

Visibility and Measurability in Health Care

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FROM THE EDITOR IN CHIEF

Invisibility of Anti-Asian Racism

Audiey C. Kao, MD, PhD

Parallels

Imagine being confined and feeling trapped in your own house or apartment for months on end, afraid to leave the relative safety of your home because contact with other people could possibly bring you harm. Being **isolated at home** without an end in sight is no way to live. Fear, anxiety, depression, and even anger become your quarantine companions. During this past year, most of us can wholly grasp and empathize with this state of pandemic being.

Now consider living this way for a reason other than a pandemic: your hesitancy and trepidation about walking out the door is because some hate you enough to harm you ... just because of how you look. What is worse than being a target yourself is conjuring up a worst-case scenario befalling your mother or elderly family member halfway across the country or college-age nephews and nieces living away from home for the first time. This inescapable torment is the current reality for many Asians, Asian Americans, and Asian-appearing people in this country.

Mob Murder

Resurgence of anti-Asian racism and xenophobia during the COVID-19 pandemic is not surprising. On October 24, 1871, one of the largest mob lynchings in US history—the “Chinese Massacre”—took place in Los Angeles. According to a 1999 *Los Angeles Times* account:

One by one, more victims were hauled from their hiding places, kicked, beaten, stabbed, shot and tortured by their captors. Some were dragged through the streets with ropes around their necks and hanged from a wooden awning over a sidewalk, a covered wagon or the crossbeam of a corral gate. Finally, 15 corpses—including those of a 14-year-old boy and the Chinese community’s only physician, Chee Long Tong—dangled in the City of the Angels. Four others died from gunshot wounds, bringing the death toll at the hands of the mob to 19–10% of the city’s tiny Chinese population.¹

Not a Singular Incident

On March 16, 2021, a shooter targeted 3 Asian-owned businesses in the Atlanta area, killing 8 people, including 6 women of Asian descent, and raising the dark specter of misogyny and sexualized racism against Asian women.² At a press briefing the day after the shooting, a sheriff spokesperson described the apparent hate crime as possibly reducible to a single errant guy who claimed to have a “sex addiction”—denying that the

shootings had been racially motivated. The sheriff spokesperson described the shooter as being “pretty much fed up and kind of at the end of his rope. Yesterday was a really bad day for him and this is what he did.”³ Around the same time as this briefing, a 75-year-old Asian woman and grandmother was brutally assaulted in San Francisco, one among many unprovoked attacks across the country.⁴ Despite suffering multiple injuries, she insisted on donating the nearly \$1 million raised to help with her medical bills and recovery to fight racism.⁴

Beyond these and countless other personal acts of racial terror, **anti-Asian racism** has long been institutionalized in this country—from the 1882 Chinese Exclusion Act,⁵ to internment of Japanese Americans during World War II,⁶ to racial profiling of South Asians after September 11th.⁷ These and many examples of transgenerational trauma suggest that, although a “lone wolf”⁸ commits a hate crime as an individual, it takes a society long-steeped in White supremacy and xenophobia to raise and nurture wolves. Given this country’s **racist history**, why is anti-Asian racism invisible to and denied by so many? Doing justice to the harms of anti-Asian racism’s invisibility is ambitious in a brief essay, yet I humbly offer the following.

Teachings

As a Chinese immigrant kid in Los Angeles during the 1970s, I was not formally taught the history of America’s anti-Asian racism, and I probably didn’t need to be, since I experienced it. After many years of divisive debate, the country’s most populous, diverse, and economically powerful state is moving forward with a K through 12 curriculum focused on the history and contributions of people of color, including Asian Americans, and the racism that we and so many have lived with.⁹ Given the plurality of stakeholders and their personal stakes in the telling of history, perfect consensus is likely impossible.¹⁰ Nevertheless, early childhood and preadult anti-racist education is necessary and should be widely integrated into civics and history curricula. That said, elected officials and educational leaders must guard against inadvertently creating competition among historically oppressed communities that focuses on shades of difference while masking shared bonds of suffering, since this tactic has traditionally been a tool of oppression. This divide-and-conquer strategy has long pitted people of color against each other, and another lived lesson of history is that White supremacy wins when those oppressed are fighting among themselves.

Pitting one oppressed racial or ethnic group against another is nothing new. People of Asian descent comprising more than 50 ethnicities and speaking over 100 languages¹¹ have long been lumped together and labeled as a so-called “**model minority**.”¹² This apparent monolithic accolade of Asian Americans’ achievements in higher education and the learned professions has also been well used as a racial wedge: if you just study and work harder, you, too, can succeed as a self-made American.¹³

This “model” label points to individual achievement, obscuring another overlooked social phenomenon: a bamboo ceiling whereby Asian Americans are looked upon as hardworking and industrious but not suited for leadership.¹⁴ It belies the reality that Asian Americans as a group have the highest income inequality¹⁵ and have had the highest percentage of long-term unemployed during the COVID-19 pandemic.¹⁶ It discounts the fact that Asian health care workers have been racially accosted even as they care for the sick^{17,18} and have died from COVID-19.^{19,20} That Asian Americans are held up as model citizens and then face attack as a nonhuman, threatening, virulent

contagion in the seeming blink of an eye speaks to the insidiousness of anti-Asian racism.

Boats

Not rocking the boat is a behavioral stereotype of Asian Americans, and Hollywood would like you to see some truth in it.²¹ *Fresh Off the Boat* was a television sitcom featuring an Asian American immigrant family that premiered in 2015.²² Whether one considers the show's "FOB" title to be a racial slur about Asian American immigrants' or refugees' unfamiliarity with the United States or something to make light of, this striking contradiction between the model minority and FOB stereotypes speaks to the complex transgenerational experiences of Asian families and their cultural values grounded in filial piety that tend to be oversimplified.^{23,24,25} Although there are Chinese and Japanese Americans who have family lineages dating farther back than some European Americans in this country, nearly 60% of Asians in America today were not born here.²⁶

Asian refugees and immigrants who come to America to make a better life for themselves and their families will suffer, tolerate, and swallow a lot to make that dream happen. This quiet perseverance is passed on to the next generation, but, at this crucial moment of racial reckoning, such silence is deafening and deadly. With all due respect to our forebears, it is past time for Asian Americans as a community to shake up the ship of state and forge an alliance with all communities of color. We must exercise our power as consumers, workers, voters, and human beings to model and demand anti-racism as the new lifeboat of civilized society.

As an American who is proud of his Chinese heritage, I hope that our shared pandemic memories will engender greater empathy in more of us and that deeper social accountability for our common humanity will become more norm than news. History will be the judge.

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FROM THE EDITOR

Invisible Illness and Measurability

Jennifer Dobson, MD

How many people throughout history suffered from my disease and others like it but went untreated? This question is made more pressing by the knowledge that even though the disease was discovered in 2007, some doctors I spoke to believe that it's been around at least as long as humanity has.

Susannah Cahalan¹

According to the 2010 Americans with Disabilities Census Report, only about 6% of people who reported disabilities use visible supports (eg, a wheelchair or cane).^{2,3} Many living with disabilities are living with invisible illnesses,² with no bruise or rash or other empirically verifiable or measurable symptoms or indications: chronic fatigue syndrome, anti-N-methyl-D-aspartate encephalitis, fibromyalgia, **multiple sclerosis**, **postconcussive syndrome**, endometriosis, many mental illnesses, and many experiences of **gender identity** pluralism.^{4,2} A patient can appear healthy, enduring others' glares for parking in a spot reserved for people with disabilities. Her joint pain and fatigue might be dismissed by her physician as normal hormonal changes, so she endures these symptoms alone for years until finally diagnosed with lupus.

Seeing is believing is a prominent orientation to patient care, so patients with hard-to-recognize symptoms frequently receive insufficient, inequitable support.^{2,5} Lack of empathy from clinicians can leave patients feeling misunderstood, isolated, and that they must **bear the burdens** of their disease without help.⁵ Some clinicians express frustration with patients with illnesses of presently invisible etiology—blaming them, resenting symptoms without the privilege of certain expression, accusing them of being dishonest or “difficult,” **pathologizing** them as malingering or psychosomatic, or **labeling** them in ways that are dismissive of their deep knowledge and understanding of their own bodies and lived experiences.⁵ Such dismissals are common⁶ and highlight the irony of *seeing is believing* resulting in clinicians' ignorance of patients' reports, which impedes their efforts to help their patients. When patients' narratives count for too little and empirically verifiable “knowns” count for too much, progress stalls, distrust grows, and no one feels better.^{5,6}

An arc of discovery from unknown-unknowns to known-unknowns to known-knowns⁷ is possible when key beliefs are revised over time, such that unknowns can be transformed into knowns through curiosity and humility. So, too, what's invisible can become visible, unidentifiable phenomena can be rendered identifiable, and what's untreatable can be treated. This issue of the *AMA Journal of Ethics* illuminates ethical,

social, and cultural questions to help guide such discoveries, to strengthen medicine's tolerance of tension between art and science, and to pursue healing in a way that might be hardest to practice: listening could be a threshold to relieving suffering.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

When Symptoms Aren't Visible or Measurable, How Should Disability Be Assessed?

Cerise L. Glenn, PhD

Abstract

Qualitative data can supplement and contextualize quantitative data and can be useful in disability determinations to help clinicians gain fuller understanding of patients' experiences of chronic illness or disability. This commentary response to a case suggests the importance for patient-centered care of physicians guiding patients' documentation of their own illness experiences. Specifically, patients writing daily journal briefs about work-related activities and pain can help clinicians offer recommendations, facilitate disability determination processes, and motivate employers' understandings of reasonable accommodations.

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Case

CR is a 52-year-old woman who suffered a concussion in a car accident. CR struck the left side of her frontal bone against the car's dashboard and was transported by ambulance to a hospital. Computed tomography and magnetic resonance imaging ruled out hemorrhage, and imaging studies were negative. CR was scheduled for an outpatient visit with a local neurologist, Dr N, and was sent home with symptoms of headache, photophobia, nausea, and fatigue, which persisted. CR reported to Dr N about 1 week after the accident that she felt "hazy" and was crying a lot. Dr N encouraged CR to try to avoid stress, screens, and sensory overstimulation. CR used up her 2 weeks of vacation time to recover.

Now 1 year after the accident, CR's postconcussive symptoms^{1,2} are ongoing. She reports to Dr T, her primary care physician, that she's frustrated about not feeling able to return to work full time and to daily activities with family. She reports feeling guilty for resting, but sounds and light still frequently trigger disabling nausea and headaches. CR knows she needs time to heal, but she is concerned about losing her job, falling short on mortgage payments, and providing for her family. One problem is that CR's job requires nearly constant screen interaction, which also triggers debilitating symptoms. CR states that her manager has asked her to "step it up" and adds, "I look fine, so people don't

understand what I am going through and are frustrated when it takes me so long to do things I used to do quickly.”

CR presents disability benefits forms to Dr T and asks for help completing these forms. Without reliable serological tests or imaging studies to quantify CR’s symptoms’ severity or help determine her prognosis, Dr T consults Dr N. Both physicians are unsure about whether postconcussive syndrome^{4,2} is a qualifying disability. They wonder how to respond to CR’s request for help with the forms.

Commentary

Chronic illnesses and diseases that are rare, difficult to see, or have effects that are difficult to quantify can be challenging to treat and diagnose. Variability in symptom presentation and in illnesses’ clinical definitions further complicate different stakeholders’ understandings of chronic illnesses. These illnesses present additional challenges when clinicians try to assess the nature and scope of a disability or to facilitate patients’ acquisition of reasonable accommodations, which also vary by disability and by organizational programs or policies. In this case, the physicians must consider gaps in their own knowledge of CR’s chronic illness in order to collect information needed to complete CR’s forms. Patient-centered techniques, such as journaling, with guidance from Dr T, could help CR document with specificity how her illness impedes her performance of job-specific tasks. Journaling would also likely help Dr T care well for CR.

Qualifying for Disability Benefits

The 1990 Americans with Disabilities Act (ADA) defines an individual’s disability as “a physical or mental impairment that substantially limits one or more major life activities.”³ Impairments can include a variety of symptoms or illnesses, including those that are difficult to quantify or measure, but the ADA does not set criteria. Does postconcussion syndrome fit this **definition of disability**?

Concussions, which are “trauma-induced brain dysfunction,” have multiple credible definitions,⁴ so matching clinical indicators with disability designations illuminate 2 key areas of difficulty: definition agreement and short- and long-term symptom recognition and diagnosis. An additional challenge is how gender and racial/ethnic inequity, exacerbated by lack of diversity in research samples, should be addressed in disability assessment and documentation. In stroke research, for example, women of color are understudied when compared with White men, White women, and men of color.⁵ Recent concussion research has focused even more specifically on men with sports injuries.⁴

Additionally, clinical discernment of long-term chronic illnesses’ effects is difficult when patients develop chronic illnesses after initially trying to hide their job-specific impairment at work. This coping strategy might reflect some patients’ struggle to integrate their disability into their professional identity. Gender and cultural background can also influence how people **manage and express pain**.⁶ Fear of discrimination, job loss, promotion ineligibility,⁷ or marginalization can also prevent patients from disclosing a disability to an employer. Journaling could help CR clarify for Dr T how she meets criteria for accommodations or disability benefits.

Support Planning

Facilitating CR’s journaling could help CR develop a self-advocacy and self-care skill set,⁸ as well as provide Drs N and T with additional information needed for disability

assessment. Tag-it-Yourself, for example, is a digital application that helps patients with diabetes document changes in their blood glucose levels and those changes' relationships with their experiences of daily activities.⁸ CR and Dr T can work together to create a focused journal for CR to log postconcussion syndrome experiences that could help Dr T complete needed forms and develop a patient-centered care plan.

At first, journaling can feel daunting to patients already exhausted by pain and disability, but it can be critical for adding specificity to assessments of “essential” job function performance capacity, which is a key component of the definition of a “qualified individual with a disability” on the ADA “Questions and Answers” page:

A qualified individual with a disability is a person who meets legitimate skill, experience, education, or other requirements of an employment position that s/he holds or seeks, and who can perform the essential functions of the position with or without reasonable accommodation. Requiring the ability to perform “essential” functions assures that an individual with a disability will not be considered unqualified simply because of inability to perform marginal or incidental job functions. If the individual is qualified to perform essential job functions except for limitations caused by a disability, the employer must consider whether the individual could perform these functions with a reasonable accommodation. If a written job description has been prepared in advance of advertising or interviewing applicants for a job, this will be considered as evidence, although not conclusive evidence, of the essential functions of the job.⁹

Since the ADA “Questions and Answers” page considers a written job description as evidence of essential job functions, obtaining one could be a good place to start. If there is no formal written description of her current job, CR could work with her supervisor to create a list of essential job functions, such as data entry requiring a substantive amount of sedentary time in front of a computer. CR could then document her efforts to perform and difficulties in performing these functions, which would also let her employer know that she is actively working to complete her work-related tasks. To help CR record types and intensity of activity-specific pain (eg, headache), Drs T and N could recommend that CR note an activity (eg, computer use) or environment (eg, lighting, noise) that causes pain, indicate an associated pain intensity from 0 to 10 (eg, 0 = no pain, 5 = moderate pain, 10 = worst pain), and indicate which actions help mitigate pain. CR could enter such information several times throughout the day. The Wong-Baker FACES quickly enables the matching of a specific moment or activity to a pain level (see Figure).¹⁰ Both successful and unsuccessful actions should be noted to help CR give Drs T and N more context for understanding the nature and scope of her task-specific impairments.

Figure. Wong-Baker FACES® Pain Rating Scale



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Conclusion

Focused journaling can help CR cultivate self-care and self-advocacy skills and can also help Drs T and N motivate CR's care plan and access to reasonable accommodations and benefits from employers or government agencies. Journaling generates qualitative

data and offers another tool that patients and clinicians can draw upon to manage chronic illnesses and their effects on patients' social, home, and work lives.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

A Womanist Approach to Caring for Patients With Empirically Unverifiable Symptoms

Annette Madlock Gatison, PhD

Abstract

Some illnesses and diseases are not apparent to onlookers. Conditions like chronic fatigue syndrome, fibromyalgia, multiple sclerosis, postconcussive syndrome, endometriosis, and many psychiatric illnesses, for example, have symptoms that are not easily or at all measurable. Both clinicians and health care systems, however, tend to focus exclusively on measurability, which can result in evidentiary overreliance and undervaluation of experience narratives and can have clinically, ethically, and socially important consequences for patients with these conditions.

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Case

LL is 27 years old and has been experiencing fatigue, joint pain, insomnia, and muscle soreness since she was 19. She has visited many physicians during those 8 years but has not found symptom relief. Despite a family history of autoimmune disease, LL's autoimmune serological panels have always been negative. She reports that, since onset of her symptoms as a teenager, different physicians have suggested she is "malingering" and has "conversion disorder,"¹ diagnoses that have followed her for years in her health record. LL's last physician added fibromyalgia² to her list of diagnoses and prescribed amitriptyline, duloxetine, and psychological therapy for 8 weeks. Despite LL's having diligently executed interventions as directed, her symptoms persist. LL decided not to return to her last physician, who accused LL of not taking her medications.³ Most recently, severe exhaustion, muscle tenderness, and spasms have kept LL home for 5 consecutive days, so LL now visits Dr E, a rheumatologist, for the first time in hopes that Dr E will see LL as a credible patient and help her find symptom relief.

Commentary

Black women confront issues of invisibility on many sociocultural levels. Racial bias is a **real barrier** for Black women and women of color who seek medical care or services

from health care professionals. Social and cultural norms influence how Black women and women of color are perceived and, in turn, how they **make health decisions**.⁴ Katie Love⁵ and Harriet Washington⁶ write about the painful history of discrimination and wrongful treatment of Black people in the name of science. This history of discrimination persists into the 21st century. Added to this historical trauma is the cultural expectation that Black women will manage disease and cope with suffering by wearing a mantle of Black womanhood, appropriating warrior-themed tropes, and relying on religious or spiritual faith. This expectation of a trifecta of strength is grounded in Black women's survival of oppression, but it can also be considered a detriment to Black women's health.⁷ It compounds invisibility by creating a mechanism whereby Black women continue to be silenced on the state of their health.⁷ This cultural silencing is a process that is complicated by symptoms that are neither visible to nor easily diagnosed by health care professionals.

This essay focuses on the experiences of Black women and will explore how implicit bias and racism in connection with invisible illness can be ameliorated in the context of evidence-based and patient-centered health care at the individual and organizational level using *womanism* as a rhetorical framework. Such a framework creates what I call, drawing upon the work of Alice Walker, a *womanist ethic of care*.

Evidence as a Source of Bias

The Agency for Healthcare Research and Quality provides the following definition for evidence-based practice in health care: "Evidence-based practice is the use of the best available evidence together with a clinician's expertise and a patient's values and preferences in making health care decisions."⁸ However, as Kamlesh Bhargava and Deepa Bhargava⁹ and others have pointed out, evidence alone is insufficient for delivery of patient-centered care. Clinicians must overcome implicit or unconscious racial bias and affinity bias (the unconscious preference for those who are more like you) to deliver patient-centered care that applies evidence equally to all. Studies indicate that medical professionals' ability to behave or act without bias is difficult, as burnout and stress, for example, increase the likelihood of racial, gender, and socioeconomic bias that influence treatment and bedside manner.^{10,11,12}

A significant challenge to evidence-based care is the assumption that racial and ethnic minorities (ie, Black people and many people of color) are less likely to participate in clinical research. However, Jill Fisher and Corey Kalbaugh¹³ dispute this assumption, arguing that when "the entire spectrum of clinical research" is examined, evidence suggests that African Americans are overrepresented in higher-risk, lower-benefit phase I safety studies but underrepresented in phase III therapeutic trials that inform evidenced-based care. The point is that empirical findings cannot be applied to patient care when that information is not there for a particular group of patients. It is time to consider this fact and use patient experience to help fill in the blanks. This reevaluation of the evidence might provide new insights that would bring about positive change in clinicians' perceptions of Black women patients and many patients of color, regardless of gender.

Women as Knowers

Borrowed from Alice Walker, a *womanist ethic of care* refers to narrative construction of Black women's health. This perspective employs an ethos of care and concern for Black women as credible knowers of their lived experiences and of their physical, mental, and spiritual well-being. As Walker notes in the following:

A [womanist is a] woman who loves other women, sexually and/or non-sexually. Appreciates and prefers women's culture, women's emotional flexibility (values tears as natural counterbalance of laughter), and women's strength. Sometimes loves individual men, sexually and/or non-sexually. Committed to survival and wholeness of entire people, male and female. Not a separatist, except periodically, for health. Traditionally universalist...¹⁴

Layli Phillips describes womanism this way:

Womanism is a social change perspective rooted in Black women's and other women of color's everyday experiences and everyday methods of problem solving in everyday spaces, extended to the problem of ending all forms of oppression for all people, restoring the balance between people and the environment/nature, and reconciling human life with the spiritual dimension.¹⁵

Womanism is a tool for overcoming the affinity bias and implicit bias found in health care practices that too heavily rely upon measurable evidence, as it centers on methods of problem solving used by Black women and women of color. There is a systemic sociocultural and epistemic hierarchy in the United States, with Black women historically at the bottom. Health care is not immune to differential treatment of people of color, especially Black people and, specifically, Black women. Black women's ability to provide information as they see it and experience it is relevant to responding with care to Black patients' clinical need. Adding their **narrative perspectives** and insights to considerations of evidence or its absence would likely contribute to healthier outcomes and mitigate health inequity.

A necessary step towards healthier outcomes for Black patients is to face racism in health care. For example, Denise Hooks-Anderson and Reynaldo Anderson¹⁶ used autoethnography to identify and locate intersecting oppressions that marginalize Black people along the lines of race, class, and gender within the health care system and determined that the behavior of clinicians who otherized Hooks-Anderson, who was a chronically ill patient with lupus, resulted in improper care and concern for her. Similarly, Elizabeth Desnoyers-Colas¹⁷ shared a personal narrative as a service member returning home with what the media initially dubbed "Gulf War Syndrome," an illness fraught with debilitating health problems that no one could explain and no one would believe. Desnoyers-Colas describes how the stoicism of duty and honor (a cultural norm) was not enough to overcome her symptoms and that speaking up about the disease to health professionals did not prompt their belief in or relief from her symptoms.¹⁷ She began researching, experimenting, and collecting empirical evidence for herself to find relief. Using a womanist ethic of care when approaching women's—especially Black women's—experiences of empirically unverifiable symptoms is one way to center patients' experiences during clinical encounters and mitigate bias in health care.

Responding With Care

A womanist ethic of care would bring an added dimension to patient-centered, evidenced-based care. Womanism draws on inclusion to center lived illness experiences of Black women. Let the words and experience of a patient be the first thing counted in remediating the suffering from invisible illness: when a woman describes her symptoms, believe her. Symptom verification and identification will come. Health care professionals need to stop and consider a patient's experience without dubious condescension and must recognize a patient's narrative's truth, even when one can neither measure nor see symptoms.

When employing a womanist ethic of care, one must do more than express empathy. There are still action steps that require one to question oneself, perhaps by asking, "Is

this the diagnosis or treatment plan I would come to if this were a White middle-class patient, myself, or a family member?” Womanism can be taught as a clinical skill of regard for patient’s epistemic authority, perhaps as a part of learning bedside manner or **cultural humility**.¹⁸ Students and clinicians are obligated to cultivate and practice the self-awareness necessary to overcome biases that increase the likelihood of the continued invisibility of Black women’s illness experiences.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

When Imaging Data Contradict a Patient's Self-report, How Should Clinicians Proceed?

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Abstract

Following a case in which a patient's self-report contradicts imaging data, this commentary considers how patient-clinician communication, including an assessment of and accommodations for maximizing health literacy and shared decision making, can elucidate a patient's values and preferences. Patients' perceptions of how much input they have in making their health decisions influences the patient-clinician therapeutic alliance and outcomes and can support patients' physical and emotional well-being.

Case

JM is a 46-year-old woman who has lived with primary progressive multiple sclerosis (PPMS) for over 20 years. She visits her neurologist, Dr N, regularly to review symptoms (mainly chronic fatigue, intermittent pain, right-side weakness, difficulty with word finding and recall, and spasticity) and revisit therapeutic options. She gets a magnetic resonance image (MRI) every year when she visits her neurologist and had her most recent MRI one month ago. JM has been taking glatiramer acetate injections as directed for the last 7 years, during which time her symptoms have not worsened and fewer than 5 new plaques have been visible on imaging during this therapy.

JM has been ambulating without gait disturbances and states that she's been feeling better. JM attributes feeling better to a now 3-month-old regimen of daily exercise and eating a Mediterranean diet. "After a month of my new exercise and diet routine, I stopped the glatiramer acetate injections, and I feel so freed from having to do that to myself. And I feel terrific."

"I'm so glad you're feeling better," Dr N says. On physical exam, JM's symptoms have not worsened, and Dr N notices that JM certainly looks energized and content. Upon reviewing her MRI, however, Dr N noticed 2 new plaque lesions in her motor cortex, and she wonders what to say next.

Commentary

A 1982 President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research identified **shared decision making** as the ideal

manner of reaching patient-clinician consensus on a treatment plan following a discussion to ensure informed consent.¹ Given patients' vulnerability, the patient-physician power differential, and **diagnostic or therapeutic uncertainty**, tending to patients' emotional and relational well-being through shared decision making is a crucial component of patient care.² In December 1990, Congress passed the Patient Self-Determination Act, which went into effect in 1991 and included a mandate to provide written information to patients regarding their right to make health care decisions and the right to refuse treatment.³ One of the clinical tools to arise from this act was the patient decision aid—a written, auditory, or visual summary of information to promote patient education and improve health literacy. In conjunction with shared decision making, decision aids can be means to increase patient autonomy. In 2010, Section 3506 of the Affordable Care Act included a Program to Facilitate Shared Decision Making, but little was done to implement its use.⁴ In the case of JM and Dr N, it is crucial to utilize the tools of **decision aids** and shared decision making in formulating a care plan that JM can accept.

Shared Decision Making

Clinical care involves a melding of patient narratives with objective data, and both should be documented and weighed in formulating clinical recommendations. An abnormality identified in empirical data without associated subjective symptoms is often called an incidental finding. The weight given to such a finding and the need to treat depends entirely on the risk the abnormality carries for the patient who may be asymptomatic. In cases in which treatment is imperative, it is important for the clinician to invest time in explaining to the patient why they should be treated despite the lack of symptoms. Failure to do so might contribute to patient nonadherence. If the patient has a novel or understudied disease, the extent of therapeutic benefit of available interventions may be unknown or relatively modest. In that case, there is a further tipping of the scales toward patient autonomy, the bioethical principle underlying shared decision making. The caveat is the presumption that the patient has the health literacy and decisional capacity to give informed consent based on a thorough discussion of the risks and benefits of proposed treatment options.

Health literacy is a modifiable social determinant of health that can be improved through dedicated patient education and training. Greater **health literacy** allows for greater patient autonomy in shared decision making.⁵ As patients improve their health literacy, they increase their knowledge of their disease, learn how to better manage their condition, and become more engaged in discussions regarding their care. Simplifying information is one way to help patients with lower healthy literacy participate in shared decision making. However, patients still need the cognitive, social, and communication skills to partake in shared decision making. These considerations speak to the principles of beneficence and nonmaleficence along with autonomy.

Clinical Considerations

Because JM has disease activity based not on clinical symptoms but on an MRI, her PPMS would be categorized as active but without progression according to the most recent guidelines.⁶ Both her age (less than 55 years old) and the presence of new lesions on an MRI would make her a candidate for ocrelizumab, the first US Food and Drug Administration (FDA)-approved treatment for PPMS.⁷ A double-blind, randomized-controlled trial of ocrelizumab vs placebo found modest effects, with 6% fewer patients on ocrelizumab than on the placebo having confirmed disease progression at both 12 and 24 weeks.^{8,9} Additional benefits of ocrelizumab included improved performance on

the 25-foot hall walk test, decreased radiographic burden of disease, and decreased overall loss of brain volume relative to the placebo. The side effects of long-term use of ocrelizumab included higher risk of infections, including influenza, herpes, and shingles.^{8,9} The immunosuppressive effects of ocrelizumab affect not only the risk of infection, but also the body's ability to keep cancer at bay. Thus, patients receiving ocrelizumab had a higher risk of cancer than those receiving the placebo.⁸

In considering the use of ocrelizumab to treat PPMS, clinicians need to weigh the slightly lower rate of disease progression against the higher risk of complications, including slightly higher rates of infection relative to placebo (71.4% v 69.9% overall and 10.9% v 5.9% for upper respiratory tract infections), and a small risk of breast cancer (less than 1% of cases).⁹ It could be reasonable to treat a patient with ocrelizumab whose goal is to slow the progression of PPMS, no matter the risk or cost, especially if the patient is young and has active disease, both clinically and radiographically. In contrast, by discontinuing her treatment, JM has made clear her preference to be off medication. What isn't clear is if she understands the risks and benefits of doing so. Having JM "teach back" her understanding of risks vs benefits following a detailed discussion of the pros and cons of remaining off therapy vs resuming glatiramer acetate or switching to ocrelizumab would be essential for Dr N to assess JM's understanding of the treatment. It would also provide an opportunity to correct any misunderstandings and to fill in any residual knowledge gaps.

To better understand JM's preferences and values regarding treatment, Dr N could ask questions geared towards eliciting her hopes and fears regarding treatment at present and in the future. Fears of side effects would be especially important for Dr N to address in order to empathize with her concerns, address any fears that are disproportionate to their likelihood of occurrence (eg, by giving statistics on the likelihood of the various side effects), and educate her on the side effects she'd most likely encounter, potential treatments for or the reversibility of the side effects, and the importance of informing her of any side effects so they can address the issues as they arise. Dr N's conversation with JM should also focus on the benefits of treatment and, more specifically, on how these benefits might help JM attain her top treatment-related goals, such as avoiding medicines with fatal side effects, maintaining or improving memory, preventing brain atrophy, maintaining her ability to walk, maintaining her cognition, staying relatively healthy, avoiding vision loss, minimizing weakness and deconditioning, and remaining as active as possible.¹⁰

Following this discussion, if JM continued to decline treatment because the risks were too high or treatment wasn't in keeping with her goals, it would be reasonable for her to forgo ocrelizumab, given her lack of clinical symptoms combined with the drug's modest benefit and risk of infectious disease and cancer. JM developed 5 lesions over 7 years while on therapy, averaging under one lesion per year, so an additional 2 lesions in the year since she self-discontinued therapy represents a moderate but not alarming increase in frequency of plaques. If JM had a more rapid objective decompensation off therapy and if PPMS had a highly effective treatment with minimal side effects, then Dr N would have a stronger basis for recommending that JM adhere to the proposed treatment regimen. In the absence of such a highly beneficial treatment, it is even more important for Dr N to facilitate shared decision making based on JM's own values and preferences, as those are the main factors in the treatment decision equation. If her disease continues to progress—either radiographically or with new symptoms—the risks vs benefits of treatment should be readdressed with the patient at that point. When

clinical data run counter to patient self-report, allowing extra time for a detailed review of that data, comparing the patient's test results with normal values, and even bringing up the concerning imaging findings for the patient to see for herself could help the patient better understand the physician's concerns, the disconnect between objective data and subjective symptom report, and the need for treatment despite minimal symptoms.

Decision Aids

One effective means to promote shared decision making is to use patient decision aids in written, video, or online interactive formats that delineate the various care options, the frequency of side effects or complications, and potential benefits and costs. Patient decision aids should be written at an eighth-grade literacy level and, additionally, should be brief and readable.^{4,5} Dr N should provide JM with decision aids regarding her treatment options as a basis for further discussions of care to uphold her values and preferences. Shared decision making has numerous potential benefits, including increasing knowledge, decreasing anxiety, improving outcomes, and decreasing costs, as well as better aligning care with patient preferences and values.⁴

In MS, the initiation, continuation, and withdrawal of treatment are key decisions to be made over the waxing and waning course of the disease. One study found that 80% of patients with MS prefer an autonomous role in treatment decisions.¹¹ Despite this overwhelming patient preference, clinicians decide whether to involve patients with MS in the decision-making process. In cases in which patients' wishes are not factored into the treatment decision, the only means they have to voice their opposition is through willful nonadherence.¹² In offering a treatment recommendation to JM, Dr N should rely on both the patient's self-report of symptoms and the MRI showing the 2 new plaques, especially as both are factored into the assessment regarding disease progression. Dr N also should set the stage for a plan B if the patient develops more plaques on an MRI or more clinically apparent symptoms. Dr N and JN could together set a threshold above which they both agree that treatment would be initiated because the likelihood of benefit would outweigh the risks. Doing so would help balance respect for her autonomy with beneficence and would avoid significant harm.

Available decision aids to enhance patients' understanding of the risks and benefits of treating their MS include a 4-hour education program as well as an educational leaflet on relapse treatment options.¹¹ Another approach is decision coaching by qualified MS nurses that is tailored to the needs of a particular patient. All the approaches are contingent on a trusting relationship between the patient and clinician.¹²

One study demonstrated that patients' perception of their role in decision-making processes can improve therapeutic outcomes independently of what would be expected based solely on improved adherence to treatment. Specifically, a "sustained partnership" approach to treatment decisions had beneficial effects on emotional well-being, symptom burden, and physiologic parameters.¹³ In the case of JM, the harms of stopping her glatiramer acetate injections may be diminished and the benefits of adjusting her diet and exercise may be augmented disproportionately to what could otherwise be expected due to the patient's beliefs regarding how these changes will impact her health.

Conclusion

Overall, shared decision making, a process rooted in upholding a patient's autonomy, is known to be beneficial but is not practiced as much as it should be. Health literacy goes hand in hand with the capacity to participate in shared decision making and can be improved through patient decision aids. It is important for clinicians to invest time in educating patients to help inform and empower them to make the best treatment decisions for themselves. A crucial step in shared decision making is discussing patients' values and goals for their clinical care. In the case, JM's discussion with Dr N revealed that, barring a highly effective or even curative treatment, JM prefers maintaining her health through diet and exercise. Furthermore, she'd like to avoid treatment in the absence of symptoms, least of all treatment options with infectious and oncologic risks. JM understands that, despite her lack of symptoms, she has active disease, as evident from her MRI, and this disease process could be mildly mitigated by ocrelizumab. Accordingly, it would be reasonable for JM to defer the only FDA-approved treatment for her disease until her symptoms reach a threshold agreed upon by JM and Dr N. Allowing the patient's self-report narrative to trump empirical data in this type of a case could improve many outcomes, including the patient's emotional well-being and therapeutic relationship with her doctor, as well as her physical well-being and symptom burden. These benefits occur independently of adherence to any specific treatment regimen and make a strong case for promoting shared decision making as much as possible.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Clinicians Minimize Harms and Maximize Benefits When Diagnosing and Treating Disorders Without Biomarkers?

Benjamin Tolchin, MD, MS, Dorothy W. Tolchin, MD, EdM, and Michael Ashley Stein, JD, PhD

Abstract

Ethical obligations to minimize harms and maximize benefits of diagnosis and treatment of disorders without biomarkers include navigating difficult-to-measure, perhaps clinically inexplicable, symptoms. Among potential harms are public stigma, self-stigma, label avoidance, and the negative influence these stigmas have on self-esteem, quality of life, employment, and housing. Among potential benefits are patients becoming active agents in managing their illnesses, social acceptance, and access to evidence-based treatments. Ethical complexities clinicians face when trying to develop treatment plans while heeding key details from patients' narrative accounts prompt questions about how to best adhere to evidence in understudied domains of medicine.

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Case

J sobbed in frustration in Dr R's office. After 4 years of unsuccessful treatment with an array of anti-tremor medications from her primary care physician and then a general neurologist, J had been referred to Dr R, a movement disorder specialist, for further evaluation. Based on a history and physical examination, Dr R diagnosed J with a functional movement disorder, a form of functional neurological disorder or conversion disorder. Initial referrals for treatment—to a psychotherapist for cognitive behavioral therapy and to a physical therapist for a motor reprogramming treatment protocol¹—had not gone well.

J felt like her caregivers had given up, and Dr R recognized J's feelings of abandonment. J stated, "I've been having this shaking for 5 years now. I lost my job, and nobody wants to hire me once they see me shaking. The judge took my kids away. My last 2 doctors gave up on me and think I just make this up, and now you're telling me to go see a psychotherapist and a physical therapist. The psychotherapist I saw before took one

look at me shaking and kicked me out, and my insurance company won't pay for physical therapy." Dr R responded, "Your tremor is having a terrible impact on your life, and it feels like people who are supposed to be helping you are turning their backs on you." Dr R sat and continued, "I'm sorry that you've faced stigma and poor care on top of your illness. I'm not going to give up on you. I know you're not making up these symptoms and that the suffering you're experiencing is real. I want to work with you, so you can get your life back on track. How does that sound?"

J replied, "I'd like that."

Commentary

Despite rapid advances in our understanding of pathophysiology and in diagnostic techniques, there remain a wide variety of disorders for which there are no **biomarkers** (ie, measurable indicators of the presence or severity of a disease) available for clinical use. This category of disorders without biomarkers includes many difficult-to-measure disorders and most medically unexplained symptoms, such as functional neurological disorders, fibromyalgia, chronic fatigue syndrome, and chronic pain syndromes. These disorders together contribute to up to roughly half of primary care and specialty clinic visits, a significant fraction of emergency department visits and hospital admissions, high health care costs, and markedly impaired quality of life for patients and their families.^{2,3,4} In assessing and diagnosing these disorders, clinicians depend primarily upon expert history taking and examination.

The diagnosis and treatment of difficult-to-measure disorders and medically unexplained symptoms have long been complicated by individuals with these disorders being stigmatized by clinicians, the general public, and sometimes by patients themselves.⁵ From ancient Egypt to Charcot to the modern health care system, patients with difficult-to-measure disorders—and especially women and other marginalized populations—have been dismissed as “hysterical,” deceitful, and even dangerous.⁶ In part because of the lack of biomarkers, there are sometimes limitations to the amount and quality of quantitative evidence regarding the etiologies and treatments of these disorders, leaving clinicians to make important clinical judgments and to counsel patients on the basis of limited information. Here, we evaluate risks of harm and obstacles to helping people with difficult-to-measure disorders and offer recommendations for diagnosing and treating these disorders, focusing on minimizing **risks of harm from stigma** and maximizing opportunities for benefit through diagnosis.

Harms

Among what many regard as 4 foundational principles of modern medical ethics, the principle of nonmaleficence requires clinicians to avoid actions that harm their patients and to take action to minimize harms.⁷ Diagnosis of a medically unexplained symptom incurs real risk of harm to patients, most notably in the form of stigma.^{8,9} Stigma is the assignment of disfavor or negative moral value to a characteristic that distinguishes an individual or group from others and can be enormously damaging to stigmatized individuals, resulting in worsened prospects for employment,¹⁰ housing,¹¹ and health care,¹² and lower self-esteem and quality of life.¹³ The common occurrence of stigma affecting those with poorly measured disorders raises special ethical concerns for clinicians caring for these patients.

Studies of stigma in the health care system identify 3 avenues through which stigma can harm patients.¹⁴ *Public stigma* encompasses negative moral judgments made by

others—including clinicians, family members, employers, and the general public—about an individual or group with a specific diagnosis or other characteristic. Public stigma can lead to discrimination in multiple domains, including housing, employment, and health care.^{10,11,12} *Self-stigma* occurs when stigmatized individuals internalize and accept negative moral judgments about themselves, leading to diminished self-esteem, self-efficacy, and self-investment, as well as self-caused impediments to the pursuit of life goals.¹³ *Label avoidance* occurs when individuals avoid the health care system in order to avoid a diagnosis associated with negative moral judgments. Patients with difficult-to-measure disorders and medically unexplained symptoms are at risk for harm from stigma through all 3 of these pathways.

Clinicians heeding the ethical principle of nonmaleficence need to take the problem of stigma seriously. Addressing stigma begins with empathic, nonjudgmental patient-clinician communications and extends to active advocacy for and education of patients and family members concerning available support services and legal protections from discrimination. Empathic, nonjudgmental communications may be enhanced in some circumstances by the use of inclusive person-centered or person-first language,¹⁵ although some individuals and groups within disability communities may not endorse such language. Clinicians can better understand individual patients' perspectives by asking them about their preferred terminology. Advocacy and educational efforts are often most effective when *physicians and nurses collaborate* with social worker colleagues and advocacy organizations and when patients participate in peer support.¹³ Interventions to enhance self-efficacy and patient-centered decision making can further reduce the negative impact of stigma.^{16,17}

Although stigma can cause inadequate medical evaluation and treatment, patients with difficult-to-measure disorders generally—and with medically unexplained symptoms in particular—also face significant risk from excessive testing and misdiagnosis.^{18,19,20} Misdiagnosis can result from false positive test results or incidental findings unrelated to a patient's symptoms. For example, the majority of patients with functional seizures (a common form of functional neurological disorder) are misdiagnosed with epileptic seizures for multiple years and treated with antiseizure medications that provide no benefit but cause real adverse effects.²¹

Rigorously evaluating patients' symptoms and concerns, while also avoiding unnecessary and potentially harmful tests and treatments, is a difficult balance requiring significant clinical judgment. This judgment requires clinicians' sincere attention to patients' perspectives and also a willingness to offer strong, clear recommendations based on clinical experience and the limited but growing body of evidence concerning these disorders. Seeking interdisciplinary expertise, including from consult-liaison psychiatry and neurology, can be extremely helpful when challenging clinical judgments must be made. In the case, a specialist is consulted who elicits the patient's experiences of her disorder and stigmatization through reflective listening. The clinical specialist and patient partner together to address instances of public stigma (the psychotherapist's reluctance to provide treatment, the insurance company's refusal to pay for physical therapy, the nurse's disparaging comments), avert self-stigma, and ensure access to an interdisciplinary team.

Opportunities

Providing an accurate diagnosis requires a clinician's time, energy, and collaboration with both patient and colleagues. As clinician and patient come together to understand

the nature and implications of a patient's symptomatology, a clinician heeds the bioethical principle of beneficence, and a meaningful patient-clinician relationship and clinical approach can emerge. Diagnostic labels disconnected from a patient's experience and needs carry risk of stigma, unnecessary interventions, and harm.²² Conversely, a diagnosis that engenders understanding of a patient's lived experience can provide benefits, including closure on a prolonged diagnostic period and an end to the risks of diagnostic inquiry. A meaningful diagnosis also engenders a strong patient-clinician relationship, in which patients feel understood and stay engaged with the medical system. Such a relationship facilitates ongoing care for all dimensions of health, both related and unrelated to a primary diagnosis (eg, routine health care screenings and preventive care). Furthermore, a diagnosis allows for evidence-based treatment when possible and, when none yet exists, for referral to experts who can optimize care using best practices, educate a patient's other clinicians about the diagnosis, engage patients in research, and reduce isolation by connecting patients with peer mentors and community support.

Moreover, as health care systems begin to address **systemic ableism**, individuals with medically unexplained symptoms will be able more fully to experience the aforementioned benefits of diagnosis. Ableism is a pervasive form of discrimination based upon the assumption that life without a disability is preferable to life with a disability, and it contributes to the stigma that individuals with medically unexplained symptoms face.²³ Acknowledging the implications of ableism may help foster opportunities for clinicians and institutions to identify and address biases in care for individuals with all types of disabilities.²⁴

Diagnoses can also create opportunities for patients to become active agents in the management of their own illness. For example, a diagnosis can allow patients and families to create or join **patient advocacy organizations**. These organizations serve important roles in raising awareness about disease symptoms and treatment, providing services to patients, and promoting research on cures and prevention.²⁵ Clinicians involved in medical education can also empower patients as teachers by inviting them to speak about their experiences to medical students.

In addition to assigning a diagnosis, prescribing evidence-based treatments when available, and referring patients to available experts and resources, clinicians should also provide thoughtful documentation in notes and in the medical literature to foster culture change within the health care system. In their writing, as in their speech, clinicians should model person-centered language—unless a patient prefers otherwise—and an empathic, compassionate attitude toward individuals with difficult-to-measure disorders and medically unexplained symptoms.²⁶ By taking these steps, clinicians can enhance patient welfare and empower patients to make meaningful health care decisions, in line with the bioethical principles of beneficence and respect for autonomy.

Case Revisited

Three months later, J was thriving in physical therapy and psychotherapy. Dr R had supported J's appeal to her insurance company with a letter including references to published guidelines calling for the use of physical therapy in the treatment of functional movement disorders. J and Dr R had jointly called J's psychotherapist to discuss her diagnosis and plans for treatment with cognitive behavioral therapy. Finally, Dr R had connected J to a patient advocacy organization through which she had enrolled in a clinical study and was leading a peer exercise group.

Caring for patients with disorders lacking biomarkers requires clinicians to be sensitive to the implications of the diagnoses they assign. When clinicians act in accordance with bioethical principles, they acknowledge and address the realities of stigma; they describe symptomatology and approach diagnoses in ways that facilitate patient engagement; they take patient-reported symptoms seriously and evaluate patients with rigorous history taking and physical examination while avoiding unnecessary tests and interventions; they consult relevant experts, including consult-liaison psychiatrists and neurologists when appropriate; they connect patients to pertinent resources, including social workers, research opportunities, and patient advocacy organizations; and they aim to strike a balance between benefit and harm associated with diagnosis. Although there is limited scientific evidence on treatment for patients with difficult-to-measure disorders and medically unexplained symptoms, it remains each clinician's duty to help patients flourish within the health care system and beyond it.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.



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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Questioning Biomedicine's Privileging of Disease and Measurability

Camille Kroll, MA

Abstract

Within biomedicine, the diagnosis of disease is often privileged over a patient's experience of illness. Yet up to 30% of primary care visits might be attributable to persistent illness without a diagnosed disease, including functional somatic syndromes like fibromyalgia and chronic fatigue syndrome. When clinicians are unable to diagnose disease or correlate symptoms with measurable changes in biomarkers, patients experiencing such an illness are at increased risk for suspicion, misplaced questioning, or having their motives misinterpreted through damaging social and cultural narratives about gender, race, ethnicity, socioeconomic status, or disability. Adhering strictly to a biomedical model of thinking about disease and diagnosis can prevent clinicians from empathically engaging with patients and helping them navigate their illness experiences.

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Biomedicalization

Traditional biomedical approaches often assume that physiological changes in bodies generate predictable, measurable effects. In this model of thinking, a patient's subjective experience of *illness* is validated mainly by empirical verification of the presence of *disease*. In contrasting disease with illness, I will be adhering to the distinction that psychiatrist and medical anthropologist Arthur Kleinman has made.¹ Practitioners of biomedicine focus on what they consider to be a distinct disease entity, with the patient's symptoms reliably correlating with an identifiable lesion or a change in biomarkers, such as fluctuations in vital signs or lab values. Illness, however, refers to the experiences and meaning making of both the individual with symptoms and his or her family and social network.¹ Within the **biomedical model**, illness with disease (such as the sore throat that is found to be caused by strep infection) and disease without illness (such as the often-asymptomatic conditions of diabetes or hypertension) are given greater epistemic authority than illness without disease. Accordingly, without a diagnosis of disease, a patient's pain might be questioned and interpreted through

damaging cultural narratives, such as those about gender, race, ethnicity, socioeconomic status, or disability.

Illness Without Disease

Individuals who experience illness without disease may be told that their illness is less real or even be accused of malingering.² Functional somatic syndromes, a group of chronic illnesses without disease that includes **chronic fatigue syndrome**, fibromyalgia, irritable bowel syndrome, chronic pelvic pain, and multiple chemical sensitivity, to name only a few, thus exist at the margins of biomedicine. These illnesses do not fit neatly into the biomedical model, and those who have them continue to suffer even when reassured by practitioners of biomedicine that they have no disease.^{3,4} Functional somatic syndromes are persistent and painful, lack organ pathology and abnormal lab results, and have symptoms that do not correspond to a “conventionally defined medical disease” diagnosis.⁵ In some estimates, up to 30% of primary care visits are attributable to patients with functional somatic syndromes, making this a significant yet often unacknowledged part of general medical practice.⁶

The chronic and intractable nature of these illnesses is what makes many practitioners feel at a loss when attempting to treat them.⁷ The initial specialist to whom the patients are referred often dictates their diagnostic path: “A gastroenterologist will probably diagnose IBS [irritable bowel syndrome], a rheumatologist ... fibromyalgia, and a gynecologist ... chronic pelvic pain syndrome.”⁴ Thus, many diagnostic names exist for the patient’s ultimately irreducible experience. The individual insists that something is corporeally wrong, and the practitioner of biomedicine attempts to reassure that individual that he or she is able to read the body better than the patient.⁸ The physician’s belief that the patient’s body is fine might result in a referral to psychiatry because of the sharp divide biomedicine maintains between mind and body.^{9,10,11}

It is important to remember that the medical gaze’s privileging of disease over illness was not the inevitable march of scientific progress. The **medical gaze** ascended to its current place of power in the 19th century in part due to the professionalization of medicine and its institutionalization in the clinic and in hospitals, as care stopped being delivered in the patient’s home.¹² The rise of biomedicine meant that patients and their healers no longer shared the conception of the body as a system interacting with its environment.¹³ Therapeutics became increasingly invisible, and patients were no longer able to witness them working, instead relying on the physician’s safeguarded knowledge. As visits more often occurred in the physician’s own domain rather than in the patient’s home, patients became further removed from their own care. In this new model, only the medical gaze could penetrate the opaque body to see whether disease was actually lurking and, if so, verify the patient’s illness.¹²

When physicians are unable to find the biomarkers of disease, they must inevitably rely on their own assumptions. In such cases, a diagnosis might be affected by the physician’s own implicit biases and his or her ideas about how sickness should appear.¹⁴ Clinical medicine is much less of a lab science and more of a hermeneutical endeavor than many admit.¹⁵ In the absence of a disease diagnosis, patients must appear sick enough to be taken seriously, but not so sick as to be suspected of exaggerating. For instance, a study published in the *Annals of Internal Medicine* explains to its readers—presumably, internal medicine physicians—that individuals with functional somatic syndromes often demonstrate “disability out of proportion to physical exam findings.”³ These subjective criteria encourage physicians to decide what are acceptable

levels of pain and functional impairment for certain conditions. For illness without a disease diagnosis, any pain may be questioned.

Physicians are taught to watch for the risk factors of functional somatic syndromes: female gender, low socioeconomic status, lack of education, a history of trauma (particularly sexual abuse as a child), actively seeking disability benefits, and comorbid medical and psychiatric conditions.^{5,16,17,18} As with all chronic illness, risk factors prime the physician's interpretation of the patient's illness.¹⁹ Once a patient has received a functional somatic syndrome diagnosis, he or she is likely marked for all future encounters. As psychiatrist P.D. White notes: "Probably the most replicated risk marker for a functional somatic syndrome (FSS) is that having one is strongly associated with having another."²⁰ We cannot know whether this stacking of functional somatic syndrome diagnoses is due to the specialization of medicine, physicians' biases and positionality, or a yet-to-be-identified underlying disease. However, that gender, socioeconomic status, and other culturally charged classifications are accepted risk factors for functional somatic syndromes empowers physicians to make potentially problematic judgments about how different types of people, such as women and those seeking disability benefits, should "normally" present, both inside and outside of the clinic.

Gender and Functional Somatic Syndromes

Although functional somatic syndromes vary in their gender distribution, women predominate in each condition, with the female to male ratio ranging from 2:1 to 6.8:1.⁷ Women's increased incidence of illness without disease cannot be explained away by biological differences or by an increased likelihood to present for medical examination and subsequent medicalization.²¹ Instead, a more phenomenological perspective must be considered that does not reduce a woman to her body's hormonal differences and ability to reproduce or to her allegedly fragile psyche. Negative life experiences, which women might be more likely to endure, cause invisible wounds and physical pain that is just as real as that caused by an organic lesion.²¹

The patient-physician relationship is inherently unequal. Furthermore, Western narratives often gender doctoring as male, so when the patient is female, the preexisting power imbalance is only augmented as gender inequalities come into play.²² Female patients' complaints are more often taken less seriously or dismissed as psychosomatic or hysterical.^{7,14,22,23,24} Women's pain is often read through moralizing cultural narratives that see women as less rational than men and more likely to be hypochondriacs.²³ Although women may experience illness without disease more often than men due to negative life experiences, they might also be more frequently given a functional somatic syndrome diagnosis because of the gendered cultural narratives they encounter.

Future Directions

How might physicians care for individuals with functional somatic syndromes? Many of these patients refuse cognitive behavioral therapy, antidepressants, or other psychological treatments because they worry that opening the door to a mental source of their symptoms might permanently close the door to finding a somatic cause.² Even if these therapies might help, as they often do in treating pain for patients with cancer, they must be rejected because, unlike individuals with cancer, those with functional somatic syndromes have not had their pain validated by the presence of disease.²

Some individuals with functional somatic syndromes seek acknowledgment of their suffering, something that the field of medical humanities has increasingly made possible by introducing narrative ethics into medical school education. These patients wish to partake in “joint storytelling”²⁵ with the physician, asking not necessarily to be given a traditional biomedical diagnosis but to have the physician help them make meaning out of their illness experience, empathically witness their pain, and acknowledge that biomedicine may not have all of the answers.^{1,24} Anthropologist Megan Crowley-Matoka advocates for cultural competency training that focuses not just on teaching physicians about patients’ cultures but also on a closer examination of the culture of biomedicine and physicians’ own assumptions.¹¹ Unfortunately, with the increasing bureaucratization of medicine and physicians’ often expected patient quotas, a renewed focus on and empathic attention to patients’ **illness narratives** may not always be possible. Functional somatic syndromes serve as an important reminder that physicians’ ability to care is often just as important as their capacity to cure.

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

How Pharmaceuticals Mask Health and Social Inequity

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Abstract

Medications, like all interventions, shape the ways in which physicians see disease, provide care, define successful outcomes, and organize health care systems. Pharmaceuticals make symptoms and biological drug targets more visible while rendering individuals and their social suffering invisible, thereby focusing our profession on the intracellular effects of an unequal society. This article uses psychopharmacology as a probe to trace a more general problem within contemporary medicine: the pervasive influence of biomedical narratives and therapeutic rationales extending from clinical practice, to medical education, to health care finance.

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Introduction

Medications, like all interventions, shape the ways in which physicians see disease and their roles as healers. Across medical specialties, pharmaceuticals influence the way physicians prioritize drug targets and biomedical (ie, biological and physiological) narratives of illness, shape clinical practice and health care systems, and obscure social contexts and interventions. The ubiquitous influence of medications on our understanding of illness and the practice of medicine is often hidden and uninterrogated. We begin by investigating the rise and evolution of psychotropic medications in psychiatry as a case study for examining the pervasive influence of medications on physicians and modern health care. We then reveal this phenomenon to be operating broadly within medical education and health systems financing. We conclude with recommendations for reversing this disturbing trend. This paper does not espouse a repudiation of pharmaceuticals but interrogates the ways they have made symptoms more visible while rendering individuals and their social suffering invisible.

Psychopharmacology in Context

When Nobel Laureate Paul Ehrlich coined the phrase *magic bullet* as he searched for a specific drug to kill the syphilis spirochete in the early 1900s, he expressed our modern ideal of disease and its treatment, in which the disease entity is biologically identifiable

and the treatment directly and specifically targets the pathogen or illness process.¹ For acute infectious diseases, nonbiological factors can be largely bracketed off when choosing an effective treatment. Yet most illnesses, especially chronic ones, pose more complications, as psychological, social, and cultural realities are embedded in pathophysiology and directly shape management decisions and outcomes. The infectious disease model hides contextual factors that are critical for understanding and treating a person's illness.

Psychiatry's growing dependence on psychotropic drugs in the treatment of mental illness is an exemplar of biomedical reductionism and provides an ideal probe into the ways that pharmaceuticals can have unintended and hidden consequences.^{2,3} Modern psychopharmacology began with the 1950 synthesis of chlorpromazine.² Although chlorpromazine was not expected to be a psychotropic drug, psychiatrists soon discovered that this new agent treated some of the core symptoms of psychotic disorders, such as hallucinations, agitation, and disorganized thinking. Not only did chlorpromazine become one of the first blockbuster drugs of the 20th century, its success led other pharmaceutical companies to produce similar drugs that would later be called antipsychotics.²

While psychiatrists readily adopted these new drugs, their use did not necessarily dictate a reductionistic view of psychiatric disease and its treatment. Typically, psychiatrists saw medications as adjuncts to the more fundamental talk and social therapies. This orientation is apparent in an excerpt of a 1955 medical record, in which a state hospital psychiatrist who prescribed chlorpromazine for a young man upon his admission clarified: "The patient appears to be responding to Thorazine, reducing his agitated behavior. This is only an added effect. It is not affecting the components of his illness."⁴ The core of the illness was complex, involving unconscious conflicts and family relationships:

The father appears to be very rigidly and aggressively domineering, and the mother appears to be a warm and loving, but ineffectual, parent. There appears to be a great deal of conscious and unconscious hostility between these parents.... It is possible that the patient is torn between the desire to act out his father's hostility and the desire to be more positive or submissive like his mother. Official Diagnosis: schizophrenic reaction.⁴

Psychoanalytic and psychodynamic thought had reached its zenith in American psychiatry by the early 1960s. In 1962, for example, 90 of 91 medical schools taught students psychodynamic psychotherapy, and 52 of 89 psychiatry departments were led by members of psychoanalytic institutes.⁵ As this case illustrates, far from creating a new therapeutic rationale, psychotropic drugs fit easily into existing psychodynamic paradigms in which psychological, familial, and social forces were seen to be as important as biological ones in shaping illness and its outcome.

The dizzyingly rapid emptying of state hospitals from the late 1960s to the end of the 20th century is seen by some as a pharmaceutical triumph, proving that psychiatric illness had been traced to its biological roots, enabling recovery in the community.⁶ Historical analysis, however, shows that drugs played, at best, a secondary role in **deinstitutionalization**.⁷ From the mid-1960s, state hospital closures were driven by fiscal crises of state governments, the passage of Medicaid and Medicare, and ideological beliefs about community care.⁷ This sequence of events, not medications, propelled deinstitutionalization. Moreover, the push to empty state hospitals and shift care into the community, accompanied by fiscal pressures to quell psychotic symptoms rapidly

with few of the promised resources of the 1963 Community Mental Health Act, compelled the rise of psychotropic medications as psychiatrists' primary treatment modality.⁸

Biological Reductionism

Historical misattribution of deinstitutionalization to the emergence of psychotropic drugs provides a window on a larger transformation of American medicine in which our therapeutics—largely in the form of pharmaceuticals and biologics—have come to define our understanding of illness. In 1976, sociologist Nicholas Jewson described the evolution of medicine from “bedside,” to “hospital,” to “laboratory” medicine, with the subject of the physician’s focus moving from the whole person, to anatomic structures that manifest disease, to cell complexes, respectively.^{9,10} Reflecting this evolution, schizophrenia came to be understood as an excess of dopamine, and depression, as famously described by Tipper Gore, as a deficiency of serotonin, “like [your brain] running out of gas.”¹¹ Biologically **reductionistic illness narratives** emphasize intracellular processes and drug targets and hide from view the complex, intersecting levels of disease causation, illness experience, and outcomes that are as much social as biological. None of this is to deny the often lifesaving importance that our biological therapeutics provide, yet this transformation of American medicine, reinforced by medical education, is so thorough that it can be difficult to see.

Medical schools dedicate semesters to organ systems and understanding the pharmaceutical mechanisms of action on intracellular targets but, in general, dedicate relatively little time to teaching students about the cities in which they live and the ways in which local laws and social conditions create inequitable burdens of illness and death.¹² When the social world is included in illness models, as in the allostatic load model of chronic stress¹³ or the 2-hit model of tumorigenesis,¹⁴ it is funneled into broad categories of psychosocial and environmental stressors that activate neuroendocrine or transcriptional regulation of genes, respectively, directing physicians’ gaze intracellularly instead of to the social world itself.^{13,14,15} Similarly, the Centers for Disease Control and Prevention’s report on the 10 leading causes of death in the United States lists only 2 causes of death, suicide and unintentional injury, without clear biological targets.¹⁶ Missing from this list are social forces, laws, institutions, and the environment, demonstrating how thoroughly causes of death and health are understood to reside within the body, within cells. This sidelining of the social world or its translation into targets for drug intervention strips away the specificity of our patients’ sociopolitical contexts and demonstrates contemporary medicine’s obsession with mitigating the intracellular effects of an unequal society.^{10,16}

Health Systems Financing

Biological therapeutics have come not only to define our understanding of illness and treatment, but also to be encoded in our medical economy, circumscribing physicians’ work and health care systems’ priorities. Medical reimbursement constructs, such as medical necessity determinations, Current Procedural Terminology (CPT®) codes, and relative value units (RVU), imbue biomedical interventions with monetary value while marginalizing “cognitive” visits that involve complex social interventions to address patients’ social determinants of health.^{17,18} Within these rubrics, for example, the act of prescribing a medication defines moderate-to-high medical decision-making complexity, which in turn justifies higher financial reimbursement.¹⁹ By contrast, social determinants of health are recorded using Z codes, which are a group of codes for the “factors influencing health status and contact with health services,”²⁰ within the *International*

Classification of Diseases, Tenth Revision.^{21,22} These Z codes are assigned zero monetary value.^{21,22} A subsidiary industry of physician conferences, medical billing specialists, and undergraduate and graduate medical curricula have been developed to teach physicians how to code to maximize reimbursement, with little reflection on the biological narratives that shape this economy.^{23,24,25}

Medical necessity determinations, CPT and Z codes, and RVUs elevate, incentivize, and monetize biomedical expertise and interventions, which in turn shape the everyday work of physicians and health care systems.²⁶ Physicians confronted with patients' complex social needs face financial pressures that are in conflict with their desire to engage in the complexity of their patients' sociostructural lives, despite the profound effect such engagement would have on illness trajectories.¹³ The financial constructs above do not reward physicians for tackling the fundamental sociostructural causes of illness, such as housing and environmental policies, by advocating for social change, despite the impact that advocacy would have on health inequity at a public health level.²⁷

Alternative models for health care system organization and funding exist that elevate social interventions, including some value-based care models, integrated budgets across health care and social services, and social prescribing models, to name a few examples.^{28,29,30,31,32,33,34} These demonstrate the promise of structural reforms that reinforce multidimensional conceptualizations of illness, treatment, and physician labor in addressing social inequity.

Reform

The belief (especially among psychiatrists) that antipsychotic drugs emptied the state hospitals helped make that historical moment more palatable. As the narrative went, state hospital closures were ushered in by scientific advancements. The quick cures that were envisioned, unfortunately, have not come to fruition, nor have pharmaceuticals comprehensively addressed the needs of patients leaving state hospitals, contributing to social inequity in the form of homelessness and the reinstitutionalization of people with mental illness in jails and prisons.³⁵ To reiterate, pharmaceuticals and biomedical narratives of illness have made symptoms more visible and individuals and their social suffering invisible, but countering this trend requires more than a simple call for humanism in medicine.³⁶

As physicians, we have obligations to ensure that our narratives reflect the realities of our patients' illnesses, rather than reinforcing just-so stories constructed from political and economic exigencies of health care systems' profit maximization and American neoliberal tendencies toward **free-market capitalism**, reduced government spending, privatization of public services, deregulation, and a hyperfocus on individual responsibility. The reality of our patients' health, at the population level, has been shown to be driven more by socioeconomic contexts (eg, income, neighborhood safety) and the physical environment (eg, pollution, housing conditions) than by health care access and quality.³⁷ Multidimensional narratives that highlight the social and environmental causes of illness demand that health care systems and financial structures incentivize and support social interventions, recognizing the profound effect of unmet social needs on our patients' health.^{28,29,30,31,32,33,34} Such narratives also call on physicians to develop new skills to ameliorate the laws, policies, institutions, and systems (both within and outside of health care) that make our patients sick and are at the root of health and social inequity.²⁷

Medical education reforms can be a starting point for this renegotiation of physician expertise.¹¹ We must insert **structural competency**, health equity, and social responsibility into medical care and ourselves into sociopolitical movements, in humble allyship with community leaders and for the benefit of our most vulnerable patients.¹² To guide such reforms, we can look to leaders like those in the Student National Medical Association who put forward a detailed “Petition for Racial Justice in Academic Medicine and Research,” which calls for a thorough integration of structural competency, anti-oppression, and antiracism in medical curricula and urges reforms to support Black, Indigenous, and other minoritized professionals in medicine.³⁸ Alongside other social medicine and medical education researchers, these student leaders recognize that medical education without “structural or socioecologic context inevitably reinforces an inadequate and detrimental understanding of how to best treat our patients” and that “individuals and institutions—including academic medicine and research—perpetuate systems of inequality” that in turn fuel health and social inequity.³⁸

To counteract biomedical reductionism, we must embrace, as medical historian Jeremy Greene and physician Joseph Loscalzo describe, a multidimensional (biological, psychological, social, environmental, political, and historical) understanding of illness and illness causation.¹⁰ As individual physicians, we must develop the skills to activate social resources to address the root causes of our patients’ suffering, and our health care systems must adopt structural reforms (eg, reforming physician reimbursement) and cross-sector partnerships to support this work. As adequate social safety nets do not exist in many American communities, physicians must also learn the **skills of advocacy**, and structural action must be built into our job descriptions and the everyday work of our institutions.^{39,40} This historical moment has revealed that our vision of disease and treatment, if it is to reflect our patients’ realities, requires a new engagement with our patients—one that makes individuals and their sociopolitical and psychological lives more visible and that places the physician in partnership with communities to address social needs and heal injustices.

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

A Call to Update Standard of Care for Children With Differences in Sex Development

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Abstract

For years, physicians have debated how best to care for children with differences in sex development (DSD, also termed *intersex*). Stories of suffering of adults who underwent early surgical intervention for DSD have led many health organizations to call for deferral of unnecessary procedures. While some have instituted full deferral of cosmetic procedures, standard of care remains an interdisciplinary team approach informed by parents' wishes. As the medical community hesitates to institute full deferral, citing absence of long-term data, legislation restricting early procedures is mounting. This article highlights recent data from the DSD-LIFE Study and considers whether and to what extent they support deferral.

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Sex Development and Best Interests

Differences in sex development (DSD, also termed *intersex*) comprises multiple diagnoses in which there is a congenital condition with inconsistent chromosomal, gonadal, or anatomic sex development.¹ These conditions provoke many questions: What are the potential health risks and **future fertility options** for children with DSD? What surgeries should be offered to parents of children with DSD? What gender should parents raise their child, and what will be the gender identity of the child? Grounded in the historical notion that gender and anatomy are linked, surgical interventions have been performed on infants to align their anatomy with their "optimal gender," often chosen for them based on potential for heteronormative sexual relationships.^{2,3,4} Today, intersex children continue to receive early cosmetic genital surgery at medical institutions across the United States and worldwide.^{5,6,7} As we discuss here, whether or not to perform early surgical intervention has been framed as a bioethical conflict between upholding the bodily autonomy of the child vs acting on behalf of what are perceived to be the child's best interests. Yet there is little evidence to show surgical intervention supports these children's best interests.

Are Early Surgeries Best?

In 2016, the Global DSD Update Consortium consensus statement reiterated its 2006 recommendation of a multidisciplinary team approach for children with DSD to help ensure that the patient and family were being provided optimal and thorough counseling. This recommendation focuses on **shared decision making** with the parents.⁷ Some have argued that when patients are too young to make their own decisions, the most ethical thing to do is to honor the preferences of parents—who are legally entitled to make health decisions for their minor children—when it comes to surgical interventions.⁸ With this position, however, there is the danger of prioritizing parental wishes and anxieties over supporting the child’s autonomy.⁹

Many individuals upon whom these procedures were performed have come forward as adults to share their dissatisfaction and health complications.^{5,10} National intersex organizations, such as InterACT, have formed worldwide and advocate for the cessation of early surgical intervention on intersex children.¹¹ Members of this community have produced movies and books sharing how the medical interventions performed on them resulted in both physical and psychological harm.^{12,13} Some of these interventions include clitoral reduction, vaginoplasty, and gonadectomy and are accompanied by multiple genital examinations.^{10,12,13} Supporting these stakeholder claims, many prominent national and international health organizations and legislative bodies have issued recommendations arguing for deferral of elective procedures until the child can actively participate in the decision-making process (see Table).

Table. Organization Statement Timeline

Year	Organization Statement
2013	WHO issues a statement that called for the cessation of medically unnecessary surgeries and sterilizations on individuals born with DSD. ¹⁴
2014	Provisional section on LGBT health and wellness of the AAP states that medically unnecessary irreversible procedures can be postponed until a child “is old enough to agree to the procedure.” ⁵
2015	Six UN committees call for regulation of medical interventions of nonconsenting intersex individuals. ¹⁵
2016	GLMA: Health Professionals Advancing LGBT Equality issues a recommendation to delay all medically unnecessary surgeries on intersex children until they “can provide informed consent/assent” (excepting procedures addressing emergent medical need). ¹⁶
2017	Physicians for Human Rights issues a statement calling for deferral of unnecessary surgical procedures on intersex children before they can “give meaningful consent.” ¹⁷
2017	Former US Surgeons General Joycelyn Elders, David Satcher, and Richard Carmona determined that current research does not support performing cosmetic genitoplasty on infants. ¹⁸
2018	California Senate passes SCR-110, which recommended delaying any procedure on children with DSD until the “child is able to participate in decisionmaking.” ¹⁹

Abbreviations: AAP, American Academy of Pediatrics; DSD, differences in sex development; LGBT, lesbian, gay, bisexual, transgender; UN, United Nations; WHO, World Health Organization.

Despite the stated positions of reputable health organizations and legislative bodies and anecdotal reports of suffering, a battle has engulfed the medical community regarding deferral of elective surgical interventions. Arguments for deferral focus on protecting the bodily autonomy of the child and preventing **potential harm** that can come from an irreversible intervention.²⁰ Harms cited that can carry significant implications as a child matures include a sex assigned at birth that does not align with the individual's eventual gender identity and surgical complications that affect sexual functioning.²⁰ In favor of early surgical intervention is the argument that a child with ambiguous genitalia could face psychosocial distress because of this difference as well as the belief that younger children heal more easily and will not remember undergoing surgical correction.^{21,22,23} However, these arguments have little supporting data, while data supporting the opposite position continues to mount. There is an accretion of data that early interventions, their inevitable medical follow-up, and frequent need for surgical revisions later have led to the development of psychological distress.^{5,10,18} Supporters of early surgery counter with claims that these reports are anecdotal and that there is insufficient high-quality outcomes data to support deferral.⁹ However, this argument from inadequate evidence is equally applicable to the outcomes data referenced to support continuation of early, elective surgical interventions.

Evidence and Deferral

Organizations have repeatedly found that the data are insufficient to support DSD procedures as necessary, beneficial, or safe. In 2012, the Working Party on DSD concluded that more rigorous outcomes studies are needed to evaluate the success of early genitoplasty, noting that surgery for some conditions is associated with impaired sexual function and quality of life.²⁴ The Global DSD Update Consortium 2016 consensus statement, updated from the 2005 International Consensus Conference on Intersex, similarly concluded that current data is inadequate regarding key aspects of DSD interventions, including sex assignment and surgical outcomes.⁷

The latest and most rigorous study that assesses long-term outcomes of patients with DSD appropriately compares large samples of individuals who did and did not have surgical interventions. In the DSD-LIFE study, participants who had Turner syndrome, Klinefelter syndrome, congenital adrenal hyperplasia (CAH), or XY-DSD were recruited from 14 European clinics.^{25,26} Researchers examined rates of gender change and dysphoria as well as components of sexuality in this population. For those with CAH, rates of anorgasmia and genital anesthesia were higher among those who had undergone surgery than among those who had not.²⁵ Those who had undergone surgery also reported less intercourse and experienced more difficulties with vaginal penetration.²⁵ Across DSD conditions, having had genital surgery was negatively associated with satisfaction with sex life.²⁵ For those with DSD conditions other than Turner and Klinefelter syndromes, rates of gender dysphoria and subsequent gender transition after puberty were higher than in the general population.²⁶ This study is one of the first to examine quality-of-life outcomes in a large adolescent and adult sample with DSD. These results support deferral of intervention, as DSD individuals were more likely to change assigned gender than the general population.²⁶ The study's concerning findings that those who had undergone surgical intervention had worse sexual health outcomes add to the growing anecdotal reports of harm shared by members of DSD communities.

Part of the reason it has taken so long for changes to be made in the care of children with DSD can be attributed to how the biomedical community ranks the quality of

information according to the hierarchy set forth by the evidence-based medicine (EBM) model.²⁷ In medicine, anecdotes and case reports are considered the lowest quality of data on which to base standards of care. Relegating anecdotal information to a lower tier has been called into question, as it can hinder communication between doctors and patients and delay updates in care models.²⁸ Anecdotes can be interpreted through the lens of autonomy, as bioethicists recognize that to truly uphold patient autonomy, one must respect the individual experiences that motivate a patient's decision making and ownership of their narrative.²⁹ The EBM model is a step forward in clinical practice, but we must recognize that it can unintentionally devalue patient experiences and thus autonomy.

Defining Normal and Optimal

The parental role in a pediatric surgical intervention decision is critical, and a shared decision-making approach is the current standard of care. Critiques of this model highlight that gaps in parental knowledge of DSD hinder parents' perceived and actual participation in these decisions.²⁰ Lack of common understanding of DSD elevates the importance of what information is provided to parents during the decision-making process. One study analyzing parent-clinician interactions found that discussion of surgery to "normalize" the child's anatomy prevails over discussion of the controversies that surround early surgery and the child's autonomy.³⁰ True **informed consent** requires an increased emphasis on the clinician's responsibility to protect the child's autonomy in these discussions. This responsibility includes describing new outcomes data and mention of the multiple organizational calls for deferral of surgical intervention.

More recently, Boston Children's Hospital and the Ann and Robert H. Lurie Children's Hospital of Chicago have stated they would stop performing certain cosmetic genital surgeries on children born with DSD.^{31,32} However, in our experience, clinicians and professional societies hesitate to follow suit or update what constitutes standard of care. Given the growing frustration of health organizations and organizations representing the interest of DSD communities, legislative bodies have begun to recommend deferral of nonessential surgical interventions on children with DSD. Passed in August 2018 in California, Senate Concurrent Resolution 110 recommends delaying any procedure on children with DSD until the individual "child is able to participate in decision making."⁴⁹ The associated bill did not advance out of committee, but efforts toward its passage are ongoing in California, with similar legislation being developed in other states.^{33,34}

Medical experts and patient advocates alike continue to call for more research to determine the optimal treatment for children born with DSD. Meanwhile, reports of suffering by those in the intersex community continue to be devalued, as such anecdotal reports do not take the form of privileged evidence. The new data highlighted in this article and in health care organization statements reinforce the multitude of anecdotes that support deferral. We call on clinicians to heed these repetitive calls to action and to recognize that when an individual is born with atypical genitalia that poses no physical risk, treatment should focus not on surgical intervention but on psychosocial and educational support for the family and child. Cosmetic genitoplasty should be deferred until children are old enough to voice their own views and meaningfully assent to undergoing surgery.

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Invisibility of “Gender Dysphoria”

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Abstract

Tension between naming *gender dysphoria* to render an important kind of suffering among transgender people more visible and avoiding pathologizing experiences of transgender people in a gender-binary world can be keenly felt among patients seeking gender-affirming services. This article suggests why clinical “verification” of a patient’s need for gender-affirming care is likely less important than clinicians’ expressions of empathy and respect for patients’ autonomy. This article also suggests that fostering transgender patients’ sense of agency should be prioritized.

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What’s Wrong With Verification?

The consequences of extended, untreated *gender dysphoria*, as it’s called in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, are observable in higher rates of suicide and mental illness among transgender patients; gender-affirming care reduces these patients’ suicide risk significantly.^{1,2} Harder to observe and measure is the pain and suffering of transgender people struggling to access gender-affirming care. Such suffering stems from a **biomedical epistemology** that privileges objective and measurable data over subjective experience. This privileging of measurement becomes more problematic the further a patient’s subjective experience of gender departs from societal norms. When subjective experiences are not shared, a patient’s words are harder to understand and believe.³ As such, it makes sense that physicians turn to empirically verifiable test results. In the case of gender dysphoria, however, such an endeavor is, we argue, unethical because it requires a patient’s participation in their oppression in order to be seen as eligible for services.

Transgender patients seeking care suffer for 2 important reasons: first, because their symptoms cannot be measured or visualized using technology; and second, because their experiences of gender are outside the norm and counter to the hegemonic **binary notion of gender**. It is the combination of these factors that makes accessing gender-affirming care particularly challenging. We argue that the medical establishment must

do more to validate the lived pain of transgender patients and ensure equitable access to gender-affirming care by removing barriers and additional gatekeeping and verification measures that make access to care more difficult. In this article, we will first approach the problem from a traditional bioethics lens, arguing that medicine should take more seriously the autonomy of transgender patients and that it unnecessarily privileges the principle of nonmaleficence by presuming that we must protect transgender patients from the consequences of their own decisions. Next, we will present an urban bioethics framework and argue that a stronger focus on agency and social justice should further motivate medicine to take seriously the experiences of transgender patients and remove **unnecessary gatekeeping measures** that make it more difficult to access gender-affirming care.

Expressing Empathy and Respect for Autonomy

Autonomy, one of the highest pillars of traditional bioethics, refers to the rights of competent adults to determine what happens to their own body. Rights are never unfettered, however, and the right to autonomy doesn't mean that patients alone dictate their medical care; in practice, patient-clinician relationships should be partnerships.

Transgender patients attempting to access gender-affirming care, however, more often find their encounters with clinicians to be adversarial ones, wherein their experiences of suffering are met with burdensome verification measures. For example, clinicians generally use an informed consent model for adults with decision-making capacity—as long as the intervention is within standard of care for the patient, the patient should be informed of the risks and benefits and can freely choose the intervention. Informed consent is seen as the clearest way to protect autonomy. However, in the case of hormone therapy for transgender care, even though professional societies are beginning to recommend an **informed consent model**, many physicians deem themselves unable to assess whether the transgender patients they treat are competent to make decisions about their own bodies.⁴ These physicians might suspect that gender dysphoria is itself a sign of other mental illnesses and that a patient might regret a decision to initiate care.

Thus, in an attempt to privilege nonmaleficence over autonomy, physicians require other clinicians, typically mental health professionals, to verify the assessment by asking for letters that lend medical credence to the patient's wishes. In a national survey, one-third of transgender people reported having a negative experience with physicians, including having to educate them about transgender care and "being refused treatment."⁵ This level of due diligence disproportionately affects transgender people, especially given data suggesting that regret after gender-affirming care is "exceedingly rare."⁶ Requesting additional verification measures when such measures are overly burdensome or stigmatizing is problematic, particularly when the rationale is not fully evidence based. Transgender patients' experience of having their subjectivity reframed as a potential mental health problem is dehumanizing.⁷ Privileging nonmaleficence thus results in a shrinking of transgender patients' right to autonomy.

The health care experiences of patients seeking gender-affirming care can be contrasted to those of other patients seeking care primarily for conditions the subjective experience of which can be considered within the range of "normal" for cisgender people. Treatment for erectile dysfunction is illustrative. The American Academy of Family Physicians suggests that a history and physical are sufficient to diagnose erectile dysfunction and that a few simple tests can also be performed to rule out organic

causes.⁸ Rarely is there an extensive vetting process to establish the truth of this form of suffering. The autonomy of the patients who suffer from it is respected, and the condition is treated with well-studied pharmaceuticals. Transgender patients' pain and suffering, on the other hand, is often subjected to double and triple verification before these patients can access gender-affirming care. When patients are outside the cisgender or heterosexual norm, their experiences may not be believed, and extra measures are taken to "protect" them from the harm of a wrong diagnosis or intervention they might later regret. However, when patients are squarely within the norm, even when their suffering cannot be objectively verified, physicians nonetheless take their self-reports at face value.

It could be argued that, because helping some transgender patients motivate authentic expression of their gender identity requires invasive surgical interventions with permanent consequences and potential for harmful complications, gatekeeping is warranted. On this view, it does make sense to institute system-wide protections to ensure that the clinical intervention is warranted and will be, on the whole, more beneficial than harmful. However, it is imperative that gatekeeping measures are narrowly tailored to the circumstances and data and that they minimally curtail autonomy. For example, in recent years, we have come to understand the dire consequences of overprescription of opioids without sufficient tracking and strong history taking.⁹ As a result, the medical field has instituted several gatekeeping measures in an effort to balance the benefit of pain relief with the potential harm of substance use disorder. However, most of these gatekeeping measures involve burdens to physicians, pharmacists, and systems (such as tracking physician prescription habits, maintaining databases, and requiring physicians to receive special permission to prescribe opioids), not to patients themselves.¹⁰ Even our most urgent efforts to address overprescription do not involve verifying that patients' pain is real. Again, when patients' subjective experience is within the norm, gatekeeping efforts to verify their claims of suffering do not emerge. The further away a patient's experience is from the norm, however, the greater is individual and systemic disbelief in that experience, a trend best demonstrated by studies that show that Black patients' pain is taken less seriously than White patients' pain.¹¹

We argue that gatekeeping for gender-affirming care is out of proportion to the potential consequences that could result from removing barriers precisely because transgender patients' experiences of pain and suffering are treated as less creditable, whereas being able to freely access gender-affirming care reduces risks of harms, such as life-long suffering and suicide.¹² In fact, autonomy and beneficence can both be adequately protected using an informed consent model for gender-affirming care, as was eloquently argued in another article in this journal.¹³ Supplemental gatekeeping measures that burden transgender patients and treat their experiences as inherently not creditable only serve to reify hegemonic cisgender and heterosexual norms.⁵

Agency and Social Justice

We now turn our attention to urban bioethics, a subset of bioethics that enhances the traditional ethical principles, to more thoroughly consider equity and social context in relation to gender-affirming care. In this framework, the concept of autonomy is broadened to include agency (the ability to execute one's right to self-determination), and justice is broadened to include society as well as individuals.¹⁴

Already, we have seen that a stronger reliance on informed consent and moving away from gatekeeping measures can both be protective of autonomy and promote beneficence. Considering agency makes the case for patient autonomy even stronger. Agency refers not only to a patient's ability to execute an autonomous choice, but also to the actual range of actions that are plausible for a particular patient within their social context. Clinician discrimination, happenstance of geography, and differential access to the resources required to overcome gatekeeping barriers all represent impediments to transgender patients' agency. For example, national surveys indicate that transgender patients have difficulty accessing health care for a multitude of reasons, including denial of coverage for certain services, experience of discrimination or harassment, and fear of being mistreated, all of which are compounded by employment and socioeconomic barriers.⁵

Whether transgender patients can fulfill gatekeeping demands will vary depending on their context. When it is not strictly necessary, asking a patient for verification of their suffering in the form of referrals to or letters from other clinicians becomes burdensome, especially if that patient has insufficient insurance coverage or scheduling or transportation problems, for example. The need to reduce patient burden is all the more reason why an informed consent model should be employed when caring for transgender patients: it would allow clinicians to better understand a patient's wishes in context rather than relying on verification of suffering from other sources deemed more credible, enabling transgender patients to exercise their own agency.

When we consider the need for gender-affirming care of transgender patients, especially those at the intersection of other marginalized identities, we must center social justice. For example, transgender patients who are also Black and poor are more likely to be homeless, without strong social support, without health insurance, and exposed to more violence.¹⁵ While it might not be difficult for some transgender patients to obtain letters from therapists or meet other gatekeeping requirements, it is certainly difficult for others, especially Black transgender patients, who may be unable to access mental health care or who fear violence, not unreasonably, if their identity is exposed. Requiring proof of suffering to affirm identity is both a product of and a contributor to racism and cissexism. A commitment to social justice requires that we do not institute system-wide gatekeeping measures that disproportionately burden the already vulnerable among us.

The default assumption that being cisgender and heterosexual are the norm is the reason for the unduly burdensome gatekeeping to which transgender patients are subject. When a patient's chief complaint is not objectively verifiable in the ways that medicine teaches, it is even more important that we teach future physicians to be comfortable with immeasurable truths and to cultivate understanding and empathy at the intersection of marginalized identities. We call for critical reevaluation of our evidentiary expectations and a foregrounding of the subjective experience of the least visible and most marginalized among us—a move away from a purely positivist epistemology to a worldview that recognizes that subjective truths can also be valid, embodied truths that only patients themselves can know.

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Bisexual Women's Invisibility in Health Care

Carly P. Smith, PhD and Daniel R. George, PhD, MSc

Abstract

Invisibility of racial and ethnic inequity in clinical research means many important features of disease etiology and symptom presentation are often unaccounted for. Similarly, binary (ie, gay or straight) definitions of sexuality render bisexual women's experiences invisible, and this invisibility has 2 important consequences for minority groups' members' health, which this article considers.

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Binary as Paradigm

Philosopher of science Thomas Kuhn argued that entities or phenomena incompatible with a current paradigm in a scientific field are not recognized for what they are, or possibly not seen at all, since paradigms discourage unexpected discoveries.¹ Continued invisibility of bisexual women in medicine, we argue, demonstrates this dynamic and too often blocks bisexual women's access to resources, including care. Making access to health services equitable will require paradigm-shifting confrontation with cultural biases and dismantling of persistent myths that have generated and sustained bisexual women's invisibility in health care.

Starting in 2011, the US Department of Health and Human Services (HHS),² the Institute of Medicine (IOM),³ and the National Institutes of Health (NIH)⁴ recognized the health inequity suffered by sexual and gender minorities (SGMs) and recommended prioritizing these minorities' health interests. Although these efforts promised departure from "gay vs straight" binary definitions of sexuality, a follow-up NIH report explained that, among 279 studies focused on SGM health that it funded in 2012, only one focused solely on bisexual women; roughly 20 grouped bisexual women with other sexual minority women.⁴ Setting aside implications for gender equity, these numbers are troubling for another reason: bisexual women are the largest subgroup within lesbian, gay, bisexual, and transgender (LGBT) sexual minority communities, a fact that tends to surprise many, including bisexual women.⁵ A national 2019 Centers for Disease Control and Prevention (CDC) survey of high school students documented that a median of 9% of students identified as bisexual compared to a median of 3% identifying as gay or lesbian.⁶ Yet the

CDC's report of sexual contacts among high school students represents sexual minority students monolithically, folding bisexual contacts into the category "same sex only or both sexes" and treating "gay, lesbian, and bisexual" as a single category of sexual identity.⁷

Despite being common, grouping bisexual and lesbian women together makes little sense and needs correction in health equity research because it reproduces monosexism (ie, the view that sexual attraction is only to one gender) and thereby **categories that are reductionist**—but familiar—to researchers generating the evidence base that clinicians use to care for patients. For example, a National LGBT Cancer Network report indicating that lesbian and bisexual women are at increased risk for some cancers implicitly compares these women to heterosexual women.⁸ Grouping bisexual women with lesbian women seems to express hope that eventually this group will become more homogeneous (ie, when some bisexual women begin identifying as lesbian and others "return" to heterosexuality), reproducing a neat and tidy monosexual, straight vs gay binary.⁹ Such hope, rooted in the discomfort of those who view the notion of bisexuality as too liminal, too disruptive of culturally dominant definitions of sexual desire,¹⁰ is harmful to patients whose health depends on more inclusive acceptance of sexual and gender diversity and plurality.

Comfort and Clinical Encounters

Puritanical roots run deep in the United States and still manifest in clinical encounters. Oppression incurred by binary monosexism is exacerbated by sexuality being a culturally taboo subject, even when it is clinically relevant. Data collection about sexual orientation and gender identity (SOGI) is relatively new in federally funded health research and even newer in clinical documentation. In fact, HHS has only recently required electronic health records (EHRs) to contain a modifiable field for including a patient's SOGI data in the EHR, which was first suggested by the Centers for Medicare and Medicaid Services in 2015.²

It doesn't help that some clinicians assume that patients don't want to be asked about sexual orientation because it would be uncomfortable or inappropriate. One study found that 80% of physicians thought patients would decline to answer questions about their sexual and gender identities.¹¹ But in national surveys of LGB and heterosexual patients, 10% of respondents reported that they would not disclose their sexual identity to their doctors and 60% felt that disclosure was relevant to their care.^{11,12} One explanation for this discrepancy is that physicians—who, unlike their patients, might see **sexuality as taboo**—might themselves feel uncomfortable discussing the topic. Some respond to nondichotomous sexual identities by invoking a range of sexual stereotypes (eg, that bisexual people are hypersexual, unfaithful to their partners, or never monogamous)^{9,13} that perhaps generate more discomfort. Possibly for this reason, physicians either refrain from asking sexuality questions or frame sexuality questions so as to discourage disclosures (eg, by incorporating some of the above stereotypes),^{14,15} which can then make patients uncomfortable. This dynamic can exacerbate the invisibility of bisexual women.

Discomfort can also be managed with (unreliable) shortcuts, perhaps by looking for clues in the gender of a patient's romantic or sexual partner. Two women in a relationship tend to be read as lesbian, 2 men as gay, and a woman and a man as straight, when any of these apparently conventional couplings might involve bisexual people and could be relevant to a patient's health. Asking, "Do you have sex with men,

women, or both?” (a current standard in history taking taught to medical students¹⁶) suggests that a right answer is one that reduces sexual orientation to current sexual behavior. Given the definition of *bisexual* used by the NIH’s SGM Research Office that is attributed to bisexual researcher and educator Robyn Ochs (ie, “the potential to be attracted—romantically and/or sexually—to people of more than one gender, not necessarily at the same time, not necessarily in the same way, and not necessarily to the same degree”¹⁷), it is no wonder that monogamous bisexual patients might feel puzzled by this question.^{9,10} Since bisexual people compose the largest subgroup of the LGBT population,¹⁸ it is likely that a patient who identifies as an SGM will be answering in a way that is more amenable to an open-ended prompt. Instead of asking a rote question, clinicians might more fruitfully introduce the topics of gender and sexual identity by asking their patients what they would like them to know about themselves and their partners, past, current, or potential.

Reducing Harms of Invisibility

Under-researched, undisclosed, and undiscussed issues are naturally less understood or acted upon. The NIH 2012 Strategic Plan featuring a single study on the health of bisexual women indicated that 75% of all studies in the SGM portfolio were about HIV/AIDS and 69% were focused on men who have sex with men.⁴ In **medical education**, the median amount of curricular time for all SGM health topics is 5 hours, with HIV content being taught in 80% of schools with any SGM curriculum.¹⁶

SOGI patient data collected by health systems might again be conflating bisexual patients with lesbian or gay patients; conflation exacerbates invisibility, and invisibility harms bisexual women’s health. Bisexual youth are less likely than lesbian and gay youth to be “out” to their clinicians,¹⁹ yet they are at increased risk for some health-related issues. Bisexual women are at increased risk of reproductive coercion (ie, partner interference with contraception use during sex) compared to heterosexual women.²⁰ When bisexual women in a relationship with a woman are presumed to be lesbians by their physicians, it obscures their higher rate of cervical cancer compared to lesbian women^{21,22} and reduces prevention opportunity. In addition, one study found that, compared to lesbian women, bisexual women were more likely to smoke and be at risk for alcohol use disorder—factors related to the stress of being an SGM—but to score lower on measures of social support.²²

Failing to challenge binary sexuality means enabling some of the most pernicious biphobic stereotypes: that bisexual women are actually closeted lesbian women or straight women going through “a phase.” Biphobia contributes to minority stress, the cumulative stress of **stigma and discrimination**.²³ Minority stress exacerbates mental and physical health risks but is mitigated for individuals with strong connections to their minority communities and positive affiliations with their identities.²⁴ Although bisexual women are the largest subgroup under the LGBT umbrella, they are less likely to be welcomed into LGBT spaces.⁵ When a bisexual patient comes out during a clinical encounter, some clinicians respond by recommending LGBT resources, which could be experienced as negative by a bisexual patient who doesn’t feel that LGBT is inclusive.

A cultural view of bisexuality as a “trend” can also exacerbate the invisibility of older bisexual adults; compared to 71% of lesbians, only 28% of bisexual elders report being out to the most important people in their life.²⁵ Knowledge that a patient is less likely to be out to family and friends because of biphobia should prompt a clinician to ask to whom she is out and whether there are ways to express support. Such an approach is

informed by current bisexual-specific research and could help bisexual women feel safer.

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

When Disability Is Defined by Behavior, Outcome Measures Should Not Promote “Passing”

Ari Ne’eman

Abstract

When disability is defined by behavior, researchers and clinicians struggle to identify appropriate measures to assess clinical progress. Some choose the reduction or elimination of diagnostic traits, implicitly defining typical appearance as the goal of service provision. Such an approach often interferes with more meaningful, person-centered goals; causes harm to people with disabilities; and is unnecessary for dealing with traits that are intrinsically harmful or personally distressing, such as self-injury. Disability stakeholders should reevaluate outcome measures that seek to eliminate disability-related traits that are stigmatized but not harmful. Using autism and the emergent neurodiversity movement as a case study, this article explores ethical challenges in selecting outcome measures in behaviorally defined disability diagnoses.

Measures and Values

Many disabilities are diagnosed through **biomarkers**. Others can only be identified via behavior. Particularly in the latter context, clinicians and researchers often seek specialized instruments to assess service-provision outcomes. Measures are not neutral, however. They carry their creators’ value judgments.

In some conditions defined by behavior, a disturbing trend has emerged: researchers, clinicians, and paraprofessionals are using measures that prioritize reducing diagnostic traits that are neither harmful nor personally distressing, defining typical appearance as the goal of service provision.^{1,2,3} Such thinking ignores the stress that passing for normal places on people with disabilities and fails to consider the ethical dimensions of behavior modification in response to stigma.^{4,5} This article explores ethical problems with using diagnostic trait reduction as an outcome measure, drawing on autism as a case study.

What’s Wrong With Passing?

Some approaches to autism intervention, such as applied behavioral analysis, emphasize making autistic people (the term preferred in the autistic community)⁶ “indistinguishable from their peers.”^{7,8,9} This approach defines success as typical behavior, such that a person no longer meets diagnostic criteria for autism.

Autistic adults have criticized this promotion of *indistinguishability* through the **neurodiversity movement**, which argues that autistic traits are not inherently in need of correction and that the goal of autism service provision and research should not be to make autistic people nonautistic.^{10,11} Neurodiversity advocates critique interventions that seek to suppress autistic traits in favor of “passing” (ie, attempting to hide stigmatized identity by pretending to be a member of the unstigmatized majority).¹² In both disability and nondisability contexts, passing has been associated with significant harm.^{12,13} Efforts to pass have been identified as a risk marker for suicidality in autistic adults.¹⁴ Such “camouflaging” is also associated with other mental health challenges.^{15,16,17,18} One contributor to the Autistic Passing Project, a collection of autistic adults’ experiences with passing, shares: “I am actually at a point now where I rarely leave the house because I don’t have the energy to pass.”¹⁹ Another adds: “These days i am pretending to be normal for them not myself and thats what hurts [sic],” adds another.²⁰

Despite these serious ethical problems, autism outcome measures often prioritize the reduction of diagnostic traits.^{2,3} The burden has been on critics to show that any given autistic trait does not require suppression. But the opposite should be true: because passing demands impose harm, clinicians and paraprofessionals should instead default to avoiding them, making exceptions only when doing so is: (1) necessary to prevent harm and (2) the least onerous path to preventing harm for the autistic person.

When a behavior is intrinsically harmful, such as self-injury, it is appropriate to seek to address it. But many targeted autistic traits do not meet the high standard of intrinsic harm. Lack of eye contact, unusual prosody and the hand-flapping, rocking, and other stereotypies colloquially referred to as “stimming,” among many other autistic traits targeted for intervention, usually pose no problem other than social stigma. Some might argue that while these traits are not harmful, they reflect underlying challenges that *are* harmful. For example, lack of eye contact is associated with social communication difficulties. It is ethical to ameliorate such challenges. But enforcing typical appearance is rarely the most effective or least onerous way to do so.

While some contend that typical eye gaze is necessary for expressive communication, autistic people often use other means to signal attention and reciprocity.^{21,22,23} If autistic people derive less information than others from facial expressions,²⁴ making eye contact might not improve receptive social communication. Since eye contact is difficult for autistic people,²⁵ it might even distract from relationship building. In requiring that autistic people imitate the form of typical social communication, clinicians might be imposing a cognitive demand that interferes with its function.

Such “teaching to the test” of typical appearance might be actively destructive when autistic traits are personally meaningful, useful, or simply not harmful. Instead, the underlying goal of communication should be prioritized, accepting that even successful autistic people will present differently. While some actions are intrinsically harmful or dangerous, others simply appear unusual or require additional interpretative effort. Although delineating these categories might require debate, acceptance of the latter should be considered part of accessible and culturally competent service provision.

Family members might desire behavior modification to promote typical appearance. But given that passing demands impose harm, it is unethical to attempt to suppress an autistic trait solely because a parent wishes their child to look normal. While

professionals should consider harm to others when evaluating the ethics of behavior modification, they must scrutinize such requests to confirm that such harm actually exists. There might be limited circumstances in which an autistic person chooses to engage in situational passing (eg, to avoid prejudice), but these should remain personal choices, not normative expectations reflected in an outcome measure.

Responding to Neurodiversity's Critics

Manuel Casanova, a neurodiversity critic, argues that “it’s not a blessing to have head-banging, eye-gouging or self-biting,”²⁶ implying that neurodiversity precludes interventions seeking to address such problems. Perceiving neurodiversity’s emphasis on acceptance as incompatible with severe disability, some suggest it should only apply to less-impaired autistic people.^{27,28,29} This viewpoint misconstrues neurodiversity’s claims. Neurodiversity proponents generally support enhancing the adaptive skills of autistic people.^{30,31}

Neurodiversity is best considered a lens through which to evaluate the goals of autism interventions. Does an intervention seek to modify a given trait solely because it is autistic? Or does it proceed more modestly, only targeting that which is intrinsically harmful? This approach is consistent with addressing self-injury or promoting communication. Just as surgically shaping the eyes of people with Down syndrome to look normal is now considered barbaric, neurodiversity requires us to recognize as unethical measures to enforce typical appearance solely to avoid stigma.³² Suppressing autistic traits in order to promote typical appearance is problematic regardless of level of impairment, while reducing personally distressing or harmful behaviors or developing skills is not.

A Call to Reevaluate Autism Outcome Measures

Many autism outcome measures would benefit from reevaluation using a neurodiversity lens. A common measure of repetitive behavior helps illustrate relevant principles. Because autistic repetitive behaviors present differently than those in obsessive-compulsive disorder (OCD), researchers modified the Children’s Yale-Brown Obsessive Compulsive Scale (CYBOCS) for autism-spectrum disorder (ASD) by adapting the CYBOCS’s compulsions checklist.³³ The CYBOCS-ASD was developed in order “to document the current severity of repetitive behavior” in autistic children.³⁴ It has been used as a primary outcome measure in clinical trials.^{34,35} But autistic repetitive behaviors are different from those in OCD not only in presentation but also in experience. Autistic people generally engage in repetitive behaviors for pleasure or emotional self-regulation, while OCD repetitive behaviors are a cause of distress.^{5,36,37} The ethics of seeking to suppress behaviors that are pleasurable or helpful obviously differ from the ethics of treating distressing behavior. To justify the former, one must show not only that behavior is aberrant but also that it is harmful. Among the behaviors targeted by the CYBOCS-ASD are hand flapping, drawing objects of special interest, lining up objects, and rereading or watching the same media over and over.⁵ These are certainly autistic traits, but they are not harmful ones. It is possible for certain repetitive behaviors to cause harm—for example, if they involve compulsions or violence—but the CYBOCS-ASD casts a less modest net. Similar issues exist with other common autism measures, which prioritize eye contact and eliminating unusual hand/finger/body mannerisms alongside more legitimate priorities.^{38,39}

These examples of outcome measures speak to the danger of conflating diagnostic traits and outcomes. Instruments such as the CYBOCS-ASD could be retooled to only

include items that measure intrinsically harmful behaviors as outcomes. Or they could be used exclusively to explore autism in a value-neutral fashion—with clear instructions that they should not be used to assess clinical progress. But in their current form, their use violates the principle of nonmaleficence by imposing upon autistic people unnecessary and potentially harmful passing demands.

Additional work is required to develop new measures or revise existing ones to address these ethical concerns. Most existing work in autism outcome measurement has focused on topical and psychometric properties rather than ethics.⁴⁰ To change this orientation, researchers would be well advised to partner with autistic people themselves.^{41,42,43} Community-based participatory research efforts are already underway regarding patient-reported outcome measures.⁴¹ Similar work is necessary to evaluate whether clinical outcome measures target intrinsically harmful behaviors or if they must be revised to remove harmful or unjustifiable passing demands. Stakeholder engagement in the **diagnostic criteria** for autism in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* helped address similar ethical concerns, leading to the removal of language implicitly encouraging clinicians to suppress autistic people's valued special interests.¹²

When the suppression of diagnostic traits is seen as an appropriate outcome, people with disabilities are done a grave disservice. Suppressing atypical behavior might not bring increased quality of life—and in some cases might actively reduce it. Although this critique is most developed in autism, it has relevance to many other diagnoses. Further work is needed to integrate neurodiversity into service provision and research.

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ART OF MEDICINE

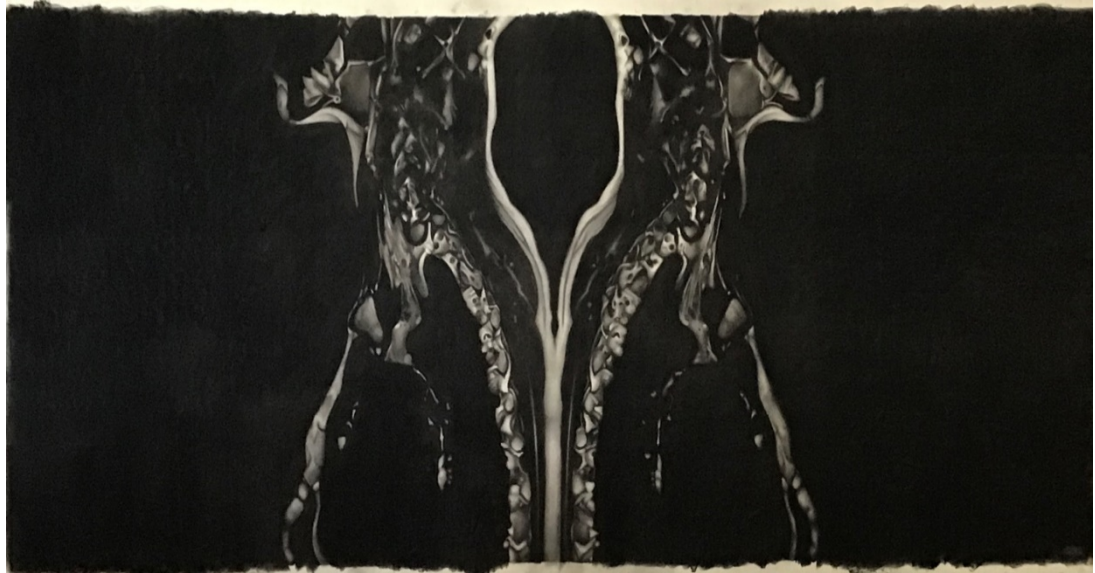
Imaging, Visibility, and Rendering My Body to My Self

MacKenzie Davis

Abstract

A series titled *BRAINEATERS* includes abstracted self-portraits of different media. The portraits consider an artist's experiences of diagnosis, routine magnetic resonance imaging, and ongoing demands to reorient herself to her future with an invisible illness.

Figure 1. *MRI (#6)*, 2019



Media

Charcoal on paper, 60" x 27".

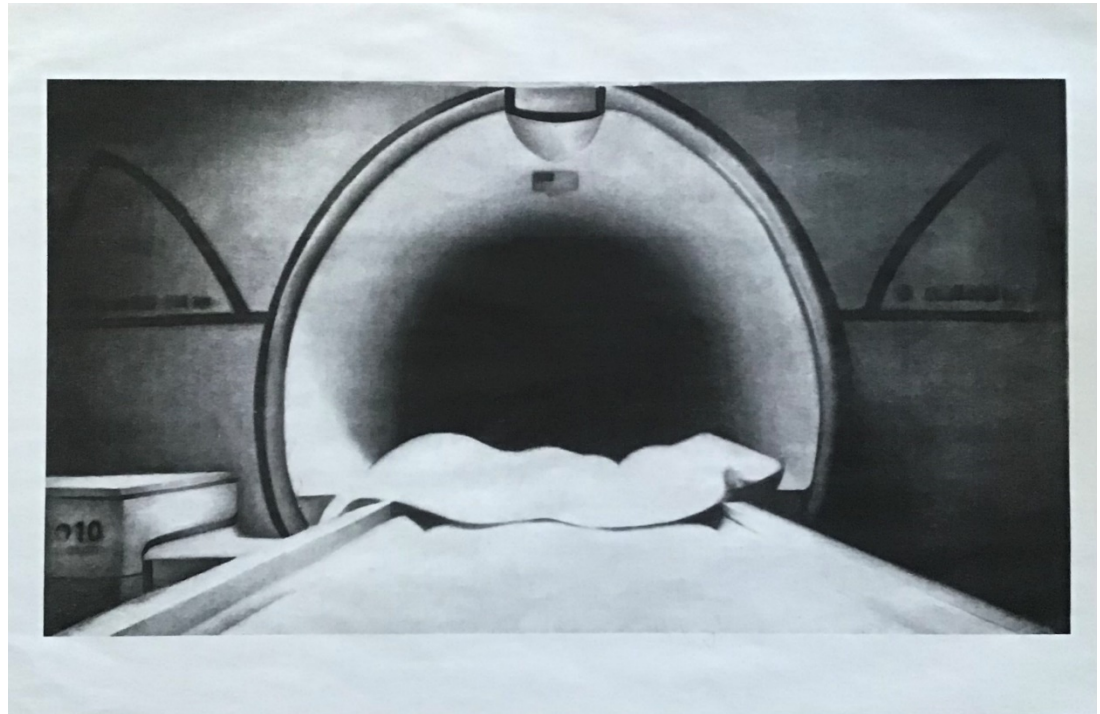
Caption

I was diagnosed with **multiple sclerosis** (MS) at age 19. For a long time after my diagnosis, I felt anger, fear, and sadness towards my body. This experience prompted me to dissociate my *self* from my *body*. The series *BRAINEATERS* started with an impulse to spread awareness about MS. I quickly realized that these drawings were a

way to help me connect with the invisible part of myself and allowed me to accept my body and my illness.

I obtained all copies of my imaging and captured stills. I then flipped and repeated these images, creating more complexity from the single saved image, and made an increasingly abstracted self-portrait reference. I then created these drawings photo-realistically, using a grid from the reference.

Figure 2. *Another Round*, 2020



Media

Photo lithography on newsprint, 20" x 11".

Caption

Life with MS means regular encounters with clinicians and regular MRIs. During this project, I focused on my own MRIs as a means by which MS is rendered visible to me and to those who can help me. This is one in an edition of 12 prints, which illustrate the repetitiveness of monitoring my body and its mysteries. These prints were made by photo-realistically drawing this image in charcoal on paper. I then transferred this image to a photo lithography plate and began printing this series.

Figure 3. *Monotony*, 2019



Media

Charcoal on paper, 36" x 13".

Caption

This drawing was made from a photo I took of my medications strewn on a surface. I then drew the image in charcoal photo-realistically, based on a gridded reference. When my physician delivered the news to me that I will live with MS for the rest of my life, I felt the weight of the word *forever*. My experiences of **feeling overwhelmed** by uncompromising and invasive changes were immediate. One of these changes involved choosing which, if any, disease-modifying therapy (DMT) was right for me. This drawing represents one full week of DMT that I was taking when creating *BRAINEATERS*. This illness demanded—and will forever demand—that I reckon with the emotional work of making high-stakes health decisions: balancing prospective risks and benefits and consenting, refusing, and choosing treatments will be ceaseless.

MacKenzie Davis is a multimedia artist and printmaker based in Omaha, Nebraska, and has lived with multiple sclerosis for 8 years. Davis studied at the University of Nebraska at Omaha, where she received her bachelor of fine arts degree.

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ART OF MEDICINE

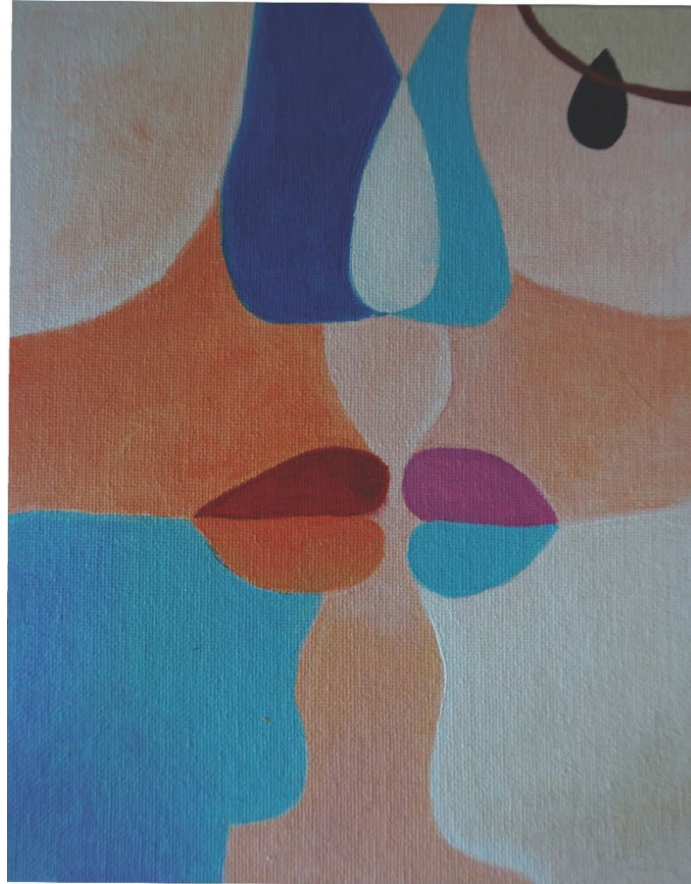
Ethics of Being Close

Megan Ashley MacKenzie

Abstract

This acrylic painting considers intimacy and its ethical demands during our personal and professional encounters with one another, drawing on Pablo Picasso's 1907 *Head of the Medical Student*.

Figure. *Unwavering Silence*



Media

Acrylic on canvas.

Caption

Pablo Picasso's 1907 *Head of the Medical Student* depicts a figure with one eye open and one eye closed. Inspired by that abstract exploration of interpersonal relationships, this painting uses 2 color-blocked facial profiles to convey an up-close moment of intensity. Color blocking is a technique that allows for the juxtaposition of color in order to elicit divergent emotional responses. The figures' noses overlap, their lips almost collide, and a single dark tear drops from an eye of the figure at right, suggesting, perhaps, that intimacy in personal or **professional encounters** demands our acceptance that both pleasures and threats, both revelations and confrontations, are possible when we are this close.

Megan Ashley MacKenzie is a third-year medical student in the School of Medicine at Wayne State University in Detroit, Michigan. She enjoys running, boxing, slacklining, traveling, and trying new foods. She plans to pursue residency training in neurology, continue her research, and incorporate art into her practice.

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ART OF MEDICINE

Wayfinding

Brent R. Carr, MD

Abstract

This charcoal gesture drawing was inspired by a mid-adolescent nonbinary patient, who once suffered suicidal thoughts and has recovered. The drawing investigates a caregiver's and patient's journey from despair to hope.

Figure. *Free to Choose*, 2020



Media

Charcoal on paper 5.2 cm x 22.9 cm (6" x 9").

This gesture drawing was inspired by a mid-adolescent patient progressing

through a **gender transition**, despite enduring others' biases. This patient shared that they finally felt free from suicidal thoughts after years of failed attempts to control their depression with medication. After researching **electroconvulsive therapy** (ECT), they requested it, despite its status as a stigmatized intervention.

After ECT, the patient's suicidal thoughts ceased, and they reported excitement about having found ways to more freely and nimbly move within, and respond more dexterously to the demands of, their emotional world. This patient now had the internal resources to transform a frightening, narrowing bleakness into a capacious future, with space for movement, growth, and life.

Brent R. Carr, MD is faculty member in the Department of Psychiatry at the University of Florida College of Medicine in Gainesville. He is also the chair of electroconvulsive therapy services and practices neuromodulation and college health. He completed residency at Tulane University.

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ART OF MEDICINE

Three Things to Learn and Do in Practice With Patients With Disabilities

Jessica Delli Carpini

Abstract

Clinicians can practice **disability humility** by developing social understandings of disability. This can help clinicians improve communication and express respect for patients' authority on their experiences.

Figure. Three Things to Learn and Do in Practice With Patients With Disabilities



Jessica Delli Carpini is a student at the School of the Art Institute of Chicago and was an intern at the American Medical Association in Chicago, Illinois, in the spring of 2021.

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PERSONAL NARRATIVE: PEER-REVIEWED ARTICLE

Depression's Problem With Men

Nathan Swetlitz

Abstract

Too many men who suffer from depression remain undiagnosed. While men are diagnosed with depression at half the rate of women, they die by suicide 3 to 4 times as frequently. Gendered processes of socialization affect how some boys and men express depression. Notably, gender disparities in diagnosis disappear when “male-typical” symptoms of depression are incorporated. Historically and to this day, masculinities have created barriers to care. Addressing disparities in depression diagnoses and treatment requires making psychological services affordable, adopting collaborative care models, revisiting sex as a risk factor for depression, and reexamining major depressive disorder’s diagnostic criteria.

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Depressed and Alone

I was severely depressed for the entirety of my junior year of college. My depression consumed me, breaking my identity into pieces so small I thought I barely existed. The person I had known for the past 20 years now seemed a carefully constructed illusion.

During that year, I never sought treatment. For months I could not acknowledge I was angry with myself, let alone depressed. There were days when I screamed so loudly in my head, I couldn't hear what my professor was lecturing about. There were times when I thought about how easy it would be just to fall into traffic and escape the pain of daily living. But I told myself I could get through it alone.

I remember the horrors of my depression, how much I denied what I was feeling, and how getting care felt like an insurmountable obstacle.

Five years later, I returned to that experience as a medical student. I am exploring specific barriers to care that men with depression face, and my experience is far from unique.

Masculinities

Current data on depression in the United States indicate that women suffer from depression more than men.¹ A closer look reveals that, while men are diagnosed with depression half as often as women and are less likely to attempt suicide, men die by suicide 3 to 4 times more frequently.² Although there is no one-to-one correspondence between **depression and suicide**, depression is one of suicide's most significant risk factors.³

Many boys are taught by parents, teachers, and peers to express themselves and their emotions differently than girls,⁴ and gendered processes of socialization can affect how boys and men express depression.⁵ When a study accounted for “male-typical” symptoms of depression (eg, overworking, substance misuse, and aggression), the difference in rates of depression between the sexes disappeared,⁶ suggesting that depression in many men remains unrecognized. The data also indicate that female sex is not a risk factor. Rather, the gendered ways we think of ourselves and treat others influence how some men experience, manage, and present with depression.

Masculinities include ideals of what it means to be a man and are influenced by our intersecting identities and social and cultural environments. Experiences of people who are **gender nonconforming are underrepresented** in depression research, which constitutes a major clinical research gap. Some men draw on aspects of traditional Western masculinities (eg, self-reliance and emotional control) to improve their mental health on their own.⁷ Nonetheless, there are clear obstacles that these masculinities pose to depression help-seeking. When I wanted to die, I never sought out help, and I struggled to acknowledge my emotions. I might die, but I refused to compromise who I expected myself to be.

Gendering Men Out

Assumptions about traditional gender roles are critical barriers to diagnosing men with depression. Participants in studies conducted before **major depressive disorder (MDD)** was included in the *Diagnostic and Statistical Manual of Mental Disorders* in 1980 were predominantly female.⁸ The idea that depression afflicted women more frequently than men predated MDD's canonization, and it persists to this day. An article published by the American College of Physicians includes a 1-page summary informing patients: “You may be at risk for depression if you ... are female.”⁹ This is a powerful message to men—you are not depressed—and to clinicians, who might not as readily consider depression a source of suffering in male patients.¹⁰ Stigma against depression exists for everyone, and traditional Western masculinities (eg, toughness and stoicism) can make it even more difficult to acknowledge and express feelings.¹¹ Men who most strongly subscribe to these traditional masculinities are particularly liable to suffer from depression,¹² but they are the least likely to seek help for their symptoms.^{13,14}

Recommendations

With the COVID-19 pandemic, most **people are more isolated** than ever from their social support networks. Unemployment and poverty worsen uncertainty about the future. But the pandemic has also created opportunities. Expanded telehealth and the availability of virtual mental health resources could increase the accessibility of services to help men with depression.

Furthermore, the collaborative care model is an evidence-based way to cut costs and minimize barriers to mental health care.⁹ Appreciating the social and historical

contingency of the assumption that women experience depression more often than men, clinicians, researchers, and medical institutions should revisit female sex as a risk factor for depression. More research into expanding MDD's diagnostic criteria to include "male-typical" depressive symptoms should be conducted. Clinicians should consider the demands that gender makes on all of us, as well as its influence on patient-clinician relationships.⁴⁵ Introducing these changes will make it easier for those of us who have grappled with depression to speak and be heard.

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PERSONAL NARRATIVE

The Importance of Listening in Treating Invisible Illness and Long-Haul COVID-19

Dorothy Wall, MA

Abstract

Primary and specialty care clinicians strive to base diagnoses and treatment on specific, measurable abnormalities. Yet those with invisible, controversial illnesses such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) often have symptoms not explained by standard laboratory values. For instance, one of the cardinal features of ME/CFS is postexertional malaise, the exacerbation of symptoms—fatigue, pain, cognitive dysfunction—following exertion, which contradicts studies showing the health benefits of exercise. In these cases, overly physicalist approaches to caring for patients are not likely to be helpful, and a clinician’s willingness to listen to a patient’s experience of illness becomes essential.

Onset

In 1978, when I was 30, I became ill with a vicious case of mononucleosis from which I never fully recovered. Since then, I’ve become accustomed to conducting my work, home, and social life at about half my pre-illness energy level, and I am unable to exercise normally. I remember clearly those early years of illness, lying in a state of exhaustion on my couch, not understanding why I felt a heavy pressure like a weight pushing my body down. Maybe I need fresh air, some exercise, I thought. I’d pull myself up and put one foot in front of the other up the street. Within 20 yards I’d feel heavy as lead, my head swimming in a thick swamp of exhaustion. My body was telling me loud and clear: I needed rest, not exertion.

Aftermath

Although I knew instinctively that I was experiencing the chronic aftermath of mono—constant sore throat, swollen glands, brain fog, fatigue—all lab values were normal. I have an enduring memory of physicians peering at me with suspicion when I described my symptoms: Was I experiencing family problems? Work stress? Depression?

It wasn’t until 1988 that the Centers for Disease Control and Prevention (CDC) recognized this illness and gave it the radically misleading name, *chronic fatigue syndrome* (CFS), as if those of us with CFS were just tired from busy lives.¹ Today, this illness is called *myalgic encephalomyelitis/chronic fatigue syndrome* (ME/CFS) and is

more widely understood as a serious illness, but clinical suspicion and misunderstanding persist.² The majority of textbooks and health professions curricula still include little or nothing about ME/CFS,³ and even well-intentioned clinicians often cannot provide the information their patients need.

A neurologist I saw recently, trying to help me stay active, raised her eyes from her computer screen to encourage me. “I read a study recently that recommended graded exercise for CFS.”

I was seated on the crinkly paper of the exam table, not sure where to begin. This assertion gets me—and so many patients with ME/CFS—where it hurts, since I love to exercise and for decades have tried repeatedly, and failed repeatedly, to increase how far I can walk. I took a breath. “Studies recommending graded exercise for ME/CFS have been discredited,” I said. “Or they included people who were depressed, who do benefit from exercise. But for people with ME/CFS, if we push ourselves to do more, we can make ourselves worse. That’s been my experience.”

She shrugged, “I can’t remember where I read it, but the study did recommend graded exercise.”

My time was up, and I left it at that. But this brief medical encounter was a complex moment, frustrating for me and probably for her, too. It’s worth unpacking.

My neurologist’s recommendation was based on an article she’d read—which she assumed to be based on reliable science—that concluded graded exercise therapy (GET) could produce positive outcomes for those with ME/CFS. Yet I knew from 42 years of experience that my pain and fatigue get worse if I consistently increase my exercise despite how I’m feeling, as GET recommends. I’m like a car with one piston. I can go 10 miles an hour. But if I try to go 20 miles per hour next week, 30 the next, 40 the next, the car will simply break down. To go faster, I have to fix the car (something no one yet knows how to do).

My exchange with the neurologist didn’t simply reflect conflict between **biomedical and experiential** ways of knowing or a dispute over who owns expertise. In fact, there are many reasons why my physician and I are in the positions we’re in—reasons having nothing to do with evidence-based science.

Making ME/CFS Invisible

First, the National Institutes of Health (NIH) has consistently failed to fund robust investigations of ME/CFS, although between 836 000 and 2.5 million adults in the United States are estimated to have ME/CFS, with annual health care costs and lost productivity estimated to be between \$17 and \$24 billion.³ While there have been “thousands of studies” over the past 35 years revealing alterations in the immune, autonomic, and neuroendocrine systems in those with ME/CFS compared to controls,² most of these studies were small and often privately funded, and many clinicians remain unaware of this information.

Yet many researchers find the evidence of these alterations compelling. ME/CFS researcher and clinician Nancy Klimas, professor of medicine at Nova Southeastern University, cites the “strong evidence of neuroinflammation, systemic inflammation, autonomic dysfunction, and oxidative stress” in studies by many investigators.⁴ Exercise

physiologist Staci Stevens and her team in Ripon, California, use a 2-day cardiopulmonary exercise test, which shows a significant drop in energy production (oxygen consumption) on the second day of exercise for ME/CFS patients compared to controls, as well as lower heart rate, blood pressure, and arterial oxygen saturation.⁵ Particularly in light of these and other studies' compelling findings, the absence of national, large-scale NIH research support is keenly felt and is another way the voices of those with ME/CFS have been marginalized and ignored.

Second, the case definitions used to guide research and clinical care for patients with ME/CFS since 1988 have de-emphasized postexertional malaise (PEM), despite the fact that PEM is a hallmark of the illness.^{1,3,6} Not until 2015 did the Institute of Medicine (IOM, now the National Academy of Science) create a new clinical case definition of ME/CFS that recognizes PEM as a central symptom, defining it as “worsening of a patient’s symptoms and function after exposure to physical or cognitive stressors that were normally tolerated before disease onset.”³ As Leonard Jason, professor of psychology at DePaul University, has pointed out, without a rigorous, effective case definition, further research, search for biomarkers—which many see as an empirically verifiable indicator of legitimacy for a disease or its symptoms—and treatment are all on tenuous ground.⁷

Most upsetting to patients has been the **ongoing mischaracterization** of ME/CFS as psychiatric in origin, which found its strongest voice in the PACE trial, published in *The Lancet* in 2011.⁸ Led by a group of British psychiatrists and mental health professionals who had long proposed that patients with ME/CFS were making their illness worse through unhelpful illness beliefs and deconditioning, it was no surprise that the study claimed cognitive behavioral therapy (CBT) and GET to be effective treatments for ME/CFS.^{8,9}

The Lancet posted the study as an open-access article, the authors gave many interviews, and the press pounced. As of April 2019, the study had been cited 675 times by other journals,¹⁰ and the media carried headlines, such as “Psychotherapy Eases Chronic Fatigue Syndrome, Study Finds” (*New York Times*), “Pushing Limits Can Help Chronic Fatigue Patients” (*Reuters*), and “Therapy, Exercise Help Chronic Fatigue Syndrome” (*WebMD*).¹⁰

The PACE study has since been roundly critiqued by patients, academics, and experts alike for serious methodological flaws.⁹ A subsequent 2018 reanalysis of the PACE results published in the peer-reviewed journal *BMC Psychology* “documented that the benefits for CBT and GET reported in multiple PACE papers were either exaggerated or illusory when the data were assessed per the methods detailed in the trial’s published protocol.”¹¹ The CDC has since retracted its support for GET and CBT as treatments for ME/CFS, as has the National Institute for Health and Care Excellence, which provides treatment guidelines for the UK health system.^{11,12} But headlines stick in the minds of the public, media, and medical practitioners long after they’re debunked.

Research investigating exercise in ME/CFS by Leonard Jason and colleagues at DePaul University, which received much less media attention, reveals “potential difficulties using graded activity approaches.”¹³ Contrary to the PACE findings, Jason and colleagues recommend that patients follow the energy envelope theory, in which patients monitor their perceived energy capacity and stay within those boundaries on any given day. The authors state: “We learned that by avoiding overexertion, people with

CFS could avoid setbacks and relapses while also increasing their tolerance for activity”¹³—something ME/CFS patients have long understood.

Listening to Patients

I knew, as I left my neurologist’s office that day, that she couldn’t be expected to keep up on the latest information about ME/CFS. It’s not uncommon for informed patients with ME/CFS to know more about their illness and the current research than their physicians. But I do expect the following:

1. Physicians unfamiliar with the latest clinical science about ME/CFS will listen to me and respect me as a reliable narrator of my illness experience, *and*
2. When my narratives of my experience conflict with physicalist clinical views that privilege measurability, physicians will acknowledge the limitations of their diagnostic technologies, the contingent nature of biomedical “knowing,” and how social factors shape disease perception.

Had government institutions, researchers, and clinicians taken patients’ subjective reports of illness seriously over the last 35 years, I and others with ME/CFS could today enter a medical office and find physicians who could more effectively guide our care. Until that happens, physicians must have, as Nancy Klimas pointedly says, “the ability to say ‘I don’t know’ rather than ‘there is nothing wrong with you.’ Some **medical humility** is a critical part of being a good doctor.”⁴

Stay Tuned

In a devastating twist no one anticipated, we’re now seeing significant numbers of Covid-19 patients who continue to have debilitating symptoms, including PEM, months after contracting the SARS-CoV-2 virus or a variant, the so-called Covid long-haulers.¹⁴ Anthony Fauci, head of the National Institute of Allergy and Infectious Diseases, has said: “And it’s extraordinary how many people [with Covid-19] have a postviral syndrome that’s very strikingly similar to myalgic encephalomyelitis/chronic fatigue syndrome. They just don’t get back to normal energy or normal feeling of good health.”¹⁵ He and many others have been stressing the urgent need for a coordinated effort—among researchers, physicians, government agencies, patients, and policymakers—to collect data on people with ME/CFS and Covid-19 long-haulers. On February 23, 2021, the NIH announced a major new initiative—with \$1.15 billion in funding from Congress over 4 years—to study the long-term effects of SARS-CoV-2 infection.¹⁶ This initiative should increase our understanding of Long Covid and other postviral syndromes and finally make them more visible.

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