



FROM HYSTERIA TO THE CREATION OF A FUNCTIONAL NEUROLOGICAL DISORDER CLINIC

ALISON HERU

ABSTRACT This personal essay details a psychiatrist's experience of her female patient's dissociation, which led to questions about the role of women in society. A brief review of societal norms reveals that women have always presented in medicine with disguised disorders. Collaboration with a neurologist and a team of like-minded providers leads to the development of a nonepileptic seizure (NES) disorder clinic.



*want you to just listen to me.
Don' t hospitalize me and don' t medicate me.
Just listen. I want to tell my story.*

SUSAN IS IN MY office at the National Jewish Health in Denver, where I see patients from across the country. Patients are referred to pulmonologists, cardiologists, immunologists, and other specialists, when their symptoms persist and become a puzzle. A consultation with a psychiatrist is part of the evaluation, sometimes unwelcome, but Susan comes willingly. Maybe she trusts me because I am in the medical setting and not in a psychiatric hospital, a common finding for treating patients who also have medical illnesses. The medical hospital reduces the stigma of seeking mental health treatment, and the fear of entering a psychiatric institution. I give Susan my usual caveat about my legal responsibility to act

University of Colorado, 13001 E. 17th Place, Aurora, CO 80045.
Email: alisonheru@gmail.com.

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if I think her life or someone else's life is in danger, and I add that if I think that a medication will help, I will tell her, but that she can refuse, as that is her right. She agrees, and we have a contract.

Susan settles herself, brushing her wild black hair behind her, and with an eager expression begins to tell her story. Within five minutes, she slumps to the floor, seemingly unconscious. When she comes around, she cannot walk, so I fetch a wheelchair. She is petite, and despite her bundles of winter clothing, easy to maneuver into the chair. She slowly begins to come to, and is able to help me place her feet on the footrest.

The staff ask if I will send her to the emergency room, wondering if she had had a seizure. No, I say, just let her sit until she is herself again. This is a dissociative episode brought on by her telling of her trauma; I have seen this before. She has had extensive workups and a long psychiatric history, all of which I had read before she came to see me.

This pattern repeats itself each time Susan visits with me: she begins to tell her story, then she begins to look dazed and goes into an event. It becomes our practice that when she starts to dissociate, I divert her into the present by focusing her attention on something in the room, like her shoes, the plant on the window sill, or the snow gently falling outside the window. Soon she learns to do this herself, suddenly interrupting her story by commenting on the color of my dress, or the sunlight hitting the pattern on the carpet. She understands that her dissociation is a mechanism that protects her from facing the overwhelming emotion associated with her retelling of her past experiences. At the beginning, our sessions are short. It takes two years of sitting for her to tell her story. At the end of the two years, she says she is very angry. We both laugh when we realize that she had at last told her story.

It is right that you feel angry!

I am puzzled by how the body metabolizes trauma in this way: through what brain pathways? How is consciousness cut off, how does the rising up of emotions turn the patient unconscious? The brain plays possum. Not flight nor fight: freeze and play dead instead.

In Victorian times, when women fainted, they took a whiff from their bottle of smelling salts as a remedy, a habit derived from the belief that the wandering womb disliked the pungent odor. When it returned to its place, the woman would recover her consciousness. This was called Hippocratic fumigation therapy: "If a woman inhaled fumes of an unpleasant odor, the womb was induced through repulsion and attraction to return to its correct position" (Flemming 2000, 220). People wondered why women were having these fainting attacks. Were their corsets too tight?

By the early 1900s, there was a new explanation. Freud thought that hysteria was caused by “a lack of libidinal evolution,” resulting in frigidity, but Mabel Dodge revealed in her diaries that the reason that upper-class women did not want to have sex with their wandering husbands was because of the fear of catching syphilis, and that there was plenty of libidinal energy directed elsewhere (Rudnick and Heru 2017). However, influenced by Charcot, Freud was able to shift the focus to the psychological factors contributing to hysterical symptoms, particularly unconscious conflicts and traumas. His focus on the psyche of women still troubles our collective imagination.

But it is the early 2000s, and women are still swooning and falling. What bothers me most is that many male physicians use techniques to demonstrate that the female patient is “not really ill.” One commonly used technique is to lift the arm of the unconscious woman and then release it. If the arm falls to the woman’s side and not onto her face, then she is accused of “faking it.” This intervention seems to me to belong at the Salem witch trials. The doctor is supposed to help the patient, not punish her for bad behavior, nor be suspicious of her motives. It reminds me of the comments of Professor Thomas Laycock, who opposed women’s right to study medicine. In the years before the UK Medical Act 1876, he voiced the concern that women seeking medical careers might be “basely inclined” or might even be “Magdalenes,” or wayward women.

Even though no one calls it hysteria these days—using more socially acceptable euphemisms, such as “functional neurological disorders” or “dissociative disorders”—women are still presenting with symptoms that defy classification. By this point in my career, I am aware that psychiatry still wrestles with the “woman problem,” so when I have the opportunity to work with these patients on a grand scale, I jump at it.

In addition to working in the National Jewish Health clinic, I also work at the University of Colorado Hospital, providing psychiatric consultation on the inpatient medical and surgical units. I am called to the epilepsy monitoring unit to see a patient with persistent hallucinations. Laura Strom, an epileptologist, is the requesting physician, and I tell my team of resident and medical students, “Don’t ever block a consult if it comes from Dr. Strom. She will try everything she knows before calling psychiatry. She is not one of those neurologists who punts any patient with psychological symptoms.”

Dr. Strom smiles widely and broadly, appreciating the compliment from me. She tells me later that she saw me as a “well-dressed purposeful woman.” There are few well-dressed women in medicine, she reflects, remembering a friend from medical school days, who said to her: “Don’t become one of those women doctors who are not well put together. Don’t become one of those lady doctors

who never brushes her hair. One of those women who doesn't take care of her appearance."

Yes, it's clear that they were defeminizing themselves, says Laura over coffee. She adjusts her intricate delicate knitted sweater; one of her hobbies is knitting. "Lady doctors,' that's what we used to be called," she exclaims with a flourish, and we laugh, knowing that we have come a long way.

Laura and I are meeting to discuss a call for a project that would join the Departments of Psychiatry and Neurology. She suggests a project to help the patients with nonepileptic seizures (NES). Hysteria reimaged, I whisper to myself, how perfect is this! It fulfills my academic dream of reimaging the fraught history of female patients in psychiatry by creating, developing, and delivering a program conceptualized by women doctors and bringing a new treatment to troubled women who languish at the margins of neurology and psychiatry.

We are gathering in a small cramped conference room, down the end of a long corridor, around the oversized table. Suzanne Sullivan is in charge of the initiative; the other attendees are the two Chairs of Departments, two other men, and Laura and me. A Parkinson's project is suggested by the two men (who are golfing buddies, one a psychiatrist and one a neurologist), but Laura and I have come to the meeting with details and a rudimentary budget. We hand out copies and talk eloquently about how we will establish a new clinic for patients with NES. We walk out feeling confident.

We wait two weeks before we are told that our project is approved. The Chairs had satisfied the hospital's request and had delivered up a team with a plan. We are two women who are about to change the lives of many patients and their families, and we couldn't be happier. Laura's open welcoming stance to me, and her belief in our project, represent a rare moment in medicine, when two people who actually respect each other and like each other can embark on a medical journey together. We feel like we are making history—or rather that we are mending history, knitting from a new pattern that highlights the dignity of women.

Neurology and psychiatry used to be considered as a single, unified branch of medicine, called neuropsychiatry. In 1844, a group of superintendents of 13 American insane asylums met to ponder their fate, and they began the organization called the American Medico-Psychological Association, later to become the American Psychiatric Association. Neurologists tended to patients in their private practices, and psychiatrists managed the institutions. Neurologists focused

on those brain disorders with cognitive and behavioral abnormalities that could be localized in the neuro-axis, such as stroke, epilepsy, Parkinson's, and so forth, while psychiatrists focused on those disorders of mood and thought associated with no or minor physical signs found in the neurological examination of the motor and sensory systems—schizophrenia, depression, anxiety disorders, and so on.

It was a neat division of labor, or so they thought at the time. In the US, this division deepened when the American Academy of Neurology was founded in 1948 to deal with “pure” neurological issues, and neurology departments were established throughout the country. After World War II, the division between neurology and psychiatry became more explicit.

Many patients, especially women, fall between the two fields and are inadequately served by either specialty, so collaboration between the two specialties is an idea destined to be revived, considering that we are now more able to image the brain and allow it to tell us its secrets. It is also said that functional neurological disorder is a feminist issue, with many strands that contribute to its dismissal in medicine, strands such as historical and contemporary clinical, research, and social perspectives (McLoughlin et al. 2023).

Dr. Strom has the facts: patients with NES show up in the emergency room and get admitted to the epilepsy monitoring unit (EMU), have interventions that are harmful, such as intubation, and get put on medications that they do not need. She defines NES as the diagnosis when a 24-hour EEG does not show any epileptic activity while the patients are having their events. The patients have hitherto been dismissed as not having a “real” epilepsy, despite the fact that they continue having these events. Sometimes they are told to go and see a psychiatrist, that it is all in their head. *Where else do brain disorders reside?*

It is an absurd situation, and we are about to provide a solution. The literature shows that nationwide, it takes on average 10 years for these patients to access proper care. The patients and families are traumatized by the disregard of the medical professionals, who want nothing to do with them. This is the problem we set out to solve with our new clinic for patients with NES.

It takes two years to open the clinic because we want to get everything right. We develop a team of six: three psychiatrists, two neurologists, and a nurse from the EMU. We take a hospital course that offers mentoring, statistical support, and strategic planning. We have to decide on a name. Brian does not want the clinic to be called PNES, the tag that other neurologists are giving to these patients. He does not want to go around saying he works in the penis clinic. We want avoid the *P* too, because it stands for *psychogenic*, too close to the stigmatizing “psycho.”

Every detail of our clinic is scrutinized. We develop scenarios for patient flow. The patients come from the emergency room, inpatient units, outpatient offices, the community, out of state, and other hospitals. How many patients are there? Who would assess them? How many patients could the clinic handle? Could any physician assess them, or do we only want the EMU staff and the NES psychiatrists to assess them? What tools do we need to assess them? How should the diagnosis be given? Who would give the diagnosis? How do we code these encounters for billing and record-keeping? How do we manage the variations of insurance and patients without insurance, and those with multiple diagnoses? We develop algorithms for every eventuality, covering white boards with arrows and lines and circles.

We develop a business case. We calculate the cost of treatment and the cost-saving if we take the patients into our clinic. We review the literature. In 2003, 75% of NES patients had about six ED visits, costing \$3,400 per visit prior to diagnosis. The NES patients had more ICU admissions than patients with epilepsy (27.8% vs. 23.3%), and 40% were taking one or more anti-epileptic drug, even 10 years after accurate diagnosis. In 2007, the total cost prior to being properly diagnosed was \$15,000 per patient (Libbon et al. 2019).

We hone our message. Do the right thing: improve the quality of care for our patients, address safety concerns by reducing the number of unnecessary admissions and procedures, show cost efficiency. Like graffiti, we draw The Triple Aim of Health Care on every surface: patient experience of care (voice of the patient), their clinical outcome, and safety of care, divided by the cost per capita.

We tailor our message to specific groups. We tell the neurologists that we will decongest the neurology clinic so that they can treat the patients they want to treat. We will improve access to care for their patients. We will reduce the reemergence of symptoms as other functional symptoms. (An old Freudian idea, that you need to treat the underlying psychic injury, the cause not the symptom.) The neurologists are concerned about this. If you “cure” one functional symptom, another will pop up. We tell the ER physicians that we will keep these patients out of the ER. We tell health-care planners that we will improve population health, reduce cost per patient care episode, and reduce harm.

We calculate the cost per capita by considering the contribution margin on selected cases. We compare ER high-frequency utilizers with low-frequency users. If we divert the high utilizers, the ER will function more effectively and their market share will increase. We find the contribution margin in the ED to be favorable. We calculate the cost of a stay in the EMU, and the cost of ongoing care for patients with NES in the regular epilepsy clinic. If we divert the NES patients, then the flow of patients through the EMU will increase by 5%, and that extra revenue will easily pay to set up the clinic. The contribution margin for the EMU is highly favorable. We create our budget, because money is where the project will rise or fall. We calculate our costs to the dollar and the hour.

Our vision to the world reads as follows: “To embed behavioral health care in the neurology clinic, and to address the co-morbid underlying psychiatric diagnoses and substance abuse problems which present as functional neurological symptoms.” As proof of principle, we focus on patients with NES. Once short- and long-term benefits are demonstrated, expansion of the service to other clinics with functional neurological presentations can be implemented. In line with University of Colorado Hospital population management planning, we will provide short-term treatment to the NES patients and return them to their primary care providers.

We have our own vision too: to advance medicine by providing appropriate clinical care. For me, this vision is about helping women who have always been objectified and treated poorly by the medical system. Developing this clinic will make me feel right with the world of medicine.

We work steadily as a team, relying on each other’s strengths. We meet each week. We give formal presentations to hospital staff to see what hits home and what needs to be tweaked. Every piece of writing is scrutinized for accuracy and impact. We choose our words carefully.

Next, we must decide on a cost-effective treatment for the patients. The literature focuses on individual cognitive behavioral therapy, but for us, this would require too much time and training. We decide on group therapy because it has been shown to be of benefit for patients with chronic medical illnesses (Steinglass et al. 2019). It is also a treatment that can be replicated and is sustainable. Allied health professions, such as nurse practitioners and physician assistants, can be trained to run these groups with six hours of basic group process instruction supplemented by ongoing supervision. This treatment has never been used in NES, mostly because psychiatry has never shown any interest in these patients, punting them to neurology because they are too difficult to manage. Most psychiatrists do not want their patients, like Susan, falling on the floor.

Anna, a patient on the EMU, has given me permission to tell her story (Heru 2018). Anna and her mother describe her events as ranging from mild twitching of her right side to full body events. All these events are captured during her hospital stay, and no “epilepsy” is found. When I visit her, she is sitting up in bed surrounded by magazines brought by her mother. Her blonde hair frames a face that scowls. Initially reluctant to talk to yet another psychiatrist, she begins angrily:

A lot happened from when I was 4. I was molested by day care providers, my dad died, in total seven other people died. My mom was stalked, so she wouldn’t let me play outside. I was stalked and harassed in fifth grade by a classmate. At age 13, I had PCOS [polycystic ovary syndrome], and they threw

hormones at me. I heard voices to get a gun and shoot myself in the head. I was taken off all my meds. . . . I've had a diagnosis of depression since age 4, PTSD since age 15, bipolar disorder with depression from age 16, and borderline personality disorder. I was manic when I was a teenager, after more deaths, sexual assaults, and after a guy I knew committed suicide.

Anna lives with her mother, her brother, and the father of her child, who is planning on moving out soon. Regarding the pregnancy, he had wanted Anna to “get rid of it,” but with the support of her mother, Anna wants to keep the baby. Her mother is her closest support, but they have a “complicated relationship, with much tension.” The brother has a job, but Anna and her mother believe he uses his money to support his drug habit. He does not contribute to the household, is rarely home, and leaves his dog for his sister and mother to care for; he avoids his parole officer and is in danger of being returned to jail.

I talk with Anna's outpatient psychiatrist, who fills me in on her past history. Anna has had eight inpatient psychiatric admissions, including a year in residential care at age 16. Her family history is significant for unspecified mental illness, addictions, and suicides. She has been on disability for two years for bipolar disorder and PTSD and has worked only intermittently in entry-level jobs. She has completed some college, but for the past two years her mother has been her paid caregiver. Anna reports chronic anxiety, depression, insomnia, and hallucinations, but she states that these symptoms are currently well managed. Her outpatient psychiatrist agrees, and says that if the patient chooses to attend our clinic, then her individual sessions **will** be cut back. On referral to the NES clinic, Anna remarks sarcastically, “Therapy for NES? Tell me something useful.” Little did she or I know that it would improve her life dramatically. But first, Anna's continuous NES events need to be reduced before she can participate in group therapy.

As a matter of routine, I see the family of each patient, including friends and case workers, if these people are seen as family. I find that it enhances outcomes, even if I only use family education about the illness (Heru 2013). So, I invite Anna's mother to our next session and complete a family assessment.

The family functions poorly, although they have a few strengths. The mother makes most or all of the major decisions, but she is overwhelmed with her responsibilities. She tries to give some responsibilities to Anna, depending on the severity of her NES symptoms, which vary from day to day. The mother practices poor self-care. Anna is frustrated because she cannot talk to her mother, because most of the time her mother is sad, angry, or afraid. Anna says that she is happy “a good part of the time,” but when she becomes distressed, angry, sad, and worried, she has an NES event. Anna and her mother have similar interests, such as favorite movies, but they do not spend much quality time together, and they keenly indicate that they would like this to improve. Their emotional in-

volvement is characterized as empathic, meaning that they truly care for each other.

They also agree on house rules and their areas of difficulty, such as frequent name-calling when they get into arguments, a general lack of respect, and the brother being in the house. The brother is not being responsible for his dog, not picking up his things, and not participating in chores or paying for anything; there is difficulty enforcing rules with him. The dominant interactional family pattern is as follows: Anna's illnesses, especially her NES, frighten her mother, who tries to protect her daughter by not expressing her feelings and anxieties. Anna is aware that her mother keeps things to herself, and she is concerned about her mother's well-being, so she avoids talking about emotional issues, resulting in more NES events.

The family begins family therapy and agrees to start with a discussion of the brother's presence in the house. Anna has more NES events when the brother is there. The mother feels she is stuck between her children and has to choose between them. She wants to support her son, but she recognizes that his behavior is upsetting her daughter. The mother wants Anna to confront her brother about his behavior, as she herself does not want to be the one to put her son out. Anna thinks this is her mother's role, and that she will leave if her brother stays in the home. The mother knows she has to make a decision soon, so that if Anna needs to move out, she will need to have time to make arrangements. The mother spends much of the session explaining how many chances she has given her son and how he does not live up to his agreements. No decisions are made, but this is the first time they have calmly discussed the options and consequences.

Surprisingly, prior to the next session, Anna and her mother have posted basic house rules on the refrigerator, and the brother agrees to abide by them. They doubt that he will comply, but they want to give him a chance. The next problem they want to address is the mother's lack of self-care. They discuss the problem, and with the therapist's guidance agree that the mother will reserve Friday for self-care, including attending her own medical appointments. Anna offers support and suggestions to her mother, such as taking warm baths, watching their favorite movie together, and frequent 10-minute time-outs from worrying during the day. The mother agrees to follow through with these suggestions and will use sticky notes to remind herself to take a time-out. They begin to discuss a plan to use a time-out hand sign to reduce conflict in conversation and to try to regroup an hour later to discuss the issue that brought up the conflict. They will do this a maximum of three times, and if they are unable to discuss the issue satisfactorily, they will bring it to the next session.

Prior to the following session, the mother asks her son to move out and sets a date, although both express their skepticism that she can stick to this, as she frequently backs down when he pressures her. Anna and her mother both want to set a daily time to talk, to try to improve their relationship. They identify a

negative interactional pattern that occurs: mother is upset, vents to daughter who takes things too personally and regresses, then mother gets upset, and then they don't talk anymore, and so it continues. They decide to do daily check-ins between 5 and 6 p.m. They discuss strategies for minimizing miscommunication, and Anna agrees to ask for clarification if something upsets her. Anna practices this in the session.

The mother holds firm, and her son moves out. Communication improves between Anna and her mother, and they enjoy time together, preparing for the baby. The mother is practicing adequate self-care and feels less overwhelmed. They agree that their goals have been met, and they both feel happy with their progress. Anna has few NES events and now can start group therapy.

I tell this story because Anna is a challenging patient, but with our program that can handle both her psychiatric symptoms and her NES events, as well as the family triggers, she improves. The symptoms and sources of these disorders may be mysterious, but they are not rare. All told, functional neurological disorders (FND) are the second-most prevalent neurological diagnosis, behind only headache.

After we have treated about 100 patients, we take a peek at the data. Unsurprisingly, most of our patients are female (74%) and young, between 20 and 50 years old. In addition to a diagnosis of NES, 92% meet criteria for "other anxiety disorder," 60% for PTSD, 58% for insomnia, and about 50% for other psychiatric disorders, such as depression or panic disorder. We are able to show that health-care utilization drops—that there are reduced emergency care visits and urgent care visits—compared with the prior year.

We have added to the evolving story of symptoms formerly known as known as hysterical, and have provided a new path forward for woman. Hysteria is undoubtedly the first mental disorder attributable to women. Described since the second millennium BCE and for over 4,000 years, this disease has been considered from two perspectives: scientific and demonological. Dispensing with the demonological causes took centuries, and the science is only slowly becoming available. Neuroimaging studies point to alterations within and across multiple brain systems, specifically dysfunction involving emotion processing. The brain areas in question are the anterior cingulate cortex, insula, pre-central sulcus, inferior frontal gyrus, and parietal cortex (Perez and LaFrance 2016). The patients and their families get excited when we talk about this; it is validation that there is something wrong with the brain and that current available tests are not sensitive enough to pick it up.

The journey is not over for the physicians who want to treat these mysterious functional diseases. Although men also have functional symptoms, these illnesses

are still conceptualized as diseases of women. We know that sex and gender disparities exist in medicine in both diagnosis and treatment, and that the constructs of gender affect the behavior of the community, clinicians, and patients in the health-care system (Mauvais-Jarvis 2020). Have women been socialized into presenting to physicians with these disorders?

When I worked in Jamaica, there were no women with an eating disorder, because Jamaican society likes their women “nice and roun’.” In Eurocentric psychiatry, many theories have been proposed for the presence of eating disorders in women, from a disordered psychosexual development, resulting in oral fixation, to the disordered family dynamic where the mother (always the mother) pressures the young girl to conform to social pressure for thinness. It seems that societies have for centuries assigned women a place supporting a stance of weakness and dependency, and when women internalize this position, they present as helpless, like a dog lying on its back to show its submission, or a hedgehog curling up so that it cannot be harmed, or like a possum playing dead. Some women may resort to playing the victim, throwing themselves on the mercy of others, where there is hope for empathy and compassion. But once you dive down into these depths, strange things happen—such as the woman who found her fame with her birthday cake with 12 candles, one for each of her personalities. As a female physician, I want women to be able to access care that is straight and true, where they do not need to resort to subterfuge to get their distress acknowledged.

The development of our NES clinic shows that two determined female physicians, tired of how the medical profession treats women, can come up with a plan, write it out, and enlist an army to help them. We are ordinary women—and at least in my case, a woman with no special gifts—who came to believe in Eleanor Roosevelt’s words:

About the only value that my life can have is to show that one can, even without any particular gifts, overcome obstacles that seem insurmountable, if one is willing to face the fact that they must be overcome. In spite of timidity and fear, in spite of the lack of special talents, one can find a way to live widely and fully. (xix)

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