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Neuropsychiatric Complaints in Graves' Disease: Webinar Highlights

A chance meeting at a medical conference in the early days of the Graves' Disease and Thyroid Foundation (back then the National Graves' Disease Foundation) led to a groundbreaking research paper on neuropsychiatric complaints in Graves' disease. More than 20 years later, a member of the original research team set out to see if anything has changed.

You might have read the GDATF's patient bulletin, *"What's Wrong With Me? I'm Not Myself Anymore?"* You might have even downloaded or printed a copy to help your friends and family members better understand how Graves' disease can affect issues like mood, sleep, and concentration. But you might not know that the origin of that bulletin goes back to the early days of the Foundation's history (we were known then as the National Graves' Disease Foundation) when founder Dr. Nancy Hord Patterson was exhibiting at a meeting of the American Psychiatric Association. There, she met Dr. Robert A. Stern, who (along with Dr. Arthur J. Prange) happened to be interested in doing a survey of Graves' disease patients. Dr. Patterson offered to assist with the distribution of surveys – which back then was done via snail mail!

Dr. James Arruda, at the time a postdoctoral student working with Dr. Stern, was brought in to assist with data

analysis and interpretation. The results were published in the Spring 1996 issue of *The Journal of Neuropsychiatry and Clinical Neurosciences* under the title "A survey study of neuropsychiatric complaints in patients with Graves' disease" by Stern et al. Almost 20 years later, Dr. Arruda had a graduate student, Diane Fralix, who happened to have Graves' disease. She was interested in a project for her master's thesis and decided to revisit the original research. Dr. Arruda reached back out to the GDATF, who agreed to help distribute a new survey – this time over the Internet!

The finished product - *"A survey study of neuropsychiatric complaints in patients with Graves' disease: A reassessment of self-reported symptoms and current practice 20 years later"* – is now available as an e-manuscript that is free with Kindle Unlimited or \$2.99 with Amazon. Dr. Arruda is generously donating 70% of the proceeds to the GDATF!

On February 17th, Dr. Arruda, Dr. Patterson, research associate Madison McInnis, and GDATF Executive Director Kimberly Dorris recorded a webinar to highlight some of the key findings and to answer questions from Graves' patients about their own experiences with neuropsychiatric complaints. You can read on for highlights or view the full program – along with other educational programs from the GDATF – on the

GDATAF's YouTube Channel at <https://www.youtube.com/user/GravesAndThyroid/videos>.

Madison kicked off the program with an overview of Graves' disease and an explanation of two classes of symptoms: somatic and neuropsychiatric. Somatic symptoms include physical manifestations such as goiter (enlarged thyroid), eye signs (like bulging and swelling), atrial fibrillation, dermatopathy (which often appears as a red rash on the shin with the consistency of an orange peel), and acropachy (tissue swelling in the hands and clubbing of the fingers.) In contrast, neuropsychiatric symptoms involve the mind and the nervous system – for example, irritability, anxiety, sadness, impaired cognitive abilities, and insomnia. These are real issues that have a real impact on your quality of life, but these issues are more challenging for your doctor to measure and monitor, than, for example, how many times your heart beats per minute or how many millimeters of bulging you have in each eye. These neuropsychiatric symptoms can also sometimes linger even after your thyroid dysfunction has been corrected.

Madison noted that in the original study, the authors found that the presence of neuropsychiatric symptoms often caused primary care physicians to misdiagnose Graves' as a mood disorder. "They were actually prescribing psychotropic medications instead of addressing the Graves' disease."

In the next portion of the webinar, Dr. Arruda discussed the new survey's format and findings. Some of the measures from the original study were retained, including time to seek treatment, time to diagnosis, and symptom prevalence. The new

survey also added information on misdiagnosis and treatment prevalence. The prior study included 137 respondents, and the new study had 1,603 respondents. The mean age was 47 years old, and 91% of the respondents were female. Dr. Arruda then shared some of the key findings from the new survey:

- In the prior investigation, 15% of respondents sought treatment within one month of symptom onset. However, only 8% of the more recent respondents had sought treatment within one month of symptoms. In fact, in the new study, 55% of respondents reported taking six or more months to seek treatment.
- Time to diagnosis actually worsened from the original to the new survey, with 30% of the original respondents getting a diagnosis within one week of seeking treatment, while only 16% of the current respondents received an accurate diagnosis within one week of seeking treatment.
- The original survey asked participants to report ("endorse") whether they were experiencing specific neuropsychiatric symptoms, and then the authors ranked the symptoms in order of how many patients "endorsed" them. This was repeated in the new survey, and the findings were similar, with the top five being irritability, anxiety, visible shakiness, feeling hot most of the time, and inability to sleep.
- The new study found that 42.50% of respondents were misdiagnosed before receiving an accurate diagnosis. Common misdiagnosis

were general anxiety, depression, and panic disorder. Factors that increased the risk of a misdiagnosis included lower education level, lack of employment, and longer time to seek treatment.

- The new survey also examined treatment prevalence. (Note that percentages add up to more than 100, as some patients take antithyroid medications before moving on to RAI or surgery.) Of the three conventional treatment options, antithyroid drugs was the most common at 78%, radioactive iodine next at 38.1%, and then surgery at 12.30%.

Dr. Arruda noted, “We really had to conclude that in fact people are still presenting with many of the same neuropsychiatric symptoms and that they continue to have some of the same problems in terms of not only seeking treatment but also getting an appropriate diagnosis in time.” Dr. Arruda explained that the research team was surprised with the new results, as they expected that access to technology would help reduce the time to seek treatment by helping both patients and clinicians gain information about Graves’ disease.

A major limitation of the study was self-selection. Rather than drawing upon a random sample of all Graves’ patients, the research team recognizes that people who chose to respond tend to be either more symptomatic or more dedicated to finding answers. Therefore, the results might not generalize to the entire population of Graves’ disease patients.

The authors had originally hoped to publish the results in the same journal in which Stern and colleagues reported their findings. Unfortunately, Dr. Arruda recalls, “We were told it wasn’t appropriate for the journal, - we got that same message across a number of journals - which really surprised me, given the success of the first article, which has been highly cited, and a follow-up would have been a fantastic thing to publish.”

However, Dr. Patterson noted that this research is still valuable, particularly to the patients who are struggling with severe symptoms. She explained, “Typically, the type of patients that become involved with the GDATF are what Dr. Carol Greenlee referred to one time as ‘fourth standard deviation patients’ – meaning there’s the whole bell-shaped curve, but the fourth standard deviation is just a very small slice of the full population. We’re the ones that are very challenging to doctors. There’s many people for whom Graves’ is no big deal, and that’s wonderful for them – but very difficult for the difficult patients.” She reminded the audience that when you see patients posting on the Internet, those are usually the patients who are experiencing the most challenges. “People who are doing fine with Graves’ aren’t on the Internet going ‘Oh, by the way everybody, I’m doing great.’ It’s the ones that are having problems.”

Dr. Patterson then provided additional insight on the patient experience. She shared two slides that list traditional physical manifestations of Graves’ disease – but noted that even information from credible sources doesn’t always mention neuropsychiatric symptoms. This is why it’s critical to have a thyroidologist

on your team - doctor who is very familiar with thyroid issues.

Dr. Patterson also discussed quality of life issues in Graves', which can include fatigue, difficulty concentrating, employment concerns, relationship problems, fear of the unknown, and emotional problems like anxiety and depression. "The thing I want people to take away from all this is that these are not personal failures. Being a person that's very involved in mental health, I think all of us know that mental health is still very stigmatized. It's hard to make people understand that this is very, very real. We look pretty normal, and people go, 'I don't know what your problem is. Just get over it.' Now trust me, if we could, we would. So there's that lack of communication, lack of understanding between us and other people in our lives."

Dr. Patterson also addressed quality of life issues that come with thyroid eye disease. Patients can experience double vision and appearance changes, and light sensitivity – and can end up unable to drive, engage in hobbies, read, and participate in social activities. This leaves patients with a sense of isolation that affects quality of life.

She noted that support groups can provide a sense of validation that patients don't often get from other people in their lives.

Dr Patterson also discussed the Graves' disease experience from different perspectives. Patients themselves experience all of the personal physical and emotional symptoms. However, families only experience the emotional

symptoms – often in a negative atmosphere. "Sit your family down and talk to them when your levels are fairly calm," Dr. Patterson explained. "Say, 'Y'all, I'm so upset that I do this, I don't do it on purpose, please just come give me a hug and help me settle down. It will get better.' If you haven't told them, they don't understand why. We make it hard on the families, and the family tends to just back off."

Given that the medical system limits the time that doctors are allowed to meet with patients, Dr. Patterson noted the importance of being very clear in order to help both patient and doctor. For example, "I just feel terrible" won't get you closer to getting help. However, more detailed information such as "I'm only sleeping two hours a night, "I get breathless walking up five steps," I need eye drops 20 times a day, or "my spouse says my eyes are not closing when I sleep", can help your doctor better help you.

At the conclusion of the webinar, the presenters took patient questions, which had been submitted in advance.

How can we make sure that new patients get correctly diagnosed with Graves' disease at the beginning instead going through the whole gamut of mental health diagnoses like depression or anxiety disorder or panic disorder?

Dr. Arruda noted the importance of having a primary care physician who understands and appreciates the behavioral side of the equation. When making a new patient appointment, Dr. Patterson recommended asking the office manager how many

Graves' patients a doctor sees. ("If it's only a couple a month, that's probably not who you need to go see.") She also noted that the Graves' Disease & Thyroid Foundation and the American Thyroid Association can help patients locate an experienced doctor. She also noted that a good doctor will be understanding of a patient seeking a second opinion and will be willing to work together with your primary care doctor.

Are there "natural" cures or supplements that help my Graves' disease?

Dr. Patterson: "There are none that have evidence. Graves' disease takes a tremendous toll on your body, on your brain, on your heart, and on your bones. What I'm always afraid of is that people will try them and delay proper diagnosis. Whatever you take, talk to your doctor about it. Don't just go off on your own and go to a health food store and pick up bottle after bottle."

If I have a new symptom or complaint, how do I know if it's my Graves' causing the problem?

Dr. Arruda suggested getting thyroid levels checked for any new symptom onset, but also notes that some issues might require evaluation from another specialist. The issue could be something separate that needs a separate diagnosis and treatment.

Does the ability to concentrate get better when your thyroid levels are stabilized?

Dr. Patterson noted that the original Stern paper found that cognitive functioning was

reported to be below pre-hyperthyroid levels, even after the participants returned to the euthyroid state. "I think we can make lots of adjustments. One of my favorites for years before the Internet or smart phones is to keep literally a notebook. Everything gets written in that notebook, and it gets written plainly. Sticky notes have become our enemy: we lose them. You write someone's phone number down; you also learn to write their name down. I have lots of phone numbers that I don't know who they are!" Dr. Patterson also recommended using positive language. Because of the way that the brain processes information, "remember" is more helpful than "don't forget".

What can I do to get a good night's sleep?

Dr. Arruda: "Assuming the patient is euthyroid, really, it's good sleep hygiene. Although the course of the disease can be unpredictable, it's important that we focus on things that we can control. Going to bed on a regular schedule, getting up on a regular schedule, not exercising late at night, not eating late at night, getting exercise during the day...basically, maintaining a good sleep/wake cycle is important. Also eating correctly. White noise at night. Instead of abruptly going to sleep, having some sort of stepping down of the day where you might engage in behaviors that are kind of relaxing before actually trying to fall asleep. It may be quite natural for somebody to wake up in the middle of the night. I would just caution against doing things that would result in different arousal systems in the brain kicking into gear – thinking about job, due dates, etc. Avoid exposure to

bright light, which tends to reset the circadian rhythm. Trying to get back to sleep would be the thing to do.”

Dr. Patterson added that she sleeps with a sleep mask and earplugs if needed to block out noise. “Also, there’s nothing wrong with talking to talk to your doctor if you do need medication. I would rather do that than go to the drug store.”

How can you deal with feelings of rage – which can be so destructive to relationships?

Dr. Patterson: “It’s very real, it’s very embarrassing, and you feel completely out of control. You know pretty much what you’re doing, but there’s no off button. Talk to your family, because that’s usually where you’re doing it. When things are calmer, sit down and talk to them and say, ‘I do not mean to do this.’ Try to explain it to your family. Apologize. At least acknowledge, ‘I really made a fool of myself last night, and I am so sorry.’ Sometimes we don’t like to apologize, so get over it and apologize!”

At the conclusion of the webinar, we asked Madison – who is in the process of applying to medical school – if the findings had affected her perspective as a future physician. She noted, “I think it’s really eye-opening to the realities of the patient/physician relationship, the fact that the physician is not always able to provide a cure, and the fact that medicine is not always black and white. Even when that is the case, the physician is still able to hear that patient in their suffering and manage their symptoms on a daily basis as best as possible. And I think from a scientific standpoint it is motivating to see the areas where progress still needs to be made

and the work that needs to be done. We’ve made a lot of advances in curing diseases and providing medications that help patients, but there is work that needs to be done, especially in Graves’ disease and so with that you can only hope that in the future we’ll continue to make new discoveries and new advancements that will be able to help patients.”

Dr. James Arruda is a professor of psychology at University of West Florida, teaching courses in cognitive neuroscience, biological psychology, sensation and perception, research methods, and behavioral statistics.

Madison McInnis is currently a research associate at the Institute for Human and Machine Cognition in Pensacola, FL where she works towards developing mitigation strategies for cognitive and environmental stressors in extreme military environments.

Dr. Nancy Hord Patterson is the founder of the Graves’ Disease & Thyroid Foundation. She is an Advanced Registered Nurse Practitioner and has spent 43 years working in psychology and mental health.