Published in final edited form as:

J Cancer Surviv. 2020 December ; 14(6): 847–857. doi:10.1007/s11764-020-00897-5.

Looking Under the Hood of “the Cadillac of Cancers:” Radioactive-Iodine Related Craniofacial Side Effects among Patients with Thyroid Cancer

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Compliance with Ethical Standards:
Ethical approval: 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.
Informed consent: Informed consent was obtained from all individual participants included in the study.

Conflict of Interest: Samantha A. Diamond declares that she has no conflict of interest. Jacqueline Jonklaas declares that she has no conflict of interest, Roxanne E. Jensen declares that she has no conflict of interest, Charlene Kuo declares that she has no conflict of interest, Selma Stearns declares that she has no conflict of interest, Giuseppe Esposito declares that he has no conflict of interest, Bruce Davidson declares that he has no conflict of interest, George Luta declares that he has no conflict of interest. Gary Bloom declares that he is the co-founder and executive director of ThyCa. Kristi D. Graves declares that she has no conflict of interest.

Disclaimers: The article was prepared as part of one of the authors’ (REJ) official duties as employee of the US Federal Government. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the National Cancer Institute.

Abstract

Purpose—Despite having a generally favorable prognosis, differentiated thyroid cancer is known to have a significant, long term impact on the quality of life of survivors. We wished to investigate short and long-term effects among thyroid cancer survivors following radioactive iodine therapy.

Methods—We conducted 8 focus groups (N=47) to understand patients' experiences of short- and long-term effects after radioactive iodine treatment and the impact these treatment-related side effects had on patients' quality of life. We elicited responses regarding experiences with side effects following radioactive iodine treatment, particularly salivary, lacrimal, and nasal symptoms. We transcribed audiotapes and conducted qualitative analyses to identify codes and themes.

Results—We identified eight broad themes from the qualitative analyses. Themes reflecting physical symptoms included dry mouth, salivary gland dysfunction, altered taste, eye symptoms such as tearing or dryness, and epistaxis. Psychosocial themes included lack of knowledge and preparation for treatment, regret of treatment, and distress that thyroid cancer is labeled as a "good cancer."

Conclusions—Thyroid cancer survivors reported a wide range of radioactive iodine treatment related effects and psychosocial concerns that appear to reduce quality of life. The psychosocial concerns reported by participants underscore the significant unmet information and support needs prior to and following RAI treatment among individuals diagnosed with thyroid cancer.

Implications for Cancer Survivors—Future research is needed to help both patients and physicians understand the effect of radioactive iodine on quality of life, and to better assess the benefits versus the risks of radioactive iodine therapy.

Keywords

radioiodine; thyroid cancer; symptoms; salivary; lacrimal; quality of life; benefit/risk

INTRODUCTION:

Differentiated thyroid cancer (DTC) comprises the vast majority of overall thyroid cancer diagnoses, and its incidence has steadily increased over the last 40 years across all demographic groups (1, 2). Despite this increase, DTC maintains excellent survival outcomes largely due to treatment composed of appropriate combinations of surgery and radioactive iodine (RAI) (3–6). RAI use is associated with extended survival and decreased disease recurrence in patients with intermediate to high-risk DTC (5–8). Following surgical removal of the thyroid, initial RAI is employed either as a treatment for patients with residual or metastatic disease, or as "adjuvant" therapy in intermediate-risk patients who have no evidence of residual DTC. RAI therapy can also be repeated, if indicated (5, 6). Immediately following administration of RAI, patients must stay separated from others to avoid exposing others to radiation (9). Patients should follow specific steps to reduce radiation exposure to others (e.g., separate rooms, sleeping arrangements, utensils; avoiding public transportation), with special attention to maintaining their distance from children and pregnant women (6 feet away). The disappearance of RAI from the patient's body depends on the activity of RAI administered but precautions about limiting exposure for the most vulnerable individuals (pregnant partners and children) are no longer needed after 21 days (9). Almost all high-risk DTC patients receive RAI, but administration to intermediate-risk patients varies with 13% to 88% of intermediate-risk patients receiving treatment (10–12).

A well-documented, dose-dependent side effect of RAI use is salivary gland damage. Salivary inflammation and dry mouth occur in 7 to 86% of patients, with the wide range likely being due to varying methods of ascertainment (13–21). The full spectrum of salivary gland damage is extensive and includes decreased or altered taste, salivary infections, salivary stones, and dental caries (13, 22). Additional craniofacial consequences of RAI treatment include lacrimal (eye) and nasal symptoms. Lacrimal symptoms include dry eyes, over-flowing tears, and conjunctivitis associated with nasolacrimal duct obstruction (23, 24), with 92% of patients showing abnormal lacrimal function tests after RAI therapy in one study (24). Nasal symptoms, although not well-studied to date, include nasal irritation, dry nose, and epistaxis (nose bleeds) (25, 26). The true incidence and consequences of lacrimal and nasal damage following RAI therapy are unknown.

These salivary, lacrimal, nasal and other side effects negatively impact health-related quality of life (HRQOL) by causing problems such as pain, poor sleep, distress, and impaired social functioning (27–36). Furthermore, many providers may not recognize these effects as related to RAI therapy, leading to patient frustration, confusion about causation of symptoms and thus further negative effects on HRQOL (26, 36, 37). Patient frustration may be exacerbated by categorization of thyroid cancer as the “good cancer” given the expected favorable prognosis (35, 38, 39). In prior work, individuals with thyroid cancer reported that labels of having the “good cancer” invalidated their concerns and individual experiences with short- and late effects (35).

Few studies have explored the spectrum, intensity, frequency, and time course of these symptoms following RAI although this information is needed to inform better ways to identify, evaluate, and manage these effects of RAI therapy. We do not know whether and how patients are informed about these potential side effects prior to RAI treatment. An online survey of over 1,000 thyroid cancer survivors revealed that less than half recalled receiving information about possible side effects of RAI (40). These gaps in the literature support the need for research that focuses on patient-reported side effects and their impact on HRQOL among patients with DTC.

We sought to identify the full range of salivary, lacrimal, and nasal symptoms following RAI, along with patient perspectives on preparation for RAI therapy and other aspects of HRQOL. We conducted focus groups of patients with DTC who had undergone RAI treatment and elicited patients’ reflections about their experiences following RAI, including craniofacial symptoms, information needs and overall well-being.

METHODS:

Focus groups

We conducted 8 focus groups with patients diagnosed with DTC who received RAI to ascertain the spectrum of salivary, lacrimal, and nasal symptoms following treatment, as well as to assess information needs and other aspects of HRQOL. We recruited patients 18 years and older from the Endocrine Division, the Head and Neck Surgery department, and the Nuclear Medicine department at Medstar-Georgetown University Hospital. We distributed fliers to these offices, other local physicians' offices, and the local support group of ThyCa; Thyroid Cancer Survivors' Association. We held 3 focus groups at a conference room of Georgetown Lombardi Comprehensive Cancer Center. We also recruited and held 5 focus groups at the Thyroid Cancer Survivors' Annual Conference in Los Angeles, California in 2016. Focus groups were 60–90 minutes long and included participants across a spectrum of time since diagnosis and with various stages of thyroid cancer at diagnosis.

Our study was approved by the Institutional Review Board of Georgetown University. We obtained written informed consent from each participant prior to initiating the focus group sessions. At the beginning of each focus group, we asked participants to complete a brief questionnaire to gather demographic and cancer history and treatment information. Two team members led each focus group and used semi-structured facilitation guides during the discussion. Another member of the team attended as an observer to take notes. We audio recorded focus group discussions with participants' permission. We began each session by describing that the purpose of the discussion was to learn more about patients' experiences and quality of life following RAI treatment. We then asked participants open-ended questions to elicit responses regarding their experiences with salivary, lacrimal, and nasal symptoms. We also asked participants an open-ended question about their quality of life following RAI treatment. If needed, facilitators used prompts included in the guide to elicit further discussion on specific topics. Following completion of the focus groups, we transcribed the recordings verbatim and removed any identifying information from transcripts to protect confidentiality.

Analysis

We conducted analyses following approaches of qualitative description and thematic analysis. (41) We were guided by our clinical experiences in endocrinology and research experience in cancer survivorship and symptom assessment. Four members of the team first read all transcripts prior to codebook development to gain a full understanding of participants' experiences (CK, SD, KG, SS). We used NVivo qualitative software to organize and support analysis of the transcripts.

We then developed and refined the codebook throughout the coding process as themes emerged. Three team members coded the transcripts (CK, SD, SS) and another team member reviewed codes to ensure consistency (KG). We discussed emergent themes with all team members. We derived codes from the transcripts to match participants' comments. We sought to remain true to the data and limit abstract interpretation of participants' comments (42). Coders used memos and notations to track commonalities across transcripts, associations between codes and relevant ideas/comments (43). We grouped codes by combining similar topics to form themes. Coders also investigated how well the synthesized data mapped onto existing empirical data and team members' clinical experiences of identifying and managing symptoms following RAI treatment. Senior members of the team with experience in behavioral science and survivorship (KG) and endocrinology and clinical management of thyroid cancer (JJ) provided further guidance to the coders.

RESULTS:

Demographics

Our eight focus groups were comprised of 47 people (Table 1), with 4–12 individuals participating in each focus group. The majority of participants were women (n=37, 78.7%) and participants had a mean age of 52.1 years (SD=14 years). The mean time since RAI treatment was 3.9 years and ranged from 2 months to 10 years. The majority of participants (n=41, 87%) had been diagnosed with papillary thyroid cancer, the most common histology of DTC.

Themes

We identified 8 broad themes from the qualitative analyses: dry mouth, salivary gland dysfunction, altered taste, eye symptoms (tearing or dryness), epistaxis (nose bleeds), lack of knowledge and preparation for treatment, regret of treatment, and distress that thyroid cancer is labeled as a "good cancer." In Table 2 we indicate the percent of participants who commented on specific symptoms (dry mouth, salivary gland dysfunction, altered taste, eye symptoms, epistaxis). Below we describe each theme and present exemplar quotes. Additional illustrative quotes are displayed in Table 3.

1. Dry mouth—

In our sample, about one-fifth of participants reported dry mouth among whom a small subset reported associated mouth sores. Participants described varying degrees of dryness over a variable time course; some had persistent dry mouth while others' symptoms improved over time, but not necessarily to pre-treatment functioning.

> "Over the past 10 months or so, I have not really improved - very, very dry mouth, to the point where I can't swallow unless I have a tiny sip of water."

> "I have so much dry mouth sometimes I notice I can't eat certain things. Sometimes I might eat it and not think about it – like I might get a ham sandwich or something then all of a sudden bread's just stuck in there like glue. And I'm pouring all this water and taking my toothbrush trying to dig bread out. I guess - yes, I have noticed some of that."

> "I, over the years, get more sores in my mouth easily and that's from dry mouth where I've had to get like dental paste from time to time… even if I accidentally bite my tongue or something that could be a sore, [it] takes longer to heal so that has been an issue."

2. Salivary gland dysfunction:

Salivary gland issues were prevalent amongst focus group participants. The salivary gland dysfunction appeared to affect participants in different ways, including changes in eating habits due to pain from swelling and the need for additional procedures to remove salivary stones.

> "I had swollen salivary glands 9 months after I had the RAI… anytime I would smell any kind of food, any oh my God, I've never experienced anything so painful. So I had the swelling and I couldn't eat because it was just too painful, and I lost 20 pounds in three months."

> "So, it's a procedure in through the salivary gland, like they would do an angioplasty for someone with a heart issue. Roto-Rooter …into the salivary [duct] and bust open the -- it was blocked with a… the stone."

> "I ended up having my first salivary surgery which helped, and they ended up removing a lot of scar tissue. And the doctor kept say[ing] there's not scar tissue in there, we're probably not going to find anything, but I kept saying please go in and do something because my mouth is so dry. And when he went in there, he was surprised how much scar tissue was in there as a result of the radioactive iodine. There were a couple of stones in there because of the scar tissue. So, ended up developing stones."

3. Altered taste: A number of participants reported short-term and long-term changes in taste perception that returned to pre-treatment levels for some, but not all, participants. Interestingly, some participants also noted enhanced sensitivities to temperature of food or drinks following treatment.

> "[Taste was] metallic and everything like that… and it did come back but I don't think it came back to the pre-RAI existence."

> "I didn't taste anything for about six months before it came back. And then there was the heavy metallic taste; sensitivity to not only spices but to temperatures, hot and, you know, extreme cold, extreme sensitivity to that."

> "I had to force myself to eat. There was no joy in eating. It was just going through the motions, putting something down."

4. Eye symptoms (tearing or dryness)—Excessive tearing (epiphora) and dry eyes were equally described by a large portion of the focus group participants. Notably, participants frequently reported symptoms alternating between eye tearing and dryness. Participants also indicated that some of their clinicians did not appear to identify symptoms as due to RAI.

> "I have a lot of eye watering. Like, if I stare at the computer screen for too long even though I have special glasses. But they'll start watering and it's hard to tell if that's a side effect or is it conjunctivitis that the ophthalmologist thinks it is?"

> "It's getting worse where my eye keeps running and I have to go see the eye doctor now… and I had the dry eyes, where your eyes are just like, oh, it's just so dry. Had that too."

In a few cases, the excessing tearing led patients to seek additional medical procedures such as dacryocystorhinostomy. The following patient had to seek out several different specialists before he had surgery to resolve the problem.

> "…about 6 months after my first radioactive iodine treatment…I would just have tears welling up in my eyes…I started seeing a psychologist…because I thought I was getting depressed…and he finally referred me to an ophthalmologist. …I'm just constantly [having] tears running down my cheeks and I'm having to constantly tell people, that no I'm not crying, uh, it's just I got an eye problem and I'm fine. …There is a surgery for it, it's called a DCR, a Dacryocystorhinostomy… . When both eyes were tearing, welling, welling up with tears all the time, the tears would sit on my lower eyelids… I couldn't read the pieces of paper, I'd be driving, the speedometer's' blurry… so it was very inconvenient and you were talking about quality of life impact… it was always blurry and I would need to dab my eyes and stuff all the time."

5. Epistaxis (Nose Bleeds)—A small portion of the focus group participants reported epistaxis, while others reported associated dryness. Symptoms were variable, ranging from isolated incidents to intermittent, light nasal bleeding. A few participants reported heavier nose bleeds, with a small number of participants reporting nose bleeds that lasted several days.

> "Yeah, a lot of that – dry blood and burn, and just cracked, mucous, everything."

> "My nostrils also became kind of, like, bloody with scabs right on the tips… and that also lasted about maybe a month or two."

> "I had a horrendous bloody nose that I actually had to call my… regular GP for. But I would have never connected it to the…RAI…it [the nose bleed] was just once. But it was really, really bad…. like, gushing blood… .It lasted a good couple of days."

6. Lack of knowledge and preparation for treatment—Quite a few participants, at least a couple within all of the focus groups, expressed dissatisfaction with the pre-RAI counseling they received regarding side effects of treatment. These participants stated that they felt unprepared for RAI and its potential side effects. Another, smaller group of participants reported a lack of knowledge of the connection between certain experienced side effects and the RAI therapy received.

> "I was having issues with dry mouth, pain, and so much was going on I didn't really bring it up to my doctor because I didn't know that was a side effect of everything that was going on."

> "… I'm just having all these issues now in my face no one really warned me about."

> "I just remember them [the medical care team] having me, you know, sign paperwork. But there was nothing that disclosed, maybe even just common side-effects, let alone maybe all the potential side-effects."

> "I'm angry because… I feel like I was fed a fairy tale when I did the research before my surgery. Oh, it's easy. You have the surgery. Then, you have RAI. And you're good to go. …I feel like I was fed lies. … no, I'm not good to go. I still have

> something microscopic, and I have to have PET scans and CTs. And that's more radiation and, you know, so, yeah, that's my anger.

Some participants even pointed out that the printed or online educational materials they were given prior to RAI seemed old or outdated. Others detailed their confusion regarding where they could safely go after treatment without putting other people at risk for radiation exposure.

> "I was three days in isolation. Then I went to sleep at my friend's house for two nights. And then I went to sleep in a hotel for three nights because my sister didn't want me in the house. She said you better go somewhere else for one week."

> "My doctor's like "You can't go to a hotel. It goes through walls." You know, all this other stuff. So, my children and my husband were like nomads… we got them a hotel room so they would feel like it was going to be like a mini-vacation for a little bit. But then, you know, they couldn't eat out every day. So, then they stayed at my mom's house for two days. And then they stayed at his mom's house for three days. And my dog was freaking out. So, you know, that was a hard part to figure out."

7. Regret of treatment: A few participants explicitly declared that they wished they had not had RAI treatment, although this idea was mentioned only in about half of the groups. These sentiments stemmed from the side effects experienced and from the ineffectiveness of treatment in those who had recurrence or were later declared to have RAI-refractory disease. Of note, these participants reported that they were not informed that their thyroid cancer could be refractory to treatment. These participants also indicated that they did not remember talking with their providers about the option of not receiving RAI therapy.

> "I would not do the RAI, all things considered equal, because…I did feel that the side-effects were not worth, in my particular…situation…. But, I wouldn't do it again."

> "But I was never told there was a possibility of being refractory, which I took issue with the previous doctor who did that, because they should have known… that I was probably going to be refractory. And maybe we should have reconsidered even doing it."

> "I feel like I wasted almost a year, you know, almost a year with the two treatments that we could have been jumping to more advanced treatments. Something, you know, [like] the TKIs [Tyrosine Kinase Inhibitor] that I eventually got on… we could have started things a lot earlier. And I could have just avoided the whole RAI and radiation because it was so ineffective. And it was just a waste of time, you know?"

8. Distress that thyroid cancer is labeled as a "good cancer": A common theme throughout all of the focus groups was frustration with the idea that since DTC has a favorable prognosis, it is a "good cancer." Similarly, several participants specifically expressed feeling alone in their diagnosis. These reports appeared to be associated with others' perceptions that thyroid cancer is a "good cancer" and also a lack of shared experiences with others. Participants also noted psychosocial concerns following diagnosis and commented on ways in which their diagnosis and treatment interfered with certain activities (e.g., cooking and entertaining friends). A smaller number indicated that perceptions of thyroid cancer as a good cancer caused a sense of distress (identified by one patient as ‘moral pain’ following diagnosis).

> “…they say thyroid cancer is the best kind of cancer and you’re fine, it’s nothing. Like, people need to know the reality of it when you’re first diagnosed because it could go really wrong.”
>
> “It’s hard to, to share with people who have not gone through it.”
>
> “I remember honestly saying that I would’ve rather lost my hair I think for a couple of reasons. 1. That’s visible to other people and it’s not that I was looking for sympathy, but again because you hear “the Cadillac of cancers” all the time I don’t think people realize all the psychosocial things you’re dealing with. But I also happen to be a very avid, active cook so not only was it affecting my ability to enjoy food but also my ability to prepare and host other people.”
>
> “But the most important thing, from my recollection, on this procedure, which is very painful -- morally painful, because as you say, except a little pain in my throat, I didn’t have any pains in my body…. But there is a moral pain, which you experience in your soul that you are not well.”

DISCUSSION:

Our study highlights the wide range of side effects experienced by patients following RAI administration that include and expand beyond the expected salivary, lacrimal, and nasal symptoms. Participants elaborated on both the physical aspects of these symptoms, such as altered taste, and also how these symptoms affected their HRQOL, such as the social impact of not being able to properly prepare food for others or the psychological impact of a diagnosis. Interestingly, contradictory symptoms such as having both eye tearing and dry eyes were reported by several participants. These results highlight the complexity and individuality of symptom patterns following RAI. For example, our findings suggest that the dual presentation of both eye tearing and eye dryness may be related to RAI-specific mechanisms of damage to the eye combined with intermittent lacrimal duct occlusion. We are unaware of prior research that has reported the range and type of short-term and late effects following treatment of thyroid cancer.

Our results related to thyroid cancer survivors’ expressed frustration with the idea of thyroid cancer as a “good cancer” is consistent with and expands upon other recently published research (39). The participants in the present study reported that conceptualization of thyroid cancer as ‘the Cadillac of cancers’ invalidated its negative impact on their lives and led some survivors to blame themselves for experiencing detrimental effects from such a “good cancer.” Other participants noted that they held back from sharing their experiences and feelings with others, or that they were not sure other people could relate to their experiences. Future research can further investigate the psychosocial effects of the isolating nature of both the treatment and lack of general awareness about thyroid cancer and its treatment.

Findings from the present study build upon prior work that has investigated HRQOL in patients with thyroid cancer (27–35). A small but growing body of work has explored topics such as the effects of the surgical thyroidectomy scar on HRQOL (44), to methods of preparation for RAI administration (45), to overall HRQOL in disease-free DTC survivors (33), and evidence of cognitive impairment in survivors (46). Compared to a control group of individuals without cancer matched by sex and age, disease-free thyroid cancer survivors (33), reported significantly worse HRQOL scores across domains of depression, anxiety, and fatigue. The psychosocial effect of RAI side effects reported by our focus group participants expands upon the evidence to date by highlighting DTC survivors' concerns and frustration related to lack of information about side effects.

These results underscore the need for increased provider awareness of both the short-term and late effects of RAI and the consequences for HRQOL and the importance of patient-provider communication to promote informed decisions prior to delivering RAI. Our study reinforces prior evidence that patients often feel unprepared for the possible side effects of RAI and desire more detailed information prior to treatment (47–50). For example, a Dutch survey-based study reported that almost half of the patients treated for thyroid cancer over an 18-year period were dissatisfied with the information received about their diagnosis (50). The present results thus complement and expand upon research in the United States, Canada and Europe that indicates patients with thyroid cancer have significant unmet information needs (50). The frustration associated with lack of knowledge appeared to frequently lead to feelings of isolation as patients reported experiencing side effects that limited their social functioning. Furthermore, our results indicate healthcare professionals may not attribute side effects to RAI, or may believe that symptoms only occur in close proximity to the RAI administration. Providers' lack of awareness about the severity, frequency and time course of RAI side effects appears to further compound survivors' uncertainty and distress about identifying and resolving both short-term and late effects of treatment. A specific example of lack of attribution is both survivors' and their primary care physicians being misinformed that epistaxis was not a consequence of RAI therapy.

Several of our study participants reported they regretted having RAI treatment and noted disappointment that the option of not using RAI therapy was not discussed. Survivors noted lack of understanding, or even undermining of their experience, when such concerns were shared with health care professionals. Recent research has also highlighted the striking issue of patients feeling they had a lack of choice regarding their therapy (51). While some of the feelings expressed by our participants appeared to stem from the refractoriness or recurrence of cancer, other participants noted treatment regret after experiencing disruptive side effects or having delayed child bearing in order to first receive radioiodine therapy. With respect to this issue, although a one year delay in conception is generally accepted as a strategy to avoid adverse consequences on fertility and pregnancy outcomes, RAI treatment may in fact have some negative consequences on fertility and pregnancy outcomes over time (52–54).

Treatment regret is also relevant to the topic of overdiagnosis and overtreatment of thyroid cancer (39, 51, 55). A recent study of patients with suspected or confirmed incidentally found thyroid malignancies who chose surveillance over intervention highlighted the anxiety and isolation patients felt as they coped with an uncertain diagnosis (55). Indeed, some patients in this recent study considered the finding of their DTC to be an “overdiagnosis.” The psychosocial consequences highlighted in the present study raise questions about possible overtreatment with RAI. Our results reinforce the importance of clear presentation of the risks and benefits of treatment and management options, including the option to not have RAI therapy, for patients with low risk DTC and perhaps selected cases of intermediate risk DTC.

The strengths of our study include the diverse patient population in terms of age, race and geographic representation and our focus on a wide range of RAI-specific side effects. Women comprised approximately 79% of our focus group participants, which is in keeping with a recent report using the Surveillance, Epidemiology, and End Results (SEER)-9 database revealing that women make up 75% of thyroid cancer cases (1). Papillary thyroid cancer was the most prevalent type of DTC in our cohort, which also is consistent with population trends. Unlike previous studies exploring HRQOL in patients with thyroid cancer (27–36), our study focuses specifically on the side effects of RAI and the effect of these side effects on patients’ physical and social functioning. Other studies have focused on overall HRQOL issues related to DTC and did not separate out RAI-related short-term and late effects from overall DTC treatment effects. Our primary focus on RAI helped identify issues that have been less explored in the literature and that may go unaddressed by healthcare providers. We learned that many of the focus group participants did not appear to connect their symptoms as side effects from RAI treatment until much later (if at all). We hope the present results will begin to raise awareness of the important concerns identified by DTC survivors, including unmet information needs, frustration over on-going late effects and, in some cases, treatment regret. The present findings not only provide insights into the under-investigated lacrimal and nasal effects of RAI, but also on the psychological and social well-being of DTC survivors following treatment.

The present results should be interpreted in the context of study limitations, including the self-selection of participants; it is likely that our focus groups may have attracted patients who experienced more side effects during or following treatment. In addition, the time since RAI among our participants extended up to ten years, thus introducing a risk of recall bias. Also, most patients could not recall specifics about the activity (intensity) of RAI with which they were treated. We also did not systematically track the identity of each participant within our de-identified focus group transcripts; thus we were not able to provide context for the extracted quotes in terms of participant age and gender. Finally, these patient-reported symptoms of salivary, lacrimal, or nasal dysfunction cannot definitively be linked to RAI treatment given the heterogeneity of time since treatment, lack of specifics about RAI activity, and different treatment and follow-up patterns of care in different geographic areas of the country.

Our study has implications for future research. Although there is recognition of salivary symptoms following RAI in the literature, there is a dearth of information about risk factors and associations between salivary symptoms and salivary function. Previous investigations have shown that salivary scintigraphies performed prior to and following RAI ablation reveal salivary gland dysfunction in 20% of patients, correlating to patient-reported dry mouth (56). However, correlation between salivary function and symptoms can also be poor (57). The present results provide rich data from which to extract topics for systematic approaches to assessing short-term and late effects following RAI therapy. Immediate next steps could include development of a questionnaire to better assess patients' salivary, lacrimal, and nasal symptoms before and after RAI therapy for DTC. This type of a questionnaire will allow for future research to validate patient-reported side effects following RAI with measures of objective gland function such as salivary scintigraphy and salivary flow assessments. Identification of the frequency and quality of life impact of patients' experiences will help us to gather valuable insight into the risk factors for development of salivary, lacrimal, and nasal dysfunction related to RAI.

Conclusion

The salivary, lacrimal, and nasal short-term and late effects of RAI are extensive and range in severity from mild to burdensome. Moreover, the impact of RAI reaches beyond the physical symptoms and affects many aspects of HRQOL. Identification of the specific effects of RAI on physical, psychological, and social areas of functioning will provide information needed to help patients and providers understand and make informed shared decisions about treatment for DTC.

Acknowledgements

The authors would like to thank all the individuals who participated in our focus groups and express our gratitude to the many members of ThyCa who assisted and supported our recruitment effects.

Funding: This study was funded by NIDCR Grant R01DE025822 to JJ and KG, including funding support to CK and REJ (support to REJ was prior to joining the National Cancer Institute). Partial support was provided by the Survivorship Research Initiative for Taylor Schulte's assistance with manuscript preparation through NCI grant P30-CA051008.

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Table 1.

Demographics of Focus Group Participants (N=47)

Characteristic	**Results**
Mean Age, years (SD, Range)	52.1 (14; 28–89)
Mean time since RAI, years (SD; range)	3.9 (3.3; 0.17–10)
Sex (N, %)	
Male	10 (21.3%)
Female	37 (78.7%)
Race (N, %)	
White	33 (70.2%)
Black or African American	6 (12.8%)
Asian	1 (2.1%)
More than one race	6 (12.8%)
Other	1 (2.1%)
Ethnicity (N, %)	
Hispanic or Latino	6 (12.8%)
Not Hispanic or Latino	37 (78.7%)
Marital Status (N, %)	
Married/Partnered	29 (61.7%)
Single or never married	11 (23.4%)
Divorced or separated	6 (12.8%)
Education (N, %)	
College graduate or beyond	40 (85.1%)
Some college	5 (10.6%)
High school graduate/GED	2 (4.3%)
Employment Status (N, %)	
Full-time employed	22 (46.8%)
Part-time employed	2 (4.3%)
Retired	14 (29.8%)
Not employed	7 (14.9%)
Receiving disability	2 (4.3%)
Annual Household Income (N, %)	
Under $25,000	3 (6.4%)
$25,001-$50,000	4 (8.5%)
$50,001-$75,000	10 (21.3%)
$75,001-$100,000	10 (21.3%)
Over $100,000	14 (29.8%)
Health Insurance (N, %)	
Yes	46 (97.9%)
No	1 (2.1%)

Characteristic	**Results**
Differentiated Thyroid Cancer Histology (N, %)	
Papillary Thyroid Cancer	41 (87%)
Follicular Thyroid Cancer	6 (13%)

Table 2.

Prevalence of Participants Mentioning Specific Symptoms During Focus Groups

Symptom	Prevalence (%)
Altered taste	19.8
Eye symptoms: dry eyes[*]	18.9
Dry mouth	18.3
Eye symptoms: excessive tearing[*]	16.8
Salivary gland dysfunction	14.8
Epistaxis	4.2

[*] Dry eyes and excessive tearing classified under eye symptom theme

Table 3.

Exemplar Quotes for each Theme

Theme	**Quotes**
Dry mouth	*“I was having issues with dry mouth, pain, and so much was going on I didn’t really bring it up to my doctor because I didn’t know that was a side effect of everything that was going on.”* *“10 months ago the dry mouth started. Even though I sucked on lemon candies continuously, it hasn’t gotten better.”*
Salivary gland dysfunction	“*I would salivate at night a lot… wake up with my mouth closed full of saliva… and then it went to nothing”* *“…actually just the best way that I could have just described it to anybody, to my doctors and to my friends, it’s like when you get sick and you feel like your, your glands are kind of swollen.”* *“And I’m crying in the bathroom, and my face was swollen, and it was like sharp pain shooting through every time I would try to swallow. So I think it was, whatever was inflamed or clogged, and saliva was trying to get through, it was kind of reacting.”*
Altered taste	*“I used to get up every morning… you know those lemon juice bottles? I used to squirt some on my tongue to try and decide how much I could even taste. One day I couldn’t even taste it at all.”* *“You see something and you want to eat and your brain’s saying it should taste this way but then you eat it and you’re like ew this doesn’t taste right.”*
Eye symptoms	*“Over time both of my tear ducts are blocked permanently. I had surgery to put a temporary stent in… over the next couple of months it closed again. As far as I know, it [blocked tear ducts] has not ever been listed as a side effect for RAI.”* *“I find that my eyes seem to be dry. And sometimes they tear. But, what irritates me most is the dryness.”*
Epistaxis	*“I also found out that the blood vessels in my nose thinned out. I’m just having all these issues now in my face no one really warned me about.”* *“The time I saw blood coming to my nose, I was talking to my doctor. She stated it’s a normal side effect of radiation.”* *“…bloody scabs. I pull something out, you know, bloody. And that -- they didn’t explain that to me. And I didn’t anticipate that.”*
Lack of knowledge and preparation for treatment	*“I wish I just had known, instead of having these symptoms and then, you know, going back, and then hearing, well, oh, yeah, you know, that’s common. There -- I think there were just a lot of things I just didn’t know”* *“Why didn’t they forewarn me that this could happen? No one even told me that I could have a salivary issue. So I was a little upset about that because no one told me.”*
Regret of treatment	*“…I was having issues…and to hear her say, yes, I’ve seen this and it could be long-lasting was when I said, I, I wish I hadn’t done the RAI.”* *“If I got my tumor now, I’d probably would not have RAI, so I’m frustrated with that a little, I might not have even had a total thyroidectomy now.”* *“I’m angry. I’m angry I had it. It didn’t work.”*
Distress that thyroid cancer is labeled “good cancer”	*“It is hard to convey to somebody that there is a shadow. It follows us everywhere. It is lifelong.”* *“I’m here to tell you no cancer is good cancer… We live with a lifelong, ongoing relationship with your Endocrinologist.”* *“Because so many people say that, that I don’t even feel right saying I have cancer, because other cancer is so much worse.”*