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ORIGINAL ARTICLE

# Documentation and incidence of late effects and screening recommendations for adolescent and young adult head and neck cancer survivors treated with radiotherapy

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## Abstract

**Purpose** A retrospective review of adolescent and young adult (AYA) head and neck cancer (HNC) patients treated with radiation therapy (RT) at British Columbia Cancer was performed to determine the incidence of late toxicities, the documented late side effects discussed and the screening recommendations provided at the time of transfer of care to primary care providers (PCPs).

**Methods** Charts ($n = 162$) were reviewed for all patients 15 to 35 years at diagnosis with HNC treated with RT from 1960 to 2010 who survived $\geq$ 5 years after diagnosis.

**Results** A discussion regarding the risk of long-term side effects was documented in the initial consultation for 85% of patients. The majority of patients (78%) developed $\geq$ 1 documented late effect. The most common were xerostomia (44%), skin changes (28%), neck fibrosis (22%), nasal crusting (16%), epistaxis (16%), and dental decay (14%). In all, 20% were currently followed or were followed until they died. Of the 80% transferred to their PCP, 14% had a formal discharge summary. For those discharged from British Columbia Cancer, documented recommendations included regular dental care (34%) and screening for hypothyroidism (5%) and second malignancy (4%).

**Conclusions** The majority of AYA HNC patients treated with RT developed late side effects, and most PCPs were not sent a discharge summary outlining screening recommendations for delayed late effects.

**Implications for cancer survivors** AYA HNC survivors treated with RT are at high risk for late effects and would benefit from a survivorship care plan outlining these risks and screening recommendations.

**Keywords** Adolescent and young adult · Head and neck cancer · Cancer survivorship · Radiation late effects

## Introduction

Adolescent and young adult (AYA) cancer is increasing in incidence. In the USA, 700,000 patients age 15 to 39 years are diagnosed with invasive cancer each year [1]. Mortality rates are improving in this population with 5-year survival rates exceeding 80% [2]. AYA cancer survivors are at risk for significant long-term toxicities. These patients represent a unique population that faces different psychosocial, emotional, and physical issues than pediatric and older adult patients [3]. AYA survivors have reported worse physical and emotional wellbeing compared to healthy age-matched controls [4]. They also have a higher prevalence of smoking, obesity, and chronic disease compared to the general population [5]. Two out of three of all AYA survivors will experience late effects from treatment, and one in four will have a severe or life-threatening toxicity [6].

Thyroid cancer represents 11% and oral cavity/pharynx cancer represents 2% of malignancies in the AYA age group [1]. Studies have shown that head and neck cancer (HNC) is increasing in incidence in AYA patients [7, 8]. A recent publication analyzing AYA HNC outcomes in the Surveillance, Epidemiology, and End Results database demonstrated a survival rate of 73% after 8 years of follow-up [9]. HNC treatment often requires multi-modality therapy, which usually includes surgery and may also include radioactive iodine (for

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thyroid cancer), external beam radiation therapy (RT), and chemotherapy [7, 8]. Adult survivors of HNC report significant long-term problems with dentition, trismus, xerostomia, dysphagia, odynophagia, and dysgeusia relative to healthy controls, even 3 years after treatment [10]. Long-term survivors of HNC who were treated with RT are also at risk of delayed late effects that can occur more than 5 years after treatment such as dental decay, hypothyroidism, stroke, and second malignancy [11]. There is a paucity of literature assessing long-term complications and screening recommendations specific to AYA survivors of HNC.

Generally, patients are discharged from oncologic follow-up at British Columbia Cancer to their primary care providers (PCPs) at 5 years after treatment provided they are recurrence-free. Studies have suggested that many PCPs are not comfortable with providing follow-up care and management of late effects in pediatric and AYA survivors [12]. Many PCPs surveyed stated that they did not receive a patient-specific survivorship care plan (SCP) and long-term follow-up guidelines when care was transferred back to them [12]. SCPs were ranked as the most useful modality to enable them to provide community care for pediatric and AYA survivors [12].

Given the lack of published literature assessing AYA HNC survivors treated with RT, we aimed to assess (1) the incidence of late effects diagnosed prior to discharge, (2) the proportion of patient charts that documented the risk of late effects, and (3) the screening/surveillance recommendations given to PCPs at the time of transfer of care.

## Methods

This study included all AYA HNC patients who were treated with RT at the British Columbia Cancer (BC Cancer) between 1960 and 2010. BC Cancer is comprised of six regional cancer centers and is responsible for the delivery of RT for the entire province of British Columbia (population 4.7 million), thus allowing for a large population-based study. Inclusion criteria were age between 15 to 35 years at diagnosis, post-diagnosis survival of at least 5 years, and RT to one or more of the following head and neck regions: pharynx, thyroid, paranasal sinus, oral cavity, and/or salivary gland. Patients with lymphoma or sarcoma histology were excluded from this study.

Participants were identified and data were collected retrospectively using the BC Cancer Information Systems (CAIS) electronic and paper charts. Data collected included patient demographics, treatment details, documented long-term treatment side effects that were experienced by patients, and follow-up recommendations. Patient demographics included age at diagnosis, sex, year of diagnosis, tumor subsite, tumor pathology, and TNM staging. Treatment details included RT technique, dose, and number of fractions given, whether chemotherapy was given as well as chemotherapeutic drug regime, timing, and number of cycles given, whether surgery was performed and which surgical procedures were utilized, and whether radioactive iodine-131 treatment was given for thyroid cancer.

As part of routine clinical care, every patient had a radiation oncology consult, and patients receiving chemotherapy also had a medical oncology consult. These meetings typically included a discussion of potential long-term RT and chemotherapeutic side effects. In our study, variables of interest regarding this discussion included whether the discussion itself was documented in the patient's chart and if so, whether there was any documentation of any specific potential side effects that were discussed. For this study, long-term side effects were defined as side effects present at 1 year or later following RT, and where applicable, chemotherapy. Data regarding the incidence of long-term toxicities were collected from progress notes from radiation and medical oncology follow-up visits and dental consultations. The incidence of second malignancies was captured through the BC Cancer registry, which is linked to the CAIS. Discharge status data and length of time for which patients were followed at BC Cancer were collected from the last known assessment by radiation oncology. Lastly, post-treatment screening recommendations were obtained from progress notes and discharge letters from BC Cancer to primary care providers.

## Results

Study demographics are outlined in Table 1. Our retrospective observational study included a total of 162 AYA HNC survivors treated between 1960 and 2010. However, 145 (90%) of these cases were diagnosed more recently, between 1990 and 2010. The median age at the time of diagnosis was 31 (range 15–35) years, with 101 (62%) of participants being 30–35 years old. Sex was evenly distributed, with 82 (51%) of participants being female.

Nasopharynx primary malignancies were the most common tumor site, with 48 (30%) cases, followed by salivary gland malignancies ($n = 36$; 22%) and thyroid cancer ($n = 30$; 19%). Squamous cell carcinoma was the most prevalent pathological diagnosis, with 65 (40%) cases. T-stage was nearly equally distributed, with 38 (23%) T1, 42 (26%) T2, 25 (15%) T3, and 40 (25%) T4 patients. For N-stage, 83 (51%) were N0, 34 (21%) N1, 24 (15%) N2, and 7 (4%) N3. All participants ($n = 162$; 100%) were M0.

Treatment details are outlined in Table 2. All participants received RT, while 96 (59%) also underwent surgical treatment. The most commonly used RT technique in this cohort was three-dimensional conformal radiation therapy (3DCRT), with 152 (94%) of patients receiving 3DCRT. The remainder of patients underwent intensity-modulated radiation therapy (IMRT) ($n = 10$; 6%) and some also received brachytherapy

**Table 1** Patient demographics ($N = 162$)

| Characteristic | Subgroup | Number | Percent |
|---|---|---|---|
| Age at Diagnosis (years) | 15–19 | 7 | 4 |
| | 20–24 | 17 | 11 |
| | 25–29 | 37 | 23 |
| | 30–35 | 101 | 62 |
| | Median age at diagnosis | 31 years | |
| Sex | Male | 80 | 49 |
| | Female | 82 | 51 |
| Year of diagnosis | 1960–1964 | 2 | 1 |
| | 1965–1969 | 0 | 0 |
| | 1970–1974 | 2 | 1 |
| | 1975–1979 | 2 | 1 |
| | 1980–1984 | 5 | 3 |
| | 1985–1989 | 6 | 4 |
| | 1990–1994 | 45 | 28 |
| | 1995–1999 | 47 | 29 |
| | 2000–2004 | 35 | 22 |
| | 2005–2010 | 18 | 11 |
| Tumor subsite | Nasopharynx | 48 | 30 |
| | Salivary gland | 36 | 22 |
| | Thyroid | 30 | 19 |
| | Tongue | 14 | 9 |
| | Vocal cord | 11 | 7 |
| | Paranasal sinus and nasal cavity | 9 | 6 |
| | Oral cavity | 7 | 4 |
| | Tonsil | 4 | 2 |
| | Other | 3 | 1 |
| Tumor Pathology | Squamous cell carcinoma | 65 | 40 |
| *Other includes all pathologies with a total of ≤ 2 study participants | Papillary carcinoma | 23 | 14 |
| | Adenoid cystic carcinoma | 12 | 7 |
| | Undifferentiated carcinoma | 11 | 7 |
| | Mucoepidermoid carcinoma | 9 | 6 |
| | Acinic cell carcinoma | 9 | 6 |
| | Adenocarcinoma | 7 | 4 |
| | Medullary carcinoma | 4 | 2 |
| | Poorly differentiated carcinoma | 4 | 2 |
| | Acinic cell adenocarcinoma | 3 | 2 |
| | SSC in situ | 3 | 2 |
| | Other | 12 | 7 |
| T-stage | In situ | 2 | 1 |
| | 0 | 1 | 1 |
| | 1 | 38 | 23 |
| | 2 | 42 | 26 |
| | 3 | 25 | 15 |
| | 4 | 40 | 25 |
| | X | 14 | 8 |
| N-stage | 0 | 83 | 51 |
| | 1 | 34 | 21 |
| | 2 | 24 | 15 |
| | 3 | 7 | 4 |
| | X | 14 | 9 |
| M-stage | 0 | 162 | 100 |

($n = 11$; 7%). Radiation dosage was variable, with four (2%) patients receiving less than 4000 cGy, 57 (35%) receiving 4001–5000 cGy, 47 (29%) receiving 5001–6000 cGy, and 52 (32%) receiving 6001–7000 cGy. Patients received a median of 25 (range 1–35) fractions of RT. The most frequently performed surgical interventions include neck dissection ($n = 39$; 24%), thyroidectomy ($n = 34$; 21%), and parotidectomy ($n = 28$; 17%). Of the 30 cases of thyroid malignancies, 23 (77%) patients received radioactive iodine-131 therapy. A small number of patients ($n = 17$; 10%) underwent chemotherapy, with a median of three (range 1–7) cycles. Of these patients, 14 (83%) were treated with a cisplatin-containing regimen. Chemotherapy was given concurrently with RT for nine (53%) of these patients, while the rest ($n = 8$; 47%) had neoadjuvant chemotherapy.

There was documentation of a discussion of long-term side effects of treatment in consult notes with 138 (85%) charts, though 50 (31%) of these consult notes did not specify which

**Table 2** Treatment details

| Treatment | Number | Percent |
|---|---|---|
| Surgery | 96 | 59 |
| Type of surgery[a] | | |
| Neck dissection | 39 | 24 |
| Thyroidectomy | 34 | 21 |
| Parotidectomy | 28 | 17 |
| Craniofacial resection | 9 | 6 |
| Glossectomy | 9 | 6 |
| Submandibular gland resection | 6 | 4 |
| Temporal bone resection ± | 4 | 2 |
| Aural glomus excision | 3 | 2 |
| Other | 11 | 7 |
| Radioactive iodine ablation given for thyroid cancer[b] | 23 | 77 |
| Radiation technique | | |
| Brachytherapy | 11 | 7 |
| 3DCRT | 152 | 94 |
| IMRT | 10 | 6 |
| Dose of radiation (cGy) | | |
| ≤ 4000 | 4 | 2 |
| 4001–5000 | 57 | 35 |
| 5001–6000 | 47 | 29 |
| 6001–7000 | 52 | 32 |
| Unknown | 2 | 1 |
| Number of fractions (median [range]) | 25 [1–35] | |
| Chemotherapy given (y/n) | 17 | 10 |
| Chemo regime (drugs used)[c] | | |
| Cisplatin | 6 | 35 |
| Cisplatin + gemcitabine | 3 | 18 |
| Cisplatin + etoposide | 2 | 12 |
| Cisplatin + 5-FU | 3 | 18 |
| Carboplatin + 5-FU | 1 | 6 |
| Carboplatin | 1 | 6 |
| Methotrexate | 1 | 6 |
| Chemo timing[c] | | |
| Neoadjuvant | 8 | 47 |
| Concurrent | 9 | 53 |
| No. of cycles (median [range]) | 3 [1–7] | |

[a] Includes multiple surgeries performed on same patient

[b] Total taken from all thyroid cancer cases

[c] Total taken from all cases that received chemotherapy

side effects were discussed during consultation (Table 3). Of potential RT side effects, documentation indicated that patients were most commonly informed about the risk of xerostomia ($n = 68$; 42%), osteoradionecrosis of the jaw ($n = 43$; 27%), chronic skin changes ($n = 32$; 20%), and second malignancy ($n = 27$; 17%). Of the 17 patients that received chemotherapy, there was documentation of a discussion of potential chemotherapeutic side effects that included risk of renal failure ($n = 13$; 76%), neuropathy ($n = 12$, 71%), hearing loss ($n = 11$; 65%), and infertility ($n = 8$; 47%). Most patient ($n = 127$, 78%) charts had one or more documented late toxicity (Table 4). The most common long-term RT toxicities (defined for this study as side effects present at more than 1 year post-treatment) identified in patient charts included xerostomia ($n = 68$; 44%), chronic skin changes ($n = 43$; 28%), and neck fibrosis ($n = 34$; 22%). A second malignancy was diagnosed in 14 (9%), and for three patients, it developed within the prior RT field (2%). With regard to chemotherapeutic side effects, neuropathy and hearing loss were the most commonly experienced side effects, with five (29%) patients each.

Documented follow-up recommendations and follow-up status are outlined in Table 5. Patients were followed at BC Cancer for a median of 6.4 years, with two thirds (65%) of patients being followed for 5 or more years. In all, 65% of patients were followed for 5 or more years post RT, and 20% are currently followed or were followed up to the time of death. Of the 80% ($n = 130$) discharged, 57% ($n = 75$) were discharged with a progress note in their medical record, but without a formal discharge summary of their care, 24% ($n = 30$) were lost to follow-up (had a scheduled appointment but did not attend), 14% ($n = 18$) had a formal discharge summary, and 5% ($n = 7$) moved outside the province to be followed at another cancer center.

Of the 38 (23%) patients who died, cancer was the cause of death for 35 (92%) cases. For discharged patients, there was documentation of regular screening recommendations for routine dental care ($n = 44$; 34%), hypothyroidism ($n = 7$, 5%) for those without pre-existing hypothyroidism, and a second malignancy ($n = 5$; 4%).

## Discussion

This is, to our knowledge, the first study assessing long-term toxicities experienced by AYA HNC patients treated with RT. A large proportion (78%) of survivors had at least one documented late side effect from RT in the clinical chart. There were a large variety of toxicities experienced due to the varying tumor subsites and RT fields. Additionally, patients were treated over a long period of time during which radiotherapy techniques improved significantly with the introduction of IMRT, which may reduce the risk of late effects. The third most common HNC in our study was thyroid cancer. Over the study era, the indications for RT in this population have narrowed, and a proportion of these patients would no longer be treated with RT with modern management guidelines.

Predictably, the most common side effect reported was xerostomia. Even in the IMRT era, xerostomia is a significant symptomatic burden for survivors of HNC that can lead to speech, swallowing, and dental complications [13, 14]. Chronic skin changes and neck fibrosis were also common

**Table 3** Documentation of long-term side effects discussed at the time of initial oncologist consultation

| Characteristic | Number | Percent |
|---|---|---|
| Discussion of long-term side effects documented | 138 | 85 |
| Specific long-term side effects that were discussed were not listed in consult | 50 | 31 |
| Radiation side effects | | |
| Xerostomia | 68 | 42 |
| Osteoradionecrosis of jaw | 43 | 27 |
| Chronic skin changes | 32 | 20 |
| Second malignancy | 27 | 17 |
| Dental decay | 24 | 15 |
| Taste changes | 23 | 14 |
| Trismus | 21 | 13 |
| Spinal cord injury | 17 | 10 |
| Visual impairment | 14 | 9 |
| Decreased hearing | 13 | 8 |
| Swallowing difficulties | 12 | 7 |
| Feeding tube dependence | 9 | 6 |
| Voice changes | 8 | 5 |
| Hypothyroidism | 8 | 5 |
| Brainstem injury | 7 | 4 |
| Temporal lobe injury | 4 | 2 |
| Neurotoxicity | 4 | 2 |
| Cerebrovascular accident (CVA) | 3 | 2 |
| Chronic otitis media | 3 | 2 |
| Tinnitus | 3 | 2 |
| Chemotherapy side effects | | |
| Renal failure | 13 | 76 |
| Neuropathy | 12 | 71 |
| Hearing loss | 11 | 65 |
| Infertility | 8 | 47 |
| Mucositis | 3 | 18 |
| Tinnitus | 1 | 6 |

which are associated with chronic pain, restricted mobility, and neuromuscular dysfunction [13, 14]. The reported incidence of dental decay in our study was 15%; this is likely underreported as not all patients received routine dental care at our institution. Nasal crusting, chronic sinusitis, and epistaxis were also common, attributable to the higher proportion of patients treated with high dose RT to the nasopharynx in our study. Trismus occurred in 12% of patients, which can be progressive over time and cause significant difficulties with oral intake, speech, and dental hygiene [15]. Long-term toxicities from HNC RT can progressively worsen or develop after discharge from oncologic follow-up. A recall of adult survivors of childhood cancer found that 80% had a severe chronic condition, and the incidence and severity increased over time, and many of these late effects were unrecognized prior to the study [16].

The Children's Oncology Group (COG) and National Comprehensive Cancer Network (NCCN) have published recommendations for late effect screening in AYA and adult HNC survivors, respectively [11, 17]. The COG and AHNS both recommend that patients receiving RT to the head and neck have a dental examination and cleaning every 6 months after treatment due to the ongoing risk of dental decay; only a third of patients in our study had this recommendation documented anywhere in their clinical chart [11, 17]. Additionally, NCCN recommends that dental extractions should be done in conjunction with oral surgeons experienced in the care of patients receiving RT due to the persistent elevated risk of complications such as osteoradionecrosis [17, 18]. If the neck is in the RT field, the COG recommends yearly thyroid examination, TSH, and fT4 with a thyroid ultrasound for evaluation of palpable nodules, and the NCCN recommends TSH every 6–12 months [11, 17]. In our study, screening for hypothyroidism was listed in the discharge summary for 5% of patients. Although many patients had developed hypothyroidism at discharge, RT-induced hypothyroidism can have a long

**Table 4** Documented long-term side effects experienced (present at > 1-year post-treatment) by patients

| Radiation side effects | Number | Percent |
|---|---|---|
| Xerostomia | 68 | 44 |
| Chronic skin changes | 43 | 28 |
| Neck fibrosis | 34 | 22 |
| Nasal crusting | 25 | 16 |
| Epistaxis | 24 | 16 |
| Dental decay | 21 | 14 |
| Trismus | 19 | 12 |
| Taste changes | 17 | 11 |
| Second malignancy | 14 | 9 |
| Chronic sinusitis | 12 | 8 |
| Voice changes | 12 | 8 |
| New onset hypothyroidism | 10 | 6 |
| Chronic pain | 10 | 6 |
| Swallowing difficulties | 9 | 6 |
| Decreased hearing | 9 | 6 |
| Osteoradionecrosis of jaw | 8 | 5 |
| Paresthesias | 7 | 5 |
| Chronic headache | 4 | 3 |
| Cerebrovascular accident (CVA) | 3 | 2 |
| Cranial nerve palsy | 3 | 2 |
| Vision changes | 3 | 2 |
| Localized edema | 3 | 2 |
| Tinnitus | 3 | 2 |
| Depression | 2 | 1 |
| Pituitary dysfunction | 2 | 1 |
| Shoulder weakness | 2 | 1 |
| Otitis media/Otalgia | 2 | 1 |
| Recurrent skin infection | 2 | 1 |
| Chemotherapy side effects | | |
| Neuropathy | 5 | 29 |
| Hearing loss | 5 | 29 |
| Infertility | 1 | 6 |
| Tinnitus | 1 | 6 |
| Renal failure | 0 | 0 |

latency period with only half of cases occurring before 5 years post-treatment [19]. There is an ongoing increased risk of stroke after RT for HNC, with studies showing the highest relative risk in patients receiving RT who were 40 years and younger [20, 21]. The COG recommends a color Doppler ultrasound for baseline at 10 years to assess for carotid artery disease, with follow-up Doppler ultrasound or magnetic resonance imaging with angiography for any abnormalities [11]. This was not recommended in any of the discharge summaries in our study, likely as it is not a routine recommendation in the adult population [11, 17]. The above long-term follow-up guidelines were not commonly communicated in the progress notes or discharge summaries to PCPs, likely because they were published in 2006 after the majority of the patients in our study had already been discharged from our institution.

The incidence of second malignant neoplasms (SMN) in AYA survivors is greater than in the general age-matched population with an elevated risk in those treated with RT [22, 23]. Similarly, adults diagnosed with HNC are at an elevated risk of SMN [13, 24]. In our study, 9% developed a SMN and 2% of all patients had a SMN develop within the prior RT field; however, a direct comparison to the general population is not possible due to the small sample size. These patients are at risk for a SMN for several potential reasons, including the mutagenic effect of radiation therapy, lifestyle risk factors (i.e., smoking and alcohol) and genetic predisposition. The COG recommends that patients are made aware of this risk and to report new symptoms to their care providers, reduce cancer risk factors (for example, not smoking, moderate alcohol intake, and a low fat, high fiber diet), and undergo annual physical examination (including inspection and palpation of skin, bone and soft tissues in the RT field) to promote reduction and early identification of SMN [11]. Patients and PCPs should be aware of these recommendations as the risk of SMN is cumulative, persists beyond the standard 5-year post-treatment follow-up and is a significant cause of late mortality [22, 23].

Although most of the radiation oncology consultations indicated that the potential side effects of treatment were discussed with the patient, one third did not mention the specific side effects that may occur. This results in PCPs being uninformed of their patients' risk of late effects. In addition, only 14% of patients had a formal discharge summary sent to their PCP summarizing their treatment course. A survey of PCP preferences and knowledge of follow-up of AYA survivors of childhood cancer similarly indicated that half did not receive a treatment summary from the referring cancer center, and most did not feel comfortable with the guidelines for ongoing surveillance of late effects [12]. The survey also found that access to guidelines and a treatment summary would be the most helpful tools in guiding ongoing care of childhood cancer survivors [12]. Similarly, a study of AYA survivors found that a lack of clear provider recommendations and not perceiving a need for routine follow-up due to lack of symptoms were barriers to survivorship care [25]. Another study found that most survivors preferred continued follow-up with their oncologist, due to a concern about other providers having adequate knowledge of their treatment and potential late effects [26].

A survey of HNC survivors found that many patients had unmet survivorship care needs, and younger age was associated with greater unmet needs [27]. A publication assessing key stakeholders preferences for HNC SCPs found strong support for SCP use in survivorship care [28]. Both patients and providers indicated that better documentation of late effects in the SCP was required [28]. Another study found that

**Table 5** Follow-up recommendations and follow-up status

| | | |
|---|---|---|
| Discharge status | | |
| Ongoing F/U until death or currently followed | 32 | 20 |
| Discharged | 130 | 80 |
| Discharged patients | | |
| Discharged in progress note w/o formal discharge summary | 75 | 57 |
| Lost to F/U | 30 | 22 |
| Formal discharge letter | 18 | 14 |
| Transfer out of BC | 7 | 5 |
| Screening recommended for patients no longer being followed (y/n) | | |
| Regular dental care | 44 | 34 |
| Dental care frequency specified | 17 | 13 |
| Hypothyroidism (y/n/pre-existing) | 7/122/33 | |
| CVA (Doppler U/S) | 0 | 0 |
| Second malignancy | 5 | 4 |
| Follow-up time (years) | | |
| 0 | 12 | 7 |
| 1 | 10 | 6 |
| 2 | 7 | 4 |
| 3 | 13 | 8 |
| 4 | 15 | 9 |
| 5+ | 64 | 40 |
| 10+ | 41 | 25 |
| Discharged before 5 years (y/n) | 57/105 | 35/65 |
| Patient status | | |
| Alive | 124 | 77 |
| Dead | 38 | 23 |
| Cause of death | | |
| Cancer | 35 | 92 |
| Other or unknown | 3 | 8 |

only 32% of PCPs felt confident in managing late effects of HNC treatment, and only 29% felt they could provide appropriate cancer screening [29]. The above findings, taken together with our study, suggest that there is a significant burden of late effects in AYA HNC patients treated with RT, and improved coordination and communication in survivorship care with PCPs are needed.

Our study should be interpreted in the context of its strengths and limitations. The strengths include that it is the first study specifically assessing AYA HNC survivors treated with RT. The sample size is large given the relative rarity of HNC in this age group. All RT in our province is delivered through BC Cancer, allowing for a population-based analysis. The major limitation includes the retrospective nature of the study; late toxicities were not collected in a prospective fashion and therefore are likely underreported. Additionally, our study was limited to 5-year survivors, and patients can develop late effects prior to this, such as osteoradionecrosis and second malignant neoplasm. We did not capture if trainees (residents and medical students) were involved in the consultations discussing late effects. We were unable to determine whether written information regarding late effects and screening recommendations were provided to patients, but this is not the standard pattern of practice in our institution and there was no documentation that this was undertaken.

## Conclusion

Overall, our study showed that a majority of AYA HNC patients treated with RT experienced late side effects prior to discharge from oncologic follow-up. These patients are at risk for developing late effects after discharge, and most PCPs were not provided with a summary outlining these risks. Development of SCPs including individualized treatment summaries and late effect screening guidelines would be a first step to attempt to improve communication and transition of care to the community.

## Future directions

Given these findings, we are currently performing a prospective recall of surviving AYA HNC patients treated with RT to evaluate the prevalence of late effects. Assessments will be performed using patient-reported outcomes, physician and allied health examinations, and the COG long-term follow-up guidelines. We will be developing survivorship care plans (SCPs) for this population, individualized to each patient based on the treatment received, to facilitate improved survivorship care.

## Compliance with ethical standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the BC Cancer research ethics review board. As a retrospective study, informed consent was not required.

**Conflict of interest** The authors declare that they have no conflict of interest.

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