



“Your cancer is no longer considered cancer”: Psychological reactions to reclassification information and communication preferences

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ARTICLE INFO

Keywords:

Cancer
Cancer reclassification
Patient-provider communication

ABSTRACT

Objective: In 2016, the encapsulated follicular variant of papillary thyroid carcinoma (EFVPTC) was reclassified as non-invasive follicular thyroid neoplasm with papillary-like nuclear features (NIFTP). This reclassification removed the word “carcinoma” and the definition of cancer from the diagnosis. While the nomenclature change was expected to psychologically impact patients, that question has not been systematically explored. Using qualitative methods, we aimed to explore the psychological impact of reclassification on thyroid cancer patients and their preferences for receiving reclassification information.

Methods: Semi-structured interviews with nine non-EFVPTC thyroid cancer survivors were conducted. Participants were presented with a hypothetical reclassification scenario, and interview transcripts were analyzed using a thematic content analytic approach.

Results: Participants expressed a range of psychological reactions to reclassification information, primarily negative, including anger, mistrust, and uncertainty, but also relief. All participants expressed difficulty understanding the concept of reclassification. Communication preferences favored conversation with an established medical provider over written materials, such as a letter.

Discussion and conclusion: Communication must align with patient preferences. Being mindful of potential negative psychological reactions when providing information on cancer reclassification is vital.

Innovation: This study examines reactions to cancer reclassification information and preferences for how this information should be communicated.

1. Introduction

What if the cancer you were treated for was no longer considered cancer? In 2016, practice guidelines for a thyroid tumor with low recurrence rates (*noninvasive encapsulated follicular variant of papillary thyroid carcinoma*; EFVPTC) changed to prevent overdiagnosis and overtreatment [1], removing the word “carcinoma” from the diagnosis, and reclassifying EFVPTC as *noninvasive follicular thyroid neoplasm with papillary-like nuclear features* (NIFTP). The guidelines and subsequent commentaries [1,2] posited NIFTP reclassification would create psychological burden—a question that remains unexplored.

Some patients might express anger at potentially unnecessary surgery or radioiodine therapy [1,2]; others might express relief they no longer have a cancer history. Should cancer reclassification information always be pre-

sented, and if so, by whom, and how? While no studies of cancer reclassification exist, two qualitative studies on genes with variants of unknown significance (VUS) provide insight. In one, most patients expressed neutral emotional reactions to reclassification information to a pathological or benign gene sequence [3]. In another [4], those reclassified to a benign (vs. pathological) gene sequence expressed greater dissatisfaction with the information. Across studies, difficulty understanding reclassification abounded.

Our aims were 1) to document psychological reactions described in the guidelines for reclassification of EFVPTC to NIFTP, and 2) to identify participants' preferences for reclassification information. This formative and exploratory early phase study provides a foundation for a future intervention trial [4], falling within phase 1a of the ORBIT model [5], with the goal of providing early and preliminary support for the relevance

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of a clinically-significant question (for additional details on the ORBIT model for developing behavioral treatments, including Phase 1 designs, see Czajkowski et al., 2015).

2. Methods

2.1. Recruitment and procedures

Participants treated ≤ 10 years ago for a thyroid cancer *other than* *EFVPTC* (to avoid upsetting those who might be reclassified) were identified from electronic health records at a major urban medical center from February–June 2021. After obtaining consent, participants read a hypothetical letter from their physician informing them their thyroid cancer had been reclassified as “not cancer” (see ESM). The interview guide was designed to capture understanding of and emotional reactions to reclassification information, trust in their physicians, and communication preferences (See ESM). Participants received a \$30 gift card. One-on-one interviews with participants were conducted by trained research assistants and advanced doctoral students. The protocol was approved by the appropriate review boards.

2.2. Coding and data analysis

Interviews were recorded and transcribed verbatim. A content analytic approach [6,7] was applied, using Dedoose software (version 9.0.17). Development of initial themes (codes) was conducted by all authors and corresponded to the interview guide. Transcripts were coded by the first and second authors using line-by-line coding in which initial themes were identified and labeled. An iterative process was followed in which irrelevant codes were eliminated and codes were added through discussion among all authors. Discrepancies were resolved through discussion between authors.

3. Results

The nine women interviewed were aged 31–61 and largely non-Hispanic White (88%), with two identifying as Asian and Latina. All had at least a high school degree, half had a graduate degree. Interviews averaged 34 min.

3.1. (not) understanding reclassification and the uncertainty it creates

All participants expressed difficulty understanding the concept of cancer reclassification, despite it being “explained” in the physician’s letter. “*In a quick synopsis—we might’ve screwed up, but this is what we knew at the time, but we would like to reassess or reevaluate the situation with the new knowledge that we have.*” (53-year-old, diagnosed 8 years ago, P21203). Other participants equated reclassification with changes in diagnostic testing: “*Well, I mean, I guess they were telling you that [...] diagnostic tests or whatever are changed now that you didn’t have cancer. To me it’s like if you do a biopsy, [...] whenever you send out for testing, it shows cancer cells, how come if it showed cancer cells in 2012, in 2016, there are no cancer cells? Like what’s the difference? And does that mean — like is it just for that type of thyroid cancer or is this a test that like if you had breast cancer, would that show that maybe those really weren’t cancer cells. Would it be the same thing in different parts of the body?*” (61-year-old, diagnosed 9 years ago, P21209).

Even among participants with a clearer understanding of reclassification, concerns about past and future treatment abounded. Participants wondered, should they continue current treatment, e.g., hormone replacement therapy? If they no longer had cancer, would future care be covered by insurance? Did this new information mean the surgery had been unnecessary? One participant believed that despite having had what would now be considered an unnecessary thyroidectomy, she still would have opted for surgery: “*I’m a type of person who would rather not take chances, so I would rather know that I’m being treated in the most aggressive manner possible,*

instead of a ‘wait and see’ approach” (31-year-old, diagnosed 7 years ago, P21204).

3.2. Reclassification information and psychological distress

Overwhelmingly, participants expressed negative emotional reactions. All but two exhibited anxiety when discussing reclassification, despite the letter being hypothetical. Several expressed distress about having undergone unnecessary surgeries or long-term effects of hormone treatments: “*To think that the surgeries could’ve been unnecessary, and especially the one concern, [...] I don’t know if there’s a correlation or not between this and my huge drop of calcium levels... if I break bones because of this, it would be awful*” (53-year-old, diagnosed 8 years ago, P21203).

Other worries involved future health: “*This is going to be for the rest of my life, I’m going to be monitoring it, and take my medicine daily, I’ve come to grips with it, and that just became my life. And now, this, I think — it would just make me anxious. Like what else is going to change?*” (42-year-old, diagnosed 10 years ago, P21202). Anxiety over past treatments was more common among participants with greater difficulty understanding reclassification: “*The fact that I had the radioactive iodine, I know it can predispose you to other cancers. Is that something that I never should’ve had? It’s concerning. It’s not something I would elect to have.*” (51-year-old, diagnosed 3 years ago, P21201).

Only two participants expressed a positive emotional reaction to reclassification—relief: “*I guess, in some ways relieved, because I think that when you get a cancer diagnosis—and it’s been almost five years since any of my treatments, so I’m definitely almost cancer-free... But you always think about, ‘How might this affect me in the future?’ People who are diagnosed with one form of cancer are often at higher risk for having a second cancer in their lifetime. Or genetics— could this affect my children? ... Certainly, ‘relieved’ is a fair feeling to say*” (31-year-old, diagnosed 7 years ago, P21204).

3.3. Trust in the Medical Profession and One’s physician

Most participants (7 out of 9) expressed great trust in their physicians, accompanied by an understanding of how scientific evidence evolves. The same woman who experienced positive emotions said, “*Just knowing that research changes all the time, and medicine is always developing... it was reassuring to know that, at the time, that this was considered cancer, and so we treated you as such, and now it’s been redefined, because we’ve learned more... I’m not angry, just more reassured that I was treated accordingly*” (P21204). Still, two participants expressed substantial mistrust, questioning whether their physicians might have been aware of upcoming guideline changes: “*I think the surgeon and the doctors would have known that this was happening. So, for them to not tell me that there’s a study underway which may determine that it’s not as malignant as we think it is—just even suggesting that would make me think about whether or not I want to get the surgery tomorrow*” (42-year-old, diagnosed 10 years ago, P21202). Further, there was a concern that reclassification may affect trust in future cancer screenings for one participant: “*If they come back benign, I’d probably trust them. But if they came back as cancer, I’d probably want to have it done again*” (61-year-old, diagnosed 9 years ago, P21209).

3.4. Preferences for the communication of information

We used a hypothetical letter to frame the interview, as the physicians we consulted said they would not have time for individual phone calls. Overwhelmingly, participants expressed the notion that the ideal approach would entail multiple forms of communication, e.g., an initial letter from the endocrinologist/surgeon, followed by a phone call. Others requested resources *before* talking to the physician (e.g., a website link). Participants unanimously felt a letter alone was insufficient, and that personal communication was needed. The sample was split on whether communication should come from treating providers or a (possibly unknown) physician assistant or nurse, but consistently stated that communication should include specifics on future screening and impact on insurance coverage.

4. Discussion and conclusion

4.1. Discussion

Given NIFTP may be one of the first reclassified cancers, we explored a new phenomenon—thyroid cancer survivors' psychological reactions to reclassification and communication preferences. For ethical reasons, we interviewed participants treated for a thyroid cancer *other than* EFVPTC, presenting it as hypothetical. At the end of the interview, participants were debriefed by being provided with further information on NIFTP reclassification and study hypotheses, and had the opportunity to discuss details of the research fully with study staff. For the most part, participants expressed negative emotional reactions and uncertainty, which largely did not affect their trust in providers. While participant views on *which* providers should be communicating with patients varied, the consensus was that multiple forms of communication would be needed to discuss reclassification and its implications in detail. Findings emphasize the importance of communication [8], especially given the association between treatment uncertainty and negative emotional reactions.

A small number of participants experienced mistrust—in line with prior studies on rates of mistrust in one's provider in the general population [9]—and, notably, mistrust was accompanied by requests for clarification and negative emotional reactions such as worry. However, most participants expressed no change in trust in their providers due to reclassification information, in line with prior work on VUS that suggests that variant reclassification can actually build trust between providers and patients by demonstrating that even in the context of uncertainty, their medical case is being managed with ongoing care and reassessed as scientific knowledge evolves [10,11].

Beyond addressing overtreatment, the consensus panel discussion that led to the reclassification of NIFTP was guided by the view that discarding the stigma of a “cancer label” (Titus, 2016) would be beneficial to both future and past patients. However, we found that most participants presented with reclassification information expressed largely negative reactions, including distress and worry about the impact of reclassification on future health and whether the treatments they had received had been necessary. Our study highlights that cancer reclassification may not be universally received as “good news,” and greater research is needed into how to communicate reclassification information as such advances become more common.

How should reclassification be communicated? Unsurprisingly, participants preferred personal communication over letters and voiced a need for two-way communication, with unambiguous and clear information. Across diseases and clinical settings, it is well established that better patient-physician communication can predict lower psychological distress [12-14]—yet physicians at all training levels, however, report a lack of self-assessed preparedness for delivering bad news to patients [15]. Several barriers to effective and patient-centered delivery of bad news have been identified, such as insufficient time, difficulty in being “straightforward” with patients, discomfort, and lack of formal training and resources [15].

In oncology, specifically, patients' unmet communication needs have been previously reported as occurring in 84%–94% of all clinical encounters [16]. Although communication skills training and protocols have been developed for in-person encounters [8], it may be unfeasible for providers to communicate in person with reclassified patients. Diagnostic or prognostic information is usually given in person, but alternative means, such as email, have been found to be appropriate for some patient-centered interactions [17]. Thus, more work is needed on how to communicate reclassification information in a manner both feasible and concordant with patients' needs.

Participants expressed difficulty comprehending the concept of reclassification based on the hypothetical letter provided, and uniformly voiced support for multiple types of communication (e.g. a letter or website coupled with an in-person encounter) over a single form of communication. While the readability of the hypothetical letter developed for this study (Flesch Kincaid grade level of 12.6) was purposefully designed to be in

line with prior studies on patient education resources in palliative care and oncology [18], the use of specific strategies to further improve comprehension of written materials should guide future studies on NIFTP reclassification. Plain language is tied to higher-quality communication in healthcare encounters [19], and recommendations have been made to limit jargon, use short sentences, and second-person pronouns [20,21] in written materials. Future studies may benefit from empirically evaluating materials at a reading level consistent with those seen in regular care—as was the case in our study—compared to materials designed at a lower readability level in order to limit possible bias on understanding reclassification by readability level. Further, future studies combining written and verbal communication—as suggested by our participants—may benefit from including techniques such as the use of metaphors, ask-tell-ask, and teach-back, which could help meet varying levels of health literacy among participants [22].

Likhterov et al. [2] argue for physicians' “moral obligation” to evaluate and inform former patients of possible reclassification, as it may affect future care. However, there is little information about how physicians should present reclassification information in a legal and ethical manner [1]. A single qualitative study of UK health care professionals soliciting their opinions of recontacting patients about changes in genetic test information [23] reported concerns about how to communicate this information, given time constraints and the question of whose responsibility it is to provide this information. Nonetheless, retroactive reclassification is logistically and financially constrained, contingent on old pathology reports or degraded slides. It has now been seven years since the guidelines have changed and the estimated incidence of NIFTP among thyroid malignancies or papillary thyroid carcinomas is approximately 6% [24]. However, patients may be unaware of their disease reclassification because of logistical difficulties by healthcare systems to investigate whether or not patients should be reclassified as having NIFTP [25], which involves finding the (old) pathology slide and re-examining it.

To the best of our knowledge, this study is the first to explore the concept of reclassification of a thyroid cancer diagnosis. This study emphasizes the importance of communication as outlined by Back et al. [8], especially when considering the association between uncertainty about medical treatment and negative emotional reactions.

Nevertheless, a number of limitations affect the generalizability of study findings. While small sample sizes for a Phase 1a study are acceptable within the ORBIT model [5], the sample is composed of women from high socioeconomic backgrounds. Prevalence of small papillary thyroid cancer is four times greater in women compared to men. This, along with pauses on recruitment during the COVID-19 pandemic made recruitment of men difficult. In addition, for ethical reasons, our sample was composed of thyroid cancer survivors who *did not have* EFVPTC, so that it was presented as a hypothetical situation and not applicable for their type of cancer. Future research should be conducted with NIFTP patients receiving reclassification information, and with larger samples with greater gender diversity and range of time since surgery, and with comparisons of different methods of communicating reclassification information.

4.2. Innovation

The fact that negative emotional reactions were predominant even with a hypothetical scenario suggests the need to address the “good news” of cancer reclassification in clinical practice. As this was formative research, future studies with larger samples and EFVPTC patients are needed to develop communication protocols and tools.

4.3. Conclusion

With rapid changes in cancer diagnosis and treatment, understanding patients' emotional reactions helps guide communication. All participants expressed difficulty understanding reclassification and its meaning for future health. Their resultant anxiety and worry is not a personal failing; it reflects the complexity of communicating reclassification. As a

phase 1a study within the ORBIT model [5], we provide early support for a clinically-significant question—specifically, insight into patient reactions and preferences, which can aid providers with informing patients about reclassification.

Funding sources

This work was supported by a grant from the Professional Staff Congress of the City University of New York [Grant Number TRADB-49-347] awarded to Tracey A. Revenson.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgments

The authors would like to thank Samantha Udondem, Alecia Charles, and Beesham Dayal for their assistance with study administration and participant enrollment; as well as the City University of New York's Professional Staff Congress for their funding.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2023.100165>.

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