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Chemical Reactions:
an autoethnography of neuroendocrine illness & Facebook support groups

By

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THESIS

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Committee in Charge

2021

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Abstract

Neuroendocrine conditions (illnesses impacting the relationship between the nervous system and hormone function) are complex, often manifesting as overlapping layers of physical, cognitive, and emotional symptoms. As such, these conditions are highly specialized and often difficult to diagnose, treat, and receive adequate social support for. This project is a mixed-methods investigation of neuroendocrine support groups on Facebook, wherein I examine the difficulty of identifying and finding help for these nebulous neuroendocrine experiences as they slip fluidly between chemical, emotional, cognitive, situational, and social planes. Drawing on autoethnographic accounts of my own patient experience, ethnographic observations of Facebook support communities, and in-depth interviews with patient advocates and Facebook group administrators, I ask how people make sense of the embodied hormonal experiences that biomedicine might not provide satisfying answers for, and how neuroendocrine patients utilize online communities to help parse mind-body experiences that are deeply felt but also invisible, mysterious, and easily misunderstood.

Part One — *Facts* — focuses on evidence and medical legitimacy: how people use Facebook support communities to plug the informational gaps in their own diagnosis and treatment paths, and the effects of these informational exchanges on patients and their social networks. Part Two — *Feelings* — focuses on the slipperiness between cognitive, emotional, and interpersonal experiences of neuroendocrine illness, and how patients conceptualize or compartmentalize their experiences to suit their individual needs. I suggest that facts and feelings are equally malleable — bended toward a variety of strategic, emotional, and social ends.

Prologue

You're at a patient conference for people with various neuroendocrine disorders, standing in a noisy, marbled lobby. You and the other patients chat casually as you mingle around, pretending like you aren't slyly sizing each other up with loving, but compulsive, curiosity. Most of you have already had major surgery at least once. Those who haven't are quite possibly well on their way. Many of you hadn't spent much time among your own kind.

The day is programmed with a series of lectures by leading surgeons and other distinguished guests — the literal ins and outs of various surgical approaches, how to hack insulin pumps to secrete other types of medication, the difference between proton and photon beams. Directly before lunch, you watch a surgeon take to the podium to display a rousing montage of endoscopic footage — a tiny camera plunging up a darkened cavity, digging around in glistening sinews, aggressively biting into a bleeding bit of off-white mozzarella — the tumor, presumably — with what appears to be a miniaturized version of garden shears. You nearly pass out at the back of the lecture hall. You remember giving consent to have your first surgery recorded.

At break, you woozily wander into the restroom, which is brimming with the excited patter of conference attendees and the roar of electric hand dryers. People call back and forth over metallic stall dividers, comparing medical histories and medication regimens. What are you taking? How much? You smile knowingly at one other in the mirror, leaning over the sinks. Everyone says things like, "GOOD LUCK, ladies!" on their way out the door.

As you queue up in the lunch line for half sandwiches, cookies, and table grapes, another patient strikes up a conversation with you. He has travelled from well out of the area to be here. You don't remember the beginnings of the conversation; probably something like, "How many have you had?" (Meaning surgeries.) You have had two. He has had at least one. It wasn't from a hospital with reputable specialists, unlike the one you're standing in today. It didn't go well. You expect the rest of the conversation to wend toward the "usual" things you all have in common — pain, fatigue, nausea, brain fog. Instead:

"I'm angry all the time now," he says.

You freeze between bites, paper plate sagging in the palm of your hand, and look at him. He presses on.

"I don't have any friends left."

Those words ring out for a long time, drowning out the rest of your conversation. After lunch, you filter back into the lecture hall with everyone else for plenaries. A talk eventually begins on radiation. You are in the back, but you noticed the man you had been speaking with has stationed himself in the very front row. When the talk finishes and the surgeon opens the floor for questions, the man's hand shoots up — instantly. The surgeon calls on him. The man begins to speak. It is less of a question and more of an outpouring. He opens up about the inability of his team to care for him, or even answer his own questions about his experience. He talks about being radiated improperly. He talks about how it changed him. He talks about being angry. He talks about being alone. Everyone he knows can't stand to be around him anymore, he says. You feel yourself tense up along with everyone

else in the hall at this testimony, delivered before a world-class surgeon operating at the bleeding edge of the field.

The surgeon pauses a beat before saying calmly and directly:

"Sometimes people change, but we don't know why."

...

Introduction

I realize now that I have been researching the connections between emotions, personality, and neuroendocrine malfunction long before I decided to take the subject up at university. Those tense moments at the patient conference ignited a glimmer of insight, illuminating years of what I had alternately suspected and doubted through my own illness — that somehow, after surgery, I was "different."

Unlike the man in the above story, I have been lucky to receive the highest standard of care throughout my illness. However, the possibility that I might feel a bit like a different person was not something that came up in any of my appointments. Certainly, when it comes to neuroendocrine conditions that require surgery, my particular case doesn't top the list of the most physically or emotionally disruptive, and I am unlikely to ever require the type of radiation that is known to potentially alter cognition and emotions. But still, it is easy to imagine that any major disruption in neuroendocrine function might shape the way a person feels in their mind, body, and world in complicated and perhaps unpredictable ways. And for

patients managing cascading symptoms, endless tests, and, if they're lucky, a coterie of specialists, it is easy for this particular issue — themselves — to get lost in the shuffle.

On hormones

Hormones, more or less, interface between everything in the body. Colloquially described as “chemical messengers,” hormones are a major part of every biological system, mediating how we grow, eat, digest, reproduce, respond to stress, feel. Secreted by specialized cells organized in various glands, these chemicals seep through our blood and tissues and act on distant targets — a hallmark of endocrine function. Operating in complex feedback loops, hormones affect, and are affected by, nearly everything.

However, “the hormone system” is a relatively new subfield of medicine (what we now call endocrinology). It was only in 1905 that the word “hormone” was coined by Ernest Starling (borrowing on the Greek verb “ormao,” meaning to “excite” or “arouse”) to refer to agents released into the bloodstream that affect different, distant, parts of the body (Henderson 2005; Tata 2005). In the process of investigating patterns of abnormal bone growth, doctors in the early 20th century began noticing tumors in various glands of their patients, which eventually led to new understandings of the endocrine system (Kattah, Tsung, and Hanovnikian 2019; Pearce 2002). Over time, certain hormones became recognized as the culprit behind a number of previously obtuse pathologies and malformations, and as mediators of myriad biological processes. These findings built on prior experiments on animals that proved that snipping away the wrong gland entirely would significantly modulate physiology or result in certain death (Brunori et al. 1995; Cushing 1912; Del Maestro 2007). As surgeons developed new techniques for removing the types of tumors

that disrupted hormone function in animal bodies, it became clear that the endocrine system was vulnerable to imbalances and deficiencies brought about by surgical intervention as well as other endocrine pathologies. Hormones would need to be replaced exogenously (from external sources) if the glands ordinarily responsible for producing them were damaged by physical or pathological means (Cushing 1912). While early hormone replacement modalities utilized mashed-up replacement glands taken from animals (or in some cases, human cadavers) to medicate patients, today, regulated synthetic pharmaceuticals have rendered hormone replacement therapies common practice in modern endocrinology (Warner 2012).

Hormones and society

However, while technologies in imaging, surgery, and hormone replacement therapies have advanced significantly in the last 100 years, our understanding of hormones remains in flux — both scientifically and socially. As medical knowledge on hormones continues to evolve, a number of feminist and critical science studies researchers have taken up hormones — often sex hormones — as a central object of study. Because of hormones' embeddedness in processes like gender presentation and fertility, researchers have inquired as to how these chemicals not only organize tissues in bodies, but bodies in society. In the autotheoretical *Testo Junkie*, Paul B. Preciado voluntarily applies testosterone gel to enact what he calls an “auto-experimental form of do-it-yourself bioterrorism of gender” — not for the purposes of transitioning to another gender, but to evade a socially constructed experience of gender altogether (Preciado 2013). In another look at estrogens and androgens, Ostertag investigates the relationship between pharmaceuticals and gender, interrogating the assumptions that our hormones create our gender at all, as a social

technology of identity (Ostertag 2017). As evidenced by these explorations, it can be hard to parse what ideas about hormones are culturally constructed versus scientifically constructed. As noted by Rebecca Jordan-Young and Katrina Karkazis, the construction of scientific knowledge itself is permeable to cultural, racial, and gendered assumptions. In writing about testosterone, the authors examine how testosterone has become laden with associations of masculinity and aggression that perhaps obscure other inequities and social causes of violence (2019).

For these reasons, hormones — particularly their social and cultural effects — warrant careful examination. Hormones often serve as containers for ideas about gender roles, youth, and vitality, and social discourse surrounding hormones often points to societal anxieties and ideals. However, such anxieties and idealizations play out on individual scales as well. Within the confines of a single body, hormones and their impacts are slippery and easily blamed for hard-to-pin-down feelings like fatigue and unease, especially when there is little other satisfying explanation. Obviously, hormones are suffused with gender norms, in the case of “low-T” marketing campaigns for men and estrogen replacement regimes for women navigating menopause. Hormones can be coveted as means to actualizing a true self, in the case of gender transition. And, hormones are highly contextual — something like human growth hormone may serve as a chance at “normal” development for an ill child, but as a black-market performance-enhancer for an adult athlete. Perhaps most of all, while relatively few lay people may really understand what hormones do, most understand on some level that they ought to be “in balance” — whatever that may mean.

As such, hormones are an auspicious subject in studying how everyday people grapple with arcane, abstract processes of illness. The reason hormonal conditions have historically

been (and continue to be) difficult to diagnose and treat is because they are the problem behind the problem. Hormones themselves are not a disease; they are the chemical signals behind a number of diseases, telling bones to grow too big, stress responses to linger too long, menses to stop too soon. Seemingly spectral from the outside looking in, they can haunt the entire body, manifesting in almost any system as almost any symptom, invoked in limitless health problems and limitless health marketing schemes. Intervening in hormones is equally complex — endocrine conditions that current medical consensus deems outside “normal” limits can be treated with myriad medications, possibly causing myriad complications. Hormones are deeply entangled in many ideas of health, identity, and disease. Combine these ambiguities with the mysteries of the brain and nervous system, and things get even more complex.

The neuroendocrine system

The neuroendocrine system is the interface between our hormones and neurology — the brain and nervous system. At its most basic level, the neuroendocrine system hinges on special cells that respond to neuronal cues (neurotransmitters across synapses) and, in response, secrete an endocrine output (hormones into the blood). This process of converting the short-term messages of neurons into more enduring hormonal messages in the bloodstream is a process that allows the brain control over hormone-secreting glands, and vice versa (Fink 2015; Le Tissier et al. 2017). The complex integrations of neurons, hormone-secreting glands, and the vascular system forms the nexus addressed by the medical discipline of neuroendocrinology.

The neuroendocrine system can be broken down into a number of primary axes — constellations of interacting glands. Crucial examples are the hypothalamic–pituitary–adrenal (HPA) axis, the hypothalamic–pituitary–thyroid (HPT) axis, and the hypothalamic–pituitary–gonadal (HPG) axis. In each of these systems, regions of the brain (hypothalamus and pituitary gland) produce hormones that interact with other glands in the body (adrenals, thyroid, gonads) to regulate many life functions ranging from stress response to metabolism to reproduction among others in a cascading chain of chemical signaling.

Issues with tissues

While the bulk of my investigation is explicitly social in focus, I do want to call attention to the nature of these neurological and endocrine processes as material. In a multi-pronged examination of the neurological body, Elizabeth Wilson notes that contemporary researchers' rejection of biological reductionism — the understanding of a disease solely based on biological pathology, stripped of social valences — forecloses new possibilities of understanding the body in all its tissues. In exploring a version of feminism that is “affectionately involved with neurobiological data,” Wilson lets nerves be nerves. And humble nerves, by the very nature of their structure and function, end up patching themselves into complex social interplays of connection and power anyway (2004: 13).

From simply following these nerves, Wilson shows us how biological processes underlie, animate, and literally bleed into social processes all the time. One demonstration Wilson uses (that also perfectly illustrates neuroendocrinology in action) is the simple human reaction of blushing. Blushing is a process that implicates not only nerves and hormones, but also social life. Referencing Charles Darwin's 1872 text, *The Expression of the*

Emotions in Man and Animals, Wilson (ibid: 75) cites, “it is not the simple act of reflecting on our appearance, but the thinking of what others think of us, which excites a blush.” Here, Wilson notes that blushing is not only a biological response, but an intersubjective reaction to being seen. While blushing, technically speaking, is a neurological and hormonal reaction of nerves that triggers the release of the hormone adrenaline, which triggers the swelling of capillaries in the skin (O’Neill 1987), it is not brought about by a straightforward physical stimulus, nor by an interior emotional state. To blush requires the presence of another. These ideas about the complex interplay of “self” and “other” echo George Herbert Mead’s writings on social psychology in the first part of the 20th century. Mead suggests that the “self” itself is inherently relational — in constant dialogue with any organized social group, conceptualized as the “generalized other.” As the individual “[takes] the attitude of the generalized other toward himself,” social groups and social processes exert control over individual thinking and behavior (1934: 155). Put simply in Mead’s words, “no very sharp line can be drawn between social psychology and individual psychology” (ibid: 1).

Privacy concerns & specificity

This interplay between chemical, physiological, and social processes will resurface later in my analysis. Regrettably, I will not be able to outline the mechanics of these processes at a level of detail similar to Wilson. Out of an abundance of caution and respect for the privacy of everyone I have consulted in this work, I have chosen not to identify diseases or glands by name when it comes to my own diagnoses, the diagnoses of others, or the professional realms of anyone I have consulted with on this project. Where these terms appear in direct quotes from interviews, I have redacted them in brackets: [gland], [diagnosis], etc. I have also redacted specific hormones as [hormone] when they could give away a particular

diagnosis in context. I realize that this makes my work less usable for anyone looking for information on a specific gland, disorder, hormone, or treatment path. However, due to the sensitive nature of this exploration, I have prioritized privacy over specificity. To include specific information on glands and diagnoses could leave the individuals I consulted vulnerable to deductive disclosure — wherein patternings of individual traits make participants identifiable, even in the absence of direct identifiers (Kaiser 2009). Scholars have noted the myriad ways that deductive disclosure has come to harm research participants, especially when the issues at hand are sensitive or stigmatized (Tolich 2004, Sieber and Tolich 2013). As the vast majority of people involved in this study are neuroendocrine patients (including myself), even disclosing too many of *my own* treatment details could inadvertently reveal information about other participants similar to me. Extra caution is warranted on all accounts.

That being said, when it comes to neuroendocrine conditions, glandular specificity can be hard to parse by default. One significant feature of the neuroendocrine system is that the hypothalamus, pituitary, adrenals, thyroid, ovaries, and/or testes are all inextricably connected. Red-rover one gland, and the whole chain buckles in response. In this way, neuroendocrine conditions are often characterized by multiple loci of pathology and intervention. Many times, neuroendocrine conditions overlap — problems with one gland often lead to problems with another. And it is these complex *interactions*, beyond the function or pathology of any one gland itself, that form the real focus of this investigation.

This complexity is also what makes neuroendocrinology such a difficult subfield of medicine. Specialists with extensive training in neuroendocrinology are not available in every hospital or every community. Because of this, it frequently takes patients years — sometimes

decades — to get an accurate diagnosis. Even after diagnosis, treatments (which can range from surgery, radiation, medications, and/or hormone replacement) are highly individualized and notoriously finicky to dial in. Symptoms and side effects are multifold. The inherent complications of neuroendocrine illnesses, when paired with geographic, social, and informational barriers to appropriate treatment, create something of a vacuum of understanding for many patients — a cavern of the unknown, in need of filling. In writing about chronic illness, Kalindi Vora speaks of this “uncertainty as a continuous cycle of symptoms and unease,” as medical uncertainty “leads some to despair, and others to cycles of self-tracking, self-diagnosis and self-treatment” (Vora n.d.). When the chemical messages of the body are scrambled, when specialists are hard to find, when 15-minute appointments leave little time for follow-up questions, when friends and family do not understand — where do patients turn for clarity and support? And when patients experience symptoms and feelings that might be mysterious, falling outside conventional diagnostic categories, where do they turn to make sense of themselves?

Objectives

This project explores these questions in the context of neuroendocrine support groups on Facebook, which I suggest serve as one venue of such sense-making. In these groups, I investigate how patients use one another to parse mind/body/social/hormonal experiences that are deeply felt, but also invisible, enigmatic, and easily misunderstood. I focus specifically on aspects of neuroendocrine conditions that conventional biomedicine struggles to fully capture and explain — symptoms that do not necessarily register in diagnostically predictable ways, as well as symptoms that blur the boundaries between physical, cognitive, emotional, and interpersonal experiences.

Drawing on my own experiences, observations of support groups, and interviews with experts, I examine the difficulty of pinpointing and finding help for these nebulous experiences, as they slip fluidly between chemical, emotional, cognitive, situational, and social planes. I ask how patients make sense of a felt experience that biomedicine might not explain in a satisfactory way, and how patients draw the lines around their own illness experience, strategically including or excluding the ways in which it ripples out into their personal lives — trying to both articulate the nuances of their own experience while remaining legible to the medical system on which they rely for care. Simply put, I seek to understand how patients make sense of themselves together, and make sense of each other themselves — especially as the lines around normality, facts, illness, psyche, feeling, and life context must be continually (re)negotiated.

To do this, I am dividing my analysis into two parts that each cover a major theme, or shared experience, within neuroendocrine treatment. Part One — *Facts* — focuses on evidence and medical legitimacy: how patients use Facebook support communities to plug the informational gaps in their own diagnosis and treatment paths, and the effects of these informational exchanges on people and their networks. Part Two — *Feelings* — focuses on the slipperiness between cognitive, emotional, and interpersonal experiences of neuroendocrine illness, and how patients decide to conceptualize or compartmentalize their experiences to suit their individual needs. In the end, facts and feelings are equally malleable, and bended toward a variety of strategic, emotional, and social ends.

Because of the tensions between felt experience and medically legitimized experience, I believe neuroendocrine disorders are a particularly rich way of illustrating the conceptual turmoil that biomedicine can engender through means of knowing and not-knowing. While

biomedicine has positioned itself as the gold standard for treatment for these complex neuroendocrine conditions (and it most certainly saves countless lives), what happens when there are experiences it cannot fully remedy or even explain? And how do patients (and communities of patients) come to embody the strange, jarring combination of evidence-based certainty pitted against the inner void of the unknown?

Methods

To answer these questions, I am combining my own autoethnographic reflections as a patient, ethnographic observations of neuroendocrine Facebook support groups, and in-depth interviews with group administrators (admin) and neuroendocrine patient advocates. This mixture of methods allows me to triangulate my own experiences with the experiences of other patients, as well as the expertise of admin and advocates who routinely interface between patients and the medical establishment. I include my own patient experiences to make my positionality transparent and my research inquiries tangible. As a counterbalance, I include interviews with “expert” voices to ensure that my analyses of patient group activity are not too distorted by my individual patient perspective. And as yet another counterbalance, I make sure that findings from my “expert” interviews are well-grounded in the voices and concerns of other patients themselves, as directly observed on Facebook. Thus, the findings I describe here are three layers deep: things I have experienced personally, things I have witnessed other patients talk about online, and things that seasoned patient advocates and admin believe to be important.

In-depth interviews with patient advocates & group administrators

The first phase of the project was to interview neuroendocrine patient advocates, as well as Facebook neuroendocrine support group admin — five, in total. There is no one way to be a patient advocate, and my interviewees conducted their work within a wide array of official and unofficial capacities. Common roles and responsibilities ranged from fielding questions from patients in need, referring individuals to the correct specialists, helping with insurance and disability claims, sharing emerging research, facilitating focus groups and support groups, moderating online communities, and serving as a liaison between the worlds of patients and doctors by attending conferences and (co-)authoring articles, op-eds, and scholarly publications. I anticipated that these advocates, immersed in the issue at many scales and in constant contact with patients, would be able to offer deep insight into the high-level "trends" related to neuroendocrine conditions. I asked specifically about the types of struggles and complaints they saw in patients over and over, the major stumbling blocks to appropriate treatment, and patterns witnessed in patient-centered online spaces (including Facebook support groups). While many online medical support groups operate in similar ways, the particulars of the medical condition at hand undoubtedly play a role in structuring a given community — how people come to discover the illness, how treatment tends to unfold, and the types of help certain patients might seek. I thought that beginning with deeply informed advocate perspectives would help me ensure that I was grounding my investigation in the most important landmarks of the neuroendocrine illness experience (beyond my own), and also provide guidance on what to look for in the groups themselves.

Interviews with advocates and admin were about an hour, semi-structured, and conducted over video chat. I asked each advocate and group admin about their backstory (which

frequently involves personal experiences in healthcare), then we talked about key aspects of advocacy and illness. I also asked them about their thoughts on Facebook support communities (including, when applicable, their own group), as well as the kinds of things they noticed there, and if they had curiosities or concerns related to how people use Facebook to connect with one another in a neuroendocrine support group context.

Notably, the admin and advocates I interviewed wore many hats and had a number of overlapping identities. Here is the breakdown for the different populations they represented. All participants are represented by pseudonyms, and I am not divulging the names of official organizations. All (deidentified) transcripts and code sheets were stored on an encrypted hard drive.

Sampling breakdown of interviewees & their experience

<i>interviewee</i>	<i>patient</i>	<i>advocate (professional)</i>	<i>fb group admin</i>	<i>expert (counselor)</i>
Brandy				
Candy				
Hope				
Liz				
Owen				

Ethnographic observations of Facebook communities

For the next phase of my project, I conducted autoethnographic observations of neuroendocrine communities on Facebook. Facebook is home to countless support groups for every medical condition imaginable. While these groups vary in size and style, they have

become incredibly popular resources for people to seek out information and support for their health conditions. Neuroendocrine conditions are no exception, and there are scores of available groups to join — some general, some particular to very specific diagnoses, some particular to lifestyle concerns (like fitness), and others still for spouses, friends, and family of neuroendocrine patients. Many of these groups have thousands of members (the largest group I observed had over 7,000 members at the time of this writing), making them a trove of ongoing community conversation. While there are other types of online support communities available to neuroendocrine patients (such as on Reddit, as well as other dedicated sites for particular diagnoses), I restricted my observations to Facebook for a number of reasons. Facebook is ubiquitous and widely used across age groups and geographies, its interface is familiar for most people (lowering the barrier to wide participation), and the consistency of the platform naturally helps make groups more easily comparable to one another. Furthermore, all group interactions are linked to people's individual profiles, which helps staunch the infiltration of bots and fake profiles and also offers a direct line of private communication to group members and admin via Facebook's direct messaging feature.

A brief review of online health communities

Health communities on Facebook have become their own particular object of study in recent years, in large part because the internet plays an outsized role in how people seek out health-related information and support. The internet is teeming with people interacting about illness — in forums, adverts, private groups, content marketing, how-tos, and email lists. And people use all of it. As early as 2011, the Pew Research Center reported that 80% of internet users — 59% of all adults — had used the internet to look up information about a

health condition (Fox 2011). One of many areas of interest for health media researchers has been online health communities — groups centering on a particular diagnosis, medication, or treatment — and how they influence everything from outlooks to outcomes. These health groups — often billed as support groups — show up all around the internet, from blogs to forums to social networking sites themselves.

There is a growing body of literature on Facebook medical support communities specifically. When Facebook rolled out its Groups feature in 2010, patients immediately started using it to organize communities around a variety of health conditions. In response, health researchers sprang into action, asking questions about what types of groups were forming, how people used the groups, what types of content were being shared. Even now, most work in this nascent field has been largely exploratory in nature, seeking to categorize rather than theorize online group behaviors. Early work on Facebook groups for chronic illnesses focused on analyzing the types of groups that exist for a given illness (De la Torre-Díez, Díaz-Pernas, and Antón-Rodríguez 2012) and defining the types of interactions and content present within groups — distinguishing between information-seeking and support-seeking behaviors (Koball et al. 2017; Zhang, He, and Sang 2013). Others have delved more deeply into the effects of participating in online health communities, proposing that such participation builds what Pierre Bourdieu (1986) termed “social capital,” which can in turn have a positive effect on health outcomes (Beaudoin and Tao 2008). Although it is difficult to generalize findings across a sweeping expanse of health concerns like cancer, diabetes, bariatric surgery, HIV/AIDS, and more, there is emerging consensus among researchers that these Facebook groups serve a variety of informational and social needs, and in some cases might have the potential to influence well-being and treatment. However, others note that the field is still fresh and argue that much more work needs to be done in

investigating group dynamics while improving evaluation mechanisms (Partridge et al. 2018).

Much of the work mentioned above probes for broad trends across a large sample of groups and/or posts. Although these broad quantitative categorizations of Facebook content are crucial to building out a body of literature for this field, such bird's-eye perspectives alone might pass over some nuanced particulars of what it means to be sick online with others. Additionally, while much academic discussion of Facebook illness groups is oriented toward their utility in terms of sharing information or mitigating isolation, many broader questions remain about the felt experiences of those who navigate these support communities. To that end, some online ethnographers have entered the fray to take a closer, more qualitative look at these group dynamics. In a virtual ethnography of people living with HIV/AIDS, Oliveira Neto and Camargo Júnior were able to identify key elements of the online experience of their subjects, namely the importance of supportive online spaces to reduce the suffering of alienation and stigma (2019). In an ethnography of Facebook groups for new mothers, Darryn Anne Wellstead explored Facebook groups not only as support systems, but “persuasive ideological spaces” that mothers used to confirm their own ideologies and bolster certainty in their parenting decisions (2020).

Following Neto, Júnior, and Wellstead, it seems safe to assume that illness groups might transect social and ideological dimensions, beyond merely seeking information and support. The relationship between a person and an online health group is complex, intimate, psychological, and embodied. I suggest that the social and experiential contours of a particular illness itself might actually shape the dynamics of a group, and that an

ethnographic investigation of neuroendocrine groups will certainly reveal complex ways of thinking, feeling, and knowing beyond the simple pursuit of health information.

Sampling & observational protocol

To conduct my virtual observations, I joined a wide variety of support groups for neuroendocrine disorders to get a feel for each community (and to see if there were meaningful differences between them). Although I joined close to 20 groups in my early explorations, I closely observed five Facebook neuroendocrine communities from October 2020 through April 2021. I approached this process fluidly, as I would as a patient seeking information for my own use. I used Facebook's search tool to find the groups, querying for terms related to particular glands and diagnoses. I joined the groups that ranked highest in search results — these unanimously showed robust membership, from around 800 to almost 8,000 members, and activity metrics (quantity of daily posts and interactions). All groups were listed as "private" and required a series of screening questions to confirm my identity as a patient, so I only joined groups that corresponded directly to my own diagnostic history. My observations were mostly passive — I liked a few posts here and there and made the occasional comment, but mostly observed. I kept a running journal of field notes for my own analysis.

Although I looked at countless posts and threads throughout months of observation in "the field," I have focused the major analysis of this paper on the top three groups with the most "activity" — not number of new posts per day, but number of comments per post. I believe that this type of activity would better indicate true group engagement rather than number of

new posts alone. From these select three groups, I consulted all posts throughout the month of April 2021 for close readings.

Ethics & privacy

I did not disclose my status as a researcher in my presence in the groups, for a number of reasons. First, it is logistically impossible to ask for (let alone secure) the consent of thousands of people linked to a Facebook community, all with different levels of engagement and different technological literacies. I also did not feel that receiving admin permission to conduct observations would serve as a proxy for real group consent, or a substitute for aggressive privacy protections on my part. There is also a deep, understandable suspicion of researchers in these groups, as my interviewees have reported that they are often targeted for infiltration by supplement marketers, pharma reps, and other "researchers" seeking information for hard-to-verify purposes. To protect the atmosphere of the groups and the integrity of this study, I decided that the least disruptive approach would be to not disclose my presence as a researcher, but to take exceptional precautions in protecting privacy. The observational portion of this project was deemed "exempt" from human subjects research consent procedures by the UC Davis Institutional Review Board (though verbal consent procedures remained in place for the interview portion).

At no point in this research am I making available individual names or other identifying information. However, even without citing this information, Facebook group content is still searchable. For example, if someone knew what group to look in, querying a phrase verbatim within the group's search bar could potentially reveal a post on the group timeline, which would be linked to the original poster's identity via their Facebook profile. To eliminate

any possible chance that someone could be identified at any point in my project, I have omitted all group names (and have replaced them with codes in my own records), redacted all specific diagnoses and glands referenced in observations (and interviews), and proposed to not directly quote any content found in the groups. When writing about Facebook group content in this work, I will refer to it in generalities only — giving a "feel" for the discussions without including any revealing phrases or details as they actually appear on-screen.

Even with robust precautions in place, I am aware of the ethical implications of conducting undisclosed research in these groups, many of which operate under the explicit expectation that they are for patient information only, and joining for any other purpose is strictly prohibited. Although I have full access to these groups as a neuroendocrine patient myself, my additional status as a researcher puts me in an ethical gray area. In determining my approach, I felt that a conventional protocol of (secretly) copying posts and comments from group timelines and pasting them into documents for offline coding would not be respectful to the privacy of the people at the very center of this story — the patients. Because of this, I opted to leave the content undisturbed in its natural environment, to conduct my analyses in-situ, and to only take my own observations away with me. I have also included an autoethnographic approach that weaves my own story throughout this work — tempering the inherently extractive research process with my own disclosures and allowing my own patient status to shape my process and inquiry.

Autoethnography

Instead of harvesting and coding the content I found, I decided to conduct my analysis more organically, in the exact same way most patients would — by simply reading a lot of

threads, following my nose, and making notes on what I found most interesting. In this way, I would try to make sense of my questions with the same rudimentary "methods" any other patient would use for theirs — the same methods I have really been using all along in seeking my own care.

Self-as-data

While I did not initially intend to include my own autoethnographic experience as a neuroendocrine patient in this work, I eventually realized the difficulties of ethically distinguishing my analyses as a researcher from my lived experience as a patient. Including fragments of my own story makes my own positionality clearer, and my findings more accessible. Navigating the complexity of medical information only is inherently fragmented, and without my own body in the mix, wholly abstract. As I have not received formal medical training, it would be disingenuous for me to pass off this work as anything more “objective” than my own experiences in and interpretations of the field.

A number of scholars have turned to the autoethnographic method for this very reason — the ability to use one’s experience, oneself, as data. Autoethnography blends personal experience with direct observations of the world, often emphasizing “personal narrative, story, the literary and the aesthetic, emotions, and the body” — (Adams, Holman Jones, and Ellis 2014: 8). As a somewhat literary or “performative” method, autoethnography also allows for particular ethical reflexivities. By not imposing (or presuming) immutable results from a particular event, autoethnography allows room for interpretation by simply “showing” the world as it appears to the researcher rather than “telling” the reader how to interpret it. This provides an openness to multiple, nuanced conclusions, and also helps to “provoke

critique, resistance and political action rather than appeal for agreement, conformity and indifference” (Redwood 2008: 1). In this way, autoethnography makes space for uncertainty, and the possibility of multiple knowledges and interpretations of complex phenomena (Adams and Holman Jones 2011).

Autoethnography also acknowledges that “knowledge about the social and human world cannot exist independent of the knower; that we cannot know or tell anything without (in some way) being involved and implicated in the knowing and the telling” (Douglas and Carless 2013: 84). This invites researchers to implicate themselves in their work and to explore their personal entanglements in a given scene. This approach is particularly significant in writing about healthcare, where scientific and expert opinions dominate the literature and patient voices are often deprioritized. Laurel Richardson argues that writing about one’s life can circumvent “the homogenized ‘science’ writing voice,” expand “strategies for knowing and telling,” and close the gap between work and life (2002: 417).

Closing the work-life gap here allows me to tap my parallel perspectives as patient and researcher. The questions I ask as a researcher connect directly to curiosities about my own treatment as a patient, and I offer my own patient experiences to “set the scene” for my inquiries and analysis as a researcher. This interplay blurs the researcher-patient distinction, especially given that my “research methods” of observing group conversations for social trends are functionally quite similar to my own lay-practices as a patient, wherein I observe group interactions to connect the dots surrounding my own condition. When I am poring over comment threads, I have found it hard to distinguish between my curiosities as a patient (*How do I make sense of my experience?*), and my questions as a researcher (*How are other people making sense of their experiences?*). It is equally hard for me to

separate out the "findings" from my patient self and my researcher self, as my experiences with my own illness are entangled with and informed by the words of others — lay and expert alike. But my takeaway is not that I am uniquely situated as both a patient and a qualitative researcher — rather, to seek insight as a neuroendocrine patient is, inherently, to practice qualitative research. Many patients attempting to figure out their conditions are likely already working through some version of this process: talking to specialists, reading peer-reviewed articles, consulting with peers, asking questions on forums, trying to comb through all of this information and integrate into some kind of conclusion that makes intellectual and emotional sense.

That being said, the “methods” I share with my fellow patients do not conveniently override researcher-subject power imbalances, nor negate the ethical fraughtness of this work. I am a patient *and* a researcher, and as such, I benefit from my findings in more ways than one. To those in the groups from whom I have consulted posts, comments, and questions and who have unexpectedly (though anonymously) become woven into this thesis, I must ask for forgiveness, rather than permission. I would fully understand if I never receive this forgiveness. But hopefully by offering up my own experiences in return, I am moving this work slightly more toward reciprocity, toward righting the imbalance of what counts as "knowledge" in medicine. I am throwing my body on the data pile, too.

Narration perspective

In this work, I engage with autoethnography by offering my own experiences as a neuroendocrine patient as a collection of vignettes. (While I kept autoethnographic field notes of my observations and interactions in the patient groups themselves, I do not include

autoethnographic accounts of my observations there in order to protect the privacy of the group members.) I do not, however, present my autoethnographic retellings as ultimate truth, nor myself as a “trusted guide,” to borrow the words of Kathleen Stewart. In *Ordinary Affects*, Stewart narrates her ethnography in the third person — she, the researcher, becomes a nameless “she” that serves as a “point of impact, curiosity, and encounter.” This removed “she” character “gazes, imagines, senses, takes on, performs, and asserts not a flat and finished truth but some possibilities (and threats) that have come into view in the effort to become attuned to what a particular scene might offer” (2007: 5).

Like Stewart, I seek not to offer my own experiences as the conclusive recounting of a situation, but rather to present them as a window into a still-unfolding scene. My autoethnographic passages are less about me as a researcher than me as yet another anonymous patient whose observations remain muddled and unresolved. For these reasons, I avoid the kind of first-person narration that is conventional to autoethnographic writing. However, in contrast to Stewart’s use of third-person perspective, I instead employ second-person perspective — transfiguring myself into an anonymous, entangled “you” — to simultaneously help defamiliarize my own history to myself while opening up my experiences to be more easily embodied by others. While I recount events as faithfully as I can in this work, down to my own thoughts in the moment, I use second-person perspective to situate the reader as the protagonist in the present, as my/their/our decision-making process unfolds.

I employ second-person perspective particularly for its intimacy and immediacy — a feeling-through of situations in real time. Those who create narrative role-playing games often employ second-person perspective to situate the reader as the protagonist while helping to

neutralize some barriers to identification and empathy (like age or race), thereby allowing the reader to more freely interpret the “story” for themselves firsthand (Starks et al. 2016). Furthermore, in a health context, the “primordial, human” second-person perspective may even help to “[deconstruct] the dichotomy of the expert third-person perspective of the clinician and the unreliable first-person perspective of the patient” by presenting a situation where “...neither the inaugural utterance or immanent goal of the exchange is fixed in advance or transparent to the participants” (Colapietro 2010: 70). Rather than recounting a scene as it happened, the reader experiences it as it happens. As precedent, Simon Paul Clarke provides an excellent example of second-person autoethnography in the health field. By flicking between perspectives of clinical notes (third-person), present-self as researcher (first-person), and past-self as psychiatric inpatient (second-person), and Clarke employs second-person perspective to create “dialogue with the reader” and reflect the experience of the “dissolution” inherent in the “dissonant experience of madness” (Clarke 2018: 257, 248). In this work, I take a similar approach in presenting my analyses as a researcher in first-person and third-person, while keeping my ethnographic vignettes as a patient in second-person. This allows me to switch between my dual perspectives on this subject while maintaining the integrity of my analysis.

Part One: Facts

You are a few months out from your second surgery. You cleared your recovery period with flying colors, and your last MRI was spotless. You've been told that as long as you stay on your meds and attend routine follow-up appointments, you can more or less live a "normal" life.

It's early fall, and you are traveling for work in a remote part of the state, piloting a new study. It's your first work trip since your operation, and the first time you've had to work overtime. You stay busy for three adrenaline-soaked days — whizzing up and down mountainsides with reams of surveys slipping around in the backseat, running trainings, attending meetings, and dropping off supplies.

After three days, you come home from your last meeting, exhausted. You know you overdid it, but so far it seems like you'll get away with it. You collapse on the couch and try to unwind.

That evening, you start to feel sick. And faint. Your muscles get weak. You suspect you're getting dehydrated. You call your surgeon's office and talk to the after-hours resident. He advises you to be seen at the local ER.

You call a friend who drives you to the hospital (you can barely sit up). You stumble across the drop-off loop and hand an efficient, caffeinated triage nurse your insurance card. You explain you've had a couple of recent surgeries. You ask for an MRI and some bloodwork. You're handed a cup for a pregnancy test. You're too weak to properly seethe. You find the

restroom. You stare in the mirror for a moment and wonder if you can even get pregnant if you wanted to now. You haven't asked. You've always had more pressing questions.

You go back out and sit in the vinyl chairs in the waiting room. No matter where you sit, you are facing a TV playing some version of Food Network. They are slow-cooking meat. You too, are meat. You try not to throw up.

You are finally invited back to a bed. You are told you are not pregnant. You lie on the bed for hours until the doctor comes by. It's around 2am. The doctor is adept and attentive, but doesn't really know what to do with you, given your history. Your vitals are pristine. Your lab draws are perfect. And by then, you've already started feeling better on your own.

Your friend drives you home.

In the following days, you begin to theorize: Why did this happen? What are the new variables? Stress? It has to be something to do with stress. Anxiety? Is anxiety the same as stress? You try to research how stress reactions play out in the endocrine system. WebMD is worthless. You use your university credentials to harvest a couple megabytes of PubMed articles. You know you don't know how to interpret them, but through picking out certain familiar words you convince yourself that you can make out certain relationships.

A few days later, you talk to someone from your surgery team on the phone. You appreciate her immensely because she always takes time with you and seems to appreciate your neurotic enthusiasm for self-tracking exercises. You tell her your new theories about stress and anxiety and rebound reactions involving hormonal processes you don't actually understand. She is very patient. She says they're interesting ideas (is she being nice?). She

also says that nothing you've mentioned really represents a trend she's seen or knows about, but you should keep paying attention. And that you should probably take it easy.

She was away from the office a few months prior, when you were getting your second operation. You were in the hospital for almost a week, throwing up your weight-gain milkshakes and crying and breaking out into a rash from the IV antibiotics.

Trying to comfort you, another nurse says, "You're young. You're healthy. You'll be fine."

...

Matters of facts

I have yet to receive or formulate any real answers as to why I ended up in the emergency room years ago. However, I have still had to structure my life around that gap in my knowledge, skirting it as if it were a deep crevasse cracked through the middle of a familiar street, invisible to all but me. I superstitiously avoid situations that might engender a similar biological reaction, and fret over symptoms that signal its possible approach. Even without a verified physiological explanation, I experienced physical proof that "something" is there — a ghostly presence that requires my caution and adaptation, lest the same mysterious cascade of hormone dysfunction descend upon me again. I monitor myself closely, and know when to keep to the sidewalks.

There is a gaping chasm between being medically fine on paper and intuitively fine in tissue. In the misty realm of neuroendocrine pathology, it is common to feel very poorly, but to test within normal ranges. This has come up over and over in my own story, and in the

stories of others I have encountered in this work. It usually means one of two things — that something else is off that is currently unexamined, or that “normal range” doesn’t capture the nuances of what an individual really needs to feel well. No matter the case, it tends to precipitate crises of understanding that must be reconciled.

Owen, an administrator of a large neuroendocrine community that I interviewed, spoke at length about his own experiences navigating, and eventually altering, biomedical goalposts.

What I've seen out there with endocrinologists is they have a book, they go by the book, they go by their training. If your results are within range, you're healthy. And I learned, working with my endo — my third endo — that just because it's in range does not mean it's in range for you. So, we worked diligently over a two- to three-year period to optimize my hormones, and how that meant for me. And then that's trying to get most of my hormones into the upper two thirds of the range. If we felt that wasn't right, reducing it a little bit, you know? And we tweaked for a long time until I got to the point where I feel probably 99% of who I was before. I don't think I'll ever be 100 and that's okay. I've accepted that. But to get to, to get to this place that I'd never thought I'd get to. By experimenting and trying and having a good endo who was willing to try new things that are, you know, new information.

I don't think I'd be where I am now if I was relying only on my doctors to do, and prescribe, and read my results and come back and say, "Yeah, you're in normal range, you're good." Well, I wouldn't be where I am now. So I had to fight to get to where I am now. And I'm trying to help others to fight to make their lives better.

From my interviews and group observations, Owen’s story touches on multiple layers of trial-and-error that make up a typical neuroendocrine treatment story — trial-and-error of finding the right specialist, trial-and-error of finding the right dosages, and trial-and-error of determining an ideal “normal range” that supports an individual’s quality of life. For Owen, this process took years. All trial-and-error processes involve error by definition. To knowingly embrace the expectation of error requires a certain degree of trust between patients and providers and often makes neuroendocrine treatment an uncomfortable process where encountering difficulty is expected.

In this section, I am interested in how people navigate this process while trying to determine what is really “fine” and “not fine” for themselves. I am particularly interested in how facts factor into this relationship, and how people seek evidence to validate their experiences. Due to the barriers of receiving proper neuroendocrine treatment (and the difficulties of dialing it in, even with a trained specialist), tensions between what should be fine and what actually feels fine are endemic to neuroendocrine conditions. This phenomenon is one aspect of how biomedical interpretations of wellness collide with personal intuitions and expectations of the body. From my firsthand experience and many of my observations, this collision detonates an explosive form of doubt that can be experienced internally as lacerating insecurity or externally as deep distrust of doctors and even the medical system writ large. One way to think about neuroendocrine support groups on Facebook is to see them as a forum to reconcile these doubts — either by shoring up the validity of an individual experience even when it goes unrecognized by the medical establishment, or by subjecting an individual’s experience to ever more granular inquiries — more tests, more drug trials — in order to *truly* determine the cause (and validity) of a particular experience.

These practices are important because accurate diagnoses are the coin of the realm, and lifesaving treatment is often impossible to access without one. Because of this, Facebook support groups are places where people can go to help identify and knit over the informational gaps in their own diagnostic tapestry. When an individual’s test results alone are not convincing enough to yield results from the biomedical institution, that person can take their individual data set to a group, where they have access to thousands of other stories. The odds are good in these communities that there are at least a handful of other people online who have had similar experiences. By soliciting these experiences, the patient seeking a diagnosis and/or particular treatment can borrow on the case studies of

others in bolstering their own claims of legitimacy, or in strategizing to find the right test to reveal the missing information that will render their experiences legible to the biomedical system.

Becoming the doctor

However, none of this is possible without some established baseline of what counts as medical knowledge. Conversations surrounding medical legitimacy are sometimes contentious. There exists a certain amount of what I have heard some advocates call “doctor-bashing” in these groups — while it is often against the rules of the group to single out and excoriate medical providers by name, comment threads are frequently peppered with frustrations related to negative experiences at the hands of healthcare professionals. I have seen many group members comment on how they were misdiagnosed, and some have reported that they almost died due to inadequate medical response to their condition. People talk about how they feel like the size of their lesion gets downplayed, or how they feel that they were inappropriately medicated, or how a doctor doesn’t seem to be connecting the dots properly between symptoms, or how they’ve been told they’re just depressed, or, of course, that their levels look fine and there’s nothing wrong.

However, despite widespread frustrations with medical providers, there are very few individuals I observed in the groups who seemed to defect from biomedical paradigms completely. In the three groups I observed closely, I have only seen the occasional supplement enthusiast get ousted from the community after plugging their brand of herbal capsules in a comment thread as a cure-all. In fact, the groups I observed closely explicitly describe themselves as evidence-based. All of them have rules that ban solicitations for

supplements and any other “natural” remedy without empirical research behind it. Some groups also ban certain phrases that correspond to what some may consider “pseudo-diagnoses” most frequently seen in the alternative health sphere. By and large, even when group members become frustrated with their treatment, I have observed that they often take it upon themselves to seek the information and evidence needed to improve their care, rather than seeking a new paradigm entirely.

One way to resolve the dissonance of having a felt experience but a lack of medical evidence is to seek more evidence. When it comes to complex neuroendocrine disorders that require precise intervention from the biomedical establishment, having a condition that registers as an official diagnosis can be the difference between life and death. However, these diagnoses require facts. In researching “contested illnesses” that one has to “fight to get” (in this case, Chronic Fatigue Syndrome and Multiple Chemical Sensitivity), Joe Dumit suggests that an inability to provide adequate “biological facts” can exclude patients from accessing treatment from the biomedical bureaucracy. In response to this gate-keeping, patients develop counter-tactics to organize with one another in mobilizing “facts” that will allow access to better care, or at the very least, medical recognition. Dumit (2006) notes that while the medical legitimacy and its reliance on categorizations of doctors and medical bureaucrats serves as a form of domination, patients subvert these categorizations by learning to frame their symptoms and conditions in precise ways, often in conference with one another. In other words, “patients often discuss in support groups and online the possibilities to take this increasingly mechanical form of diagnosis and use it to emplot their doctors, telling them exactly what needs to be said to get what they want” (ibid: 585). I suggest that while neuroendocrine conditions are more widely recognized diagnoses than Chronic Fatigue Syndrome and Multiple Chemical Sensitivity, their diagnostic complexity

likely gives rise to similar dynamics within online support groups. It is with this dynamic lightly in mind that I approach the following analysis, in assessing how "facts" are invoked and negotiated within these groups.

Testing patients

One behavior I observed frequently during my immersion in neuroendocrine Facebook groups is the practice of sharing test results for feedback from other patients. Sharing screenshots of actual test results and asking others to weigh in is common practice, and group members may make these posts at a number of points in their diagnostic journey. Patients that suspect they might have symptoms of a neuroendocrine condition (but might not have access to a quality specialist) might share early lab results when they feel like their primary doctor or hometown endocrinologist might be missing something. In these cases, other group members may offer a bevy of responses, from suggestions of other tests to request, to pleas to find a better specialist immediately. People well-advanced in their treatment might share results as well, often as context when asking a detailed medical question. Frequently, this happens when a group member is trying to make sense of new symptoms, or, as in the first case, is dissatisfied with their treatment or care team.

It is also common practice for people to share radiology notes from recent scans. When it comes to masses on glands, one particularly confounding facet of neuroendocrinology is that the presence or size of a lesion alone does not necessarily determine the kind of effect it could have on someone's system. Depending on the type and placement of the mass and the tissue of the affected gland, even small lesions may disrupt neuroendocrine function significantly. However, it is also possible to have lesions with little to no impact on feeling or

function. When a small lesion shows up in imaging results and a medical provider doubts its relationship to a series of symptoms, a group member may post their results to ask for feedback from other group members. Those who have had a similarly sized mass may weigh in, offering their own diagnostic experience as anecdotal data. The original poster can then reassess the perceived accuracy of their provider's assumptions within the context of others' experiences.

It bears repeating: neuroendocrine conditions are hard to diagnose in the best of circumstances. It must also be said that widespread awareness of neuroendocrine disorders saves lives, as it makes people more likely to identify diseases earlier in themselves and loved ones. According to the advocates I interviewed, doctors who do not see many neuroendocrine patients on a regular basis might very well miss early signs of such conditions. The interrelationships between test results are hard to parse, and the nuances of what to test for, how to test for it, and how to interpret the tapestry of results is not universally understood by every specialist. While a number of the advocates I interviewed expressed concerns over these Facebook support group practices of soliciting medical advice from non-professionals, they also acknowledged a real informational gulf in people's ability to find the care they need for the symptoms they have.

However, again, this is not to say that asking thousands of strangers in a Facebook group always delivers accurate results, and any group moderator worth their salt knows this. As an administrator, Owen and other group moderators in his support community try to intercede in these discussions when they can. As experienced patients, they know the complexities that go into getting a diagnosis, and they are also very aware of the

importance of context. Without proper reference ranges, test results are meaningless.

Experienced admin like Owen will ask group members clarifying questions when necessary:

A lot of it is, people come to you with some symptoms, and then they've got blood test results, and they want you to look at it. Well... We always have to tell people because they typically give you the results, but they don't give you the reference ranges that came with the results. So we always got to go back to them and say, "Well, every lab is different, give us some reference ranges to work with." And a lot of people want you to give them a diagnosis, and we can't. We're not doctors; we can't diagnose. We can tell you where we see something's off, that matches your symptoms, and suggest your path forward — you need to maybe go get these tests, talk to your endocrinologist, talk to your GP, whatever...

While realizing that it is out of his purview as a group admin to actually help diagnose group members, Owen still tries to help people home in on how to interpret their results accurately. Even though group discussions may not result in legitimate diagnoses, this discourse reinforces biomedical knowledge conventions and orients group members to the process of interpreting their disease in the same way a medical professional might. In this way, admin involvement actively ensures that group discussions hew closely to evidence-based understandings of neuroendocrine conditions.

In addition to moderating timeline content itself, admin and moderators must also guard their communities against infiltration. Ensuring that community dialogue stays focused and productive requires a combination of enforceable community guidelines and screening protocols. Hope, a Facebook admin and seasoned patient advocate with over a decade of experience, spoke at length about the importance of admin involvement in community timeline content.

So, I know people that have dealt with other communities, and they've told me that my community is special. You have to remember that my community is full of patients that have probably suffered more than what the average patient does. And I think that we have more empathy.

But I've been approached by some real crazies, especially when I used to, before we had the standard set of questions. I would reach out to any person that, that asked for entrance, and I would say, "do you or a loved one have [condition]?" And let me tell you I've gotten some... I've gotten naked pictures of people. I've gotten some crazy... Yeah, yeah.

Now there's a set of questions that they have to answer and if they don't answer them correctly, they don't get in. And I feel really bad, you know, especially if they are a true patient. And the group itself, um, we don't allow talk of politics or religion, because we're dealing with a, with a hormonal condition — you don't need to give people a reason to fight. And I'm often told, pretty much on a daily basis, what a positive impact our group has made on the lives of patients. And I, just last week, someone reached out to me and said, could you please teach others how to do groups like yours because your group is the best that they had ever been in. Because we don't allow fighting, you know? I've heard in some of the other [diagnosis groups]... there's tons of arguing and bickering, and we don't allow any of that. And our site is monitored 24-7, and we do everything that we can to protect the patient.

Hope and her admin team monitors every aspect of group life, from screening people on the way in to making sure that group conversations adhere to certain guidelines. She also posts articles from medical journals to the groups she moderates to help everyone access up-to-date information. This ensures that group interactions align with established medical conventions and discourse.

Admin say that this type of intervention is crucial to maintaining high-quality, productive dialogues in the group. However, even with stringent protocols in place, the ability to consult a community of patients as an informational database can quickly veer away from the evidence-based ethos of these groups. Candy, an experienced patient advocate who periodically engages with neuroendocrine groups to share resources and information about patient events, told a story of how group threads are vulnerable to misinformation and misinterpretation, depending on who comments and how.

...this is a perfect example of what I saw about a month ago. I popped online, and I was reading, and a gentleman had put his lab work up online. And it was a [hormone] level. That's all the information he gave. He said, "This is my [hormone] level. Should I be worried?"

You know, people start chiming in. Like they're frickin' authority, you know? And I look at it and it is borderline high. And so one that struck me the worst — the biggest offender, in my opinion — was a woman that chimed in and says, "No, you have nothing to worry about. I'm a nurse." Okay, that just gave him some kind of an authority. First of all, nurses know very little — almost zero, most of them, if they're not in the neuroendocrine field — about hormonal disorders and [gland] [diagnosis]. So right there, this gentleman doesn't know that, obviously, or he wouldn't have posted his personal information on a Facebook page. And then she says, "No, you have nothing to worry about. I'm a nurse, and I had [diagnosis] and my [hormone] levels were through the roof." True story, that is your perspective. And that is your story. But the fact that you are a nurse is irrelevant to help this gentleman, or to give any kind of advice on what that test means.

So other people are writing in, "Oh, yeah, it's not above normal. Ya-da-da..." Okay. Well, a) again, not true. You know, so I chimed in, and I said, "Well, with this amount of information, I want to tell you nobody should be giving you advice. We don't know your information. It's on the high side in normal — a) why were they testing your [hormone] levels? b)..." You know, like, there was just a whole list of things that nobody knows, to be giving you advice? And of course, people didn't like that, because they're like, "Well, I, you know, but..." Well, you know what? Again: not an authority. To me, that's part of the problem, not part of the solution.

And I realized the people doing it are not thinking that way. You know, they're thinking they're part of the solution — "Look at what I'm doing to help patients." But it's like what I say — it's the blind leading the blind, you know? There are so many aspects to helping patients. And none of them are by us giving any kind of advice, like, if their lab results are right or wrong, or if their surgeon said this or that, because we don't know. I found to be... There's 100 different sides of the story. And on social media, we don't get that.

When shared to a group, test results and radiology notes serve as a form of “evidence,” but one open to endless interpretation. This creates something of a biomedical paradox — while diagnoses require “evidence,” usually in the form of imaging or test results, this evidence also requires interpretation. And interpretations can vary widely — between specialist and specialist, between specialist and patient, between patient and patient. When it comes to complex neuroendocrine disorders, doctors and patients can sometimes be

grasping different parts of the invisible elephant — primary care doctors are immersed in the practice of medicine and have deep knowledge of other systems of the body, but perhaps little direct experience with neuroendocrine conditions. Patients in neuroendocrine Facebook groups are deeply immersed in the data and stories of thousands of people with conditions similar to theirs, but might lack other medical literacy or analytical tools to make sense of it.

Brandy, an interviewee with experience in patient advocacy at a global scale, described health literacy as a key stumbling block to patients being able to make sense of their own conditions and treatment.

...they ask the group, which is always, you know, medical mumbo-jumbo. And unless you have a degree in medicine, or you are a patient advocate, you have no idea what they're saying. You really don't understand. And so they say, "So what is the doctor saying?" "Okay, let me get my medical degree out. I'll try to say it in lay language." So, yeah. I don't agree with this thing of sharing your medical results.

Well, it's a long process, but then I would say, okay, ever heard of health literacy? Learn to be informed. ...Literacy means being able to understand something as simple as reading the — what do you call it, not the instruction booklet, but the leaflet. The leaflets in the medicines. Now, the majority of the people a) don't read that, b) sometimes they don't understand what is written. So why don't we start health literacy from that? ...I mean, where do you go, if you have a feeling, if there are adverse effects? Who do you call? Ghostbusters? No, I don't think so. So, if something is happening to me, because usually all the medicines contain at least 15 different side effects or things that can happen... So I go in, I read this, and I find one of my symptoms in it, it's okay, that's fine. But if I didn't have that?

Although Brandy recognizes that there are major holes in many patients' understandings of their condition, she's also leery of people seeking information from non-professionals in online group settings. To her, it is safest to go straight to the source — reading prescription information and learning about potential side effects — rather than consulting a group that could provide a myriad well-meaning but potentially uninformed opinions.

What facts matter?

Whether a post or comment in these groups is ultimately “informed” or “uninformed,” “true” or “false,” these groups, by and large, respect medical knowledge and prioritize evidence-based treatments. The discursive work that unfolds within each group is rich with the types of facts that the biomedical establishment accepts as legitimate. In alignment with Dumit’s (2006) work on “illnesses you have to fight to get,” these communities do seem to approach such facts strategically — organizing themselves around soliciting and verifying the types of medical facts needed to secure appropriate diagnoses and treatment. But strangely and ironically, these groups have seemed to form as a response to biomedical uncertainty itself. When a doctor cannot provide an answer, the question is brought to the group. But often, that question is broken down into ever-smaller biomedical inquiries — what about this level, this test, that drug? Have you talked to this specialist, that specialist, a psychiatrist? When there is not a doctor who can provide a big, integrating overview of someone’s experience, they in turn seek it out from thousands of “doctors” in the form of group members, each operating at micro-scales. The search for answers and integration leads, more or less, to ever more fragmented lines of questioning and understanding. Undoubtedly, some answers have emerged from this process. And for those without access to quality care, these are certainly important resources. But they, by nature, are just as fragmentary as the system that initially failed them.

I would hazard a guess that in a world where every neuroendocrine patient was able to get a swift, accurate diagnosis, plain language explanations of their conditions and their treatment, and world-class care, these support communities would look very different. Likely, they would mostly be about, well, support. But the informational slipperiness of

neuroendocrine diagnoses has led to the formation of groups with their own informational slipperiness. One way to think of these groups is as the inverse image of biomedical knowledge — people rushing to fill in the gaps in what their doctors cannot tell them. But, at the same time, perhaps they are a hall of mirrors — reflecting and refracting and endlessly repeating and hashing out the same uncertainties that led to their creation.

In documenting medical discourse surrounding the AIDS crisis, Epstein (1996: 17) speaks to how biomedical uncertainty engenders certain social and political reactions: he speaks to the power struggle that occurs when “the normal flow of trust and credibility between experts and laypeople has been disrupted.” In these credibility struggles, Epstein describes “the constant attempt by different players to rephrase the definition of ‘science’ so that their particular ‘capital’ — their forms of credibility — have efficacy within the field.” In turn, these negotiations of credibility serve “as mechanisms for the management and resolution of scientific uncertainty.” Importantly, though, Epstein notes that science cannot usually “settle” such a controversy through simply producing more facts, and that “uncertainty is often not just the cause of scientific controversy but its consequence” (ibid: 333).

Controversy — here, the lack of biomedical answers — animates the experience of diseases that are not thoroughly understood institutionally. Neuroendocrine conditions, in many ways, are a medical world apart from the AIDS crisis. But it is worth noting that similar social dynamics may be in play when biomedicine is unable to produce satisfying answers or treatment outcomes. This is visible in how people leverage their own anecdotal experience and the experiences of others in negotiating for their care, and how biomedical strategies (seeking additional scans or tests, asking for different drugs) comprise a large part of these negotiations. However, in stark contrast to the visible activism in response to

the AIDS crisis, neuroendocrine “controversies” — where they exist — are diffuse, existing among a small group of people with an extremely rare disease, or even within the confines and ambiguities of a single, medically uncooperative body. While patient activism and discursive tactics for building legitimacy surely cut across health conditions, neuroendocrine disorders do not represent a culturally legible “epidemic,” and their advocacy does not represent a political movement in the way AIDS activism does.

In this way, perhaps each neuroendocrine patient represents a movement of one. Although online patient networks are rich in the experiences and strategies of others, each patient ultimately has to square off against medical uncertainty alone — in their dealings with family and friends, in their appointments with their endocrinologists, in making sense of their own experiences. When I asked the advocates I interviewed what makes people gravitate toward Facebook support groups, they unanimously mentioned patients’ driving need to not feel alone. Within Facebook support groups spaces, they certainly are not. But in the context of their actual treatments and offline lives, it is much harder to say.

Part Two: Feelings

You think you've changed. No one else has really brought it up, but you feel sure. People say that illness is stressful, surgery is stressful. But everyone passes through stress. This isn't that.

You lose things now. Your memory was always good, and now you just put sunscreen on your toothbrush. You find your wallet in the fridge. You are not sure where the time goes. One day, you catch yourself staring at the wall and realize you'd been sitting there for well over an hour. Years down the road, you will boot up an old hard drive to find gigabytes of files from your surgery year that you have no memory of working on. Time slips by you easily, but people don't. They abrade you more than they used to. Everyone always said you were patient. It feels like you lost that too.

There isn't really anyone you can talk to about this. You learned that it freaks other people out. "You still seem like yourself to me," they say, instantly, without even considering another possibility. It feels much more like fear than kindness on their part. To them, of course you still seem like you, but you know they're just filling in the gaps with ideas about the person they knew before. You think back on when you were little — learning the constellations at the planetarium — and scoffing. There are infinite pictures you can make by connecting the same group of stars. And you can call anything a bear, if you want to.

You struggle to articulate these new changes to yourself. You try on different ways of explaining it. It is difficult to capture a nebulous chemical phenomenon in the act of becoming a feeling. Every feeling you have has some other alibi. "Maybe this is because I'm

tired.” “Maybe I am bad at grieving.” “Maybe I actually am just stressed.” But patterns are patterns. It takes you years, but you slowly arrive at your own explanation.

If you were to explain it to someone, you would say this:

Envision your emotions spread out on a map. You are familiar with this map — you've been using it to orient yourself for your entire life. You know where the major territories lie, and eventually you figure out the different ways of passing between them. After a while, you come to know what it's like to be in sadness, and you get better and better at plotting out the gradations of terrain around it — disappointment, worry, numbness. You know that happiness is a long way from there, but if you take certain paths, you can eventually reach it. Every realm is distinct — anger, joy, excitement, envy. They are ordered predictably in space, and the journeys between them are well-trodden.

You would then say:

So, a hit to the neuroendocrine system is like having your emotional map cut up and rearranged by a preschooler with safety scissors.

Now, you are lost. The feelings themselves are the same — you can recognize each emotion you're in, when you're in it. Anxiety still feels like anxiety, like it always did. But you have no idea how you got there, or which way you might go to leave. The usual paths lead to different places. The proximities between feelings are suddenly scrambled — it makes no sense why certain things are suddenly next to one another, why one feeling abuts something entirely different. Regions that used to exist as entire discrete geographies are suddenly shredded and scattered in next to everything else. There is a little bit of numbness

next to everything. You are never too far from incandescent angst. You take a few steps, thinking you'll be one place, and suddenly you're somewhere different, marveling at what you've just heard yourself say out loud. You might not know why you laugh, or why you suddenly can't cry. And soon enough, vice versa.

You try to be your own cartographer, but you are starting from zero and you don't even have an outline of the continent to fill in. You've even lost your boundary, the outline of you.

...

Catching feelings

In my experience, to make sense of a neuroendocrine condition is to require multiple levels of somatic translation. First, you have to track how chemical changes manifest as new patterns of feeling. Then you have to track how those new feelings interface with your ideas about yourself, your relationships with people around you, and, should you desire treatment, various disciplines such as biomedicine, psychology, and psychiatry. Ultimately, each of these negotiations hinges on *someone's* ideas about neuroendocrine illness — ideas about what it is and is not, how far it stretches into a person's body and social world, and the effects it is ultimately responsible for at every scale of life.

Though I think it is futile (and often dangerous) to try to disentangle the “physical” from the “mental” or “emotional” when it comes to matters of sensation or feeling, for the purposes of this analysis, I will pay particular attention to things like thoughts, feelings, relationships — things more or less encapsulated in the now-ubiquitous phrase “mental health.” It is an expression I use here in service of convenience, rather than utmost accuracy, and also

because I have found it to be common parlance throughout both my interviews and observations. In that spirit, I will reference these issues using people's own terminology, and following the logic of Facebook communities and my interviewees as they seek to tease these things apart, or weave them together, in relationship to their own concepts about neuroendocrine illness. From my observations and interviews, it appears that people have many different opinions on what felt experiences their neuroendocrine condition is directly responsible for, and what types of support they feel entitled to. Ultimately, the boundary work of suturing (or releasing) nebulous emotions to or from a neuroendocrine illness experience seems to have deeply impacted how people conceptualize their own healing.

But first — while still amorphous, it is not as if these hormonal-emotional linkages are wholly undocumented. Liz — a marriage and family counselor who also writes and speaks about neuroendocrine issues from a therapeutic perspective — spoke to her own experience with this, as well the growing interest on both sides of the biomedical and mental health fence in better understanding the complex relationship between hormones and mental/emotional health.

Many, many of the people I've spoken to report that their earliest symptoms after they got diagnosed, and they looked back... And oftentimes this is years, sometimes decades later. The average [diagnosis] patient still to this day takes eight to 10 years to get an accurate diagnosis. That's ridiculous. But many people are much, much longer. But many of them will say that the first symptoms were mental health. The earliest symptoms. Obviously, they didn't know it then. They didn't know what was going on.

And anecdotally, I have just... I've talked to so many patients and family members who talk about major depression, mood swings, anxiety — those are the biggest ones, mental health-wise, that co-occur with these disorders at such an alarming rate and aren't being seen by the medical professionals or acknowledged. Because that's not their area of expertise, and they don't even ask, oftentimes. And so a lot of patients are left feeling crazy, or like they're inventing this, that it's all — not to use a pun — all in your head.

A lot of times the surgeons will say, "I did my wonderful magic, goodbye, that's it." And, people are left with their lives in tatters and they don't feel healed. They may feel physically better, but their lives are terribly impaired. And some of that is the direct, as well as the indirect result of the disorder itself.

Liz's practice has developed around the overlap between "physical" (hormonal) and "mental" health, and she has counseled people dealing with neuroendocrine conditions throughout their diagnosis and treatment paths. Interestingly, while there is clearly enormous carryover between mental and physical health in neuroendocrine conditions, Liz also notes that these mental health effects may be "direct" (via a hormone [im]balance that affects mood) and/or "indirect" (as a product the isolation and stress brought on by any major disease or surgery). Both processes affect how a person feels, but the boundaries between those processes are blurry. Liz notes that while the mental health impacts of neuroendocrine conditions are increasingly well-documented and well-understood, there is not yet, in her words, a "clear and simple line" between emotions and particular neuroendocrine diagnoses.

This is once again because neuroendocrinology is complex, and physical and mental effects of a condition are contingent upon interdependent relationships between glands across the body. But even more than that, one person's emotions can ripple out to affect their social life as well. When one considers how an individual's neuroendocrine system links up with the neuroendocrine systems of others — and eventually the social system — the concrete emotional effects of a disease become even harder to attribute to a single physiological process in a single body. As a mental health practitioner, a large part of Liz's own understanding of (and interest in) neuroendocrinology stems from this complexity.

My training was in marriage and family work, which is relationship work. And which is different than strict psychology. That was my hook in getting really interested in this

way back when... When it was described that the HPA axis was a system in the body. And that caught me, because my training is in systems theory, and relationship systems, family systems, how they, how we become connected to one another. And I started to realize, "Whoa, that internal system connects to the external system." And vice versa. You've got family relationships, you've got support, whatever, it's going to help calm that inner stress response. So it is a reciprocal system.

So that was my hook, really, because of my training. And, and so and again, most doctors — Western medicine — looks at a patient, individual patient, individual doctor, individual treatment, as opposed to maybe also asking, "What is your support?" "Who else has been impacted by this?" "Have you had a job, are you able to function at work," you know? "Has your boss fired you because they don't understand this either?" That's all part of the system. And so when I write, when I speak, I try to involve all of that. And I'd say more and more physicians are beginning — the top physicians are beginning — to acknowledge that maybe there's something to that. Rather than that simple one-than-the-other, than-the-other kind of thing. It's kind of broader than that.

From Liz's perspective, understanding the layered interrelationships between neuroendocrinology and emotions is important to receiving adequate treatment for both. By this logic, it is easy to trace how a disruption at the chemical level could ripple out into disruptions of feeling and keep rippling out into disruptions of social systems. In observing neuroendocrine support communities on Facebook, I was curious whether and how these complex diseases would begin to manifest socially. I paid particular attention to how patients described their "mental health" and social concerns, and to what extent they seemed to identify them as part of their disease or not. In alignment with Liz's commentary, I observed a large number of posts in the support groups that spoke of emotional, mental, and interpersonal challenges. However, while the presence of these types of challenges was omnipresent at all times and in all groups, discussions of them varied greatly.

Mental health, together

In observing neuroendocrine Facebook groups, I saw patients use posts and comment threads to talk directly about their mental health challenges, referencing issues like depression and anxiety in both their posts, and in their comments back and forth to one another as they compared treatments and experiences. I noticed that these invocations of “mental health” concerns were frequently listed alongside other “physical health” symptoms as people described their experiences. A number of group members even reassured one another that things like depression were a common, documented part of the disease, and to still try to seek help for it. However, while even a cursory skim of these group timelines would seem to indicate that mental health concerns are a major part of the neuroendocrine illness experience, some group members seemed to struggle with getting the care they needed for those aspects of the disease. Interestingly, group members reported problems with doctors who would not recognize their mental health symptoms at all, while others reported problems with doctors who recognized symptoms of depression and anxiety but refused to see it as a part of the disease — passing the patient off to a mental health specialist as if their complaint were an unrelated diagnosis.

Group members also reflected on how their conditions affected their social and work lives. One particularly prominent theme was people “venting” about people in their own social circles — friends, spouses, and/or family — who did not seem to fully understand their condition or appreciate their struggle. Sometimes patients would post memes about common misconceptions about chronic illness, which would be swiftly trailed by a long string of comments. In such threads, many group members offered messages of affirmation and encouragement to one another. Since managing a neuroendocrine condition can

involve an array of life changes (from diet to managing physical exertion to needing to take particular medications at particular times), many group members seemed to struggle with close relationships with people who were not properly acknowledging how their condition made them different, or in need of accommodations. Many talked about how their friends and family seemed to write them off as lazy or self-pitying without trying to understand the chronic exhaustion that commonly accompanies a complex neuroendocrine condition. Some people talked about unforgiving bosses, unaccepting spouses, and some even went as far as to say their disease destroyed their entire life.

In these mental health threads, many group members affirmed one another's stories with *yeses* and *me toos*. Overall, there seemed to be a broad consensus on the types of experiences neuroendocrine conditions might engender when it comes to mental health and relationships — in the group threads I observed closely, I never saw someone question another person's mental health story or accuse them of dishonesty. However, while most seemed to agree that neuroendocrine conditions are responsible for a wide (almost infinite) range of social conflicts and mental health effects, I also noticed that there seemed to be varied interpretations of what a neuroendocrine condition actually *is or is not*.

Ideas about disability and illness

Thus is the paradox of these groups and neuroendocrine conditions in general. Most group members certainly have a general sense of the types of effects their condition(s) might engender. However, they (and sometimes even their doctors) might not know all the mechanisms by which these effects are caused, or how to precisely delineate the boundary between what is neuroendocrine and not (whether or not such a distinction is possible).

Although I never once observed a heady, academic discussion on the true nature of neuroendocrine disease, I did see a number of ad hoc attempts to hash out understandings of disability and illness. These discussions cropped up somewhat unpredictably. Conversations about disability seemed particularly rife for these types of disagreements. Sometimes disability would be the primary subject of the initial post, with people wondering about what benefits they might be entitled to if they were to try to file. However, conversations about disability also started organically on other types of threads as well, including those related to mental/emotional health and overall life disruption. I noticed one thread in particular get derailed by a side conversation between an admin and a patient (not the original poster) disagreeing on whether a particular neuroendocrine condition was truly a “chronic illness.” (It most certainly is in medical terms, along with any health problem lasting over 6 months.) But interestingly, in these discussions that invoked charged phrases like “disability” and “chronic illness,” most people did not seem to converse using standard definitions of the terms — medical or legal. What I noticed was more of a series of personal interpretations of these ideas, likely based on individual self-concepts and values.

The opinions were diverse, but they traversed between two poles. On one extreme were patients who seemed to believe that there are no limits to the disruptive potential of a neuroendocrine condition. These patients emphasized that the illnesses are lifelong, and without proper medical intervention and access to drugs, deadly. These people also did not hesitate to name their diagnoses as serious chronic illnesses — permanent features of their lives, regardless of the ups and downs of treatment. I saw patients in this camp react strongly when they perceived others to not be taking their illness as seriously, and fiercely defended their claims with links to articles and research studies talking about the effects of neuroendocrine illness. It is possible that these perspectives may stem from the fact that

diagnoses can be hard-won, and that patients who've fought tooth and nail to legitimize their condition are reluctant to have it discounted as anything less than a serious illness.

On the other side of the spectrum were people who acknowledged their health challenges, but were very opposed to being “defined” by them. Patients in this category seemed reluctant to use phrases like “chronic illness” or “disability” in relation to themselves. Many of these patients were successfully managing their condition through medications and other treatment, and seemed to think that this successful management (and the life of relative normalcy it allowed them) meant that they weren't living with a “chronic illness” or “disability” at all. To them, illness was a particular felt experience rather than a diagnostic category, and they had already moved past it to something better. Interestingly, though, one would assume that these patients *did* have some attachment to their diagnosis, given their presence in and involvement in the groups defined and moderated by that diagnosis. Their reactions show that some people are able to separate their specific diagnosis from more general ideas about “illness” that are laden with the subtext of suffering and limitations.

Suffering & strategy

These differing perspectives on illness reveal a wide gulf in perception about the perceived boundaries of a neuroendocrine condition. It is worth considering, though, what might lead people to approach their condition in such different ways, and to what ends. Candy, over decades of advocacy work and observation, has developed her own theory about this.

First of all, there's two types of people that I've learned. I mean, there's lots of types of people, but I mean, for this particular question, there's two types. I deal [with] a lot of patients that come from all over the world. And from multi-billionaires to whatever. Those people do not go to social media, AT ALL, for their medical advice, or for their

mental health advice, or coaching, or whatever it is, you know? Those people are always going to seek medical professionals or things like that.

I guess there's really three types. So there's that type.

Then there's the other ones that go to social media, and not their doctor, because they may not have good medical insurance, or maybe they live in a small town or an area where they really are not seeing neuroendocrine experts anyway. So they're going and getting very, very little information. They could ask, and the doctor looks at them like a deer in headlights, because that doctor just doesn't know. So that patient gets tired of asking and not getting any answers. And that patient then goes to social media, because now they've gotten attention, and their needs are probably being met to a certain degree, good, bad or otherwise, you know? But I guess it's better than not having any anyone listening or anyone helping. That's that extreme.

And then there's a broad band in the middle, where... So those ones I've noticed, they'll go to their doctor. And they will make a lot of educated decisions based on medical, sound medical advice. But perhaps something is going askew in their life also, or maybe they don't have the skills for critical thinking. And they don't understand the difference between critical thinking and just getting an easy fix. And those people, maybe they don't have the skills to compartmentalize what part that they need to not lump into this disease. And so when that happens, they do go to a doctor, the doctor starts giving a medication a lot of times because, you know, [the patient has] anxiety, they have this or that... And unfortunately, you get five minutes of their time there. "Here's the prescription." You know?

And then that person takes that information and goes to the internet. Because now: validated. "Yep, I have every right to say it on the internet, because this is what my doctor said. And now I'm going to tell you that that's what you should do too."

In Candy's observations, some people strategically fold their mental health and interpersonal problems into their neuroendocrine diagnosis for a number of reasons — to elicit sympathy, to be taken seriously, or perhaps to delay some painstaking inner work. Then, the medical validation they receive from their doctor in the form of medication or other treatment, however (in)accurate, gets fed back into the group as community data. Notably, in contrast to the patients I observed firsthand who reported struggling to get their doctor to integrate their mental health concerns into their neuroendocrine diagnosis, it also appears that the opposite is also true: some patients have found success in negotiating for their

mental health care by strategically invoking “mental health” concerns as *inherent* to their neuroendocrine condition. This allows them to access medications and treatment options that might not have ordinarily been within reach, had the “mental health” symptom not existed within this neuroendocrine context. Interestingly, in those cases, it is the fact that neuroendocrine conditions do *not* tend to be deeply understood by most non-specialists that allows them to serve as leverage for patients seeking particular forms of care. Although medical attention may at times be withheld from patients by medical providers due to deficits in understanding and evidence, apparently, these deficits can also serve as access points to care as well.

This again points back to the types of social actions and individual strategizing that gaps in “legitimate” medical knowledge engenders. Between my own observations and the deep experience of the advocates I talked to, it appears that the issue of whether a mental health concern is “legitimately” part of a diagnosis is highly contested, rife with conceptual turmoil, social discussion, and even medical strategizing. But it is worth considering the effects that these ideas and strategies might have on someone’s treatment outcomes. Although Candy fully recognizes that mental health plays a large role in any neuroendocrine recovery story (and advocates for hospitals to incorporate counseling into standard neuroendocrinology care), she believes that there are dangers of wrapping every life problem into a neuroendocrine diagnosis. Doing so can result in patients seeking treatment for symptoms rather than underlying causes and can result in confusing messaging in support group forums.

On the other hand — as evidenced in Candy’s “first type” of patient — some people may choose to distance themselves from their diagnoses in order to compartmentalize it into

nothing more than a separate problem, manageable through the correct intervention. The wealthy businessmen she speaks of do not seek to offer up their illnesses for community discussion or support, instead preferring to handle them privately with the correct specialists. Owen, a group admin, has noticed a parallel trend in how some people seem to stop engaging with his group over time. He talks about how he's noticed people "graduate" from his group once they attain a stable treatment path.

I guess there's still a few patients that we have that are 40 years into this illness that still feel horrible. But a majority get better and then they disappear from the groups, you know, the support groups. So that's kind of how you see it, right? They're not talking anymore, they just kind of fade away. And that's good. That they find their peace, and that makes me happy to give someone some peace.

In these scenarios, people who no longer need support from patient groups no longer seek support. They simply move on. While there are undoubtedly many motivations for a person choosing to leave or stay in a group at any point in their treatment journey (and such decisions are beyond the scope of this work), one might conjecture that for such patients, a support group served as a temporary source of support when it was needed, and not a permanent venue for engaging with illness as a durable facet of identity. It is even possible that patients' ideas about illness are fluid throughout the treatment process. Early on, proving the veracity and seriousness of an illness is crucial to receiving timely intervention. But perhaps later on, once it becomes possible to restore some semblance of life balance through appropriate treatment, these allegiances to illness become less crucial. In any case, it is possible that a person's ideas about illness are modulated by certain needs that are more intense at certain times — needs to be taken seriously by doctors, needs to be taken seriously by friends, needs to solidify a personal identity. These needs are both fluid from

individual to individual, and possibly fluid over time. These perspective shifts — and the online community dynamics they engender — warrant close, longitudinal study.

What *feels* important?

Even from this preliminary investigation, the way a patient draws boundaries around their own neuroendocrine condition appears to be incredibly important, affecting treatment options, community support, and even the development or maintenance of a particular self-concept. This fluidity with which people seek or do not seek to implicate their emotions, relationships, and lives in their neuroendocrine condition speaks again to the seriousness of properly treating these complex conditions in a way that truly serves the individual. In writing about non-consensual surgeries on intersex children, Katrina Karkazis (2008) speaks to the fraughtness of overlaying medicalized determinations of identity, and the importance of catering to a full spectrum of human variance in medical practice. To this end, she asks two very important questions worth borrowing here. The first: “Who has the authority to determine what constitutes a good result in medical treatment?” And the second: “What are the legitimate boundaries of medical intervention, especially regarding treatments meant to address social, rather than medical, difficulties?” (2008: 16) In an earlier exploration on intersex children and surgery, Suzanne Kessler notes that many surgical interventions, in one way or another, are knee-jerk reactions to uncertainties and anxieties — many of which are social (1990).

Although directed at the institutions that seek to medically manipulate “biological sex,” these issues have undeniable salience for the neuroendocrine realm, especially when neuroendocrine disturbances ripple so readily out into the social realm, in the form of

shifting moods and strained relationships. Since neuroendocrine conditions are also rife with uncertainty and similarly trouble the waters of emotional and social experience, it would make sense to consider those arenas of experience in determining ideal treatment outcomes. More than that, I suggest that it may be a valuable thought experiment for anyone involved in neuroendocrine care to consider what happens therapeutically in redrawing the boundaries around a neuroendocrine condition differently.

To do this, we must consider the existing therapeutic practices and boundaries implicated in neuroendocrine treatment. Annemarie Mol provides a praxiographic template for how this might be conducted. In *The Body Multiple* — a detailed ethnographic investigation of atherosclerosis treatment — Mol (2002) describes how a single disease is differently enacted through a diverse array of medical procedures: physical examinations, radiography, surgery, bloodwork, autopsy. While the disease in question remains constant through these investigations, the way in which it is felt, visualized, and literally peeled apart results in seemingly divergent types of data and interpretations of a medical condition. A radiologist peering into a vein has a very different vantage point into a disease than the general practitioner inquiring about a patient's leg pain, and while the two practices overlap in a person's therapeutic story, they may each also invite different types of intervention (surgical removal of the arterial obstruction in the first case, versus walking therapy in the second). Mol describes how this "ethnography-of-a-disease became a study into the coexistence of multiple entities that go by the same name," and suggests that these very medical practices not only describe but interfere with what we understand as medical knowledge. In this way, "knowledge is no longer treated primarily as referential, a set of statements *about* reality, but as a practice that interferes with other practices. It therefore participates *in* reality" (Mol 2002).

By Mol's logic, it is impossible to extricate the practices of diagnosing, naming, visualizing, and treating a disease from the disease itself. However, throughout her meticulous investigation, Mol was aggressive in limiting her analysis to a single condition in a single hospital. Even within that limited scope, she found a seemingly limitless array of ways to conceptualize a comparatively straightforward condition through a range of diagnostic and therapeutic modalities. If we were to apply a similar framework to neuroendocrine conditions — which arguably implicate a much wider array of specialists, departments, facilities, and therapies than atherosclerosis — we may quickly find that there are too many “versions” of even a single neuroendocrine diagnosis to even make sense of.

But the possibilities are worth considering. How does a neuroendocrine disease appear to a family doctor? To a neuroendocrinologist? To a surgeon? A counselor? A psychiatrist? What is it through an endoscope, a vial of blood, and MRI? What would change if one were to view a neuroendocrine disorder as a primarily psychological condition, versus a physical or biochemical one? Or a social condition? In that case, what issues and outcomes might be foregrounded instead of the usual scans and test results? Would one pay more attention to a patient's affective experience in those cases? Would one move more swiftly in providing for a patient's holistic quality of life?

These questions certainly seem to lead to more fragmentation, on the surface. I am not advocating for doing away with scans and test results, nor do I mean to suggest that an ideal neuroendocrine treatment path is one that narrows in on certain realms of pathology at the expense of others. And perhaps most importantly, I would never campaign for a version of endocrinology that aggressively dissects and pathologizes each and every “non-normative” aspect of a life: medical, social, or otherwise. However, I would like to suggest

that ontological multiplicity, in the context of neuroendocrinology, could perhaps render these complex health conditions visible, tangible, recognizable in new ways — allowing doctors to see diagnoses in patients and patients to see themselves in diagnoses with more accuracy and compassion. Conceivably, simply changing our vantage point on what a neuroendocrine condition “looks” or “feels” like — or just recognizing that such perspectives can be easily cycled between — could provide some conceptual relief. In the end, acknowledging that our medical knowledge — to the best of our knowledge — is multiple, might leave more room for patients to acknowledge that their experience is as well. And we would be constantly reminded that a big part of that knowledge, and that experience, is deeply emotional and inextricably social.

Conclusion

In Part One, I described how facts are generated and deployed in neuroendocrine Facebook support communities, noting how biomedical uncertainty gives rise to lay practices of soliciting and utilizing facts to secure ideal treatments. In Part Two, I make a similar claim regarding feelings — experiences relating to mental health and social life — and how people strategically locate their own “mental health” inside or outside their conceptions of neuroendocrine dysfunction in order to harmonize their self-concepts and/or receive appropriate care. In both cases, calculated negotiations of facts and feelings have the potential to impact how a patient is recognized by and treated within the biomedical system and the world at large. Neuroendocrine Facebook communities are one forum in which these strategies are constructed and shared.

Limitations

However, these observations and analyses hardly scratch the surface of the biological, social, and political complexities of negotiating a convoluted health condition online with thousands of other people. Nor do my findings suggest that these negotiations are necessarily effective (and data from my direct observations and interviews would confirm that they frequently are not). More in-depth research is needed to truly get a sense of how group interactions ripple out into someone’s treatment path or real-world life, including further inquiries into the social, political, regional, and economic factors that drive people to these groups, as well as longitudinal analyses of group members’ experiences over time. A better understanding of how a person’s involvement in a group — down to the smallest

interaction — influences how they articulate their condition and manage their care would be a boon to medical providers, public health experts, and other patients alike.

Another area ripe for further exploration is in the role of advocates specifically. In the strict confines of this project, I have not done the advocates I talked to justice. In fact, here, many of the most fascinating insights into advocacy work lie on the cutting room floor. This is a shame, because even from my small collection of interviews, it appears that advocates are uniquely able to crisscross nearly every (if not every) boundary in biomedicine, moving fluidly from renowned medical conferences to hospital bedsides, to patient support meetings to pharmaceutical research focus groups, from peer-reviewed publications to exam rooms as patients themselves. They travel from hospital to hospital and country to country, keeping track of how individual patients heal over time, which doctors to contact for which issues, and how health insurance programs differ around the world. A praxiography of neuroendocrine advocacy alone would reveal how these different spheres of medical influence overlap (or do not overlap) and would undoubtedly reveal the most salient barriers to proper neuroendocrine care today. One would be hard pressed to think of a question that an advocate could not speak to at length.

Picking up the pieces

And this ability to cross borders is everything the future of patient-centered neuroendocrinology requires. As I conclude this writing, I would also like to touch upon one last key theme that emerged at every level of this work, from observations to interviews: the inability of any one person to see the “whole picture” of a neuroendocrine condition.

Patients bemoan that 15-minute appointments are insufficient for capturing the breadth of

their symptoms and experiences. (And I would guess that many doctors bemoan the same.) Facebook group admin and moderators lament that comment threads are insufficient in capturing the true context of a person's story. And advocates, whose direct dealings with both patients and medical professionals give them the vantage point by far, speak to how hard it can be for patients to connect all the puzzle pieces properly, from facts to feelings, in putting together the right diagnostic picture for the right specialist to decode in the right way in order to enable the right treatment. There are many sides of the story, but it is hard to see the story as a whole — patients do not necessarily get it in their appointments, and they do not get it in their Facebook groups. They might not even be able to make sense of their own felt experiences. And so, through online comment threads, gaps in knowledge are filled with more knowledge that also happens to be filled with gaps.

When each story has gaps, many patients may turn to overarching narratives to make sense of imperfect information and bewildering experiences. A number of scholars have written about the limitations of conceptualizing illness in purely biomedical terms, and many have spoken to the importance of individual perspectives and stories. In *The Wounded Storyteller*, Arthur Frank speaks to the need of many patients to make sense of their seemingly fragmented illness experiences through narrative. Frank writes of the “narrative wreckage” engendered by a serious illness event, and the importance of acknowledging an illness experience as more than a biomedical diagnosis. When life is disrupted by uncertainty, some may crave narratives as a way to repair a lost sense of direction or self (2013: 53). According to Frank, narratives offer a way to reclaim personal experience, even in light of medical ambiguity. But at the same time, Kathy Charmaz notes that these narratives, while powerful practices of sense-making, might not align accurately with medical reality, nor even fully encompass all illness experiences. Furthermore, she writes

that “the raw experience of suffering may fit neither narrative logic nor the comprehensible content of a story” (2002: 303). Imposing a narrative structure over a disjointed collection of events, facts, and feelings may result in some kind of internal resolution, but may fall short of “objective” truth. Narratives may offer internal resolution at the expense of external reliability.

Objectivity and even feasibility aside, the desire for some kind of narrative integration — a reconciliation of facts and feelings, diagnoses and intuition, likely animates the way people with neuroendocrine conditions interact online. While securing adequate care is undeniably a primary motivation for what happens in the groups I observed, I would guess that many are also seeking to better integrate their experiences in the healthcare system into their own self-concepts. This desire for integration is something I can speak to directly as a neuroendocrine patient — I have not yet had a biomedical experience that treats the physical, mental, emotional, and relational effects of my condition as a cohesive whole. However, I also fully understand why this has not happened yet. While personal narratives that acknowledge the physical *and* mental *and* emotional *and* social components of a diagnosis are undoubtedly liberating, these insights do not have much purchase in actually manifesting a treatment that integrates a person’s being on all fronts. In fact, in the current system, these narrative impulses might even preclude such an outcome. Lauren Berlant writes of the “cruel optimism” of precarity, when the hope of betterment fixes someone in the very situation that forecloses it entirely (2011). To seek treatment for a neuroendocrine disorder is to submit to this cruel optimism. To deeply heal in all regards, a person needs proper medical treatment, but they probably also need to have psychological support and social-emotional integration. But to get proper medical treatment and psychological support, a person might have to subject themselves to diagnostic dis-integration — parsing every

symptom into its separately billable category, seeking answers from separate specialists in separate offices, sometimes separate towns. The process of getting lifesaving care (assuming one is even lucky enough to get that) can pull someone apart, literally by definition(s). And as of yet, there are few places that pull people back together.

But biomedical neuroendocrinology and the embodied experience of neuroendocrinology are not the same, and it is important to remember that no matter how biomedicine parses a body, a body is its own experience. When it comes to hormones modulating the brain and nervous system, the diagnostic distinctions of modern medicine that make the body billable are rendered meaningless. When does a chemical problem register as a physical sensation? When does a physical sensation register as a known symptom? When does a symptom register as part of a diagnosis? When does a chemical diagnosis become an emotional problem? When does an emotional problem become a personality problem? And when does a personality problem become an interpersonal problem? When do interpersonal problems become chemical, emotional, and interpersonal problems for other people? For entire communities? Neuroendocrine conditions are boundary objects that dissolve boundaries entirely.

But while these questions may tempt one to grumble over the inherent fragmentation that the biomedical system provides, another interpretation is possible. In the first few paragraphs of her book, Mol explicitly delineates between fragmentation and multiplicity, cautioning that though a certain disease may be enacted through medical practice in varying ways, these enactments are inherently coordinated. She writes, “the body and its diseases are more than one, but this does not mean that they are fragmented into being many” (Mol 2002). In the end, futile questions about where a certain aspect of a disease

begins and ends may be less about pointing out the flaws in biomedical diagnostics and more about indicating where intervention could be most effective. Foucault (1994: xix) notes that “what counts in the things said by men is not so much what they may have thought or the extent to which these things represent their thoughts, as that which systematizes them from the outset, thus making them thereafter endlessly accessible to new discourses and open to the task of transforming them.” We have tremendous power in the way we choose to look at things.

If we take this as our charge, we can turn our focus to the systemization of biomedicine not as a project of condemning it, but as a project of reconceptualizing it. Perhaps the very multiplicities inherent in a neuroendocrine condition — of perspectives, of specialists, of therapies, of visualizations, of bodies themselves — can be empowering. They offer an array of choices in which to intervene in an illness, handholds of influence for patients to grasp, discrete windows for providers to peer into a condition that may be otherwise incomprehensibly expansive. While questions regarding the “true” boundaries of hormones, glands, sensations, emotions, and reactions may always be devoid of satisfying answers, they will always be replete with strategy. And perhaps we will discover that all these efforts in the sense-making of sickness actually create new ways of togetherness, of being, all in themselves. In a world where we have infinite access to information, but sporadic access to expertise, people will inevitably come up with new ways to co-create knowledge of bodies, bodies of knowledge.

Epilogue

You are finishing your thesis on neuroendocrine disorders, and, inexplicably, you are being tapered off your meds. It was always your understanding that because you had multiple surgeries and a fair bit of tissue scraped out, you would be on hormone replacement for the rest of your life. But somehow, your glands — perhaps out of spite — have started to function at something approaching normative capacity again. You are recovering. Maybe not all the way. But you are recovering.

At your most recent appointment, your primary doctor utters the word “miracle” and tells you not to look a gift horse in the mouth.

You are terrified that it’s all some mistake, that it isn’t actually happening. You had finally gotten used to living with your condition, and now suddenly, once more, you are without a blueprint for how you should be feeling.

Even stranger: you do feel “different.” Again. But differently. The last five years since your surgeries seem vaguely like a bad dream. You thought you were fine during that time. You survived grad school, after all. But now, you realize you were on screen-saver. You weren’t you. But is this you? You think you feel more like you, but at the same time, “you” are also very unfamiliar now. It is difficult to describe.

It occurs to you that because of the timing of your illness, you have never experienced what a “normal” adult body feels like. You are elated and terrified.

You keep reading posts in your hormone Facebook groups. You read them for school and for you. You honestly don't know which is which anymore. And now, you have so many questions you'd like to ask — Hi, guys, has this type of recovery happened to anyone else? Did it end up being permanent? How have other people navigated their tapers? If my energy level is up and down, is that bad? Am I still sick? How do I know?

You find yourself projecting and imagining what people might say. Would people assume in disbelief your (extremely competent) doctor is reckless for snipping what should be your lifeline? Would they tell you to “find another endo” like they tell each other all the time? Would they resent you for getting better? Would they congratulate you and call you sweetie? Would they tell you to go read an article? Would they ask more questions, ask for more test results, suggest more resources, tell more stories?

You can't bring yourself to post, so you never find out.

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