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Clinical Thyroidology® for the Public

AMERICAN THYROID ASSOCIATION
Optimal Thyroid Health for All

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Clinical Thyroidology® for the Public

www.thyroid.org

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Editor's Comments

Welcome to another issue of *Clinical Thyroidology for the Public*! In this journal, we will bring to you the most up-to-date, cutting edge thyroid research. We also provide even faster updates of late-breaking thyroid news through X (previously known as Twitter) at @thyroidfriends and on Facebook. Our goal is to provide patients with the tools to be the most informed thyroid patient in the waiting room. Also check out our friends in the **Alliance for Thyroid Patient Education**. The **Alliance** member groups consist of: the *American Thyroid Association®, Bite Me Cancer, the Graves' Disease and Thyroid Foundation, the Light of Life Foundation, MCT8 – AHDS Foundation, ThyCa: Thyroid Cancer Survivors' Association, Thyroid Cancer Alliance* and *Thyroid Federation International*.

We invite all of you to join our **Friends of the ATA** community. It is for you that the American Thyroid Association® (ATA®) is dedicated to carrying out our mission of providing reliable thyroid information and resources, clinical practice guidelines for thyroid detection and treatments, resources for connecting you with other patients affected by thyroid conditions, and cutting edge thyroid research as we search for better diagnoses and treatment outcomes for thyroid disease and thyroid cancer. We thank all of the *Friends of the ATA* who support our mission and work throughout the year to support us. We invite you to help keep the ATA® mission strong by choosing to make a donation that suits you — it takes just one moment to give online at: www.thyroid.org/donate and all donations are put to good work. The ATA® is a 501(c)3 nonprofit organization and your gift is tax deductible.

November is Hyperthyroidism Awareness Month.

In this issue, the studies ask the following questions:

- How has the trend for Graves' disease treatment changed in the last 10 years?
- How well can we predict thyroid problems in the mother during pregnancy?
- Is my TSH normal - for me?
- Do personality traits affect patient satisfaction in hypothyroidism?
- What is the association between TSH levels and heart health in patients with hypothyroidism?
- Do patients choosing active surveillance for their small, low-risk papillary thyroid cancer experience regret for their decision?

We welcome your feedback and suggestions. Let us know what you want to see in this publication. I hope you find these summaries interesting and informative.

— Alan P. Farwell, MD

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HYPERTHYROIDISM

How has the trend for Graves' disease treatment changed in the last 10 years?

BACKGROUND

Graves' disease is the most common cause of hyperthyroidism, where the thyroid gland becomes overactive and makes too much thyroid hormone. Graves' disease is caused by the body making an antibody that attacks the thyroid and turns it on. The diagnosis is made by lab tests, including measuring the antibody level. Occasionally, the thyroid gland activity can be measured with a nuclear thyroid scan to diagnose Graves' disease. Treatment options for Graves' disease include antithyroid drugs (ATDs), radioactive iodine (RAI) ablation (where the thyroid gland is destroyed by radiation over time), or thyroid surgery (thyroidectomy where the thyroid gland is removed). The goal of treatment with ATDs is to control the thyroid activity in the hope of a remission, where the antibody decreases or goes away, and the thyroid function returns to normal. RAI and surgery are called definitive therapy as they destroy the thyroid and make the patient hypothyroid, which is treated with a thyroid hormone replacement pill.

Traditionally, RAI ablation was the most common form of therapy in the United States and was recommended if Graves' disease does not go into remission (no longer overactive) after treatment with ATDs for 18-24 months or if there is recurrence of Graves' disease (coming back after remission). Thyroidectomy has been less common and often reserved for patients with very large thyroid glands. In recent years, there has been more data showing the safety and higher chance of remission with long-term ATD treatments. In addition, there are some concerns about potential risk of cancer development and worsening of thyroid eye disease after RAI ablation. These may have resulted in changing trends in Graves' disease treatment among clinicians over the years.

This study was done to evaluate current clinical practices in Graves' disease treatment and to identify any changes in trends over the past 10 years.

THE FULL ARTICLE TITLE

Villagelin D et al. A 2023 international survey of clinical practice patterns in the management of Graves' disease: a decade of change. J Clin Endocrinol Metab. Epub 2024 Apr 5:dgae222; doi: 10.1210/clinem/dgae222. PMID: 38577717.

SUMMARY OF THE STUDY

A total of 1252 responses to a survey of endocrinologists and specialists treating patients with Graves' disease from 85 countries were obtained between May and August of 2023. The survey presented a case of Graves' disease with 31 questions on the treatment options and reasons for choosing specific treatment. The questions were made similar to those in previous 2011 survey to compare and assess potential changes in treatment trends over time.

For the diagnosis of Graves' disease, there was an increase in use of thyroid stimulating antibody test (94% vs 58% in 2011), likely related to improving assay accuracy. On the other hand, radioactive iodine scans are less frequently used (16% vs 47% in 2011). More clinicians also obtained thyroid ultrasound at initial evaluation (61% vs 26% in 2011).

For treatment options, ATDs were most frequently used as the initial treatment (92%), followed by RAI ablation (7%) and thyroidectomy (2%). In the past, RAI ablation was much more frequently used as the initial treatment. This decrease in preference of RAI ablation as the first-line therapy was most notable in the United States (11.1% compared to 69% in 1990), although also shown in other countries. The top reasons to choose long-term ATDs over RAI ablation were "to avoid hypothyroidism" and "to achieve remission."

For patients who had persistently elevated thyroid stimulating antibody levels after treatment with ATDs for 18 months, 69% of respondents preferred continuing ATDs. Similarly, 60% of respondents chose to restart

HYPERTHYROIDISM, continued

ATDs if there was a relapse of Graves's disease rather than recommending RAI ablation or thyroidectomy.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

This international survey of clinicians treating Graves' disease showed that there was a significant decline in the use of RAI ablation and increase in the use of ATDs as the initial and long-term treatment over the last 10 years. Overall, there appear to be changing trends in how Graves' disease is diagnosed, an increasing desire to avoid hypothyroidism, and increasing acceptance of long-term ATDs use.

The large number of responses across many different countries in this study provides unique perspective into the current global trend. The findings of this study provide important insights into the changing approaches in diagnosis and treatment of Graves' disease by international clinicians. Understanding current clinical practices and preferences for treatment is important to provide directions for future research, practice guidelines, and allocating resources, and addressing potential barriers and disparities in care. Most notably, given increasing use of long-term ATD, further studies on potential side effects, predictors of remission, and how to monitor long-term ATD therapy would be needed with ongoing evaluation on how to best individualize therapy for Graves' disease for each patient.

— Sun Lee, MD

ATA RESOURCES

Hyperthyroidism (Overactive): https://www.thyroid.org/hyperthyroidism/
Graves' Disease: https://www.thyroid.org/graves-disease/

ABBREVIATIONS & DEFINITIONS

Hyperthyroidism: a condition where the thyroid gland is overactive and produces too much thyroid hormone. Hyperthyroidism may be treated with antithyroid meds (Methimazole, Propylthiouracil), radioactive iodine or surgery.

TSH (Thyroid Stimulating Hormone): produced by the pituitary gland that regulates thyroid function; also the best screening test to determine if the thyroid is functioning normally.

Radioactive iodine (RAI): this plays a valuable role in diagnosing and treating thyroid problems since it is taken up only by the thyroid gland. I-131 is the destructive form used to destroy thyroid tissue in the treatment of thyroid cancer and with an overactive thyroid. I-123 is the non-destructive form that does not damage the thyroid and is used in scans to take pictures of the thyroid (*Thyroid Scan*) or to take pictures of the whole body to look for thyroid cancer (*Whole Body Scan*).

Thyroidectomy: surgery to remove the entire thyroid gland. When the entire thyroid is removed it is termed a *total thyroidectomy*. When less is removed, such as in removal of a lobe, it is termed a *partial thyroidectomy*.

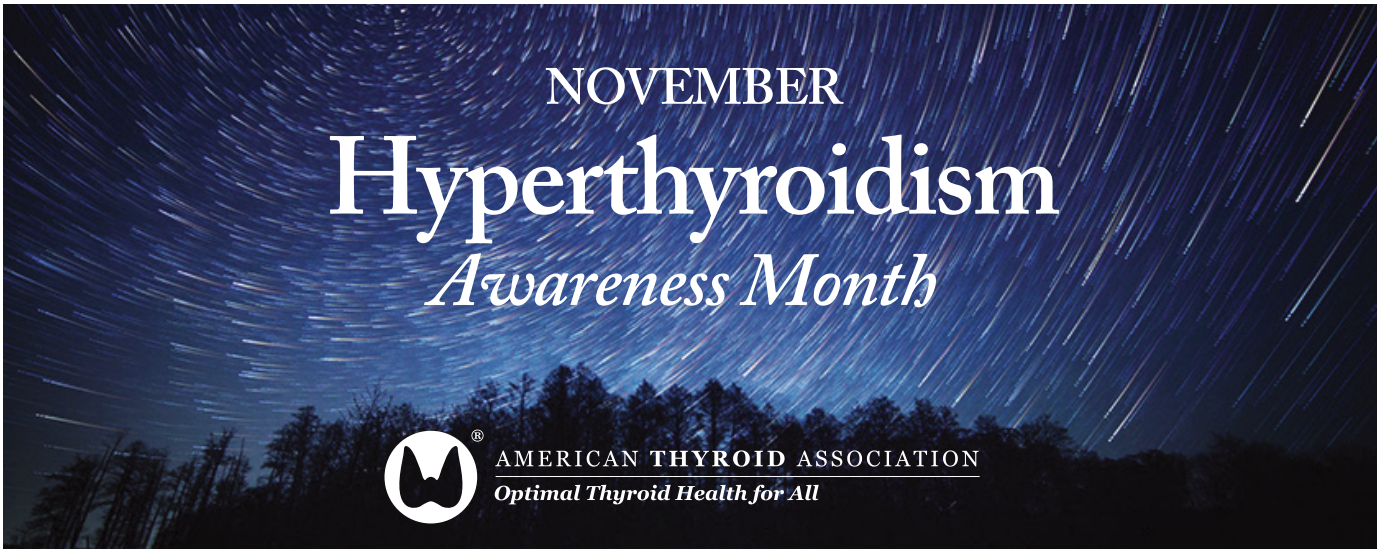
Thyroid hormone therapy: patients with hypothyroidism are most often treated with Levothyroxine in order to return their thyroid hormone levels to normal. *Replacement therapy* means the goal is a TSH in the normal range and is the usual therapy. *Suppressive therapy* means that the goal is a TSH below the normal range and is used in thyroid cancer patients to prevent growth of any remaining cancer cells.

HYPERTHYROIDISM, continued

Thyroid stimulating antibodies: antibodies often present in the serum of patients with Graves disease that are directed against the TSH receptor, often causing stimulation of this receptor with resulting hyperthyroidism.

Radioactive iodine uptake (RAIU): this is a measurement of activity of the thyroid gland and is reported as the percent of a dose of radioactive iodine that is retained in the thyroid gland 24 h after the dose is given. An increase in RAIU usually indicates hyperthyroidism.

Thyroid Ultrasound: a common imaging test used to evaluate the structure of the thyroid gland. Ultrasound uses soundwaves to create a picture of the structure of the thyroid gland and accurately identify and characterize nodules within the thyroid. Ultrasound is also frequently used to guide the needle into a nodule during a thyroid nodule biopsy.



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THYROID AND PREGNANCY

How well can we predict thyroid problems in the mother during pregnancy?

BACKGROUND

Thyroid hormone is essential for normal development of the baby during pregnancy. Early on, the baby gets all of their thyroid hormone from the mother. It is clear that untreated overt hypothyroidism (low FT4 and high TSH) in the mother needs to be treated with thyroid hormone to prevent any harm to the developing baby. What is not so clear is the effect of untreated subclinical hypothyroidism (high TSH, normal FT4) has on the baby. Because of this, the need to treat mild hypothyroidism in the mother, much less screen for this during pregnancy, is less clear. Guidelines recommend screening for thyroid problems in the mother based on both major established risk factors (such as positive TPO antibodies, a marker of autoimmune thyroid disease) as well as more common characteristics, such as advanced maternal age and number of pregnancies. However, studies have shown that using these risk factors alone is likely insufficient to identify all cases of thyroid problems in the mother that my need to be treated.

This study looks at additional risk factors that may predict risk for thyroid problems in the mother than are recommended by current guidelines.

THE FULL ARTICLE TITLE

Osinga JAJ et al. Risk factors for thyroid dysfunction in pregnancy: an individual participant data meta-analysis. Thyroid 2024;34(5):646-658; doi: 10.1089/thy.2023.0646. PMID: 38546971.

SUMMARY OF THE STUDY

This study was conducted within the Consortium on Thyroid and Pregnancy, a group of population studies with information on thyroid function in the mother during pregnancy. They looked at potential risk factors, including positive TPO or thyroglobulin (Tg) antibodies, the age of the mother, body mass index (BMI), number of pregnancies, smoking status, pregnancy by in-vitro fertilization, twin pregnancy, maternal education, and maternal iodine status.

A total of 65,559 women from 25 studies were included. The screening rate in these groups using risk factors currently recommended (age >30 years, ≥2 pregnancies, BMI ≥40) was 58%, with a detection rate for overt and subclinical hypothyroidism of 59%. Risk of overt hypothyroidism was 7 % if both TPO and Tg antibodies were positive, 3.8% if only TPO antibodies were positive, 2.4 % if only Tg antibodies were positive and 0.1% if both TPO and Tg antibodies were negative. Risk of subclinical hypothyroidism was 20 % if both TPO and Tg antibodies were positive, 14.2% if only TPO antibodies were positive, 8.1% if only Tg antibodies were positive and 2.2 % if both TPO and Tg antibodies were negative. Twin pregnancy was associated with a higher risk for overt hyperthyroidism (5.6% vs. 0.7%). None of the other risk factors assess were able to predict thyroid problems in the mother.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

These data show that thyroid antibody positivity, especially TPO antibody, was associated with a higher risk for both overt and mild hypothyroidism in the mother during pregnancy. However, other risk factors such as the age of the mother, body mass index (BMI), number of pregnancies, smoking status, pregnancy by in-vitro fertilization, twin pregnancy, maternal education, and maternal iodine status did not predict thyroid problems in the mother. This study suggests that more research into effective screening strategies would be helpful to identify mothers with thyroid problems during pregnancy.

— Alan P. Farwell, MD

THYROID AND PREGNANCY, continued

ATA RESOURCES

Thyroid Disease in Pregnancy: https://www.thyroid.org/thyroid-disease-pregnancy/
Thyroid Function Tests: https://www.thyroid.org/thyroid-function-tests/
Hypothyroidism (Underactive): https://www.thyroid.org/hypothyroidism/

ABBREVIATIONS & DEFINITIONS

Hypothyroidism: a condition where the thyroid gland is underactive and doesn't produce enough thyroid hormone. Treatment requires taking thyroid hormone pills.

Subclinical Hypothyroidism: a mild form of hypothyroidism where the only abnormal hormone level is an increased TSH. There is controversy as to whether this should be treated or not.

Overt Hypothyroidism: clear hypothyroidism an increased TSH and a decreased T4 level. All patients with overt hypothyroidism are usually treated with thyroid hormone pills.

TSH (Thyroid Stimulating Hormone): produced by the pituitary gland that regulates thyroid function; also the best screening test to determine if the thyroid is functioning normally.

TPO antibodies: these are antibodies that attack the thyroid instead of bacteria and viruses, they are a marker for autoimmune thyroid disease, which is the main underlying cause for hypothyroidism and hyperthyroidism in the United States.

Thyroglobulin antibodies: these are antibodies that attack the thyroid instead of bacteria and viruses, they are a marker for autoimmune thyroid disease, which is the main underlying cause for hypothyroidism and hyperthyroidism in the United States.

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THYROID FUNCTION

Is my TSH normal - for me?

BACKGROUND

Thyroid problems are very common and may affect 5-10% of people in the world. The best way to diagnose abnormal thyroid function is to use TSH (thyroid stimulating hormone) levels. The standard, population-based reference range for TSH is found by checking the TSH levels of healthy people who do not have thyroid disease or other problems that may affect the thyroid. Reference range is the range of values that are in the middle 95% of the results. Serum TSH levels can vary a lot between different people, so the reference range defining what is normal for the population is wide. However, for each person, their TSH levels usually stay within a smaller range, which means everyone has their own point where their thyroid works best. This means even the best of the currently available methods we have to diagnose thyroid disease may lead to incorrect diagnosis and potentially over- or under treatment. We know from the findings of past studies that many factors can affect TSH levels such as age, sex, ethnicity, weight, iodine intake, and most importantly genetic factors. Over the last 20 years, scientists have found many genetic differences that affect the TSH levels. However, no one has tried to use these measurable genetic variants to personalize TSH reference ranges.

The authors designed this study to learn more about the effects of genetic factors on TSH reference ranges by using a method for the first time to determine genetically determined reference ranges.

THE FULL ARTICLE TITLE

Kuś A, et al. Towards personalized TSH reference ranges: a genetic and population-based approach in three independent cohorts. Thyroid. Epub 2024 Jun 26; doi: 10.1089/thy.2024.0045. PMID: 38919119.

SUMMARY OF THE STUDY

The authors collected information from three separate groups of people from the Netherlands and Norway. They used polygenic score (PGS) which is a number calculated by adding up the effects of many small genetic variants that can affect the TSH level in a person and they factored the score into finding out the genetically determined reference ranges. They first studied 6834 individuals without thyroid disease from the Rotterdam study. They used 59 genetic variants to calculate the PGS and genetically determined TSH reference ranges. They compared these TSH reference ranges with the standard reference ranges in this group. Then they studied 3800 individuals without thyroid disease from a second study to confirm their findings. A third separate large group of people were studied to find out the impact of using personalized reference ranges on 26321 individuals without thyroid disease and 1132 patients on thyroid hormone treatment.

They found that the TSH values were much better estimated by PGS than free thyroid hormone levels or other factors such as age, sex, or weight. PGS explained 9-11% of the difference in TSH compared to 2.4-2.7% that would be explained by the difference in free thyroid hormone level. Individuals whose PGS scores fell into higher ranges were more likely to be treated with thyroid hormone. Up to 25-30% of individuals who would be diagnosed with mild thyroid disease when standard population based reference range was used were classified as having normal thyroid function when the genetically based TSH reference ranges were used, while 0.6-0.8% of patients with normal TSH levels with standard ranges were reclassified as having mild thyroid disease.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

The authors found that TSH reference ranges based on genetics differ from standard population-based reference ranges. By considering individual genetic profiles we could personalize TSH reference ranges which would lead to more accurate diagnosis and treatment decisions. These findings are very important for patients even though it is challenging to currently

THYROID FUNCTION, continued

apply them in routine practice. This is an important study that opens the door for further studies to find additional genetic markers and factors to improve the reference ranges and to develop better personalized treatments for thyroid disease.

— Ebru Sulanc, MD

ATA RESOURCES

Thyroid Function Tests: https://www.thyroid.org/thyroid-function-tests/

ABBREVIATIONS & DEFINITIONS

Genes: a molecular unit of heredity of a living organism. Living beings depend on genes, as they code for all proteins and RNA chains that have functions in a cell. Genes hold the information to build and maintain an organism's cells and pass genetic traits to offspring.

Thyroid hormone therapy: patients with hypothyroidism are most often treated with Levothyroxine in order to return their thyroid hormone levels to normal. *Replacement therapy* means the goal is a TSH in the normal range and is the usual therapy.

TSH (Thyroid Stimulating Hormone): produced by the pituitary gland that regulates thyroid function; also the best screening test to determine if the thyroid is functioning normally.

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HYPOTHYROIDISM

Personality traits and patient satisfaction in hypothyroidism

BACKGROUND

Hypothyroidism, or underactive thyroid, is common, with symptoms including fatigue, constipation, dry skin and weight gain. Hypothyroidism is treated by thyroid hormone replacement in the form of levothyroxine, the main hormone the thyroid makes. While the symptoms of most hypothyroid patients resolve on levothyroxine (T4), about 15% still report symptoms despite achieving normal serum thyroid hormones levels. It is unclear why these patients still experience symptoms. Some potential causes include not having all the thyroid levels back to normal and the worry of having a chronic disease or an autoimmune cause, among other causes. Options to address these symptoms have included adding the other thyroid hormone, triiodothyrodine (T3) to the levothyroxine replacement or changing to desiccated thyroid, which is dehydrated thyroid extract. These treatment options have varying results.

In this study, the authors analyzed if some personality traits could be the association between hypothyroidism and residual symptoms, especially, type D personality, which is characterized by a tendency to pessimism, worry, and negativity. This personality trait has been associated with persistent symptoms in other conditions, such as heart problems.

THE FULL ARTICLE TITLE

Perros P, et al. Hypothyroidism and type D personality: results from E-MPATHY, a cross-sectional international online patient survey. J Clin Endocrinol Metab. Epub 2024 Apr 9; doi: 10.1210/clinem/dgae140. PMID: 38591918.

SUMMARY OF THE STUDY

A survey was conducted by affiliates and partners of the patient advocacy group Thyroid Federation International via social media and web pages from 68 countries between April 2020 and January 2021, during COVID-19 pandemic. In addition to personality assessment, the survey included questions to assess: (i) control of symptoms of hypothyroidism by medication, (ii) satisfaction with treatment and care for hypothyroidism, and (iii) impact of hypothyroidism on everyday quality of life.

The survey received 3523 responses, of which 94.3% were women, 89.1% were white, 74.3% were employed, 87.1% had received more than 8 years of education, 75.1% were treated with levothyroxine alone, and about 20% were treated levothyroxine and T3 or desiccated thyroid extract. Around 16% of the ones who responded had no other medical conditions. In addition, 54.2% of the respondents had type D personality. Type D personality was found to be associated with other medical problems such as mental illness. In addition, type D personality was associated with dissatisfaction with the thyroid medication controlling symptoms, with care and treatment of hypothyroidism, and with a negative impact on quality of life.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

This study showed that type D personality was present in the majority of patients with hypothyroidism that responded to this survey. This suggests that having type D personality may be associated with negative patient-related outcomes in hypothyroidism. Further studies are needed to sort out this association.

— Joanna Miragaya, MD

ATA RESOURCES

Hypothyroidism (Underactive): https://www.thyroid.org/hypothyroidism/

Thyroid Function Tests: https://www.thyroid.org/thyroid-function-tests/

Thyroid Hormone Treatment: https://www.thyroid.org/thyroid-hormone-treatment/

HYPOTHYROIDISM, continued

ABBREVIATIONS & DEFINITIONS

Hypothyroidism: a condition where the thyroid gland is underactive and doesn't produce enough thyroid hormone. Treatment requires taking thyroid hormone pills.

Levothyroxine (T4): the major hormone produced by the thyroid gland and available in pill form as Synthroid™, Levoxyl™, Tyrosint™ and generic preparations.

Thyroid hormone therapy: patients with hypothyroidism are most often treated with Levothyroxine in order to return their thyroid hormone levels to normal. *Replacement therapy* means the goal is a TSH in the normal range and is the usual therapy. *Suppressive therapy* means that the goal is a TSH below the normal range and is used in thyroid cancer patients to prevent growth of any remaining cancer cells.

Desiccated thyroid extract: thyroid hormone pill made from animal thyroid glands. Currently desiccated thyroid extract is made from pig thyroids and is available as Armour Thyroid™ and Nature-Throid™.

Triiodothyronine (T3): the active thyroid hormone, usually produced from thyroxine, available in pill form as Cytomel™.

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HYPOTHYROIDISM

What is the association between TSH levels and heart health in patients with hypothyroidism?

BACKGROUND

Hypothyroidism is a common disorder associated with high levels of TSH and low levels of thyroid hormone. Hypothyroidism is usually treated with levothyroxine in a dose to normalize TSH levels. However, we know that many people on levothyroxine do not always have normal TSH, with frequent high (undertreatment) and low (overtreatment) TSH levels commonly seen. These results usually lead to a change in the levothyroxine dose.

Thyroid hormone has a direct effect on the heart. High levels of thyroid hormone, as seen in hyperthyroidism, leads to increase heart rate, palpitations and irregular hear rhythms. Low levels of thyroid hormone can lead to a low heart rate. Both conditions can cause heart problems. Studies have shown that both under and over treatment with levothyroxine are also associated with increased heart problems and can lead to an increased risk of death. In most of these studies, thyroid function was evaluated over a short period of time.

This study sought to assess changes in thyroid function (called the TSH trajectory) over a longer time frame and evaluate how that correlated with heart health markers.

THE FULL ARTICLE TITLE

Ettleson MD, et al. TSH trajectories during levothyroxine treatment in the Brazilian Longitudinal Study of Adult Health (ELSA-Brasil) cohort. J Clin Endocrinol Metab. Epub 2024 May 23:dgae294; doi: 10.1210/clinem/dgae294. PMID: 38780968.

SUMMARY OF THE STUDY

The authors used data from the Brazilian Longitudinal Study of Adult Health (ELSA-Brasil), a group of over 15,000 Brazilian civil servants ages 35 to 74 years from six Brazilian cities. Only participants with a reported history of hypothyroidism and continuous levothyroxine treatment were included. They excluded patients with a history of thyroid cancer and recent /current pregnancy and identified 621 participants with data over 3 time periods called waves (wave 1 at baseline in 2008–2010, wave 2 in 2012–2014, and wave 3 in 2017–2019). Data collected included health questionnaires, clinical measurements and blood samples. It was also noted whether participants were taking medication for high blood pressure, elevated cholesterol and/or diabetes. An advanced statistical method was used to identify groups with similar changes in TSH levels (TSH trajectories) and then changes in cardiovascular health markers and related medications were compared between the three study waves.

Of the 621 participants with an average age of 54.2, 85.7% were female, 63.6% were White, and 63.4% had completed college. Four TSH trajectories were identified. (1) high–high normal TSH (HHN) (55.9%); (2) normal TSH (N) (30.3%); (3) normal to low TSH (NL) (6.8%); and (4) low to normal TSH (LN) (7.1%). Changes in cardiovascular health markers and cardiovascular medication over time were compared within each trajectory. At baseline (wave 1) there were no significant differences in cardiovascular health makers between the four groups. However, current smokers were more common in the LN group, while males were more common in the HHN group and the average baseline levothyroxine dose was lowest in the HHN group.

One or more cardiovascular health marker increased over time in all the groups, as well as usage of cardiovascular related medication. The biggest changes appeared in the HHN and LN classes.

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

This study expands upon previous reports showing the association of poor thyroid hormone control and worsening CV health. Its strength is the longer duration

HYPOTHYROIDISM, continued

of time that subjects were monitored. However, the sample size was too small to compare results between the 4 groups. Thus, it is difficult to separate the effect of thyroid hormone control versus aging over the ten years of observation. More studies are needed to fully evaluate the risks of over- or under-treatment of hypothyroidism and heart problems.

— Marjorie Safran, MD

ATA RESOURCES

Hypothyroidism (Underactive): https://www.thyroid.org/hypothyroidism/

Thyroid Hormone Treatment: https://www.thyroid.org/thyroid-hormone-treatment/

ABBREVIATIONS & DEFINITIONS

Hypothyroidism: a condition where the thyroid gland is underactive and doesn't produce enough thyroid hormone. Treatment requires taking thyroid hormone pills.

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THYROID CANCER

Do patients choosing active surveillance for their small, low risk papillary thyroid cancer experience regret for their decision?

BACKGROUND

Thyroid cancer is common and the prognosis is excellent. This is because we have excellent treatments, with surgery being the mainstay. This is especially true with small papillary thyroid cancers. The treatment of these low-risk papillary thyroid cancers has recently shifted toward less extensive surgery, specifically lobectomy as opposed ot total thyroidectomy. Although the standard of care for papillary thyroid cancers is surgery, some patients have opted for following these small cancers with ultrasound. This is called active surveillance. Surgery is deferred, usually until the cancer grows or the patients decides to move forward with surgery. Since the patient is living with a known cancer, there is the possibility that their quality of life may be affected with regret for the decision for active surveillance.

This study assessed the presence and extent of decision regret, fear of cancer progression, anxiety, depression, and quality of life 1 year after choosing between active surveillance and immediate surgery for low-risk papillary thyroid cancer.

THE FULL ARTICLE TITLE

Sawka AM, et al. Decision regret following the choice of surgery or active surveillance for small, low-risk papillary thyroid cancer: a prospective cohort study. Thyroid 2024;34(5):626-634. doi: 10.1089/thy.2023.0634. PMID: 38481111.

SUMMARY OF THE STUDY

This was a study from a major Canadian hospital system. Adults with low-risk papillary thyroid cancers <2 cm were offered active surveillance or surgery. The treatment options were explained to patients, and surgery was reported as the standard of care. Patients choosing active surveillance were asked to follow up in clinic. Patients who chose surgery or switched from active surveillance to surgery, which was recommended if cancer growth was observed, received standard postoperative follow-up. All patients consented to short-term follow-up regarding treatment choice and again at 1 year. The study used multiple questionnaires to assess patient perspectives. The primary outcome was the Decision Regret Scale (DRS) score, which measures distress or remorse after a health care decision. Scores range from 0 to 100, with 100 representing maximal regret. A score of 25 was used to distinguish between lower versus higher decision regret. Patients who changed from active surveillance to surgery were compared to those who continued active surveillance.

Of the 191 patients studied, most were women (147, 77%) and the average age was 53 years; 151 (79.1%) opted for active surveillance. Patients who chose surgery were younger (average age 47 years vs. 55 years), more likely to be married (90% vs. 72%), have a college or advanced degree (97% vs. 67%), and have larger cancers (average size, 13 mm vs. 11 mm) than active surveillance patients. There were 11 (7.2%) active surveillance patients who crossed over to surgery: 2 due cancer progression and 9 due to personal preference. These patients were younger (45.2 years vs. 55.8 years) than other active surveillance patients. Of the 51 patients who underwent surgery, most (40) underwent lobectomy. No patient had cancer recurrence at the 1-year follow-up appointment.

At 1 year, there was no difference in decision regret in the active surveillance and surgery groups (average score, 22.4 vs. 20.9). Patients who crossed over from active surveillance to surgery had a significantly greater decision regret score. Patients choosing surgery had greater initial fear of cancer progression as compared to the active surveillance group (29.9 vs. 24.2), but there were no differences at 1-year follow-up (24.4 vs. 23.1) due to a significant reduction in fear of progression in the surgery group.

THYROID CANCER, continued

WHAT ARE THE IMPLICATIONS OF THIS STUDY?

This study shows that many patients with small low risk papillary thyroid cancers will choose to follow with active surveillance and defer surgery if they are given that option. Patients choosing surgery appeared to do so because of a greater fear of cancer progression. Patients that do move from active surveillance to surgery do have a greater decision regret. Of the rest, there is no significant difference in the level of decision regret between patients who chose active surveillance rather than surgery for small, low-risk papillary thyroid cancers.

— Alan P. Farwell, MD

ATA RESOURCES

Thyroid Cancer (Papillary and Follicular): https://www.thyroid.org/thyroid-cancer/

ABBREVIATIONS & DEFINITIONS

Papillary thyroid cancer: the most common type of thyroid cancer. There are 4 variants of papillary thyroid cancer: classic, follicular, tall-cell and noninvasive follicular thyroid neoplasm with papillary-like nuclear features (NIFTP).

Thyroid Ultrasound: a common imaging test used to evaluate the structure of the thyroid gland. Ultrasound uses soundwaves to create a picture of the structure of the thyroid gland and accurately identify and characterize nodules within the thyroid. Ultrasound is also frequently used to guide the needle into a nodule during a thyroid nodule biopsy.

Active surveillance: the practice of deferring surgery for small, low risk thyroid cancers following them with serial ultrasounds.

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info@ngdf.org

Light of Life Foundation
www.checkyourneck.com
info@checkyourneck.com

MCT8 – AHDS Foundation
mct8.info
Contact@mct8.info

Thyca: Thyroid Cancer Survivors' Association, Inc.
www.thyca.org
(Toll-free): 877-588-7904
thyca@thyca.org

Thyroid Cancer Alliance
www.thyroidcanceralliance.org
www.thyroidcancerpatientinfo.org
Rotterdam, The Netherlands

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