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Post-thyroidectomy neck appearance and impact on quality of life in thyroid cancer survivors

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ABSTRACT

Background: There is a paucity of patient-reported data on thyroidectomy scar perception. The effect of neck scarring on quality of life is not known. We hypothesized that worse perception of neck appearance would be related to worse health-related quality of life and that perception improves with time.
Methods: Survivors of thyroid cancer ($n = 1,710$) were surveyed online. Respondents were asked to score the appearance of their neck via a 5-point Likert scale. Quality of life was evaluated via the Patient-Reported Outcomes Measurement Information System 29. The relationships between neck appearance, patient characteristics, quality of life, and Patient-Reported Outcomes Measurement Information System domains were analyzed with multivariable models and Spearman partial correlations (r_s).
Results: Older age was associated with better perception of neck appearance (odds ratio 0.975/year; 95% confidence interval 0.967—0.983; $P < .001$). Greater time since surgery was also associated with improved perception (odds ratio 0.962/year; 95% confidence interval 0.947—0.977; $P < .0001$). We observed no statistically significant difference between current and preoperative baseline perception >2 years after surgery. On multivariable analysis, age >45 years, >2 years since surgery, and higher self-reported quality of life were independent predictors of better self-reported neck appearance ($P \leq .0003$). In patients ≤2 years after surgery ($n = 568$), the PROMIS domains of anxiety, depression, social function, and fatigue had weak but statistically significant correlations with worse perception of neck appearance ($P < .0001$).
Conclusion: Age >45, >2 years since surgery, and higher quality of life were independently associated with better self-reported neck appearance. Perception of neck appearance returned to preoperative baseline 2 years after surgery. PROMIS domains had a weak but significant association with neck appearance perception in patients ≤2 years after surgery. The impact of post-thyroidectomy neck appearance on quality of life appears to be mild and transient and returns to preoperative levels after 2 years.

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Introduction

Approximately 760,000 thyroid cancer survivors are currently living in the United States, and an estimated 53,990 new cases of thyroid cancer were projected to be diagnosed in the United States in 2018.[1,2] For the majority of people with thyroid cancer, the standard treatment begins with a thyroid operation.

The conventional thyroidectomy procedure involves creating a 3 cm to 6 cm horizontal incision at the base of the neck through which the thyroid can be directly accessed and removed. Various remote-access and minimally invasive techniques have been developed with the goal of reducing or eliminating postoperative scar, but these procedures are used relatively infrequently in the United States.[3] Multiple procedures have been developed, including minimally invasive video-assisted thyroidectomy, trans-axillary thyroidectomy, transoral endoscopic thyroidectomy, and the bilateral-axillo breast approach. Although innovative, these techniques may be associated with increased cost and, in some cases, increased surgical risk.[4–7] Comparative effectiveness data between these various remote-access techniques and conventional thyroidectomy are limited, but existing cost comparison studies

show that remote-access procedures are associated with increased hospital costs and time in the operating room.[5,7]

Given that improved cosmetic outcome is presumed to be the main driving factor for the development of these techniques, it is necessary to understand the importance of post-thyroidectomy neck appearance for thyroid cancer survivors in the United States in order to conduct a proper cost-benefit analysis in the context of the US healthcare system. Currently, a paucity of data are available regarding the impact of neck scarring on patient-reported health-related quality of life (HRQoL) and the duration of impact. Patient-reported outcome (PRO) information is essential to understand the influence of neck appearance on quality of life (QoL) from patients' perspectives. Earlier studies have shown no lasting difference in cosmetic perception between minimally invasive and conventional thyroidectomy groups.[8–11] Here we evaluate the perception of the postoperative neck appearance in thyroid cancer survivors along with patient-reported HRQoL, using the Patient-Reported Outcomes Measurement Information System (PROMIS) 29-item profile. We hypothesized that worse perception of neck appearance would be related to worse HRQoL and that perceived appearance improves with time.

Methods

An online survey was designed in collaboration with the Thyroid Cancer Survivors' Association, Inc (ThyCa) and consisted of two parts. The first portion assessed patient demographics, clinical characteristics, and treatment history, along with questions about neck appearance perception and overall QoL. The second portion consisted of the PROMIS 29-item profile. The cohort of respondents to this survey has been designated as the ThyCa cohort and is more fully described elsewhere.[12] This survey was used in a study comparing thyroid cancer with other chronic disease states and was modeled from an earlier survey assessing HRQoL in patients with multiple endocrine neoplasia, where further details on survey design are described.[12]

To assess neck appearance perception, we asked participants to recall and rate their level of concern about neck appearance using a 5-point Likert scale at 3 time points: before surgery (baseline), the first few months after surgery, and at the time of survey completion (current). A score of 1 indicated no concern over neck appearance, and a score of 5 indicated significant concern. Patient HRQoL was evaluated with a global response item asking patients to rate overall QoL on a 5-point Likert scale and with the PROMIS 29-item profile. The PROMIS tool, funded by the National Institutes of Health, was created by a nationwide cooperative group of investigators and has been validated in the general US population and in multiple cohorts with chronic illness to assess HRQoL across 7 domains: depression, anxiety, fatigue, ability to participate in social roles (ie, social function), physical function, pain interference, and sleep disturbance.[13–16] Worse HRQoL is indicated by lower scores in the domains of physical and social function, and higher scores in the domains of anxiety, depression, fatigue, pain interference, and sleep disturbance.

The survey was administered online and was open from January 2017 to June 2017. In collaboration with ThyCa, the survey was distributed through the ThyCa Web site, social media, and online newsletters. All data were self-reported. Adults ages 18 to 89 years who reported a physician-made diagnosis of thyroid cancer and who resided in the United States at the time of survey completion were eligible for this study. Individuals who did not complete both parts of the survey were excluded from our study. The survey was administered using Research Electronic Data Capture, a secure web-based platform for gathering research survey data.[17] After completion of an electronic consent, participants were presented

Table I
ThyCa surgery cohort demographics and clinical characteristics

Patient characteristics	Statistics
Total cohort	1,710
Female	1,511 (88%)
Caucasian	1,621 (95%)
Asian	32 (1.9%)
Black	28 (1.6%)
Other/not reported	29 (1.7%)
Mean age at survey	51 y (± 13)
Mean age at diagnosis	44 y (± 13)
Mean time since surgery	6.8 y (± 7.3)
Treatments received	
Surgery	1,710 (100%)
RAI	1,338 (78%)
Chemotherapy	40 (2.3%)
External beam radiation	62 (3.6%)
Alternative therapies	52 (3.0%)

Values in parentheses are presented as n (%) or n (± standard deviation).

with the 2-part survey. Responses were kept anonymous by assigning a unique identifier code to each participant in the Research Electronic Data Capture database. The study protocol was reviewed and approved by the Northwestern University Institutional Review Board (Chicago, IL) before the launch of the survey.

The PROMIS questionnaire was scored using the Health-Measures Scoring Service (www.healthmeasures.net). The PROMIS metric is the T-score, where 50 is the mean of a relevant reference population (usually the US general population) and 10 is the standard deviation (SD) of that population. A score is reported for each of the 7 domains. A difference of 3 points or more was considered to be a clinically meaningful difference based on PROMIS validation studies in cancer.[18] The relationship between neck appearance perception, patient characteristics, and HRQoL were analyzed with univariable and multivariable models. Variables were included in the multivariable model based on their significance in univariable modeling. The relationships between PROMIS domains and perception of neck appearance were analyzed using the Spearman partial correlation coefficients (r_s) adjusted for age and years after surgery. A P value of < .001 was considered statistically significant. Kruskal-Wallis, Fisher exact test, and cumulative logistic regression were used to compare categorical variables. SAS v 9.4 (SAS Institute, Cary, NC) was used for data analysis.

Results

A total of 3,174 individuals accessed the survey online. Of those, 2,209 consented to participate and also indicated that they were diagnosed with a form of thyroid cancer. A total of 1,922 respondents completed the entire survey (participation rate 61%). Of these respondents, 1,743 reported living in the United States, and 1,710 underwent surgery for thyroid cancer. These 1,710 were therefore included in the study group.

Characteristics of our cohort are described in Table I. The majority of participants were Caucasian (95%) and female (88%), with a mean age of 51 years at the time of the survey and a mean age of 44 years at the time of diagnosis. At the time of the survey, patients in our cohort had been living with thyroid cancer for a mean of 6.8 years. Patients with all subtypes of thyroid cancer were eligible for this study, and the majority of respondents reported a diagnosis of papillary thyroid cancer (76%). In addition to surgery, radioactive iodine ablation (78%), chemotherapy (2.3%), external beam radiation (3.6%), and other adjuvant therapies (3.0%) were reported. A total of 30% of the cohort reported stage 1 disease, 17% stage 2, 14%
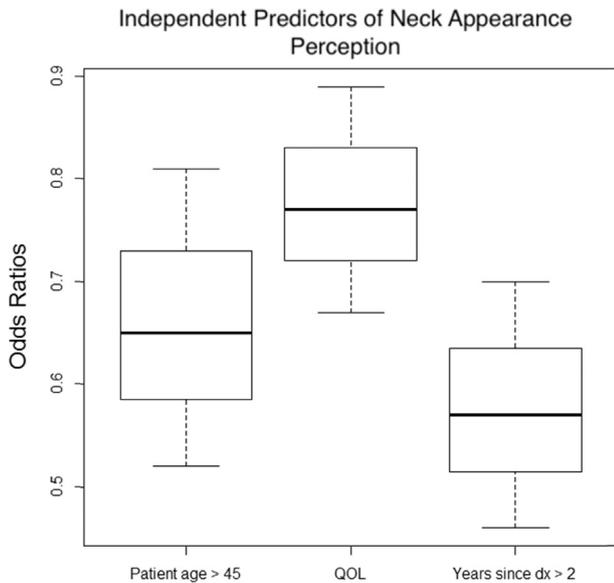
Fig 1. Independent predictors of better neck appearance perception based on multivariable modeling. The variables identified as independent predictors of better neck appearance are indicated on the X axis. Odds ratios and 95% confidence intervals are indicated on the Y axis. Odds ratios are relative to perception of poor neck appearance. Odds ratios <1 indicate a reduced concern about neck appearance (ie, improved neck appearance perception).
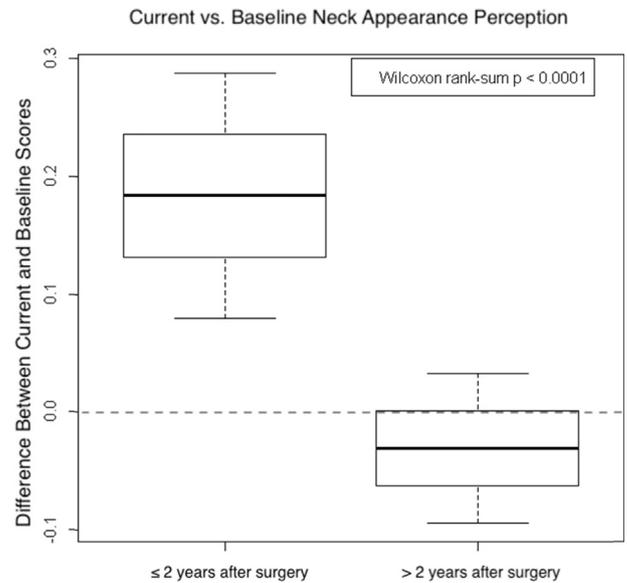

Fig 2. Current versus baseline neck appearance perception scores. Respondents were dichotomized and grouped based on the time after surgery (greater or less than 2 years) and are represented on the X axis. The difference between mean current neck appearance and preoperative neck appearance scores is displayed on the Y axis. A value of 0.0 (*dotted line*) signifies no change between current and baseline neck appearance perception. Positive values indicate that current appearance is worse than before surgery and negative values indicate current appearance is better than before surgery. Error bars indicate 95% confidence intervals.

stage 3, 11% stage 4, and 28% reported unknown stage or not staged. Postoperative infection was reported by 66 patients (3.9%). A total of 562 patients (33%) required more than 1 operation for thyroid cancer. For the cohort as a whole, patients had an average of 1.4 operations. For the subgroup of patients receiving multiple surgeries, there was an average of 2.4 surgeries per patient.

To assess changes in the perception of neck appearance with time, responses were analyzed both continuously and in a dichotomous fashion. Neck appearance perception ratings were dichotomized into groups of "no concern" or any level of concern. Respondent ages were dichotomized around age 45 years based on the American Joint Commission on Cancer 7th edition staging system.[19–21] An improvement in neck appearance perception was defined as a shift in responses from any level of concern to "no concern." With continuous data analysis, we found that older age was associated with better perception of neck appearance (odds ratio [OR] 0.975/year; 95% confidence interval [CI] 0.967–0.983; $P < .001$). A total of 71% of respondents >45 years of age reported no concern about neck appearance compared with only 53% of respondents ≤45 years of age ($P < .0001$). Greater time since surgery was also associated with improved neck appearance perception (OR 0.962/year; 95% CI 0.947–0.977; $P < .0001$).

On multivariable analysis, we found that age >45 years (OR 0.65; 95% CI 0.52–0.81; p = .0001), >2 years since surgery (OR 0.57; 95% CI 0.46–0.70; $P < .0001$), and higher self-reported overall QoL as measured by the Likert scale item (OR 0.77; 95% CI 0.67–0.89; $P = .0003$) were independent predictors of better self-reported neck appearance (Fig 1). Patients ≤2 years after surgery ($n = 568$) had more concern about neck appearance at the time of survey completion (mean 1.66; 95% CI 1.59–1.73) than at baseline (mean 1.48; 95% CI 1.41–1.55). For patients >2 years after surgery, there was no significant difference between current neck appearance (mean 1.39; 95% CI 1.35–1.43) and baseline preoperative neck appearance (mean 1.42; 95% CI 1.37–1.47 [Fig 2]). Multivariable analysis of patients >2 years after surgery with persistent concern about neck appearance ($n = 344$) revealed that age >45 was

independently associated with lower concern about neck appearance (OR 0.60; 95% CI 0.46–0.79; $P = .0002$).

To analyze PROMIS data for the group of patients ≤2 years after surgery, Spearman partial correlations were used and adjusted for variables found to be significant on multivariable analysis. On analysis with partial correlations adjusted for age and years since surgery, the PROMIS domains of anxiety ($r_s = 0.19$; $P < .0001$), depression ($r_s = 0.21$; $P < .0001$), social function ($r_s = -0.18$; $P < .0001$), and fatigue ($r_s = 0.21$; $P < .0001$) had weak but statistically significant associations with worse perception of neck appearance and are summarized in Table II. Sex was not associated with neck appearance perception based on multivariable modeling (OR 1.24; 95% CI 0.88–1.75; $P = .23$). This study was underpowered to draw conclusions about the association between race or ethnicity and neck appearance perception.

Discussion

To our knowledge, this is the largest study conducted using the PROMIS measure in the United States to evaluate patient-reported neck appearance perception after thyroidectomy and the first to assess its relationship with HRQoL. We found that age >45 years, >2 years since surgery, and higher self-reported overall HRQoL were

Table II
Correlations between PROMIS scores and neck appearance perception

PROMIS domain	Spearman partial correlation coefficient (r_s)	Adjusted P value (significance level $P < .001$)
Anxiety	0.19	**< .0001**
Depression	0.21	**< .0001**
Social function	−0.18	**< .0001**
Fatigue	0.21	**< .0001**
Sleep disturbance	0.008	.99
Physical function	−0.14	.006
Pain	0.11	.08

independently associated with a better perception of neck appearance. In addition, we found no significant difference between current and baseline neck appearance perception in the group of respondents who were >2 years from thyroidectomy, suggesting that the scarring associated with thyroidectomy does not impact patient QoL after 2 years.

We observed a weak but statistically significant correlation between neck appearance perception and the PROMIS domains of anxiety, depression, social function, and fatigue in patients who had surgery within 2 years of responding to the survey. This suggests that during the first 2 years when patients are experiencing concern about scarring, these domains may reflect the manner in which QoL is negatively affected. Overall, it appears that the impact of post-thyroidectomy neck appearance on HRQoL is mild and transient, and neck appearance perception returns to preoperative levels after 2 years. Patients >2 years after surgery with persistent concern about neck appearance tended to be younger than 45 years of age. Overall, older patients appear to experience less concern about neck appearance than younger patients.

One strength of our study is the large sample size ($n = 1,710$). By partnering with ThyCa to distribute this survey through their online platforms, we were able to gather a large number of responses from across the United States. However, this online recruitment method allows for the possibility of selection bias. Thyroid cancer survivors who did not have internet access or were not connected with the ThyCa support group or website were unable to participate. Despite this potential bias, the resulting sample demographics of age, sex, and stage of cancer at time of diagnosis are representative of the US population of thyroid cancer survivors and similar to published thyroid cancer trends in several ways.[22] The association between post-thyroidectomy neck appearance and race and ethnicity could not be evaluated in this study because the ThyCa cohort is underpowered to determine differences based on discrete nonwhite races and ethnicities. It has been observed that there is an increased risk of keloid and hypertrophic scarring in more highly pigmented skin, potentially increasing scar visibility and decreasing satisfaction.[23] Our conclusions should not be extrapolated to those populations that are under-represented in our study population.

A limitation of our study is that several questions in the survey asked the patient to recall data or their past perceptions. However, most analyses in this study utilized data from current neck appearance at the time of the survey completion. We acknowledge that this methodology introduces the potential for recall bias. In addition, the cross-sectional nature of the study means that the direction of causation between neck appearance and HRQoL cannot be inferred. The large sample size inclusive of survivors at various stages of treatment allows us to be confident in our conclusion that concern about neck appearance returns to preoperative levels after 2 years.

Another limitation is that the survey and analysis did not consider size of incision or number of thyroid surgeries when assessing satisfaction with postoperative neck appearance. Patients with larger incisions may experience more concern than those with smaller incisions, and repeat surgeries may theoretically have worse scarring. Furthermore, the exact surgical approach was not captured in this study, however remote-access methods were used infrequently in the United States during the time encompassed by the survey.[24] Given the predominance of the transcervical approach, our survey asked patients about concern about neck appearance rather than scar appearance to capture preoperative and postoperative data points. Because of the large size of the ThyCa cohort and the consistency between our findings and other findings on thyroid scar perception in the United States and Europe, we believe our results are valid and can be applied to the US population of thyroid cancer survivors.[11,25]

Other studies on the relationship between incision length and scar satisfaction have shown no significant difference in patient satisfaction between groups with smaller incisions versus larger ones and no continuous relationship between incision length and level of satisfaction.[8,10,26] These studies revealed comparable satisfaction scores for incisions in the range of <4cm to >6cm. These scar cosmesis studies, along with many others, do not take into account the variable risk of hypertrophic or keloid scarring across populations of patients. In patients at risk for abnormal scar remodeling, it is possible that minimally invasive or remote-access procedures could provide a durable HRQoL benefit. Preliminary cost-effectiveness data for procedures like the transoral endoscopic thyroidectomy using a vestibular approach, bilateral-axillo breast approach, and minimally invasive video-assisted thyroidectomy show increased costs and operative time. Our findings suggest that the majority of patients would not derive enough long-term HRQoL benefit to justify these costs, and that these procedures may be best reserved for patients with excess scarring risk.[6,27] Further studies are needed to adequately assess the value of these techniques.

Aesthetics is undoubtedly important to thyroid cancer survivors and plays some role in HRQoL. However, our results suggest that the association between postoperative neck appearance and QoL may be transient in the ThyCa cohort and that neck appearance may not be a longitudinal concern for thyroid cancer survivors. Therefore, efforts to reduce scarring through minimally invasive and remote-access techniques may only affect QoL during this initial 2-year period. Future studies should focus on obtaining and comparing prospective primary data from patients with conventional cervical incisions and remote-access procedures, and longitudinally examining the patient-reported HRQoL differences that may be attributable to scar or neck appearance. It will also be valuable to examine the differences in costs, complications, and convalescence between conventional and remote-access procedures.

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