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The authors made no disclosures.

Author Contributions

Debbie Chen: conceptualization, visualization, writing-original draft, writing-review and editing. David Reyes-Gastelum: data curation, formal analysis, methodology, writing-review and editing. Lauren Wallner: visualization, writing-review and editing. Maria Papaleontiou: visualization, writing-review and editing. Ann Hamilton: conceptualization, data curation, funding acquisition,

methodology, visualization, writing-review and editing. Kevin Ward: conceptualization, data curation, funding acquisition, methodology, visualization, writing-review and editing. Sarah Hawley: conceptualization, funding acquisition, methodology, visualization, writing-review and editing. Brian Zikmund-Fisher: conceptualization, funding acquisition, methodology, visualization, writing-review and editing. Megan Haymart: conceptualization, data curation, funding acquisition, methodology, visualization, writing-original draft, writing-review and editing. All authors reviewed and approved the final version of the article.

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Precis: Less educated and Hispanic thyroid cancer survivors were more likely to overestimate recurrence risk, with the former also more likely to overestimate mortality risk. These inaccurate risk perceptions were associated with increased worry about recurrence and death, respectively, and decreased physical quality of life among those who overestimated mortality risk.

ABSTRACT

Background: Studies on risk perception among thyroid cancer survivors are scarce.

Methods: We surveyed patients with differentiated thyroid cancer from Surveillance, Epidemiology and End Results registries of Georgia and Los Angeles (N=2632; 63% response rate). Analytic cohort was defined by ≤5% risk of recurrence and mortality (N=1597). Patients estimated recurrence and mortality risk separately (increments of 10% and endpoints ≤5% and ≥95%). Both outcomes were dichotomized between reasonably accurate estimate (risk perception ≤5% or 10%) versus overestimation (risk perception ≥20%). We used multivariable logistic regression to identify factors associated with risk overestimation, and evaluated the relationships between overestimation and both worry and quality of life.

Results: In this sample, 24.7% overestimated recurrence risk and 12.5% overestimated mortality risk. Lower education was associated with overestimating recurrence (high school diploma and below: odds ratio (OR) 1.64, 95% confidence interval (CI) 1.16-2.31; some college: OR 1.36,

95% CI 1.02-1.81) and mortality risk (high school diploma and below: OR 1.86, 95% CI 1.18-2.93) compared to college degree and above. Hispanic ethnicity was associated with overestimating recurrence risk (OR 1.44, 95% CI 1.02-2.03) compared to whites. Worry about recurrence and death was greater among patients who overestimated versus had reasonably accurate estimate of recurrence and mortality risk, respectively ($p<0.001$). Patients who overestimated mortality risk also reported decreased physical quality of life (mean T-score 43.1, 95% CI 41.6-44.7) compared to general population.

Conclusion: Less educated and Hispanic patients were more likely to report inaccurate risk perceptions, which were associated with worry and decreased quality of life.

Keywords: thyroid carcinoma, healthcare disparities, Hispanics, mortality, recurrence, quality of life

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Introduction

The majority of patients with differentiated thyroid cancer (DTC) have low-risk disease.[1-4] Despite having an excellent prognosis, prior work has shown that patient worry about recurrence and death is common, with underrepresented minority groups especially at risk.[5] In addition, there are conflicting data on patient quality of life (QOL) with some studies finding that patients with thyroid cancer have a worse QOL than those with melanoma, colorectal cancer, and the general population, and other studies finding that QOL is similar to healthy patients without cancer.[6-9] The reasons for the discordance between patient prognosis and patient worry and QOL remain unknown.

Although studies on recurrence and mortality risk perception among thyroid cancer patients are lacking, it is plausible that inaccurate risk estimates by patients might contribute to persistent cancer-related worry and poor QOL. In particular, there is little information regarding

which thyroid cancer survivors with a favorable prognosis are at risk for overestimating risk of recurrence and death. The identification of thyroid cancer survivors who are vulnerable to inaccurate risk perceptions is needed to effectively tailor risk communication and patient education.

The goal of this study was to determine low-risk patients' level of perceived risk of recurrence and of mortality from thyroid cancer. We hypothesized that overestimation of recurrence and mortality risk would be associated with both increased cancer-related worry and decreased QOL.

Methods

Study population and data collection

Between February 1, 2017 and October 31, 2018, we conducted a large cross-sectional, population-based survey of patients aged 18 to 79 years diagnosed with DTC between January 1, 2014 and December 31, 2015. Patients were sampled from the Surveillance, Epidemiology and End Results (SEER) registries of Georgia and Los Angeles County. To improve response rates, we used a modified Dillman method, which consisted of a $20 cash incentive included with the initial mailing, contact tracing, follow-up telephone calls, and multiple mailings to nonresponders.[10] Patients with Spanish surnames were mailed surveys in both English and Spanish and bilingual interviewers conducted follow-up calls. Survey data were electronically entered using a double entry method to ensure <1% error. Survey responses were merged with clinical cancer data from the respective SEER registries to create a de-identified data set. The study was approved by the Institutional Review Boards of the University of Michigan, University of Southern California, Emory University, the California Committee for the Protection of Human Subjects, the California Cancer Registry, and the Georgia Department of Public Health.

Of the 4,317 patients identified and mailed a survey, 4,185 were determined to be eligible. A total of 2,632 patients responded, yielding a 63% response rate, calculated as number of respondents divided by eligible patients, and 77% cooperation rate, calculated as number of respondents divided by all patients who were able to be contacted.[11] For these analyses, we restricted the analytic sample to low-risk patients with both clinically determined ≤5% risk of persistent structural or recurrent thyroid cancer and ≤5% 10-year mortality risk (N=1,597;

Figure 1). All patients in the analytic sample had intrathyroidal classic papillary or follicular thyroid carcinoma with no evidence of lymph node or distant metastases.

To determine patients' clinical 10-year risk of persistent structural or recurrent thyroid cancer, we adapted information from the 2015 American Thyroid Association risk stratification system and findings by Tuttle et al. on recurrence risk estimates in patients with DTC.[1, 12] We defined such risk to be ≤5% in patients with a ≤4 cm intrathyroidal papillary or follicular thyroid carcinoma with no evidence of lymph node or distant metastases. We excluded patients whose risk of persistent structural or recurrent thyroid cancer was >5% (N=992) or unknown (N=43). This exclusion category included patients with more aggressive variants of papillary or follicular thyroid carcinomas as their risk for recurrence would be higher. These aggressive variants were identified by the following SEER ICD-O-3 morphology codes for thyroid cancer diagnosis: 8290 (Hürthle cell cancer), 8332 (trabecular follicular thyroid cancer), 8337 (insular carcinoma), and 8344 (columnar cell variant of papillary thyroid cancer).

Patients' clinical 10-year mortality risk was determined by using age at time of diagnosis and SEER Summary Stage to assign individuals to one of four distinct prognostic groups identified by Banerjee et al. in their study of 43,392 well-differentiated thyroid cancer patients using SEER data.[2, 13] Mortality risk was defined as ≤5% in patients of any age with localized disease or ≤63 years old with regional disease.

Measures

The survey instrument was developed based on the research questions and hypotheses, systematic review of the literature, and prior work in other low-risk cancers (Supplement).[1, 2, 12, 14-18] We utilized standard techniques to assess content validity, including review by design experts, content experts, and experts in risk perception, and pilot testing in a selected cohort of patients at the University of Michigan.

Patient perceptions about recurrence and mortality risk from thyroid cancer

Patients were asked to "Imagine 100 patients with the same size and type of thyroid cancer as you" followed by "How many of these patients do you think will have their thyroid cancer come back within the next 10 years (that is have cancer recurrence)?" and "How many of these patients do you think will die in the next 10 years?" Response categories for both questions

were based on an 11-point scale with increments of 10 and endpoints of ≤5 and ≥95. For the analysis, we converted responses into percentages (11-point scale: increments of 10% and endpoints of ≤5% and ≥95%). Using categories similar to that in breast cancer studies by members of our team to assess risk estimation, we categorized the outcomes into two groups: reasonably accurate estimate (risk perception of ≤5% or 10%) versus overestimation (risk perception of 20% to ≥95%) of recurrence and mortality risk in this analytic sample of patients with clinically determined 10-year recurrence and mortality risk of ≤5%.[14, 19]

Patient report of worry

To determine worry about recurrence and death from thyroid cancer, we adapted questions from worry scales used in the breast cancer literature.[15-17] Patients were asked to rate how much they worried about "thyroid cancer coming back" and "death from thyroid cancer" in the past month. A 5-point Likert scale with the following response categories was used: not at all, a little, somewhat, quite a bit, very much. For the analysis, we defined patient-reported "worry" as those who worried somewhat, quite a bit, or very much. This categorization was used to identify those patients who had a degree of worry that could potentially influence health behaviors.

Patient report of QOL

The Patient-Reported Outcomes Measurement Information System (PROMIS®) Global Health v1.2 questionnaire, which is based on item response theory, was used to measure QOL.[18] Physical and mental health raw scores were summed and converted into T-scores, which are normalized to a sample population that represent the 2000 general United States population with a mean of 50 and a standard deviation of 10. Accurate conversion to T-scores requires completion of all four items for each subscale, so we excluded patients who did not respond to all the required items (N=38 for physical QOL; N=38 for mental QOL). Higher scores indicate better outcomes such that higher physical QOL scores indicate better physical function.

Covariates

We obtained the following demographic characteristics from the survey: sex (female, male), race/ethnicity (Hispanic, black, white, other), and highest level of education (high school

diploma and below, some college, college degree and above). In regard to race/ethnicity, patients were asked to check all options that best described their race/ethnicity. Similar to prior studies, patients who selected multiple options for race/ethnicity were assigned to one category according to the following priority order: Hispanic, black, white, and other.[5, 20] Each individual was analyzed as having one race/ethnicity. Clinical cancer characteristics obtained from the SEER registries were age at time of diagnosis (years), ICD-O-3 morphology codes for thyroid cancer diagnosis, and the tumor size and extension from both clinical and pathologic sources which the SEER registries used to derive a T category following definitions from the American Joint Committee on Cancer 7th edition staging system.[21]

Statistical Analyses

We generated descriptive statistics for all categorical variables, and we report non-weighted frequencies and weighted percentages. We used multivariable logistic regression analysis to determine factors associated with the overestimation of recurrence risk and of mortality risk. We report adjusted odds ratios (OR) with 95% confidence intervals (CI) for all logistic regression models, with p-values <0.05 considered statistically significant.

We used Rao-Scott adjusted chi-square tests to test for a relationship between patients' perception of recurrence and mortality risk (reasonably accurate estimate or overestimate) and worry about recurrence and death, respectively.

We compared between-group mean physical and mental health T-scores of the analytic sample, grouped by patients' perceived risk (reasonably accurate estimate or overestimate) of recurrence and of mortality, by using a regression analysis to the general population. A meaningful change in global physical or mental health was defined as a minimal difference of one-half standard deviation, or 5 points, compared to the mean for the sample population that represent the 2000 general United States census (mean T-score = 50).[18]

All statistical analyses incorporated weights to account for differential sampling and reduce potential nonresponse bias. This included the use of design weights to account for differential probability of sample selection and nonresponse weights to account for disproportionate nonresponse rates across different patient subgroups. This weighting aims to generate statistical inferences which are more representative of the target population.[22, 23] Percentages and odds ratios reported are weighted and number of participants, when provided,

are unweighted for clarity. Analyses were performed using STATA version 15.1 (StataCorp), R version 3.5.2, and SAS 9.4 (SAS, Cary, NC).

Results

Table 1 provides the distribution of patient demographics, tumor characteristics, and risk perception of the study sample. Of the 1597 low-risk patients in the sample, 1285 (80.9%) were female, 997 (58.5%) were white, and 719 (45.9%) had a college degree and above. The majority had T1a (52.5%) or T1b (26.7%) disease at diagnosis. Approximately one-quarter of the sample (24.7%) overestimated their 10-year recurrence risk from thyroid cancer, and 12.5% overestimated their 10-year mortality risk.

Figures 2 and 3 display the multivariable-adjusted OR and 95% CI of correlates of overestimation of recurrence and mortality risk, respectively. Lower education was associated with overestimation of both recurrence (high school diploma and below: OR 1.64, 95% CI 1.16-2.31; some college education: OR 1.36, 95% CI 1.02-1.81) and mortality risk (high school diploma and below: OR 1.86, 95% CI 1.18-2.93) compared to college degree and above. The odds of overestimating recurrence risk were greater among Hispanics (OR 1.44, 95% CI 1.02-2.03) compared to whites. Sensitivity analysis excluding patients who self-reported persistent or recurrent thyroid cancer, or unknown disease status on the patient survey (total analytic N=1,422) yielded similar results with lower education associated with overestimation of both recurrence (high school diploma and below: OR 1.60, 95% CI 1.10-2.34; some college education: OR 1.57, 95% CI 1.15-2.14) and mortality risk (high school diploma and below: OR 1.74, 95% CI 1.04-2.91) compared to college degree and above. Similarly, when we restricted the cohort to patients who had undergone both a total thyroidectomy and radioactive iodine ablation (total analytic N=585), lower education was again associated with overestimating recurrence (high school diploma and below: OR 2.06, 95% CI 1.19-3.57; some college education: OR 1.67, 95% CI 1.03-2.70) and mortality risk (high school diploma and below: OR 2.49, 95% CI 1.15-5.42; some college education: OR 2.07, 95% CI 1.05-4.04) compared to college degree and above. However, in both sensitivity analyses, Hispanic ethnicity was no longer associated with overestimation of recurrence risk.

Figure 4 shows the distribution of worry about recurrence and death from thyroid cancer relative to patient perception of recurrence and mortality risk. Worry about recurrence (62.0%

versus 30.8%; p<0.001) and death (43.0% versus 19.0%; p<0.001) was greater among those who overestimated recurrence and mortality risk, respectively, compared to those who had a reasonably accurate risk estimate. Sensitivity analysis with patient-reported "worry" defined as any worry yielded similar results with greater worry about recurrence (79.5% versus 55.5%; p<0.001) and death (59.6% versus 36.8%; p<0.001) among those who overestimated recurrence and mortality risk, respectively, compared to those who had a reasonably accurate risk estimate. Similarly, when we excluded patients who self-reported history of depression (new total analytic N=1275), there was still greater worry about recurrence (62.4% versus 29.3%; p<0.001) and death (44.6% versus 18.1%; p<0.001) among patients who overestimated recurrence and mortality risk, respectively, compared to patients with reasonably accurate risk estimates.

Figure 5 illustrates physical and mental QOL by patient perception of recurrence and mortality risk. Compared to the 2000 general United States population, a lower mean physical QOL T-score among patients who overestimated mortality risk met criteria for meaningful change (mean T-score 43.1, 95% CI 41.6-44.7). Mean physical and mental QOL T-scores in patients who overestimated recurrence risk or who had reasonably accurate risk estimates did not meet criteria for a meaningful change compared to the general population. Furthermore, when compared to patients with reasonably accurate risk estimates, those who overestimated recurrence risk were more likely to have low physical (36.9% with at least 1 standard deviation (SD) below mean versus 19.3%, p<0.001) and mental QOL T-scores (28.1% with at least 1 SD below mean versus 17.3%, p<0.001). Similarly, those who overestimated mortality risk were also more likely to have low physical (43.6% with at least 1 SD below mean versus 21.0%, p<0.001) and mental QOL T-scores (31.5% with at least 1 SD below mean versus 18.2%, p<0.001). In sensitivity analysis excluding patients who self-reported history of depression (new total analytic N=1275), mean physical QOL T-score in patients who overestimated mortality risk was 44.9 (95% CI 43.2-46.6). Since T-score of 45.0 is within the 95% CI, this is no longer statistically significantly different from the general population.

Discussion

This large population-based study provides novel insights regarding risk perception among low-risk thyroid cancer patients. Less educated and Hispanic thyroid cancer survivors were more likely to overestimate recurrence risk with the former also more likely to overestimate

mortality risk. These inaccurate risk perceptions were associated with increased worry about recurrence and death, respectively, and decreased physical QOL among those who overestimated mortality risk.

It is plausible that the association between lower education and overestimation of recurrence and mortality risk is secondary to lower health literacy and numeracy. In a study of women attending a high-risk family history clinic, Rutherford et al. demonstrated a correlation between education level attained and health literacy, and a correlation between low health literacy and inaccurate risk perception of developing breast cancer.[24] Moreover, Lipkus et al. showed that breast cancer patients with greater numeracy were more likely to provide estimates of cancer-free survival that matched estimates provided by a decision aid program for different treatment options compared to patients with lower numeracy.[25]

The greater likelihood of overestimating recurrence risk among Hispanic patients may in part be due to physician-patient communication barriers or differences in acculturation, two topics largely unexplored in thyroid cancer patients. Alternatively, it may be related to differential access to and quality in thyroid cancer care for Hispanic patients compared to their white counterparts, with the potential for true differences in health outcomes.[26-28]

Worry about recurrence and death is common among thyroid cancer patients.[5, 6] However, there is a lack of data on the relationship between risk estimation and worry in thyroid cancer survivors. Consistent with studies in the breast cancer literature, we found that patients who overestimated recurrence and mortality risk were more likely to report cancer-related worry.[19, 29, 30] Additionally, Papaleontiou et al. demonstrated that in a cohort of patients with DTC, lower education was associated with more worry about recurrence and death from thyroid cancer, and Hispanic patients were more worried about death compared to their white counterparts two to four years after diagnosis.[5] Despite the observed cross-sectional association between recurrence and mortality risk overestimation and cancer-related worry, with both more likely to occur among less educated and/or Hispanic patients, the causality between these two variables remains unknown. Risk overestimation leading to increased cancer-related worry is as conceivable as is increased worry leading patients to report higher risk estimates. Further research is needed to elucidate the relationship between risk estimates and worry.

Our findings provide new insight into the relationship between thyroid cancer survivorship and QOL. While QOL is an important area of research, prior studies have been

discordant regarding the association between thyroid cancer history and QOL.[6-8] In our analytic sample, only patients who overestimated mortality risk exhibited a meaningful decrease in physical QOL compared to the general population although the decrease was no longer statistically significantly different from the general population when we excluded patients who self-reported a history of depression. This suggests that a better understanding of risk perception is an important aspect for helping to understand QOL among thyroid cancer survivors.

A major strength of this study is the combination of clinical cancer data from the SEER registries and a complementary patient survey, which provided granular details on patient report of risk estimation, worry, and QOL. Collaboration with the Georgia and Los Angeles County SEER sites provided for a large and diverse population-based cohort of low-risk thyroid cancer survivors with adequate representation of Hispanic and black patients. Additional strengths include a high response rate among surveyed patients; focus on an understudied cancer; and use of the validated PROMIS® scale to assess physical and mental QOL. The multiple sensitivity analyses performed is another strength of the study although the new cohorts were smaller, so it is unclear whether some of the subsequent results were no longer statistically significant due to exclusion of a specific variable or due to smaller cohort size.

Some potential limitations should be noted. First, because this study was cross-sectional, the observed associations do not imply causation. Second, although mortality data is straightforward, patient-reported risk of thyroid "cancer recurrence" was compared to data on clinically determined risk of persistent structural or recurrent thyroid cancer. We did not distinguish biochemical versus structural recurrent or persistent disease in the questionnaire, largely because although patients will likely recall being told their cancer is cured, came back, or still present, they may not be able to differentiate biochemical versus structural recurrence. We did, however, add sensitivity analyses to assess translatability of findings in more specific cohorts. Third, the cohort only included patients from two geographic areas and, thus, may not be representative of all thyroid cancer patients. However, the population covered by SEER is comparable to the general United States population. Fourth, patients were not asked about resources they used to learn about thyroid cancer or their comfort in communicating with physicians, both of which may influence their risk perception. Furthermore, the survey did not assess health literacy and numeracy or evaluate acculturation among Hispanic patients,

information that could provide insight into risk overestimation among less educated and Hispanic patients.

The study implications are relevant to patients and physicians. Despite the favorable prognosis of low-risk thyroid cancer, many vulnerable patients, including those with lower education and Hispanic ethnicity, inaccurately perceived their risk of recurrence and/or death, reported more worry, and experienced decreased physical QOL. Patient education that is appropriate for varying education levels and culturally sensitive, and improved risk communication by physicians is necessary to address inaccurate risk perceptions. Improving psychosocial support, including the availability of online websites and in-person support groups, for patients with thyroid cancer-related worry is also imperative. Effective communication and appropriate reassurance by physicians may help patients to create a framework for understanding their cancer prognosis so that they can make informed treatment decisions and adequately cope with the psychosocial stress related to having a cancer diagnosis. Such interventions may translate to an improved QOL for thyroid cancer survivors.

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Tables

Table 1. Distribution of patient demographics, tumor characteristics, and risk perception of the analytic sample (N=1,597).

Characteristic	N[a] (%)[b]
Sex	
Female	1285 (80.9)
Male	312 (19.1)
Age at diagnosis (years)	
≤44	517 (35.3)
45-54	386 (23.4)
55-64	405 (24.1)
≥ 65	289 (17.2)
Race/ Ethnicity	
White	997 (58.5)
Black	200 (14.3)
Hispanic	248 (17.2)
Other	138 (10.0)
Highest level of education	
High school diploma and below	362 (23.0)
Some college	488 (31.1)

College degree and above	719 (45.9)
Derived T category	
T1a	820 (52.5)
T1b	438 (26.7)
T2	339 (20.8)
Risk perception	
Overestimate 10-year recurrence risk	354 (24.7)
Overestimate 10-year mortality risk	178 (12.5)

[a]Unweighted number.

[b]Weighted percentage.

Figure Legends

Figure 1. Flow diagram demonstrating analytic sample selection. Response rate was 63% and cooperation rate was 77%.

Figure 2. Multivariable-adjusted odds ratios (OR) and 95% confidence intervals of characteristics associated with overestimation of recurrence risk.

Figure 3. Multivariable-adjusted odds ratios (OR) and 95% confidence intervals of characteristics associated with overestimation of mortality risk.

Figure 4. Patient reported worry about recurrence and death from thyroid cancer relative to patient perception of recurrence and mortality risk, respectively. Rao-Scott adjusted chi-square p-values are <0.001.

Figure 5. Physical and mental quality of life by patient perception of recurrence and mortality risk. Lower T-scores indicate a worse quality of life. The mean T-scores and 95% confidence intervals (CI) are compared to that for the 2000 general United States population. A meaningful change is defined as a minimal difference of 5 points compared to the mean T-score of 50 for the general population.

Figure 1. Study cohort selection (N = 1,597)

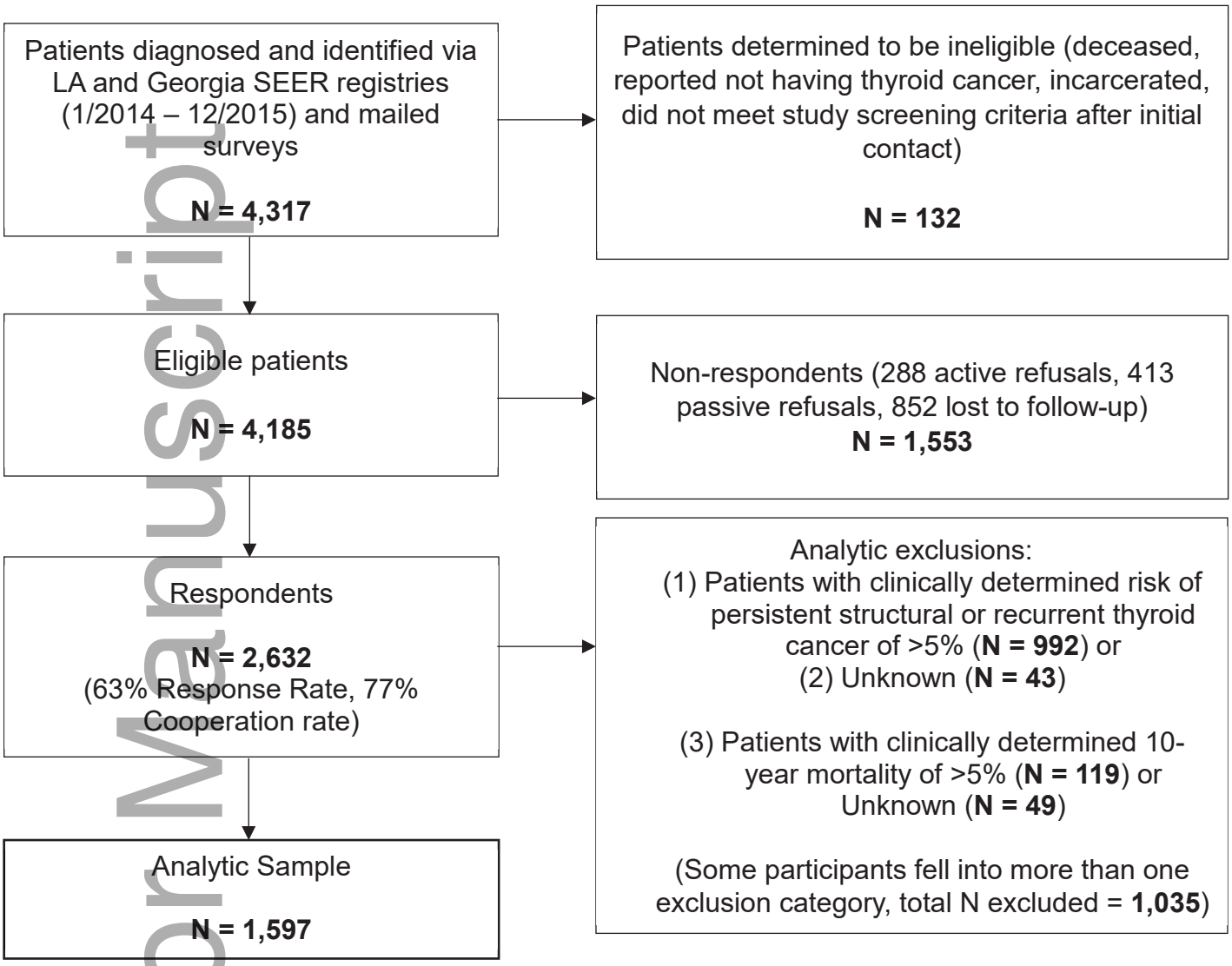
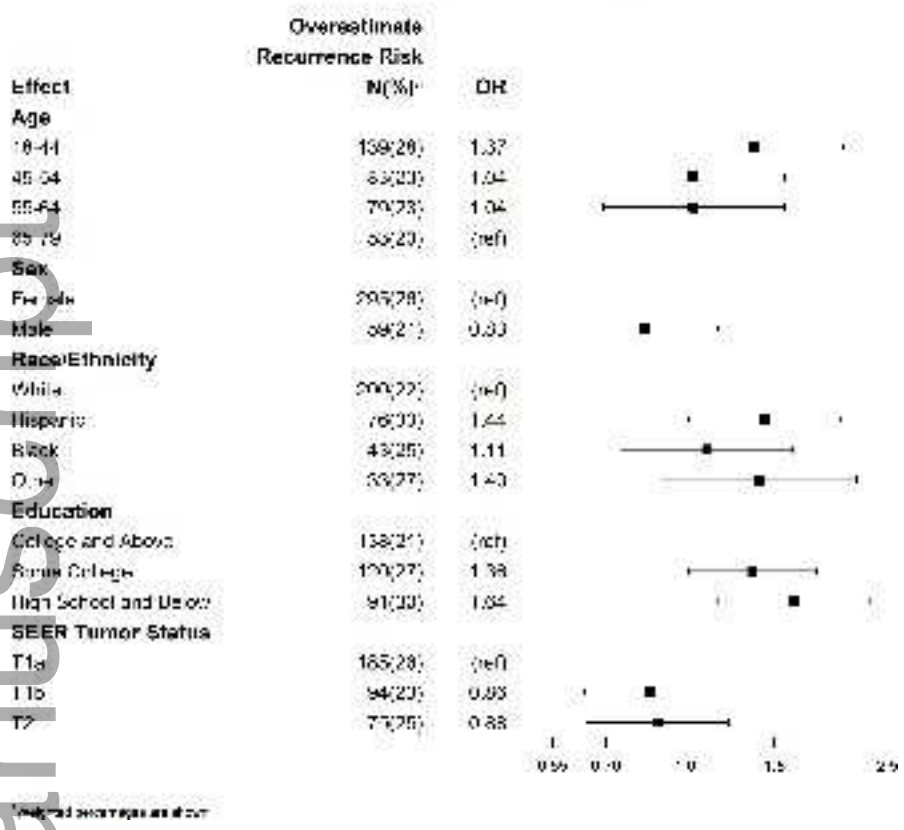
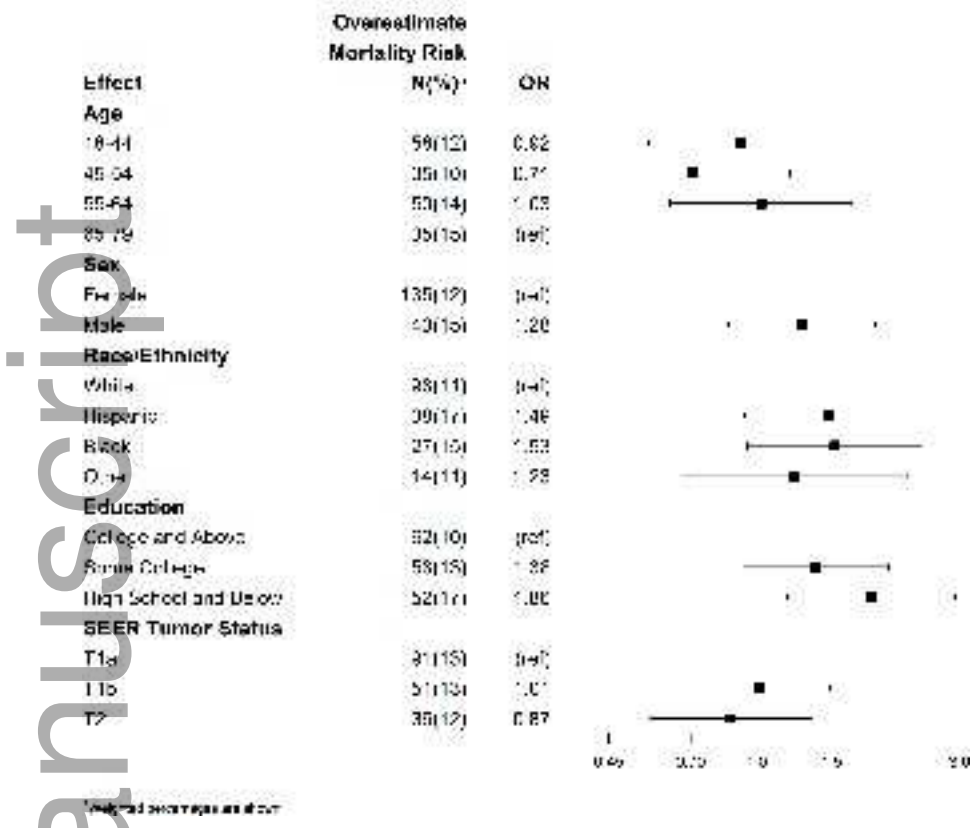


Figure 2. Characteristics associated with overestimation of recurrence risk.



cncr_32670_f2.tif

Figure 3. Characteristics associated with overestimation of mortality risk.



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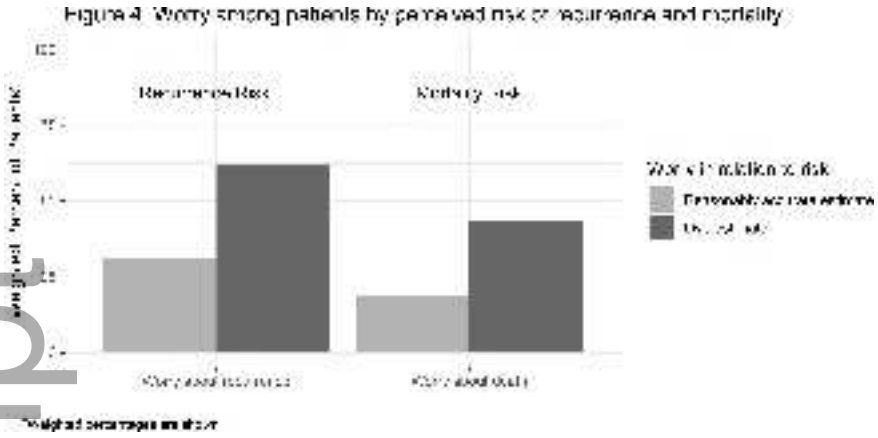

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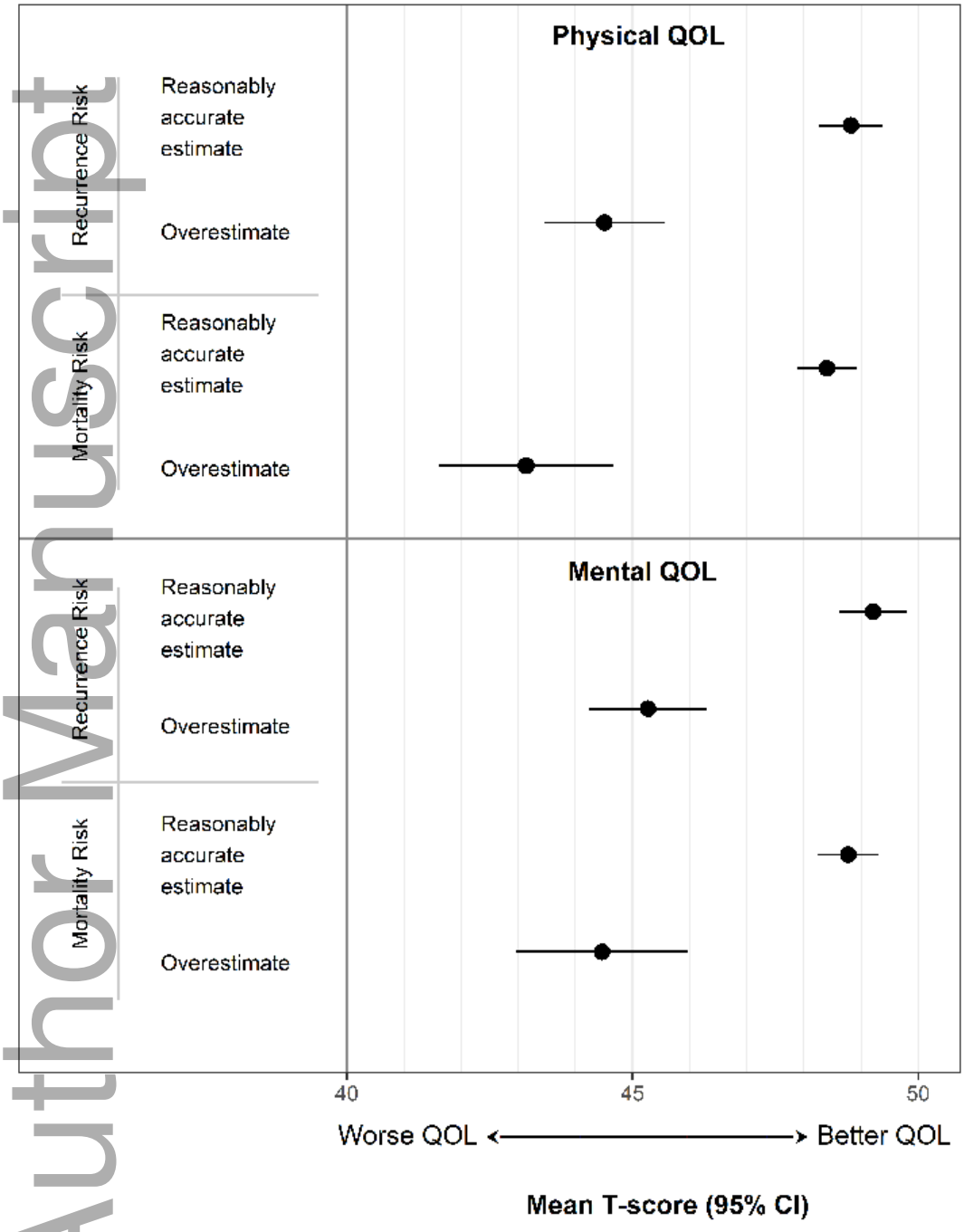
Figure 5. PROMIS® quality of life (QOL) among patients by perceived risk of recurrence and mortality.



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