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The Life Story Analysis of Those Suffering from Autoimmune Thyroiditis

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The Life Story Analysis of Those Suffering from Autoimmune Thyroiditis

Azalea Di Nardi

A Dissertation Submitted to the Faculty of

Illinois School of Professional Psychology At

National Louis University

In Partial Fulfillment of the Requirements

For the Degree of PsyD in Clinical Health Psychology

Bradley Olson, PhD, Research Chair

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April 14, 2022

The Doctorate Program in Clinical Psychology

Illinois School of Professional Psychology
At National Louis University

CERTIFICATE OF APPROVAL

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The Life Story Analysis of Those Suffering from Autoimmune Thyroiditis

This is to certify that the Clinical Research Project of:

Azalea Di Nardi

Has been approved by the CRP Committee on:

May 5, 2022

As satisfactory for the CRP requirement for the

Doctorate of Psychology degree with a

major in Clinical Psychology

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DEDICATION

This dissertation is dedicated to my participants and anyone who has ever been diagnosed with an autoimmune disease, specifically, Hashimoto's or Graves' disease. Your struggles are seen, and efforts are being made to help, support, and improve your lives.

ACKNOWLEDGEMENTS

I would also like to dedicate this dissertation to my family, friends, and committee, who have helped and supported me throughout this long journey of becoming a doctor. To my incredible husband, you have been my rock and best friend through this journey, and this success is ours to share. I could not have made it this far without you, your support, and delicious meals!

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Thanks to the never-ending support of my best friends, Dr. Stephanie and Dr. Natalie, who were always there and ready with great advice, support, and wine from the very beginning. The dissertation writing/feedback groups were everything. We are finally done, and all doctors nonetheless! I am so proud to call you both my best friends.

Last but not least, to my family, who housed, fed, and encouraged me while I went through all of my graduate school struggles. A special thanks to my dad, who also experienced doctoral-level graduate school and was willing to listen, empathize, and offer words of wisdom each time I did not believe I could do it.

Words cannot describe my appreciation enough. Thank you all!

ABSTRACT

The purpose of this study was to understand the pervasive impacts of autoimmune thyroiditis, specifically Hashimoto’s and Graves’ disease. To accomplish this, the life story methodology was utilized to gather individual experiences from 11 participants diagnosed with Hashimoto’s or Graves’ disease. The participants completed a background and general health questionnaire and 45- to-100-minute virtual interview disclosing their journey from the onset of symptoms, through diagnosis, to their most recent state. Themes were compiled from the interviews, which allowed identification of the largest areas of impact, needs, and future implications for practitioners and providers. Major themes identified were decreased quality of life, a lifelong medical/physical diagnosis requiring treatment, comorbid psychological implications, decreased executive functioning, as well as social, work, and/or academic, and financial impacts. There are many deficits in Western medicine, specifically needs for more accurate diagnostic measures and more immediate forms of intervention. Feedback was provided from participants regarding areas of improvement for providers, including providing better education to patients regarding their diagnosis and forms of treatment, not making assumptions, and asking more questions to get a better understanding.

INTRODUCTION

Autoimmune thyroiditis (AITD) is one of the most commonly occurring autoimmune diseases in the United States, specifically Hashimoto's and Graves' disease. Due to the progressive degenerative nature of these diseases, early detection and intervention are vital. However, differential diagnosis can be challenging due to the significant overlap in somatic and psychiatric symptom presentation. Promoting specialty education, ensuring competency, and disseminating information associated with these diseases are crucial aspects of care.

The major component lacking in Western medicine is the use of person-first ideology, where the patient is an expert of their body, while the provider is the expert in theory and medicine. Working together offers the highest good for the patient while allowing the provider to offer the best care and service. This can be a challenging feat at times while rewarding at other times, especially as it relates to the complex and challenging nature of AITD.

LITERATURE REVIEW

What is the Thyroid Gland?

The thyroid is a major hormone gland in charge of regulating and releasing hormones (Institute for Quality and Efficacy in Health Care, 2018). The thyroid gland directly affects metabolism, brain development, breathing, heart and nervous system functioning, body temperature, muscle strength, skin dryness, menstrual cycle, weight, and cholesterol (National Endocrine and Metabolic Diseases Information Service, 2008). Considering that the thyroid gland must maintain widespread homeostasis, dysregulation from an autoimmune disease could wreak havoc on organs and body systems.

Autoimmune Thyroid and Diseases

Due to the ever-changing nature of autoimmune diseases and new developments, medical professionals are challenged to give an exact definition of what constitutes an autoimmune disease or to even offer a prevalence rate. The U.S. National Institute of Environmental Health Sciences (2020) offered the most up-to-date description, defining autoimmunity as “a condition in which the body’s immune system reacts with components of its own cells.” The U.S. National Health and Nutrition Examination Survey found an increase in prevalence rates from a 1988-1991 cohort study that yielded 11% to a 2011-2012 cohort study that showed a 15.9% prevalence rate. Researchers are unsure why autoimmunity rates are rising so quickly but are concerned that this could become a public health crisis.

In this case, AITD could be broken down into two of the most prevalent thyroid-related diseases, Hashimoto’s and Grave’s disease. These disease processes lead to the inflammation of the gland and cause the thyroid to either overproduce (hyperthyroidism) due to the effects of Grave’s disease or underproduce (hypothyroidism) thyroid hormones from Hashimoto’s, creating a cascade effect of symptoms throughout the body. It may take time for the individual to notice the effects as the symptoms typically increase slowly over time. If this is not addressed, physical and psychological difficulties, among other problems, could worsen.

Hashimoto's Thyroiditis

Hashimoto's thyroiditis (HT) is the most common form of autoimmune thyroiditis. HT is the most common cause of hypothyroidism and impacts 5 of 100 people in the United States. HT is 8 times more common in women than in men and typically appears between ages 40 to 60. Research is not clear about what causes someone to develop Hashimoto's disease. HT has also been found to have a genetic component making it more likely to be diagnosed in individuals with family members who suffer from it. This disease tends to co-occur with other autoimmune diseases such as Addison's, autoimmune hepatitis, celiac disease, lupus, rheumatoid arthritis, type 1 diabetes, and vitiligo (National Institute of Diabetes and Digestive and Kidney Diseases, 2017). Standard treatment is the replacement of thyroid hormone via an artificial free thyroxine pill every morning prior to eating (Quinque et al., 2014). Common symptoms of Hashimoto's disease are temperature dysregulation, slowed processing speed, dysregulation of executive function, migraines, joint pain, dry skin, hair loss, leaky gut, dysregulated bowel movements, depression, anxiety, and reproductive difficulties. If left untreated, it can result in Hashimoto's encephalopathy and, in some cases, even death (National Institute of Diabetes and Digestive and Kidney Diseases, 2017).

Graves' Disease

Graves' disease is another leading autoimmune disease in the United States, impacting approximately 1 in 200 people (National Institute of Diabetes and Digestive and Kidney Diseases, 2017). It is also the leading cause of an over-functioning thyroid, also known as hyperthyroidism. Graves' disease is 7 to 10 times more likely to impact women than men, and chances of developing this disease increase with family history. Symptoms of Graves' disease include fast and irregular heartbeat, goiter, bulging eyes (exophthalmos), temperature dysregulation, nervousness or irritability, anxiety, weight loss, fatigue, trembling hands, insomnia, and irritable bowel syndrome (National Institute of Diabetes and Digestive and Kidney Diseases, 2017). One study found significant disturbances in working memory and executive functioning in hyperthyroid patients with Graves' disease compared to healthy participants. They also found that longer disease duration was correlated with worse psychological test results (Jabłkowska et al., 2009). This research indicates the progressive degenerative nature of this disease and how crucial early detection and intervention are for both Graves' and Hashimoto's disease. Treatment for Graves' disease depends on the quantity of overproduced hormone and the severity of damage caused. The first level of treatment includes medication to block or reduce thyroid hormone production. The second level of treatment standard in the United States is radioiodine treatment, which will either cause it to significantly underproduce thyroid hormone or will cause it to die. This treatment leads patients into hypothyroidism, requiring daily hormone replacement medication. The last resort in treatment is thyroid removal surgery, which also results in the requirement of hormone replacement surgery (National Institute of Diabetes and Digestive and Kidney Diseases, 2017).

Purpose of the Study

The objective of this study was to bridge the gap between medical and qualitative psychological research via the utilization of the life story narrative. This would allow for more understanding and insight into the depth and breadth of the nature of these invisible diseases and the pervasive global impacts these diseases have on individuals' lives. Due to the invisible and chronic nature of these diseases, some potential problem areas have been identified. These potential problem areas have been identified in previous literature as well as from the researcher's personal and professional experience. The problem areas are necessary lifestyle changes, treatment and medication difficulties, financial and insurance challenges, lower quality of life, negative impacts on mental health, reproductive difficulties, and being misdiagnosed or feeling dismissed by medical or mental health professionals. Many could experience significant cognitive difficulties associated with slowed processing speeds, challenges with executive functioning, and impaired inhibition. There could be a potential stigma associated with invisible diseases in work, social, and academic environments, which could inhibit an individual with these diseases from feeling safe and comfortable with others, which could further impact their productivity. Overall, the experience of AITD within the confounds of the Western medical system is a social justice issue as members of the middle and lower classes experience disparities in medical care and getting the care they need. These issues do not just impact the individual suffering from the disease but instead create a ripple effect impacting everyone around them as they are no longer able to be effective members of society. To improve the quality of life for those suffering, the system must adjust to accommodate them.

METHOD

Life Story Methodology

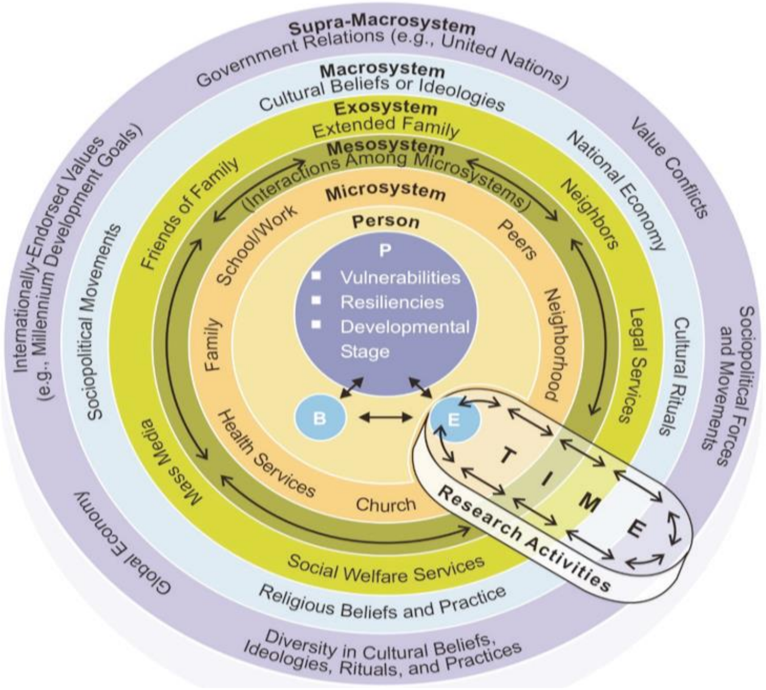
The phenomenological approach of this study focused on utilizing a life story narrative method to gain insight into each participant’s journey. Narrative storytelling is a flexible and accessible method of understanding subjective health and inequalities in health care (Stephens, 2011). Each individual is able to create their own narrative identity, which allows them the opportunity to describe their internal and dynamic experience with AITD (Bauer et al., 2008). This method is being utilized more often in healthy psychology as a means to give voice to those who suffer and offer insight into medical disparities.

This study also used a modified version of grounded theory analysis as a means of building this study from existing literature and data. The psycho-ecological systems model was utilized to exemplify the ways in which AITD impact individuals. This model was rooted in general systems theory and was developed to inform and guide the development, implementation, and evaluation of community-engaged scholarship. This model (Figure 1) integrates three conceptual models: the ecological systems model (Bronfenbrenner, 1979), the biopsychosocial model (Kiesler, 2000), and the principle of reciprocal determinism (Bandura, 1978).

At the center of the figure are letters P, B, and E, which denote person factors, behavior, and environment, respectively. The person factors include vulnerabilities, resiliencies, and developmental stages. Environmental factors include risks and resources, all of which interplay with their behaviors throughout all levels of their ecological systems. The oval depicting time with bidirectional arrows indicates reciprocal interactions among the ecological systems taking place over time.

Figure 1

The Psycho-Ecological Systems Model



This model perfectly describes individuals with AITD as the individual's health and well-being influence their ability to engage with their system and vice versa. The worse their health, the less they are capable of engaging with their environment and effectively participating in the various levels of systems. This may change over time as improvements in early diagnosis, treatment, and the overall medical system are made for AITD. However, many factors are involved in this interplay.

Method of Gathering Participants

The participants of this study consisted of 11 individuals diagnosed with Hashimoto's or Grave's disease. All participants were over the age of 18 and gave consent to participate. Given the nature of these conditions, there were more female participants than males. Participants were recruited using a number of approaches, specifically snowball sampling. The researcher's social media networks were utilized, as well as word of mouth. All potential participants were given a brief description of the study, including the logistics of the interview, and asked if they were willing to participate. All of those who expressed interest were contacted by the researcher, given a consent form (Appendix A), and asked to fill out demographic information (Appendix B) and a general health questionnaire named the SF-36 (Appendix C).

Data Collection Tools

The demographics questionnaire gathered general identifying information, which aided in better understanding the individual's life while also asking specific questions related to their condition and the research question. The general health questionnaire asked pointed questions in relation to how the individual perceived their general health, how capable they felt in completing everyday tasks, how their diagnosis forced them to make changes and any impacts on quality of life. The interview question protocol was also utilized in the interview process (Appendix D) and allowed for more structure and consistency in the data.

Data Collection Methods

Qualitative data were collected from 11 participants through a confidential Google Forms questionnaire. Data gathered included demographics, questions extracted from the general health questionnaire, as well as COVID-19-specific concerns. The questionnaire was followed up by semi-structured, in-depth, phenomenologically based interviews. There were predetermined interview questions based on the literature about AITD, which were at times followed up by probing and more detail-oriented questions. The interview protocol (Appendix D) includes questions such as, "How have you been treated by doctor(s)?", "How have your symptoms impacted your home and work life?", "What financial implications has this journey had for you?" and "How has this diagnosis impacted the way you see yourself (appearance and well-being) as well as self-esteem?". Reflection questions were also included in the interview protocol as a means of gathering participants' insights and experiences into what they learned. Responses to reflection questions also generated feedback about what could be done differently and provided key ideas for how the system could adjust and change to best serve such individuals. Reflection questions asked included, "Is there anything from this journey you believe has contributed to your overall growth as a person?", If there was advice you would want to tell doctors about your condition, what would you say?" and "What are some strengths that you had prior to your diagnosis or that have developed on your journey?". Participants provided various responses to some questions while answering similarly on other questions. However, each response provided insight into what the participants struggled with most and the support they could benefit from throughout their journey.

Interviews were conducted and recorded on Zoom on a convenient day and time for the researcher and interviewee. One interview per participant occurred, lasting 45 to 100 minutes per session. All interviews were audio, and video recorded on the Zoom site and saved to password-protected files.

Data Analysis

The first step of data analysis using the phenomenological paradigm was epoche and bracketing. The process of epoche included the removal of researcher bias by acknowledging personal past experiences and judgments associated with autoimmune thyroiditis via the utilization of phenomenological reduction. Bracketing allowed the researcher to set aside all preconceived notions and ensured that the research was firmly established and rooted in the lived experiences of the participants (Moustakas, 1994). These processes allowed the researcher to acknowledge their own biases and own diagnoses of Hashimoto's and hypothyroidism. The researcher was better able to take an unbiased approach.

The next four stages allowed for themes to be extracted from data. Each recording was transcribed, read, and flagged line by line for experiential significance. Theme development was based on three factors. First, the psycho-ecological systems model had the largest influence as the intersection of systems and biopsychosocial models created a foundation. Second, the researcher's personal experience with hypothyroidism and Hashimoto's allowed further challenges to be explored. Third, commonality in participant responses reinforced the themes that were being established. Common themes or groups were reassessed after all transcripts were flagged and clustered further based on similarity of topic, emotional significance to participants, or chronological order from onset of symptoms to present day to create the primary themes utilized in the results.

One participant's story was an outlier as her participation included retelling her mother's narrative with Hashimoto's encephalopathy as her mother passed away from the disease. This participant contacted the researcher after being informed of the study via another participant. Prior to the interview, the participant met with other family members to gather all collateral information to provide the most accurate details possible. These data were chosen to be included as this study intended to understand the pervasive nature of this disease, including social and familial impacts that the participant clearly displayed. Her mother's death resulted from late diagnosis and treatment, which is the sole purpose and epitome of this research.

RESULTS AND DISCUSSION

Five primary themes emerged from the data concerning autoimmune thyroiditis. Participant quotes were used to demonstrate each theme and subthemes. The themes were as follows: traumatic precursors, biopsychosocial impacts, providers involved in the care of participants and treatment of participants, medication and treatment management, and participants' reflections upon their experience.

The themes that developed also indicated a clear trajectory from the experience of the traumatic precursor through receiving treatment. The trajectory is depicted in Figure 2, which can be viewed in Appendix E. The trajectory depicts the typical delay in diagnosis of HT compared to Graves' disease. This is due to the hallmark and unique symptomology that allows Graves' to be identified and treated relatively quickly. Alternatively, hypothyroidism tends to be diagnosed and treated prior to HT, while the development of HT may be delayed after damage has been caused to the thyroid gland. Participants also noted exploration of options after not experiencing improvement in symptoms with protracted distress after receiving a hypothyroid diagnosis, which leads to meeting with a specialist, making lifestyle changes, and/or trying alternatives such as Eastern medicine. This is all apparent in themes.

Theme One: Traumatic Precursor

Each participant identified a stressor, physical transition, or trauma that they believed triggered this epigenetic disease to become activated. The most common experiences included a major hormonal shift such as puberty or menopause. Tsatsoulis (2006) identified the significant impact stress has on the immune system via the neuroendocrine pathway. Glaser and Kiecolt-Glaser (2005) found that the neuroendocrine system is bidirectional, causing any hormonal shifts to trigger the excess release of stress hormones, further contributing to the development of chronic autoimmune dysregulation and potential development of an autoimmune disease. These findings explain the effects of each participant's trigger, which included an adolescent eating disorder, excessive stimulant use, contracting MRSA, and over-usage of antibiotics. One participant attributed her Hashimoto's to:

> They say that when you experienced hormonal shifts in your life, that's the onset, so mine was probably more the perimenopausal postmenopausal hormone shift that may have triggered something to do with the autoimmune and I do believe stress and other things in your life, certainly, certainly contribute to all that as well but I I'd never underestimate the power of those hormone shifts.

Another participant stated:

> I developed an eating disorder, anorexia, when I was 17 or 18. There is probably a really good chance that my eating disorder, in part, triggered some of the autoimmune issues. I wouldn't be surprised if the eating disorder actually triggered the Hashimoto's. And because of what you do to your body, and what you do to your thyroid, and what you do to your metabolism, it was definitely a little bit of a reckoning to come to terms of not just like what I had done to my body but that my body was susceptible to the reality of it.

This participant identified the challenges their body experienced and years of nutritional deprivation as the stressors that triggered their body's immune system response. These major stressors during a critical developmental period could have come together to cause Hashimoto's disease autoimmune response.

Theme Two: Biopsychosocial Impacts

This theme is divided into three parts, including biological, psychological, and social factors involved in living with Hashimoto's and Graves' disease. Each of the three factors is divided into subthemes. The subthemes are directly associated with the implication of living life with AITD and the challenges each participant faced. Factors associated with biological impacts are genetics, comorbid diagnoses, health complications, and lifestyle changes.

Subtheme One: Biological Factors

Each participant identified family members (all female) who also received AITD (Hashimoto's or Graves' disease) or thyroid disease (hypothyroidism or hyperthyroidism) diagnoses. Having a family history of AITD is a diagnostic criterion. This genetic component aided the participants in getting diagnosed. Many participants identified other significant health conditions, including other autoimmune diseases. Bliddal et al. (2017) identified poly-autoimmunity explaining the predisposition of most individuals with autoimmune diseases, making them much more susceptible to developing other autoimmune diseases or reproductive challenges. The findings of that study were supported by participants of this study. One participant stated, "I also already had an autoimmune disease. I've been diagnosed with psoriasis since I was nine. I know that's a very different condition, but in both cases, I had an overactive immune system."

Participants also included other health complications commonly associated with AITD. One participant reported, "I have severe, severe endometriosis, and I was told I would never have children."

Thyroid conditions can lead to difficulty conceiving and increased rates of miscarriages. These challenges could be compounded by co-occurring reproductive conditions such as endometriosis and polycystic ovarian syndrome, among others.

Many individuals are forced to make lifestyle changes to accommodate and improve their quality of life and aid in weight-related challenges. Every participant with Hashimoto's disease reported hearing statements from at least one health care provider that their overall health conditions would improve “if only they would lose weight.” Participants’ responses to their provider’s statement all included resounding emotions of anger, frustration, sadness that their bodies were betraying them, and their doctors were not supportive and/or helpful in some instances. Participants described feeling further challenged by AITD and comorbid diagnoses as lifestyle changes were a strong recommendation to improve the overall quality of life.

Cullingford (2012) and many others indicated the common co-morbidity between Hashimoto’s and celiac disease. They found an association between thyroid and gluten antibodies, indicating that those with autoimmune diseases experience gluten sensitivity or gluten intolerance. Celiac and AITD have inflammation as a common underlying factor causing those suffering from AITD to change their diet to reduce inflammation to assuage their negative symptoms, and in some cases, improve their chances of fertility.

Participants identified other recommended dietary changes, such as a plant-based diet, but also indicated a moderate level of difficulty in initiating and maintaining those changes. One participant stated:

> I think it’s just such a different way of life. I used to be able to eat whatever I wanted and a size three and be a normal human. On one hand, I want to have the energy, and the other part of me wonders if I really want to be that restricted in my life. So, part of me is committed and sometimes wants to do really well. The other part of me is so tired of doing this.

Her description directly speaks to the dynamic nature, including energy, dedication, and motivation associated with AITD, which ebbs and flows constantly. Such common descriptions indicate significant challenges and frequent impairments as there is no way to predict and prepare for how one may feel the same day, the next day, the next week, or the next month.

Participants identified the same challenges associated with initiating and developing a consistent exercise routine. Through a significant body of literature, exercise has been linked to the reduction of stress and inflammation. Participants agreed regarding the importance of exercise. However, they voiced significant difficulty initiating an exercise routine due to chronic fatigue, pain, dynamic changes in motivation, etc. One participant reported:

> Most days, I eat under 1000 calories, and it doesn’t matter. On my worst day, my calorie count is 1500, and I’m still significantly overweight, and I can’t lose it. Everybody says to exercise and walk. When the joint pain is so bad that when I get into bed at night, I can’t sleep because it hurts to lay on my side because I can feel my entire hip bone. And my knees are aching, and my ankles hurt every joint in my body hurts now. What is that doing for me except adding sleep deprivation on top of everything else? And I think that’s the other piece they don’t look at, which is the impact of that joint pain and what that does.

A different participant reported her difficulty with lifestyle changes being:

> I’ve always been a healthy eater and gotten daily exercise. But when my numbers were off, and I’m having terrible palpitations and dizziness that I can’t even stand up, it’s like, okay, well, I probably shouldn’t be on my treadmill today. So just trying to give up some of those expectations of my body and my ability level because where my health is doesn’t match what my internal motivation is. My health isn’t feeling quite right, so I can’t do it, so I’ve learned to let go of some of those things.

These participants indicated that making lifestyle changes was not enough. They also had to learn to accept bodily limitations and plan accordingly as it changed from day to day.

Participants with Graves' disease reported difficulty gaining weight and struggled with constantly looking and feeling underweight. Many participants with Graves' disease underwent treatment that caused them to become hypothyroid and eventually struggle to maintain a healthy weight as well. Many of those individuals expressed frustration with not knowing such changes would happen and struggled with how to manage such a drastically different body type.

One participant identified as being transgender female to male. However, he was diagnosed with Graves' disease and started thyroid treatment prior to his transition. He reported working closely with his doctors and being told that the testosterone treatment transition would not impact his thyroid treatment. Within several years, he reported being in remission and continued to monitor his thyroid functioning.

Many lifestyle changes require mental capability and functioning, such as executive functioning to plan out meals, exercise, medication management, etc. The added challenge in managing and executing such tasks begins when accounting for the slowing of processing speed capabilities, difficulties paying and sustaining attention and concentration, and executive dysfunction.

Subtheme Two: Psychological Factors

Biological and physical factors already impede quality of life and activities of daily living. Adding psychological components only intensifies the experience. Common psychological impacts include anxiety, depression, adjustment disorders, grief and loss, isolation, loneliness, low self-esteem, and overall lower quality of life. Participants commonly identified depression, anxiety, "feeling like I'm going crazy" as common experiences associated with AITD prior to receiving the diagnostic label. Many participants described feeling "lazy" due to chronic fatigue and lack of motivation. They also described feeling "dumb, like I can't think or have an intelligent conversation with friends or family, so I noticed I was distancing myself from them more and more."

Participants later learned that the culprit causing them to feel this way was a phenomenon labeled "brain fog." One participant described it as:

> feeling like I'm underwater. And like someone's trying to talk to me, and they're expecting me to fully understand every word, and I'm like, how do you have this expectation of me right now. But it feels like you just feel numb and stupid. And just like you're there, but you're not there.

Two participants diagnosed with Graves' disease reported having exophthalmos (bulging eyes), which is a common hallmark symptom. They reported getting diagnosed upon being seen by a healthcare provider after this observation was made by family regarding their eyes. One participant described her experience, stating:

> when I first was going through the process of having Graves' disease, I was in my teenage years, and it was really hard. I even discussed surgery with the endocrinologist because that's how bothered I was with my physical appearance. I just wanted to look normal. I was even bullied in school…for the first year, I didn't want to go places, meet new people, go to the grocery store, and I didn't want my picture taken.

She reported continuing to feel the psychological effects of exophthalmos, such as self-consciousness, to the present day.

Another common subtheme was feeling "like a different person" when thyroid levels were not regulated. One participant stated:

> when I run hyperthyroid, I get extremely rageful. I would get these fits of rage, like when some guy was driving like a maniac on the highway, and I'm like screaming at them, or I totally lose my cool with my husband just over really stupid stuff like that would normally be minor things that wouldn't normally bother me, but I go from zero to rageful in like two seconds. And so that I know when I start feeling like that, it's like PMS times 100. I know what I start feeling like that. I need to pay attention because my numbers are probably off, and I might need a med tweak.

This participant expressed sadness as she described "becoming someone else" out of fear of damaging interpersonal relationships, including her marriage.

One participant described a time when her doctor recommended beginning an antidepressant to manage her depressive symptoms. Her response was:

> Please just fix my thyroid first. If you fix my thyroid and I still have problems afterwards, then we'll talk about it. It is so visibly apparent when my thyroid is in line, and so is my depression. I am normally a little bit of an anxious person, but that's my baseline. It is manageable when my thyroid is fine. It gets more unmanageable when my thyroid levels start to run. My TSH rises; it gets more difficult to manage and gets more prevalent.

Her experience was common as many other individuals with AITD expressed frustration with feeling that their symptoms were being treated rather than the underlying cause. It can also be challenging to identify how much of an individual's mental health symptoms could be attributed to personal traits and/or underlying mood disorders compared to their autoimmune disease.

Another participant reported her symptoms leading her to get tested for dementia. She stated:

> I saw my endocrinologist once a year, and she said I no longer had to take the medication. Unbeknownst to me, I didn't realize that once you're diagnosed, you will always be required to take your Levothyroxine. At one point, my husband even used the word bipolar because I didn't realize that my thyroid had affected my personality. I was becoming forgetful and was, isolating myself and believed I would have dementia at the age of 60 and felt that I would be put to pasture because my brain wasn't functioning and never thought it could be my thyroid and Hashimoto's.

She described her narrative as impacting her sense of self and her overall functioning as a human, believing that her journey was coming to an end at 60 years old. She believed that she was losing her memories and her mental health was negatively impacting her relationships.

In one extreme case, a participant provided an observer perspective on her mother's experience of Hashimoto's disease, including medical records. Her mother's disease undetectably progressed over many years, causing her to develop Hashimoto's encephalopathy (HE). Her symptomology was described as beginning with petite mal seizures and transitioning to grand mal seizures. This resulted in drooping facial muscles, depression, and anxiety. The participant was not able to report if her mother experienced other classic Hashimoto's symptoms prior to the onset of the seizures. Menon et al. (2017) reported that HE often initially presents with psychiatric symptoms such as acute psychosis and depression. They found schizophrenia and dementia to be uncommon presentations. However, their findings seemed to be partially different from this individual's lived experience.

After seeing many doctors, she was placed on anti-seizure and psychiatric medication. Her life stressors increased. Worsening her symptoms, eventually leading to severe memory loss prompting an Alzheimer's diagnosis. Eventually, the participant's mother became bedridden, unable to care for herself, and unable to speak. Toward the end of her life, doctors diagnosed her HE through a spinal tap. At that time, her symptoms were too far gone to reverse any damage. The participant's mother eventually died. Learning from such situations to prevent the loss of another life to such a preventable disease is imperative. Although she did not survive, this individual had her spouse and children who advocated for her at every turn to get help and medical care.

Every participant in this study reported some form of advocacy, whether a family member advocated on their behalf or self-advocacy was used. Participants reported difficulty in speaking up for themselves, reporting:

> I definitely had to develop self-advocacy skills along the way because, in my parents' generation, the doctors know everything, and you just go with what they say… I mean, I'm not rude or disrespectful, but they have to be willing to be a team player and honor my wishes too.

Another participant described having a positive experience with a doctor as her mother helped advocate for options to minimize exophthalmos. She stated, "Anything that I suggested or had concerns about were addressed. The whole idea behind the surgery was my idea, and she made me tell him what I wanted and ask about the options."

Participants reported difficulty developing this skill but expressed feeling that it was necessary to learn to ask for the care they needed.

Next, participants reported relationships with their body to be challenging; also, many experienced grief and loss for "normal functioning" and acceptance for how they function now. Each participant's experience with their body differed based on their disease type and symptomology. The only consistent experience for all participants was difficulty with weight and body image. Each participant reported difficulty with either gaining weight or losing weight. However, no participant identified feeling healthy or happy with their weight and/or body style. Participants made associations between their bodies and lack of self-esteem, motivation, and consistency. One participant mentioned, “I would just like a body that functions like a normal person.” Some participants also reported fear and/or concerns around fertility and reproduction. These concerns were especially true among individuals with AITD and comorbid reproductive diagnoses.

Participants were also interviewed about their concerns surrounding their health and COVID-19. In March 2020, information was provided from the World Health Organization and Centers for Disease Control and Prevention that immuno-compromised individuals (among others) were at highest risk for contracting COVID-19. This left some participants wondering if autoimmune diseases were considered immuno-compromised. One participant’s response was, “I have multiple autoimmune disease, and hearing the research and stories. I was absolutely concerned that I would be at higher risk for having complications from COVID.”

Many reported feeling fearful and concerned at the beginning of quarantine, but as more information and guidelines were released, many participants believed they were at lower risk, and continued taking precautions as recommended.

Subtheme Three: Social Factors

Each participant reported significant financial and insurance implications associated with having this medical diagnosis. Most participants reported the importance of having a job with good medical benefits to ensure they had access to specialist medical providers, medications, and mental health providers. Many reported undergoing more work-related stressors despite feeling chronic fatigue, migraines, and other invisible symptoms to ensure they had adequate care. Some participants described feeling that Western medicine had not answered the call to provide care to those with chronic and complex diseases. This caused two participants to turn to naturopathic medicine, feeling that they were better able to provide care and resolve the underlying conditions rather than address the symptoms individually. The problem for many was cost and lack of insurance support for naturopathic medicine and even Western medicine. Each participant acknowledged the astronomical costs associated with blood tests, primary care and specialty provider visits, medical treatments, and lifelong required medications. One participant described her experience, stating:

> I know that I can’t go without health insurance. I absolutely have to have health insurance in order to cover medical, medication and get bloodwork done. That impacts what I can do and how often I will stay in a hard or difficult job.

Participants reported being willing to stay at a stressful or demanding job as long as they received “good benefits” despite psychological tolls.

Finances played a very large role in being able to receive and maintain care. However, time was also a significant component that many participants reported being a barrier to care (e.g., finding time in the middle of a work or school day to attend appointments, stop at the pharmacy, contact their insurance company). One participant reported, “This whole thing, it just keeps getting bigger and bigger and requiring more time and more management and more doctors, and it’s been a very frustrating journey.”

Another participant reported feeling as though she could sleep “20 hours a day if I didn’t have a job to tend to,” which indicated a requisite of more time than their peers and partners to recover from activities of daily life. At times, they might need more time to complete tasks than peers due to chronic fatigue, slowed processing speeds, challenges with executive functioning, pain, etc.

These AITD symptoms directly impacted an individual’s ability to work and feel effective and efficient. One participant described a work-related challenge as:

> I feel like it doesn’t affect me physically going into work or my attendance at work. But I notice when I have a break, and I eat lunch or something, then I go into session, then I will have moments where I don’t even think I can keep my eyes open while I’m talking to someone. It makes me feel like a really bad counselor. But I just feel so lethargic that I just have to power through it.

Many participants were reportedly told they were “lazy” or “not applying yourself” by others in their life, contributing to a negative sense of self. One participant described her experience with Hashimoto’s disease while in graduate school as:

> I feel like it’s ironic that I was telling my advisor I’m depressed and having a hard time right now. I was struggling to get up and shower, and I have a 15-page paper. I don’t want to think about that right now. I think she was trying to be supportive, but her response was basically to get over it. That’s just what graduate school is like. You need to get with it. I feel like we’re in the mental health field, but even our field is very much about production in how little of time. The lack of understanding, even from fellow mental health professionals, is upsetting sometimes.

This participant’s narrative was an exemplary description of society’s expectations without regard and consideration for visible/invisible diseases/disabilities.

Participants described experiencing a similar lack of regard from others at times in interpersonal relationships with those who did not suffer from chronic diseases, while others believed that their friends, family, peers, and partners might do an exceptional job at understanding and tending to their needs. A significant body of literature found social supports to play a critical role in healing and stress reduction for any individual living with chronic disease, including AITD. However, this could be difficult when individuals believe their major sources of support do not understand the chronicity and debilitation of their disease.

Theme Three: Providers Involvement in Care and Treatment of Participants

Most study participants reported beginning their health journey with a primary care provider. However, one started with an internist, another at a psychiatric facility. All participants worked with an endocrinologist to stabilize thyroid functioning; however, each participant was at a different place in their health care journey. Two participants reported working with a naturopath and identified making more progress toward wellness than when working within Western medicine. One participant reported developing heart disease and worked closely with a cardiologist. Most participants who reported valuing fertility reported seeing a gynecologist as well.

When asked participants' views on how they were treated by medical and mental health providers, they provided mixed responses. Two participants reported no problems with providers, while nine participants reported at least one bad interaction with a provider where they felt judged, unheard, misdiagnosed, dismissed, spoken to with medical jargon, or not educated on their condition. One participant provided a doctor's response to her concerns as, "I went from 156 pounds to 210 pounds. And I couldn't make it stop, and when I asked her what is happening, she said stop eating so much."

She expressed concern and desperation at times, just looking for answers, support, and validation. Another participant stated:

> They don’t necessarily ask what my eating patterns are, or they don’t ask specifics. They just make comments that my weight has either increased or maintained, or I’m above what I should be for my age and my height, right? And it sounds incredibly invalidating when you know that you’re putting in the effort at home, you’re doing everything you possibly can, and you’re already frustrated, and then the doctor just automatically writes you off as if you haven’t done anything.

Most participants expressed frustration over assumptions they believed were made about them by providers. They also felt that those assumptions impeded any help, support, or progress they could have received from that provider. Another participant stated:

> I felt like a lot of jargon was being used. It could be that over time I just had a better understanding of the information, but I think doctors I met with knew they were not going to see me again. That’s where I felt like those doctors had a different rapport style with me. It wasn’t until the second doctor I saw who took time to explain the disease, how it impacts my body that I actually realized what was happening.

Participants also reported having positive experiences with providers and expressed kind bedside manner, being willing to listen, asking in-depth questions, not making assumptions based on appearance, and providing appropriate bloodwork based on symptoms reported and past bloodwork as some of the most valued traits. They also identified open and honest communication, as well as a willingness to meet the patient where they were in the journey, as important factors too.

Theme Four: Medication and Treatment Management

Medication and treatment management should be considered based on whether the individual has a diagnosis of Hashimoto’s or Graves’ disease, as each has differing protocols.

Participants experiencing Graves' disease reported being told that standard practice in the United States consisted of daily medicine (beta-blockers) to lower thyroid functioning, radioiodine treatment to obliterate thyroid function, or thyroid surgery in extreme cases to remove the thyroid. Three of five participants in this study opted for medication treatment. Two participants were in remission after managing their disease with medication, while one continued to work with medical professionals in the hopes of resolving any inconsistencies. Two participants with Graves' disease underwent radioiodine treatment and were on thyroid hormone replacement therapy. No participants required thyroid removal surgery.

Five participants were diagnosed with Hashimoto's disease and were all managing their disease with daily thyroid hormone replacement medication. One participant was asked to do two fine needle aspirations to ensure her thyroid was not cancerous. She reported yearly thyroid ultrasounds as part of her care regimen as well. Several participants reported not fully understanding their conditions or the need for lifelong medication.

All participants described one of the most challenging parts of having AITD as the resources necessary for upkeep of their health. The resources included time, money, energy, medication, attending doctors' appointments, bloodwork on regular intervals, diet and exercise changes, and research involved in ensuring they received the best care and provided themselves the best quality of life possible.

Theme Five: Participant Reflections

Participants were asked five reflective questions during the interview. Reflective questions provided space for more consistency within the interviews. The purpose of the reflective questions was to cause participants to stop and think critically about their health journey. The reflective questions also allowed the participants to provide insight and feedback into their experiences and what could be learned for the future. As the questions are listed below, the responses from participants are also listed per question.

The first reflective question asked of all participants was, “If you could give any health care or mental health providers advice on your condition, what would it be?”

Participants’ responses were as follows, “I would love for them to be more aware of the patient’s questions and to take time to answer them.” “Listen to your patients and trust them because they know their bodies. A lot of times, doctors come in with their agenda, and preconceived notions and people get blown off.”

> Don’t just assume that a person like understands everything that you’re saying. They might be stressed or just like a little overwhelmed by the information to fully grasp what you’re saying. Just being more mindful of, whether it’s like having like handouts that are less jargony to like give something more concrete for them to look at later.

A final comment by one participant was:

> Don’t just assume I eat terribly and don’t take care of my body. Ask questions and be curious. My labs aren’t the only thing that tells you how my body is doing. Please hear me out when I tell you I am not okay and something needs to change.

The consensus appeared to surround the concept of providers listening, asking questions and validating concerns, while not making assumptions about their lifestyle.

The second reflective question was, “Could you describe one of the hardest times you had while living with AITD, and how did you cope?” Participant responses were as follows:

> I think it was definitely when we were titrating off my thyroid-blocking medication and discontinuing it and then waiting to see if my body was going to adjust on its own. I knew it wasn’t right. I think just going to my support system and communicating what’s

> going on and this is why I'm not feeling or acting right, and just getting support and validation from my support system.
>
> Before I got diagnosed, I was in freshman year, taking two or three hours of lecture a day, and I would skip and stay in bed, and it was just like, I thought like I was going crazy, like there was something wrong with me. I was expressing suicidal ideation but purely passively, like is this all my life is right now. I just felt like I had always been a driven, passionate person, but to feel like that was completely drained from me at the time was hard. Getting a diagnosis and treatment changed everything for me. I've been thankful to have that label and know I wasn't crazy.

Overall, participants thought that going through transitions posed significant challenges, and remembering that their situation would improve with social support was a big factor.

The third reflective question was, "What about your health journey do you believe contributed to your overall growth as a person?" Participant responses were as follows:

> Well, I think just not trusting doctors to be the expert of my body. And that advocacy piece that if I want to be tested for an autoimmune disease that isn't the result of all my depressive symptoms, then I should be tested because it's my body, and it's my money.
>
> Everything that happens to you makes you stronger and more resilient if you allow it to. So, here's one more difficult experience, one more challenge that didn't get me down that I overcame, and I have more insight, and I have more empathy for people who are going through the same thing.
>
> I think it's helped my empathy and ability to be more compassionate to people who do have physical illness, especially with energy levels and things like that because like, even

> if you want to be awake, even if you want to be functional, your body won't let you. So, it's definitely helped me have more compassion toward others.

When reflecting on their overall growth, participants believed that their suffering offered them the insight and perspective to be compassionate and supportive of others who were also suffering.

The fourth reflective question was, "What strengths do you think you developed that you did not have before you started this health journey?" Participant responses were as follows:

> I mean, there are aspects that are within my control. You know the food I eat or exercise, I do things like that, but there are some things like this that is completely outside of my control. So, it's like learning how to let go of those things that you can't control. And I feel like I'm learning how to be better at that.
>
> I think taking it like day by day, and trying to perseverance, is a pretty big thing because when you do get diagnosed with it and when you get medication for it, it doesn't necessarily work immediately. It has to build up in your system, so understanding that and just kind of persevering through it is super important to be able to successfully manage it.
>
> I would say my strength is giving myself some slack. But by giving myself permission to take a day to not exercise or not workout or to just foster sleep, and that's probably another strength, is just giving myself a little bit more compassion that I just may not be able to do everything like everyone else does.

Most participants found that practicing grace and patience with their condition, therefore with themselves, offered them a better perspective. Readjusting expectations allowed them a better sense of control in their life when most factors felt out of control.

The fifth reflective question was, “What do you know now that you wish you knew what you first started your health journey?” Participant responses were as follows. “I wish I knew that my eyes would get smaller and that it wouldn’t be a permanent issue.”

> I wish I knew Hashimoto’s existed and what tests needed to be run to be diagnosed because I wouldn’t have been pushed around for 10 years by a doctor if I knew what I needed. At least you know you’re not crazy, and you’re not making it up, and you’re not a fanatic, and all the labels that they put on me and my stomach stuff because we would otherwise know I have celiac.

> If I could turn back the hands of time, the one thing I would not do is let them touch me with radioactive anything. I would not have allowed them to kill my thyroid because I think it really just changed everything else in my life. I wish I had found a provider that would listen. Like, really listen, yeah, and try to do something to help instead of just telling me that it’s in my head. You have to trust your providers before letting me do anything to you.

Participants identified a lack of education around their condition or treatment as concepts they wished they had known earlier. Participants found that they became more educated on their condition as time went on, but they also found that it was too late to mitigate treatment or that they suffered an emotional toll.

CONCLUSION

This study attempted to bridge the gap between medical knowledge on AITD and qualitative research through utilizing a phenomenological life story approach. Through hearing participants’ lived experiences with Hashimoto’s and Graves’ disease, information is provided as to the pervasive impacts and suffering those individuals lived with, the aspects of medicine that need improvement, and methods to expedite and improve diagnosis. One of the most common and detrimental problems identified was the length of time passed from onset of symptoms through diagnosis, specifically for Hashimoto’s disease. They also identified maltreatment as a common experience during provider interactions leading to negative and/or harmful psychological impacts. Many participants were not aware they felt so strongly or were still processing the grief and loss of their old selves until they were in the midst of completing the interview. Participants’ stories shed light on the negligence of Western medicine to identify and resolve underlying problems. This has been a longstanding problem in the U.S. medical system that must be addressed. Otherwise, more individuals will fall victim and continue living in this system with a limited quality of life.

This study also shed light on the strength and resilience of humans to struggle and “push through” challenging times. Much of their developed skills were embodied as patience, perseverance, community building, advocacy, boundary setting, communication, etc. Despite the pervasive impacts—at times very challenging—this group of individuals was able to turn negative experiences such as grief, loss, pain, and struggles into positives such as empathy for self and others, patience with self, perspective-taking, and many other positive attributes that could improve their perspective on life.

This study had some limitations that might impact the generalizability of results. The sample size was small, although it was permissible due to the qualitative nature of the study. The sample only consisted of females (one participant was female at birth), which was consistent with the natural occurrence rate in any population, however, was not representative of the male perspective with AITD. Another limitation was based on researcher bias as the researcher has had personal experience with hypothyroidism and HT. The researcher's bias might have impacted questions asked during the interview and theme development as they were subjective to the researcher. The outcomes of this study may not be generalizable to all who are diagnosed with AITD as experiences may differ based on country, medical systems, and treatment availability.

Autoimmune thyroiditis could significantly benefit from earlier detection, which falls into the domain of medical and mental health professionals. Implications for future research include specific training in autoimmune diseases for medical and mental health professionals to delineate autoimmune-related diagnoses more accurately. The more medical and mental health professionals are trained in identifying such diseases, the more likely individuals are to receive earlier diagnoses. Development of tools to help expedite timelines and improve accuracy of diagnoses are imperative in receiving proper treatment as well. Development of a diagnostic tool such as a screener could provide quick and easy detection for medical and mental health professionals, as well as individuals at home wondering if they fit the criteria for these diagnoses. This is especially true because blood tests are not the only diagnostic tool necessary. Mental health professionals should be aware and assess clients who are not showing improvement with typical forms for mental health treatment.

Encouraging interdisciplinary and wrap-around care is the best way for patients to feel heard, safe, respected, and cared for, which is truly what the participants of this study reportedly wanted. If providers were able to receive better education about AITD, they would be better prepared to offer education to their patients and their families. Instead, patients have been educating themselves after diagnosis and providing education to their family members, friends, and many others throughout their system, including their medical and mental health providers. Patients should not have to shoulder such responsibility as they may not feel stable or educated enough at times to advocate for themselves. Individuals suffering from these diseases deserve help and support to regain their energy, self-esteem, brain functioning, and all other resources to rejoin society and get back to who they were before AITD or a chance to develop their new "normal."

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Appendix A

Informed Consent

My name is Azalea Di Nardi, and I am a doctoral student at National Louis University. I am asking you to participate in this study, “Life Story Analysis of Individuals Suffering from Hashimoto’s and Graves’ Disease,” occurring from 5/2020 to 5/2021. The purpose of this study is to understand the pervasive impacts of autoimmune thyroiditis (AITD), specifically Hashimoto’s and Graves’ disease using the life story methodology. This study will help medical and behavioral health professionals develop a deeper understanding and appreciation of the challenge’s individuals diagnosed with these diseases face and contribute to the body of qualitative health literature. This form outlines the purpose of the study and provides a description of your involvement and rights as a participant.

By signing below, you are providing consent to participate in a research project conducted by Azalea Di Nardi, doctoral student, at National Louis University, Chicago.

Participation in this study will include:

- Completion of a demographic’s questionnaire and general health questionnaire

- 1 approximately 60-90 minutes long interview about your life story and journey with Hashimoto’s or Graves’ disease which will be conducted and recorded over a HIPAA compliant software system

Your participation is voluntary and can be discontinued at any time without penalty or bias. The results of this study may be published or otherwise reported but participants’ identities will in no way be revealed (data will be reported anonymously and bear no identifiers that could connect data to individual participants). To ensure confidentiality the researcher will secure recordings, transcripts, and field notes in an encrypted flash drive in a locked cabinet in her home office. Only the researcher will have access to the flash drive which will be kept for 5 years and then destroyed.

There are no anticipated risks or benefits, no greater than that encountered in daily life. Further, the information gained from this study could be useful to medical and behavioral health professionals working with other individuals who experience similar sets of symptoms. This could also aid in better understanding invisible diseases/disorders and how they impact functionality in a variety of settings, specifically a work environment requiring accommodations.

Upon request you may receive summary results from this study and copies of any publications that may occur. In the event that you have questions or require additional information, please contact the researcher, Azalea Di Nardi at [redacted] or [redacted].

If you have any concerns or questions before or during participation that has not been addressed by the researcher, you may contact Dr. Bradley Olson: email: Bradley.olson@nl.edu, or the co-chairs of NLU’s Institutional Research Board: Dr. Shaunti Knauth; email: Shaunti.Knauth@nl.edu; phone: (312) 261-3526; or Dr. Kathleen Cornett; email: kcornett@nl.edu; phone: (844) 380-5001. Co-chairs are located at National Louis University, 122 South Michigan Avenue, Chicago, IL.

Thank you for your consideration.

Consent: I understand that by signing below, I am agreeing to participate in the study “Life Story Analysis of Individuals Suffering from Hashimoto’s and Graves’ disease.” My participation will consist of the activities below during 5/2020 to 5/2021:

- Completion of two questionnaires
- 1 approximately 60–90-minute recorded interview

Appendix B

Demographics Questionnaire

What is your age?

A. 18-24 years old
B. 25-34 years old
C. 35-44 years old
D. 45-54 years old
E. Over 55 years old

What is your gender?

A. Male
B. Female
C. Other (please specify)
D. Prefer not to say

What is your ethnicity?

A. White
B. Hispanic or Latino
C. Black or African American
D. Native American or American Indian
E. Asian/Pacific Islander
F. Other

What is the highest degree or level of school you have completed?

A. Less than high school diploma
B. High school degree or equivalent
C. Bachelor’s degree (e.g., BA, BS)
D. Master’s degree (e.g., MA, MS, Med)
E. Doctorate (e.g., PhD, EdD)
F. Other (please specify)

What is your current employment status?

A. Employed full-time (40+ hours a week)
B. Employed part-time (less than 40 hours a week)
C. Unemployed
D. Student
E. Retired
F. Self-employed
G. Unable to work

Where are you located?

(Write in answer City, State format)

Marital Status?

A. Single (never married)
B. Married
C. In a domestic partnership
D. Divorced
E. Widowed

If you are a parent, how many children do you have?

A. None
B. 1
C. 2-4
D. More than 4
E. Prefer not to say

What is your household Income?

A. Below $10k
B. $10k-$50k
C. $50k-$100k
D. $100k-$150k
E. Over $150k

Which diagnosis were you given?

A. Hashimoto's
B. Graves'
C. Other, please specify: ___________________

Do you have access to a medical specialist with knowledge about your diagnosis?

A. Yes
B. No

At what age were you officially diagnosed?

A. 15-24 years old
B. 25-34 years old
C. 35-44 years old
D. 45-54 years old
E. Over 55 years old

If you have received any other diagnosis(es), what is it?

A. None
B. Please specify:___________________

Appendix C

RAND 36-Item Health Survey

Choose one option for each questionnaire item.

1. In general, would you say your health is:
1 - Excellent
2 - Very good
3 - Good
4 - Fair
5 - Poor

2. Compared to one year ago, how would you rate your health in general now?
1 - Much better now than one year ago
2 - Somewhat better now than one year ago
3 - About the same
4 - Somewhat worse now than one year ago
5 - Much worse now than one year ago

HEALTH

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes limited a little	No, not limited at all
3. Vigorous activities, such as running, lifting heavy objects participating in strenuous sports	1	2	3
4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5. Lifting or carrying groceries	1	2	3
6. Climbing several flights of stairs	1	2	3
7. Climbing one flight of stairs	1	2	3
8. Bending, kneeling, or stooping	1	2	3
9. Walking more than a mile	1	2	3
10. Walking several blocks	1	2	3

11. Walking one block	1	2	3
12. Bathing or dressing yourself	1	2	3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	Yes	No
13. Cut down the amount of time you spent on work or other activities	1	2
14. Accomplished less than you would like	1	2
15. Were limited in the kind of work or other activities	1	2
16. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?	Yes	No
17. Cut down the amount of time you spent on work or other activities	1	2
18. Accomplished less than you would like	1	2
19. Didn’t do work or other activities as carefully as usual	1	2

20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
1 - Not at all 2 - Slightly 3 - Moderately 4 - Quite a bit 5 - Extremely

21. How much bodily pain have you had during the past 4 weeks?
1 - None 2 - Very mild 3 - Mild 4 - Moderate 5 - Severe 6 - Very severe

22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
1 - Not at all 2 - A little bit 3 - Moderately 4 - Quite a bit 5 - Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

	All of the Time	Most of the time	A good bit of the time	None of the time
23. Did you feel full of pep?	1	2	3	4
24. Have you been a very nervous person?	1	2	3	4
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4
26. Have you felt calm and peaceful?	1	2	3	4
27. Did you have a lot of energy?	1	2	3	4
28. Have you felt downhearted and blue?	1	2	3	4
29. Did you feel worn out?	1	2	3	4
30. Have you been a happy person?	1	2	3	4
31. Did you feel tired?	1	2	3	4

32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
1 - All of the time
2 - Most of the time
3 - Some of the time
4 - A little of the time
5 - None of the time

How TRUE or FALSE is each of the following statements for you.

	Definitely True	Mostly true	Don’t know	Mostly false	Definitely false
33. I seem to get sick					

a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5
36. My health is excellent	1	2	3	4	5

ABOUT

The RAND Corporation is a research organization that develops solutions to public policy challenges to help make communities throughout the world safer and more secure, healthier, and more prosperous. RAND is nonprofit, nonpartisan, and committed to the public interest.

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Appendix D

Interview Question Protocol

Thank you for agreeing to do this interview. I understand that you have been diagnosed with AITD and I would like to learn more about the progression and experiences with your diagnosis.

1. Tell me about your journey from when you first started experiencing your symptoms through when you received your diagnosis until now. If this was a book, give me some (7) chapters, with titles and a summary as to what each one was like for you.

2. Tell me more about your reaction to your diagnosis(es)? Give me details of your thought processes and what you were thinking and feeling, as well as how your reaction progressed over time?

3. How have you been treated by doctor(s)? Was their methodology and treatment of you what you were expecting/hoping for? What were the best and worst experiences with doctors?

4. Tell me an episode in your life when you had the hardest time in relation to this condition. What was the most effective way you coped with the hardest times?

5. How have your symptoms impacted your home and work life?

6. What financial implications has this journey had for you? What role has insurance played in all of this and has it been beneficial?

7. Have there been any dietary implications due to your symptoms? What have you found to be effective if anything?

8. In general, how has this diagnosis impacted your identity and how you see yourself today? How has this diagnosis impacted the way you see yourself (appearance and well-being) as well as self-esteem?

9. How has your diagnosis impacted your ability to socialize with others and ask for and gain support from friends and family? Has it limited or expanded your social network in any way?

10. What do you know now that you wish you knew when you started this journey?

11. Conditions such as these could be debilitating. Is there anything from this journey you believe has contributed to your overall growth as a person?

12. If there was advice you would want to tell doctors about your condition, what would you say?

13. What are some strengths that you had prior to your diagnosis or that have developed on your journey?

14. Has Covid-19 impacted you and your diagnosis? If so, how?

15. Is there anything we have not touched upon that you believe is important for myself and others to know?

Appendix E

Disease Progression Trajectory