

PSYCHOLOGICAL IMPACT OF ¹³¹I RADIOPROTECTION MEASURES ON THYROID CANCER PATIENTS

ELENA BARBUS¹, CLAUDIU PESTEAN¹, MARIA IULIA LARG¹,
KATALIN GABORA¹, EDUARD-ALEXANDRU BONCI²,
CLAUDIU BADULESCU³, ANDRA PICIU⁴

¹Nuclear Medicine Department, Iuliu Hatieganu University of Medicine and Pharmacy; “Prof. Dr. Ion Chiricuta” Institute of Oncology, Cluj-Napoca, Romania
²Surgical Oncology Department, Iuliu Hatieganu University of Medicine and Pharmacy; “Prof. Dr. Ion Chiricuta” Institute of Oncology, Cluj-Napoca, Romania
³Iuliu Hatieganu University of Medicine and Pharmacy Cluj-Napoca, Romania
⁴Oncology Department, Iuliu Hatieganu University of Medicine and Pharmacy; “Prof. Dr. Ion Chiricuta” Institute of Oncology, Cluj-Napoca, Romania

Abstract

Background and aims. It is very well known nowadays that despite all the good and qualitative information available, the patients who are supposed to be treated with radioiodine for differentiated thyroid cancer suffer from a lot of concerns prior the treatment. The aim of our study is to investigate the level of anxiety and lessening of the concerns pre and post RIT (radioiodine therapy) using a dedicated, special designed questionnaire.

Methods. A cross-sectional study of 54 differentiated thyroid cancer patients was conducted. Patients who met the inclusion criteria were invited to complete the radioprotection questionnaire pre and post RIT. The questionnaire comprises two sections (pre and post radioiodine treatment) with specific questions regarding aspects of radioprotection measures and the impact on the overall well-being. For uniform distribution of variables we used Pearson correlation and for monotonic relationship between variables, Spearman correlation.

Results. The pre-treatment questionnaire reported a strong confidence of the patients in the medical team, good and accurate information regarding the treatment, >50 % suffering from anxiety and concerns before the radioiodine treatment. The post treatment questionnaire revealed no fear of isolation, a lot of useful information and most of the patients would undergo another treatment, if necessary and also recommend it to others.

Conclusion. The milestone in having a good and compliant patient remains a very good communication between the medical team and the patient. We are able to influence and change things and have fewer patients with fear from radioactivity and treatment concerns if we dedicate enough time to give them the adequate information in the best way so it will be correctly received.

Keywords: thyroid neoplasms, iodine radioisotopes, surveys and questionnaires, radioactivity

Background and aims

The early history of radioiodine used as a treatment for human patients starts on the 31th of March 1941 when the first patient with hyperthyroidism was treated in the United States by Hertz and Roberts [1]. Since that moment the development of radioiodine has grown and now most of the

patients with differentiated thyroid cancer are treated with ¹³¹I [2,3]. The radioiodine therapy (RIT) is a safe therapy procedure, used for decades and almost unchanged. RIT is performed similarly among countries, especially in Europe, regarding the isolation and radioprotection measures with at least 48 hours of mandatory isolation (depending on the administered activity, the patient's dosimetry, the radiation protection regulations and guidelines).

The fear of radiation started to be an interesting study

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Address for correspondence: elena.barbus@umfcluj.ro

in the early 60's [4]. Fear of radiation was reported also among the military medical personnel in 2001 in a study reported by the Armed Forces Radiobiology Research Institute [5].

“Fear of radiation” is frightening, as it was mentioned in the Australasian Physical and Engineering Science in Medicine in 2010 by M. Bhat [6]. Public and health care providers were called to be radiophobic in a review published in 2016 by R. Beauchamp [7].

The relationship between psychological stress and ionizing radiation was mentioned in a study from 2016 by B. Wang et al. It was showed that fear of ionizing radiation is a cause of psychological stress and the long-lasting psychological stress may affect the overall health and the ability to cope with cancer [8].

The medical team who deal with patients that need to undergo RIT know very well that it is difficult to explain the side effects and the benefit of radiation, and also the protection measures. Fear among these patients is the first feeling that they experienced the moment they open the door of the nuclear medicine department. Our role is to make this fear disappear and try to make them feel comfortable [9].

We conducted this study because we wanted to identify the changes in fear and the reduction of concerns regarding the pre and post radioiodine treatment [10]. For this fact we used a dedicated questionnaire adapted from a German existing questionnaire used in a study in 2014 by the Friederike von Muller and his team [11].

This is the first study for thyroid cancer patients from Romania, related to the psychological impact of the

radioprotection measures in thyroid cancer patients treated with ¹³¹I, regarding the fear of radiation and concerns related to radioprotection measures.

Methods

We conducted a cross-sectional study on 54 patients from the nuclear medicine department of “Prof. Dr. Ion Chiricuta” Institute of Oncology Cluj-Napoca, Romania (IOCN) between October and December 2016. IOCN is a reference centre for thyroid cancer with 726 new cases in 2017. Subjects who met the inclusion criteria were able to participate in our study: age of the subject between 18-80 years, previously diagnosed with DTC (differentiated thyroid cancer), patients with total thyroidectomy who were admitted for radioiodine ablation after effective TSH (thyroid stimulating hormone) stimulation by thyroid hormone withdrawal. The exclusion criteria included: patients with other type of thyroid cancer (medullary, anaplastic), patients who were unable to complete the questionnaires, history of other types of cancer or prior radioiodine therapy. The study was approved by the Ethics Committee of IOCN. Every patient gave an informed consent to participate in the study. All the 54 questionnaires were validated and well completed because they were previously explained by a trained medical nurse and a specialized psychologist.

The questionnaire is based on a German questionnaire that was adapted and translated into Romanian, it contains 20 questions and comprises two sections: pre-treatment and post-treatment with 10 subsequent questions each. The questions of the questionnaire are shown in Table I.

Table I. Radiation protection measures questionnaire.

PRE-TREATMENT – 10 questions	SCORE
Q1. When you first came to the nuclear medicine department did you knew what was going to happen? Q2. From where did you get the information regarding the procedures in the nuclear medicine department (surgeon, online websites, patient’s brochure, other patients, other sources - please write them)? Q3. Have you experienced fear/anxiety regarding your admission in the nuclear medicine department? Q4. Do you have any knowledge regarding radiation? Q5. Do you have any knowledge regarding radioprotection measures? Q6. Do you experience fear regarding the subsequent treatment (radioiodine therapy)? Q7. Do you trust and feel confident with your medical team? Q8. Have you been informed about the radioactive substance used for therapy? Q9. Did you benefit from the brochures and information sheets? Q10. Are you anxious about the isolation during the treatment?	0-10 (0= not at all; 10= very much)
POST-TREATMENT- 10 questions	SCORE
Q11. Are you still afraid of a therapy with radioactive substances? Q12. Do you still have reservations about contact with radioactive substances? Q13. Do you still have problems with the isolation? Q14. Did you find the information given by the medical team during ward rounds sufficient? Q15. Did you have problems with the non-smoking rule? (Smokers only). Q16. If you experienced side effects: were you significantly impaired? Q17. If medically necessary, would you undergo further radioiodine therapy? Q18. If medically necessary, would you recommend radioiodine therapy to others? Q19. Have you been affected by restrictions to personal hygiene? Q20. Have you been affected by safety measures due to radiation protection?	0-10 (0= not at all; 10= very much)

We first explained the questionnaire to the patients and asked them to complete the first section which comprises aspects regarding the radioiodine procedures before the conversation with the nuclear medicine physician. The day before the discharge from the department the patients were asked to complete the second part and give it to the trained medical nurse.

The patient was asked to read each question and decide if he/she agrees or disagrees with the statement by circling a number to indicate the degree to which he/she agrees or disagrees with the statement according to the word anchors on each end of the scale. The scoring is based on a scale of 0 = worst outcome to 10 = best outcome. A descriptive analysis of the demographic variables was performed. We reported continuous variables as mean \pm standard deviation. For assessing the relationship between each item on the questionnaire we used Pearson correlation (parametric test, bivariate correlation) for uniform distribution of variables and Spearman correlation (non-parametric test, bivariate correlation) for monotonic relationship between variables. Results were considered significant at p values below 0.05.

It is very important to mention that this paper is the second part of an ongoing study regarding the aspects in the quality of life in thyroid cancer patients.

Results

A total of 54 patients were recruited and eligible for the study. The pre and post treatment answers were analyzed. The patients' age ranged between 18 and 80 years old, 49 women and 5 men. In the pre-treatment category

we analyzed all the questions and subsequent answers except the question number 2: "From where did you get the information regarding the procedures in the nuclear medicine department (surgeon, online websites, patient's brochure, nuclear medicine physician, other patients, other sources - please write them)?" Each patient responded according to their knowledge with many options, not by just one option, so we tried to harmonize the answers. Regarding the source of information most of the patients (>70%) received it from the endocrinologist/surgeon and brochures that they found on a dedicated website we developed for thyroid cancer patients.

It is very interesting that 21/54 (38.8%) patients responded not being afraid about the nuclear medicine procedures in the department and 20/54 (37%) patients were not afraid of the treatment supposed to be given. 51/54 (94.4%) patients were very confident (score 10) with the medical team and 37/54 (68.5%) had been informed very well regarding the radioactive substance through the brochures/videos given by the medical team (Table II).

We found a good correlation statistically significant $p < 0.05$ ($p = 0.001$), linear and positive between Q3 "Have you experienced fear/anxiety regarding you admission in the nuclear medicine department?" and Q10 "Are you anxious about the isolation during the treatment?" (Pearson correlation $r = 0.408$) (Figure 1). We also found good correlation, linear and positive between Q6 "Do you experience fear regarding the subsequent treatment (radioiodine therapy)?" and Q10 "Are you anxious about the isolation during the treatment?" (Pearson correlation $r = 0.430$) (Figure 2).

Table II. Pre-treatment questions analyzed.

Question (Q)	Number (N)	Mean	Interval of confidence (IC95%)		\pm SD	Median	Mode	Frequency	Min.	Max.
Q1	54	6.41	5.40	7.41	3.68	8	10	17	0	10
Q3	54	3.43	2.43	4.43	3.66	2	0	21	0	10
Q4	54	4.81	3.80	5.83	3.72	5	0	15	0	10
Q5	54	5.30	4.23	6.36	3.89	5	0	14	0	10
Q6	54	3.04	2.09	3.98	3.46	1	0	20	0	10
Q7	54	9.93	9.84	10.02	0.33	10	10	51	8	10
Q8	54	8.65	7.90	9.40	2.76	10	10	37	0	10
Q9	54	7.98	7.01	8.95	3.54	10	10	36	0	10
Q10	54	2.87	1.90	3.84	3.55	1	0	26	0	10

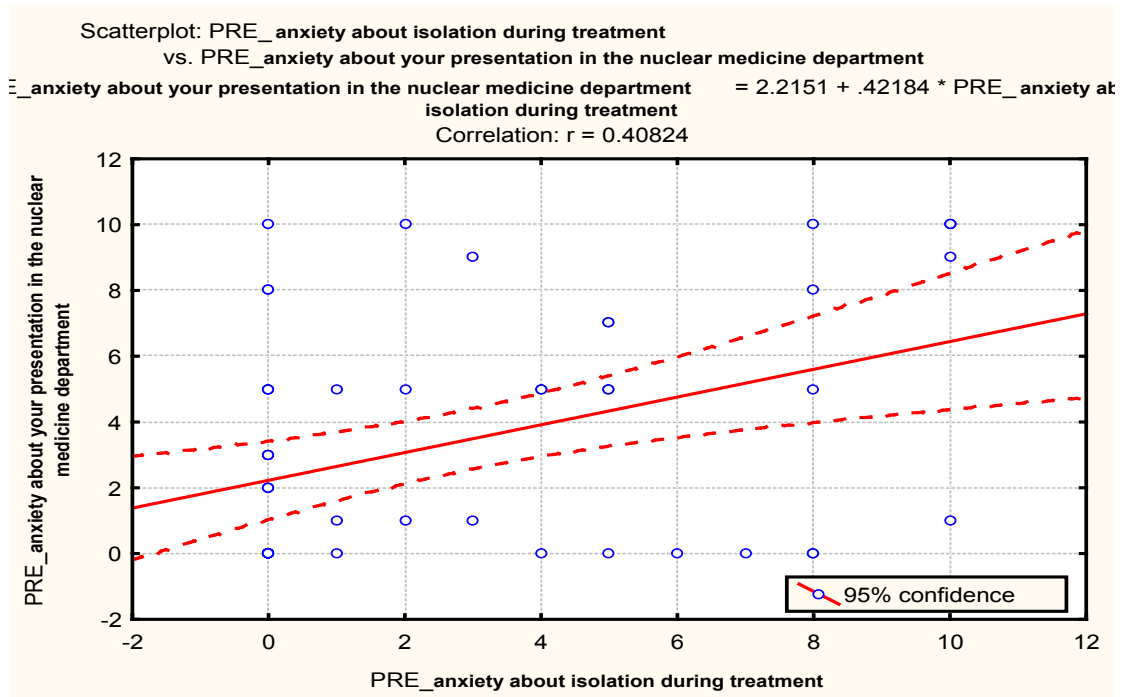


Figure 1. Correlation between isolation during the treatment and fear regarding the presentation in the nuclear medicine department.

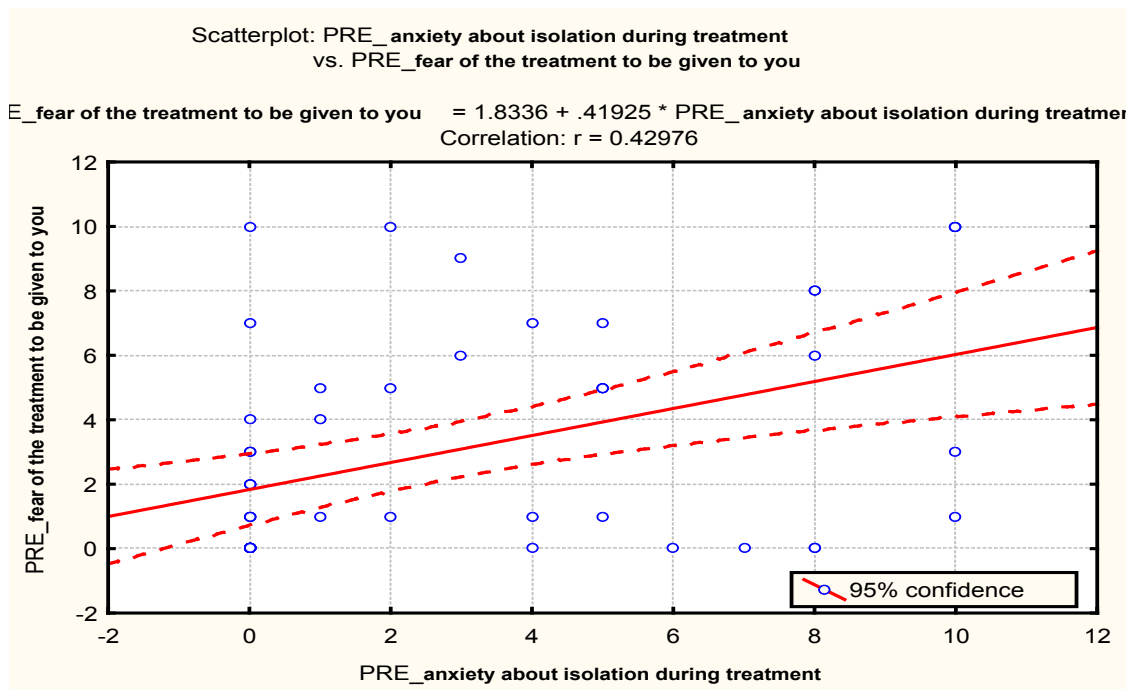


Figure 2. Correlation between isolation during the treatment and fear of the treatment (radioiodine therapy).

Regarding the post-treatment part of the questionnaire the results were very interesting: 31/54 (57.4%) patients answered that now they weren't afraid of the therapy with radioactive substances (score 0); 39/54 (72.2%) patients thought that the information received was enough (score 10); 49/54 (90.7%), patients did not have a problem with the non-smoking rule during the treatment (score 0); between 42-45 out of 54 patients would undergo the treatment again if medically necessary and would recommend it to other patients; most of the patients (between 41-44 out of 54) were

not affected by the hygiene restrictions or radioprotection measures received (Table III).

According to the pre and post-treatment questionnaire we tried to analyze if there was any correlation between questions and identify the changes after our intervention on the information given to the patient. We found 3 categories of correlation between questions in the pre and the post treatment sections of the questionnaire, summarized in table IV.

Table III. Post-treatment questions analyzed.

Question (Q)	Number (N)	Mean	Interval of confidence (IC95%)		± SD	Median	Mode	Frequency	Min.	Max.
Q11	54	1.89	1.04	2.74	3.10	0	0	31	0	10
Q12	54	2.24	1.39	3.10	3.13	1	0	24	0	10
Q13	54	2.00	1.12	2.88	3.21	0	0	34	0	10
Q14	54	9.22	8.78	9.67	1.63	10	10	39	3	10
Q15	54	0.78	0.09	1.47	2.54	0	0	49	0	10
Q16	54	2.04	1.26	2.81	2.85	0	0	28	0	10
Q17	54	9.46	8.99	9.93	1.72	10	10	45	0	10
Q18	54	9.20	8.59	9.82	2.25	10	10	42	0	10
Q19	54	0.87	0.24	1.50	2.32	0	0	44	0	10
Q20	54	1.19	0.44	1.93	2.72	0	0	41	0	10

Table IV. Analysis and correlation between questions from the pre and post-treatment questionnaire's sections.

Question analyzed (Q)	Question analyzed (Q)	Spearman's rho correlation coefficient	p value	Type of correlation
Q10 "Are you anxious about the isolation during the treatment?"	Q13 "Do you still have problems with the isolation?"	0.772	0.001	good
Q3 "Have you experienced fear/ anxiety regarding your admission in the nuclear medicine department?"	Q12 "Do you still have reservations about contact with radioactive substances?"	0.493	0.001	moderate
Q14 ". Did you find the information given by the medical team during ward rounds sufficient?"	Q20 "Have you been impaired by safety measures due to radiation protection?"	0.414	0.002	moderate
Q9 "Did you benefit from the brochures and information sheets?"	Q14 "Did you find the information given by the medical team during ward rounds sufficient?"	0.414	0.002	moderate
Q4 "Do you have any knowledge regarding radiation?"	Q20 "Have you been affected by safety measures due to radiation protection?"	-0.170	0.220	weak
Q6 "Do you experience fear regarding the subsequent treatment (radioiodine therapy)?"	Q17 "If medically necessary, would you undergo further radioiodine therapy? "	-0.242	0.07	weak

Discussion

When it comes to the nuclear medicine field and the idea of “radioactivity” most of the patients experience fear in coming to such a department, fear of the necessary treatment resulting in a lot of concerns during the treatment and regarding the isolation [12]. The idea of being alone and isolated makes them feel like they are in prison even more when they became radioactive. We faced the situation of refusing the curative treatment with ^{131}I because of these feelings which are very hard to handle. Of course, as doctors we must do everything in our power to explain everything to the patient and convince him/her that the situation is under control.

It is mandatory to explain to the patient all the steps in his treatment and what follows afterwards in order to have his total trust and to make him/her feel comfortable. The online is full of good and bad information and most of the patients don't have the scientific knowledge to distinguish them. We can't make inadequate information disappear but we can offer our patients different ways to communicate the correct and scientific knowledge. In order to improve the clinical reality we developed a dedicated website with all the needed information, photos and brochures even a short movie with all the steps from the admission into the department to the discharge moment. We also tried to persuade most of the referral endocrinologists to provide this information to their patients in order to lower the number of those refusing treatment and to reduce the concerns regarding the admission in the nuclear medicine department.

Applying the above rules, this questionnaire's results confirmed the real benefits of good communication [13].

There is a general negative perception towards radioactivity with many patients expressing fears regarding the atomic energy or the contamination with radioactive material [14]. The fear of radioiodine therapy is directly related to the general fear of radioactive substances and is quite hard to fight; it's the invisible threat. If there are patients who still experience fear and anxiety at high levels, they tend to refuse to deal with either therapy or radioactive substances. When the fear of isolation is difficult to manage prior to the treatment it remains at least on the same level after the treatment as well. Also, the fear of second malignancies due to radiation exposure might be another issue to take into account [15]. There is a negative connotation of the word “radiation”. Side effects were reported as concerns including the misperception of becoming radioactive as it was mentioned in a study from 2014 by C. Gillan et al [16].

Part of the patient population which had the initial level of fear very high tend to have the same level after treatment as well, despite all the given information [17]. It might be related to the level of education; highly educated people are very scared about a lot of things due to the self-research they made prior the treatment. Despite the fact that

we make a lot of efforts to make them feel comfortable with the treatment decision and the implications of the treatment, they tend to be more conscious about the disease and speed up the level of distress pre and post-treatment [18]. That is why the referring physician is very important in the education of the patient. As long as the physician tends to be more communicative with the patient, the fear and anxiety on admission to the nuclear medicine department might be lower. There is a study which demonstrates that the overall quality of life is not affected despite the treatment and radioprotection measures [19].

If the quantity and quality of the information given prior to admission is good, the patient tends to better understand the things that are happening to him and to consider the explanation of the nuclear medicine physician to be sufficient. The radioprotection measures and their impact on the patient are very important and we managed to make this impact lower but still a part of the patients do not react by decreasing the anxiety despite our team work and all the brochures and video communications, they still have adapting problems and disagree with their status being affected by the radioprotection measures [20].

Unfortunately, we found a weak correlation between the patient's level of knowledge regarding radiation and the impairment due to radiation protection. Also, the existing fear regarding the radioiodine therapy cannot define accurately if the patient will or will not undergo further radioiodine therapy. There are a lot of patients who experienced fear before the treatment and after as well, but when it comes to undergo another treatment they do understand that this is the treatment of choice to become cured and they chose to do the treatment despite the anxiety. The fear of death by cancer becomes more important than the fear they feel during and after the radioiodine treatment.

There was no problem with the non-smoking acceptance rule and with the hygiene restrictions. Our results are similar with the ones from Friederick von Muller team [11].

Our study also has some limitations. We included patients with no prior radioiodine therapy so we don't know what is the trend in the acceptance of the radioactive treatment compared to the patients with multiple radioactive treatments. Also we don't know if there is a difference in the level of fear and concerns regarding the treatment between old patients comparing to the new ones. We did not get information about the level of education of our patients. It will be interesting to know if this fact influences the overall impression on radioactivity and the manner to treat all the included nuclear medicine procedures. It might be possible that a high level of education tends to make the patient more communicative and open-minded to our explanation, to understand better the physical processes behind the radioprotection measures, according to the literature studies [17]. Also highly educated patients may have multiple fears and concerns but it might be easier to

explain and to achieve their consent to treatment [21].

Another area of development will be the study of the correlation between the stage of the disease and the impact on radioprotection measures and the acceptance of the treatment. Also, our patients were under thyroid hormone withdrawal prior therapy and it would be interesting to see if there is any difference in distress in patients with thyroid hormone withdrawal versus patients who undergo TSH stimulation using recombinant human TSH [22,23].

Conclusion

Most of our patients have a lot of fears and concerns regarding nuclear medicine procedures and treatment, despite of the high confidence in the medical team. It was showed that improving the communication and offering our patients dedicated information (brochures, informed medical team, specialized website) we might reduce “the fear of radioactivity” and part of its concerns. It is mandatory to have a very well informed patient who is conscious and in total agreement with the procedures and treatments that s/he will receive.

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