Benchmarking health-related quality of life in thyroid cancer versus other cancers and United States normative data

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ABSTRACT

Background: Thyroid cancer survivors may experience long-lasting physical, psychosocial, and financial challenges. No previous studies have compared health-related quality of life in thyroid cancer survivors to United States normative data and patient-reported outcomes from other types of cancers. We hypothesized that thyroid cancer survivors would report health-related quality of life poorer than the general United States population but similar to individuals with other cancers.

Methods: Thyroid cancer survivors were recruited online January 2017–June 2017. Individuals completed a two-part questionnaire to assess clinical characteristics and health-related quality of life, using the Patient-Reported Outcomes Measurement Information System 29-item profile. Patient-Reported Outcomes Measurement Information System T-scores obtained from the literature were compared with United States normative data and T-scores from patients with breast, prostate, uterine, cervical, colorectal, non-Hodgkin lymphoma, and lung cancers.

Results: A total of 1,743 US respondents completed the survey. Thyroid cancer survivors reported statistically significantly worse health-related quality of life across all seven Patient-Reported Outcomes Measurement Information System domains compared with United States normative data ($P < .05$). Surveyed individuals reported statistically significantly worse scores for anxiety, depression, fatigue, and sleep disturbance than respondents from non-Hodgkin lymphoma, breast, colorectal, uterine, and prostate cancer cohorts ($P < .01$) but less pain and greater physical functioning than most other groups in this comparison ($P < .01$).

Conclusion: The importance of health-related quality of life among thyroid cancer survivors should not be obscured by the relatively high survival rate of thyroid cancer compared with other cancers. Our results demonstrate that thyroid cancer survivors may be encumbered with greater psychologic and social burdens than survivors of several cancers that have a worse prognosis.

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Introduction

The incidence of thyroid cancer has nearly tripled in the last four decades, from 4.56 to 14.42 per 100,000 individuals.[1] The national burden of thyroid cancer in the United States, both in terms of the number of affected individuals and the absolute economic cost, is projected to continue to rise in the future.[2–4] Although thyroid cancer is associated with a high survival rate, individuals diagnosed with thyroid cancer experience physical, mental, and financial challenges as a consequence of diagnosis and treatment.[5–7]

This physical and emotional burden is often experienced throughout many decades attributable to the excellent survival.[8–10] A better understanding of health-related quality of life (HRQOL) from patients' perspectives is needed to correctly characterize the degree of physical and psychologic distress from thyroid cancer.

Few studies that describe HRQOL in thyroid cancer survivors have compared patient-reported outcomes (PROs) with US normative data or PROs from other types of cancers.[11] Earlier studies have indicated the need for a more concise yet valid questionnaire to ascertain HRQOL in the thyroid cancer survivor population.[5,8,12] We assessed quality of life in thyroid cancer survivors using the Patient-Reported Outcomes Measurement Information System (PROMIS) 29-item profile (funded by the US National Institutes of Health), an instrument that enabled us to

compare PROs against US normative data and other disease cohorts.[13,14] We hypothesized that the surveyed thyroid cancer survivors would report HRQOL poorer than that of the US general population but similar to that of individuals with other cancers.

Methods

We designed a survey to assess demographics, diagnosis history, clinical characteristics, treatment history, adverse effects of treatment, and financial characteristics among thyroid cancer survivors in collaboration with the Thyroid Cancer Survivors' Association, Inc (ThyCa, Olney, MD). This survey was based on a quality-of-life study conducted in multiple endocrine neoplasia patients and is described in detail elsewhere.[15] The survey was piloted by 10 individuals with thyroid cancer plus four clinicians, and survey content was adjusted based on their feedback. The PROMIS 29-item profile measure was used to assess HRQOL. PROMIS-29 measures dimensions of mental, physical, and social health across seven domains (depression, anxiety, pain interference, physical function, fatigue, satisfaction with social role participation [ie, social function], and sleep disturbance). PROMIS measures have been used in a wide range of clinical settings and have been demonstrated to be reliable and valid.[16–18] PROMIS-29 has been demonstrated to be valid in several chronic conditions.[19,20] The PROMIS metric is the T-score, where a score of 50 represents the mean response for the general US population (standard deviation = 10).[21] Worse HRQOL is indicated by higher scores in the domains of anxiety, depression, fatigue, pain interference, and sleep disturbance, and, conversely, lower scores in the physical functioning and social function domains. PROMIS measures are based on responses from the US general population, and it is possible to make statistical comparisons between responses from thyroid cancer patients and expected responses from the general US population for each domain. Furthermore, PROMIS was developed to measure PROs and function and aspects of HRQOL across a variety of chronic diseases and conditions and is not disease specific in its approach. The disease-agnostic nature of PROMIS allows the comparison of PROs across a variety of chronic medical conditions within the US population.

Adults with a history of thyroid cancer were recruited online through ThyCa for a six-month study period (January 2017–June 2017). The ThyCa organization has approximately 70,000 members in various stages of thyroid cancer treatment. A survey uniform resource locator was distributed online via the ThyCa website, e-mail newsletter, and social media pages (Facebook and Twitter). The survey was entirely online; no paper surveys were distributed. Study eligibility criteria included the following: a diagnosis of thyroid cancer, residency in the United States, and age 18–89 years at the time of survey participation. Participants who reported that they had not been diagnosed with thyroid cancer by a physician were excluded from this study. The cohort of respondents to this survey has been designated the ThyCa Cohort.

Study participants who completed an electronic consent took a two-part questionnaire online through REDCap (Nashville, TN), a secure, Web-based platform for collecting and managing survey data for research purposes.[22] Participants self-reported their clinical characteristics, including stage of cancer, if known. Participants were excluded from our analysis if they did not complete both parts of the two-part questionnaire. Responses were recorded anonymously by assigning participants a unique subject identifier code in the REDCap database. The Northwestern University Institutional Review Board approved this study.

T-scores corresponding to each PROMIS-29 domain were generated using the HealthMeasures Scoring Service (www.healthmeasures.net) for all respondents. PROMIS T-scores were compared with US normative data using a one-sample T-test. PROMIS T-scores from short forms completed by patients with

Table 1
Thyroid cancer sample demographics and clinical characteristics.

Value	US adults with thyroid cancer (n = 1,743)
Mean age y (± SD)	51 ± 13
Sex	
Female	1,541 (88%)
Race	
Caucasian	1,654 (95%)
Clinical history	
Mean age y (± SD) at thyroid cancer diagnosis	44 ± 13
Type of thyroid cancer	
Papillary	1,313 (85%)
Follicular	97 (6.3%)
Medullary	74 (4.8%)
Hürthle cell	42 (2.7%)
NIFTP	12 (0.8%)
Anaplastic	7 (0.5%)
Stage	
Stage I	522 (30%)
Stage II	298 (17%)
Stage III	243 (14%)
Stage IV	199 (11%)
Unknown or not staged	481 (28%)
Treatment history	
Surgery	1,710 (98%)
Radioactive iodine	1,366 (78%)
Chemotherapy	42 (2.4%)
External beam radiation	66 (3.8%)
Alternative	55 (3.2%)

SD, standard deviation.

breast (n = 1,588), prostate (n = 1,140), uterine (n = 388), cervical (n = 141), colorectal (n = 890), non-Hodgkin lymphoma ([NHL] n = 443), and lung (n = 694) cancers were obtained from the literature.[23] These patients were between the ages of 21–89 years and recruited through the National Cancer Institute's Surveillance, Epidemiology, and End Results Program at 6–13 months after the diagnosis of their cancer.[23–25] These cancer cohorts represent a diverse group of patients with various stages of cancer and at varying cancer treatment stages (active, cured, or in remission). These individuals took a self-administered paper PROMIS survey received via mailing. These data were compared with the T-scores of our thyroid cancer cohort using the Wilcoxon signed-rank test. Based on earlier PROMIS validation studies in cancer, we considered a difference of three points or greater to indicate a clinically meaningful difference.[26] The Bonferroni-Holm method was used to correct for multiple comparisons. Data analysis was conducted in SAS, Version 9.4 (SAS Institute, Cary, NC).

Results

During the six-month study period, January 2017–June 2017, the thyroid cancer quality of life survey uniform resource locator was accessed 3,174 times. A total of 1,978 individuals consented to take the survey, and 1,923 individuals completed both components of the survey (clinical conditions and factors survey and the PROMIS-29 instrument). Of those complete surveys, 1,743 (55% of those who accessed the survey, 91% of completed surveys) were from the United States and, therefore, only these respondents were included in the final analysis.

The sample characteristics of the final cohort of 1,743 US adult respondents are reported in the Table 1. The majority of participants were female (88%) and white (95%). The mean participant age was 51 years, with a mean age at thyroid cancer diagnosis of 44 years. The largest subgroup of cancer stage in our sample was stage I (30%), with nearly as many reporting unknown stage or not staged (28%). Our sample represented a range of pathologic