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## Change in worry over time among Hispanic women with thyroid cancer

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**Abstract**

**Purpose:** The purpose of this study is to assess change in worry over time in Hispanic women with thyroid cancer.

**Methods:** Worry about recurrence, quality of life, family at risk, death, and harm from treatments was assessed in 273 Hispanic women with thyroid cancer diagnosed in 2014–2015. Subjects were recruited from Surveillance, Epidemiology, and End Results (SEER) Los Angeles. Participants were surveyed at two points in time (time 1: 2017–2018 and time 2: 2019). Multivariable logistic regression was used to determine correlates with high worry (somewhat, quite a bit, very much) versus low worry (not at all, a little) at time 2.

**Results:** For the five worry items, 20.1%–39.6% had high worry at both time 1 and 2. An additional 7.6%–13.4% had low worry at time 1 that became high worry at time 2. In multivariable logistic regression controlling for age, recurrence status, education level, and number of symptoms, younger age (20–39) as compared to older (40–79) was associated with high worry about thyroid cancer recurrence (OR 2.16, 95% CI 1.12–4.17). History of recurrent or persistent disease was associated with high worry about harms from treatment (OR 2.94, 95% CI 1.29–6.67). Greater number of symptoms was associated with more worry across all five items.

**Conclusions:** Some Hispanic women with thyroid cancer have persistently high worry, with young adult Hispanic women vulnerable to worry about recurrence.

**Implications for survivors:** Hispanic women with thyroid cancer may benefit from targeted psychosocial support during survivorship, with interventions informed by patient and cancer characteristics.

**Keywords**

thyroid cancer; worry; AYA; women; survivorship; psychosocial

**INTRODUCTION**

Thyroid cancer is the second most common cancer in Hispanic women [1]. Prior research has shown that Hispanic thyroid cancer survivors, women with thyroid cancer, and thyroid cancer survivors with lower education are uniquely vulnerable to cancer-related worry, even when they have low-risk thyroid cancer [2]. In addition, it is well known that for cancer survivors in general, including for survivors of thyroid cancer, younger patient age is associated with more worry [2–7]. Younger cancer survivors face unique, age-related psychosocial challenges [8–10] and Hispanic women often face exacerbated health disparities related to cancer outcomes [11, 12]. As such, there is a need for more research

to understand cancer-related worry in Hispanic women, especially since younger Hispanic women may represent an especially vulnerable patient population.

Cancer-related worry has been reported at various phases of disease trajectory, including diagnosis, treatment, and post-treatment survivorship [13–17]. Cancer-related worry is discriminable from anxiety or depression as worry is not a clinically established condition [18, 19]. Nevertheless, very little is known about change in cancer-related worry over time. For example, it is not known if worry is static or if there is improvement or worsening of worry over time in cancer survivors from vulnerable patient groups, such as Hispanic women. The extent to which worry over time is associated with certain patient characteristics, such as number of complications or side effects, and the degree to which worry over time may differ based on various domains of worry, including worry about recurrence, quality of life, family at risk, death, and harms from treatment, remains unknown. Physicians deliver clinical care to cancer survivors across the disease continuum, not just at time of diagnosis, and therefore, a lack of understanding of change in worry over time leaves a gap in the cancer survivorship literature regarding optimal psychosocial care for post-treatment survivors [20, 21].

Therefore, the aims of this study were to understand change in worry over time in a vulnerable patient cohort: Hispanic women with thyroid cancer. We assessed five worry outcomes, four key patient characteristics, and two different time points in order to better understand factors that may be associated with persistent high worry or worsening worry over time. We hypothesized that younger survivors would experience sustained or increased worry over time across all domains. Additionally, we hypothesized that survivors with greater number of complications or side effects would experience sustained or increased worry about harms from treatment over time.

## METHODS

### Data Source and Population

Figure 1 describes the cohort selection process at two time points: Time 1 (T1) and Time 2 (T2).

Survey respondents at time 1 (collected February 1, 2017 to October 31, 2018) were comprised of male and female survivors aged 18–79 years who had diagnoses of differentiated thyroid cancer reported to the Georgia and Los Angeles Surveillance Epidemiology and End Results (SEER) registry between January 1, 2014 and December 31, 2015 ( $n=2632$ ; 63% response rate) [22, 23, 24–28]. To provide greater detail on an important yet understudied patient population, a subset of survey respondents from time 1 were surveyed at time 2. Between May 2, 2019 and December 31, 2019, Hispanic women aged 18–79 years who had previously completed time 1 survey were surveyed again. Using methodology similar to prior studies on Hispanic women, we selected female survivors from Los Angeles County who completed our time 1 survey in Spanish or were identified in the SEER database as having a Spanish surname or being of Hispanic origin [29, 30]. To improve response rates, we provided a \$20 cash incentive and used a modified Dillman method, which included multiple reminders by phone and mail to nonresponders [31].

Survivors were mailed surveys in both English and Spanish, and bilingual interviewers conducted follow-up calls.

As shown in Figure 1, amongst the n=362 participants from time 1 who were potentially eligible for time 2 survey, n=20 participants were determined to be ineligible and thus n=342 response eligible participants were contacted for recruitment [30, 32]. A total of n=273 participants (80% response rate) ultimately completed the time 2 survey [30, 33, 32]. Hispanic women who had survey data from time 1 and time 2 were included in the final analytic cohort (n=273).

Survey data were electronically entered using a double entry method to ensure <1% error. Survey responses were merged with clinical cancer data from the Los Angeles SEER registry to create a de-identified data set. The study was approved by the Institutional Review Boards of the University of Michigan and the University of Southern California, the California Committee for the Protection of Human Subjects, and the California Cancer Registry.

## Measures

**Patient report of worry**—Using a worry scale that was originally designed for breast cancer patients and previously adapted for and used with thyroid cancer patients, participants were asked to rate how much they worried about five worry outcomes in the past month: “thyroid cancer coming back; quality of life being the same as before the thyroid cancer diagnosis; other family members being at risk; death from thyroid cancer; harm from treatments” [34–36, 2]. Survey items were presented identically at time 1 and time 2. A 5-point Likert scale with the following response categories was used: “not at all;” “a little;” “somewhat;” “quite a bit;” “very much.” Motivated by clinical significance and criteria for targeted psychosocial services, “low worry” was defined as those who reported “not at all,” or “a little worry,” and “high worry” was defined as those who reported “somewhat,” “quite a bit,” or “very much” [37]. Worry level between time 1 and time 2 was assessed with clinical focus on post-treatment survivors who had sustained high worry over time and those who had low worry at time 1 that became high at time 2.

**Complications or side effects**—Complications or side effect as a result of treatment were assessed as follows: “Many people experience complications or side effects as a result of treatment. Please select all of the complications or side effects you have experienced as a result of your thyroid cancer treatment.” These complications or side effects included such conditions as lack of energy, low calcium, voice changes, pain, weight gain, weight loss, osteoporosis, dry mouth or eyes, racing or fluttering heart, and pregnancy issues, among others [28]. Respondents were instructed to select all that apply with respect to 24 complications or side effects (one item indicates “other” self-report open-response and one additional item indicates no complications). Identical survey items were administered at time 1 and time 2 with time 2 data used for the study.

**Additional covariates**—Demographic items related to education level (College degree and above, Some college, High school diploma and below) were self-reported at time 1. Thyroid cancer status was self-reported as either gone or recurrent/persistent at time 1. Age

at diagnosis was determined with the SEER database. Younger and older age groups were dichotomized in accordance with the definition of adolescent and young adult (AYA) clinical subgroup (15 to 39 years old) [37]. The younger age group is defined as 20 to 39 years and the older age group is defined as 40 to 79 years. Table 1 describes the demographics and the additional covariates of Hispanic women at time 1 and time 2.

### Statistical Analyses

We first generated descriptive statistics for all categorical variables and non-weighted frequencies were reported. All statistical analyses incorporated nonresponse weights to reduce potential nonresponse bias. Nonresponse weights account for disproportionate nonresponse rates across different patient subgroups. Multivariable logistic regression analysis was used to determine correlates of high worry at time 2 for each type of worry (thyroid cancer recurrence; quality of life being the same as before the thyroid cancer diagnosis; other family members being at risk; death from thyroid cancer; harm from treatments). We report adjusted odds ratios (OR) with 95% confidence intervals (CI) for all logistic regression models, with p-values <0.05 considered statistically significant. Analyses were performed using Stata 15.1 (StataCorp LLC, College Station, Texas) and R Version 3.5.1 (The R Project for Statistical Computing).

## RESULTS

### Characteristics of the study cohort

The final analytic cohort included 273 Hispanic women aged 20–79 years at the time of thyroid cancer diagnosis (2014–2015) who completed both the time 1 survey (2017–2018) and the follow up time 2 survey (2019). The majority of respondents were of Mexican (n=203, 74.6%) or Central American origin (n=53, 19.4%), with high school education and below (n=140, 52.1%) or some college level education (n= 71, 27.3%), and with stage I/II disease (n=192, 72.7%) [30]. Of the 273 women surveyed at time 2, n=34 (13.4%) reported that they had recurrent/persistent thyroid cancer at time 1. At time 2, participants reported a median of 4 (range 0–24) ongoing complications or side effects.

### Distribution of worry over time

As demonstrated in Figure 2, we used weighted percentages to assess distribution of worry over time across five worry outcomes. In this figure, we dichotomize low worry (which includes “not at all” and “a little”) and high worry (which includes “somewhat,” “quite a bit,” and “very much”). Worry categories included: low worry at time 1 that remained low at time 2, high worry at time 1 that became low worry at time 2, low worry at time 1 that became high worry at time 2, and high worry at time 1 that remained high at time 2. For the five worry items, 20.1%–39.6% had high worry at both time 1 and 2. An additional 7.6%–13.4% had low worry at time 1 that became high worry at time 2. Of the five worry domains, the greatest percentage with high worry was for worry about recurrence as 33(13.4%) had low worry at time 1 that progressed to high worry at time 2 and 94(39.6%) experienced sustained high worry from time 1 to time 2. Additionally, some survivors had high worry at time 1 that changed to low worry at time 2, and some survivors had low worry at time 1 that remained low at time 2.

### Multivariable logistic regression of correlates of high worry

In univariate analysis, younger age was associated with a greater percentage of survivors having high worry about cancer recurrence ( $n=54$ ; 61.3% vs.  $n=85$ ; 47.6%,  $p=0.04$ ) and about family at risk ( $n=48$ ; 56.1% vs.  $n=74$ ; 41.0%,  $p=0.02$ ). To further understand the relationship between patient age at diagnosis and worry in the context of other risk factors, multivariable logistic regression of characteristics associated with sustained or increased worry was performed for each of the five worry items. As shown in Table 2, in multivariable analysis, younger age was significantly associated with high worry about cancer recurrence (OR 2.16, 95% CI 1.12–4.17). History of recurrent/persistent disease was associated with high worry about harms from treatment (OR 2.94, 95% CI 1.29–6.67). Greater number of complications or side effects was significantly associated with more worry across all five items: cancer recurrence (OR 1.20, 95% CI 1.10–1.30); quality of life not the same (OR 1.31, 95% CI 1.20–1.44); family at risk for thyroid cancer (OR 1.19, 95% CI 1.10–1.28); death from cancer (OR 1.17, 95% CI 1.07–1.28); harms from treatment (OR 1.21, 95% CI 1.11–1.30).

### DISCUSSION

Our current study provides novel insights into change in worry over time across two time points for Hispanic women with thyroid cancer. Key findings indicate that subgroups in our study cohort experience low worry that progresses to high worry over time or experience sustained high worry over time with respect to certain worry outcomes. We hypothesized that younger survivors would experience sustained or increased worry over time across all domains. Multivariable logistic regression controlling for age, recurrence status, educational level, and number of complications or side effects, indicates that younger age is significantly associated with high worry about thyroid cancer recurrence. Additionally, we hypothesized that survivors with greater number of complications or side effects would experience sustained or increased worry about harms from treatment over time. Our findings indicate that history of recurrent/persistent disease is significantly associated with higher worry about harms from treatment, and that greater number of complications or side effects is significantly associated with more worry across all five worry outcomes.

This study builds on prior work from our team that has identified the importance of worry at a single point in time in the lives of thyroid cancer survivors, both within and beyond the clinic. Patient worry about thyroid cancer has been associated with physician report of increased healthcare utilization in terms of increased frequency and duration of clinic visits and increased treatment intensity [38]. Additionally, worry about thyroid cancer has been shown to cause major disruption in the social and emotional lives of survivors, even amongst those with a favorable prognosis [2]. Furthermore, Hispanic patients were more likely to report inaccurate risk perception which was associated with high worry at a single point in time [23]. Therefore, understanding change in worry over time in a vulnerable population has implications for improving tailored psychosocial support and education services, both during active treatment as well as into post-treatment survivorship.

The findings from our current study also complement previous research in other cancer types on the prevalence of worry about recurrence in the adolescent and young adult



(AYA) population (15–39 years old) [39]. Prior research has shown that high worry about recurrence is more prevalent in younger age survivors compared to older age survivors or survivors of mixed ages [40–42]. Worry about recurrence for younger survivors may increase over time compared with older survivors, for whom worry may remain stable or decrease in the same time frame [43, 44]. Furthermore, prevalence of sustained or increasing high worry in this younger population has been associated with impaired physical and psychological functioning and low scores on overall health-related quality of life measures (HRQoL) measures [19, 45, 46]. Higher treatment intensity, which included more invasive regimens with longer-term side effects, is also positively correlated with high worry about recurrence [6, 19]. Complementing existing literature on AYAs' worry about recurrence with other types of cancer, our finding that younger Hispanic women with thyroid cancer experience more worry about recurrence, and that such worry may increase over time, makes a novel contribution to the growing body of knowledge regarding cancer-related worry.

Our finding that women with a history of recurrent/persistent disease worry about harms from treatment is an expected finding. Patients with recurrent/persistent disease often need additional treatments and it is well known that additional treatments, especially second and third operations, are associated with greater risk of complications [47, 48]. Patients with recurrent/persistent thyroid cancer may receive more treatments and therefore may be at greater risk for treatment complications. Thus, worry about harms from treatment may be based on awareness of risks and may be separate from symptom burden.

Our finding that those with greater number of complications or side effects experience greater worry overall aligns with the concept of “symptom burden” as a correlate of high worry in cancer patients and post-treatment survivors. “Symptom burden” refers to “the subjective, quantifiable prevalence, frequency and severity of symptoms, placing a physiological burden on patients and producing multiple negative, physical and emotional patient responses” [49]. The concept of symptom burden is complex and extends beyond numerical symptom-scoring systems, since determining the presence, severity and impact of symptoms is largely dependent on individual's experiences and perspectives [50, 51]. Nevertheless, conceptualization of symptom burden as the summative impact on patient reported outcomes (PRO) and HRQoL scores has been assessed in cancer patients [52]. A study on breast cancer survivors indicated that higher sustained worry at 3-years post treatment completion was correlated with greater self-reported symptom burden [53]. Furthermore, per prior research, younger age is also associated with elevated symptom burden [54], so younger survivors may be particularly vulnerable to both worry about recurrence as well as worry associated with greater symptom burden. Therefore, the finding that those with greater number of complications or side effects – similar to “symptom burden” – experience greater worry overall aligns with the scientific knowledge base about the impacts of symptom burden on psychosocial well-being over time.

It is important to acknowledge the strengths and limitations of the current study. Our study is novel compared to prior studies as it focuses on a vulnerable, understudied patient cohort: Hispanic women with thyroid cancer. Such emphasis elevates attention to the needs of this population and contributes to empirical discourse about their psychosocial well-being during survivorship. Our methodology was carried out with attention to cultural responsiveness

in that we provided English and Spanish language questionnaires and provided bi-lingual follow-up phone calls at both time points in our study. Finally, the response rates are high, improving generalizability of the findings and suggesting these women wanted to share their experiences. Despite the many strengths, there were some limitations. First, a common risk with studies focused on patient-reported outcomes is recall bias. However, in order to minimize recall bias, our survey questions on thyroid cancer-related worry focused on worry during the past month. Second, we acknowledge that “worry” and “fear” are not empirically validated psychosocial items, nor are they circumscribed by a comprehensive, consensus-driven theoretical framework [55, 56]. As such, “worry” and “fear” are not clinical psychosocial conditions. However, since patient-centric care is important, we also recognize the importance of exploring the phenomena of worry and fear. Finally, our cohort was limited to Hispanic women with thyroid cancer from Los Angeles County of predominantly Mexican and Central American origin. Thus, findings may not be generalizable to Latinas with origins from the Caribbean or South America.

Cancer-related worry is a major issue for cancer survivors. This study of Hispanic women who were diagnosed with thyroid cancer in 2014 to 2015, surveyed in 2017 to 2018 and then again in 2019, further emphasizes the clinical relevance of worry as we found that worry can be persistent or even worsen in a substantial proportion of post-treatment survivors. By focusing on a vulnerable and at-risk population, we further emphasize the need for tailored support tools to help manage cancer-related worry during the survivorship period. Hispanic women with thyroid cancer may benefit from targeted psychosocial support during survivorship, with interventions informed by patient characteristics, such as younger age and those experiencing greater symptom burden. Ongoing development of psychosocial assessment tools and interventions that appropriately capture and respond to the experiences of worry and their mutability over time are suggested as further directions for the field.

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## Data and/or Code Availability:

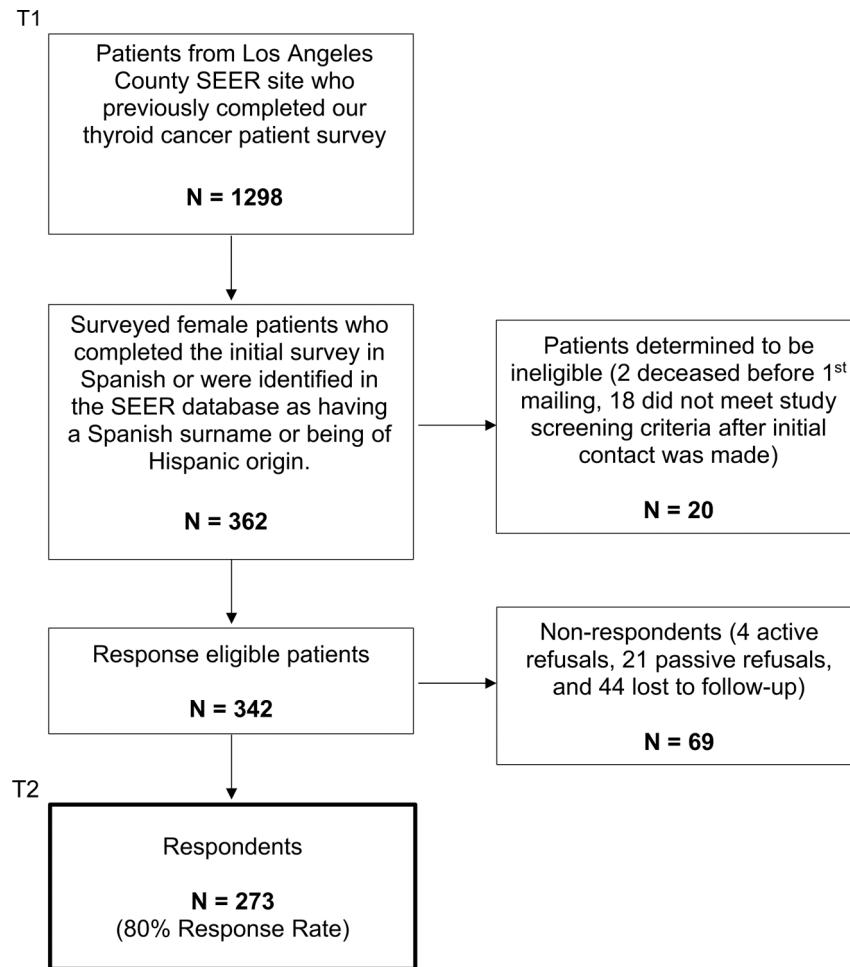
The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

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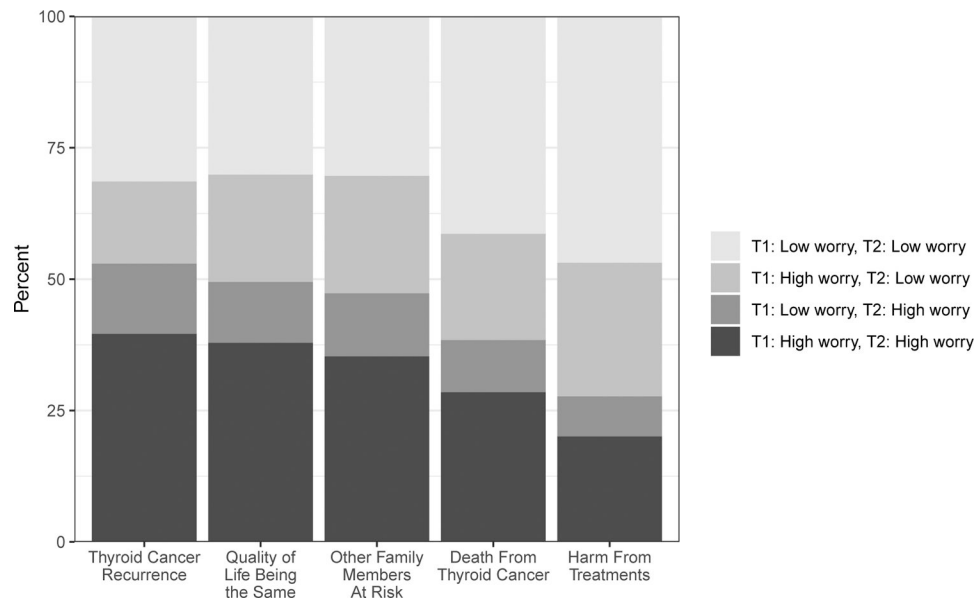
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**Figure 1. Study cohort selection (N=273).**

Survey respondents at time 1 (2017–2018) are comprised of post-treatment survivors aged 18–79 years who had diagnoses of differentiated thyroid cancer reported to the Georgia and Los Angeles Surveillance Epidemiology and End Results (SEER) registry between 2014 and 2015. Survey respondents at time 2 (May 2019 through December 2019) are comprised of Hispanic women aged 18–79 years who had previously completed time 1 survey.



**Figure 2. Distribution of Worry Over Time**

Distribution of worry over time across five worry outcomes: Thyroid cancer recurrence; Quality of life being the same; Other family members at risk; Death from thyroid cancer; Harm from treatments. Percentages are represented for four groups: low worry at time 1 that remained low at time 2, high worry at time 1 that became low worry at time 2, low worry at time 1 that became high worry at time 2, and high worry at time 1 that remained high at time 2.

**Table 1.**

Demographics and the Additional Covariates of Hispanic Women at Time 1 and Time 2

	N (%)
<b>Time 1</b>	
Age at diagnosis (years)	
20–39	88 (34.3)
40–79	185 (65.7)
Disease Status	
Gone	217 (86.6)
Recurrent/Persistent	34 (13.4)
Education Level	
College degree and above	54 (20.6)
Some college	71 (27.3)
High School Diploma and below	140 (52.1)
<b>Time 2</b>	
Complications or side effects <sup>*</sup> in the past year	
Lack of energy	168 (61.5)
Weight gain	143 (52.4)
Low mood	106 (38.8)
Dry eyes or increased tearing	95 (34.8)
Racing or fluttering heart	95 (34.8)
Voice changes for over 3 months	93 (34.1)
Low calcium for over 3 months	90 (33.0)
Dry mouth	89 (32.6)
Pain for over 3 months	67 (24.5)
Skin changes	63 (23.1)
Difficulty swallowing	61 (22.3)
High blood pressure	60 (22.0)
Unattractive scar appearance	58 (21.2)
Altered taste/smell	42 (15.4)
Salivary gland swelling	35 (12.8)
Diarrhea	27 (9.9)
Weight loss	26 (9.5)
Osteoporosis	26 (9.5)
None	26 (9.5)
Other	25 (9.2)
Early menopause	24 (8.8)
Delayed getting pregnant	14 (5.1)
Bleeding event	7 (2.6)



		N (%)
	Broken bones	5 (1.8)
	Tracheostomy	3 (1.1)
	Leukemia	1 (0.4)

\* Complications or side effects were measured at T1 and T2 and T2 was used in analysis

**Table 2.**

Multivariable Logistic Regression of Correlates of High Worry

	Cancer Recurrence OR (95% CI)	Quality of Life not Same OR (95% CI)	Family at Risk OR (95% CI)	Cancer Death OR (95% CI)	Harms from Treatment OR (95% CI)
<b>Patient Factors</b>					
Age					
40–79	Ref	Ref	Ref	Ref	Ref
20–39	2.16(1.12–4.17) *	1.33(0.70–2.51)	1.74(0.93–3.28)	0.94(0.46–1.92)	1.39(0.69–2.82)
Disease Status					
Gone	Ref	Ref	Ref	Ref	Ref
Recurrent/Persistent	1.49(0.64–3.49)	1.81(0.80–4.08)	1.21(0.54–2.72)	1.73(0.79–3.80)	2.94(1.29–6.67) *
Education Level					
College degree and above	Ref	Ref	Ref	Ref	Ref
Some college	1.20(0.55–2.64)	0.81(0.37–1.76)	2.10(0.96–4.59)	2.02(0.84–4.82)	0.46(0.18–1.16)
High School Diploma and below	1.38(0.64–2.96)	0.94(0.43–2.03)	0.99(0.45–2.19)	2.34(1.00–5.49)	0.83(0.39–1.80)
Complications or side effects					
Number of complications	1.20(1.10–1.30) *	1.31(1.20–1.44) *	1.19(1.10–1.28) *	1.17(1.07–1.28) *	1.21(1.11–1.30) *

\* Values indicate significance