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[Original article]

Psychosocial support for the examinees and their families during the secondary confirmatory examination : Analyses of support records at first visit

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Abstract

Background and Purpose

The Thyroid Ultrasound Examination (TUE) program is conducted as part of the Fukushima Health Management Survey. Following the established criteria, examinees are called in for a secondary confirmation examination, which may induce high anxiety related to a thyroid cancer for both the examinees and their families. Therefore, Fukushima Medical University created the Thyroid Support Team to reduce anxiety. The purpose of this study is to analyze the psychosocial support for examinees and their families through two types of records, and to clarify the current issues and determine future directions of support.

Materials and methods

We analyzed 223 records of support for the first visit of examinees who attended the secondary confirmatory examination, conducted at Fukushima Medical University from September 2018 to March 2019.

Results

During the first visit, frequent topics and questions brought up by the examinees and their families were about the "Thyroid Ultrasound Examination (TUE) program" and "Examination findings". The Thyroid Support Team members assisted them by "Responding to questions", "Confirming the doctor's explanation" and "Providing information". The percentage of people with high anxiety decreased in both examinees and their family members after the examination. The level of anxiety was lower among those who had already taken the secondary confirmatory examination. Family members' anxiety was significantly higher than that of the examinees, and anxiety levels were highly correlated between examinees and their families.

Conclusion

The psychosocial support for examinees and their families was important in reducing their anxiety. Currently there are changes in social conditions and various opinions concerning the TUE. Thus, careful explanation and the need for decision-making supports for the examinees and their

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families increased. Also, we should take into account the aging of the examinees and expanding the available psychosocial support.

Key words : psychosocial support, Ultrasound Thyroid Examination (TUE), the secondary confirmatory examination, Thyroid Support Team

Introduction

The Great East Japan Earthquake on March 11, 2011 not only caused earthquake damage, but also the resulting tsunami-triggered a nuclear hazard event that dispersed radioactive substances into the environment. The accident at the Fukushima Daiichi Nuclear Power Station has continued to have various forms of influence in Fukushima even 10 years later. Approximately 185,000 residents of Fukushima Prefecture were forced to evacuate immediately after the earthquake and even today, it is estimated that more than 40,000 people remain exiled from their homes, both in and out of the prefecture. Since this accident was rated as a Major Accident (Level 7) by the International Atomic Energy Agency (IAEA), equivalent to the 1986 Chernobyl disaster, great concern arose about a possible increase in the number of childhood thyroid cancer cases, one of the effects of Chernobyl. As a result, starting in October of 2011, Fukushima Prefecture began a large-scale Thyroid Ultrasound Examination (TUE) program for children[1,2].

The TUE program is a part of the Fukushima Health Management Survey conducted by the Radiation Medical Science Center of Fukushima Medical University, commissioned by Fukushima Prefecture. Approximately 385,000 children aged 0 to 18 who were living in Fukushima Prefecture at the time of the earthquake are examined once every 2 years[1,2]. The examinations consist of primary and confirmatory examinations. The primary examination (E1) consists of an ultrasound examination on the thyroid. If nodules measuring >5.0 mm and/or cysts measuring >20.0 mm in diameter are found, a secondary confirmatory examination (E2) is scheduled. E2 includes a precise ultrasound examination, blood and urine tests, and fine-needle aspiration cytology if sonographic findings of nodule or cysts met the FNAC criteria. The survey was divided into the Preliminary Baseline Survey and the Full-scale Survey. The Preliminary Baseline Survey began on October 9, 2011 and was mostly completed by the end of March, 2014[3]. The first Full-scale Survey was conducted from April, 2014 to the end of March, 2016. Thereafter, all subjects have been and will be included in further Full-scale Surveys every two years until they reach the age of 20, and every five years after that for the rest of their lives[4]. By March 31, 2020, the third Full-scale Survey (the fourth-round survey) was almost complete.

After the nuclear power station accident, residents in Fukushima Prefecture became extremely anxious about the impact on their health due to radiation exposure. The exposure doses received by the residents immediately after the disaster were uncertain due to the lack of direct measurements[5], and the residents tended to directly correlate results of the thyroid examinations of their children to the effects of radiation exposure[6]. Many family members had strong anxiety and blamed themselves, especially in regards to the actions that they took to protect their children. Examples include not evacuating and staying behind right after the accident, and unknowingly moving to higher contaminated areas. This gave a lot of people strong feelings of anxiety and guilt. And family anxiety about thyroid cancer was heightened by the discovery of even a small nodule or cyst[7,8].

These substantial concerns and fear of thyroid cancer were particularly high for examinees and their families during E2. Since the psychological impact of disasters is particularly high on mothers with children, programs and/or psychosocial support for children and families are recommended to reduce psychological distress and post-disaster impact and promote adaptation[9,10]. Addressing the strong needs for improving quality of life (QOL), even if disaster effects are not life-threatening, is considered to be one of the most important public health challenges[11]. In response, Fukushima Medical University established its Thyroid Support Team in November of 2013 to provide psychosocial support to those examinees and their families.

Currently, the Thyroid Support Team consists of 4 members (3 nurses and 1 psychologist). We support examinees and their families twice a week during E2 and also on other days for those who are referred to the departments of thyroid surgery and internal medicine for treatment and follow-up at Fukushima Medical University Hospital.

At present, several years after the nuclear acci-

dent, the importance of psychosocial support for examinees and their families has been emphasized[12], but there are few reports concerning related issues. Taking into consideration that E2 tends to increase the anxiety level of examinees and their families compared to E1, it is important to devise appropriate strategies for them on the basis of the current situations. Therefore, the purpose of this study is to evaluate the psychosocial support provided by the Thyroid Support Team for examinees and their families, and to sort out future support issues.

Materials and methods

The flow of psychosocial support by the Thyroid Support Team in E2 is as follows.

An examinee usually visits at least twice during E2. One support member will be assigned to each examinee. On the first visit, the examination procedure is explained prior to the actual examination. Then the medical and sonographic examination are conducted by medical doctors followed by blood and urine examinations. The results of the ultrasound examination are explained by the doctors on the same day. At the second visit, the results of blood and urine examinations are explained. If fine-needle aspiration cytology (FNAC) is not needed to confirm the diagnosis, that set of E2 is concluded, and information on taking future TUE is provided.

Support team members try to listen carefully to the examinees and their families' anxieties and thoughts before and after the medical doctor's examination, to ease their tension and sufficiently communicate with them. Additionally, before the examination starts, we encourage the examinees and their families to ask questions of medical doctors and staff about any issues that remain unclear.

Also, the support member always accompanies the examinee and his/her family and listens to the medical doctor's explanation together. After the examination, we take the time to talk with them to confirm that they understood the explanation, and if necessary, provide further supplementary explanations and information. Throughout the examination, the support member tries to encourage the examinees and their families to express their feelings and thoughts in their own words.

As a result of the Preliminary Base-line Survey and past Full-scale Surveys, FNAC was not required for nodules in many participants who subsequently underwent the confirmatory examination after the primary examination[7,8]. However, the sonographic findings of the thyroid nodules sometimes meet the guideline for implementation of FNAC in E2[9]. In such a situation, a very heavy psychological burden can occur in examinees and their families. Therefore, in this situation, after the medical doctor explains the necessity of the examination, the support team members take sufficient time to try to alleviate the anxiety of the examinee and his/her family.

Sometimes, it is recommended that examinees continue follow-up and treatment using their health insurance. For example, when the thyroid nodules are diagnosed as malignant and interpreted to be unsuitable for medical follow-up, the examinee is referred to the thyroid surgery department and counseled about surgical treatment. When the treatment is started under health insurance, we deliver the prospects for the future and information about procedures while answering questions and carefully attempting to alleviate the anxiety of the examinee and his/her family.

One support team member keeps two types of records (detailed below) during and after such support.

Objects of analysis

The analysis was based on two types of support record of examinees who had undergone E2 conducted at Fukushima Medical University during the seven-month period from September 2018 to March 2019. The number of examinees given support during this period was 408 (236 examinees), which consisted of 223 for the first E2 visit, 158 for the second visit, and 23 for additional visits (FNAC and/or its explanation). In the present study, we analyzed the support records for the 223 first visits (69 males and 154 females).

The two types of records are a check-off sheet of support records (Record 1), on which support members marked with a number at each visit, and a free detailed description of support which the support members recorded after the examination (Record 2).

Record 1 is a unique chart, as shown in Table 1, in which we extracted items based on our experience. The thyroid support member who was in charge of the examinee on the day selected the appropriate option for each of the items, "Basic information", "Concerns of examinees/family", "Level of anxiety", and "Support". In addition, for each item, "item definitions" and "check criteria" were created so that would be as little bias as possible among the support members. For the analysis, every item in Record 1 was first tabulated. Second, in order to see changes in "anxiety level", in both pre- and

Table 1. Items of Record1

1) Basic Examinee Information	
① Gender	1. male 2. Female
② Age	number
③ Student or other (working adult etc.)	1. sutudent 2. other
④-1 Previous confirmatory examination taken	1. Yes 2. No
-2 Number of confirmatory examination taken	number
⑤ Family history of thyroid disease	1. Yes 2. No
2) Contents of consultation	
① Examination findings	1. Yes 2. No
② Program of TUE (Thyroid ultrasound examination)	
③ Causes	
1. Radiation 2. Heredity 3. Daily life style	
4. Diet 5. Others	
④ Health insurance treatment	
⑤ Examinee's health problems	
⑥ Examinee's mental and social problems	
⑦ Examinee's future matters	
⑧ Reflections on the time of the earthquake	
⑨ Social support	
⑩ Medical subsidies and services	
⑪ Dietary habits and lifestyle concerns	
⑫ Others	
3) Examinee's and Family Members' Anxiety Level	
Anxiety Level	1. Very Low 2. Low 3. High 4. Very High 5. Absent 6. Unknown
4) Support	
① Listening to examinee's thoughts	0. Not conducted or 1. Conducted
② Listening to family's thoughts	
③ Confirmation of the doctor's explanation	
④ Responding to questions	
⑤ Feedback to medical doctors	
⑥ Providing information	
1. Next and/or future TUE rounds	
2. Treatment	
3. Special telephone number for medical information	
4. Subsidies	
5. Supplemental explanations	
6. Offering pamphlets	
7. Others	
⑦ Daily life and dietary habits support	
⑧ Self health management	
⑨ Decision-making support for future rounds of TUE	
⑩ Decision-making support for FNAC and medical care	
⑪ Others	

2-2) TUE : schedule of E2 in this round of TUE and/or next round of TUE
2-5) health problems : relationship between thyroid nodule (s) and examinees current symptoms, etc
2-6) mental and social problems : very shy, school truancy, etc.
2-7) future matters : going to higher education, future careers, etc
2-8) Reflections on the time of earthquake : actions and feelings (guilty and anxiety etc.) at the time of the earthquake
2-11) dietary habits : thyroid-related dietary life such as intake of iodine, etc.

post- examinations, and in examinees- and families-, a McNemar test was conducted over the degree of the examinee's and their family members' anxiety setting Very High/High as the "high anxiety group" and Very Low/Low as the "low anxiety group", excluding "Absent" and "Unknown", and calculated a significance probability. Next, Spearman's correlation coefficient and significance probability were calculated to evaluate the relationship to the degree of each examinee's and their family members' anxiety levels. Furthermore, we hypothesized, based on our experience that people who underwent E2 for the first time would have a higher level of anxiety. Thus, a t-test was conducted for each anxiety level with and without E2 history, in order to calculate a p-value. The risk ratio of significance level was set at <0.05 or lower.

Also, we extracted the questions from Record 2 which were asked by the examinees and their families during the support. These statements were intercepted one by one and given code names. Then, the similar code names were classified into several categories, and the final category names were generated by two analysts. One analyst is a psychological researcher and the other a medical researcher, both with more than 20 years of experience.

This study was approved by the Research Ethics Committee of Fukushima Medical University (approval number 2019-113).

Results

General Characteristics

The basic characteristics of the 223 first-visit examinees are shown in table 2. 217 (97.3%) were students and the average age was 16.0 years. The AYA (adolescent & young adult) generation, aged 15 and older, accounted for more than 70% of the examinees. Over 90% of the examinees were residents of the Naka-dori area, which is located in the central part of Fukushima prefecture and where approximately one third of the target persons were living. 74 examinees (33.2%) were found to have taken E2 before ; Forty-seven were taking it for the second time, 24 for the third time, and 3 for the fourth time.

Contents of consultation

Figure 1 shows the content of consultation from examinees and their families during the first visit. The most frequently consulted context was about "Program of TUE" including its procedures, schedule and system at this- and the next- round of examination, followed by the "Examination findings" and "Health issues" of the examinees. There were 30 cases of cousultation for the "Cause" of growing nodules including 15 inquiries concerning heredity such as a family history of thyroid disease, and 9 about the impact of radiation on their health.

Degree of anxiety

Figures 2 and 3 show the change in the degree of anxiety level pre- and post- examination as evaluated by the support team members. Family members are often more anxious than examinees before the examination, and approximately half of them showed High and Very High levels of anxiety. However, after the examination, the percentage of high-level anxiety decreased to about 11% for both examinees and family members.

According to the results of statistical analyses, the degree of anxiety before and after the examination significantly decreased for both examinees and families ($p<0.01$). Also, the percentage of families with a high level of anxiety was higher than that of the examinees ($p<0.01$), both pre- and post- exam. Spearman's correlation coefficient of examinee and family anxiety was 0.519 before the examinations ($p<0.01$), and 0.644 afterwards ($p<0.01$), both of

Table 2. Basic Information of Examinees ($n=223$)

	n (%)
Female	159 (69.0%)
AYA generation (≧15 years)	163 (73.1%)
Area : Naka-dori[1)]	201 (90.1%)
Accompanied by family	217 (97.3%)
Taken confirmatory examination before	74 (33.2%)
Family history of thyroid disease[2)]	36 (16.1%)

1) Naka-dori is central Fukushima prefecture
2) Family history of thyroid disease includes a relative's thyroid tumor, thyrotoxicosis such as Graves' disease, and hypothyroidism such as Hashimoto's thyroiditis, etc.

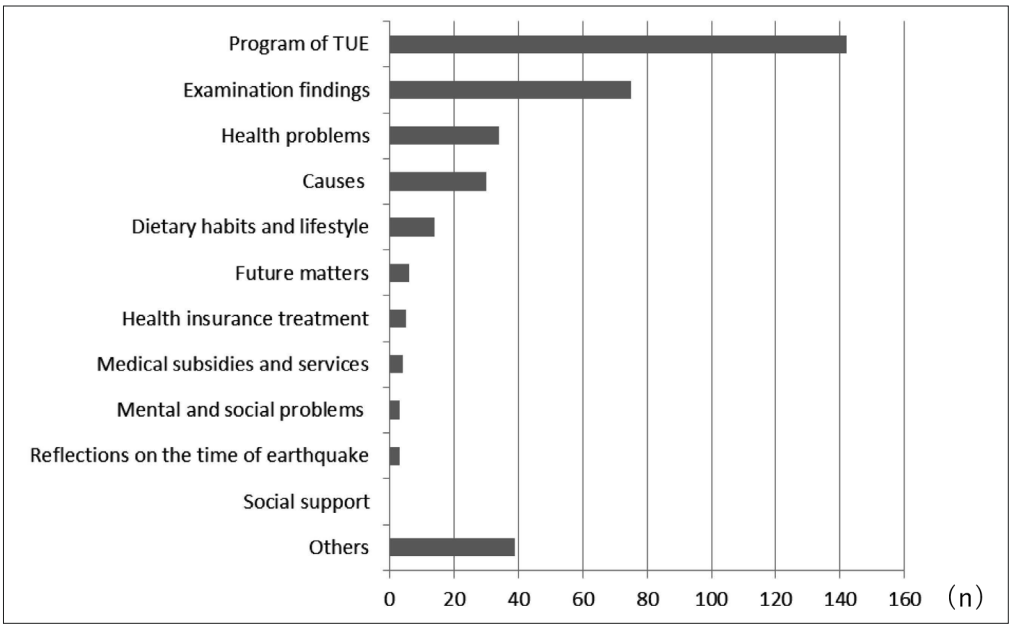

Figure 1. Contents of Consultation
Ψ This figure shows how often these topics arose when support members consulted with examinees and their families during E2 support (N=223)

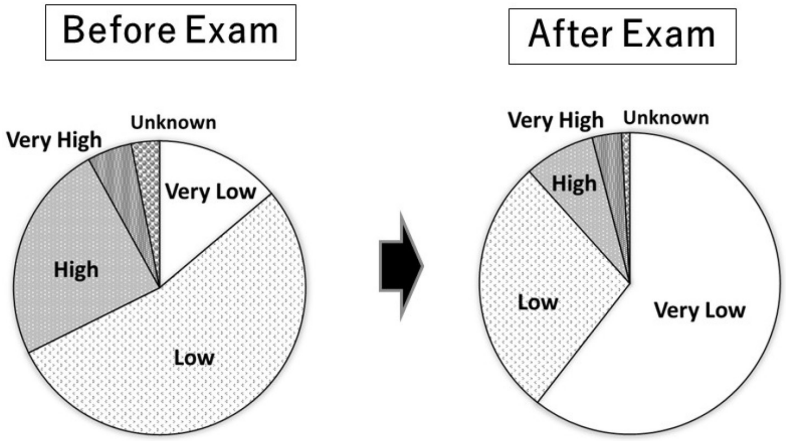

Figure 2. Examinee's anxiety levels pre- and post- exams
Ψ The degree of anxiety was shown in 5 levels [Very High, High, Low, Very Low and Unknown]

which showed a high correlation. The anxiety level was lower for both the examinees and their families who had a previous confirmatory examination experience (examinees $p<0.01$, families $p<0.01$).

Support provided by the support member

Figure 4 shows the content of the support provided by the thyroid support team members. Categories included "Responding to questions", "Confirmation of explanation from the doctor", "Providing information", "Listening to the examinee's and family's thoughts" and "Decision-making support for future rounds of TUE". Provided Information included 209 inquiries about the dedicated-line telephone service to obtain medical information (see note below), 125 about next and/or future TUE, and 54 supplemental explanations.

Note) Special number for medical information
The Thyroid Examination Section of the Radiation Medical Science Center of Fukushima Medical University provides a dedicated-line telephone service (telephone service for medical questions) to respond to questions about thyroid examinations.

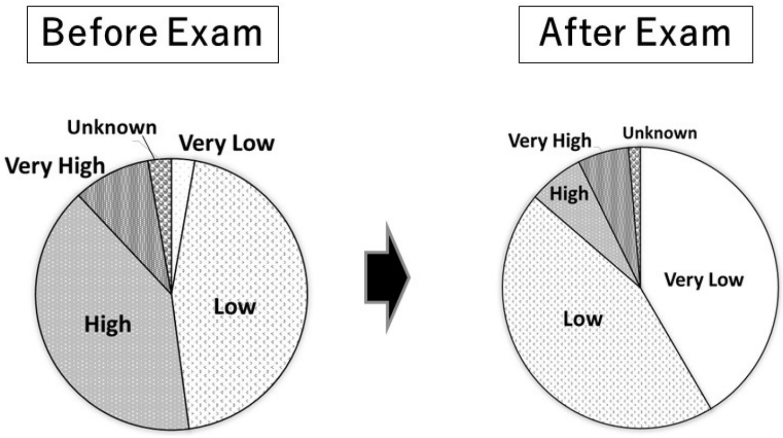

Figure 3. Family member's anxiety levels pre- and post- exams
Ψ The degree of anxiety was shown in 5 levels [Very High, High, Low, Very Low and Unknown]

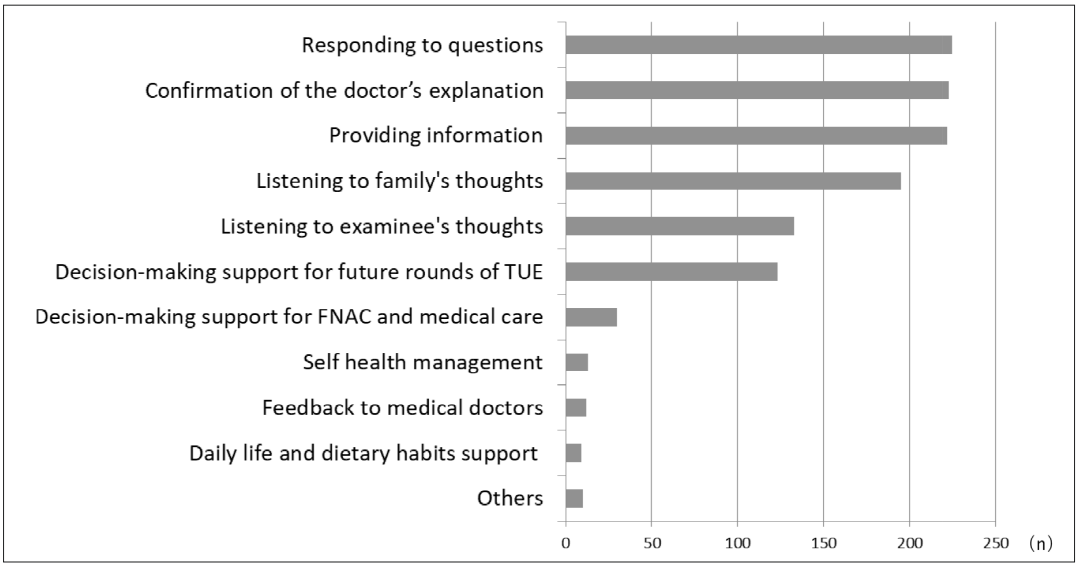

Figure 4. Support provided by the Thyroid Support Team members
Ψ This figure shows numbers of times these items were provided in support of examinees and their families during E2 (*N*=223)

Categories of the questions asked by the examinees and their families

From the descriptive record (Record 2), we extracted 254 questions asked by the examinee and family members. 18 questions were asked by the examinees, and 236 were asked by family members. Specific examples of questions among examinees and their families are shown in Table 3. They are divided into 4 categories ; "Program of TUE", "Findings and causes of nodules", "Changes in nodules", and "Thyroid cancer".

For TUE-related questions, some felt taking E2 allowed them be more relieved, while others, especially those who had been subject to E2 multiple times and who came to the hospital from a long distance away, felt taking these examinations was a burden.

Discussion

Analysis of the support records revealed several findings. First, the concerns of examinees and their families during this period were related to TUE, followed by examination findings (Figure 1). Also, there were many questions asked by examinees or family members about TUE, such as "Will this examination continue?" and "Is it better for me to undergo this examination next time?" (Table 3). Regarding the TUE-related questions, some people

Table 3. Frequent questions among examinees and their families (excerpts)

Category	*n*	Question
Program of TUE	88	· Will this examination continue?
		· Is it better for me to undergo this examination next time?
		· If I am employed outside Fukushima prefecture, which Medical institution should I be examined at?
		· Are the criteria for E2 based on size?
Findings and causes of nodules	86	· Is my symptom (swelling in the neck, etc.) related to this nodule?
		· Has the nodule grown larger than before?
		· Why was the nodule formed?
		· My family has thyroid disease. Is it related to the child's nodule?
Changes in nodules	45	· Will the nodule grow larger? (or Will it shrink smaller?)
		· Can benign nodules turn into thyroid cancer?
		· What symptoms will be appeared If the nodule grows larger?
Thyroid cancer	22	· How many people have been diagnosed as malignant cases?
		· Are there many malignant cases in Fukushima Prefecture?
		· What kind of treatment is given for thyroid cancer?
		· Is there anything that I need to be aware of in my daily life to avoid thyroid cancer?

found great relief in receiving E2, while others felt a burden to undergo the examination, especially those who had undergone E2 many times or came from far away. Because E2 examinees already have nodules or cysts above a certain size, they are often subjected to secondary examinations every time they undergo TUE, and they often have to adjust their school or work schedule. Therefore, some people wonder what to do about future examinations.

One of the reasons for the large number of TUE concerns and questions must take into account that the social environment for TUE have changed over the years. For example, in the report from the International Agency for Research on Cancer (IARC) in 2018, the Expert Group stated that within the thyroid monitoring programme, there should be a shared decision-making process between individuals, families, and clinicians about whether and how to engage in thyroid examinations[16]. Although this report is not a recommendation with regard to the current TUE program in Fukushima prefecture, more attentive explanation for the understanding of its advantages and disadvantages on TUE is socially recommended. On the other hand, experts in Japan are divided on whether TUE should continue under the current system, considering the risk of over-diagnosis and the increased psychological anxiety of examinees and their families[17,18].

However, the discussion of over-diagnosis of thyroid cancer is extremely specialized and quite difficult for the general public to understand. Therefore, the support members at E2 have tried to communicate with examinees and their families in as neutrally as possible, helping them to understand the background and the current status of TUE. As Figure 4 shows, "Responding to questions", "Confirmation of the doctor's explanation" and "Providing information" were provided to almost examinees and their families. Additionally, "Decision-making support for future rounds of TUE" was provided to about half of examinees and families. For the process of decision-making support, we try to 1) identify what they understand about TUE, 2) answer their questions, 3) sort out confusing information, and 4) provide appropriate information. In addition, we encourage examinees and their families to think about future examinations independently.

Following consultations about TUE, the common topics were questions about the results of the examination, such as the findings of nodules, and their cause (Figure 1). And the specific questions were categorized as "Findings and causes of nodules", "Changes in nodules", and "Thyroid cancer" (Table 3). All of these are directly related to the ef-

fects of radiation exposure and the anxiety and fear of thyroid cancer.

A number of studies have found that health effects due to exposure to radiation from the nuclear power plant accident in Fukushima prefecture are unlikely[19], and rather the deterioration of the health conditions of the affected people is pointed out to be caused due to the evacuation[20]. On the other hand, there are quite a few people, especially those who lived close to the nuclear accident, who are still worried about the effects on the next generation, even several years after the disaster[21]. In the aftermath of the Chernobyl accident, the incidence of thyroid cancer increased several years after the accident[22], and the health effects of continuous low-dose radiation exposure remain largely unexplained[23]. Therefore, there are still many people who continue to have concerns about the radiation exposure of children in Fukushima. In this study, there were also many questions and consultations regarding the current condition of the nodules, the causes of the nodules and future changes.

The examinees and their families often have insufficient medical knowledge about the thyroid gland, nodules, cysts, and thyroid cancer. Therefore, the support members helped examinees and their families understand by repeating the doctor's explanations, providing supplementary explanations and feedback to the doctor if needed (Figure 4). For those who had high anxiety about radiation exposure, the support members also listened to their anxieties and explained the results of the 2016 interim report[24], which is based on epidemiological analysis of the first and second round of TUE and states that "At this point, there is no evidence of a link between thyroid cancer and radiation exposure". Midorikawa *et al.* reported that holding explanatory meetings for children and parents helped to reduce their anxiety[8]. In this study, we also consider that careful explanations to help understanding and sharing of anxious thoughts through dialogue reduced the proportion of highly anxious examinees and their families significantly after E2 ($p<0.01$) (Figure 2, 3).

In addition, it has been confirmed that the anxiety levels of those who had taken E2 before, were significantly lower than those who had not ($p<0.01$). This may have been due to the fact that those who had experienced E2 had asked questions and received information about their concerns during previous E2, which may have contributed to their reduced anxiety. Many examinees and family members expressed reassurance when they know that young people often develop thyroid nodules and cysts[1], that not many people are diagnosed with malignancy, even in those who undertake E2[1], that most thyroid cancers, unlike other cancers, have a good prognosis[25], and that most of the thyroid cancers found by TUE are less than 20 mm in size[1] and are in the very early stages. Hino *et al.* reported that careful explanation of objective facts is important when explaining TUE to affected residents, and such explanations and question-and-answer sessions, can reduce anxiety and increase subjective understanding, especially in small groups[18]. Particularly for support during E2, it is possible to provide face-to-face dialog and respond to questions, which may directly help reduce the anxiety of examinees and their family members by providing sufficient explanation and information.

Also, families were significantly more likely to have high anxiety than examinees ($p<0.01$). Examinees and their families had a high correlation coefficient in their anxiety levels, ($R=0.519$ before the examinations and $R=0.644$ after them), according to statistical analyses. A report of the Chernobyl disaster showed that maternal anxiety was strongly associated with their children's negative self-evaluation of health after the incident[28]. Another report found that mothers' concerns about their children's health persisted for a long time, and undergoing a medical examination or clinic attendance was also associated with their health risk perceptions[29]. Following the Fukushima nuclear accident, it was reported that parental disaster-related guilt is strong[6,7], and disaster-related experiences and family stress are significantly associated with radiation-related anxiety[30]. Therefore, considering the high correlation between parent-child anxiety in the present results, it was considered important to provide careful explanations and continuous psychological education to both examinees and families on matters related to radiation anxiety, as well as psychological support to encourage family communication.

We found three issues in term of future TUE support. One is the aging of the examinees. Children were generally aged 0-18 at the time of the nuclear accident, but in this study, the percentage of the so-called AYA generation aged 15 and above exceeded 70%, and the number of the AYA generation (adolescents and young adult generation) will increase more and more in the future. In the past, many examinees had been relatively passive about taking the examination, based on parental recommendations or examinations in their schools. From now on, explanations to examinees themselves in E2 should be enhanced so that they can decide

whether or not to undergo TUE. In addition, psychosocial support tailored to the unique needs of that generation, such as employment, marriage and childbirth[31], should be taken into consideration.

The second issue is how we expand the psychosocial support by specialized trained staff and the system in TUE. As shown in table 2, most of the subjects of this study live in Naka-dori, where Fukushima Medical University is located, but many of those who live in other areas visit other facilities, where few professional staff for psychological care are assigned.

The third issue is to address the information gap inside and outside the prefecture, and the strong stigma, especially outside the prefecture. Many young people in Fukushima prefecture also leave the prefecture to attain the next step of education or find a job. Since stigma may causes great psychological burden and trauma[32], it is important to establish accessible counseling or support services and to educate the public to correct prejudice.

The Chernobyl Forum Report from the 20th anniversary of the Chernobyl nuclear power plant disaster and the presidential review of the health consequences of the Three Mile Island nuclear accident, concluded that mental health effects were the most significant public health consequence of the accident[33,34]. Thyroid Support Team members would like to ensure that the examinees' and their families' wellbeing will be protected in the long term by enhancing the psychosocial support of the current and future TUE.

Study limitations and future issues

The data for this study was not obtained on standardized scales, but was recorded by members of the Thyroid Support Team. Another limitation is that this study is retrospective one and in order to clarify the effects on the mental health and quality of life among examinees, we need a cohort study based on prospective design. Additionally, the residential areas of the examinees did not cover the entirety of Fukushima prefecture, and the period was limited. We'd like to analyze the support data and identify the characteristics for each TUE period in order to prepare for nuclear accidents that may occur in the future.

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Conflict of interest disclosure

We declare that we have no competing interests.

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Abbreviations

TUE : the Thyroid Ultrasound Examination
E1 : the primary examination
E2 : the secondary confirmatory examination