that can cause significant morbidity. Using a patient guided, Internet-based survivorship care plan program, we obtained and looked at patterns of patient-reported outcomes data from survivors seeking information after treatment for head and neck cancer.

**Methods:** The Internet-based OncoLife and LIVESTRONG Care Plan programs were employed, which design unique survivorship care plans based on patient-reported data. Care plans created for survivors of head and neck cancer were used in this evaluation. Demographics, treatment modality, and toxicity were included in this evaluation. Toxicity was further analyzed, grouped into system-based subsets.

**Results:** A total of 602 care plans were created from self-identified head and neck cancer survivors, from which patient-reported outcome data were attained. A majority of patients were Caucasian (96.2%) with median age at diagnosis of 55 years, living in suburban locations (39.9%), with ~50% receiving care within 20 miles of their residence. There was an equal distribution of education levels from high school only to graduate school. The majority of patients received care through cancer centers (96.7%), with a split between academic and non-academic centers. Ninety-three percent of patients had radiation therapy as part of their treatment modality, with 70.3% having chemotherapy and 60.1% having surgery. The most common system toxicities affected the oropharynx, followed by epithelium (skin/hair/nail), and then general global health. Specifically, the most common side effects were difficulty swallowing (61.5%) and changes in skin color/texture (49.7%). One third of patients experienced hearing/tinnitus/vertigo, xerostomia, loss of tissue flexibility, or fatigue.

**Conclusion:** The current work demonstrates the ability to obtain patient-reported outcomes of head and neck cancer survivors through an Internet-based survivorship care plan program. For this group dysphagia and dermatitis were the most commonly reported toxicities, as was expected; however, global effects of therapy, such as fatigue, were also significant and should be addressed in future survivorship planning.

**Keywords:** head and neck radiation, surgery, chemotherapy, patient reported outcomes, survivorship care plan, Internet, patient-reported outcomes

## Introduction

Head and neck cancer represents the 6<sup>th</sup> most common cancer group in the world and comprises a diverse collection of disease sites, histology, and pathogenesis.<sup>1</sup> While the incidence of tobacco-related head and neck cancer has decreased over recent decades, cases related to human papillomavirus (oropharyngeal cancer) have increased.<sup>3</sup> Significant progress has recently been made in disease management, with

a significant portion of patients cured with current practice. This management is often multimodal and not infrequently trimodal, involving surgery, chemotherapy, and radiation therapy. Given the multiple organs/systems in the head and neck region, including the constrictor muscles involved in swallowing, neck muscles, salivary glands, taste receptors, and cranial nerves, head and neck cancer survivors often face substantial late and long-term effects of the disease and its treatments.<sup>4</sup> Further, p16-positive oropharyngeal patients may develop disease at a younger age,<sup>3</sup> thus creating a population of cancer survivors that will live with potentially significant treatment-related morbidity for decades. The potential severity of toxicity in head and neck cancer survivors highlights the importance of survivorship, defined by the National Cancer Institute as the “focus on the health and life of a person with cancer post treatment until the end of life”.<sup>5</sup> A crucial part of general survivorship care is the need for survivorship care plans (SCPs), defined as “comprehensive care summaries and follow-up plans that are clearly and effectively explained” and that include diagnosis/treatment-specific information regarding potential adverse effects, interventions, oncologic/primary follow-up, legal information, and availability of psychosocial services.<sup>6</sup>

Survivorship and SCPs are guided by an understanding of the types and extent of toxicity expected for specific disease sites and treatment modalities. While these data points are frequently obtained in follow-up and more broadly from clinical trials/studies, there is often discordance between objective physician measurements and the more subjective experiences of the patient.<sup>7,8</sup> Further, physician interpretation of patients’ subjective experience often underreports the breadth and intensity of these experiences. For this reason there has been greater emphasis placed on patient-reported outcomes (PROs),<sup>7</sup> a concept first emphasized by the US Food and Drug Administration in 2006 and described as “self-report of disease and/or treatment effects in clinical research”. Beyond their value in detailing survivorship, PROs have been shown to be prognostic for survival and correlate with tumor response. Combining PRO information with physician observational endpoints therefore provides a more complete picture of survivorship that can enhance the understanding of the outcomes from different modalities of therapy, and help contribute to management of post-treatment toxicity in SCPs.

In this study, anonymous patients throughout the world utilized an Internet-based program to create SCPs (available at [www.OncoLink.org](http://www.OncoLink.org)). Longitudinal PROs were obtained from patients who self-identified as head and neck cancer

survivors when they created care plans. Items queried in this process included treatment types, toxicity, symptoms, and development of other disease. These characteristics, generated from the survivorship plans of over 600 patients, were compared against delivered treatment modality to determine any patterns of patient-reported toxicity associated with treatment type.

## Methods

OncoLink is an online cancer website designed and established at the University of Pennsylvania in 1994, and with survivorship care planning tools included on the site since 2007. Briefly, patients voluntarily using these tools are asked to anonymously provide cancer type, treatments received, and current symptoms which are used to generate customized survivorship care plans. During the self-directed inquiry regarding symptom experiences, questions are created based on previously completed responses with regard to diagnosis and treatment modalities. This logistical strategy allows targeted questioning about late effects that are most likely to be significant to a given patient. Data input is not limited to cancer survivors but was also obtained from relatives, friends, and members of the treatment team including health care professionals creating care plans for patients. The details of how SCPs are created have been previously described.<sup>9</sup>

Using the care plan databases, all patients identifying as survivors of head and neck cancer were selected for analysis as part of this study. In 2011, an expanded number of PRO questions in regard to long-term toxicity were added to the care plan tool, and data collection for this study began at that time. Collectively, demographics, treatment, and toxicity information gleaned from SCP data were included in this analysis. Patients were surveyed for a diverse collection of post-treatment toxicity. Questions for each particular side effect were answered in a multiple choice format with the options of “yes”, “no”, and “I don’t know”. Only the questions with at least ten individuals responding “yes” were included in the data collection to decrease sampling error. Only the information obtained from cancer survivor, family member, or friend survey responders was used in our analysis. Physician-obtained diagnoses or physician interpretation was not included. The toxicity was grouped into systems to see if there were any unexpected side effect trends.

All data acquisition and research was carried out under an institutional review board-approved protocol at the University of Pennsylvania. Entries were screened by user IP address and data so that duplicate entries could be identified and removed from the data set.

## Results

A total of 602 care plans were created from patients self-identified as head and neck survivors out of a total of 17,128 plans created between October 2011 and December 2016. The sample population was mostly Caucasian (86.2%) and predominantly male (65.4%) (Table 1). The level of

education was well divided, with a majority (39.9%) residing in suburban locations. Only 7.3% of patients had care directed primarily through a private physician practice, while the remainder of survivors had care split between academic and non-academic cancer centers. Approximately 50% of patients' care was received within 20 miles of where they lived. Only 10.5% of survivors were previously offered survivorship information.

**Table 1** Head and neck cancer survivor survivorship care plan demographic information

Characteristic	Total survivors (N=602)
Sex, n (%)	
Male	208 (34.6)
Female	394 (65.4)
Current age, median years	57
Age at diagnosis, median years	55
Time since diagnosis, median years	2
Race, n (%)	
African American	39 (6.5)
Asian	23 (3.8)
Caucasian	519 (86.2)
Hispanic/Latino	9 (1.5)
Mixed race	2 (0.3)
No response	2 (0.3)
Other	8 (1.3)
Living location type, n (%)	
Rural	121 (20.1)
Suburban	240 (39.9)
Urban	156 (25.9)
No response	85 (14.1)
Education, n (%)	
Grade School	16 (2.7)
High School	133 (22.1)
Some College	141 (23.4)
College Degree	124 (20.6)
Graduate School	86 (14.3)
Don't know	102 (16.9)
Treatment location type, n (%)	
Private doctor	44 (7.3)
Non-University	215 (35.7)
University	203 (33.7)
Combination	55 (9.1)
No response	85 (14.1)
Cancer center proximity, n (%)	
Less than 20 miles	302 (50.2)
Greater than 20 miles	215 (35.7)
No response	85 (14.1)
Offered survivorship care plan, n (%)	
Yes	63 (10.5)
No	469 (77.9)
I don't know	70 (11.6)
Survivorship personnel, n (%)	
Self	573 (94.8)
Family member/friend	1 (0.2)
Health care provider completing plan with patient	30 (5.0)

**Note:** Percentages may not sum to 100.0% because of rounding.

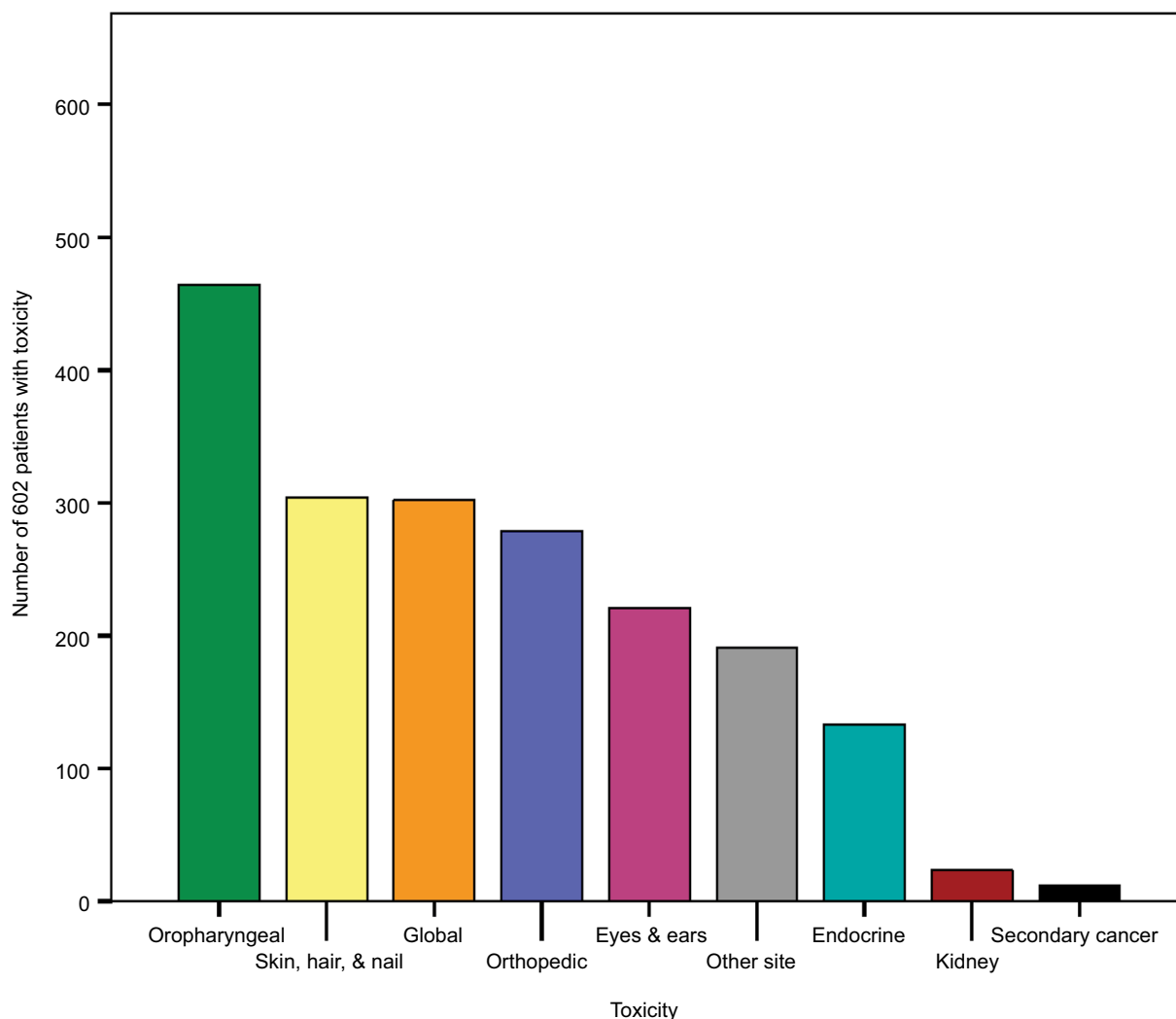
Nearly all patients (93%) had radiation therapy as part of their care, while 60.1% and 70.3% had surgery and chemotherapy, respectively (Table 2). Most survivors underwent multimodal care, with trimodal therapy representing 35% of queried survivors and chemoradiation 34%. Surgery was combined with only chemotherapy or only radiation therapy in 1% and 19% of survivors, respectively. Only 5% of survivors were treated with surgery alone, 5% radiation therapy alone, and <1% chemotherapy alone.

Overall, long-term side effects and the development of treatment-related late effects involved multiple systems. When late and long-term effects were grouped into systems, the majority of reported toxicity was oropharyngeal, followed in decreasing order morbidities within the following categories: epithelial (skin/hair/nail), overall global health (such as fatigue), orthopedic, eyes/ears, endocrine, kidney, and lastly secondary cancers (Figure 1). Specifically, the most commonly reported toxicities were difficulty swallowing (61.5%), and change in skin color/texture (49.7%) (Table 3). Approximately one third of those queried reported decreased hearing/tinnitus/vertigo, xerostomia, loss of flexibility in irradiated region, and fatigue (defined as overwhelming physical, mental, or emotional exhaustion). Slightly less common were dental problems (26.7%) and thyroid disease, with 20.3% of survivors diagnosed with hypo- or hyperthyroidism. One of four patients (25%) was concerned about cognitive changes, such as memory loss, difficulty with short-term memory,

**Table 2** Head and neck cancer survivor survivorship care plan treatment modality information

Treatment modality	Total survivors (N=602)
Surgery, n (%)	
Yes	362 (60.1)
No	240 (39.9)
Radiation, n (%)	
Yes	506 (93.0)
No	42 (7.0)
Chemotherapy, n (%)	
Yes	423 (70.3)
No	179 (29.7)

**Note:** Percentages may not sum to 100.0% because of rounding.



**Figure 1** The number of patients reporting various systems of toxicities in decreasing order including oropharyngeal (green), skin/hair/nail (yellow), global (orange), orthopedic (purple), eyes/ears (plum), other site (grey), endocrine (teal), kidney (red), and secondary cancer (black).

**Note:** Global includes fatigue, weakness, hypertension, and hyperlipidemia.

concentration, or learning new skills. The remaining side effects/newly diagnosed conditions were experienced by less than 20% of the cohort.

## Discussion

The group of head and neck cancer survivors living in the USA is expected to continue to increase: disease incidence is increasing, disease demographics are changing with younger age at diagnosis more common, and cure rates continue to increase. Further, with advances in immunotherapy for head and neck cancer,<sup>10</sup> those patients with incurable disease at presentation or recurrence after multimodal therapy may have viable treatment options which will increase overall survival.

With an anticipated increase in cancer survivorship for head and neck cancer, understanding the true impact of therapies has great significance for both the cancer survivor

and the newly diagnosed patient. First, greater understanding of the full array and magnitude of toxicity from each treatment modality will allow for more informed decisions for the newly diagnosed patient. For the cancer survivor, this enhanced understanding will be important in shaping new toxicity interventions and post-treatment care, including the SCP. In this regard, PROs will become an essential endpoint, as physicians are only able to capture a limited picture of the cancer survivor experience. This has been demonstrated in more recent prospective cancer trials of multiple sites in which there was significant discordance in patient-reported symptoms and physician interpretation, with physicians most frequently underestimating severity<sup>7,11</sup> and breadth of toxicity.<sup>12</sup> Regarding head and neck cancer specifically, two studies have observed this relationship for patients treated with chemoradiation.<sup>13,14</sup> Most problematic is that the breakdown

**Table 3** Head and neck cancer survivor survivorship care plan toxicity information

Side effect/diagnosis	Total survivors (N=602)
Loss of strength or paralysis in the arms and/or legs, n (%)	
Yes	93 (15.4)
No	509 (84.6)
Inability to move your neck in all directions, n (%)	
Yes	101 (16.8)
No	501 (83.2)
Diagnosis of lymphedema (swelling of the area below where the lymph node(s) were removed), n (%)	
Yes	47 (7.8)
No	555 (92.2)
Pain, numbness or tingling in the arm or leg below/ adjacent to the area where the lymph nodes were removed, n (%)	
Yes	43 (7.1)
No	559 (92.9)
Developed decreased hearing, ringing in the ears or vertigo, n (%)	
Yes	191 (31.7)
No	411 (68.3)
Have persistent numbness and tingling in the hands and/or feet, n (%)	
Yes	71 (11.8)
No	531 (88.2)
Chronic changes to your nails or skin color, n (%)	
Yes	13 (2.2)
No	589 (97.8)
Diagnosed with kidney problems, n (%)	
Yes	23 (3.8)
No	579 (96.2)
Decrease or loss of saliva production, n (%)	
Yes	209 (34.7)
No	393 (65.3)
Dental problems (including tooth decay or loss of teeth), n (%)	
Yes	161 (26.7)
No	441 (73.3)
Osteoradionecrosis of the jaw, n (%)	
Yes	40 (6.6)
No	562 (93.4)
Difficulty with swallowing, speaking or breathing, n (%)	
Yes	370 (61.5)
No	232 (38.5)
Chronic sinusitis	
Yes	59 (9.8)
No	543 (90.2)
Loss or decrease of tear production, n (%)	
Yes	35 (5.8)
No	567 (94.2)
Partial loss of vision or blindness, n (%)	
Yes	25 (4.2)
No	577 (95.8)
Developed cataracts, n (%)	
Yes	21 (3.5)
No	581 (96.5)

(Continued)

**Table 3** (Continued)

Side effect/diagnosis	Total survivors (N=602)
Developed other eye problems, n (%)	
Yes	41 (6.8)
No	561 (93.2)
Changes in color or texture of the skin or hair loss in the area treated with radiation, n (%)	
Yes	299 (49.7)
No	303 (50.3)
Development of chronic swelling in the irradiated area, n (%)	
Yes	101 (16.8)
No	501 (83.2)
Loss of flexibility in the irradiated area, n (%)	
Yes	206 (34.2)
No	396 (65.8)
Arthritis at the site of the radiation therapy, n (%)	
Yes	21 (3.5)
No	581 (96.5)
Diagnosed with hypo- or hyperthyroidism (under- or over-active thyroid), n (%)	
Yes	122 (20.3)
No	480 (79.9)
Diagnosed with hypoparathyroidism, n (%)	
Yes	13 (2.2)
No	589 (97.8)
Are you concerned about cognitive changes, such as memory loss, difficulty with short-term memory, concentration or learning new skills, n (%)	
Yes	151 (25.1)
No	451 (74.9)
Are you experiencing fatigue (overwhelming physical, mental or emotional exhaustion)? n (%)	
Yes	216 (35.9)
No	386 (64.1)
Development of thyroid nodule or tumor, n (%)	
Yes	21 (2.2)
No	589 (97.8)
Diagnosed with a skin cancer in the irradiated area	
Yes	12 (2.0)
No	590 (98.0)
Diagnosed with hypertension (high blood pressure), n (%)	
Yes	80 (13.3)
No	522 (86.7)
Diagnosed with high cholesterol levels (hypercholesterolemia), n (%)	
Yes	56 (13.3)
No	546 (90.7)
Have developed erectile dysfunction or required medical intervention to achieve an erection	
Yes	29 (4.8)
No	573 (95.3)
Experience sexual changes (vaginal dryness, shrinkage, painful intercourse)	
Yes	28 (4.7)
No	574 (95.3)

**Note:** Percentages may not sum to 100.0% because of rounding.

of those items that have the most discordance between patients and physicians highlights symptoms that have the greatest impact on quality of life.<sup>15</sup> Here, we demonstrate that PRO data can be gathered efficiently and from a large number of patients using an Internet-based tool.

Having a better understanding of the patient experience has been shown to enhance physician outlook. For example, one prospective work demonstrated increased concordance with interpretation of lung cancer patient toxicity when PRO was available to the physician versus when not.<sup>16</sup> For head and neck cancer in particular, the incorporation of PRO has been appreciated by physicians to enhance their assessment of late symptoms.<sup>17</sup> However, knowledge is only one aspect of survivorship, as an actionable plan to maximize post-treatment quality of life and function is the end goal. On the surface SCPs appear a natural offshoot of normal post-oncological treatment follow-up. There are many resources available such as the National Comprehensive Cancer Network clinical practice guidelines that provide advice on post-treatment management such as disease surveillance intervals and screening modalities;<sup>18</sup> however, such guidelines do not emphasize toxicity management or psychosocial aspects of survivorship. This is where incorporation of PROs into SCPs can lead to follow-up plans tailored to the survivor.

For the typical oncologic physician there are several practical and logistical barriers to creating comprehensive SCPs for patients which encompass all aspects of survivorship. This was demonstrated by a study that looked at the value and feasibility of a computer-based head and neck cancer PRO and SCP system similar to what is offered by OncoLink.<sup>19</sup> Physicians enrolled in the study indicated that it was difficult to develop SCPs on their own due to difficulty detecting symptoms, lack of patients' perception for the need of supportive care, and lack of time. Given these constraints, it is not surprising that in the current work only 10.5% of patients obtained survivorship plans, a similarly small percentage was found in other works.<sup>20</sup> Therefore, more widespread use of programs such as that offered by OncoLink has great potential to expand tailored SCPs for patients in what is a busy clinic environment, using meaningful endpoints to develop these plans from PROs.

Since the emphasis of PROs' importance in the mid-1990s, they have been incorporated into research, the first large head and neck study utilizing such endpoints in 1999 for combination chemoradiation.<sup>21</sup> However, compared to other disease sites the number and breadth has been small in comparison. Most methods for gathering PROs encompass common quality of life surveys or symptom questionnaires that focus on most commonly faced head and neck toxicity

such as mucositis, dysphagia, and voice quality. For example, studies have incorporated the MD Anderson Symptom Inventory - Head and Neck Module,<sup>23</sup> the MD Anderson Dysphagia Inventory,<sup>24</sup> and the European Organisation for Research and Treatment of Head & Neck35 (H&N35) quality of life module<sup>27</sup> among others.<sup>14,22,25,26,28,29,30</sup> However, using such modules and not obtaining broader PRO may lead to investigators and physicians missing toxicity that may significantly impact quality of life and even survival. For example, utilizing OncoLink PRO of lung cancer patients, it was determined that neurocognitive and musculoskeletal side effects caused a high incidence of morbidity, something that physicians did not focus on for this particular disease site.<sup>31</sup> In the study reported here, survivors reported some toxicities, such as dysphagia, that might have been anticipated by providers, but reported others, such as fatigue, that are often minimized by health care providers despite significant impact on quality of life.

## Limitations

While there is significant strength to the collection of PROs and incorporation into SCPs, there are limitations to the current implementation in OncoLink and limitations to PROs themselves. First, the study uses a convenience sample frame, and patients are asked to provide relatively limited information regarding treatments that they received. Bias may exist due to the sampling method, although this will be reduced by the large sample size. Although specific patient treatment details are not available, the information garnered from this large population will inform clinicians caring for any cancer patient regarding areas of toxicity that may impact patients after head and neck cancer treatment and warrant up-front attention and, potentially, discussion.<sup>32</sup>

Another limitation from the current OncoLink implementation is that most of the questions are binary in that symptoms are not qualified but rather, responses are "yes", "no", or "I don't know". Thus, there could be minor symptoms shared by most survivors that do not significantly impact quality of life, but these will be overrepresented compared to less frequent but more severe symptoms in the generated SCPs. In the future, a scaling to symptoms would add a significant extra dimension to PROs in this system. Again, however, these early data may draw attention to areas of potential late toxicity.

Regarding the participating population, there is a concern that those responders are more technologically advanced, which may make such Internet-based PROs and SCPs unrepresentative of the general population. However, older proportions of the population each year have increasing access to technology. Further, the age of p16-positive head and



neck cancer patients is younger than historic head and neck cancer patients. There are also other potential demographics other than age that may lead to bias toward participation. For example, there were barriers to technology based on socioeconomic status, race, and culture. However, with the expanding use of and access to smart technology such as cell phones this is increasingly of less concern.

Another limitation of the current study is that extensive data do not exist to show the efficacy of PRO-based SCPs. A small prospective single institution study was recently performed using digitized PROs during and after head and neck cancer radiotherapy.<sup>33</sup> The physicians involved in the study felt that the addition of PROs improved follow-up care and improved communication with the patient and treatment team, essentially resulting in an enhanced SCP. Another study demonstrated that PROs in the form of subjective dysphagia measures were predictive of internal lymphedema,<sup>34</sup> a symptom that normally requires endoscopic evaluation to diagnose. This would support weighting of subjective dysphagia in SCPs as a predictor of internal lymphedema. Similarly, PRO data in regard to social effects of post-treatment jaw function precluded decreased maximal interincisal opening distances,<sup>35</sup> thus allowing an earlier intervention against trismus to prevent what can be a significantly morbid and permanent condition. Lastly, when PRO data were compared to objective assessments for patients undergoing oropharyngeal radiation therapy, it was determined that patients interpreted xerostomia as dysphagia, thus allowing more appropriate intervention.

## Conclusion

These data demonstrate the feasibility of improving understanding of PROs after treatment for cancers of the head and neck using an Internet-based tool for survivorship planning. The population of head and neck cancer survivors is increasing in size, and is a group that remains at high risk for significant late effects that may impact speech, swallowing, and nutrition. Our study demonstrates the high incidence of many late effects in a large group of survivors: these include local toxicities, such as dysphagia, but also toxicities such as fatigue and thyroid disease that impact multiple organ systems. The majority of these late effects have potential to significantly impact quality of life, and many may be treatable or even preventable. At minimum, PROs should impact patient counseling. The large number of late effects reported by head and neck cancer survivors supports the need for extensive survivorship care planning for this patient population.

## Disclosure

The authors report no conflicts of interest in this work.

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