

Supplementary Online Content

Davies L, Hendrickson CD, Hanson GS. Experience of US patients who self-identify as having an overdiagnosed thyroid cancer: a qualitative analysis. *JAMA Otolaryngol Head Neck Surg*. Published online March 9, 2017. doi:10.1001/jamaoto.2016.4749

eAppendix. Methods

This supplementary material has been provided by the authors to give readers additional information about their work.

eAppendix. Methods

Conduct of the Interviews

The interview guide covered the topics of interest regarding the participants' experience of discovering the thyroid finding and the subsequent events. The guide was pilot-tested during practice interviews and, based on those conversations and the initial interviews, revised until it included all relevant topic areas brought up by the interviewees. Field notes and initial findings of the interviews were reviewed weekly at team research meetings to assist in analysis and preparation for subsequent interviews.

Research Team Description and Participation in the work

Two team members with no prior relationship with any of the research participants (CDH and GSH) conducted all of the interviews. CDH, an endocrinologist, had clinical knowledge of the interview topic areas and basic expertise in qualitative interviewing. CDH conducted approximately half of the interviews, participated in the qualitative data analysis extensively, and assisted in writing the manuscript. No biases or assumptions were identified. GSH, a medical student with a Masters degree in public health, had limited knowledge of the interview topic areas and a basic expertise in qualitative interviewing. GSH conducted approximately half of the interviews, managed the quantitative data and its analysis, participated in the qualitative data analysis and assisted in manuscript writing. No biases or assumptions were identified. LD, a physician with advanced expertise in the research methods and the content area of the work, was the principal investigator. As she had a prior relationship with some participants, she did not conduct interviews. She designed the study, and led the quantitative data analysis and the qualitative data coding, analysis, reduction and interpretation process.

Recruitment

Study candidates were directed to an IRB-approved informational website (archived at www.louisedaviesmd.us) that served as an approved alternative to a signed consent form. Once participants completed that process, interviews were scheduled. At the beginning of each interview, the interviewer again reviewed the information website content and allowed the interviewees to ask any clarifying questions prior to beginning the interview. No deception of interviewees was utilized at any time during this project. The team exclusively utilized email communication with participants prior to and after the interviews.

Interview guide - development and content

Initial development of the interview guide was based on the hypothesis that patients who decide not to have immediate intervention of their thyroid finding have common experiences of detection, decision-making, and surveillance that could be analyzed and collated into coherent themes or domains. The primary objective was to gather data on 1) how patients came to the decision not to intervene on their finding, 2) their experiences of deciding not to intervene, and living with that decision and 3) reasons for shifting from non-intervention to intervention, for people who went on to have an intervention.

Practice interviews were used to refine the interview instrument, resulting in the 'Main Guide'. Audits of field notes and initial findings at the weekly team meetings identified 'Additional areas to explore', which were incorporated into subsequent interviews. The final interview guide is shown in the **Box**.

Box. Interview Guide

Main Guide

How thyroid finding initially discovered
(self, provider exam, incidentally on imaging, etc.)

Decision to not intervene

Experience of not intervening

Personal experiences

Reaction of others (family, friends, providers, etc.)

What led to deciding not to intervene

Information (which information)

Talking to people (who?)

Thinking

Other influences

If surgery, what led to that change in plans

“Based on your experience, how do you feel about knowing about this?”

Additional areas to explore

- impact of word ‘cancer’ on the initial experience
- being upset with the healthcare system
- what would you like to see us have available (or be able to find in general) on the internet about this?

Data analysis

All team members participated in coding of the transcripts. On a rotating basis, one team member served as the primary coder, the second as the secondary coder to confirm accuracy and completeness, and the third as reconciler in the case of disagreement. All members of the team participated in data reduction and interpretation. Theoretical saturation was reached for the major domains of experience for the 18 participants who elected non-intervention. Findings from the four remaining participants who had different paths of experience were more heterogeneous and saturation was not reached.

Redcap¹ Electronic Research Data Capture System (Nashville, TN; hosted by Dartmouth College) was used to distribute secure surveys and manage demographic, quantitative and survey data for the study. Excel was used for numeric calculations of quantitative data (Microsoft,

Redmond, WA). NVivo (version 11, QSR International, Burlington, MA) was used for the qualitative data analysis.

Member checking results

A summary of the interview findings was sent to all participants for review and comment through a secure survey, 15 of 22 participants responded. All 15 responded affirmatively to the question of whether the findings overall reflected their experience accurately. Asked “Tell us your thoughts about the summary in general. What is most helpful or useful to you? What is confusing? What could be better?” 11 out of 15 said they were relieved to see there were others like them *“So refreshing to effectively hear other people tell my story. I thought I was the only one to think this way; it's comforting to know there are others out there.”*

Results

Participants who elected to undergo surgery after a delay.

All three participants who decided to undergo surgery were men, which may be due to chance, but may also partly be due to a consistently stronger tone to the advice they received, because historical data suggest that thyroid cancer is more deadly in men than women (the U.S. mortality due to thyroid cancer is actually the same for men as it is for women, but the case fatality rate is higher in men; women have been more affected by thyroid cancer overdiagnosis than men²). They had the same initial reasoning about non-intervention as those had who decided not to intervene – risk benefit analysis, lack of symptom urgency, recognition of imprecision in cancer. However their reasons to have surgery eventually outweighed the considerations that made them hesitate.

“People essentially...guilted me into it, which was: ‘okay, even if only 1% of men will ever die from this, you have kids. Why would you take a chance that you’re that 1%?’ ... ‘when it’s so easy just to get it removed surgically, why would you take that chance?’ Eventually I gave in to that pressure.” Man, ID#107

“Very significantly is that I have this friend...who had had thyroid surgery years before and [he also] had it at [Academic Center]. Talking to him had a big impact on me also because he just said it was no big deal to have the surgery and then not to have a thyroid gland. He was someone I have a lot of respect for. Very intelligent, smart guy. So that was very big.” Man, ID #128

1. Harris P, Taylor, R, Thielke, R, Payne, J, Gonzalez, N, Conde, JG. Research electronic data capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform.* . April, 2009 2009;42(2):377-381.
2. Davies L, Welch HG. Current thyroid cancer trends in the United States. *JAMA otolaryngology-- head & neck surgery.* Apr 1 2014;140(4):317-322.