

# Effect of a Change in Papillary Thyroid Cancer Terminology on Anxiety Levels and Treatment Preferences

## A Randomized Crossover Trial

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**IMPORTANCE** Given evidence of overdiagnosis and overtreatment of small papillary thyroid cancers (PTCs), strategies are needed to promote the consideration of less invasive treatment options for patients with low-risk PTC.

**OBJECTIVE** To determine the association of treatment preferences and anxiety levels for PTC with the terminology used to describe the condition.

**DESIGN, SETTING, AND PARTICIPANTS** This randomized crossover study involved a community sample of 550 Australian men and women 18 years or older without a history of thyroid cancer. Between March 16, 2016, and July 26, 2016, participants accessed an online study that presented 3 hypothetical but clinically realistic scenarios, each of which described PTC as papillary thyroid cancer, papillary lesion, or abnormal cells. Participants were exposed to all 3 scenarios with the different terminologies, and participants were randomized by the order (first, second, or third) in which they viewed the terminologies. Data analysis was conducted from September 1, 2016, to May 15, 2017.

**MAIN OUTCOMES AND MEASURES** Treatment choice (total thyroidectomy, hemithyroidectomy, or active surveillance), diagnosis anxiety, and treatment choice anxiety.

**RESULTS** Of the 550 participants who completed the online study and were included in the analysis, 279 (50.7%) were female and the mean (SD) age was 49.9 (15.2) years. A higher proportion of participants (108 [19.6%]) chose total thyroidectomy when papillary thyroid cancer was used to describe the condition compared with the percentage of participants who chose total thyroidectomy when papillary lesion (58 [10.5%]) or abnormal cells (60 [10.9%]) terminology was used. At first exposure, the papillary thyroid cancer terminology led 60 of 186 participants (32.3%) to choose surgery compared with 46 of 191 participants (24.1%) who chose surgery after being exposed to papillary lesion terminology first (risk ratio [RR], 0.73; 95% CI, 0.53-1.02) and 47 of 173 participants (27.2%) after being exposed to abnormal cells (RR, 0.82; 95% CI, 0.60-1.14) terminology first. After the first exposure, participants who viewed papillary thyroid cancer terminology reported significantly higher levels of anxiety (mean, 7.8 of 11 points) compared with those who viewed the papillary lesion (mean, 7.0 of 11 points; mean difference, -0.8; 95% CI, -1.3 to -0.3) or abnormal cells (mean, 7.3 of 11 points; mean difference, -0.5; 95% CI, -1.0 to 0.01). Overall, interest in active surveillance was high and higher levels of anxiety were reported by those who chose surgery, regardless of which terminology was viewed first (mean difference, 1.5; 95% CI, 1.0-1.9).

**CONCLUSIONS AND RELEVANCE** Changing the terminology of small PTCs may be one strategy to reduce patients' anxiety levels and help them consider less invasive management options. To curtail overdiagnosis and overtreatment in PTC, other strategies may include providing balanced information about the risks and advantages of alternative treatments.

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Overuse of medical services, which encompasses overdiagnosis and overtreatment, is now recognized as a health risk.<sup>1</sup> In the context of prostate cancer and breast cancer, evidence has emerged that the push for early detection by screening asymptomatic men and women can lead to detection and treatment of cancers that may never have caused harm.<sup>2-4</sup> More recently, evidence has emerged of a “worldwide epidemic of thyroid cancer,”<sup>5</sup> with studies indicating overdiagnosis of small papillary thyroid cancers (PTCs) as being the main driver of the increased incidence.<sup>6,7</sup> Widespread access to health services as well as technological advances in diagnostic imaging and screening have likely led to the detection of a reservoir of indolent PTCs.<sup>8,9</sup>

Total surgical removal of the thyroid (thyroidectomy) and partial surgical removal of the thyroid (hemithyroidectomy) are the most common management approaches for patients with PTC, yet these surgical procedures are associated with a degree of serious risk,<sup>10,11</sup> the potential need for lifelong thyroid replacement medication,<sup>12,13</sup> and anxiety.<sup>14,15</sup> Less invasive treatment options have garnered support in light of the suggestion of overdiagnosis of PTC and evidence from active surveillance studies.<sup>16-18</sup> These studies demonstrate that rates of metastases—progression to clinical disease and growth of the tumor—in patients with small PTC who receive immediate surgery are comparable to the rates in those who are under active surveillance management.<sup>19-21</sup>

Recommendations for active surveillance now exist, but a recent qualitative study suggests most clinicians prefer to manage small PTCs surgically.<sup>22</sup> Therefore, at this time, most patients with a PTC diagnosis are immediately recommended for and proceed to surgery, making it difficult for patients to consider and follow an active surveillance plan.<sup>23</sup>

Strategies are needed to promote the consideration of less invasive treatment options for PTCs and other indolent lesions with low malignant potential.<sup>24</sup> One such strategy is changing the terminology of low-risk PTC to exclude the term *cancer*. This change has been proposed and tested for ductal carcinoma in situ (DCIS)—a condition also known for low-risk lesions that are unlikely to cause harm if left untreated—to reduce the anxiety and shift the preferences of both clinicians and patients away from unnecessary aggressive treatments.<sup>25,26</sup> A similar change to PTC terminology has been suggested<sup>6</sup>; however, no evidence has yet emerged to show how a change in PTC nomenclature may affect treatment preferences.

Taking into account the evidence of overdiagnosis and possible overtreatment of small PTCs and the appropriateness of following an active surveillance management plan, we conducted a randomized study to determine the association between treatment preferences and anxiety levels for PTC and the terminology used to describe the condition (with and without the term *cancer*).

## Methods

The University of Sydney Human Research Ethics Committee approved this study. Verbal consent was initially obtained via telephone by the research company that sent the online link to

### Key Points

**Question** Do survey participant treatment preferences and anxiety levels differ when papillary thyroid cancer is described with or without the term *cancer*?

**Findings** In this randomized crossover study of 550 adults without thyroid cancer, when papillary thyroid cancer was described as a lesion or as abnormal cells (rather than as a cancer), participants were more likely to opt for less invasive treatment options and experienced lower levels of anxiety.

**Meaning** The terminology used to describe papillary thyroid cancer may be associated with patient perception and thus patient selection of treatment alternatives and levels of anxiety.

each study participant before their participation. Further consent was implied as the participant began and completed the online study. The trial protocol is available in [Supplement 1](#).

### Design

Between March 16, 2016, and July 26, 2016, an online study was conducted among a random community sample (N = 550) ([Table 1](#)). Based on the study by Omer et al,<sup>27</sup> which tested the association of DCIS terminology with treatment preferences, the online study presented participants with 3 clinical scenarios of a PTC diagnosis using the terminologies *papillary thyroid cancer*, *papillary lesion*, and *abnormal cells*. These scenarios were designed to be typical real-life clinical scenarios and were developed and revised with input from our study team’s thyroid cancer expert (J. P. B.) as well as consumer collaborators. Each scenario was identical except for the terminology used to describe the diagnosis and asked participants to choose among the 3 treatment options (total thyroidectomy, hemithyroidectomy, or active surveillance) to manage their hypothetical PTC diagnosis. The study specifically indicated to participants that each diagnosis was different but the 3 treatment options and their associated risks and advantages were the same.

The study followed a randomized crossover design, whereby participants were randomly assigned by scenario ordering to ensure an equal distribution of the 6 different terminology sequences; approximately one-third of participants were randomized to see<sup>1</sup> of the 3 terminologies first. Participants viewed all 3 scenarios with different terminologies, made 3 separate treatment choices, indicated their perceived level of anxiety from the diagnosis and treatment choice, and had the option of stating their reasons for each choice. The treatment table presented in each clinical scenario provided prognostic information, including the chance of needing lifelong thyroid replacement medication; follow-up required; adverse effects of surgery and medicines; and likelihood of the condition growing, becoming invasive cancer, or dying in the next 20 years (eMethods in [Supplement 2](#)).<sup>10-16,19,20,28,29</sup>

### Participants and Procedures

Participants included 550 Australian men and women who were 18 years or older and spoke adequate English. Individuals were ineligible to participate if they had a history of thyroid cancer or had no email address given that the study was sent by email

Table 1. Participant Characteristics

Variable <sup>a</sup>	Terminology Viewed First, No. of Participants (%)		
	Papillary Thyroid Cancer (n = 186)	Papillary Lesion (n = 191)	Abnormal Cells (n = 173)
Age, y			
18-25	12 (6.5)	12 (6.3)	16 (9.2)
26-35	20 (10.8)	30 (15.7)	16 (9.2)
36-45	30 (16.1)	39 (20.4)	25 (14.5)
46-55	45 (24.2)	42 (22.0)	43 (24.9)
56-65	48 (25.8)	46 (24.1)	43 (24.9)
>65	31 (16.6)	22 (11.5)	30 (17.3)
Sex			
Male	94 (50.5)	91 (47.6)	84 (48.6)
Female	92 (49.5)	99 (51.8)	88 (50.9)
Other	0 (0)	1 (0.5)	1 (0.5)
Highest educational level			
≤Intermediate school certificate	32 (17.2)	21 (11.0)	23 (13.3)
High school certificate	24 (12.9)	28 (14.7)	30 (17.3)
Trade certificate or college diploma	54 (29.0)	61 (31.9)	51 (29.5)
≥Undergraduate degree	74 (39.8)	79 (41.4)	69 (39.9)
Current employment status			
Full-time	96 (51.6)	99 (51.8)	72 (41.6)
Part-time	27 (14.5)	45 (23.6)	48 (27.7)
No paid job <sup>b</sup>	61 (32.8)	47 (24.6)	51 (29.5)
Relationship status			
Married or living with partner	139 (74.7)	140 (73.3)	123 (71.1)
Widowed, divorced, or separated	21 (11.3)	26 (13.6)	25 (14.5)
Single, never married	24 (12.9)	25 (13.1)	24 (13.9)
Main language spoken at home			
English	174 (93.5)	185 (96.9)	162 (93.6)
Other language	12 (6.5)	6 (3.1)	11 (6.4)
State/region of residence			
New South Wales	52 (28.0)	62 (32.5)	54 (31.2)
Victoria	58 (31.2)	53 (27.7)	44 (25.4)
Queensland	35 (18.8)	36 (18.8)	39 (22.5)
Australian Capital Territory	2 (1.1)	2 (1.0)	3 (1.7)
Tasmania	5 (2.7)	6 (3.1)	6 (3.5)
South Australia	18 (9.7)	12 (6.3)	12 (6.9)
Northern Territory	2 (1.1)	2 (1.0)	0 (0)
Western Australia	13 (7.0)	18 (9.4)	15 (8.7)
Private health insurance			
Yes	132 (71.0)	141 (73.8)	121 (69.9)
No	52 (28.0)	47 (24.6)	49 (28.3)
Don't know	1 (0.5)	0 (0)	2 (1.2)
Thyroid nodule diagnosis			
Yes	9 (4.8)	5 (2.6)	8 (4.6)
No	176 (94.6)	185 (96.9)	165 (95.4)
Cancer diagnosis <sup>c</sup>			
Yes	19 (10.2)	16 (8.4)	11 (6.4)
No	167 (89.8)	175 (91.6)	162 (93.6)
Immediate family member with cancer diagnosis <sup>d</sup>			
Yes	107 (57.5)	107 (56.0)	88 (50.9)
No	77 (41.4)	83 (43.5)	83 (49.0)
Health literacy <sup>e</sup>			
Adequate	176 (94.6)	179 (93.7)	166 (96.0)
Limited/marginal	11 (5.9)	12 (6.3)	7 (4.0)

(continued)

Table 1. Participant Characteristics (continued)

Variable <sup>a</sup>	Terminology Viewed First, No. of Participants (%)		
	Papillary Thyroid Cancer (n = 186)	Papillary Lesion (n = 191)	Abnormal Cells (n = 173)
Cancer worry <sup>f</sup>			
Not worried at all	46 (24.7)	32 (16.8)	41 (23.7)
A bit worried	89 (47.8)	94 (49.2)	90 (52.0)
Quite worried or very worried	31 (16.7)	47 (24.6)	29 (16.8)
Thyroid cancer worry <sup>f</sup>			
Not worried at all	122 (65.6)	112 (58.6)	101 (58.4)
A bit worried	50 (26.9)	65 (34.0)	64 (37.0)
Quite worried or very worried	14 (7.5)	11 (5.8)	6 (3.5)
General anxiety mean score <sup>g</sup>	37.9	36.3	35.7

<sup>a</sup> Data are missing for some variables as participants had the option to refuse to answer some questions.

<sup>b</sup> Variable included the following status: retired, volunteer, student, home duties, unemployed, permanently ill, and unable to work.

<sup>c</sup> Cancer other than thyroid was allowed; people with thyroid cancer were not eligible to participate in the study.

<sup>d</sup> Immediate family included parents, siblings, and children.

<sup>e</sup> This validated single item measured health literacy skills.<sup>31</sup>

<sup>f</sup> This validated single item measured level of worry about developing thyroid cancer with 4 responses ranging from "not worried at all" to "very worried."<sup>32-35</sup>

<sup>g</sup> State-Trait Anxiety Inventory (short form) was used (scale: 20-80 points, with higher scores indicating greater levels of anxiety).<sup>36,37</sup>

directly to eligible participants. In total, 606 participants began the study and were randomized. However, 56 participants (9.2%) did not complete the entire study, leaving 550 participants (90.8%) included in the analysis. Fifty-five individuals (9.0%) were lost to follow-up after randomization.

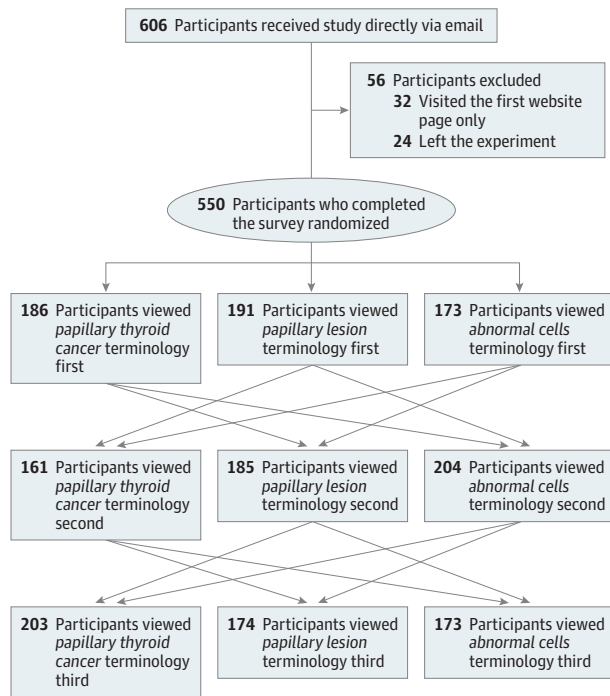
The study was administered by the Hunter Research Foundation (HRF), an independent research organization. The HRF used mobile random-digit dialing across Australia to contact potential participants from a community sample. Once the HRF obtained a verbal agreement from a participant, the HRF emailed an online link to the study along with the Participant Information Sheet to the participant. Participants were able to access and complete the study in their own time. To ensure adequate randomization and minimize the number lost to follow-up, we randomized participants only if they began the study. Participants who did not initially respond to the study received 3 reminders (2 emails and 1 text message) that included a link to the study. The median (range) time it took to complete the study was 11 (2-58) minutes. No incentives were provided to participants. The participant flow is shown in the **Figure**.

Researchers conducted a pilot of the study with a convenience sample of 12 adults, and the HRF subsequently conducted a pilot with a community sample of 30 adults. We made minor changes to the study on the basis of the feedback collected from the 2 pilots before the HRF formally administered the final study.

## Outcome Measures

The primary outcomes were treatment choice, diagnosis anxiety, and treatment choice anxiety. Treatment choice was

Figure. Participant Flowchart



All participants saw all items across 3 viewings. All participants of the first viewing were then randomized to see the 3 terms in a second viewing and a third viewing.

measured as a direct choice among total thyroidectomy, hemithyroidectomy, or active surveillance. Diagnosis anxiety and treatment choice anxiety were measured on a Visual Analog Scale with anchored end points ranging from “not anxious at all” to “extremely anxious.”<sup>30</sup> Because the study was online, participants were able to move a cursor along the scale and place it at 1 of 11 points between “not anxious at all” to “extremely anxious.” All primary outcomes were measured for each scenario according to the different terminology presented. Participant demographics health literacy,<sup>31</sup> cancer worry,<sup>32-35</sup> and general anxiety<sup>36,37</sup> levels (using validated measures) and cancer history were also collected and reported.

**Statistical Analysis**

Using the Stuart-Maxwell test,<sup>38</sup> we calculated the study to have at least 80% power to detect a difference of at least 5% in the total proportion of participants who chose less invasive treatment when a less serious terminology was used and when the marginal proportions were compared. To simplify this sample size calculation, we assumed that if a participant does not choose surgery (total thyroidectomy or hemithyroidectomy) when a more serious terminology (papillary thyroid cancer) is used, then that participant also would not choose surgery when a less serious description (abnormal cells) is used. Following the formula in Vuolo et al,<sup>38</sup> this assumption resulted in a sample size of 211. We inflated this sample size to account for the multiple comparisons of marginal proportions by setting the significance level for the Stuart-Maxwell

Table 2. Marginal Proportion of Participants Selecting Treatment by Terminology

Terminology	Treatment Selected, No. (%)		
	Total Thyroidectomy	Hemithyroidectomy	Active Surveillance
Papillary thyroid cancer	108 (19.6)	142 (25.8)	300 (54.5)
Papillary lesion	58 (10.5)	72 (13.1)	420 (76.3)
Abnormal cells	60 (10.9)	87 (15.8)	403 (73.3)

test at 0.0167. We doubled this sample size to allow for possible separate subgroup analyses of men and women. To achieve these aims, we recruited 600 participants.

Responses to treatment choice were analyzed across all 3 treatment options and then combined into 2 categories: surgery and active surveillance. Mean anxiety scores were reported numerically. For the first scenario viewed by each participant, analysis of variance was used to compare the mean anxiety scores across the 3 terminologies, and a binary regression model was used to compare the percentage of participants who chose surgery. We investigated whether the order in which terminologies were presented was associated with the proportion of participants who chose surgery and the diagnosis anxiety score by using mixed models that included interactions between terminology and the order of terminology exposure. The data were analyzed using SAS, version 9.4 (SAS Institute). Data analysis was conducted from September 1, 2016, to May 15, 2017.

**Results**

**Participant Characteristics**

The sample of 550 participants was broadly representative of the Australian public. Among this group, 279 (50.7%) were women and 269 (48.9%) were men, with a mean (SD) age of 49.9 (15.2) years. Overall, participants were slightly older and had slightly higher levels of educational attainment than the general Australian population,<sup>39</sup> as is typical of health research respondents recruited through the telephone. Forty-six participants (8.4%) reported a diagnosis of cancer (other than thyroid cancer), and more than 50% had at least 1 immediate family member with cancer, which are findings similar to those reported in Australian and international community studies.<sup>40,41</sup> Participants across the 3 treatment groups were similar in sociodemographic characteristics (Table 1).

**Treatment Choice**

The marginal proportion of participants in each of the treatment options differed depending on the terminology used in the case scenarios (Table 2). A higher proportion of the 550 participants (108 [19.6%]) chose total thyroidectomy when papillary thyroid cancer was used to describe the condition compared with the percentage of participants who chose total thyroidectomy after viewing the papillary lesion (58 [10.5%]) or abnormal cells (60 [10.9%]) terminology (eTable 1 in Supplement 2).

**Table 3. Participants Selecting Surgery (Total Thyroidectomy or Hemithyroidectomy) by Order of Terminology Viewing**

Terminology	Viewed First, No. (%)	Risk Ratio (95% CI) <sup>a</sup>	Viewed Second, No. (%)	Viewed Third, No. (%)
Papillary thyroid cancer (n = 186)	60 (32.3)	1 [Reference]	91 (48.9)	102 (54.8)
Papillary lesion (n = 191)	46 (24.1)	0.73 (0.53-1.02)	44 (23.0)	46 (24.1)
Abnormal cells (n = 173)	47 (27.2)	0.82 (0.60-1.14)	50 (28.9)	42 (24.3)

<sup>a</sup> Estimated risk ratio of surgical treatment choice for terminology viewed first by binary regression model.

**Table 4. Mean Scores by Terminology and by Order of Terminology Viewing**

Terminology	Diagnosis Anxiety Mean Scores					Treatment Choice Anxiety Mean Scores					
	First Viewing Anxiety Score <sup>a</sup>	Mean Difference (95% CI) <sup>b</sup>	Standardized Effect Size (95% CI)	Second Viewing Anxiety Score <sup>a</sup>	Third Viewing Anxiety Score <sup>a</sup>	First Viewing Anxiety Score <sup>c,d</sup>		Second Viewing Anxiety Score <sup>c</sup>		Third Viewing Anxiety Score <sup>c</sup>	
						Surgery <sup>e</sup>	Active Surveillance	Surgery	Active Surveillance	Surgery	Active Surveillance
Papillary thyroid cancer	7.8	1 [Reference]	1 [Reference]	8.5	8.9	7.1	5.8	7.7	6.3	8.2	6.5
Papillary lesion	7.0	-0.8 (-1.3 to -0.3)	-0.3 (-0.5 to -0.1)	6.8	6.7	7.3	5.4	7.5	5.6	7.3	5.6
Abnormal cells	7.3	-0.5 (-1.0 to 0.01)	-0.2 (-0.4 to 0.01)	7.3	6.7	6.9	5.7	7.6	5.6	7.3	5.5

<sup>a</sup> Anxiety scores were measured on an 11-point scale with anchored end points ranging from 1 = not anxious at all to 11 = extremely anxious.

<sup>b</sup> Mean difference, 95% CI, and *P* values were obtained from analysis of first scenario viewed using analysis of variance.

<sup>c</sup> Anxiety scores were measured on an 11-point scale with anchored end points

ranging from 1 = not anxious at all to 11 = extremely anxious.

<sup>d</sup> Effect of terminology on treatment choice and on treatment-related anxiety mean difference was 1.5 (95% CI, 1.0-1.9).

<sup>e</sup> Surgery includes the treatment choice of total thyroidectomy or hemithyroidectomy.

When treatment options were dichotomized into surgery (total thyroidectomy or hemithyroidectomy) or active surveillance, a similar association of alternative terminologies with treatment choice was observed, although when the terminologies were viewed first, the differences did not reach statistical significance (Table 3). At first exposure, the papillary thyroid cancer terminology led 60 of 186 participants (32.3%) to choose surgery compared with 46 of 191 participants (24.1%) who chose surgery after being exposed to the papillary lesion terminology first (risk ratio [RR], 0.73; 95% CI, 0.53-1.02) and 47 of 173 participants (27.2%) after being exposed to abnormal cells (RR, 0.82; 95% CI, 0.60-1.14) terminology first.

Regardless of the terminology used, the overall initial treatment preferences for active surveillance were high (72%) but decreased after the second and third scenarios were presented (66% and 65%, respectively).

### Diagnosis Anxiety

We observed the association of the different terminologies with participant-reported anxiety level in response to the diagnosis (Table 4). Participants reported higher mean anxiety scores when their diagnosis was described as papillary thyroid cancer compared with papillary lesion or abnormal cells across all orders in which the terminology was viewed. After the first exposure, participants who viewed the papillary thyroid cancer terminology reported significantly higher levels of anxiety (mean, 7.8 of 11 points) compared with those who saw the papillary lesion (mean, 7.0 of 11 points; mean difference, -0.8; 95% CI, -1.3 to -0.3) or abnormal cells (mean, 7.3 of 11 points; mean difference, -0.5; 95% CI, -1.0 to 0.01) description. The effect size between the terminologies (Table 4) is similar to the effect size between psychological interventions to manage anxiety after a cancer diagnosis.<sup>42</sup> Adjusting for the covariates had little association with results.

The first, second, and third viewing of papillary thyroid cancer description showed increases in not only the proportion of participants who chose surgery (32.3%, 48.9%, and 54.8%, respectively; Table 3) but also in the level of anxiety in response to the diagnosis (7.8, 8.5, and 8.9 points, respectively; Table 4). This increase suggests possible carryover effects of previous descriptions on current outcomes. From the mixed model analysis, there were substantial interactions between terminology and order of terminology viewing in choosing surgery (eTable 2 in Supplement 2) and between terminology and the order of terminology presentation in the diagnosis-related anxiety scores (eTable 3 in Supplement 2).

### Treatment Choice Anxiety

Participants who chose surgery reported higher levels of anticipated treatment-related anxiety compared with those who chose active surveillance, regardless of which terminology was seen first (mean difference, 1.5; 95% CI, 1.0-1.9) (Table 4).

## Discussion

In a hypothetical clinically realistic context, describing PTC without the term *cancer* led to greater response in nonsurgical options, such as active surveillance, and to lower levels of anxiety. Studies in other indolent tumor types, such as DCIS, also support our findings, demonstrating that describing DCIS without the cancer terminology decreases preferences for surgical treatment and levels of anxiety.<sup>27,43</sup>

Removing the cancer terminology has been proposed for PTC and other lesions with low malignant potential as a strategy for mitigating overdiagnosis and overtreatment,<sup>6,24</sup> although no studies in this area have been conducted in patient populations or have analyzed the possible long-term risks

and advantages of this change.<sup>44</sup> Changing the terminology of these proposed lesions, however, would not be a straightforward process because cancer is typically defined by pathologic features and behaviors. Therefore, an iterative process that involves all stakeholders may need to be adopted. Noninvasive encapsulated follicular variant of PTC is an example of a condition recently renamed to exclude the term *carcinoma* and for which a renaming process has been adopted.<sup>45</sup> This change was made to appropriately reflect the biological and clinical characteristics of encapsulated follicular variant of PTC, which rarely exhibits lymph node metastases and behaves indolently. The hope was that the new name would ultimately reduce the psychological and clinical associations (ie, long-term follow-up) with the diagnosis of cancer.<sup>45,46</sup>

We found that the order in which participants were exposed to different PTC terminology might affect treatment decision making and psychological outcomes. Across all 3 scenarios, the association of the terminology used in the description with later exposures increased; that is, those who saw the terminology at the second or third viewing compared with those who read it at the first viewing had significantly higher preferences for surgery and levels of anxiety. This important finding suggests that there may be anchoring, a cognitive bias that occurs during decision making.<sup>47</sup> Participants who did not see “cancer” the first time based their initial judgments on treatment choice and anxiety on the condition called *papillary lesion* or *abnormal cells*. They adjusted their judgment later when they saw the condition called *papillary thyroid cancer*. In a real-world context, patients have numerous consultations with different clinicians as well as receive and read information about their diagnostic pathway from a variety of sources. Encountering a different terminology or description for cancer after a diagnosis may, therefore, alter their perceptions of and reactions to the diagnosis. This finding emphasizes the need for all clinicians in the cancer pathway to agree on and implement this terminology change.

Interest in active surveillance, independent from terminology, was high (approximately 70%) even when participants were not specifically told that they could proceed to surgery later, as would be the case in clinical practice. Hypothetical studies on DCIS, in which active surveillance is not currently a standard management option (similar to PTC), have shown the proportion of women interested in active surveillance is high.<sup>27,43,48</sup> This interest level among a healthy sample is encouraging and supports previous reports that patients tend to make more conservative treatment decisions after an unbiased presentation of options. Further qualitative (eg, patient interviews) and quantitative (eg, discrete choice experi-

ments) investigations would help identify the factors in patients’ treatment decisions, including the terminology used to describe the condition and the trade-offs between treatment risks and advantages that patients may be willing to accept.

### Limitations

The study was limited by its hypothetical framework to understand how people with a real diagnosis of PTC may respond to the scenarios presented to study participants without such a diagnosis. Using this design, however, allowed us to include participants who were unbiased by previous knowledge and information about PTC. Testing people with a PTC diagnosis may not be as meaningful because their responses would be biased by their previous or current experiences, including treatment decision making, and by the terminologies used by their clinicians. We also presented standardized outcomes in the scenarios. In reality, these outcomes may vary by age, comorbidities, surgeon experience, and other factors. However, these outcomes were informed by the best available evidence. Furthermore, the sample was slightly more educated and older than the general Australian population. Recent evidence from US studies, however, suggests that individuals with higher socioeconomic status are more likely to receive a PTC diagnosis.<sup>49</sup>

### Conclusions

This study indicates that, in a hypothetical context, calling a diagnosis cancer does matter. Participants with no previous history of PTC had more interest in active surveillance and lower levels of anxiety when PTC was described without the term *cancer* and with substitute terminologies *lesion* and *abnormal cells*. Our findings support the recommendation to change the terminology for small low-risk PTCs to mitigate the problem of overdiagnosis and overtreatment in this condition.<sup>6,24</sup> In addition, the findings suggest that the order in which the terminology was presented may be a factor in participant decisions. Furthermore, interest in active surveillance to manage a diagnosis of PTC may be higher than previously anticipated, notably when the risks and advantages of alternative therapies were presented together, allowing individuals to directly compare treatment aspects important to them. Clinicians who manage patients with PTC should ensure that the diagnosis is described consistently and the treatment options are well presented to help reduce anxiety and allow for consideration of less invasive management approaches.

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## Invited Commentary

## The Evolving Nomenclature of Thyroid Cancer What's in a Name?

Andrew G. Shuman, MD

“Cancer is a word, not a sentence,” acknowledged John Diamond<sup>1</sup> as he embarked on an ultimately losing fight with oral carcinoma. It reflects the fear that the word *cancer* has instilled in the public for millennia. To many, a cancer diagnosis was, and remains, akin to a death sentence or, at the very least, a jarring call to battle. This connotation is rooted in the long-established theory of linguistic relativism, which stipulates that thought and action are determined a priori by language itself.<sup>2</sup> Even today, our nuanced understanding of cancer biology and the inherent diversity of malignant processes has not erased the stigma and terror that the word evokes in our patients.

From this background emerges the budding acceptance of the concept of overdiagnosis within the domains of oncology. No longer are indolent cancers necessarily something to be feared and aggressively extirpated but rather to be viewed as objects for observation or, at the least, less aggressive treatment. As with all paradigm shifts, clinicians and patients should adjust practices and expectations deliberately, as the needle slowly inches toward treatment de-escalation. Just as practice and perspective needs to evolve, so, perhaps, does our language.

In 2014, a National Cancer Institute working group boldly suggested the adoption of the term *indolent lesion of epithelial origin* or IDLE “for those lesions (currently labeled as cancers) and their precursors that are unlikely to cause harm if they are left untreated.”<sup>3</sup> The foundation for this conceptual shift is rooted in the hypothesis that the word *cancer* itself can be so terrifying that it may prompt overtreatment despite counseling based on data suggesting otherwise. This calls into question what truly defines a neoplasm as a cancer; is it a biological potential for

progression, a histological appearance, a genomic signature, or a cohesive permutation thereof? Recently, a subset of noninvasive thyroid neoplasms was reclassified to be more consistent with its lack of observed progression or spread.<sup>4</sup> Although this is gratifying and a meaningful change in the literature, it does not address most low-risk, well-differentiated thyroid cancers that have minuscule potential for life-threatening progression but are, histologically at least, still consistent with the contemporary definition of carcinoma.

Redefining terms may correlate with the evolution in management as well. Active surveillance of low-risk papillary microcarcinomas is not new, and a long-term follow-up study in Japan confirms the safety and practicality of this approach among carefully selected patients.<sup>5</sup> Follow-up studies confirm the replicability in American patients.<sup>6</sup> However, active surveillance is not synonymous with doing nothing and requires diligent follow-up, committed multidisciplinary teams, clear language and expectations, and expert ultrasonographers and radiologists. As a result, active surveillance of low-risk papillary microcarcinomas has yet to be fully embraced, until the test of time proves the approach's feasibility and transferability to a wider cadre of centers and practitioners. In addition, the social barriers to this paradigm are formidable, including the pervasive fear and lack of education within the community as well as the counterintuitive stigma of having a so-called good cancer, which can be simultaneously reassuring and troubling.<sup>7</sup> This stigma is reflected not only in patient understanding; clinicians are similarly reticent to de-escalate treatment for a disease that has overall excellent outcomes and a time-tested surgical approach.<sup>8</sup> Promoters of active surveillance still need to reassure the broader clinical community along with the public.



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