

UNREST: GENDER, CHRONIC ILLNESS, AND THE LIMITS OF DOCUMENTARY VISIBILITY

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The breath in the dark is a message.

This is what I think, immediately. I know what it is, that sound: the quick inhalation, the holding, the sucking-teeth sound of a difficult exhale. If you have never lived with a chronic illness or pain, the opening moments of Jennifer Brea's new documentary *Unrest* (2017), in which one is greeted by a black screen and the sounds of effortful breathing, present an interesting mystery: what is this woman doing? But I am in on the secret, even without an image. Some daily task has presented itself as a Herculean challenge and a woman is at the edge of her physical boundaries, trying to finish the walk or get to the couch or simply, sometimes, ride it out.

Jennifer Brea, the woman breathing in the dark, suffers from myalgic encephomyelitis (ME), also known as chronic fatigue syndrome (CFS). *Unrest* is the story of her diagnosis and partial recovery: part detective story, part autobiography, and part documentation of an illness-based social movement. Narratively, it follows Brea, a PhD student at Harvard as the film begins, when a strange and serious viral illness leaves her weak and exhausted, with worsening neurological and physical symptoms such as periodically losing the ability to speak and walk, particularly after physical exertion. After many visits to many specialists (ending at Princeton Hospital, in the town where Brea now lives with her husband, Omar Wasow), Brea is finally told that she has ME and is one of the small number of people who are severely incapacitated by the disease.

While *Unrest* definitely falls within the autobiography/memoir tradition of documentary, it is not all about Jennifer Brea. While conducting research on her own worsening symptoms, Brea learns that she is not as unusual as she has been led to believe: "My disease isn't rare at all," she says. One million people in the United States suffer from ME; women

comprise 85 percent of them. Moreover, it is not a new condition, having made large-scale, episodic appearances throughout history as "fever epidemics." As Brea traces a piece of this history, she keeps her eye on the dismissive—sometimes downright violent—treatment of women by the medical establishment when faced with unknown diseases and disorders that affect women more than men and that do not have obvious or simple causes.

Brea's research also uncovers a huge online community of ME sufferers, largely connected through social media sites such as Facebook, whose lives are also spent largely indoors, in bed. With the connectivity of video and Voice over Internet Protocol (VoIP) sites and an iPad, Brea is able to make contact and develop relationships with some of these people and their families. Thus, *Unrest* documents the emotional, legal, and medical struggles of a handful of people in the United States, United Kingdom, and Denmark, culminating in footage of the "Millions Missing" day of action on May 25, 2016, organized to bring awareness to ME.

After an initial Kickstarter campaign, *Unrest* received a great deal of support in the film world.¹ Outlets from PBS to Amazon Prime and Netflix picked up the film. People are watching it, listening to Brea (her Ted talk has over a million views), and reading her widely circulated *Boston Globe* article.² Viewers and commentators, including Brea herself, have located the film's feminist politics in its exposure of the medical system's misogyny and disregard for women's bodies and complaints of illness. *Unrest* casts much-needed light on the cascade of frustration, sadness, and anger that most women and gender nonconforming people have experienced as they interface with doctors and the medical system. As a woman of roughly the same generation, who is also an academic and also suffers from understudied illnesses that impact my daily life in profound ways, I locate the film's feminist intervention both in its critique of medicine and in the way Brea is able to tell the story of her illness with vulnerability and ferocity in equal measure. *Unrest* represents a refusal of "the sick woman role," an impossible position in which a woman is both entirely responsible for her own

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Jennifer Brea and Omar Wasow in their bedroom.

health issues (which are usually deemed to have a psychological cause) and is considered no longer to be a functional adult capable of meaningful thought or action due to illness and/or physical disability—and therefore unable to tell the truth about her own body.³

Neither macho survivor nor feminized victim, Brea turns her ME into politics and art. Audre Lorde's description of her journey in *The Cancer Journals*, which might be considered a literary foremother to *Unrest*, instructed readers: "That visibility which makes us most vulnerable is that which is also the source of our greatest strength."⁴ Brea seems to have taken this lesson to heart and worked to create long-awaited visibility for those who have gone missing—in the medical system and in the world of film. The search for *Unrest's* predecessors—documentaries focused on the actual pain and suffering of women due to illness or injury—by anyone trying to craft a genealogy will be frustrating and short. This notable dearth of films about women who are sick or in pain is an impetus to think seriously about the ones that do exist.

Sick women should certainly not be burdened by a demand to transform their suffering into meaningful works of art, as S. Lochlann Jain has argued in her analysis of the imperative that survivors of cancer begin to talk about "the gift of cancer."⁵ Nonetheless, *Unrest* marks an important moment in contemporary documentary film because it does more than just bring an issue to light. While doing the political work of consciousness raising, it is also a message to someone like me, who watched the film at home, in bed, waiting for the next doctor's appointment that may or may not improve my daily life. Visibility works both ways: a film can also say "I see you."

Perhaps it seems odd to claim that, in a filmic landscape obsessed with violence and death, and therefore, at some level, obsessed with the body in suffering and in pain, there are few cinematic representations of the woman's body actually in pain.⁶ War, torture, and serial killing dominate. The relentless agony of an undiagnosed autoimmune illness in which a woman's body turns against itself with fury and creative monstrosity? A rare find, certainly not widely known or available.⁷



An archival image of a woman in discomfort hints at the long tale of “hysteria.”

The film archive, then, echoes one of the primary messages of the film: millions of people, mostly women, suffer in invisibility and silence. Though everyone may know someone with a chronic illness, there has been little in the way of the representation of this reality on screen. The lack is all the more striking because film might be expected to provide a kind of privileged access to this most basic organismic experience. Susan Sontag famously warned of the dangers attending the detached spectatorship of photography in her *Regarding the Pain of Others*.⁸ Sontag’s proposed approach to regarding illness, however, as described in her well-known *Illness as Metaphor*, seems to suggest that a medium such as documentary is precisely what is needed to render the unflinching truth of the sick body.⁹

Unrest calls upon its audience to respond to Brea’s ordeal and, in the spirit of all political film, to do something about the social injustice and human suffering it presents. Through her careful attention to the historical context of her own illness, Brea admirably makes visible the deep misogyny of the medical establishment. To watch her (mis)treatment as an ME patient is to glimpse the latest installment of the medical profession’s long history of incorrectly attributing disease formations with a biological cause to women’s psyches and emotions, the latest chapter in the long tale of “hysteria.”

One could even argue that the film’s impressive multivocality and multimodal approach have emerged in part because of that misogyny not only at the level of content, but in its actual form. It is a film that no one, including Brea, ever really intended to make. She and her husband began recording her “episodes” to show to doctors at Brea’s growing number of specialist appointments. There is a funny/not-funny characteristic of mysterious illness: somehow, the day you go to show your doctor that weird swelling, or ask her to listen to those awful *cracks* in your joints when you move, your symptoms lessen and you look, to all intents and purposes, like a very articulate hypochondriac—or, worse, a lying hysteric.

The issue of belief and the unwillingness of medical establishments to trust women’s own accounts of their own bodies is central to the feminist politics of *Unrest*. One early telling scene shows Brea on a hospital gurney about to be seen by a new doctor. It’s not clear whether she and Wasow are in the ER or at a normal appointment. Brea is obviously emotionally upset by pain and sickness and the stress of never getting any answers. Wasow coaches her, warning: “. . . be a little careful. If you say too little, they can’t help; and if you say too much, you’re a kind of mental patient.”

In recent years, popular culture and the mainstream media have begun to acknowledge the fact that women have to monitor what they do and do not say to influence the outcomes of interactions with medical institutions. Joe Fassler’s article about the sexism of ER doctors in the treatment of his wife’s pain, which resulted not only in its unnecessarily long duration (nearly fourteen hours waiting for a correct diagnosis) but in the trauma of having excruciating pain minimized by hospital staff, was widely read and discussed in many social media circles.¹⁰ Similarly, Leslie Jamison’s “Grand Unified Theory of Female Pain” has influenced public conversation about gender and medicine. Jamison has provocatively asked whether “being a woman *requires* being in pain” such that “pain is the unending glue and prerequisite of female consciousness.”¹¹

So perhaps it is no wonder that within illness-related social media worlds, at least the ones I know, there is a new story posted almost daily of a doctor telling a woman that she is actually “just fine,” that she should seek psychological counseling, that she is a drug or attention seeker or, simply, “You don’t/can’t possibly have that [invisible illness that you have already been diagnosed with].” It is not only ME and its sufferers who are victimized by such dismissal, misrecognition, or infantilization, but any and all women who communicate a message about their body that is not one of total submission to the pain (often in the form of utter resistance or complete denial). *It hurts, but I’m fine. I didn’t take a single one of those pills the doctor gave me after my surgery. The show must go on, right?*

Part of what enables Brea to speak for so many women is that she does seem to be taken fairly seriously by her doctors and, implicitly, by her insurance provider, and has had access to a high-quality medical facility.¹² This may also account for why, as seen on screen, she may be sick, sad, and vulnerable, but she is rarely angry. I might even raise this issue as criticism if not for the possibility that she is editing her emotional responses in the film to balance on that razor’s edge between being a woman-who-is-suffering-and-worthy-of-empathy and being a woman-who-is-angry-and-therefore-unstable-and-not-



Wasow and Brea at a doctor's appointment.

worthy-of-concern. Maybe she didn't feel she had a choice if she wanted a large mainstream audience to see, to hear?

But the lack of anger is one aspect in which her film departs from the real world she seeks to convey. As I write this essay, for instance, I await a call from my health insurance company regarding the appeal I filed this week for the reversal of their decision not to cover a treatment that my doctor, my family, and I know will likely help me a great deal and may keep me out of a wheelchair. But the insurance company has categorized the treatment as "experimental" and since my policy does not cover experimental treatments, I will likely be denied again, no matter how eloquently my doctor pleads my case.¹³ I have a PhD and grew up in a medical family. Like Brea, I have "good" health insurance through a major research university. I know how to argue my case—and I may fail, and I will be angry. Indeed, if there is one oversight in the film's political vision, it is that the issue of access to resources, whether through the National Health Service in the United Kingdom or private insurance in the United States, is only referenced obliquely.¹⁴ Brea is a privileged spokeswoman.

Brea also has a husband standing steadfastly by her side. At least one commentator has even referred to *Unrest* as a "love story."¹⁵ To the extent that Brea and Wasow's on-screen relationship is devoted and tender, it does contain romantic

moments. Wasow takes on the role of caretaker and continually assures Brea that he will remain at her side, in sickness and health. This is not, however, the case for all women.¹⁶ The story of Leeray and Randy Denton, friends Brea met in an online ME support group, is closer to the lived reality of many sick women: Randy divorces Leeray, convinced that she is not actually sick and feeling unable to care for her even if she is. In a happy-ending scene, Randy does return to Leeray, and the couple remarries. While this reconciliation creates a touching narrative moment in the film, it also detracts somewhat from the serious point that Leeray's story was meant to convey.

Jennifer Brea has joined my personal pantheon of inspiring chronically-ill artists both because she makes visible to her audience the extent to which medicine is unconscionably sexist and because she "proliferate[s] the possible identities of illness."¹⁷ One version of the sick woman role is to be treated as the helpless and passive victim of bodies or psyches who cannot possibly know more about their body than those in medical authority; it thrives on the feminized fear of being exposed and deemed inconvenient, on one end, and of suffering and death on the other. After everything that Brea has lost, she will not pay this cost too: with an iPad and Skype she is able to produce a remarkable film within the narrow bounds defined by her ME.¹⁸ Insisting that she can create

meaningful art and work as a political activist from bed, in a culture that abhors disability and domesticity, is an act of resistance and bravery. Brea shows her fears, close up, and in so doing unseats medical authority over her body in its health and illness. Think of *Unrest*, then, as giving language and definition to a problem (women's invisible illness) that is defined precisely by the one thing documentary film can assuredly remedy: not being seen, nor narrated.

Not every scene in *Unrest* is language-giving. The filmic records of Brea's body in the throes of its worst torments defy most attempts at narrative and push documentary film to its very limits. There are echoes, in these moments of another rare view of bodily suffering: Peter Friedman's *Silverlake Life: The View from Here* (1993), the autobiographical account of Tom Joslin and Mark Massi's life with—and Joslin's eventual death from—AIDS. Much as the dizzying camera work and frantic quality of Joslin's narration during the parade scene in *Silverlake Life* convey the almost fugue-like state of being sick in a “normal” world, a parade scene in *Unrest* occupies the uncomfortable border between documentary as a story (for the viewer) and documentary as evidence (for the archive of humanity?).

In this sequence, Brea has begun a new antiviral medication that is making her feel better. She can walk, she has more energy, her mood is brighter, so she and Wasow put on their orange colors and go to attend the Princeton homecoming parade. These are happy moments for Brea, who is still in a wheelchair, along the route, smiling and cheering. But in the next series of shots, Brea effectively melts from her chair to the ground and, by the time the couple reaches the steps of their home, she falls into a fetal position and begins to sob. Her body wracked and heaving as if on a ship's deck in a storm, Brea complains about the light until words begin to fail. Wasow, naturally, goes to help his wife and carry her inside, but Brea screams at him: “Don't touch me!”

If you've been there, gentle reader, you know that this is not just because, as philosopher Elaine Scarry famously argued, pain is “language destroying” at the level of words.¹⁹ In this case, language fails in a way that surpasses Scarry's formulation: Brea's neural speech centers are acutely affected and she loses her ability to communicate entirely. This is the limit of the shared experience of film, too. Because despite Bill Nichols's compelling argument that documentary offers access to the “brute reality [of] *the world*”—albeit a construct—and thereby has an inherent urgency that calls its audience to action, the unruly, untellable bodies in *Silverlake Life* and *Unrest* exceed any sense of the real and the collective to which documentary usually grants access.²⁰ It is difficult to stand at the shared



Brea struggles on the stairs.

window offered by scenes like these. What world is being witnessed? Pain is individuating and singularizing, whereas the impetus of documentary is to build a shared world, “*the world*,” to use Nichols's term.

To return to my opening claim: rarely is the body of the woman in pain seen on screen. As Jamison explains, there is “an ethical and aesthetic commandment: Don't valorize suffering women.”²¹ The “sick woman role” does not allow for such cultural indulgences. The absence is also, I believe, due to a difficulty in creating a shared ethical imperative regarding the body itself, a limit with which documentary does not often have to contend.

One scene with Brea's husband is particularly telling. Less than ten minutes into the film, Brea is trying to get to the couple's apartment. She is on her hands and knees crawling up a flight of stairs, each movement obviously excruciating and exhausting to the extent that even this description feels frivolous and insufficient. She has demanded that Wasow record her ordeal on camera (whether for her doctors or for the already-emergent film project is not entirely clear). At one point he simply cannot take it anymore and tries to put the phone down and help his wife. She rejects his assistance and tells him “No, don't. It's fine.” Complying, Wasow responds: “This is perhaps the least chivalrous thing I've ever done in my life.” Many viewers will feel his psychological pain as much as or perhaps more than Brea's own, thus evoking one of the most difficult ethical rubicons presented by contemporary visual and social-media culture: What action is required in the face of suffering? What world does this body inhabit? What and who are you if you don't put down the phone and help?

Perhaps it was this kind of provocation that Sontag had in mind when she wrote that “illness is *not* a metaphor” and called for utter fidelity to what illness actually *is* for its sufferers when regarding the sick. In exposing the use of metaphoric thinking in the cultural treatment of illness, Sontag



Brea edits her film from her sickbed.

sought to liberate readers and viewers from the “truthful” accounts, which she called “the healthiest way of being ill.”²² To regard the sick woman this way is to perhaps deobjectify the Other and recognize in some deeply embodied, empathetic register that anyone and everyone will get sick, will hurt, will be disabled, will die.

For anyone grappling with being sick while female or non-normatively gendered, there is an archive of the sick body out there, waiting to be collected and curated. But much of the time, to be honest, those with chronic illness are too tired to demand that their stories be told. They’re too busy fighting insurance, or figuring out how to feed their kids when they can’t work and a husband has just bailed, to hold up a camera and film the struggle.

Brea’s deepest fears are articulated in the last moments of the film when she says: “What terrifies me is that you can disappear because someone’s telling the wrong story about you.” By “someone,” she means doctors and the medical establishment, to be sure, but also the world of filmic representation, upon which so much depends in today’s world of visuality.

I am grateful to her and the others who tell the right stories in *Unrest*, and hope that viewers take its messages far beyond the specifics of any particular diagnosis or documentary practice—that they will sail past any limitations to visibility-based empathy and see the film as an incitement for drastic change in the representation and care of sick women. I am also grateful that, for a moment, I saw myself and was reminded that, sick woman or not, I am part of *the* world.

Notes

1. Brea was a Sundance Fellow and received support from the Sundance Institute’s Documentary Edit and Story Lab and its Catalyst Forum, IFP’s Filmmaker Lab, and the Fledgling Fund.
2. Jennifer Brea, “They told me my illness was all in my head. Was it because I’m a woman?” *Boston Globe*, December 27, 2017, www.bostonglobe.com/magazine/2017/12/27/they-told-illness-was-all-head-was-because-woman/47zuihgBfZqPdNe7S4ohSJ/story.html.
3. I am referring here to something quite different than the “sick woman” who is the center of Johanna Hedva’s

important and moving “sick woman theory.” Much of what I argue in this article is inspired by and in conversation with Hedva’s assertion that one can actually throw a political stone through a window when one cannot get out of bed. See Johanna Hedva, “Sick Woman Theory,” *Mask Magazine*, January 19, 2016, <http://www.maskmagazine.com/not-again/struggle/sick-woman-theory>, and Johanna Hedva, “My body is a prison house of pain so I want to leave it like a mystic but I love it & want it to matter politically,” talk delivered at the California Institute of the Arts on October 7, 2015, <https://vimeo.com/144782433>. My description of the “sick woman role” is more a play on sociologist Talcott Parsons’s famous concept of the “sick role,” which he used to describe a set of “rights” and “obligations” that fall to the sick person upon their diagnosis. Interestingly, much of the recent research on gender and medicine seems to show that the two basic rights of the sick person—that the sick person is exempt from their normal social roles and that they are not responsible for their condition—do not seem to apply to women or non-traditionally gendered people, people of color, or (some) poor people. See Talcott Parsons, *The Social System* (Glencoe, IL: The Free Press, 1951). For recent studies of the treatment of women in medicine, see Maya Dusenbery, *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick* (New York: Harper One, 2018) and Abby Norman, *Ask Me About My Uterus: A Quest to Make Doctors Believe in Women’s Pain* (New York: Nation Books, 2018).

4. Audre Lorde, *The Cancer Journals* (San Francisco: Aunt Lute Books, 2006), 42.
5. S. Lochlann Jain, “Cancer Butch,” *Cultural Anthropology* 22, no. 4 (2007): 520.
6. To some extent, there is obviously a precedent for *Unrest* in the corpus of films about AIDS and AIDS activism, a possibility that warrants an entire essay of its own. I can only suggest the genealogical link here and cannot possibly do the topic justice. See B. Ruby Rich, *New Queer Cinema: The Director’s Cut* (Durham: Duke University Press, 2013) and David Román, “Remembering AIDS: A Reconsideration of the Film *Longtime Companion*,” *GLQ* 12, no. 2 (2006): 281–301, for insightful reflections on how AIDS-related films changed filmmaking and its viewing audiences. Future studies might also further consider the role of gender in representing on-screen suffering in mainstream fictional films. For instance, it might be instructive to compare a “successful” narrative film about a gay man living and dying with AIDS, such as *Philadelphia* (Jonathan Demme, 1993) with an equally well-received film about a woman living and dying with cancer, such as *Terms of Endearment* (James L. Brooks, 1983), two films separated by exactly a decade.
7. Two recent films that have featured women and chronic illness—and are each arresting in their own way—are *Indelible Lalita* (Julie Mallozzi, 2012) and *Get Well Soon* (Carolyn Lazard, 2015). I am grateful to Irene Lusztig for introducing me to both of these beautiful experimental films. It is also interesting to note that the Executive

Producer of *Unrest*, Deborah Hoffman, in addition to editing *The Times of Harvey Milk* (1984) among others, made a film about caring for her mother with Alzheimer’s disease (*Confessions of a Dutiful Daughter*, 1994). Hoffman herself lives with a chronic illness (B. Ruby Rich, personal communication with the author).

8. Susan Sontag, *Regarding the Pain of Others* (New York: Picador, 2003).
9. Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (New York: Picador, 2001).
10. Joe Fassler, “How Doctors Take Women’s Pain Less Seriously,” *The Atlantic*, October 15, 2015, <https://www.theatlantic.com/health/archive/2015/10/emergency-room-wait-times-sexism/410515/>.
11. Leslie Jamison, *The Empathy Exams* (Minneapolis: Greywolf Press, 2014), 187. Also available at <http://www.vqronline.org/essays-articles/2014/04/grand-unified-theory-female-pain>.
12. This unusual privilege is surely not incidental to her advanced degrees, profession, her marriage, or her supportive and respected husband.
13. I did lose my appeal and was denied treatment. I also subsequently lost an Independent Medical Review (IMR) of my appeal provided by the state of California. IMR decisions are not conducted by the state: they are farmed out to private, third-party firms who hire doctors to decide cases according to the dubious California Medical Treatment Utilization Schedule (MTUS). Thousands of cases are filed with DHHS every year. I am not the only one who is angry.
14. There is a good discussion of the role of National Institute of Health funding toward the end of the film in the depiction of Stanford geneticist Ron Davis.
15. Amy Kaufman, “Director Jennifer Brea exposes the personal pain of an autoimmune disorder in the documentary ‘Unrest,’” *L.A. Times*, September 29, 2017.
16. Researchers have repeatedly found that serious illness raises the likelihood of a woman’s divorce or abandonment by a male partner; men’s rates remain the same regardless of health status. See Michael J. Glantz et. al. “Gender Disparity in the Rate of Partner Abandonment in Patients with Serious Medical Illness,” *Cancer*, November 15, 2009, 5237–42; and Amelia Karraker and Kenzie Latham, “In Sickness and in Health? Physical Illness as a Risk Factor for Marital Dissolution in Later Life,” *Journal of Health and Social Behavior* 52, no. 3 (2015): 420–35.
17. Jain, “Cancer Butch,” 506.
18. I sometimes wished that the technology in the film were more explicitly explained for viewers, particularly how she was able to get footage of extremely high production value from kitchens and bedrooms abroad.
19. Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (Oxford: Oxford University Press, 1985).
20. Bill Nichols, *Representing Reality: Issues and Concepts in Documentary* (Bloomington and Indianapolis: University of Indiana Press, 1991), 109–11.
21. Leslie Jamison, *The Empathy Exams*, 213.
22. Sontag, *Illness as Metaphor and AIDS and Its Metaphors*, 1.