

Subclinical Hyperthyroid Patients' Knowledge about Radioiodine Therapy – the Key Role of Medical Information

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Abstract

OBJECTIVES: Many patients with a chronic disease are dissatisfied with the information they are given. A brief questionnaire completed by patients would assist health professionals to identify areas of information needed to be provided, tailored to the patient's mental condition. **AIM:** The aim of our study was to assess how often thyroid patients report being adequately informed about iodine treatment in connection with their real need thereof, emotional state and acceptance of the disease. **METHODS:** One hundred outpatients who had presented subclinical hyperthyroidism "[19 men (19%), 81 women (81%); mean (SD±) age 53±14, range 18–77 yr] treated with radioiodine (RAI) responded to an Experimental Questionnaire, 54 of them answered to AIS, HADS-M and Beck Inventory measuring their acceptance of the illness and depressive symptoms, 37 of them answered the Patient Request Form (PRF). **RESULTS:** The obtained results indicated that about 50% of patients treated with ¹³¹I therapy did not receive suitable information about their treatment. Neither written information prepared by the specialist, nor verbal information given by physicians were adequate for specific problems of study group. The examined patients presented with a comparable intensity of three distinct types of requests: for explanation and reassurance, for emotional support, and for investigation and treatment. The acceptance of their disease was mediocre for most of the study group. **CONCLUSION:** We conclude that the reported lack of satisfaction with medical information in study group was associated with depressive symptoms influencing cognitive efficiency, patients' great need of emotional and cognitive support, influencing the acceptance of their disease, and social prejudice to radioiodine (as a method of treatment), worrying them additionally. All thyroid patients even these with subclinical symptoms of hyperthyroidism should be treated with specific attention by physicians, especially during information process.

INTRODUCTION

Looking for the best results of medical treatments, scientists constantly ask themselves the question about the patient's active participation in therapy. It is known that the patient's engagement and proper activity depend on whether he received suitable information. In order to obtain a patient's conscious participation in therapeutic procedures he needs to know of the disease, side effects and methods of treatment, and the way treatment might affect their daily life. The right to be informed about one's condition while undergoing treatment is one of the basic patient rights. To be "well informed" means first of all to understand the message properly. The role of proper medical information during the treatment process is clear for all the physicians (Hesse *et al* 2005). It guarantees the patient's constructive adjustment to illness, his essential engagement and self-control, significantly improves drug compliance, and may reduce hospital re-admissions. Wrong interpretation of disease and treatment is associated with emotional distress, poorer quality of life, and can prolong the disease symptoms. Many patients with chronic disease are dissatisfied with the medical information they are given. Even professional information can be misinterpreted by patients because of emotional barriers, lack of medical education, or concomitant cognitive impairment, present especially in some groups of patients, including patients with hyperthyroidism (Larson *et al* 1996). The capabilities of receivers to understand the information can be one of the underestimated limitations of message effectiveness.

Tab. 1. Clinical and biochemical parameters of the study groups.

| | Study group 3 months before RAI | Study group one day before RAI | p-value |
|--------------------------------------|---------------------------------------|--------------------------------------|-----------|
| Patients (male/female), n | 100 (19/81) | 100 (19/81) | NS |
| Mean age [[yr] (range)] | 53.3 ± 14.4 (18–77) | 53.3 ± 14.4 (18–77) | NS |
| Onset of hyperthyroidism (months) | 11.2 ± 1.2 | 14.5 ± 2.2 | NS |
| Mean thyroid volume (ml) | 24.3 ± 11.2 | 23.3 ± 12.5 | NS |
| Mean serum FT4 (pmol/liter) | 40.2 ± 17.8 | 14.1 ± 2.5 | p < 0.003 |
| Mean serum FT3 (pmol/liter) | 4.9 ± 3.8 | 3.6 ± 2.8 | NS |
| Mean serum TSH (μIU/ml) | 0.1 ± 0.1 | 0.1 ± 0.2 | NS |

Mean thyroid volume was measured by ultrasonography and calculated by the ellipsoid formula. Normal values in our laboratories are as follows: TSH, 0.2–4.2 μIU/ml; FT4, 11.5–21.5 pmol/liter; FT3, 3.9–6.8 pmol/liter. NS – not significant

There are many reasons why people may distort the information, including: psychological functions, information overload, and too brief interactions with those who provided the information. Appropriate verbal and written construction of the message is the most important condition in the informing process, but is not always adequate (Kaufert & Putsch 1996). Indeed, many patients with thyroid conditions are not properly counseled about the health effects of being appropriately treated with 131-iodine and most of the patients lack the medical background to understand concepts of proportion, relative risk and the role of their participation in treatment. Medical information, though based on professional knowledge is usually prepared by experts without patients' contribution and it can be a significant reason for misunderstanding.

What does suitable information mean to patients we can learn first of all from them (Salomon *et al* 1999). All the origins of misinformation can be corrected by adequate counseling and cooperation with patients.

The aim of our study was to assess how often sub-clinical hyperthyroid patients reported having received insufficient information about RAI therapy and to find out the causes of their disappointment in this field. We tried to find out whether this report was associated with receiving a wrong message, social superstitions, or with emotional problems of thyroid patients.

PATIENTS AND METHODS

The study group (as homogeneous as possible) included 100 patients, prepared to radioactive 131-iodine, recruited from the Department of Endocrinology of the Poznan University of Medical Science, Poland, from April 2009 to July 2009. Demographic and clinical data, as well as social characteristics, were collected from medical charts. There were 19 men (19%), 81 women (81%); mean (±SD) age 53 ± 14 yr, range 18–77 yr in our study group. Patients were chosen randomly with sub-clinical hyperthyroidism. Drug regimens and principal diagnoses upon admission were collected from physicians' admission notes, and the duration of treatments was confirmed by patients. Medical conditions or drugs that could influence on psychological examination were not permitted.

Inclusion criteria were the following: recent-onset (up to 12 months); toxic nodular goiter treated with anti-thyroid drugs or unsuccessfully treated with them for less than 1 year. Medical examination conducted three months before RAI and during the time of RAI included physical evaluation of thyroid function, thyroid ultrasound and scintigraphy. Serum free T₄ (FT4), free T₃ (FT3), and TSH concentrations were measured on the day of methimazole withdrawal. Sub-clinical hyperthyroidism was defined as serum FT4, FT3 within the normal range and decreased TSH (<0.2 mU/liter) concentrations.

The study protocol was approved by the Medical Ethics Committee of the Poznan University Medical Centre, and written consent was obtained from all patients.

Medical Treatment

All patients were treated with methimazole for about 12 months to restore euthyroidism before RAI therapy. Eighth patients had a positive history for RIA. Methimazole was withdrawn 48 hours before RAI therapy.

Assays

Serum FT4, FT3 (Cobas c; Roche Diagnostics GmbH, Mannheim, Germany), TSH (third generation TSH; Cobas c; Roche Diagnostics GmbH, Mannheim, Germany), TRAb (TSH receptor antibody; TRAK human; Brahms, Hennigsdorf, Germany), TgAb (thyroglobulin antibody; Brahms, Hennigsdorf, Germany), and TPOAb (thyroperoxidase antibody; Brahms, Hennigsdorf, Germany) levels were assayed by commercial kits. Normal values in our laboratories are as follows: FT4, 11.5–21.5 pmol/l; FT3, 3.9–6.8 pmol/l; TSH, 0.2–4.2 mU/liter; TRAb, less than 2.0 U/liter; TgAb, less than 60 IU/ml; TPOAb, less than 60 IU/ml.

Thyroid ultrasonography

Thyroid volume was measured by ultrasound and calculated by means of the ellipsoid model (width × length × thickness × 0.52 for each lobe) according to Aloka SSD 3500 (Suarez-Almazor 2004).

Method of psychological assessment

Patients' reports of the information they received about iodine therapy were assessed before RAI treatment, by a postal anonymous questionnaire (inquiry form), especially constructed for the study. The questionnaire included the patient's opinion about the received medical information and helped to show their opinions and the areas where more information was necessary. It contained closed and open questions relating to reasons, course and results of iodine treatment.

Patients were also investigated with the Polish version of standard questionnaires: Acceptance of Illness Scale (AIS), the Patient Requests Form (PRF), Modified Hospital Anxiety and Depression Scale (HADS-M).

All of them responded to a postal questionnaire, 54 (54%) filled up HADS-M and AIS, 37 (37%) – answered PRF.

Hospital Anxiety and Depression Scale (HADS). The HADS-M consists of 14 items pertaining to anxiety, depression, and aggression, which are measured on a four-point scale. Scores for anxiety, depression and aggression sub-scales range from 0–21. Higher scores indicate more severe anxiety or depressive symptoms, with a total score more than 13 indicating major depression (Zigmond & Snaith 1983).

Patient Requests Form (PRF) quantified the intentions of patients attending their general practitioner

with three distinct components that described three types of requests: for explanation and reassurance, for emotional support, and for investigation and treatment. PRF application permitted research into neglected aspects of consultation behavior, including the factors that influence the patient's intentions to seek different kinds of help and perceptions of these intentions. Scales constructed to measure each type of request have high internal consistency while being sufficiently brief to be acceptable to general practice patients (Vinkers *et al* 2004).

The degree of acceptance of the illness was assessed using the Acceptance of Illness Scale (AIS). It consists of eight questions describing consequences of bad health states and questions concerning the limitations imposed by the disease such as the lack of self-sufficiency, feeling of being dependent on other people and lowered self-esteem. Each question included a five-grade scale (Felton *et al* 1984).

Lack of acceptance can lead to lower adherence to medical treatment and delayed clinical improvement.

Statistical analysis

The incidence rate was calculated using the program Statistica 7.1, StatSoft Inc. Results were expressed as mean ± SD in the text and as mean ± SEM in the figures. The Rank Order Correlation and the Mann-Whitney's tests were performed. *p*-value ≤ 0.05 was considered significant.

Study design

Study group recruitment was performed after a medical examination and exclusion of any diagnosed psychiatric illnesses.

The procedure of RAI treatment comprises medical examination of thyroid function, USG and scintigraphy which should influence decision-making about RAI therapy positively.

All patients were informed about radioiodine therapy twice: first by postal written information, sent after medical qualification. Written information was prepared by medical specialists and comprised: explanation of the necessity, activity, side effects, procedure, drugs interference, diet connection and other consequences of RAI therapy such as set of regulation for inpatients and for outpatients concerning visitors, coming close to kids and pregnant females, also concerning breast feeding, future pregnancies for female patients, future fathering fore male patients, future risk of cancer development..

Secondly, patients had the chance to ask questions and receive proper explanations during a meeting with a physician.

The main independent variables were the scores of psychometric tests and the patient's opinions about the written and oral information they received before RAI treatment initiation. Other variables were the patient's age, sex and diagnosis.

Tab. 2. Patients' opinions about information * *inquiry form* (n=100)**.

| POSITIVE ESTIMATION | Number of patients |
|--|--------------------|
| Read written information | 100 |
| Information was satisfactory | 63 |
| The main goal of treatment clear | 63 |
| Increased control of disease | 83 |
| Instruction of requested post treatment behavior was precise enough | 65 |
| NEGATIVE ESTIMATION | |
| Information clear, understood, and clearing up | 10 |
| Doubts as to treatment dispelled | 19 |
| Doubts as to treatment increased | 7 |
| Known sequence of treatment behavior | 19 |
| Practical information about side effects | 28 |
| Active participation in therapy facilitated | 15 |
| High complexity of instruction (complexities of received information) | 100 |
| ADDITIONAL REMARKS | |
| Preferring both: written and oral information (evidenced problems with their perception) | 70 |
| Informed more than once | 2 |

*experimental questionnaire developed by the authors of the paper

**Additional open question data: some of requested answer indicated inconsistency (18), deficiency in understanding (21), wrong interpretation (13), informative mess (14) and disorder (15).

RESULTS

The baseline study included analysis of patients' opinions about medical information, regarding estimation of the meaning, necessity, and usefulness of RAI treatment, their emotional stabilization, the instructive role, control improvement, and facilitation of activity. Patients' opinions about the information indicated that it was satisfactory to 63 (63%) of the study group, 83 (83%) of patients found that having better information increased their control over the disease, according to 12 (12%) of them the information had a positive influence on the results of therapy, and 15% of patients claimed that the information facilitated their active participation in therapy. Though all of them declared that the complete written information had been read, only about 85 patients (85%) in the study group declared their understanding of the basic idea of treatment and post treatment behavior. Though 70 (70%) patients thought of both written and spoken information as necessary, only to 10 (10%) of them the message was clear and understandable simultaneously. While the main sense of treatment appeared understandable to

63 (63%) patients, doubts as to justification of treatment were dispersed for only 19 (19%) of them, and 7 (7%) patients' doubts increased. Only 10 (10%) patients found the obtained information both necessary and clarifying (Table 2).

Information about RAI therapy raised various emotional reactions in the study group. 56 (56%) patients interpreted it as reassuring, 6 (6%) as worrying, 10 (10%) found the information incomprehensible, and 4 (4%) found it complicated. 55 (55%) of the patients in our study group considered instruction of useful behavior as sufficient, but just 19 (19%) understood and remembered the course of the treatment. Information regarding side effects of RAI treatment was estimated as sufficient by most patients (74%); 19 (19%) expressed that information as clarifying, and 8 (8%) found it sufficient and clarifying simultaneously. Instruction regarding recommended post treatment behavior was described as precise enough by 65 (65%) of patients, but only 28 (28%) found it practical. Contents regarding side effects of RIA were estimated by most patients as sufficient 74 (74%), 19 (19%) defined the information as clearing up, but only 8 (8%) as sufficient and clearing up simultaneously. 5 (5%) patients in the study group found the information about side effects inadequate. Most of the patients preferred to have both written and verbal information. Verbal information alone was sufficient only for 8 (8%) patients (Table 2).

Interesting results were achieved from individual remarks relating to the received information. Many patients declared having questions about different and quite spectacular points such as: sexual contacts, risk for pets, addictions, vacation spots, climate. Some of the patients' questions showed inconsistency, misinterpretation, or simply deficiencies in understanding the treatment.

Summarizing, the results of the experimental questionnaire (*inquiry form*) indicated that about half of the patients treated with RAI were not receiving suitable information about their therapy. Many respondents expressed dissatisfaction with their information, lack of knowledge about therapy and recommended behavior. Even though the given information was delivered by specialists and included all important aspects of illness, treatment, side effects and necessary behavior, patients only infrequently reported having received suitable information. They found the information impractical, not facilitating procedural activity, unclear and not understandable enough. Incorrect interpretation, informative confusion and inconsistency were observed in their notes and regards. Some of them asked already answered questions what suggested impairments of patients' attention, memory or understanding. Though they were informed twice: in a written text prepared according to medical science, and directly in conversation with a specialist, their notes and opinions indicated problems with understanding and remembering the received information. Most of the patients declared

full knowledge of behavioral instructions but they were not able to repeat them when asked and had many questions.

The obtained results of the psychometric scales indicated at least a medium level of average anxiety and depressiveness, and a low level of aggression in all examined group. Results of HADS-M indicated high anxiety symptoms in 22 patients (41%), mild anxiety symptoms in 21 (39%) (summary anxiety in 80%) (Table 3). Depressive symptoms were found in 45 patients (83%), including high depressive symptoms in 18 (34%) patients, mild depressive symptoms in 27 (50%) patients and moderate symptoms in 9 (17%). Summarizing: 22 (41%) of the patients presented with significant psychological morbidity in the anxiety scale and 18 (34%) patients in the depressiveness scale This means that 80 % of the study group might have cognitive problems generated by anxiety, and 83% influenced by depressive symptoms..

Scores of PRF (scale from 0 to 12 points) indicated a quite comparably high request for: explanation and reassurance (9.3), investigation and treatment (8.7) and emotional support (8.6) (Table 5).

Average scores of AIS indicated moderate levels of illness acceptance in the study group. Low scores were obtained only accidentally (Table 6).

The statistical analysis of our study group's psychometric scales (HADS-M, AIS, PRF) showed a significant correlation between anxiety and depressiveness ($r=0.46$; $p<0.05$; rang Spearman), and a correlation between request for information regarding disease, and treatment, and emotional support ($r=0.59$; $p<0.05$).

The role of information about emotional states confirmed the significant correlation between increased level of depression and two types of requests (explanation and reassurance, and investigation and treatment), found in males ($r=0.68$; $p<0.05$). Other correlations were not statistically significant.

DISCUSSION

There were two main problems related to thyroid patients treated with RAI projecting on the efficiency of information delivery. The first of them was connected to radioiodine, the anxiety over its use and social prejudice to nuclear treatment culturally embedded in numerous recent historical events. Diagnostic scanning and therapeutic care with RAI is the standard for thyroid patients to evaluate thyroid nodules for uptake and is common in patients with goiter and low levels of thyrotropin (or thyroid-stimulating hormone; TSH) or in patients with nodular goiter. Radio-iodine (RAI) is one of the most popular, most frequently used and safest methods in the therapy of hyperthyroidism, easily given as a capsule and rarely causing any immediate side-effects; though simple, and economic, emotional reactions and disagreement still arise in patients, especially in those with emotional disorders. Fear and

Tab. 3. The Hospital Anxiety and Depression Scale (HADS-M) (n=54)

| SYMPTOMS' LEVEL | Result (number of patients) |
|--------------------------------|--------------------------------|
| HIGH ANXIETY (score 11–21) | 22 (40.7%) |
| MIDDLE ANXIETY (score 8–10) | 21 (38.8%) |
| LOW ANXIETY (score 0–7) | 11 (20.3%) |
| HIGH DEPRESSION (score 11–21) | 18 (33.3%) |
| MIDDLE DEPRESSION (score 8–10) | 27 (50%) |
| LOW DEPRESSION (score 0–7) | 9 (16.6%) |
| HIGH AGGRESSION (score 11–21) | – |
| MIDDLE AGGRESSION (score 8–10) | – |
| LOW AGGRESSION (score 0–7) | 54 (100%) |

Tab. 4. The Hospital Anxiety and Depression Scale (HADS-M) (n=54).

| SCALE | Average scores |
|------------|----------------|
| Anxiety | 10.1 |
| Depression | 9.4 |
| Aggression | 3.4 |

Tab. 5. Patient Request Form (PRF) (n=37).

| REQUEST | Average scores (0–12 points) |
|--------------------------|---------------------------------|
| Explanation, reassurance | 9.3 |
| Emotional support | 8.6 |
| Investigation, treatment | 8.7 |

Tab. 6. Acceptance of Illness Scale AIS (n = 54).

| ACCEPTANCE LEVELS | Result (number of patients) |
|----------------------|--------------------------------|
| Low level (8–18) | 6 (10.8%) |
| Middle level (19–29) | 27 (50.0%) |
| High level (30–40) | 21 (35.12%) |
| Average score = 20 | |

anxiety over the long-term consequences of ^{131}I are apparent in the popular patient literature. There are inherent fears of RAI embedded in culture, based on numerous events in recent history of Hiroshima and Nagasaki, the Cold War, and Chernobyl (Jaworowski 2006) and reports of health effects in the popular press. Anxiety over its use and the concomitant psychological effects of illness should encourage doctors to take special care in communication with this group of patients.

Another problem was the patients' health status which played an important role in informing about the procedure (Barnes & Galton 1976; Gulseren *et al* 2006; Razvi *et al* 2005). Results of many previous psychological examinations showed emotional symptoms and a great possibility of cognitive impairment in thyroid patients even these presented subclinical symptoms (Vinkers *et al* 2004; Jabłkowska *et al* 2009; Sait Gonen *et al* 2004; Stangierska & Horst-Sikorska 2007; Tagay *et al* 2005). Hypothyroidism and hyperthyroidism have both been associated with cognitive impairment like decreased attentiveness, and poor concentration, which can occur with thyroid disorder and as well as with depression and anxiety (Stuerenburg *et al* 2006; Stangierski *et al* 2009; Warmuz-Stangierska *et al* 2002). Even a mild thyroid problem is likely to cause mood problems and is associated with poor concentration, memory disturbances, and depression generating neuropsychological deficiencies of attention, memory, psychomotor speed and executive functions (Gryczyńska *et al* 2005). Due to decreased attentiveness and poor concentration thyroid patients are likely to have problems with perception of medical information (Stangierski *et al* 2009).

This should inspire us to provide them with special care in any way, including medical information. In order to confirm the common incidence of depressive symptoms in iodine treated patients, only patients with sub-clinical hyperthyroidism were included. Depressive and anxiety symptoms appeared already in patients with sub-clinical hyperthyroidism hence we can expect that more of them can occur in symptomatic hyperthyroid patients (Sait Gonen *et al* 2004).

There is also a significant percentage of patients in our study group with informative deficiency attributed to psychological conditions of thyroid patients (Jabłkowska *et al* 2009; Razvi *et al* 2005). We found out that misunderstanding and subjective lack of information in the examined group could mostly derived from specific limitations in perception, mostly about concomitant effects in thyroid disorders. These were confirmed by the results of our psychometric exploration which indicated a level of anxiety and depressiveness regarding distress in great many of our patients.

We also noticed, that respondents rarely reported having received suitable information, because their interests were concentrated in different questions than the given content and was opposed to some of the information important from a medical point of view. Hence, we postulated that all information must be explained in a language which is easy-to understand. Original misinformation, connected with emotional conditions created by the disease should be corrected by adequate counseling, based on return message obtaining from patients.

The results of present investigations indicated that patients' requests for information were concerned with emotional support, explanation and reassurance, as well as investigation and treatment which suggested a lack

of appropriate message and deficiency of emotional support.

The obtained results confirmed that a proper educational procedure should begin by identifying patients' opinions about diagnosis, prognosis, alternatives available to manage it, cognitive status, and individual expectations. Correction of factual errors and incompleteness in the patient's knowledge fund should be the next step in education. The origins of misinformation can be corrected by adequate counseling based on return information obtained from conversation. If the possibility of individual conversation is limited, a specially prepared (short form) questionnaire or check list can be applied (Salmon *et al* 1994). Answering the questions seems to be the best way of communication because it ensures the best help in completing and developing an understanding of the situation. Afterwards, patients should be given an opportunity to ask questions, while his health care providers should be available to answer them (Salomon *et al* 1999). Unfortunately, it seems very common that medical information is created without regard to patients' questions and doubts, and without analyzing their ability to interpret them properly. It must always be remembered that affective states can influence capacity. Depressive and anxiety symptoms typical for thyroid patients, which could impair cognitive functions such as concentration or memory might be an important reason of misunderstanding and dissatisfaction with received information (Stuerenburg *et al* 2006). The professional information first of all must be suitable to the patient. Every effort should be made to clarify any limitations to comprehension and circumvent those limitations by repeating information as necessary, using alternative means of patient education for examples videotapes, instructional materials, and pictures.

Our finding of a strong association between patients' report of received information and their emotional conditions related to thyroid disease (Stangierski *et al* 2009; Warmuz-Stangierska *et al* 2002) may have important implications for effectiveness of therapy. Improvement of medical information can decrease patients' anxiety and increase the level of illness acceptance which means better cooperation, increased quality of life and less depressiveness (Brunn *et al* 1981; Salomon *et al* 2003). Because physicians often tend to overestimate the understanding of information by patients and thyroid patients treated with RAI need adequate, specially 'tailored' information, professionals providing patient-care should be trained to respect patients' expectations and to avoid emotional disturbances related to inappropriate methods of delivering information (Suarez-Almazor 2004).

Medical information needs to vary between different groups of patients and tend to be at least suitable to emotional and cognitive effects of the disease. Proper educational procedure should begin with identifying patients' opinions about diagnosis and treatment. So

far we postulate that prepared information should be at least: a) given twice as a verbal and a written part, b) given in plain language and necessarily in a limited amount to avoid redundancy, c) stimulating to different senses, such as oral and written messages, illustrations, or films, d) written information should be preceded by patients' questions (Willemsen *et al* 1993), e) oral information should allow questioning to check understanding.

CONCLUSIONS

1. The study showed that neither written information prepared by a specialist, nor verbal information given by physicians alone were sufficient to solve specific problems of thyroid patients.
2. Lack of patients' satisfaction with the received information about RAI therapy was influenced by emotional and cognitive side-effects of thyroid diseases and the social fear of isotopes.
3. The informative dissatisfaction expressed by patients with thyroid disorders may be related to their therapists' under evaluation of the non biological aspects of treatment such as their cognitive and emotional conditions.
4. All thyroid patients about to undergo iodine therapy need adequate, especially tailored information appropriate to their specific psychological condition regarding depressive and anxiety disorders, and the influence of cognitive impairment.
5. Patients should act as experts during the process of information preparation and inquiry.

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