

UCSF

UC San Francisco Previously Published Works

Title

Patient Perspectives on the Extent of Surgery and Radioactive Iodine Treatment for Low-Risk Differentiated Thyroid Cancer

Permalink

<https://escholarship.org/uc/item/36p7q9s6>

Journal

Endocrine Practice, 27(5)

ISSN

1530-891X

Authors

Lubitz, Carrie C
Kiernan, Colleen M
Toumi, Asmae
[et al.](#)

Publication Date

2021-05-01

DOI

10.1016/j.eprac.2021.01.005

Peer reviewed



Published in final edited form as:

Endocr Pract. 2021 May ; 27(5): 383–389. doi:10.1016/j.eprac.2021.01.005.

Patient Perspectives on Extent of Surgery and Radioactive Iodine Treatment for Low-Risk Differentiated Thyroid Cancer

Carrie C. Lubitz^{1,2}, Colleen M. Kiernan³, Asmae Toumi¹, Tiannan Zhan¹, Mara Y. Roth⁴, Julie A. Sosa⁵, R. Michael Tuttle⁶, Elizabeth G. Grubbs⁷

¹Massachusetts General Hospital Institute for Technology Assessment, Boston, MA;

²Department of Surgery, Massachusetts General Hospital, Boston, MA;

³Division of Surgical Oncology and Endocrine Surgery, Vanderbilt University, Nashville, TN;

⁴Department of Medicine, Division of Metabolism, Endocrinology, and Nutrition, University of Washington, Seattle Cancer Care Alliance, Seattle, WA;

⁵Department of Surgery, University of California San Francisco (UCSF), San Francisco, CA;

⁶Endocrinology Service, Memorial Sloan Kettering Cancer Center, New York, NY;

⁷Department of Surgical Oncology, University of Texas MD Anderson Cancer Center, Houston, TX

Abstract

Objectives: The 2015 updated American Thyroid Association (ATA) guidelines recommended the option of the following: 1) active surveillance (AS) of some small DTC, 2) performance of less extensive surgery for low-risk DTC, and 3) more selective administration of radioactive iodine (RAI). We sought patient perspectives regarding these changes.

Methods: A on-line 34-item survey was distributed to thyroid cancer patient advocacy organizations and members of the ATA to distribute to patients. Data were collected on demographic and treatment information, opinions about the guideline changes, and patient experience with DTC. Patients were asked “what-if” scenarios on core topics, including AS, extent of surgery, and indications for RAI.

Results: Survey responses were analyzed from 1,546 patients with previously treated DTC: 96% had a total thyroidectomy, and 76% underwent treatment with RAI. Response rate is unknown given the method of distribution. If no change in overall cancer outcome, 39% of respondents would have considered a lobectomy over total thyroidectomy; 35% would have opted

@mgh.harvard.edu .

Author Disclosure Statement

JAS is a member of the Data Monitoring Committee of the Medullary Thyroid Cancer Consortium Registry supported by GlaxoSmithKline, Novo Nordisk, Astra Zeneca, and Eli Lilly.

MT contribution to this work was supported by the Memorial Sloan Kettering Cancer Center Core Grant, P30 CA 008748 (Craig Thompson, PI) and the NCI SPORE in Thyroid Cancer, 5P50 CA172012-04 (James Fagin, PI)

Publisher's Disclaimer: This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

for AS; and 41% would have chosen to forego RAI. 64% of respondents wanted more time with their clinicians when making decisions about extent of operation. 58% of patients experienced significant side effects with RAI treatment, and 30% felt that the risks of treatment were not well explained. 80% felt that AS would not be overly burdensome, and preservation of quality of life was the main reason cited for choosing AS.

Conclusions: Patient perspective regarding choice in management of low-risk DTC varies widely and a large proportion of DTC patients would change aspects of their care if oncologic outcomes were equivalent.

Keywords

Thyroid Cancer – Clinical; Clinical Research; Surgery-Adult Thyroid; General

Introduction

With the increasing incidence of thyroid cancer, young age at diagnosis and relatively low disease-specific mortality, there is an escalating worldwide population of thyroid cancer survivors. (1) Much of this rising incidence is the result of increased detection of low-risk papillary thyroid carcinomas (PTC), with 39% of diagnosed tumors measuring <1 cm (papillary thyroid microcarcinoma, PTmC). (2) Many patients with low-risk differentiated thyroid cancer (DTC) are treated with total thyroidectomy and radioactive iodine (RAI) in the U.S without evidence of oncologic benefit. (3–5)

Concern of over-treatment of patients with low-risk DTC has prompted studies surrounding the decision to operate, extent of operation, and use of adjuvant therapy in this population. The concept of active surveillance is attributed to the results of Japanese studies of long-term follow-up demonstrating that low-risk patients with biopsy-proven PTmC can safely forego surgery for periods of 10 years without attendant morbidity or increase in disease-specific mortality. (6–8) Large-scale national database studies have shown similar oncologic outcomes between patients undergoing lobectomy versus total thyroidectomy for solitary tumors between 1 and 4 cm in size without nodal metastasis, suggesting a role for less aggressive surgery. (3, 9) Prospective data from the National Thyroid Cancer Treatment Cooperative Study Group demonstrate that treatment with RAI is not associated with improved outcomes in low-risk DTC patients, suggesting that it should be avoided in this population. (10–12) Together, these findings indicate that less treatment in low-risk DTC is often appropriate and safe.

In 2015, the American Thyroid Association (ATA) published an updated version of the Management Guidelines for Adult Patients with Thyroid Nodules and Differentiated Thyroid Cancer, this time providing evidence in support of less aggressive treatment options. New recommendations in 2015 included consideration of active surveillance for PTmCs without high-risk features and thyroid lobectomy alone for low-risk DTC (tumor size 1–4 cm, without extrathyroidal extension or metastatic disease), as well as reduced utilization of adjuvant RAI. (13) For each of these recommendations, more than one appropriate treatment option often exists for an individual patient, creating clinical equipoise and providing a decision making opportunity for the clinician and patient. The objective of the current

analysis was to measure preferences of patients with thyroid cancer and attitudes and characterize their personal experiences throughout the clinical decision-making continuum. We hypothesize that these initial findings will identify patient preferences important to consider in treatment decision making and recognize novel patient-facing themes that will generate further prospective study.

Methods

Study participants

Individuals with a diagnosis of DTC were invited to participate in an on-line English language survey to determine their perceptions regarding key recommendations in the 2015 ATA guidelines and to describe their own treatment experience. Participants read the advertisement through the ATA website or its patient alliance group websites and completed the survey administered through Survey Monkey.

Study development and distribution

The Thyroid Cancer Survey was created by the program committee members of the “The Spectrum of Thyroid Cancer: From Surveillance to Systemic Therapy” satellite symposium organized by the ATA from March 17–20, 2018 in Chicago, Illinois. The program committee members considered it important to capture the patient perspective regarding thyroid cancer as it pertained to the 2015 ATA guidelines and to share the results with symposium registrants. The survey was distributed electronically to thyroid cancer patient advocacy organizations (The Light of Life Foundation, ThyCa: Thyroid Cancer Survivors Association, Bite Me Cancer, Thyroid Cancer Canada and Thyroid Federation International) and ATA members with the purpose being that they should invite their patients with DTC to participate. The survey was reviewed and approved by the ATA Patient Affairs Committee, which is made up of clinicians and patients. The study received Institutional Review Board approval at the University of Texas MD Anderson Cancer Center.

A 34-item survey was designed to capture demographic information, patient perception of the management of their DTC, and their opinions about the 2015 changes in the ATA guideline. Briefly, demographic detail included six questions about patient age, gender, race, ethnicity, household income and zip code; all demographic questions except patient age and zip code were multiple choice. Basic information regarding the patient’s thyroid cancer diagnosis was gathered, including year in which the cancer was diagnosed; histologic subtype; initial treatment approach; and presence of disease recurrence. Four multiple choice questions were asked about active surveillance as an initial management strategy for PTmCs, with an additional fifth open-ended question. Seven multiple choice questions were asked around tailoring extent of surgery; the requested information focused on how surgical options were discussed with the patient and his or her interest in a less extensive surgical procedure if possible. Information about the use of RAI was gathered through seven multiple choice questions focused around the patient’s personal experience with RAI and his/her interest in pursuing this therapy if it were optional. Respondents were given the option of providing detail about any aspect of their RAI treatment that was not well explained to them.

From January 30, 2018 through April 30, 2018 the ATA distributed the survey to the ATA patient alliance members and posted a link to the survey on the ATA website. Given the online mode of distribution, no detail is available regarding response rate (since the denominator of people who accessed the survey is unknown). Data were collected by the ATA, tabulated by the ATA Director of Technology and Development and sent to the authors of this study.

Data analysis

All descriptive analyses were conducted using R version 3.5.1, Boston, MA. Frequency (percent) and median (interquartile range) were utilized to describe the data. Multiple logistic regression modeling using a generalized linear model was performed to determine variables that were independently associated with patient preferences for the hypothetical questions posed. The model was adjusted for patient gender, race, ethnicity, income status, presence of recurrent thyroid cancer, year of thyroid cancer diagnosis, and current age. For the open-ended question, the written answers were analyzed using thematic text analysis. (14) The responses initially were coded into as many thematic categories as necessary and then, through an iterative process intended to refine thematic groupings, final categories were determined.

Results

A total of 1937 survey responses were received between January 30 and April 30, 2018. Exclusions included the following: 66 responses because the respondent did not have thyroid cancer; 189 because the surveys were incomplete, and 136 for having a thyroid cancer diagnosis other than DTC. The total study sample was comprised of 1546 individuals (Figure 1; consort diagram). In this study cohort, the female to male ratio was 8.2:1, the median age was 48 years (IQR 40, 58), and the median year of diagnosis was 2013 (IQR 2009, 2016). The overwhelming majority (96%) of patients underwent a total thyroidectomy for their thyroid cancer, either initially or performed in a staged fashion with a lobectomy followed by a completion thyroidectomy, and 76% also received RAI (Table 1). Twenty-four percent of patients experienced recurrence of their thyroid cancer, and 71% described themselves as currently having no evidence of disease.

Extent of operation

In this section of the survey, respondents were asked about their personal surgical experience. When asked which surgical options were discussed with them prior to surgery, 1238 (80.1%) answered total thyroidectomy, 240 (15.5%) thyroid lobectomy with possible need for completion, 48 (3.1%) lobectomy only, 10 (0.3%) observation or no immediate surgery, and 10 (0.6%) did not answer the question. When asked whether the risks and benefits of the surgical options were explained thoroughly enough, 967 (62.5%) answered yes, 376 (24.3%) no, and 203 (13.2%) did not know or did not respond. When asked to name the risks of thyroid surgery that were discussed with them, 1108 (71.7%) remembered hearing about a potential change in voice, 831 (53.8%) described possible need for lifelong calcium supplementation, 757 (49.0%) described possible need for lifelong thyroid hormone

replacement, 723 (46.8%) described possible need for another surgery to remove residual tumor or lymph nodes, and 171 (11.1%) noted other risks.

Respondents were then provided with the statement “Recent studies have shown that some patients with low-risk thyroid cancer could have half of the thyroid removed instead of all of the thyroid removed with the same overall cancer outcomes. If this option had been available and appropriate for you, would you have been interested in choosing it?” 606 (39.2%) answered yes, 506 (32.7%) no, and 434 (28.1%) did not know or did not respond (Figure 2). This distribution of responses did not change when controlling for the respondents’ personal extent of the surgery; notably, the majority (96%) had undergone a total thyroidectomy. Utilizing a multiple logistic regression model that adjusted for patient gender, race, ethnicity, income status, presence of recurrent thyroid cancer, year of thyroid cancer diagnosis, and current age; only patient gender was associated with choice of extent of resection. Females were less likely to opt for less surgery given the hypothetical option of lobectomy (OR 0.57, 95% CI 0.36–0.87, $p=0.01$). Dichotomizing year of thyroid cancer diagnosis as before or after the publication of the 2015 ATA guidelines, did not change these findings. Patients were queried about what additional information could help inform their decision about extent of thyroidectomy (Figure 3).

Active surveillance

When asked the question “If an option had existed for you to observe your thyroid cancer instead of undergoing surgery, with the same outcome in terms of cancer survival, would you have considered observation?”, 536 (34.7%) responded yes, 697 (45.1%) no, 259 (16.8%) did not know, and 54 (3.5%) did not respond. (Figure 4A) Utilizing a multiple regression model that adjusted for patient gender, race, ethnicity, income status, presence of recurrent thyroid cancer, year of thyroid cancer diagnosis, and current age, only gender and current age of the respondent were found to be independently associated with choosing observation. Women were less likely than men to choose observation (OR 0.66, 95% CI 0.45–0.96, $p=0.03$). Younger respondents were slightly more likely to choose observation than older respondents (OR 0.99, 95% CI 0.98–1.00, $p=0.04$). Dichotomizing year of thyroid cancer diagnosis as before and after the publication of the 2015 ATA guidelines did not change these findings. Respondents also were asked about their perspectives regarding resource availability and burden of follow up associated with active surveillance; findings are provided in Figures 4B and 4C. 80% of respondents felt that long-term follow-up with active surveillance would not be overly burdensome. Two hundred ninety-one answers to the open-ended question asking about views on active observation dichotomized into pro-observation and pro-surgery responses (Table 2).

Radioactive iodine treatment

A total of 1167 (75.5%) patients underwent RAI treatment and make up the cohort for the remainder of the questions about personal experience in this section. Side effects of RAI therapy were significant for 621 (53.2%), while 285 (24.4%) felt they had not suffered side effects, 133 (11.4%) did not know, and 128 (11.0%) did not respond. The most bothersome side effects of treatment reported are displayed in Figure 5. When asked about the process of the treatment itself, the most burdensome aspects were potential radiation exposure to

others (325, 31.3%) and hypothyroid symptoms from withdrawal of thyroid medication prior to treatment (264, 25.4%). Most respondents 646 (55.4%) felt the risks of RAI therapy were clearly explained, whereas 351 (30.0%) respondents felt they were not explained, 42 (3.6%) did not know, and 128 (11.0%) did not respond.

When asked hypothetically if a physician had explained that RAI therapy was optional for their stage of disease and not mandatory, would they choose to pursue such therapy, 638 (41.3%) answered no, 303 (19.6%) yes, 431 (27.9%) did not know, and 174 (11.3%) did not respond. (Figure 6A) Utilizing a multiple regression model that included gender, race, ethnicity, income status, presence of recurrence, year of thyroid cancer diagnosis, current age and whether they received RAI; only gender and treatment with RAI were associated with pursuing RAI. Women were less likely than men to choose to have RAI if given the hypothetical option (OR .52, 95%CI 0.32–0.85) and those who previously received RAI were more likely to choose RAI by a factor of 3 (OR 3.53, 95% CI 2.37–5.40). For patients who underwent RAI treatment and were asked if they would pursue therapy if optional, 416 (35.6%) answered no, 271 (23.2%) yes, 352 (30.2%) did not know, and 128 (11.0%) did not respond. (Figure 6B)

Discussion

The 2015 ATA guidelines suggest patient perspective be considered in determining treatment course for low-risk thyroid cancer, including extent of initial operation, consideration of active surveillance and use of RAI when clinically appropriate. This study provides an initial characterization of the preferences of patients in regard to the guideline recommendations. The hypothetical questions specifically asked respondents to answer within the context of having low-risk disease, allowing the valuable experiences of all differentiated thyroid cancer patients, and their resulting preferences, to be considered. While the intent of the original questionnaire was not to provide the definitive summary of patient perspective on the ATA guideline revisions or personal experience, reporting the findings of this unique and timely survey adds knowledge to a growing field of inquiry and may inform the preparation of the next iteration of guidelines.

In our study cohort, most respondents reported that they were not given a choice with regard to extent of their surgery, with only 19% offered a thyroid lobectomy as an initial treatment option. This finding is most likely associated with the standard treatment recommendations during the time in which they underwent their thyroid cancer care. However, if given the option of lobectomy or total thyroidectomy in the setting of equivalent long-term outcome, 39% of respondents would have chosen a lobectomy, and 28% were uncertain. It has been projected that 60–85% of ATA-classified low-risk DTC could be eligible for lobectomy; therefore these preferences are worthy of consideration. (15, 16) Being male was the only patient factor independently associated with selecting lobectomy over total thyroidectomy. Factors identified by respondents that may help to better inform decision making with regard to extent of surgery were increased time with their doctor, access to educational materials, and diagrams/pictures and/or discussions with other patients. In a qualitative evaluation of preoperative needs of thyroid cancer patients, Pitt *et al.* similarly reported that patients desired a strong patient-surgeon relationship and wanted individualized treatment-

related information. (17) Such feedback suggests that use of decision aids could facilitate decision making efficiency during the consultation, making the time spent with the clinician more meaningful and utilizing educational materials to assist in discussion. (18) Universal accessibility of reliable patient information and decision aids through a web-based approach would allow providers, including those for whom comprehensive, multidisciplinary clinics are not available, to provide this desired level of patient care. The caveat of this approach is the requirement of high quality thyroid cancer websites (19) and determination of best practices for internet-based development and dissemination of decision aids. (20)

Over a third of respondents would consider the option of active surveillance if it were deemed to be oncologically appropriate. Previous studies on patients with well-differentiated thyroid cancer with a low risk of recurrence of their disease have varying perceptions of this risk with 25% overestimating and 12.5% underestimating.(21) In the original prospective trial of observation for PTmC, Ito *et al.* reported that 24% of patients in their cohort elected to undergo observation between 1993 and 2004, while in their more recent study following patients from 2005 to 2013, 55% chose observation. (7, 22) Our study is unique in that the preferences were elicited retrospectively from patients who had already undergone treatment, the majority of whom had undergone total thyroidectomy. Respondents who favored observation cited preservation of quality of life as a major driver of their hypothetical choice, a theme similar to that reported by D'Agostino *et al.* when interviewing early stage thyroid cancer patients who selected observation prospectively as their actual treatment choice. (23) Respondents who hypothetically chose surgery wanted the 'reassurance' that surgery provided them and expressed a desire for 'control'. Papaleontiou *et al.* reported that worry about death, recurrence, and quality of life is a major issue in half of patients in a population of low-risk, disease-free patients. (24) A recent study by Davies *et al.* based on a survey of 249 thyroid cancer patients who chose surveillance found that 'cancer concern' was common among patients undergoing active surveillance, but it was comparable to the worry experienced by patients who were treated with surgery. The level of concern decreased over time under surveillance, and the majority of patients in the study (83%) felt it was the best decision for their care. (25) While many of our respondents expressed comfort with the principle of long-term active surveillance, they did not feel they were necessarily in an environment that was conducive to that approach.

In a qualitative study by Sawka *et al.* regarding the impact of RAI treatment on thyroid cancer patients, patients expressed desire for more plain-language information on the short and long-term effects of therapy and approximately half described having one or more side effects.(26) Similarly in the current study, 50% of respondents reported side effects and a thorough discussion of the side effects of RAI often was perceived by patients to be missing during consultation. Lack of information in regards to side effects was previously reported in over half of patients surveyed unmet information needs in thyroid cancer survivors.(27) Wallner *et al.* likewise found that that over half of patients who received RAI did not feel that had a choice.(28) One of the most commonly reported side effects was a concern for development of secondary cancers, suggesting discussion must include such long-term outcomes. A significant proportion of patients in our current study would avoid RAI therapy if the outcome was oncologically equivalent. This finding supports that a clinician should consider the patient perspective when the benefit of RAI is less clear and include a detailed

discussion of side effects to allow for a more informed decision to be made by the patient. Patient counseling as related to the necessity of RAI and long-term outcomes is often challenging.

Being male was independently associated with selecting the lesser surgical treatment, choosing lobectomy over total thyroidectomy and surveillance over surgery. Being female was independently associated with being less likely to choose RAI. Understanding the reasoning behind these associations will require further study. Goldfarb *et al.* in a survey evaluating unmet information and support needs of thyroid cancer patients, found that being female was a risk factor for not having emotional and psychological needs met in regard to thyroid cancer treatment.(29) Perhaps this perceived lack of support leads women to resort to more traditional surgical choices, as seen in our study.

Limitations of this study include the biases associated with its methodologic approach. Survey respondents were recruited primarily through the ATA patient network. Therefore, the study cohort consisted largely of individuals who are cognizant of the ATA or its affiliated entities. This mechanism of survey dissemination may have created a bias, such that the study cohort included individuals supportive of the ATA's mission and/or more accepting of its guidelines than the general population. While we assume that patients with access to online access and resources may be at a higher reading level/education level, a lack of health literacy may have played a role in questions either not being answered or misinterpreted. Given the method by which patients were recruited, we cannot characterize or quantify (i.e. response rate) those that saw the advertisement and chose not to participate. While we are aware that there may be recall bias (errors in recollection), especially in patients treated several decades ago, we feel that the information gained through this large group of DTC survivors is valuable for informing future research and clinical efforts. Moreover, practice trends and guideline recommendations have evolved over the time period; as reflected by the relatively high proportion of patients having total thyroidectomy and receiving RAI.

Respondents to this survey have a similar demographic profile in regard to age, race and gender to patients diagnosed with DTC described in the Surveillance, Epidemiology, and End Results-9 (SEER-9) cancer registry program (1973–2013). (30) However, a lower proportion of respondents underwent thyroid lobectomy (3%) than the 11% rate culled from the National Cancer Database (NCDB) (3) and the 26% rate reported in SEER.(9) Additionally, a higher proportion of patients were treated with RAI than the 56% reported in SEER for patients with PTC treated from 2003–2013.(31) The recurrence rate of the study cohort was similar to the 24% recurrence rate reported by Mazzaferri in 2001 based on a cohort of patients followed over 40 years (32) and 20% cited by Liu in 2015 from 15-year follow-up (33); however, it is higher than the 6–9% recurrence reported more recently. (16, 34). Thus, comparisons of the study cohort to other groups described in the literature suggest that our respondents provided a similar demographic representation but may have had more aggressive disease and thereby received more treatment, potentially limiting generalizability.

Patient perspective regarding choice in management of low-risk DTC varies widely. However, a consistent, shared theme that emerged from this study is the desire of patients

to be well-informed and involved in the decision-making process. Inclusion of the patient stakeholder in care decisions is an integral part of the value framework described in modern cancer treatment. (35) Such inclusion is important in the management of low-risk DTC, where there is often evidential equipoise in treatment options, making patient preference a priority. Thus, comprehensive patient education and inclusion of the patient's perspective should be at the epicenter of management decision making for low-risk DTC.

Acknowledgements

The authors would like to acknowledge the work of Kelly Hoff, Adonia Coates, and Bobbi Smith of the American Thyroid Association (ATA). The survey was developed as part of an American Thyroid Association Satellite Symposium and the ATA provided resources for the survey, supporting its development and deployment.

Author Conflict of Interest Disclosure Statement

Carrie C. Lubitz: no conflicts of interest to disclose. CCL time and contribution to this work was supported by the NIH/NCI 1R37CA231957-01 (PI)

Colleen M. Kiernan: no conflicts of interest to disclose.

Asmae Toumi: no conflicts of interest to disclose.

Tiannan Zhan: no conflicts of interest to disclose.

Mara Y. Roth: no conflicts of interest to disclose.

Julie A. Sosa: No conflicts of interest. Disclosures: JAS is a member of the Data Monitoring Committee of the Medullary Thyroid Cancer Consortium Registry supported by GlaxoSmithKline, Novo Nordisk, Astra Zeneca, and Eli Lilly.

R. Michael Tuttle: No conflicts of interest. Disclosures: MT contribution to this work was supported by the Memorial Sloan Kettering Cancer Center Core Grant, P30 CA 008748 (Craig Thompson, PI) and the NCI SPORC in Thyroid Cancer, 5P50 CA172012-04 (James Fagin, PI) Elizabeth G. Grubbs: no conflicts of interest to disclose.

References

1. Society AC. Thyroid Cancer Statistics Center 2019 [Available from: https://cancerstatisticscenter.cancer.org/?_ga=2.212865491.655297014.1561406446-312879700.1546468650#!/cancer-site/Thyroid.
2. Davies L, Welch HG. Current thyroid cancer trends in the United States. *JAMA otolaryngology--head & neck surgery*. 2014;140(4):317–22. [PubMed: 24557566]
3. Adam MA, Pura J, Gu L, Dinan MA, Tyler DS, Reed SD, et al. Extent of surgery for papillary thyroid cancer is not associated with survival: an analysis of 61,775 patients. *Annals of surgery*. 2014;260(4):601–5; discussion 5–7. [PubMed: 25203876]
4. Wang TS, Goffredo P, Sosa JA, Roman SA. Papillary thyroid microcarcinoma: an over-treated malignancy? *World journal of surgery*. 2014;38(9):2297–303. [PubMed: 24791670]
5. Hu G, Zhu W, Yang W, Wang H, Shen L, Zhang H. The Effectiveness of Radioactive Iodine Remnant Ablation for Papillary Thyroid Microcarcinoma: A Systematic Review and Meta-analysis. *World journal of surgery*. 2016;40(1):100–9. [PubMed: 26578322]
6. Ito Y, Uruno T, Nakano K, Takamura Y, Miya A, Kobayashi K, et al. An observation trial without surgical treatment in patients with papillary microcarcinoma of the thyroid. *Thyroid : official journal of the American Thyroid Association*. 2003;13(4):381–7. [PubMed: 12804106]
7. Ito Y, Miyauchi A, Inoue H, Fukushima M, Kihara M, Higashiyama T, et al. An observational trial for papillary thyroid microcarcinoma in Japanese patients. *World journal of surgery*. 2010;34(1):28–35. [PubMed: 20020290]
8. Miyauchi A. Clinical Trials of Active Surveillance of Papillary Microcarcinoma of the Thyroid. *World journal of surgery*. 2016;40(3):516–22. [PubMed: 26744340]

9. Mendelsohn AH, Elashoff DA, Abemayor E, St John MA. Surgery for papillary thyroid carcinoma: is lobectomy enough? *Archives of otolaryngology--head & neck surgery*. 2010;136(11):1055–61. [PubMed: 21079156]
10. Jonklaas J, Sarlis NJ, Litofsky D, Ain KB, Bigos ST, Brierley JD, et al. Outcomes of patients with differentiated thyroid carcinoma following initial therapy. *Thyroid : official journal of the American Thyroid Association*. 2006;16(12):1229–42. [PubMed: 17199433]
11. Jonklaas J, Cooper DS, Ain KB, Bigos T, Brierley JD, Haugen BR, et al. Radioiodine therapy in patients with stage I differentiated thyroid cancer. *Thyroid : official journal of the American Thyroid Association*. 2010;20(12):1423–4. [PubMed: 21054207]
12. Carhill AA, Litofsky DR, Ross DS, Jonklaas J, Cooper DS, Brierley JD, et al. Long-Term Outcomes Following Therapy in Differentiated Thyroid Carcinoma: NTCTCS Registry Analysis 1987–2012. *The Journal of clinical endocrinology and metabolism*. 2015;100(9):3270–9. [PubMed: 26171797]
13. Haugen BR, Alexander EK, Bible KC, Doherty GM, Mandel SJ, Nikiforov YE, et al. 2015 American Thyroid Association Management Guidelines for Adult Patients with Thyroid Nodules and Differentiated Thyroid Cancer: The American Thyroid Association Guidelines Task Force on Thyroid Nodules and Differentiated Thyroid Cancer. *Thyroid : official journal of the American Thyroid Association*. 2016;26(1):1–133. [PubMed: 26462967]
14. Green JaTN. *Qualitative Methods for Health Research*. 2nd ed. ed: Sage Publications, Ltd; 2009.
15. Yang F, Zhong Q, Huang Z, Lian M, Fang J. Survival in Papillary Thyroid Microcarcinoma: A Comparative Analysis Between the 7th and 8th Versions of the AJCC/UICC Staging System Based on the SEER Database. *Frontiers in endocrinology*. 2019;10:10. [PubMed: 30733707]
16. Suh S, Kim YH, Goh TS, Lee J, Jeong DC, Oh SO, et al. Outcome prediction with the revised American joint committee on cancer staging system and American thyroid association guidelines for thyroid cancer. *Endocrine*. 2017;58(3):495–502. [PubMed: 29030773]
17. Pitt SC, Wendt E, Saucke MC, Voils CI, Orne J, Macdonald CL, et al. A Qualitative Analysis of the Preoperative Needs of Patients With Papillary Thyroid Cancer. *J Surg Res*. 2019;244:324–31. [PubMed: 31306889]
18. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. *The Cochrane database of systematic reviews*. 2011(10):Cd001431.
19. Chang KL, Grubbs EG, Ingledew PA. An Analysis of the Quality of Thyroid Cancer Websites. *Endocr Pract*. 2019;25(10):1003–11. [PubMed: 31170373]
20. Hoffman AS, Volk RJ, Saarimaki A, Stirling C, Li LC, Harter M, et al. Delivering patient decision aids on the Internet: definitions, theories, current evidence, and emerging research areas. *BMC Med Inform Decis Mak*. 2013;13 Suppl 2:S13. [PubMed: 24625064]
21. Chen DW, Reyes-Gastelum D, Wallner LP, Papaleontiou M, Hamilton AS, Ward KC, et al. Disparities in risk perception of thyroid cancer recurrence and death. *Cancer*. 2020;126(7):1512–21. [PubMed: 31869452]
22. Oda H, Miyauchi A, Ito Y, Yoshioka K, Nakayama A, Sasai H, et al. Incidences of Unfavorable Events in the Management of Low-Risk Papillary Microcarcinoma of the Thyroid by Active Surveillance Versus Immediate Surgery. *Thyroid : official journal of the American Thyroid Association*. 2016;26(1):150–5. [PubMed: 26426735]
23. D'Agostino TA, Shuk E, Maloney EK, Zeuren R, Tuttle RM, Bylund CL. Treatment decision making in early-stage papillary thyroid cancer. *Psycho-oncology*. 2018;27(1):61–8. [PubMed: 28124394]
24. Papaleontiou M, Reyes-Gastelum D, Gay BL, Ward KC, Hamilton AS, Hawley ST, et al. Worry in Thyroid Cancer Survivors with a Favorable Prognosis. *Thyroid : official journal of the American Thyroid Association*. 2019;29(8):1080–8. [PubMed: 31232194]
25. Davies L, Roman BR, Fukushima M, Ito Y, Miyauchi A. Patient Experience of Thyroid Cancer Active Surveillance in Japan. *JAMA otolaryngology-- head & neck surgery*. 2019.
26. Sawka AM, Goldstein DP, Brierley JD, Tsang RW, Rotstein L, Ezzat S, et al. The impact of thyroid cancer and post-surgical radioactive iodine treatment on the lives of thyroid cancer survivors: a qualitative study. *PLoS One*. 2009;4(1):e4191. [PubMed: 19142227]

27. Husson O, Mols F, Oranje WA, Haak HR, Nieuwlaat WA, Netea-Maier RT, et al. Unmet information needs and impact of cancer in (long-term) thyroid cancer survivors: results of the PROFILES registry. *Psycho-oncology*. 2014;23(8):946–52. [PubMed: 24619907]
28. Wallner LP, Reyes-Gastelum D, Hamilton AS, Ward KC, Hawley ST, Haymart MR. Patient-Perceived Lack of Choice in Receipt of Radioactive Iodine for Treatment of Differentiated Thyroid Cancer. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2019;37(24):2152–61. [PubMed: 31283406]
29. Goldfarb M, Casillas J. Unmet information and support needs in newly diagnosed thyroid cancer: comparison of adolescents/young adults (AYA) and older patients. *J Cancer Surviv*. 2014;8(3):394–401. [PubMed: 24570216]
30. Lim H, Devesa SS, Sosa JA, Check D, Kitahara CM. Trends in Thyroid Cancer Incidence and Mortality in the United States, 1974–2013. *Jama*. 2017;317(13):1338–48. [PubMed: 28362912]
31. Tang J, Kong D, Cui Q, Wang K, Zhang D, Liao X, et al. The role of radioactive iodine therapy in papillary thyroid cancer: an observational study based on SEER. *OncoTargets and therapy*. 2018;11:3551–60. [PubMed: 29950860]
32. Mazzaferri EL, Kloos RT. Clinical review 128: Current approaches to primary therapy for papillary and follicular thyroid cancer. *The Journal of clinical endocrinology and metabolism*. 2001;86(4):1447–63. [PubMed: 11297567]
33. Liu FH, Kuo SF, Hsueh C, Chao TC, Lin JD. Postoperative recurrence of papillary thyroid carcinoma with lymph node metastasis. *Journal of surgical oncology*. 2015;112(2):149–54. [PubMed: 26175314]
34. Chereau N, Oyekunle TO, Zambeli-Ljepovic A, Kazaure HS, Roman SA, Menegaux F, et al. Predicting recurrence of papillary thyroid cancer using the eighth edition of the AJCC/UICC staging system. *The British journal of surgery*. 2019;106(7):889–97. [PubMed: 31012500]
35. Schnipper LE, Davidson NE, Wollins DS, Blayney DW, Dicker AP, Ganz PA, et al. Updating the American Society of Clinical Oncology Value Framework: Revisions and Reflections in Response to Comments Received. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2016;34(24):2925–34. [PubMed: 27247218]

Highlights

- Patient perspective regarding choice in management of low-risk thyroid cancer varies widely
- Many survivors would change aspects of their care if oncologic outcomes were equivalent.
- 39% of thyroid cancer survivors would have considered a lobectomy over total thyroidectomy and 35% would have opted for active surveillance
- A majority of respondents wanted more time with their clinicians when making treatment decisions about extent of operation, and a third felt that the risks of treatment were not well explained.

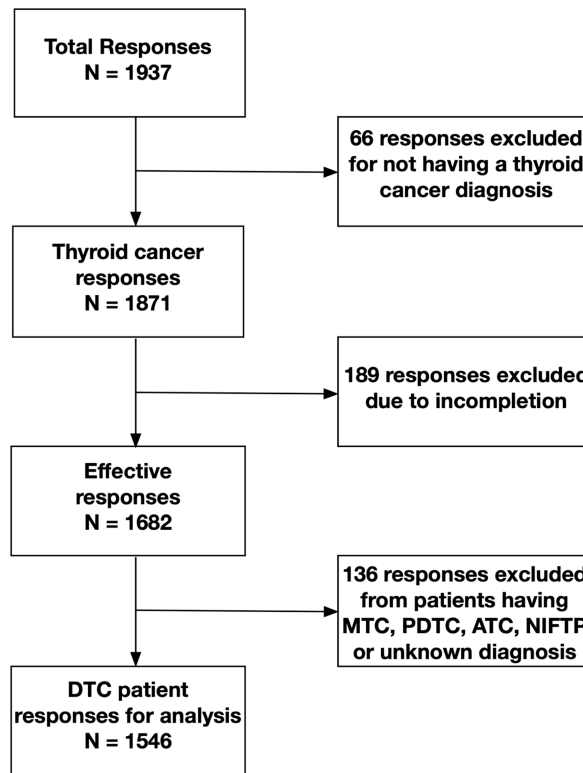


Figure 1.

Flow diagram of survey respondent eligibility.

MTC, medullary thyroid carcinoma; PDTC, poorly differentiated thyroid carcinoma; ATC, anaplastic thyroid carcinoma; NIFTP, Noninvasive Follicular Thyroid Neoplasm with Papillary-like Features; DTC, well-differentiated thyroid carcinoma

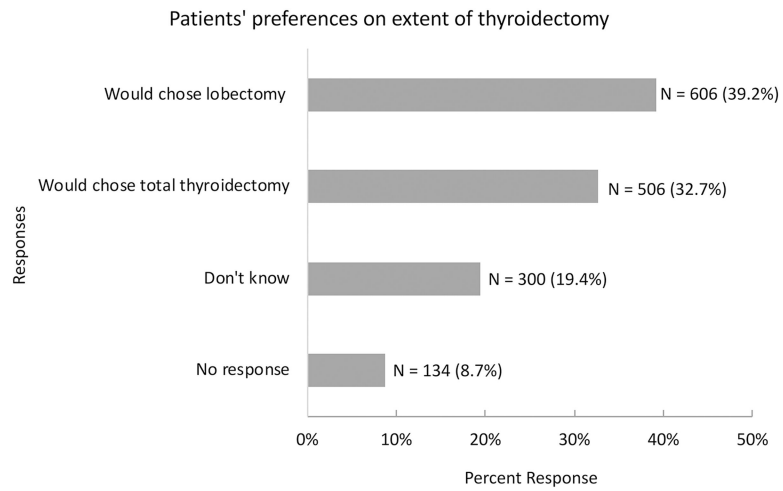


Figure 2.

Response to the question “Recent studies have shown that some patients with low-risk thyroid cancer could have half of the thyroid removed instead of all of the thyroid removed with the same overall cancer outcomes. If this option had been available and appropriate for you, would you have been interested in choosing it?”

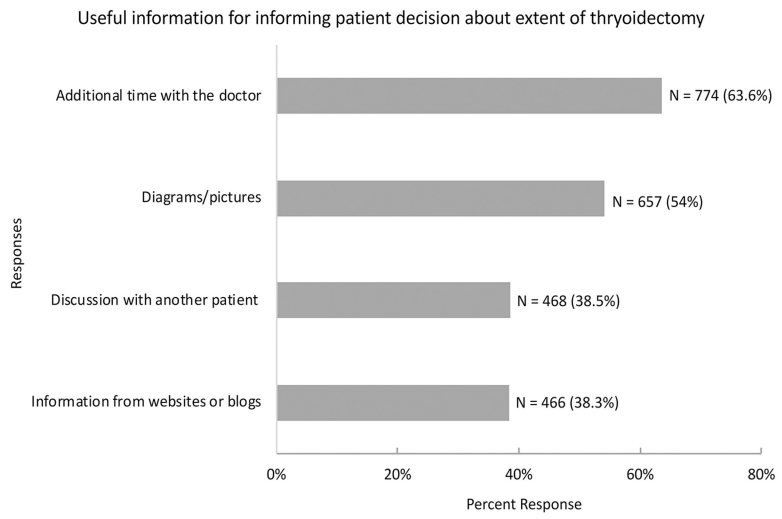


Figure 3. Response to the question “What additional information do you think could help inform your decision about extent of surgical resection? (check all that apply)” among respondents.

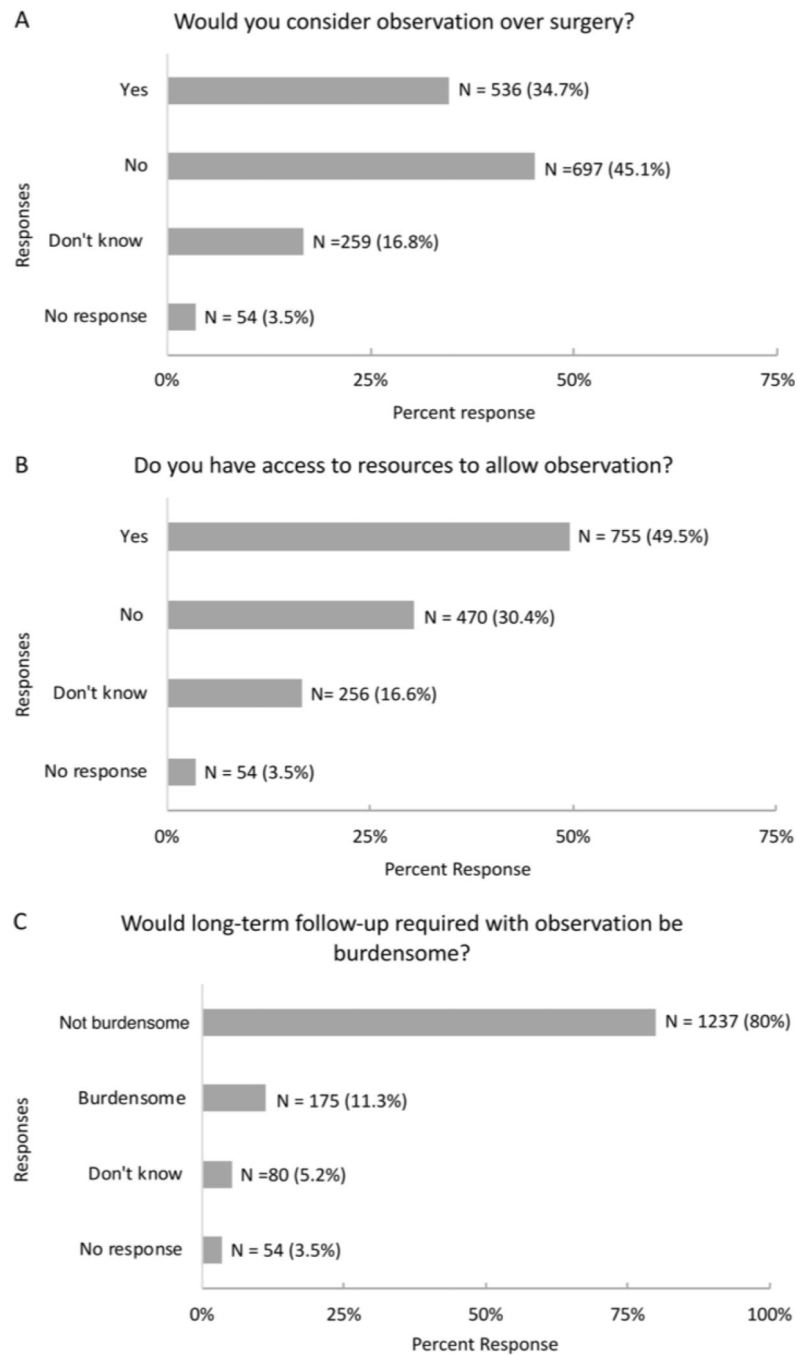


Figure 4.

A) Response to the question “If an option had existed for you to observe your thyroid cancer instead of undergoing surgery, with the same outcome in terms of cancer survival, would you have considered observation?”

4B) Response to the question “Observation should only be performed under the guidance of an experienced thyroid cancer management team that uses high quality neck ultrasound. Given your care experience, do you feel that you would have those resources readily available to allow observation as an option?”

4C) Response to the question “Observation of thyroid cancer requires regular follow-up every 6 months, then annually after 2 years. Would long-term follow-up be considered too burdensome?”

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

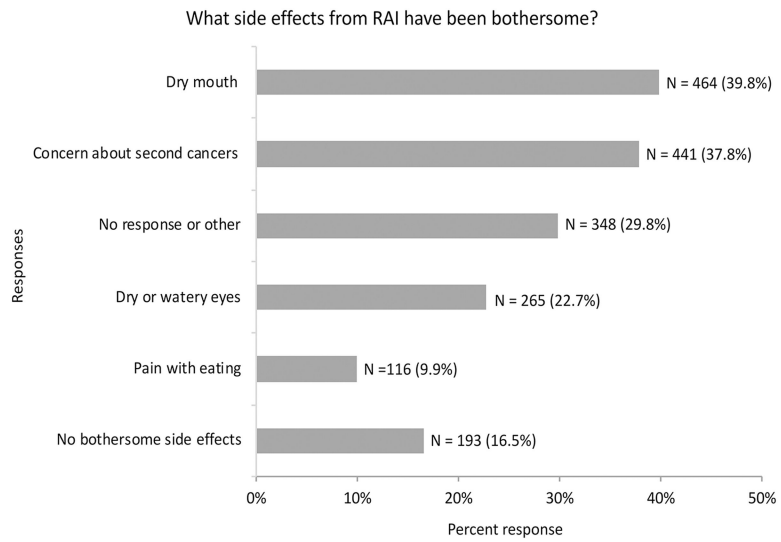


Figure 5. Response to “Do you believe you have suffered side effects from radioactive iodine therapy? If so, which side effects have been bothersome for you? (check all that apply)”

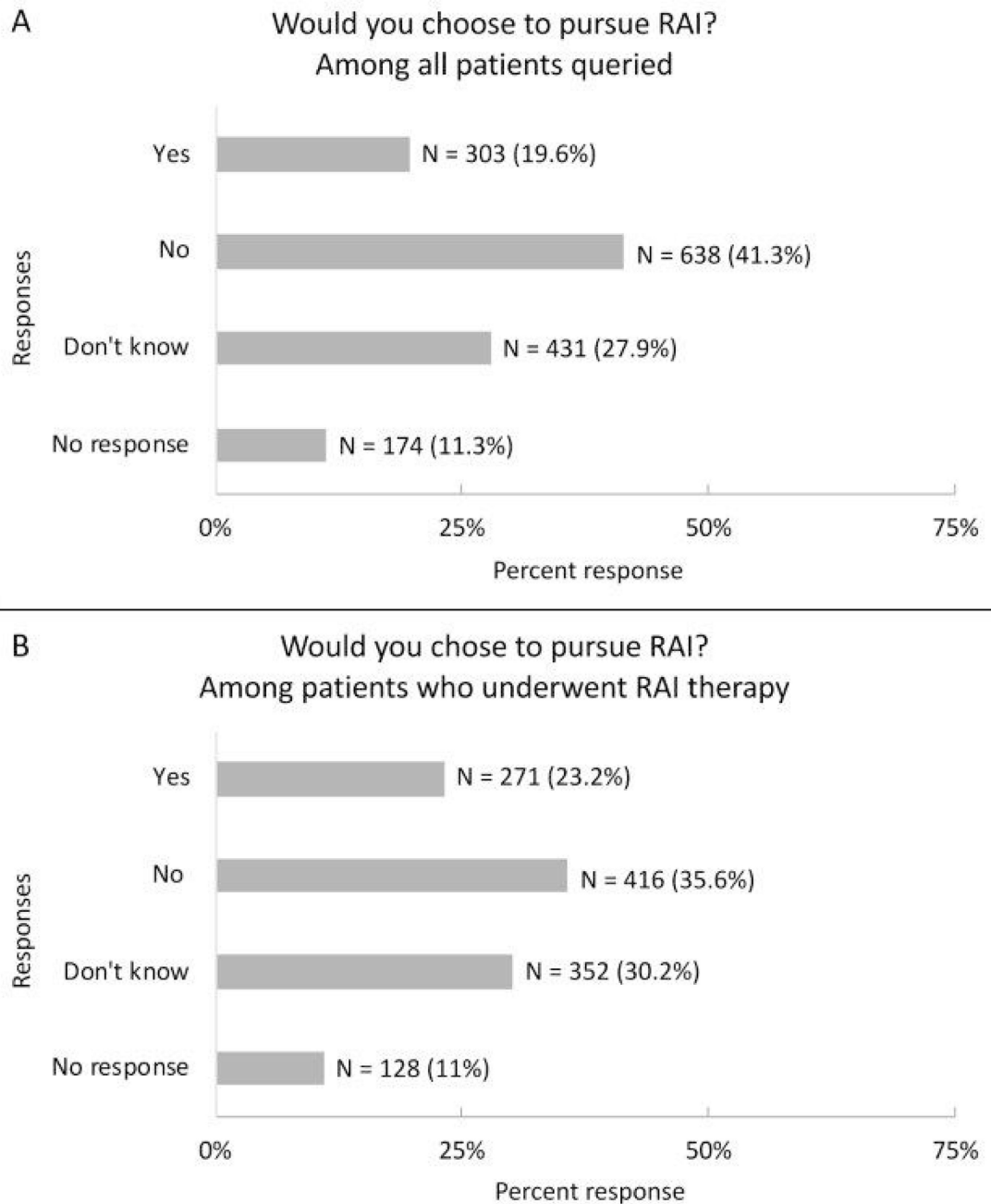


Figure 6.

(A, B). Responses to “If your physician explained that radioactive iodine therapy was optional for your stage of disease and not definitely recommended, would you choose to pursue radioactive iodine therapy?” (A) All patients, (B) Only patients who underwent RAI therapy

Table 1.

Demographic data and treatment history of patients with differentiated thyroid cancer

Total Number of DTC Patients	N=1546	
Sex (%)^a		
	Female	1184 (89.2)
	Male	144 (10.8)
Race Category (%)^b		
	Caucasian	1148 (86.6)
	Asian	45 (3.4)
	African-American	23 (1.7)
	Native American	12 (0.9)
	Pacific Islander	5 (0.4)
	Other	92 (6.9)
Current Age (median [IQR])^c		48 [40, 58]
Annual Income Category (%)^d		
	<\$50,000	259 (19.7)
	\$50,000-\$100,000	415 (31.5)
	\$100,000-\$250,000	332 (25.2)
	> \$250,000	58 (4.4)
	Prefer to not answer	254 (19.3)
Year Diagnosed with DTC (median [IQR])		2013 [2009, 2016]
Thyroid Surgery Category (%)^f		
	Lobectomy only	48 (3.1)
	Lobectomy followed by completion	240 (15.6)
	Total/Near Total Thyroidectomy	1238 (80.6)
	Active surveillance or no surgery yet	10 (0.7)
RAI (%)		
	No RAI	369 (23.9)
	RAI given	1167 (75.5)
	Don't know	10 (0.6)
RAI Prep (%)^g		
	Withdrawal	648 (47.7)
	Recombinant human TSH	560 (41.2)
	Don't know	151 (11.1)
Recurrence (%)		
	No Recurrence	1031 (66.7)
	Recurrence	367 (23.7)
	Don't know	148 (9.6)
Current Cancer Status (%)		
	No remaining cancer	1105 (71.5)

Total Number of DTC Patients	N=1546
Stable, some cancer remaining but not progressing	358 (23.2)
Cancer has progressed	83 (5.4)

^a218 did not respond

^b221 did not respond

^c220 did not respond

^d228 did not respond

^e42 did not respond

^f10 did not respond

^g187 selected "no RAI"

DTC, differentiated thyroid cancer; SD, standard deviation; IQR, interquartile range; RAI, radioactive iodine.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2.

Identified themes for hypothetically choosing active observation and surgery and representative quotes

Observation preference	
Preservation of quality of life (84%)	<p>"I only wish I could go back. Total thyroidectomy completely altered my life, my ability to think clearly, my appearance, and on and on. I will take quality over quantity. Patients need to be fully educated about options, what to expect, consequences for each decision, etc. I am not the "me" I used to be."</p> <p>"Weight management no matter what diet/exercise regimen or medication has proven very difficult. Lab results being normal every 3 months has not translated in improving the quality of life."</p>
Wanting more time for discussion (8%)	"If a physician presents active observation to the appropriate patient from the get-go, it potentially gives them the chance to research and weigh the pros and cons of watching rather than rushing into treatment."
Practicality (5%)	"I would have loved to take the active observation route mainly to avoid having to take thyroid replacement meds."
Family planning (3%)	"I was breastfeeding at the time, so I would have loved observation... I felt so alone googling for guidelines on breastfeeding around RAI time..."
Surgery Preference	
Need for reassurance/ concern for spread (54%)	"It is a huge relief to know that the cancer is removed. Observation would have meant worry and probably surgery eventually. I was glad to be done!"
Means of control (27%)	"When told you have cancer, you just want it out."
Preservation of quality of life (8%)	"Active observation doesn't take into account of how the patient will be mentally. I would always be thinking about the cancer in me and always stressed about it...To struggle with cancer in any form is very taxing on the mind just as in the body."
Concern about inadequacy of care with observation (8%)	"I'm hesitant of doctors not being fully informed sometimes, so removing my thyroid honestly felt safer. I would have to have incredible trust to have a team 'observe' cancer."
Apprehension about reimbursement (3%)	"Active observation seems more dangerous/costly ONLY because if your healthcare insurance changes/stops you may not have access to observation check-ups, at which point nobody is monitoring your cancer. Also, an insurer may not take you on because of the pre-existing condition."