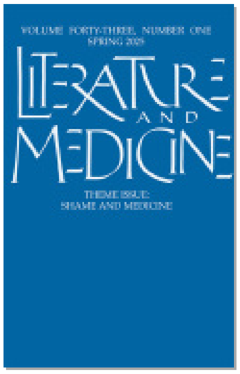
Towards a theory of unexplained illness: shame, ride, and Johanna Hedva's "Sick Woman Theory"

Hommes, M.A.

Citation

Hommes, M. A. (2025). Towards a theory of unexplained illness: shame, ride, and Johanna Hedva's "Sick Woman Theory". *Literature And Medicine*, *43*(1), 95-117. doi:10.1353/lm.2025.a975545

Towards a Theory of Unexplained Illness: Shame, Pride, and Johanna Hedva's "Sick Woman Theory"



Maaike Hommes

Literature and Medicine, Volume 43, Number 1, Spring 2025, pp. 95-117
(Article)

Published by Johns Hopkins University Press
DOI: https://doi.org/10.1353/lm.2025.a975545

Towards a Theory of Unexplained Illness: Shame, Pride, and Johanna Hedva's "Sick Woman Theory"

Maaike Hommes

Abstract: This article offers a reading of Johanna Hedva's "Sick Woman Theory" in relation to shame and pride in the context of unexplained illness—illness, that is, for which there is no found organic marker in relation to the symptoms experienced by the patient, and which is often chronic. People with unexplained illness find themselves without discursive backing and are especially prone to shame and stigmatization. Hedva politicizes their illness against the backdrop of a capitalist ideology, identifying chronic illness as a material-discursive phenomenon and uncoupling it from individual blame and responsibility. Bridging queer and crip discussions on shame and pride with approaches to illness within the medical humanities, I read Hedva's iconic "Sick Woman Theory" as an activist strategy for the emancipation of people with unexplained illness.

Keywords: Chronic illness, unexplained illness, chronic shame, queer theory, disability justice

This essay offers a reading of the productive absence of shame in the writings of genderqueer multidisciplinary performance artist and writer Johanna Hedva, most notably in their iconic essay "Sick Woman Theory," originally published online by *MASK Magazine* in January 2016. Hedva is chronically ill themselves and politicizes their illness against the backdrop of a capitalist ideology that invalidates and dismisses the lived experience of pain and suffering of people living with chronic conditions. "Sick Woman Theory" became a landmark text for disability

Literature and Medicine 43, no. 1 (Spring 2025) 95–117

activism in which chronic illness is reclaimed as a place of resistance. Hedva's affirmation of the "Sick Woman" offers a new form of political agency. This reappropriation takes place in the context of what Hedva identifies as regimes of neoliberal, white-supremacist, imperial-capitalist, cis-hetero-patriarchy, which frame illness as a temporary state and care as an exception.

In the present analysis, Hedva's explicit affirmation of the debilitating experience of illness and the politicization of the need for care provides a starting point for an inquiry into the politics of *unexplained* illness—illness, that is, for which there is no found organic marker in relation to the symptoms experienced by the patient, and which is often chronic. I explore the unexplained character of many chronic conditions in relation to a system of biomedical inclusion (wherein biomedical legibility utterly outweighs individual experience) and exclusion (wherein biomedical illegibility renders individual experience invisible). Because unexplained illness exists in a problematic and liminal space on the fringes of medical knowledge, it further complicates the possibility for the forming of a collective identity.

Hedva's essay exists at the intersection of literary artistic expression, activist manifesto, and scholarly writing, entering into discussion with Hannah Arendt's notion of the political and Judith Butler's work on vulnerability and interdependence. "Sick Woman Theory" responds to the argument made over the last decades in disability studies that disability should be considered a social construction instead of a medical problem, and translates this discussion to the specific constellation of chronic illness. This is of special importance considering the way in which the difference between illness and disability commonly results in their respective discussion within academic fields and traditions, where disability is discussed in disability studies or crip theory, and illness is predominantly addressed through the (critical) medical humanities.[1] Commenting on this division of labor, the difference between illness and disability was aptly described by Diane Price Herndl, who stated that "most people in the disability community do not want to be considered ill, and most people who are ill don't want to be considered disabled."[2]

The key to this difference is identity. Disability can constitute an identity in the positive sense, as it is claimed by disability pride, whereas chronic illness maintains a more negative relation to notions of identity. In sociological research, chronic illness is commonly described as resulting in a loss of identity, rather than a potential gain.[3] Even within critical theory it has been difficult to embrace chronic illness as a new identity. Although (chronic) illness is accorded a place within the appropriation of *crip* in crip theory,[4] it is often characterized by significant pain or discomfort—something that is not always part of disability. In short, illness can contrast with disability in the sense that illness offers less apparent possibilities to form a community based on a political formation that resists exclusionary normative frameworks.

In this essay, I work towards the formation of an emancipatory movement for unexplained illness by focusing on the tension between shame and pride as I read it in Hedva's work. Although "Sick Woman Theory" is not concerned with the extent to which different conditions are or are not explained in medical terms, I argue that Hedva's writing is especially relevant to the problem of living with unexplained illness and to the formation of such a community. Specifically, the absence of shame exhibited in "Sick Woman Theory" can be seen as a productive absence that opens a route to affirmation of unexplained illness.

Such an affirmation is considerably more complicated in cases of unexplained illness, because the lack of an identified biomarker for illness leaves patients vulnerable and exposed. Unexplained illness is often explained in psychological terms, setting up a link between the condition and the person's identity that can be charged with blame or individual responsibility. People with unexplained illness are especially prone to shame and stigmatization, as the lack of legitimization in the form of organic explanation accords them an outsider's status within medicine that is echoed in popular culture and society.[5]

People with unexplained illness often struggle to get their conditions diagnosed and thus struggle to find social acceptance and validation. When an organic cause for experienced symptoms fails to be found, patients are often told by medical professionals that "It's all in their head," sent to a psychiatrist, and prescribed antidepressants. Socially, they may even be held accountable for the creation of their symptoms. This lack of discursive backing creates a breeding ground for shame and negative attitudes centered around a body that fails to operate according to medical and societal standards of wellness and disease—a failure that is often internalized by patients.

The shame associated with unexplained conditions follows culturally dominant pathways. It usually entails feminization, notions of blame or individual responsibility for the creation of the symptoms, a psychologization of symptoms experienced as physical, a failure to validate individual experience in the face of medical authority, and possibly a (social) isolation of the patient, who is relegated to a place outside dominant medical discourse. As Sarah Ramey writes in her memoir about her life with chronic illness and her desperation over the lack of diagnostic explanation: "This must be what I want, I conceded. *I accept I may have created my own illness. . . . I am a monster*, I thought."[6] Hedva's writings offer a radical alternative to the implicit source of Ramey's anguish, for Hedva identifies and calls out the political structures at work in the dominant discourse of health and disease.

Groups of symptoms with no clearly established organic markers can be given medical diagnoses, of course. ME/CFS and fibromyalgia are among the most common such diagnoses, while other conditions are referred to by the term "functional"; all of these receive high levels of stigmatization in and outside of medical discourse.[7] While the experiences and conditions filed under various names vary across levels of found organic explicability and social acceptance, the common denominator that I am getting at here is a contested condition based on unknown physical etiologies.[8] These conditions are often chronic. Within medicine and psychiatry, but also sociology, the term "medically unexplained (physical) symptoms" (often abbreviated as MUS or MUPS) is used to refer to conditions for which there is no organic marker or structural bodily pathology found in relation to the symptoms experienced by the patient.[9] In practice, this often means that the unexplained nature of the illness is offloaded onto the patient, who comes to bear a double burden: the pain of their illness, and the burden of being undiagnosed and therefore becoming a "problem patient."

While terms like "contested" or "debatable" illness are used to refer to these conditions in the humanities and social sciences, I here maintain the term *unexplained illness*, because I want to emphasize how central the lack of organic explicability is to the difficult experience of these patients. Also, the emphasis on the unexplainedness of these etiologies contains within it the possibility of eventually resituating the problem away from individual patients and toward the structure of medical explicability as a whole.

Chronic illness in itself has a complicated relationship with notions of identity as made possible by disability scholars and activists. The positioning of the social model of disability as a counternarrative against the medical model of disability as an individual defect to be cured allowed people to claim a politics and to thus mediate the complicated terrain between pride and shame in reference to normative structures. For many chronic conditions that remain medically unexplained, this situation is further complicated by a lack of a fixed etiological place. Often, as I shall argue below, such a liminal space between medical knowledge and bodily experience exacerbates shame and complicates a collective movement toward acknowledgment of illness, advocacy, and the demand for care.

In this context, Hedva's coining of the figure of the "Sick Woman" as a political appropriation behind which to rally and unite offers a valuable opportunity: it allows for further critical discussion of the inhibiting factors of shame in relation to the particular constellation of unexplained illness. My reading of Hedva in this context also offers a bridge between queer and crip theoretical perspectives on shame and work on shame within the medical humanities. In doing so, I aim to offer a starting place to think through the specific problems that the lack of biomedical explanations for illness results in for patients today.

"It Is the World Itself That Is Making and Keeping Us Sick"

Hedva's figure of the Sick Woman addresses how people with chronic illness are feminized, in particular by being rendered as "weaker" or "more fragile."[10] Hedva explicitly explores this feminization in connection with global capitalism.[11] Capitalism defines illness by its lack of able-bodied productivity, relegating sick bodies as outsiders to an able-bodied norm.

During the Black Lives Matter protests in 2014, Hedva found themselves sick with a chronic condition that made them unable to leave their bed. Going back to this experience, Hedva opens the essay with a reflection on the intersection between activism and solidarity. The essay is written from this place of immobility, hearing the sounds of the marches outside their window. There, "attached to the bed," they write, "I raised my sick woman fist, in solidarity."[12] The isolation as a result of illness makes them unable to physically participate, and this makes them think about how many of the people who the protests are for are not able to attend (because they had to work or risked being fired, because of the threat of violence or police brutality, or because of an illness or disability—or because they were caring for a person with an illness or disability).[13] Hedva's reflections on illness and activism stem from an experience of isolation, which they use in a way that not only considers the personal as political but as a place for the formation of theory.[14] From this embodied experience, Sick Woman theory was born.

The choice to use the subject position of woman as a name-giver for the essay was meant as a radically inclusive move that addresses how disability and femininity are co-constructed. Even though they themselves did not identify as a woman, Hedva realized that that was how they were now seen: as a Sick Woman. As Hedva writes, "It did not intuitively make sense to me to say that the sick are weak because being sick is fucking metal. It has nothing to do with weakness and everything to do with blood, shit, agony, vomit, pus, and death. What narrative does it serve, then, to denigrate the sick to the sphere historically occupied by women? The one kept out of the public sphere? The one not legible as political?"[15]

Sickness is brought back to the sometimes brutal bodily manifestations (agony, death, and bodily excretions), while the representation of sickness is exposed as politics: as a narrative that serves a particular goal. For Hedva, the co-construction of disability and sickness with femininity, and femininity with domesticity, has everything to do with a system in which bodies are valued for productivity in a capitalist system. As such, care, insofar as it is not given within the closed domestic setting, becomes an exception that needs to be earned rather than a collective responsibility.

Hedva lists 26 different constellations of the Sick Woman identity, including:

> The Sick Woman is someone diagnosed with a chronic illness, whose family and friends continually tell them they should exercise more . . . The Sick Woman is a Black trans woman having panic attacks while using a public restroom, in fear of the violence awaiting her. . . . The Sick Woman is the child of parents whose indigenous histories have been erased, who carries in their body the trauma of generations of colonization and violence. . . . The Sick Woman is a fifty-year-old gay man who was raped as a teenager and has remained silent and shamed, believing that men can't be raped.[16]

This list explicitly includes not only people who identify as women but all people who have been made, in Hedva's words, "culturally illegitimate and politically invisible."[17] The list ends with an argument on care under capitalism, which is the main takeaway from the essay. Here, Hedva states that sickness is a capitalist construct that depends for its existence on its binary opposite co-concept of "wellness," which is defined, under capitalism, as being well enough to work. By making wellness into the standard mode of existence, illness is seen as temporary, and care and support as exceptions to the norm. Accordingly, Hedva concludes that care is the most anti-capitalist thing you can do: "to care for another and to care for yourself."[18] Care, here, is voiced as an act of resistance.

The figure of the Sick Woman unites all the "un-cared for, the secondary, the oppressed, the non-, the un-, the less-than."[19] Among these, the description of the fifty-year-old gay man is the only instance in the essay in which the word *shame* is mentioned, in tandem with silence and stigmatization. Like the Sick Woman, the figure of the fifty-year-old gay man, here a victim of sexual abuse, anticipates stigmatization and discrimination based on gendered stereotypes and norms. The various forms of the Sick Woman are thus clearly framed in relation to structures of oppression. Even though shame is only mentioned in passing, it is implicit in many of the descriptions, which all include marginalized subject positions; I argue further that shame sits next to violence, as in the description of the Black trans woman needing to hide in a public restroom.

One of the problems of experiencing violence and oppression is that it affectively works to individualize the effects of discrimination and thus risks placing the blame on the individual, who becomes isolated as a result. "Sick Woman Theory" must be read as a manifesto that resituates such attribution of blame towards a larger structure that is capitalist in nature. This is most aptly formulated in reference to illness in the statement "You don't need to be fixed, my queens—it's the world that needs the fixing."[20] Resonating with queer theoretical critiques of dualism and assimilation, and with the challenges brought forward by disability studies to a medical model of disability, Hedva calls for a movement that foregrounds care and collectivity.

The politics of maintaining or departing from various dualisms—gendered ones, but also those pertaining to nature/culture, mind/body, self/other, or, in Hedva's essay, sickness/wellness—have been addressed in feminist materialist arguments around the body that matters, or the implications of one's race, class, gender or nationality on how the body is lived. Here I draw on work by Butler, Karen Barad, Rosi Braidotti, and Elizabeth Wilson, but also by disability scholars like Margaret Price, Margrit Shildrick, and Rosemarie Garland-Thomson. Such materialist feminist accounts have theorized the relation between matter and meaning as one of contingency, intra-action or entanglement, viewing "personhood" or "identity"—but also materiality itself—as something that emerges through those interactions. Within disability studies, mind/body dualism was addressed by the coining of the materialist feminist concept of bodymind.[21] The term has a political value for disability studies and crip politics, which define the bodymind as an entity that is socio-politically constituted. The materiality of the body is something that is seen to emerge through what Price has termed "structural (power- and violence-laden) contexts and also individual (specific) experience."[22]

The theoretical basis for Hedva's text refers to this strand of thinking. Hedva explicitly mentions Butler's work on precarity, vulnerability, and resistance, as well as Ann Cvetkovich's work on depression as something that is responsive to oppressive structures. Building on the notion that the body is defined by its vulnerability, Hedva states that "the body and mind are sensitive and reactive to regimes of oppression" and that "all of our bodies and minds carry the historical trauma of this, that it is the world itself that is making and keeping us sick."[23]

Conceiving bodyminds as sociopolitical entities is not the same as understanding (chronic) illness as a result of the neoliberal world order or global capitalism. By linking illness to a capitalist system, Hedva implicitly speculates on the causation of (chronic) illness and places it within a political system instead of within bodies over which individuals are seen to have responsibility. Going so far as to say that it is "*the world* that is making us sick," Hedva locates the cause for illness outside the self and thus outside the realm of individual responsibility.[24]

In reference to feelings of shame in relation to *unexplained illness*, this is an important move. The lack of organic explicability of certain conditions carries with it historically implied notions of blame and individual responsibility. In 1978, Susan Sontag famously addressed how twentieth-century discourse about cancer metaphorically tied the disease to repressed emotions or anger that eventually manifested in the growth of a tumor.[25] Within nineteenth-century writings on hysteria, spearheaded by Sigmund Freud and Josef Breuer, the condition, which gradually became a container concept for organically unexplained symptoms in women, was also seen to be due to repressed emotions, now of a sexual nature.[26]

Related to these individualizing tendencies is the notion of secondary gains, which can equally be traced back to Freud and is still present in contemporary discussions of unexplained conditions. It suggests that unexplained physical conditions were unconsciously created by the patient because they would have something to gain from the sick role.[27] This idea is particularly noticeable in Regency novels such as Jane Austen's *Pride and Prejudice* (1813) and *Persuasion* (1817), in which female characters use feigned conditions, or their "nerves," in order to extract love and care from their family, keep their husbands close, or get out of unpleasant social situations. The strong associations between illness and identity find their way back to shame around unexplained conditions that remain "suspect": open to different cultural meanings that might be attached to it.[28]

Contrary to ideas that tie one's illness to one's character, personality, or emotional constitution (over which one should exercise self-mastery and control), Hedva offers an alternative that sees illness as a reaction to such oppressive regimes. Similar to how feminist theory around the 1980s addressed hysteria as a reaction to the culture's patriarchal oppression of women, Hedva's argument is predominantly politically motivated.[29] It moves away from biology or organic explicability and towards collective responsibility that uncouples the illness from a person's self and identity.

In terms of etiology, this alternative means that the cause for unexplained physical conditions is no longer assumed to be psychological, even though a physical explanation is absent. Instead, Hedva writes about medical labels and diagnosis as something that exists within the "language of the oppressor." They adopt an expression from the Native American Cree language, in which one speaks of illness that has "come to me" rather than in identity-based or possessive terms like "I am ill" or "I have x."[30] Removing the possessive from the equation altogether effectively avoids issues surrounding blame and individual responsibility that often stick to diagnoses with conditions whose etiology cannot be explained in organic terms.

Although a diagnosis does not necessarily imply a physical explanation of illness, it does offer a certain amount of legitimization, or what Sarah Nettleton has called "the permission to be ill."[31] In such a way, a diagnosis often becomes a desired status for patients with unexplained conditions. In an essay on diagnosis that narrates the writer's own experience with a diagnosis of schizoaffective disorder, Esme Weijun Wang describes this comforting effect: "I like to know that I'm not pioneering an inexplicable experience."[32] This same comfort is recognizable for many patients with conditions such as fibromyalgia and ME/CFS, helping them find a community of people who experience similar physical symptoms. Yet the lack of organic explanation that sticks to diagnoses of physically unexplained conditions also renders patients with these diagnoses more vulnerable to experiences of stigma and shame.[33] In such diagnoses, the lack of organic explanation can mean that the name offers no legitimization or any kind of safe haven, but is likely to produce even more blame and stigmatization.

The uncoupling of illness and identity in Hedva's criticism is thus vital in the fight against the stigmatization of unexplained illness.

Instead of inhabiting a liminal space outside dominant medical discourse and being vulnerable to shame as a result of a cultural psychologization of their physical conditions, Hedva's theory redirects the etiologic implications away from identity and individuality towards a commonly experienced present. It conceives of illness as a material-discursive reality instead of as a result of individual physical or mental processes, offering a politically informed theoretical framework in which chronic illness can be carried collectively.

Shame and Unexplained Illness

Hedva's essay appeared alongside a wave of critical writing about women in medicine and experiences of (chronic) illness which are connected to structural conditions like capitalism, ableism, or patriarchy: Carolyn Lazard's "How to Be A Person in the Age of Autoimmunity" (2013), Amy Berkowitz's *Tender Points* (2015), Alice Hattrick's *Ill Feelings* (2022), Lucia Osborne-Crowley's *I Choose Elena* (2019) and *On Being Ill* (2021), a collection of contemporary essays by female writers that accompany canonical writings by Virginia Woolf and Audre Lorde. Like Hedva, Lazard, Berkowitz, Hattrick, and Osborne-Crowley share their own experiences with poorly understood, contested, or unexplained conditions like autoimmune disease (Lazard), fibromyalgia (Berkowitz), ME/CFS (Hattrick) and endometriosis and interstitial cystitis (Osborne-Crowley), and connect their own experiences to a wider politics of (chronic/unexplained) illness. Most unexplained conditions predominantly affect women, making the problematic of unexplained illness an issue of ongoing gender disparities in health care.[34] Along with gender, these writings address how race, class, or late capitalism influences how (unexplained) illness is understood and experienced.[35]

There are high levels of shame and stigma related to unexplained illness, the historical origins of which can be traced back to the discourse surrounding hysteria.[36] Feelings of shame in relation to unexplained illness have been connected to the psychologization of physical symptoms and a questioning of their veracity.[37] Such attitudes, from medical practitioners as well as from patients' social surroundings, mean that patients struggle with having to account for the idea that they complain, crave attention, or feign their illness because there is something to gain from the sick role.[38] The politics of unexplained illness is closely related to issues surrounding credibility in the face of (medical) authority, something which women and minority groups have historically been denied. Shame is closely connected to the cultural discourse around unexplained or chronic illness, and strategies to avoid it are a central theme in discussions of the patient experience.

Whereas stigma is seen as a socially discrediting attribute, shame is commonly defined as a negative affect that follows a transgression witnessed by someone else.[39] When connected to unexplained illness, feelings of shame and stigmatization can be seen as the product of an ableist configuration in which able-bodied health is defined as the norm. However, a further complexity is found in the lack of discursive backing, making these patients more vulnerable and exposed.

Being a deeply relational emotion, shame is not always felt acutely; it can also be analyzed to identify how people struggle to accommodate to what is seen as normal. Luna Dolezal's philosophical analysis of the experience of *chronic shame* can be seen in this context. Chronic shame is characterized by the persistent possibility of experiencing it: without being acutely present, it functions by "structures of absence, anticipation and intersubjectivity."[40] Dolezal's concept must be understood in relation to marginalization and political oppression.[41] Dolezal separates *explicit* chronic shame, in which an individual is conscious of the fact that they are employing strategies for avoiding shame-inducing situations, from *implicit* chronic shame, which is not recognized by the individual but rather internalized imperceptibly. Dolezal addresses how implicit chronic shame might not be consciously experienced, and indeed how its anticipation may even be denied.[42] For Dolezal, chronic shame is thus "always bound up in social and/or political norms."[43] Although shame is deeply personal, Dolezal emphasizes its relational structure, foregrounding structural aspects like experiences of racism, stigma, social harms, and social inequalities over individual experiences of responsibility or low self-esteem. In this way, implicit chronic shame, though perhaps difficult to identify, also becomes a tool for addressing the way in which marginalization, stigmatization, or discrimination is internalized by individuals within dominant discourse.

In both chronic illness and chronic shame, the term *chronic*—which comes from the ancient Greek "chronos," meaning time, refers to an embodied experience of a constant state. Hedva highlights the physicality of this experienced temporality. They write how a chronic illness is often an illness that lasts a lifetime: "And there is the weight of time: yes, that means that you feel it every day."[44] Dolezal's use of the term "chronic" in the form of chronic shame has a similar connotation, but involves a more subtle sense of temporality in the form of affect and a persistent, lingering possibility for manifestation.

The interaction between shame and the unexplained nature of some chronic conditions is mostly addressed within social sciences and psychology with a focus on stigma, and its politics remain largely unaddressed within the humanities.[45] Within the medical humanities, the work done by Katharine Cheston has been important for addressing shame, specifically in the context of unexplained illness. Predominantly working on illness memoirs, Cheston illuminates the double burden (physical and social) that these patients suffer from. With the help of Dolezal's concept of chronic shame, I build on Cheston's work, expanding it to discuss the disciplinary effects of this stigma—the way in which shame is internalized by patients and can work to facilitate oppressive structures.

Different from disability pride, or the use of *crip* as an affirmative term in disability activism, unexplained illness lacks a specifically defined (academic) field in which its problematic is discussed in terms of oppression.[46] In her work on the difference between the study of illness and disability, Price Herndl observes that where disability studies locates disability in the social, illness is perceived to be located in the body instead.[47] In *unexplained illness*, this localization in the body is absent, as the lack of organic/somatic explicability is its most prominent feature. This excludes these patients from the realm of illness and disease and forces them to inhabit a liminal space. In the context of this liminality, the notion of the Sick Woman as a term that politicizes the experience of chronic (unexplained) illness and which battles against shame and emphasizes its structural conditions, can become an important concept for the emancipation of unexplained conditions. Within the problematic existence of unexplainedness, patients first need acknowledgment of the fact that they are, in fact, ill; that they are, themselves, not to blame; and that their complaints will be taken seriously.

Both disability and unexplained chronic illness are up against an able-bodied and able-minded norm. To add to this, unexplained illness also stands in direct conflict with knowledge construction, which is to say, with a version of medicine that does not incorporate, include, or legitimize their illness experience of people with unexplained conditions. As disability is marginalized based on being perceived as a medical defect, and people with (possibly invisible) chronic illness have to mediate the cultural stigma of not getting "well soon," unexplained illness includes an added epistemological marginalization; according to medical science, everything should "work just fine," and yet it does not. This marginalization can spiral into material consequences, at which point people with illness, disability, or unexplained conditions find themselves equally up against oppressive structures. However, critically zooming in on unexplained illness sheds light on an experience in which pride is less concerned with bodily difference and more with public acknowledgment—with the need for affirmation, legitimization, and care.

Considering that unexplained illness is a vulnerable and marginalized state of being that predominantly affects women—and bearing in mind the close and well-researched ties between the body, gender, shame, and politics—the coupling of feelings of shame in relation to chronic and/or unexplained illness is a pressing issue for intersectional feminist theory. The link between unexplained illness, chronic shame, and intersecting modes of marginalization has, however, rarely been addressed.[48] It is here that a reading of Hedva's work in the context of chronic shame becomes all the more relevant.

Shame, Pride, and Affirmation

Reading Hedva next to the problematic of unexplained illness leads to two main observations. First, Hedva redirects etiology away from individual responsibility. This makes them able to uncouple unexplained illness from negative connotations concerning identity, such as those identified by Sontag in 1978. Second, this redirection entails a positive gesture that does couple illness and identity, but in a fashion that appropriates illness *as* identity: they name the Sick Woman, a figuration which is only possible after having first redirected etiologic implications. In this sense, the Sick Woman represents an appropriation similar to that of the queer and the crip in their respective fields of theory.

This claiming of a positive term and revealing of structural conditions have important consequences for shame. But it does not necessarily mean that shame is completely removed or voided, as the large body of queer theory interacting with shame has demonstrated. Within queer theory, the politics of identity has been discussed in close connection with notions of shame and pride. When pride became something behind which to rally, and gained more traction in queer activism and scholarly work, shame, as its opposite, became, in the words of David Halperin and Valerie Traub, pride's "emotional antithesis and its political antagonist."[49] However, in their introduction to *Gay Shame*, Halperin and Traub comment on the intricate connection between the two, writing that "Gay pride does not even make sense without some reference to the shame of being gay."[50] Dissatisfied with gay pride movements, their intersection with neoliberalism, and the corporate selling-out of Gay Pride, activists started to organize events under the header of Gay Shame as a radical anti-assimilation project and collective move against normativity.[51] What this work has shown, most of all, is that the tension between shame and pride must be preserved, for this tension provides productive ground for a discussion of the effects of, and the appropriate resistance to, normative structures.[52]

With respect to disability, Eli Clare reflects on the intricate connection of shame and pride by pointing out the necessity, but also the difficulty, of disability pride. In *Exile and Pride*, originally published in 1999, he writes:

> Pride is not an inessential thing. Without pride, disabled people are much more likely to accept unquestioningly the daily material conditions of ableism: unemployment, poverty, segregated and substandard education, years spent locked up in nursing homes, violence perpetrated by caregivers, lack of access. Without pride, individual and collective resistance to oppression becomes nearly impossible. But disability pride is no easy thing to come by. Disability has been soaked in shame, dressed in silence, rooted in isolation.[53]

Disability pride as an activist strategy can function as the opposite of shame and as a way to move beyond the constraints of ableism. However, Clare also acknowledges the continuing difficulty of mediating ableism, feelings of shame, and political resistance. In his keynote lecture for the Gender Odyssey Conference, published in 2010, Clare responds to the framing of shame and pride as opposites and argues against the idea that there exists a distinct boundary between the two. Instead, in Clare's words: shame and pride, "dance, spar, sit at the same table."[54]

At the same time that the intricacies of shame and pride have troubled queer and crip theory, the often-unexplained status of many chronic illnesses means that they are organized around an absence that makes it even more difficult to function as a basis for pride and provides a common breeding ground for shame. The lack of biomedical etiology means that unexplained illness needs to be discussed not only in tandem with an exclusion from a social system but also in relation to epistemological constructions of evidence. In response to a system that denies certain cases of illness legitimacy and thus obstructs access to care, then, Hedva's concern is with the forming of an identity: with an acknowledgment of the many people living with chronic illness and with making them more visible. Focusing on the specific problematic of illness that is not recognized within the current medical system and thus has little currency for cultural legitimization, Hedva's call for a greater visibility of chronic illness in the public sphere becomes an indispensable step for the emancipation of unexplained illness.

Towards a Theory of Unexplained Illness

Reflecting on Sick Woman theory in 2022, Hedva writes the following:

> Before any of my other identities or occupations, and no matter what I said, did, produced, or defined myself as, I saw that I was now defined by society in terms of the care I needed—and that this was true for anyone defined by care, whether they "gave" it or "took" it—and this was a raw fucking deal. By medical doctors baffled by my symptoms and dismissive of their validity; by social workers and bosses and other cogs in the wheels of capitalism who demanded the continuity of my labor while simultaneously denigrating me to the category of worthless because my body disrupted my labor's continuity; by institutions who swept in to finesse my condition into something that could be rendered into an art-historical and cultural product; by friends, family, lovers, and enemies who didn't believe it could be as bad as I said it was: I was now seen as malingering, a burden, a drain on resources, possibly faking it, certainly hysterical, a thing resplendent with pathology—simply because I had a body that needed more than it was supposed to need.[55]

Here, Hedva shows how the lack of validation of symptoms that are seen as "baffling" by doctors makes it all the more difficult to be on the receiving end of care. This relates to practical circumstances, in which people whose conditions are not diagnosed or recognized as legitimate are unable to claim disability benefits or the necessary funds to receive care; it also pertains emotionally and socially, where the perceived malingerer is afraid to be a burden and/or loses their system of support. The delegitimization experience that fosters the notions of blame described by Hedva in terms of "malingering," "drain," "burden," and "hysterical" is built on the idea that care can only be offered when given a solid explanation for it in medical (organic) terms.

When a clear medical cause is lacking, patients often find it difficult to ask for care, since the call for it could be mistaken for a call for attention or simply seen as burdensome.[56] Social science interviews done with women with unexplained illness even show how shame in relation to chronic unexplained illness obstructs compassion. In these cases, normative notions of having to be strong and productive stand in the way of forming a community that could benefit patients.[57]

Contrary to such attitudes, Hedva calls for a politics of care that includes prioritizing the vulnerable state of the body, creating a community of support, and practicing radical kinship.[58] Hedva highlights the fact that nursing, nurturing, and caring have been historically feminized roles. To "support, empower and honor" these practices is thus, in their view, a political act towards an interdependent sociality.[59] Similar communities of support or kinship are described by Disability Justice activist and writer Leah Lakshmi Piepzna-Samarasinha in *Care Work: Dreaming Disability Justice*. Piepzna-Samarasinha describes the founding of "care webs," or self-organized care collectives amongst queer disabled people of color, as places of "deep healing."[60] Such care webs answer the activist call "Nothing about us without us" within the disability rights movement, but also redistribute care work away from the flow of capital and ableist notions of productivity.[61]

There is specific value in the way in which these works incite thought about the workings of power, intimacy, and relationality in connection to medical care, especially as it relates to those who are chronically dependent on it. Piepzna-Samarasinha explains how some people have had to run away from care because "care meant control," detailing how queer disabled people of color often suffer from "queerphobia, transphobia, fatphobia or sexphobia from our care attendants."[62] Piepzna-Samarasinha describes how shame can hinder chronically ill or disabled people from asking for care, offering as a counterpoint examples of online communities where people share their different needs and experiences and shame is overcome.[63]

Such activism shows how a reshaping of normative frameworks, even within smaller communities, can have great effects in overcoming some of the obstacles that shame poses in relation to illness. Being vocal about care needs, lack of access, or the reality of living with chronic illness helps to create a narrative reality in which the experience of chronic illness becomes recognized and can be cared for, which is of special importance to people living with unexplained conditions.

Unexplained illness is often negatively linked to identity, giving rise to shame and isolation. The coining of the Sick Woman as an affirmative identity claims illness as a material discursive entity and thereby redirects attention to the structural conditions under which illness becomes defined, and by which these conditions come to be defined as unexplained. The fact that Hedva only mentions the term "shame" once in their manifesto is part of this redirection, this redefinition. I have sought to make this absence productive by explicitly framing it in terms of affirmation of illness itself, something which is all the more important in relation to unexplained illness.

Affirmation of unexplained illness cannot be easily understood in terms of pride, itself an already complicated term in relation to queer identities or disability. What affirmation of unexplained illness can entail is explored by Hedva through their radical plea for the importance of care. Through theory, they open the way for a disability justice movement that is specifically geared toward the problematic of unexplained illness—one that understands the need for acknowledgment of illness, and can thus lead the way to better care.

NOTES

1. See also the work by Monica Greco on the medical humanities and its challenges as an interdisciplinary endeavor: Greco, "Logics of Interdisciplinarity."

2. Price Herndl, "Disease versus Disability," 593.

3. Åsbring, "Chronic Illness"; Charmaz, "Loss of Self."

4. Kafer, *Feminist, Queer, Crip*, 7; Clare, *Brilliant Imperfection*, 60–61.

5. See Vickers, "Stigma, Work, and 'Unseen Illness," 141; Werner, Isaksen, and Malterud, "I Am Not," 1036; Philips and Rees, "(In)Visibility Online," 226; Pryma, "Even My Sister"; Diedrich, "Illness (In)action"; Cheston, "(Dis)respect and Shame."

6. Ramey, *Lady's Handbook*, 109 (emphasis in the original).

7. Looper and Kirmayer, "Perceived Stigma."

8. An example of the debate—and on the progress made in terms of the organic explicability of once-unexplained illnesses—is found in a 2015 report by the US National Academy of Medicine that developed new diagnostic clinical criteria for ME/CFS. The report stressed that ME/CFS was a medical, instead of a psychological or psychiatric, condition and reviewed evidence based on physical findings. See *Beyond Myalgic.*

9. Creed et al., "Is There A Better Term," 5. For a critical discussion of the use of the term, see Greco, "Classification and Nomenclature."

10. Hedva, "Sick Woman Theory."

11. In his 2006 *Crip Theory*, Robert McRuer established the link between neoliberal capitalism as a system driven by market priorities and what he called compulsory able-bodiedness as its agent. In response to the compulsory heterosexuality that produces queerness, McRuer speaks of compulsory able-bodiedness to identify how the world is organized along ableist configurations of time and space. See McRuer, *Crip Theory*, 8. Hedva's "Sick Woman Theory" mentions the text in its extensive bibliography and incorporates a similar critique.

12. Hedva, "Sick Woman Theory."

13. Hedva, "Sick Woman Theory."

14. Here I refer to Sara Ahmed's *Living a Feminist Life* (2017), where she builds on the famous feminist notion by claiming that the personal is not only political, but theoretical as well. See Ahmed, *Living A Feminist*, 10.

15. Hedva, "Sick Woman Theory."

16. Hedva, "Sick Woman Theory."

17. Hedva, "Sick Woman Theory."

18. Hedva, "Sick Woman Theory."

19. Hedva, "Sick Woman Theory."

20. Hedva, "Sick Woman Theory."

21. Price, "Bodymind Problem" 270.

22. Price, "Bodymind Problem" 271.

23. Hedva, "Sick Woman Theory."

24. Hedva, "Sick Woman Theory" (emphasis mine).

25. Sontag, *Illness as Metaphor*, 22.

26. See the introduction by Charles Bernheimer to *In Dora's Case*.

27. Freud discussed the meaning of secondary gains in a footnote that he added later as a correction to a passage in 1923 to his Dora case—a fact that already speaks about the gender dynamics in the formulation of the concept. See Freud, *Standard Edition*, vol. 7, 43, or the editor's note in Freud, *Standard Edition*, vol. 16, 384. See also Fishbain, "Secondary Gain Concept," 264, 266–67.

28. See my mention of Ramey's memoir earlier; see also Werner, Isaksen, and Malterud, "I Am Not."

29. The nineteenth-century female body was a point of departure for linguistically or discursively oriented feminist theory in the 1970s and 1980s, and continued to be in the 1990s, with the group that Elaine Showalter called the "New Hysterians." Hysteria was understood as a cultural condition and seen as being reactive to patriarchal oppression of women. Showalter described hysteria as a form of protolanguage "communicating through the body messages that cannot be verbalized" (Showalter, *Hystories*, 286). See also Devereux, "Hysteria, Feminism," 20; Showalter *Hystories Revisited*, 28.

30. Hedva, "Sick Woman Theory."

31. Nettleton, "I Just Want," 1175.

32. Wang, *Collected*, 5.

33. Barnett et al. have shown that patients with functional neurological disorders were often seen as "attention seeking" or as malingerers by their health care professionals. See Barnett et al., "Vicious Cycle," 1807. See also Nettleton, "I Just Want," 1169.

34. On the prevalence of fibromyalgia in women, see Yunus, "Role of Gender," 129, who notes a proportion of 9:1. For a systemic overview on the prevalence of ME/CFS, see Lim et al., "Systematic Review," 4. For an overview of gender differences and the prevalence of IBS in women, see Lee et al., "Gender-related Differences," 2184.

35. The discourse around (Long-)COVID has thrown into sharp relief how illness is politicized, how not everyone accesses health care equally, and how race and class affect the type of care people receive, see Laurencin and McClinton, "COVID-19 Pandemic"; Laurencin and Walker, "Pandemic on a Pandemic"; Krieger, "ENOUGH." For media discourse on the intersection of race, class, and poverty, see Pilkington, "As 100,000 Die"; Chotiner, "Coronavirus." Research on general pain treatment and management done in an American context found that women's pain was more often psychologized than men's, and acknowledged racial and ethnic disparities in the assessment and treatment of pain. See Zhang et al., "Gender Biases"; Lee et al., "Racial and Ethnic"; Mathur et al., "Racial Bias."

36. For the historical links between unexplained illness in the present and the historical formulation of hysteria, see Johnson, *Medically Unexplained Illness*, 13. For

an example of how feminist theory has proposed to think of contemporary forms of unexplained illness as present-day manifestations of hysteria, see Showalter, *Hystories*. For a recent scholarly analysis of how disability activism in popular culture reacts to the category of hysteria that has silenced women's voices of illness, see Diedrich, "Illness (In)action."

37. Åsbring and Narvanen, "Women's Experiences"; Werner, Isaksen, and Malterud, "I Am Not"; Dickson, Knussen, and Flowers, "Stigma and the Delegitimization"; Cheston, "(Dis)respect and Shame."

38. Werner, Isaksen, and Malterud, "I Am Not."

39. Goffman, *Stigma*; Dolezal, *Body and Shame*, 4.

40. Dolezal, "Horizons of Chronic Shame," 757.

41. Dolezal, "Horizons of Chronic Shame," 740.

42. Dolezal, "Horizons of Chronic Shame," 754.

43. Dolezal, "Horizons of Chronic Shame," 755.

44. Hedva, "Sick Woman Theory."

45. Åsbring and Narvanen, "Women's Experiences"; Werner, Isaksen, and Malterud, "I Am Not"; Dickson, Knussen, and Flowers, "Stigma and the Delegitimization"; Vickers, "Stigma, Work."

46. According to Whitehead and Woods, the critical medical humanities has focused on how gender, class, race, and sexuality determine the way in which the body is met in different medical situations. The specific problematic of unexplained illness has received comparatively little attention. See Whitehead and Woods, "Introduction."

47. Price Herndl, "Disease Versus Disability," 593.

48. Special issues on "Gender and the Politics of Shame" in *Hypatia* in 2018 and "The Politics of Shame" in *Feminism and Psychology* in 2019 have addressed the way shame works to maintain oppressive structures or surveillance. See Fischer, "Gender and the Politics"; Shefer and Munt, "A Feminist Politics." Recent work by Katharine Cheston has specifically addressed the way in which shame is present in the lives of women living with chronic illness; see Cheston, "(Dis)respect and Shame."

49. Halperin and Traub, *Gay Shame*, 3.

50. Halperin and Traub, *Gay Shame*, 3.

51. See also Rand, "Gay Pride."

52. Rand, "Gay Pride," 79.

53. Clare, *Exile and Pride*, 107.

54. Clare, "Resisting Shame" 461–62.

55. Hedva, "Why It's Taking."

56. Werner, Isaksen, and Malterud, "I Am Not."

57. Werner, Isaksen, and Malterud, "I Am Not."

58. Hedva, "Sick Woman Theory."

59. Hedva, "Sick Woman Theory."

60. Piepzna-Samarasinha, *Care Work*, 28.

61. Piepzna-Samarasinha, *Care Work*, 13.

62. Piepzna-Samarasinha, *Care Work*, 18–19.

63. Piepzna-Samarasinha, *Care Work*, 26–27.

BIBLIOGRAPHY

Ahmed, Sara. *Living a Feminist Life*. Durham, NC: Duke University Press, 2017.

Åsbring, Pia. "Chronic Illness—A Disruption in Life: Identity-Transformation among Women with Chronic Fatigue Syndrome and Fibromyalgia." *Journal of Advanced Nursing* 34, no. 3 (May 9, 2001): 312–19. doi.org/10.1046/j.1365-2648.2001.01767.x.

Åsbring, Pia, and Anna-Liisa Närvänen. "Women's Experiences of Stigma in Relation to Chronic Fatigue Syndrome and Fibromyalgia." *Qualitative Health Research* 12, no. 2 (February 2002): 148–60. doi.org/10.1177/104973230201200202.

Austen, Jane. *Pride and Prejudice*. Penguin English Library, EL 72. Harmondsworth, UK: Penguin, 1972.

Austen, Jane. *Persuasion*. Penguin Classics. London: Penguin Books, 2003.

Barnett, Caroline, Rebecca Davis, Claire Mitchell, and Sarah Tyson. "The Vicious Cycle of Functional Neurological Disorders: A Synthesis of Healthcare Professionals' Views on Working with Patients with Functional Neurological Disorder." *Disability and Rehabilitation* 44, no. 10 (May 8, 2022): 1802–11. doi.org/10.1080/09638288.2020.1822935.

Berkowitz, Amy. *Tender Points*. Brooklyn, NY: Nightboat Books, 2019.

Bernheimer, Charles, and Claire Kahane, eds. *In Dora's Case: Freud-Hysteria-Feminism*. London: Virago, 1985.

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington, D.C.: National Academies Press, 2015. doi.org/10.17226/19012.

Charmaz, Kathy. "Loss of Self: A Fundamental Form of Suffering in the Chronically Ill." *Sociology of Health and Illness* 5, no. 2 (July 1983): 168–95. doi.org/10.1111/1467-9566.ep10491512.

Cheston, Katharine. "(Dis)Respect and Shame in the Context of 'Medically Unexplained' Illness." *Journal of Evaluation in Clinical Practice* 28, no. 5 (October 2022): 909–16. doi.org/10.1111/jep.13740.

Chotiner, Isaac. "The Coronavirus and the Interwoven Threads of Inequality and Health." *The New Yorker*, April 14, 2020. www.newyorker.com/news/q-and-a/the-coronavirus-and-the-interwoven-threads-of-inequality-and-health.

Clare, Eli. "Resisting Shame: Making Our Bodies Home." *Seattle Journal for Social Justice* 8, no. 2 (2010): 455–65.

Clare, Eli. *Exile and Pride: Disability, Queerness, and Liberation*. Durham, NC: Duke University Press, 2015.

Clare, Eli. *Brilliant Imperfection: Grappling with Cure*. Durham, NC: Duke University Press, 2017.

Creed, Francis, Elspeth Guthrie, Per Fink, Peter Henningsen, Winfried Rief, Michael Sharpe, and Peter White. "Is There a Better Term than 'Medically Unexplained Symptoms'?" *Journal of Psychosomatic Research* 68, no. 1 (January 2010): 5–8. doi.org/10.1016/j.jpsychores.2009.09.004.

Devereux, Cecily. "Hysteria, Feminism, and Gender Revisited: The Case of the Second Wave." *ESC: English Studies in Canada* 40, no. 1 (2014): 19–45. doi.org/10.1353/esc.2014.0004.

Dickson, Adele, Christina Knussen, and Paul Flowers. "Stigma and the Delegitimation Experience: An Interpretative Phenomenological Analysis of People Living with Chronic Fatigue Syndrome." *Psychology & Health* 22, no. 7 (October 2007): 851–67. doi.org/10.1080/14768320600976224.

Diedrich, Lisa. "Illness (In)Action: CFS and #TimeForUnrest." *Literature and Medicine* 39, no. 1 (2021): 8–14. doi.org/10.1353/lm.2021.0001.

Dolezal, Luna. *The Body and Shame: Phenomenology, Feminism, and the Socially Shaped Body*. Lanham, MD: Lexington Books, 2015.

Dolezal, Luna. "The Horizons of Chronic Shame." *Human Studies* 45, no. 4 (December 2022): 739–59. doi.org/10.1007/s10746-022-09645-3.

Fischer, Clara. "Gender and the Politics of Shame: A Twenty-First-Century Feminist Shame Theory." *Hypatia* 33, no. 3 (2018): 371–83. doi.org/10.1111/hypa.12431.

Fishbain, David A. M. "Secondary Gain Concept: Definition Problems and Its Abuse in Medical Practice." *APS Journal* 3, no. 4 (Winter 1994): 264–73. doi.org/10.1016/S1058-9139(05)80274-8.

Freud, Sigmund (Sigmund Schlomo). *The Standard Edition of the Complete Psychological Works of Sigmund Freud, Vol. 7 (1901–1905): A Case of Hysteria, Three Essays on Sexuality and Other Works.* London: Hogarth Press, 1953.

Freud, Sigmund (Sigmund Schlomo). *The Standard Edition of the Complete Psychological Works of Sigmund Freud, Vol. 16 (1916–1917): Introductory Lectures on Psycho-Analysis (Part III).* London: Hogarth Press, 1963.

Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. 1st Touchstone ed. New York: Simon & Schuster, 1986.

Greco, Monica. "The Classification and Nomenclature of 'Medically Unexplained Symptoms': Conflict, Performativity and Critique." *Social Science & Medicine*, Part Special Issue: Place, Migration & Health 75, no. 12 (December 2012): 2362–69. doi.org/10.1016/j.socscimed.2012.09.010.

Greco, Monica. "Logics of Interdisciplinarity: The Case of the Medical Humanities." *Interdisciplinarity: Reconfigurations of the Social and Natural Sciences*. Edited by Andrew Barry and Georgina Born. London: Routledge, 2013.

Halperin, David M., and Valerie Traub, eds. *Gay Shame*. Chicago: University of Chicago Press, 2009.

Hattrick, Alice. *Ill Feelings*. London: Fitzcarraldo Editions, 2021.

Hedva, Johanna. "Sick Woman Theory." *Topical Cream*, March 12, 2022. topicalcream.org/features/sick-woman-theory/.

Hedva, Johanna. "Why It's Taking So Long." *Topical Cream*, April 1, 2022. www.topicalcream.org/features/why-its-taking-so-long/.

Johnson, Susan K. *Medically Unexplained Illness: Gender and Biopsychosocial Implications*. 1st ed. Washington, D.C.: American Psychological Association, 2008.

Kafer, Alison. *Feminist, Queer, Crip*. Bloomington: Indiana University Press, 2013.

Krieger, Nancy. "ENOUGH: COVID-19, Structural Racism, Police Brutality, Plutocracy, Climate Change—and Time for Health Justice, Democratic Governance, and an Equitable, Sustainable Future." *American Journal of Public Health* 110, no. 11 (November 2020): 1620–23. doi.org/10.2105/AJPH.2020.305886.

Laurencin, Cato T., and Aneesah McClinton. "The COVID-19 Pandemic: A Call to Action to Identify and Address Racial and Ethnic Disparities." *Journal of Racial and Ethnic Health Disparities* 7, no. 3 (June 2020): 398–402. doi.org/10.1007/s40615-020-00756-0.

Laurencin, Cato T., and Joanne M. Walker. "A Pandemic on a Pandemic: Racism and COVID-19 in Blacks." *Cell Systems* 11, no. 1 (July 2020): 9–10. doi.org/10.1016/j.cels.2020.07.002.

Lazard, Carolyn. "How to Be a Person in the Age of Autoimmunity." *Cluster Magazine*, January 2013. https://static1.squarespace.com/static/55c40d69e4b0a45eb985d566/t/58cebc9dc534a59fbdbf98c2/1489943709737/HowtobeaPersonintheAgeofAutoimmunity+%281%29.pdf.

Lee, Oh Young, Emeran A. Mayer, Max Schmulson, Lin Chang, and Bruce Naliboff. "Gender-Related Differences in IBS Symptoms." *American Journal of Gastroenterology* 96, no. 7 (July 2001): 2184–93. doi.org/10.1111/j.1572-0241.2001.03961.x.

Lee, Paulyne, Maxine Le Saux, Rebecca Siegel, Monika Goyal, Chen Chen, Yan Ma, and Andrew C. Meltzer. "Racial and Ethnic Disparities in the Management of Acute Pain in US Emergency Departments: Meta-Analysis and Systematic Review." *American Journal of Emergency Medicine* 37, no. 9 (September 2019): 1770–77. doi.org/10.1016/j.ajem.2019.06.014.

Lim, Eun-Jin, Yo-Chan Ahn, Eun-Su Jang, Si-Woo Lee, Su-Hwa Lee, and Chang-Gue Son. "Systematic Review and Meta-Analysis of the Prevalence of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)." *Journal of Translational Medicine* 18, no. 1 (December 2020): 100. doi.org/10.1186/s12967-020-02269-0.

Looper, K., and L. Kirmayer. "Perceived Stigma in Functional Somatic Syndromes and Comparable Medical Conditions." *Journal of Psychosomatic Research* 57, no. 4 (October 2004): 373–78. doi.org/10.1016/S0022-3999(04)00447-7.

Mathur, Vani A., Jennifer A. Richeson, Judith A. Paice, Michael Muzyka, and Joan Y. Chiao. "Racial Bias in Pain Perception and Response: Experimental Examination of Automatic and Deliberate Processes." *Journal of Pain* 15, no. 5 (May 2014): 476–84. doi.org/10.1016/j.jpain.2014.01.488.

McRuer, Robert. *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press, 2006.

Nettleton, Sarah. "'I Just Want Permission to Be Ill': Towards a Sociology of Medically Unexplained Symptoms." *Social Science & Medicine* 62, no. 5 (March 2006): 1167–78. doi.org/10.1016/j.socscimed.2005.07.030.

Osborne-Crowley, Lucia. *I Choose Elena: On Trauma, Memory and Survival*. The Mood Indigo Essay Series. London: Indigo Press, 2019.

Phillips, Tarryn, and Tyson Rees. "(In)Visibility Online: The Benefits of Online Patient Forums for People with a Hidden Illness: The Case of Multiple Chemical Sensitivity (MCS)." *Medical Anthropology Quarterly* 32, no. 2 (2018): 214–32. doi.org/10.1111/maq.12397.

Piepzna-Samarasinha, Leah Lakshmi. *Care Work: Dreaming Disability Justice*. Vancouver: Arsenal Pulp Press, 2018.

Pilkington, Ed. "As 100,000 Die, the Virus Lays Bare America's Brutal Fault Lines—Race, Gender, Poverty and Broken Politics." *The Guardian*, May 28, 2020. www.theguardian.com/us-news/2020/may/28/us-coronavirus-death-toll-racial-disparity-inequality.

Price, Margaret. "The Bodymind Problem and the Possibilities of Pain." *Hypatia* 30, no. 1 (2015): 268–84. doi.org/10.1111/hypa.12127.

Price Herndl, Diane. "Disease versus Disability: The Medical Humanities and Disability Studies." *PMLA* 120, no. 2 (2005): 593–98.

Pryma, Jane. "'Even My Sister Says I'm Acting Like a Crazy to Get a Check': Race, Gender, and Moral Boundary-Work in Women's Claims of Disabling Chronic Pain." *Social Science & Medicine* 181 (May 2017): 66–73. doi.org/10.1016/j.socscimed.2017.03.048.

Ramey, Sarah. *The Lady's Handbook for Her Mysterious Illness*. London: Virago, 2012.

Rand, Erin J. "Gay Pride and Its Queer Discontents: ACT UP and the Political Deployment of Affect." *Quarterly Journal of Speech* 98, no. 1 (February 2012): 75–80. doi.org/10.1080/00335630.2011.638665.

Shefer, Tamara, and Sally R. Munt. "A Feminist Politics of Shame: Shame and Its Contested Possibilities." *Feminism & Psychology* 29, no. 2 (May 2019): 145–56. doi.org/10.1177/0959353519839755.

Showalter, Elaine. *Hystories: Hysterical Epidemics and Modern Culture*. New York: Columbia University Press, 1997.

Showalter, Elaine. "Hystories Revisited: Hysterical Epidemics and Social Media." In *Performing Hysteria: Images and Imaginations of Hysteria*, edited by Johanna Braun, 27–40. Leuven, Belgium: Leuven University Press, 2020.

Sontag, Susan. *Illness as Metaphor*. New York: Farrar, Straus and Giroux, 1978.

Vickers, Margaret H. "Stigma, Work, and 'Unseen' Illness: A Case and Notes to Enhance Understanding." *Illness, Crisis & Loss* 8, no. 2 (April 2000): 131–51. doi.org/10.1177/105413730000800203.

Wang, Esmé Weijun. *The Collected Schizophrenias*. London: Penguin Books, 2019.

Werner, Anne, Lise Widding Isaksen, and Kirsti Malterud. "'I Am Not the Kind of Woman Who Complains of Everything': Illness Stories on Self and Shame in Women with Chronic Pain." *Social Science & Medicine* 59, no. 5 (September 2004): 1035–45. doi.org/10.1016/j.socscimed.2003.12.001.

Whitehead, Anne, Angela Woods, Sarah J. Atkinson, Jane Macnaughton, and Jennifer Richards, eds. *The Edinburgh Companion to the Critical Medical Humanities*. Edinburgh: Edinburgh University Press, 2016.

Woolf, Virginia, Deryn Rees-Jones, Lieke Marsman, Lucia Osborne-Crowley, Nadia de Vries, Nafissa Thompson-Spires, Jameisha Prescod, Mieke van Zonneveld, Sinéad Gleeson, and Audre Lorde. Translations by Sophie Collins. *On Being Ill*. Amsterdam: Het Moet, 2021.

Yunus, Muhammad B. “The Role of Gender in Fibromyalgia Syndrome.” *Current Rheumatology Reports* 3, no. 2 (March 2001): 128–34. doi.org/10.1007/s11926-001-0008-3.

Zhang, Lanlan, Elizabeth A. Reynolds Losin, Yoni K. Ashar, Leonie Koban, and Tor D. Wager. “Gender Biases in Estimation of Others’ Pain.” *Journal of Pain* 22, no. 9 (September 2021): 1048–59. doi.org/10.1016/j.jpain.2021.03.001.