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Graves' Disease
Foundation

What is wrong with me? I am not myself anymore

By Jessica Somerville Ruffolo, M.A. and Robert A. Stern, Ph.D.

Have you felt tense and irritable? Have you had trouble concentrating? You are not alone. If you have ever wondered whether your change in mood or thinking problems might be due to your Graves' disease, keep reading. We are going to describe the emotional, behavioral and cognitive changes that may result from having Graves' disease.

Graves' related emotional and behavioral symptoms

Changes in emotion and behavior are very common in patients with Graves' disease. The changes may include emotional lability, nervousness, restlessness, irritability, fatigue and insomnia. These symptoms are very similar to those experienced by people with anxiety disorder or clinical depression. These changes are often what lead patients to treatment in the first place. However, as you can imagine, it is easy to misapply these symptoms to a "primary" psychiatric illness. Too often in fact, patients with Graves' are misdiagnosed because of the similarity in symptoms between Graves' and psychiatric disorders. (Refer to Table 1 on page 2.) This can result in inappropriate treatment. Sometimes it can also result in a further worsening of Graves' because it delays a true diagnosis and appropriate treatment. Exam-

ples of common misdiagnoses include generalized anxiety disorder, panic disorder, social phobia or depression. The symptoms of these disorders may be very similar to those of Graves' but the cause is very different. Some treatments of the presenting symptoms may be attempted such as medication and relaxation techniques. The primary treatments of the disease itself with anti-thyroid medication, radioactive iodine treatment or surgery are necessary in the patient with Graves' disease.

Figuring out the cause of the symptoms can be further complicated when a patient already has a primary psychiatric diagnosis before the development of Graves'. The emotional and behavioral symptoms of Graves' disease may keep other patients from seeking help in the first place and receiving treatment. Many people find themselves embarrassed by what they may consider "personal problems". They hope the symptoms will eventually just go away. Graves' disease will not remit without treatment. The following story could be an example. It is based on several stories of our patients:

A busy 35-year-old working mother of two children began feeling nervous, with heart palpitations, a jittery feeling and poor concentration. "It's only stress and anxiety", she told

herself. "I can handle this." Months passed with no relief. Her symptoms worsened and she felt even more out of control.

Finally she "gave in". A psychologist diagnosed her with anxiety and treated her with relaxation techniques and talk therapy. It wasn't until the symptoms worsened further that she told her family doctor of her state. This doctor put her on anti-anxiety medication. This medicine only minimally improved her symptoms and she began feeling completely out of control and "crazy." Finally, her physician did a TSH test and discovered the hyperthyroidism. This was after many months had passed from the beginning of her symptoms. This woman and her health care providers made the very common mistake of viewing her emotional, behavioral and cognitive symptoms as being caused by psychological or psychiatric factors rather than to the real source, Graves' disease.

Many or most people do receive treatment in a timely fashion. The rare condition of "thyroid storm" can occur when extremely high levels of thyroid hormone are allowed to build up in the system. In addition to the other medical problems associated with thyroid storm, this condition can also result in psychosis and profound agitation. Elderly patients with untreated Graves' disease may

present as more depressed, apathetic and slowed down. This is quite different from the anxious and irritable presentation of younger people with Graves'.

A person usually *feels* sad or anxious with the typical "psychiatric" depression or anxiety. These emotions are not always reported in Graves' disease. You may feel as if you have all the symptoms of anxiety or depression, such as palpitations, being shaky, or feeling irritable or fatigued. You may not, however, necessarily *feel* the emotions of *being* anxious or sad. The table below is an illustration of this point. It shows the shared symptoms and those that are different between Graves' disease and a primary anxiety disorder.

Many of these shared signs and symptoms are likely due to excess adrenaline, resulting in "fight or flight" symptoms. Abnormally high thyroid levels cause this. Your body is then constantly in a state of increased alertness and high energy output. It is also possible, however, that the changes in thyroid hormone levels directly affect how the brain is functioning. In addition, the autoimmune effects of

Graves' may also directly effect the brain, causing some of these symptoms. Researchers are trying to understand these mechanisms further.

"Neuropsychiatric" symptoms reported by patients with Graves'

Our group conducted a survey of the members of the National Graves' Disease Foundation in March 1992. Bulletin #43, which contains the results of this survey and the full scientific journal article (*Journal of Neuropsychiatry and Clinical Neurosciences*, 1996; 8:181-185), may be purchased from NGDF. 137 patients with Graves' disease completed a questionnaire pertaining to neuropsychiatric complaints. The neuropsychiatric impairments were clinically acknowledged to be common at the time of this survey. The prevalence of these symptoms was unknown because no studies had been conducted addressing this issue. Table 2 on the next page lists the percentages of Graves' patients who reported having these symptoms while they were hyperthyroid.

The results also indicated

that Graves' patients sometimes went for very long periods of time before seeking treatment. 23% of the survey respondents reported waiting 3 to 6 months before seeking help for their symptoms. Over 35% waited *over six months!* It took more than 3 months for another 35% of the patients to receive an accurate diagnosis *after they sought treatment!*

We expected the survey respondents to report that their overall functioning was significantly worse while they were hyperthyroid, when compared to the two years prior to the onset of their symptoms. Although they reported that their functioning did improve somewhat once they received treatment for their Graves', it was still much worse when compared to how they were functioning prior to the onset of their Graves' symptoms. This may indicate that many patients with Graves' disease do not feel that they return to their baseline level of functioning even after treatment returns their thyroid hormone levels to the normal range. Two similar survey studies of Graves' patients in other countries were published after our sur-

Table 1. Comparison of the similarities and differences among Graves' disease and anxiety

| Graves' only | Anxiety only | Both Graves' and anxiety |
|-------------------------|---------------------|---------------------------------|
| Goiter | Anxious or sad mood | Shakiness |
| Eye protrusion | Fear of dying | Palpitations |
| Heat intolerance | Dizziness | Sweating |
| Warm moist skin | Unreality | Decreased sleep |
| Increased appetite | Chest pain | Shortness of breath |
| Weight loss | Faintness | Nervousness |
| Amenorrhea or impotence | | Fatigue |
| Hyperactive reflexes | | Irritability |
| Muscle wasting | | Diminished concentration |

Table 2. Percentages of Graves' patients reporting symptoms when hyperthyroid

| Symptom | % of people with the symptom | Symptom | % of people with the symptom |
|---|------------------------------|--|------------------------------|
| Irritability | 78.1 | Tired all the time | 47.4 |
| Visible shakiness (especially hands) | 77.4 | Significant decrease in social activity | 45.6 |
| Feeling hot most of the time | 73.7 | Feelings of being out of control | 44.5 |
| Anxiety | 72.3 | Hopelessness | 42.6 |
| Inability to sleep | 66.4 | Sadness | 41.9 |
| Increased fatigue/weakness | 65.7 | Loss of sense of humor | 41.2 |
| Sensation of shakiness inside but not visible | 65.4 | Decreased sexual desire | 40.1 |
| Loss of more than 5 lb. in 3 months | 62.8 | Slowed thinking ability | 39.7 |
| Trouble breathing/shortness of breath | 59.6 | Loss of interest in the things that formerly gave you pleasure | 39.0 |
| Change in hair or skin texture | 57.4 | Chest pain | 37.5 |
| Anger | 55.9 | Not being able to "connect" with others | 33.8 |
| Increased crying | 55.1 | Changes in menstrual cycle | 33.8 |
| Inability to perform some daily tasks | 50.0 | | |
| Easily startled | 52.9 | | |
| Hot or cold flashes | 47.8 | | |

vey results became public. Both of these studies confirmed the findings of our study. They also showed that neuropsychiatric symptoms are very common in Graves' patients and may linger on for some time after treatment. The reasons for the prolonged symptoms are not currently well understood. We also do not know the reason why some Graves' patients have more of these emotional and behavioral changes than others do. There are some patients who seem to have very few of these complaints or none at all. Our group and others are currently examining these important questions.

“Neurocognitive” changes related to Graves’

Graves' patients also commonly report a variety of “neurocognitive” complaints. The most frequent are poor attention, diminished concentration and memory problems. The results of the few existing scientific studies indicate subtle deficits in concentration,

memory and reaction time in hyperthyroid Graves' patients. There is also evidence to suggest that Graves' disease may reduce “executive” functions, which control higher-order functions of the brain. These functions include:

- problem solving — being able to consider many options and alternatives and being flexible
- conceptualization — being able to see the “big” picture
- planning and organization

These executive functions are thought to involve the front parts of the brain (frontal lobes) and their connections with the deeper, inside parts of the brain. A recent study used a technique known as Magnetic Resonance Spectroscopy which examines brain activity. This study indicated that in acutely thyrotoxic Graves' patients, there was a reduction in the metabolism in the frontal lobes, particularly on the right side.

Most of these neurocognitive changes improve after successful treatment of Graves' disease according to self-report and objec-

tive measures. Some cognitive deficits may not improve so easily in patients who have had untreated Graves' for a long period of time. Comprehensive, longitudinal studies need to be done. This type of longitudinal research would follow these Graves' patients over time to assess any changes in brain functioning. Our group is currently investigating the neuropsychiatric and neurocognitive changes associated with acute hyperthyroid Graves' disease. We are also investigating whether there are changes in the brains of Graves' patients using Single Photon Emission Computed Tomography (SPECT). This diagnostic tool measures how much blood goes to different areas of the brain. *Preliminary* analysis of the data from this study suggests that there is reduced frontal lobe functioning in some hyperthyroid Graves' patients, as seen on both neurocognitive testing and with SPECT. It should be noted, however, that this study is not yet complete and much more research in this area is needed.

Our research group is evaluating whether any brain changes or neurocognitive problems remain *following* treatment of the disease. Graves' disease is an autoimmune disorder. The thyroid gland and the eyes are known to be autoimmune sites. There is some suspicion that another autoimmune site may be the brain. This is why we are investigating whether changes in the brain may continue even following treatment of the thyroid gland.

We are also conducting another study aimed to answer the question: "Is the autoimmune thyroid disorder of Graves' different from other thyroid disorders?" We are comparing treated Graves' patients to treated hypothyroid patients in this study. We are using the same comprehensive battery of neuropsychiatric and neurocognitive measures as in the first study. Our results will be shared with you.

Quality of life changes

Did you recognize yourself or your loved one in the previous descriptions? Have you found that your life has been somewhat or dramatically altered by Graves'? Again, you are not alone. Graves' patients and family members can adapt to personality, emotional, behavioral and cognitive changes that are experi-

enced by many. This can be very stressful for everyone and can dramatically affect the support system for Graves' patients. It may lead to marital stress and conflict. This is described in the NGDF Bulletin #38, "*An Open Letter to the Husbands of Graves' Disease Patients*":

"In a lot of ways my wife and I were fortunate. She was diagnosed with Graves' disease after approximately nine months; at least that is the closest she and I can pinpoint when she began to first experience the symptoms we now associate with Graves'. During that time, however, while I always knew my wife loved me, frequently who I was married to was not my wife. One aspect was the mood swings, the unexpected outbursts of anger and accusation, the unexplainable crying. This took the most work for me to deal with emotionally."

It is so important to realize that what you are going through may be very common for individuals with Graves' disease and their loved ones. These symptoms may be part of the physical disease that affects your thyroid, your eyes, and possibly your brain. Treatment of the disease is essential, though as already mentioned, some symptoms may still remain for some time following the point your doctor tells you that your thyroid hormone levels are "normal." Feel-

ing frustrated about this is also expected. Sometimes increasing your support, whether through friends and family, or by attending a support group, or by engaging in counseling or psychotherapy, may help you to cope with your feelings. People tend to dismiss their worries or concerns, especially when their cause is misunderstood or not appreciated. The following quote from a respondent in our survey illustrates this very point:

"Before I was diagnosed I felt as though I was losing my mind. I couldn't get along well with others and my marriage was affected. I would go to the family doctor and he would say, 'Oh, this is normal for a working mother of three.' I lost all self-confidence and worried a lot. I thought I had cancer or some other life-threatening disease. When I found a doctor that I was able to talk to and she understood, it was a wonderful moment."

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