

Keeping Your Thyroid Cancer in Remission - A consensus from Patients

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ABSTRACT

During recent forty years, thyroid cancer rates had gone up constantly. Generally, the best treatment for thyroid benign or malignant nodules is surgery, but surgery is very costly. This paper was about how to manage thyroid cancer through food and medication. To understand this topic, this researcher went through more than five thousand threads/emails online long-term thyroid cancer survivors' group. Among the survivors, this researcher picked out five typical cases that survived thyroid cancer from eight years to close to 50 years. From these five cases' discussion, this researcher tentatively summarized the best practices in diet and medication in improving thyroid health, and consequently keeping thyroid cancer in remission.

Keywords

Thyroid cancer, Surgery, Neuro-degenerative diseases.

Introduction

About 62,450 new cases of thyroid cancer appear in the year 2015. Among them 47,230 are women, and 15,220 are men [1]. There are about 1,950 deaths from thyroid cancer in 2015 (1,080 women and 870 men). About two thirds of the thyroid cancer cases are under 55 years old [2]. Majority of thyroid nodule/cancer patients are women [3].

Overall, surgery is a better choice for bigger than 4cm thyroid nodules than observational strategy [4]. Since surgery is very expensive, and may not be the best choice for nodules smaller than 4cm, observational strategy can be very important in small benign nodules treatments. Among thyroid nodules, some grow bigger, some stay the same, and some shrink [5]. According to a longitudinal study by Durante et al., 15.4% of thyroid nodule patients have the growth of the tumors; while tumors in 18.5% of patients shrank. If thyroid nodules have different natural histories among different patients, those whose thyroid nodules shrank or kept thyroid cancer in remission might have a successful self-management regimen. This research will be about collecting these diverse regimens in food and medicine among those who kept their tumors in control, and find a trend in these practices. Thyroid cancer treatment should be more than a local treatment. It is supposed to be a whole-body thing, because thyroid has closer

connections to the whole body than other organs do [6].

Research Method

This research is qualitative because the goal is to find answers, not to describe, find correlations, or experiment [7]. Qualitative research does not have a hypothesis. Instead, it extracts codes from phenomena to understand a topic. Unlike quantitative research, in which the researchers make hypothesis; and then examine whether the hypothesis is right; qualitative research uses interview, focus groups, documentations, and observations [8]. Quantitative research uses descriptive research, correlational research, Causal-comparative/quasi-experimental research, and Experimental research [9]; while qualitative research sometimes can be basing on how the research subjects feel.

This research will extract codes from a yahoo thyroid cancer discussion group, and uses five cases to find the answers of the research questions. Single case studies can provide vital contributions to theory-testing in social science studies. Following this example, collecting data from five thyroid cancer patients who have lived decades after thyroid cancer diagnosis is credible.

Research Question

RQ: What are the literature review and consensus-based best diet practices for preventing the growth of thyroid nodules into cancer among women thyroid nodule/cancer survivors who relied upon non-surgical self-managed dietary routines and intakes?

Result and Discussion

Most of the thyroid cancer survivors concern about fatigue, depression and difficulties in concentration. Also, they have the concern about osteoporosis. Also, most of the survivor's concern about brain fog and low energy. They believe the man-made hormone can never work as good as the real thyroid. Also, they think the current TSH normal range is not right.

The 41+ year survivor stated that the fatigue, depression, and difficulties in concentration might come from hyperparathyroidism, and calcium level is important in thyroid cancer treatment. While taking thyroid medication, a patient should have regular bone density scans. The eight-year survivor also stated that high level of free T4 affects a person's bone. This is consistent with the research done by Tárraga López, Frias López, Naharro de Mora, Rodríguez Montes, Solera Albero, ... & Galvez Casas, [10]. When people are taking thyroxin, they are likely to have osteoporosis. Acetyl carnitine, phosphide, and serine help with memory loss. These statement means of different types of protein might make a difference in thyroid health related memory problems, which is consistent with the research carried out by Deng, et al. [12]. Acetyl carnitine does help in treating memory loss among patients with alzheimer's and other neuro-degenerative diseases [12]. Carnitine is a derivative from an essential amino acid, lysine. Carnitine rich foods include red beef, milk, cod fish, and chicken breast [13]. The 47+ year survivor stated that vitamin B12 helps with low energy. It is reasonable because this survivor is a vegetarian. For people who are on vegetarian diet, Vitamin B12 can help boosting energy. B group vitamin are a group a stress vitamin, which gets low fast when people are in stress [14]. The 19 year plus survivor stated that amino sea minerals can help with the tiredness.

Phosphide contains phosphorus, which is important in bone and nerve tissues. Phosphorus does offer energy, construct cell membrane, and interact with calcium to improve bone health; but artificial phosphorus is not good for health [15]. Therefore, the suggestion of taking in phosphide is not a good one. There are many phosphorus rich foods though. Pumpkin and squash seeds, ramano cheese, salmon and nuts are some typical phosphorus rich foods [16]. Eating the above stated food can be good for energy and memory loss. Although not an essential amino acid, serine is important in human cell functions. Lack of serine can cause many nervous system problems. Some typical serine rich foods are soy bean, egg yolk, lentils, and peanuts [17]. The fermented soybeans such as natto and tempeh are some easy to digest soy foods.

A 19 year plus survivor stated that going off gluten for a while can alleviated tiredness. Gluten is in wheat, rye, and barley. Despite of being a series of healthy foods, wheat products have some downfalls. Wheat products cause several diseases such as celiac disease, wheat allergy, and non-celiac gluten sensitivity. In some celiac disease patients, the symptoms do not subside. Carbohydrates in wheat do trigger non-celiac gluten sensitivity [18]. Among people with autoimmune thyroid disease, the percentage of celiac disease is 8.6%, which is higher than general population [19]. Some hypothyroid patients need more levothyroxine than others.

The ones who need more levothyroxine might have celiac disease [20].

The 47+ year survivor stated that the plant based high carb diet is the best practice for thyroid cancer survivors. The eight-year survivor who had been pre-diabetic stated that high-carb diet was never right because carbs were not satiating. A good diet is to stay with good carbs, but stay away from meat and fat. However, low fat foods are not good either. A 19 year plus survivor stated that good carbs such as wheat/barley/rye helped a lot. Bananas do not put weight on you. From the above discussion, high carb diet seems reasonable because the 47 plus year survivor, with metastasis in lung, does not have diabetes nor heart problems from using levothyroxine. Good carbs might help, but not good for celiac disease patients. If wheat/barley/rye are not good for thyroid patients with celiac disease, rice diet might be reasonable.

TSH

The 41+ year survivor stated that hyperthyroid symptoms appear when TSH is less than 0.1. Using beta-blocker Metoprolol can decrease hyperthyroid symptoms, but it worsens depression. People who are taking thyroid medication should have regular ECGs. The 41+ year survivor stated that TSH fluctuation might have something to do with environmental temperature change, for example, too hot. The 47+ year survivor stated that thyroid cancer patients should have a TSH 0.08- 0.1 but 0.2-0.3 is Ok. She also stated that her heart function is completely normal despite of thyroid hormone supplement and she had been feeling fine, despite the cardiovascular side effects of thyroid hormones. The eight year plus survivor stated that exercise might make TSH value higher.

An 11-year longitudinal research done by Åsvold BO, et al. [21], proved that the upper limit of thyroid stimulating hormone (TSH) reference range might be too high. In Åsvold et al 's research, the researchers followed up 9709 women and 4644 men for 11 years. The result shows that among people who have normal thyroid functions, the high TSH people are less likely to have a healthy lipid and hemodynamic profile than people who have lower TSH. Therefore, among people who are free of thyroid diseases, a lower TSH within the range is a healthier number than the higher one [21]. Among thyroid cancer patients, the higher stage and more lymph nodes involved patients have a slightly higher TSH than the patients with lower stage thyroid malignancy [22]. Actually, raised TSH value within the normal range is a risk factor for thyroid cancer [23].

Among adult euthyroid population, normal range of TSH from 2.5 to 97.5 percentile is 0.4-3.4 mu/L, which is lower than the normal range, 0.45-4.5 mu/L, that most hospitals are using [24]. Some people, for instance, the 47+ year survivor felt fine with TSH slightly under 0.1, and she did not have the complications that came with high thyroid hormone level. TSH level should not be too low either. In the research conducted by Debeij, Dekkers, Asvold, Christiansen, Naess, & ... Cannegieter, [25], the researchers followed up 66140 subjects during the period of 1995-1997. The result of the research showed that high FT4 level

was a risk factor for venous thrombosis; while TSH level inversely related to venous thrombosis. In another words, when TSH level is too low, the risk of thrombosis increases [25].

Iodine, T3, T4

As important as iodine is, and as developed as the U.S. is, American people might still be short of iodine. Prior to the 1920's, the goiter belt is the places around the Great lakes, Appalachians, and Northwestern regions. These areas are the places that are iodine deficient in the soil [26]. These places got fewer goiters than before after iodine fortification. However, even after iodine fortification, people living in goiter belt are still iodine deficient. The reason is that iodine salt is not the only solution. A study in Switzerland showed that Iodized salt contributes to fifty-four percent of the total iodine intake. The prevalence of iodine deficiency was 2% for men and 14% for women [27]. If iodized salt cannot solve the iodine deficiency problem, people have to take in iodine from other food sources. Since soil iodine content decides food iodine content, in Goiter belt, food iodine content should be lower than that of coast along the sea [28]. Therefore, people living in Goiter belt still are currently iodine deficient.

All but the 47+ survivor stated that weight gain is common after thyroidectomy. The 38-year survivor stated the T4 and T3 supplements can never work as well as a real thyroid. Weight gain and depression happen even if the numbers are right. Calcium and Vitamin D deficient are common. T3 can help with weight gain, depression, and brain fog. The 41+ year survivor stated that as people get old, they need less thyroxin. The 47+ year survivor agrees. Some patients prefer armor thyroid, which is desiccated pig thyroid that contains both T4 and T3; while some people prefer levothyroxine, which is T4 only. Add cytomel (T3) helps with tiredness and brain fog. The 41 year plus survivor stated that having memory issues is common among thyroid cancer patients. The 41+ year survivor stated that thyroid cancer needs life long follow up because thyroid cancer does recur. The 47+ year survivor stated that thyroid cancer can come back even after 21 years.

Conclusion

- For people who use thyroid hormones, Osteoporosis is common.
- Acetyl carnitine, phosphide, and serine help with memory loss.
- Carnitine rich foods include red beef, milk, cod fish, and chicken breast.
- Vitamin B12 helps with low energy.
- Amino sea minerals can help with the tiredness.
- Some typical serine rich foods are soy bean, egg yolk, lentils, and peanuts.
- Pumpkin and squash seeds, ramano cheese, salmon and nuts are some typical phosphorus rich foods.
- People with auto-immune thyroid diseases have high rate of celiac disease.
- Rice is a good gluten free choice of carbohydrate.
- Bananas do not put weight on.
- Current clinical TSH normal range is 0.45-4.5mu/L is not

accurate. For thyroid cancer survivors, 0.1 is about right.

Further research will investigate whether VitD and calcium metabolism relate to thyroid hormone usage; what the functions of sea minerals are; the best ways to take in phosphorus; and the role of rice in diet.

Appendix I: Records of the Threads

Case #1:

Pap thyroid cancer

Partial thyroidectomy, London, England 09/1965

Total thyroidectomy, The Netherlands 04/1982

Low iodine diet/Radiation iodine therapy, The Netherlands 05/1982

Clean scan 09/1982

Thread #25: Extreme fatigue, mild depression, and difficulties in concentration might have something to do with hyperparathyroidism.

Thread #30: Thyroid cancer needs follow up for life because thyroid cancer does recur.

Thread #45: Calcium level is important in thyroid cancer treatment.

Thread #56: Looking forward is courageous and perfectly right, but easy said than done.

Thread #81: Wondering type II diabetes has something to do with thyroid.

Thread #153: Somehow once we've dealt with the fear, anger, denial, anxiety, and questions, it becomes something we can learn and grow from.

Thread #212: Had 17 years between my first and latest recurrence and I just passed my 20 year recurrence-free anniversary! Recurrence is common.

Thread #269: Some gentle exercise such as walk, bike or anything you enjoy will help with the fatigue.

Thread #406: As people get old, they need less thyroxin.

Thread #563: When TSH is less than 0.1, I have hyperthyroid symptoms.

Thread #671: Using beta-blocker Metoprolol can decrease hyperthyroid symptoms, but it worsens depression.

Thread #742: I once had my TSH jump to 19, which could have been

temperature...leaving them on the dashboard of the rental car.

Thread #1082: Although memory loss can have many causes, having memory issues is common among thyroid cancer patients.

Thread #1223: Exercise helped my mental well-being during hypothyroid period.

Thread #1238: taking thyroid medication is an reason for regular bone density scans and ECG's, and getting advice on how to protect agains osteoporosis.

Last thread posted: March 22nd, 2007,

Survival Time: Over 41 years.

Case #2:

dx: 1968, Total thyroidectomy, pap. & foll. Well differentiated w/hurthle cell, Radiation iodine therapy, radical neck dissection, lung surgery, hashimoto, thyroglobin antibody 575, iodine resistant, existing

thyroid cancer nodules in lungs. Last surgery 1972

Thread #1008: have your bloods checked just to make sure you are in suppression <0.10.

Thread #1052: It is true that as we age we need less medication. In some patients poor follow-up or going off meds for a scan can increase spread ... in others it will not.

Thread #1078: I was on Armour for many years. I switched to Levxoyl and cytomel because the adjustments could be individually done. You can't do that with Armour; if you need a dose change both levels get changed because it's one pill.

Thread #1126: The recurring of thyroid cancer sometimes happen after 21 years.

Thread #1134: The human body respond to thyroid medicine differently in time.

Thread #2007: Vitamin B12 helps with low energy.

Thread #3035 Although thyroid hormone supplement has the effect of racing heart and anxiety, my heart function is completely normal.

Thread #3466 Currently Tg and antibody positive means having active cancer.

Thread #3467 Before radiation therapy a thyroid patient should be on low iodine diet for two weeks.

Thread #3480 Thyroid cancer recurrence is common.

Thread #3586 My TSH is kept at 0.08-0.1 because of the metastasis.

Thread #3692 Cancer is bad, but it is how you face your disease.

Thread #3710 I am feeling fine with TSH under 0.1 for 40 years.

Thread #4323 Gold standard of 0.1 TSH is not necessarily right.

Thread #4551 Medication fillers are usually the causes for synthoid issues such as ineffective strength.

Thread #4576 For thyroid cancer patient, TSH should shoot for 0.1, but the range of 0.2-0.3 is OK.

Thread #4577 For people who do not have a thyroid, some need T3 supplement some do not.

Thread #4797 Rice diet in NC is the correct diet.

Thread #4803 Physicians at Duke are doing starch based diet.

Thread #4804 High carb diet is relative to low carb diet. It is eating good carbs, not refined carbs.

Thread #4805: Cooking with plant based food is a lot of fun.

Last post date: April, 24th, 2015,

Survival time: Over 47 years.

Case #3:

Total thyroidectomy, Radiation iodine therapy, 2006

Thread #2722 Exercise might make TSH value higher.

Thread #2960 Thyrogen TG, as a cancer marker may always present during remission.

Thread #3504 With exercise, TSH increases. The possible explanation is is increased muscle mass.

Thread #3755 Beta blockers such as atenolol is effective in treating palpitations.

Thread #3787 When FT4 is above 1.79, a person's bone is affected.

Thread #3795 Exercise cures brain fog. The breathing and increased heart rate clear the head.

Thread #3805 T4 level affect bone density, while TSH level does not.

Thread #4247 Add cytomegalovirus helps with tiredness; so does exercise.

Thread #4373 Cytomel helps with brain fogs and tiredness. Acetyl carnitine and phosphide too serine help with memory loss.

Thread #4412 People become forgetful when they get old.

Thread #4438 When thyroid cancer patients get off medications, their cancer come back.

Thread #4525 I am currently taking 5mcg of Cytomel.

Thread #4767 Family may not be supportive to thyroid cancer treatment.

Thread #4798 Never do high carb. Good carb diet might be good, but not high carb.

Thread #4800 I am currently diagnosed as pre-diabetes so I know about diet. People cannot stay with high carb diet because it is not satiating.

Thread #4801 A good diet is to stay with good carbs, but stay away from meat and fat.

Thread #4807 Low fat foods are not good. Meat has a lot of fat which is not healthy. People can not stay with vegan diet because it is not filling. I have always exercise and done weights, but end up pre-diabetic.

Thread #4808 High carb diet might eliminate issues that cause cancer/ heart diseases, but not other issues.

Last Post Date: September 4th, 2014

Survival time: Over eight years.

Case #4:

Total thyroidectomy 1995

#1631 Wheat/Barley/rye helped a lot. After the half and half thyroid operation, 200mcg of or oxide is just about enough. The other side is suspicious.

#1804 To deal with tiredness, a person may try to go off gluten for a while. Bananas do not put weight on you.

#1807 Gluten is in wheat rye and barley. Amino sea minerals can help with the tiredness.

#1808 Thyroid cancer causes hormonal change, and it causes psychological impact.

#1867 Hand tremors are common after thyroidectomy. The situation connects to too much thyroxine. Gluten might worsen the situation.

#1944 Thyroidectomy makes memory compromised.

#2006 Sea minerals boost energy levels.

#2026 Went from size 8 to 12-14 after thyroidectomy.

#2210 Exercise increases energy. Can skip a pill after exercise.

#2224 Thyroid cancer can come back on the other side after the removal of ill-side.

#2576 Sea minerals may clear up the infection.

#2634 Thyroid removal can cause stress, memory loss and depression.

#2966 Women have big babies when they are on thyroid supplements.

#3188 I have low level of calcium, and have to take supplements.

\$4764 Other people will not understand the feelings of a cancer patient unless they are in your shoes.

#4802 Desiccated pig's thyroid works better than T4 only.

Last post date: July 7th, 2014

Survival time: Over 19 years.

Case #5

papillary and follicular thyroid cancer, and surgery was January 1977.

#2012 I had brain fog ever since thyroid was out.

#2023 I had hypothyroid symptoms despite my TSH is very low.

#2229 I felt exhausted and depressed after lowering the dose of thyroid hormone supplement.

#2232 TSH and T4 are in normal range, but I still feel wasted.

#2268 I am having problems in sleeping. Sleep is very fragmented.

#2619 The important is not the numbers are in the normal range; the important is that I feel alright.

#2790 I had a year of muscle twitches, but recovered. I do not know what the reason is.

#2875 I have to be very hyper to feel normal.

#3010 Alcohol can cause heart racing.

#3186 I had vitamin D deficient.

#3882 I used suppressive dose when I was on 0.35 mg of thyroxine. After wards I was on 0.3mg (which is still a very high dose)

#3924 I become heat intolerant, I have to set the house temp at 74.

#4374 Taking T3 makes a huge differences.

#4569 After I started taking T3, weight gain, depression, and brain fog all disappeared.

Last post date: November, 28th, 2015

Survival time: Over 38 years.

Appendix II: Approval from Yahoo Long-term Thyca Group Administor

Gary Bloom <gbloom@thyca.org>
11/17/15 at 6:33 PM

Dear Dr. Xu,

I give you permission to go through the threads to extract anonymous information for your dissertation effort.

Good luck,
Gary

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