Illness (In)action: CFS and #TimeForUnrest

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I offer a snapshot of the multiple temporalities of chronic fatigue syndrome (CFS) through the experiences and events Jennifer Brea documents in her film *Unrest* (2017), where illness and illness politics operate biopsychosocially across different spaces and temporalities. The film presents the historical persistence of hysteria, a diagnostic category replaced by conversion disorder, but nonetheless haunting the phenomenological experience of illnesses, like CFS, without (yet) known biological causes. At the same time, the film captures the experience of embodiment as a kind of endurance, as extreme fatigue and sensitivity to light, sound, and surroundings makes CFS a condition of unrest—a disturbed and uneasy state that is at once physical, social, and political. Early in the film, as Brea films herself with her iPhone struggling to crawl across the floor to her bed (fig. 1), she anticipates a question that might be on the viewer’s mind: “Why would I film it?” Her answers—“Because I think someone should see this” and “I didn’t know what else to do so I just kept filming”—suggest both a politics of visibility and a politics of endurance, or the politics of making endurance visible through practices of documenting illness and illness politics that connects to other historical and contemporary examples of illness and disability in action, including to the emergent illness of Long COVID in the present. The film and the hashtags #TimeForUnrest and #MillionsMissing challenge what activism and the activist look like. By connecting with people with CFS online, Brea documents their experiences with CFS and seeks to politicize the lack of participation in public life of people with CFS, who she describes as missing in action from society and the public sphere. With the film and hashtags, Brea demonstrates illness (in)action as a kind of unrest cure against the denialism of medicine towards chronic conditions that confound easy remedies and against an ableist image of protest.
Brea presents her own experience of illness as personally, phenomenologically, and politically confounding. Clips from home movies show an active little girl and more recent film footage and still photographs give a glimpse of an adventurous young woman always on the move and determined, as she puts it, to “swallow the world whole.” This visibly active life ends when Brea is 28. While working on her doctorate at Harvard, she gets sick with a very high fever and ends up bedridden. She is exhausted in a way she has never felt before, the side of her face goes numb, sometimes she is unable to speak or think coherently, and she becomes sensitive to light and sounds. She sees “every kind of specialist,” but no one is able to say exactly what is wrong. Eventually, a neurologist diagnoses “conversion disorder,” speculating that the likely cause is either a distant trauma, that she doesn’t fully remember, or recent stress from preparing for her doctoral exams. Conversion disorder is a new term for an old illness—hysteria. The term itself emerged in 1980 as part of the biocientizing, “evidence-based” impulse of the DSM-III, and is defined as a “psychoneurosis in which bodily symptoms (such as paralysis of the limbs) appear without physical basis.” With its ever-changing terminology and multitude of somatoforms, hysteria operates historically
like the diagnosis itself: the category appears to suffer from conversion disorder, or put another way, hysteria is hysterical, an extremely labile condition diagnostically.

At its center, Brea’s film presents a short history of hysteria in a slide show of black and white, historical images (fig. 2). As they flash by, accompanied by a syncopated beat, image and sonic reverberation heighten the feeling of hysteria’s persistence as a repetition compulsion, a diagnostic category characterized by photogenicity. Unrest’s historical hysterics are all women and Brea’s treatment of them insists on the importance of photographic images in the enactment of hysteria across different times and spaces.

Hysteria has a long association with the female body and women. The symptoms and significations that concatenate around hysteria are multiple and mobile. Hysteria’s habit of mimicking other diseases makes it not one disease but many, if not all diseases. As the diagnosis of hysteria helps us understand, illness is performative, “performative” understood through the lens of social interactionist theories, which explore the constitution of the self in the practices of everyday life, and speech act theories of performative utterances, which explore how saying can be doing. Where illness is concerned, the utterance “you have ____ [choose any disease here]” doesn’t simply name an existing biological condition; it brings that condition into being. When certain conditions and procedures are met—the authority of a doctor making the diagnosis, conclusive lab work and test results—then a person can be said to be legitimately ill. When these conditions are not met, then the person often is deemed mentally rather than physically ill.

Hysteria as conversion disorder becomes a kind of ur-illness performative, a default category for persistent illnesses not yet explained biologically. This repeated “not yet” helps explain, I think, hysteria’s persistent yet divergent and multiple enactments. Unrest’s syncopated slide show visually captures this performative. Although Brea refuses the diagnosis of conversion disorder for herself, she nonetheless links her experience to hysteria’s history and its visual somatoforms. Her desire to document her own and others’ experiences of CFS is motivated by an understanding of the past that isn’t so “strange and distant”—people, women mostly, are still locked up in institutions or trapped in bedrooms they never leave because their illnesses are not considered real. Brea believes we should know and do better now, but she comes to realize from her own illness experience and from documenting the illnesses of others, past and present, that, as she repeats twice in her voiceover, “we’re still doing this,” still doing
hysteria. This is what Ed Yong, reporting on COVID “long haulers,” calls the “long history of medical gaslighting,” in which a patient’s physical suffering is downplayed “as being all in their head, or caused by stress or anxiety.”

Bedridden for several years and living in limbo without a conclusive diagnosis, Brea describes how her once wide world shrinks to one room. She begins to search online for possible clues to what has caused and what might treat her intractable condition. Her own research leads her to what she will discover is the still somewhat controversial diagnosis CFS, or myalgic encephalomyelitis (ME), and to a whole community of sufferers in the shadows of society. Brea describes in her director’s statement how she “fell down this rabbit hole and discovered a hidden world of thousands of patients all around the globe, many of whom are homebound or confined to their beds and use the internet to connect with each other and the outside world.” Along with documenting her own experience of CFS, Brea is determined to document the lives of others—some 17 million worldwide, the #MillionsMissing, as proclaimed by the hashtag created by the MEAction Network and amplified by the film to highlight the problem of lack of visibility and research on the problem of CFS.
Brea shows the importance of making connections across time and space in order to document a longer history and wider experience of CFS. Brea’s film led me back to Susan Wendell’s book *The Rejected Body*, a phenomenological account of chronic illness and an important early work in the emerging field of disability studies in the academy. Wendell explores how chronic illnesses and those with unknown etiologies pose a problem for medicine because medicine tends to dismiss or deny the existence of what it cannot explain physiologically or treat successfully. Medicine has, Wendell argues, significant cognitive and social authority in contemporary society, affecting “how we experience our bodies and our selves, how our society describes our experiences and validates/invalidates them, how our society supports or fails to support our bodily sufferings and struggles, and what our culture knows about the human body.”

Wendell’s interest in the philosophical importance of chronic illness and disability emerges out of her own experience with ME, which, as with Brea, came on suddenly and devastatingly in February 1985. Unlike Brea, Wendell is “very lucky” in relation to her doctors, who “recognized at once that something was seriously wrong,” and found evidence in blood tests that indicated a viral infection. She saw specialists in infectious disease and immunology and was first diagnosed with acute infectious mononucleosis, then chronic Epstein-Barr virus syndrome, before doctors finally arrived at the then newly emergent diagnosis ME. Wendell notes that the “history of my own illness has coincided with the gradual discovery of ME/CFIDS by the rest of the world.” She describes learning to live with chronic pain, muscle weakness, “profound fatigue (much more total and exhausting than any fatigue [she] experienced when healthy),” dizziness, depression, headaches, problems recalling words, etc.

Wendell provides an especially astute critique of what she calls the able-bodied paradigm of humanity, which relies on an idealized view of the body as young, healthy, and always up to speed. This paradigm also figures in our ableist notions of protest, an activity that is typically conceived as taking place in public and involving a capacity for rhetorical flourish and energetic modes of engagement—marching and chanting, demonstrating and occupying. Twenty years after the publication of Wendell’s incisive critique, Brea’s film documents the still significant difficulties people with ME/CFS have in finding validation for their phenomenological experiences of their bodies and for making themselves heard in medicine and in the public sphere. Very early in *Unrest*, as Brea and her husband Omar wait to see a doctor, they discuss a rhetorical tightrope: “if you say too little, they can’t help
you,” Omar says. “If you say too much, they think you’re a mental patient.” Wendell argues that medicine lacks an effective vocabulary for the phenomenology of illness. She explains that patient-support groups are valuable in that they “offer a context in which people who are ill can work together to articulate their experiences of their bodies, to find or invent a phenomenological vocabulary that is adequate.” Brea’s film and illness politics more generally continue this work by finding and inventing a phenomenological vocabulary for illness, updating and extending Wendell’s support group by connecting to others online. And, as we are seeing in the present moment, the phenomenological vocabulary and online illness politics of CFS/ME has provided a portal into the confounding experiences of long COVID, which shares many symptoms with CFS/ME, including debilitating fatigue and brain fog.

Brea’s description of her phenomenological experience of CFS is remarkably similar to Wendell’s. Both describe “cellular exhaustion,” as Wendell puts it, or becoming less and less effective at the cellular level, as Brea says. Wendell anticipates the dismissive reactions to such a theory of cellular experience: “Certainly I do not experience my body as cellular, but I experience the exhaustion as so deep and pervasive that it feels as though something is wrong throughout my body on the cellular level.” Brea moves between scales, from questions about the metabolic crashpoint and how that feels—“when we crash we disappear”—to questions that after 30 years still need to be asked: “Why do more women get it? Is it genetic? Why 30 years later are we no closer to a cure?” For Brea, it is #TimeForUnrest and her film and advocacy work operate across multiple temporalities and spaces to bring illness (in)action into the public. #TimeForUnrest makes visible what would otherwise remain hidden from public attention. Online community-building creates the conditions for the participation of people otherwise missing from public life. The narrative arc of Brea’s film moves from passivity to activism and from hidden stories to public participation. Yet the film doesn’t end with triumph but with a statement of endurance and repetition as a kind of protest, which echoes into the present moment and the emergence of long COVID as a health crisis: “I am still here. I am still here.”
NOTES

2. See, for example, Diedrich, “Illness as Assemblage.”
3. Sara Ahmed’s concept of the non-performative is useful here. Ahmed discusses this in the context of institutional diversity “commitments” that don’t change the institution in any meaningful way; see Ahmed, On Being Included. I would argue that diagnostic non-performatives work to contain illnesses of unknown etiologies so that they are not a problem for medicine and its cognitive and social authority.
5. Brea, “Director’s Statement.”
8. Wendell, Rejected Body, 2.

BIBLIOGRAPHY