Patient perspectives on the treatment for Hashimoto’s thyroiditis: a qualitative analysis

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Abstract

Hashimoto’s thyroiditis (HT) is an autoimmune disorder which can be accompanied by a myriad of symptoms. Conventional medicine currently treats only one of these symptoms, hypothyroidism, with thyroid hormone replacement therapy. The focus of this project was to obtain personal views from HT patients on their specific health care plan, satisfaction of the treatment offered, and overall burden of this disease. Individual semi-structured interviews were conducted to obtain this information. Emerging themes included patient experiences with health care providers, symptoms experienced by patients, and treatment options offered to patients. Results suggest patient-centered care is absent from their experiences in various health care settings and current protocol for management of HT is not sufficient for alleviating many disease-related symptoms. Participants often look beyond their health care professional to better understand the disease and to seek out additional treatments. Complementary treatment options to standard therapy were strongly desired. Obtaining direct insight from the patient’s perspective could be valuable for strengthening patient-provider relationships. Health care providers being mindful, informative, and empathic of patient views could improve patient’s quality of care and encourage further treatment possibilities for individuals who suffer from symptoms of Hashimoto’s.

Abbreviations: HT: Hashimoto’s Thyroiditis; TSH: Thyroid Stimulating Hormone; MDM: Minimally Disruptive Medicine

Introduction

Hashimoto’s thyroiditis (HT), also known as chronic lymphocytic thyroiditis or autoimmune thyroiditis, is now considered the most prevalent autoimmune disease and endocrine disorder [1]. One of the symptoms in individuals with HT is hypothyroidism, a deficiency of thyroid hormones that disrupts such things as heart rate, body temperature, and metabolism. Current medical protocol for treatment of HT is supplementation with the synthetic thyroid hormone, Levothyroxine [2]. This medication is only warranted if the thyroid stimulating hormone (TSH) is out of range. Symptomatic distress is often still reported independent of thyroid dysfunction [3,4] including weight gain, hair loss, cold intolerance, impaired cognitive function, and extreme fatigue.

Although conventional medicine does not offer standard treatment of HT symptoms outside of hypothyroidism, various complementary health approaches such as acupuncture [5], diet modification [6], and trace element supplementation [7] do offer treatment options in efforts to suppress the autoimmune response.

The purpose of this pilot study is to uncover the perceived level of HT related symptom load in euthyroid patients and treatment plans offered to alleviate symptoms identified by either their physician or through self-treatment. The patient’s interpretation and satisfaction level of the relationship with their past and present health care provider(s) treating them for HT will also be explored.

Methods

This study used semi-structured interviews (Table 1) with individuals diagnosed and treated for HT by a health care provider.
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Results

Through the constant comparison method, three themes emerged: 1) patient experiences with health care providers, 2) symptoms experienced by patients, and 3) treatment options offered to patients. Below we describe the key findings related to each of these themes.

Patient Experiences with Health Care Providers

Interviews revealed the term ‘health care provider’ included conventional medicine (primary care physicians and referred specialists), alternative medicine, and integrative medicine. HT patients saw a plethora of health care providers before obtaining a diagnosis and then continued on to numerous specialists to treat individual symptoms. An average of five providers were seen before diagnosis of HT was even given. Primary care physicians often referred out to endocrinology, who are known to be the first line of defense in HT treatment in conventional medicine.

When asked what type of physician gave them the HT diagnosis, answers were given such as “my primary care doctor” or “my gynecologist told me I might have it, so I asked my regular doctor to test me.” Another participant said “I knew something was wrong with me, and they tried telling me I had depression and sent me to a psych doctor who said I should have my thyroid checked.”

After the HT diagnosis all six of the participants were referred to an endocrinologist, although only two continue to see them for routine follow-ups. One participant said “I knew more about my disease than that endo doctor. I had to find someone else that looked at more than a lab test. I found an integrative medicine doctor after that, and it’s much better.”

There was a high frequency of health care provider turnover rate in the HT patient population interviewed. We found this was not exclusive to specialist referrals, as most participants switched providers within departments at various points of treatment.

Once diagnosed, HT patients were generally referred to endocrinologists who specialize in thyroid disorders even though rheumatologists focus on autoimmune diseases. Rheumatologists refused to treat four of the participants. The goal of HT treatment

| Characteristics | Frequency, n (%) |
|----------------|-----------------|
| Gender         |                 |
| Female         | 5 (83)          |
| Male           | 1 (17)          |
| Location       |                 |
| Rural          | 2 (33)          |
| Urban          | 4 (67)          |
| Age in Years   |                 |
| 18-25          | 0 (0)           |
| 26-30          | 1 (17)          |
| 31-35          | 1 (17)          |
| 36-40          | 3 (50)          |
| 41-45          | 1 (17)          |
| Years with Hashimoto’s | |
| 0-5            | 1 (17)          |
| 6-10           | 4 (67)          |
| 11-15          | 0 (0)           |
| 16-20          | 1 (17)          |
| >20            | 0 (0)           |
The interviews revealed symptoms outside of hypothyroidism often getting shorter and I could read a book and remember it the next day.” With HT disproportionately affecting women and having an average onset age of 35, this is hitting mothers who often have young children to care for. “I am too tired to chase after my 7-year-old…I get delirious from fatigue and can’t even drive.”

Quality of life can be drastically reduced from fatigue and is prevalent in the HT population interviewed. “Fatigue is the worst part of Hashimoto’s. I have to nap in my car at my job because I can’t make it through the day without one.” It has also shown to affect relationships with spouses. “I'm too tired to go to the gym with my husband, to cook him dinner, to have sex with him…it is just too much and all I want to do is sleep.” This symptom in particular can change a person’s quality of life considerably; comments in the interviews suggest a distinct difference in level of activity and overall enjoyment of life from before onset of HT.

Treatments Options Offered to Patients

The definition of treatment in this text refers to any behavioral or medical intervention aimed to alleviate symptomology of HT. As many HT patients still complain of symptoms after a euthyroid state is reached from prescription medication, we sought out to see if there were any other unconventional treatments being offered to patients by providers, or if they are self-treating through independent methods.

We asked if any providers had other recommendations for symptoms. One participant said “my doctor told me there is no other treatment and I should be fine.” Another commented “no, I was told that my other symptoms had nothing to do with Hashimoto’s.” A strong response to this interview question from participants was the recommendation from integrative and functional medicine doctors for supplement use. Ordering labs to confirm possible deficiency of such elements as zinc, selenium, Vitamin D and magnesium were done as part of regular HT treatment for these health care providers. “I didn’t realize how low my numbers were for those basic vitamins and minerals. I’m glad she (the provider) thought to have those tested.”

Self-treatment was a prominent theme in all interviews. All participants have used the internet to learn more about HT and what to expect for this lifelong chronic illness. Other reasons for internet use were to find online support groups and to gain help in understanding how to read lab test results. When asked what self-treatment the participant has tried, if any, we received a strong response for both dietary intervention and altering environmental surroundings. “There is an anti-inflammatory diet that is all over the internet and I think I am going to look into that.” Social media also seemed to be a popular entity for HT patients to use for self-guidance. “There’s like 50 different support groups on Facebook and all of them offer suggestions on how to feel better. Some of these online groups let you post your actual lab tests and other members help you read them.” Lastly, another answered “oh man, let me tell you; there are people recommending acupuncture, essential oils, and even eating organ meat to help with these insane symptoms. To be honest, I’d try them all if it meant I would feel normal again.” Comments suggest HT patients are open to new treatments and anxious for a strong social support group of others who suffer from HT.

Although not recommended by conventional medicine practitioners, dietary change for the treatment of HT was common in the interviews. Uncovering why this treatment was considered and where they are gaining information about the relationship between
diet and HT was obtained. “My doctor offered no help whatsoever so I researched myself online. A lot of people were talking about avoiding gluten and dairy and I have nothing to lose so why not.”

There is currently no scientific data regarding dietary influence on symptoms of HT, and this is likely why it is not part of treatment in conventional medicine. “I asked my doctor about diet and they said it doesn’t matter what I eat it makes no difference. But it sure does make me feel better when nothing else would.” Another commented “A nurse practitioner told me to stop eating gluten and limit my sugar.” Participants often reached outside of the medical community to seek treatment and reported success in relieving some symptoms by modifying their diet.

Dietary change is demanding and difficult for most people to adhere to over long periods of time. However, the willingness to at least try this potential treatment was astounding due to the eagerness for participants to feel relief. “I stopped eating everything I love because I read it worked for other people. It makes going out restaurants and parties really hard but having Hashimoto’s is harder.” A few participants did get recommendations from their integrative medicine providers about changing how they eat. “My integrative doctor gave me a bunch of handouts and told me I have to heal my gut.” Another person stated “She said all symptoms are from food and the goal is to reduce inflammation. I would eat dirt if she told me I’d have my life back.” Participants were eager and excited by the possibility of treatment outside of hormone replacement, although they did understand medication would still be needed for life. The interviews clearly showed HT patients want more than a one-size-fits-all treatment to this very individualized disease.

Limitations

The biggest limitation to this study, is that only six interviews were conducted. Although only six individuals were interviewed, saturation (no new themes emerged) was reached among those participants, showing appropriate sampling for a pilot study. A follow up study could include more interviews with larger demographics. This study also contained mostly females; although HT disproportionately affects women, men can also develop the disorder. Only one trained interviewer was used, and additionally completed the coding and analysis. However, the results were presented and reviewed by a qualitative consortium. This consortium consisted of two qualitative content experts and many other researchers experienced in qualitative research. This study served as a pilot for the interview guide.

Conclusion

Perception of health care provider relationships was the most intense topic discussed in the interviews. Participants saw various disciplines for different HT related symptoms, which created barriers to building personalized meaningful relationships with providers. Time to see specialists (particularly endocrinologists) was a constraint, as there were often long waits for appointments with insufficient outcomes for symptoms outside of hypothyroidism. Many symptoms of HT were often dismissed by providers and left participants feeling alone and frustrated. This also took a toll on family relationships and decreased the participant’s perceived quality of life. When a participant was satisfied with their HT provider, overwhelming positive emotions were expressed furthering the need for intimate patient-provider relationships.

The patient-provider relationship is imperative for treatment satisfaction, especially in life-long chronic illness that require physician surveillance. Trials have shown individuals with chronic illness have consistently better health physiologically, behaviorally, and also subjectively when positive physician-patient communication was present [12]. Patient questionnaires during health care appointments measuring health status, preference for active involvement in treatment decision making, and knowledge of disease and satisfaction with care could be considered [12]. Empathy, trust, and shared decision making are core constructs to support a physician-patient working alliance [13].

Treatment options are limited for HT patients in conventional medicine. Participants were all offered the same synthetic hormone replacement medication and only when the patient requested an alternative (desiccated thyroid) was it discussed. Every patient was euthyroid in this study, yet additional treatment for HT related symptoms was still desired by nearly all. Self-treatment was highly prevalent as participants sought out online resources to assist with their symptoms. Complementary methods such as diet modification and acupuncture were widely accepted and even more treatment options were desired. Social support through online social media groups specific for HT were also commonly used for resources, guidance, and as a comparative tool for treatment plans amongst members.

Health care providers who diagnose and treat HT could benefit from understanding the patient perspective of living with and being treated for this autoimmune disorder. This could strengthen the provider-patient relationship, increase patient-centered care, improve quality of care, and support treatment interventions outlined in the MDM model. Allocating resources that are reputable to patients could ward off the high level of internet searching being done to self-educate on the manifestations and sequelae of HT. Further studies are required to determine if views found in this study are similar in the general HT population.

Disclosure

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