

## RESEARCH ARTICLE

# What Do Korean Women Know and Want to Know about Thyroid Cancer? A Qualitative Study

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## Abstract

**Background:** Despite increasing debate about overdiagnosis and overtreatment of thyroid cancer in Korea, information to guide decisions on whether or not to undergo screening for and treatment of abnormal lesions of the thyroid is lacking. Moreover, studies have yet to outline what lay people know and want to know about thyroid cancer. The primary aim of this study was to explore general awareness of thyroid cancer among Korean women, their sources of information, and their satisfaction with the information they are provided. The secondary aim was to investigate information needs about thyroid cancer. **Materials and Methods:** A qualitative study using focus group interviews was conducted. Twenty-nine women were divided into four groups: (1) participants who had never undergone thyroid ultrasound screening; (2) those who had undergone screening, (3) those who continued to undergo regular check-ups with ultrasonography for benign nodules of the thyroid; and (4) participants who had undergone surgery for thyroid cancer. **Results:** A widespread lack of awareness of information on thyroid cancer was noted among participants in groups 1 and 2 who were not well aware of thyroid cancer and generally recognized it as a 'good cancer'. Surprisingly, instead of doctors and medical personnel, most participants reported obtaining information from acquaintances and media outlets. Moreover, most participants described dissatisfaction with their experience with screening and a lack of explanation on treatment and test results from medical personnel. **Conclusions:** Women in Korea seek reliable information on thyroid cancer that could help them to better understand the disease and make informed decisions regarding screening and treatment. More effort is needed from medical personnel to communicate the implications of thyroid cancer, screening results, and treatments thereof to lay people.

**Keywords:** Qualitative study - focus group - thyroid cancer - information needs - lay Korean females

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## Introduction

Over the last few decades, the incidence of thyroid cancer has increased considerably in most parts of the world (Davies and Welch, 2014; Vecchia et al., 2014). In Korea, discoveries of thyroid cancer have skyrocketed, increasing 904% between 1999 and 2012. As well, since 2004, thyroid cancer has ranked as the most common cancer among Korean women (Jung et al., 2015). Many epidemiologic studies have suggested that the recent increases in thyroid cancer incidence correspond to overdiagnosis resulting from wider implementation of highly accurate diagnostic tools for the detection of thyroid cancer, such as thyroid ultrasonography and fine needle aspiration (FNA) biopsy (Zevallos et al., 2014). Overdiagnosis of cancer refers to the detection of unthreatening cancers, which, in the absence of screening, would not progress and would not generate symptoms or signs before a patient dies of other causes. Consequently,

treatments of overdetected cancers are unnecessary (Esserman et al., 2014). In many countries, including Korea, overdiagnosis and overtreatment of thyroid cancer have spurred increasing debate (Ito et al., 2013).

Providing people with adequate information on cancer in relation to prevention, diagnosis, treatment methods, etc. is important (Ankem, 2006; Tsuchiya and Horn, 2009). Patients have a right to know about their disease, and information thereon can help alleviate psychological anxiety. Additionally, by actively communicating with medical personnel, individuals can better manage their diagnosis and determine whether seeking treatment is the right choice for them (Tsuchiya and Horn, 2009; Reyna et al., 2015). Regarding thyroid cancer, information needs may vary according to an individual's experience with thyroid screening or within which phase of the cancer care continuum (watchful waiting, diagnosis, surgical treatment, and long-term medication after surgical removal) a patient may be. Despite the controversy

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surrounding overdiagnosis and overtreatment in thyroid cancer, there is a lack of information available to lay people with which to help them better understand the debated issues, decide whether or not to undergo screening, and determine an appropriate management course for abnormal lesions of the thyroid (Yi et al., 2015).

To our knowledge, studies have not yet to investigate informational needs about thyroid cancer among the general public. Thus, we conducted a qualitative study to elicit information needs about thyroid cancer among Korean women according to their experiences with thyroid ultrasonography, the number of times they have undergone screening, and whether or not they have undergone surgery for thyroid cancer. The primary aim of this study was to explore the women's general awareness of thyroid cancer, sources from where they typically obtained information on thyroid cancer, and their satisfaction with the information they were provided. The secondary aim was to investigate information needs about thyroid cancer among the women.

## Materials and Methods

### *Study subjects*

Despite increases in the incidence of thyroid cancer for both men and women of Korea, rates remain relatively high for Korean women. As well, opportunistic screening for thyroid cancer might be associated with the implementation of a nationwide organized cancer screening program in Korea, especially for breast cancer (Ahn et al., 2014). For these reasons, we focused on women in this study.

The interviewees consisted of woman aged 30-69 years who visited the National Cancer Center in Korea and were recruited on a first-come-first-served basis among those who wished to be interviewed. The ideal number of participants for a focus group interview (FGI) is six to 10 people per group (Yi et al., 2015), and we aimed to recruit five to 10 women per group in this study. Among 51 applicants, we excluded those who did not meet criteria for inclusion in this study or could not participate in the interview due to scheduling conflicts. Finally, 29 applicants were chosen to participate in the interview.

Participants were divided into four groups according to their experiences with thyroid ultrasonography, the number of times they had undergone screening, and whether or not they had undergone surgery for thyroid cancer. Each group was defined as follows: 1) participants who have never undergone thyroid ultrasound screening; 2) participants who have undergone thyroid ultrasound screening; 3) participants who continue to undergo regular check-ups with ultrasonography because of benign nodules of the thyroid; and 4) participants who have undergone surgery for thyroid cancer.

### *Data collection*

We conducted FGIs to collect data. Interviews were conducted four times in August 2014 in a conference room at the National Cancer Center, Goyang-si, Gyeonggi-do, Korea. The FGIs lasted from 1.5-2 hours, ending only after all participants had finished answering all questions and the interviews had come to a natural conclusion.

All interviews were conducted by a single researcher (moderator) majoring in health communication with ample experience in conducting FGIs as a principal investigator.

The FGIs consisted of the following parts: explanation of the purpose of the research, description of the interview process, signing of an informed consent form to participate in the research, a survey to collect socio-demographic and general characteristics of the participants, a warm-up discussion, and a detailed discussion of several of open-ended questions (Table 1). The open-ended questions were consensually agreed upon by a research team after pilot testing involving three participants.

### *Data analysis*

All interviews were recorded and the contents thereof were transcribed verbatim. Two researchers independently reviewed all transcripts, developed initial codes, and analysed transcripts to identify categories and themes. The researchers looked for similarities and differences in the codes and the relatedness of statements with these codes to establish analytical categories and key concepts. The codes and concepts were finally classified into several themes. All statements were translated into English by two researchers and a professional translator. Thereafter, the research team confirmed that the contents in both Korean and English matched. In pre-interviews, all participants were asked to conduct a short survey. The contents of the survey were designed to assess basic socio-demographic and general characteristics of the participants. Socio-demographic and general characteristics were encoded and analysed by frequency analysis.

### *Ethical considerations*

This study was approved by the Institutional Review Board of the National Cancer Center, Korea (approval no. NCCNCS-08-129). After explaining the purpose, contents, and methods of this study, an interview was permitted only for participants who understood the research purpose and signed an informed consent form. All participants granted their permission to have the interviews recorded, and were rewarded about 70 US dollars in appreciation of their time.

## Results

### *Characteristics of the study population*

A total of 29 women took part in four discussion groups; the number of women per group ranged from five to 10. The demographic characteristics of all 29 participants in this study are listed in Table 2.

### *General awareness of thyroid cancer and thyroid cancer screening*

When asked about thyroid cancer, as shown in Table 3, the participants who had never undergone thyroid ultrasound screening (group 1) reported fragmented knowledge about thyroid cancer. Generally, they understood thyroid cancer to be a 'good cancer', meaning slow-growing with a high survival rate, and thus, did not regard it as serious.

*"I heard about thyroid cancer before, but when I looked at the questionnaire today, I think I was ill-informed. I only*

know that thyroid cancer does not spread to other organs. One of my friends got thyroid cancer, so I just heard a little, but not in detail (1A, participant in their fifties).”

“I knew of someone who got thyroid cancer, but I heard it is a ‘good cancer’. People around me said that if thyroid cancer is detected early it can be cured very easily. Also, I heard it does not metastasize to other organs early, so I did not regard it [thyroid cancer] as serious (1C, participant in their sixties).”

“These days, compared to the past, many people are getting thyroid cancer. However, I do not know much about thyroid cancer (1G, participant in their sixties).”

Participants who had undergone thyroid ultrasound screening (group 2) also generally thought of thyroid cancer as a ‘good cancer’ that mostly afflicts women. However, they reported knowing little about the function and location of the thyroid, as well as risk factors for thyroid cancer.

“Frankly speaking, I do not understand the questionnaire items. I really do not know how thyroid cancer occurs. Many people around me have gotten

thyroid cancer, so I have received and intend to undergo examination in the future. I am concerned, however, that I do not really know the risk factors for thyroid cancer (2B, participant in their fifties).”

“I have heard of thyroid cancer. I heard that thyroid cancer is not only easy to treat but also easy to detect. Compared to other cancers, thyroid cancer is not scary or a big concern for me. That said, I do not know the exact location and role of the thyroid in our body (2E, participant in their forties).”

Participants who continued to undergo regular check-ups with ultrasonography because of benign nodules of the thyroid (group 3) knew of symptoms related to abnormalities of the thyroid.

“If there is a problem with the thyroid, we know that one can feel tired, demotivated, and depressed (3A, participant in their fifties).”

“I have heard about thyroid cancer. I know that it can lead to hormonal dysfunction and physical deterioration (3C, participant in their thirties).”

Participants who had undergone surgery for thyroid

**Table 1. Open-ended Questions Used during the Interview**

1. Key questions	
Have you heard about thyroid cancer?	
What do you know about thyroid cancer?	
From where did you mainly obtain information on thyroid cancer?	
Have you heard about thyroid cancer screening?	
What do you know about thyroid cancer screening?	
From where did you mainly obtain information on thyroid cancer screening?	
What kind of information about thyroid cancer do you need?	
2. Additional questions	
What motivated you to undergo thyroid ultrasonography? (for groups 2,3,4)	
What motivated you to undergo a biopsy of nodules? (for groups 3,4)	
What motivated you to undergo surgery for thyroid cancer? (for group 4)	
Were your examination results sufficiently explained to you by your doctor? (for groups 2,3,4)	
In what ways were you satisfied or dissatisfied with the examination? (for groups 2,3,4)	
Were you given sufficient explanation about the procedure and methods of the surgery? (for group 4)	
In what ways were you satisfied or dissatisfied with the surgery? (for group 4)	

**Table 2. Demographic Characteristics of the Participants**

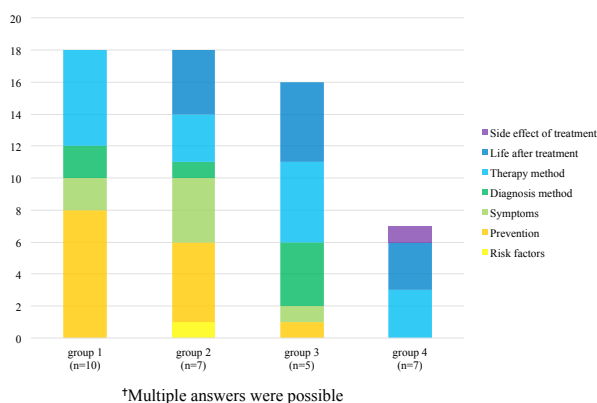
Variable	Total		Group 1		Group 2		Group 3		Group 4	
	N	%	N	%	N	%	N	%	N	%
Age										
30s	9	31	2	20	3	43	1	20	3	43
40s	7	24	3	30	1	14	2	40	1	14
50s	10	35	3	30	3	43	2	40	2	29
60s	3	10	2	20	-	-	-	-	1	14
Work status										
Not working	17	59	6	60	4	57	4	80	3	43
Working	12	41	4	40	3	43	1	20	4	57
Household income										
<200	6	21	4	40	-	-	-	-	2	29
200-400	8	28	3	30	-	-	3	60	2	29
400-700	10	34	2	20	5	71	1	20	2	29
700<	5	17	1	10	2	29	1	20	1	14
Education level										
≤Middle school	1	3	1	10	-	-	-	-	-	-
High school	11	38	5	50	1	14	1	20	4	57
University≤	17	59	4	40	6	86	4	80	3	43
Thyroid cancer screening among family/acquaintances†										
Yes	19	66	4	40	6	86	3	60	6	86
No	10	34	6	60	1	14	2	40	1	14

†Among your family and acquaintances, is there anyone who has undergone ultrasonography to screen for thyroid cancer?

**Table 3. General awareness of Thyroid Cancer and Information Sources**

	General information	Information sources
Group 1 (n=10)	<ul style="list-style-type: none"> <li>• Good cancer (6)</li> <li>• Not well known (2)</li> <li>• Others (2)</li> </ul>	<ul style="list-style-type: none"> <li>• Acquaintances (9)</li> <li>• Internet (3)</li> <li>• TV (2)</li> </ul>
Group 2 (n=7)	<ul style="list-style-type: none"> <li>• Good cancer (3)</li> <li>• Not well known (3)</li> <li>• Women get frequently (3)</li> <li>• Both sexes get commonly (2)</li> <li>• Others (1)</li> </ul>	<ul style="list-style-type: none"> <li>• Acquaintances (4)</li> <li>• TV (3)</li> <li>• Newspaper/Magazine (1)</li> </ul>
Group 3 (n=5)	<ul style="list-style-type: none"> <li>• Symptoms of thyroid abnormality (3)</li> <li>• Treatment of thyroid cancer (1)</li> <li>• Function of thyroid (1)</li> <li>• Good cancer (1)</li> </ul>	<ul style="list-style-type: none"> <li>• Internet (4)</li> <li>• TV (3)</li> <li>• Newspaper/Magazine (2)</li> <li>• Acquaintances (2)</li> <li>• Medical personnel (2)</li> </ul>
Group 4 (n=7)	<ul style="list-style-type: none"> <li>• Good prognosis (3)</li> <li>• Risk factor of thyroid cancer (2)</li> <li>• Good cancer (2)</li> <li>• Types of thyroid cancer (1)</li> <li>• Others (1)</li> </ul>	<ul style="list-style-type: none"> <li>• Internet (3)</li> <li>• Acquaintances (3)</li> <li>• TV (2)</li> <li>• Newspaper/Magazine (1)</li> </ul>

†Multiple answers were possible



**Figure 1. Information Needs about Thyroid Cancer**

cancer (group 4) were aware that thyroid cancer has a better prognosis than other cancers and that the main risk factor is stress. One participant knew detailed information about thyroid cancer (e.g., types of thyroid cancer).

“Although thyroid cancer has a good prognosis, it occurs frequently due to stress, rather than genetic problems. I heard that younger individuals with thyroid cancer show rapid progression, so they should get surgery quickly (4B, participant in their thirties).”

“Thyroid cancer has an excellent prognosis and a higher survival rate, compared to cancers at other sites. It only affects one’s quality of life (4G, participant in their thirties).”

Nine of the 10 participants (group 1) who had never undergone thyroid ultrasound screening knew very little about thyroid ultrasonography. Five participants knew of thyroid ultrasonography, one of whom had heard about it from a family member; the other four participants had never heard about thyroid ultrasonography.

“I have never heard about thyroid ultrasonography. Nobody around me has ever undergone thyroid ultrasound examination. I have only heard about ‘taking medicine’ because of thyroid dysfunction; I have not heard about ultrasonography (1D, participant in their forties).”

“I have never heard about ultrasonography from those around me. I did not know that thyroid cancer can

be detected by ultrasound, but I do know someone who was diagnosed with thyroid cancer through biopsy (1G, participant in their sixties).”

*Information sources*

Regarding where the participants had obtained information on thyroid cancer, most participants reported learning about thyroid cancer through acquaintances and media outlets (e.g., internet and TV). Surprisingly, few participants reported obtaining information from their doctors or medical personnel. The women described difficulties with obtaining detailed information from doctors and medical personnel, which forced them to rely on people they knew and mass media sources (Table 3).

“I got information from the internet and books. It is hard to get information from doctors, so I looked it up by myself. (4B, participant in their thirties).”

“A lot of information can be obtained from various media outlets or people around me, rather than medical personnel (2A, participant in their fifties).”

*Unsatisfactory experiences with information provided*

Most participants who had undergone thyroid ultrasound screening (group 2) were dissatisfied with a lack of sufficient explanation from their doctors and medical personnel. Particularly, participants expressed desires to hear more detailed explanations of test results and how to differentiate abnormal lesions from normal tissue, in addition to simple and general knowledge about the thyroid.

“I recently underwent thyroid ultrasonography, but my doctors did not thoroughly explain about thyroid cancer. I felt that they were just trying to finish the test quickly. In reality, it is hard to request information about thyroid cancer from doctors or medical personnel during examination (2A, participant in their fifties).”

“I underwent thyroid ultrasonography during a health check-up, but I could not get a thorough explanation of my results from medical personnel. Doctors have medical knowledge, and they just told me I was ‘clean’. Common people like me do not understand if additional explanation



is not given (2D, participant in their thirties)."

Two of the participants who underwent FNA biopsy said that they were not instructed that the biopsy would be conducted with a needle and felt disappointment with a lack of explanation from their doctors thereon.

"When I underwent ultrasonography the first time, twelve cysts were found, so I underwent a biopsy upon recommendations from my doctors. Trusting him, I decided to take the test [FNA], but I did not know that the fine needles could get into my body. If they had explained this to me before the test, I would not have been as caught by surprise (3B, participant in their forties)."

"I feared that the benign nodules would transform and become malignant. I was dissatisfied that there was no preceding explanation about the biopsy. I thought they would put me under anaesthesia, but I was wrong. The doctor gave me some papers with some information, but I did not read that carefully. I think doctors did not explain the procedure enough. From the perspective of patients, I wish doctors would explain a lot more (3D, participant in their forties)."

Seven participants who underwent total thyroidectomy were recommended to do so by their doctors. However, some of them stated that, from their perspective, a partial thyroidectomy would have been a better choice, because the side effects of the total thyroidectomy were a source of tremendous stress. They further explained that they were not fully aware of the side effects of the surgery beforehand and that greater access to more detailed information thereon is needed to help guide decisions on whether or not to undergo surgery.

"My biggest regret is undergoing surgery. If I knew surgery was not mandatory, I would not get it. I gained more than 30 kg, and my hair and finger nails are getting worse. They are not like they used to be. I am stressed about the large scar on my body. When I go on business trips, it is difficult to take all my pills at the right time. If I knew all of these matters before the surgery, maybe I would not have gotten the surgery. I feel so tired now after my surgery, and my life is not like before (4D, participant in their thirties)."

"My doctors said that there could be a risk of metastasis, so I decided to get surgery quickly. However, after complete excision, the quality of my life has reduced. If I could have only undergone half excision, I would feel more comfortable. I regret that I did not (4G, participant in their thirties)."

#### Information needs about thyroid cancer

Concerning information that women wanted to know about thyroid cancer (Figure 1), participants who had never undergone thyroid ultrasound screening (group 1) mainly wondered about prevention and treatment.

"I think it is important to know information on prevention of thyroid cancer in order to not get cancer (1D, participant in their forties)."

"I would like to know more about treatments and diagnosis of thyroid cancer, because it is hard to get that information (1E, participant in their thirties)."

Participants who had undergone thyroid ultrasound screening (group 2) wanted to know information on

prevention, symptoms, quality of life after treatment, and how to go about treating thyroid cancer.

"I would want to know about the quality of life after treatment, because I have experienced it already [her husband underwent treatment for thyroid cancer] (2C, participant in their fifties)."

"I want to know everything [prevention, symptoms, quality of life after treatment, etc.] (2A,

Participants who continued to undergo regular check-ups with ultrasonography because of benign nodules of the thyroid (group 3) were mainly concerned about information on diagnosis, treatment, and quality of life after treatment.

"I am concerned about prevention and quality of life after treatment (3A, participant in their fifties)."

"I wonder about the treatments, how long it takes for rehabilitation after treatment, whether drugs should be continued, my voice condition after the surgery, how to restore my voice, etc. (3B, participant in their forties)."

Finally, participants who had undergone surgery for thyroid cancer (group 4) reported a need for detailed information on treatment procedures and quality of life after treatment.

"I would want to get more detailed information about thyroid cancer. If I were to get surgery, I would want information on quality of life after surgery and details about the surgical procedure in advance. Prior to undergoing surgery, I did not know my entire thyroid would be removed (4C, participant in their sixties)."

"I would want to know the side-effects after treatment. I think we need some form of outlet through which we can communicate directly with doctors to obtain appropriate information on any condition (4E, participant in their fifties)."

## Discussion

This qualitative study highlights several important issues: First, we identified a widespread lack of awareness of thyroid cancer among women who had never undergone thyroid ultrasound screening (group 1), as well as those who had (group 2). Compared to these two groups, women who continued to undergo regular check-ups with ultrasonography for benign nodules of the thyroid (group 3) and who had undergone surgery for thyroid cancer (group 4) were better able to list and describe accurate information on thyroid cancer in greater detail. Second, except for two participants in group 3, none of the women reported seeking information from their doctors or medical personnel. Instead, most relied on information from acquaintances and media outlets. As well, most expressed dissatisfaction with a lack of explanation of test results and treatments from their doctors and complained about unfriendly attitudes therefrom. Third, the amount and type of information women wanted differed according to experiences with thyroid cancer screening and treatment.

Generally, thyroid cancer is known to be a 'good cancer', with a survival rate near 100% when caught in early stages, and to have a good prognosis after treatment. In this study, both women who had and had not undergone thyroid ultrasound screening were ill-informed about

thyroid cancer; they only understood it to be a 'good cancer'. Interestingly, a few women who continued to undergo regular check-ups with ultrasonography for benign nodules of the thyroid and a few who had undergone surgery for thyroid cancer also described thyroid cancer as a 'good cancer'. These findings are similar to those of a recent study in which patients with thyroid cancer who were told that they have a 'good cancer' did not view their disease to be serious (Gamper and Sztankay, 2015).

Unfortunately, only a few women were well-informed about thyroid cancer, and most people had obtained information from acquaintances and media instead of medical personnel. Numerous studies have reported that people want to hear detailed explanations of test results and any potential disease from their doctors, but face difficulties in getting relevant information from them (Rutten et al., 2005; Squiers et al., 2005; Smith et al., 2010). Although there are countless channels for obtaining health information, people want to be assured that they are receiving correct and reliable information (Hummelinck and Pollock, 2006; Bolderston, 2008), particularly information from specialized doctors and medical staff. Accordingly, medical personnel in Korea must strive to provide lay people, out of respect for their personhood, with more detailed information on thyroid screening and treatment.

This study highlights the information needs of Korean women about thyroid cancer. Most women who had never undergone thyroid ultrasound screening wanted information about prevention and treatments of thyroid cancer, while those who had undergone thyroid ultrasound screening wanted more specific information than the group above. They wanted to know general information about every aspect of thyroid cancer. Women who underwent surgery for thyroid cancer wanted specific information regarding side effects and quality of life after surgery, which they had not received. Generally, people want as much information as they can possibly get regarding checking for cancer (cancer screening), treatment, and post-operation (Luker et al., 1996; Degner et al., 1997; Graydon et al., 1997; Rutten et al., 2005).

This study was conducted only for women in their 30-60s; therefore, needs about information among people of other socio-demographics may differ. Notwithstanding, as there is no study on information needs about thyroid cancer, this study makes an important and timely contribution for furthering debates about what people know and want to know about thyroid cancer. Furthermore, although this qualitative study comprised a small number of participants, which would suggest a lack of representativeness, participants could share and discuss their opinions about this specific topic more freely and in greater depth (Gamper and Sztankay, 2015). In future research, comparative analysis of studies with people of more diverse socio-demographic backgrounds in relation to this study will help further our knowledge of how best to communicate information regarding thyroid cancer screening and treatment.

In conclusion, This study demonstrated that information needs about thyroid cancer among Korean

women are high and that Korean women are not satisfied with the information they have been given or are able to obtain. Doctors and medical staff should be aware that information needs about thyroid cancer fluctuate in relation to an individual's experiences with screening and treatment and that people continue to desire accurate and detailed information regardless of their familiarity with the disease. According to our results, more work is needed on the part of medical personnel to communicate the implications of thyroid cancer, screening results, and treatments of thyroid cancer to lay people.

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