Nervous Routes:
Tracing Unexplained Illness from Accountability to Affirmation

Inaugural-Dissertation zur
Erlangung des Doktorgrades
des Instituts für Anglistik des Fachbereichs 05
der Justus-Liebig-Universität Gießen

vorgelegt von
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2024

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. Tag der Disputation: 16. Januar 2025

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Abstract

Within medical practice, the term “medically unexplained physical symptom” describes symptoms for which no structural physiology or underlying physical disease can be identified in relation to the symptom. This lack, initially occurring on the side of medical knowledge, is often offloaded onto the patient. Patients whose experiences are not biomedically legitimized and recognized struggle to give an account of their pain and struggle to be heard. These patients deserve – and are especially served by – a theoretical framing of their own. This dissertation attempts to provide this framing by the identification and formulation of what I have called *nervous routes*: the lines of thought along which different formulations of unexplained illness are given shape and act to shape physical sensations themselves.

Unexplained illness is characterized by marginalization in medical discourse and dominant popular culture. When not explained in biomedical terms, the lack of physical markers leaves patients vulnerable to explanations that follow nervous routes. I define these nervous routes as epistemological movements that depart from the problem of unexplainedness, but branch out on paths already well-trodden and primed by cultural stereotypes. Nervous routes are structured along culturally dominant lines of division such as sex, gender, race, and class. They risk further marginalizing already marginalized groups. The problem at the heart of the marginalization is that people with unexplained illness are individually held accountable for the experience of unexplained illness.

Based on various close readings of cultural objects, ranging from medical texts and illustrations to case descriptions, internet memes, literary memoirs, and (documentary) films, I identify four different routes. Along these routes, both knowledge and affective experience travel, coalesce, and collide, resulting in a conflictual conceptual space in which to relate to the unexplainedly ill body. Each of these four routes – i.e. cases, classification, impasse, and transference – is treated in a separate chapter, and followed through in order to trace the way in which unexplained illness is conceptualized. This means that I look at the construction of cases as a movement from the individual instance to generalized knowledge; at the filing and classification of medical/psychiatric knowledge; at attempts at integrating mind and body; and at illness transference or the

idea that illness can be reduced to a contagious idea. All of these routes prove to be complicated by the lack of physical markers for disease, as is the case with various symptoms and conditions that count as or are experienced as unexplained.

From my various analyses, I argue that all of these routes result in a negative framing of unexplained illness that holds the patient accountable for the creation and experience of their own illness. I describe how unexplained illness is characterized by feminization, psychologization, and delegitimization of the patient and their condition. The feminization of unexplained illness is not only related to women but is also apparent in characterizations of (historical) cases of unexplained illness in men who were seen as vulnerable, weak, or too much affected by traumatic experiences such as war. Psychologization concerns the way in which, without biomedical evidence, explanations often shift towards the mental domain, following the idea that if disease does not exist in the body, it must reside "in the mind." With delegitimization, I point to the process in which the symptoms gain a status of less "real" as they are understood to emerge within the fuzzily defined domain of "the mind."

This cluster of exclusionary structures is underpinned by a conceptual separation of mind and body. In the case of unexplained illness, mind-body dualism continues to contribute to notions of blame that hold individual patients responsible for *creating* their symptoms. Moving away from this framework in which unexplained illness is understood in terms of accountability, I propose to think of what an affirmation of unexplained illness could look like. In conversation with theories around subject formation, Judith Butler's work on relationality, crip and disability theory, and materialist feminist approaches that view the bodymind as an inextricable entity, I look for such an affirmation in a relational approach. This allows for an emancipation of unexplained illness from nervous routes, and an emphasis on unexplained illness as part of a present for which a collective responsibility must be practiced.

1. Introduction: Accountability

1.1 On Speaking Felt Things

Consider one of the last scenes in *Safe* (1995). It is one of Todd Haynes' early movies set in 1987. Its protagonist, named Carol White, is a suburban housewife played by Julianne Moore. Carol suffers from an unknown illness that worsens when she is exposed to chemicals. She has moved from the Californian suburbs to a remote desert community called Wrenwood: a new-agey place run by a self-help guru who aims to cure people by sheltering them from the world and reinventing their self-love. Carol has left her husband and stepson behind and joined this community to get better. On a festive evening, the community of chronically ill people listens to the community leader who recounts one of his dreams at the dinner table, inspiring them all to think away their illnesses with positive thoughts and acts of kindness. The music starts, and the camera shifts to a dance floor, where different couples in their 80's dress slowly take each other's hands and swing to the music. As more couples join, Carol's Wrenwood friend Chris turns the volume down and speaks up. Tomorrow is Carol's birthday, so they have organized something for her. The community starts to sing, and a birthday cake appears. Chris calls for a speech from the back, to which Carol responds by saying she has never made a speech in her life.

To start this dissertation, I want to give the full quote of Carol's speech, complete with its pauses, nervousness, and omissions.

> O god uhhh, I just want to thank Chris for doing this.. and everyone here so much. It just pulled me through a really hard period anyway I couldn't have done it without you. [she chuckles and the audience applauds] I don't know what I'm saying I'm just uhm.. [chuckles, audience laughs]

In the meantime, the camera shifts from a frontal, zoomed-out viewpoint to the back of the room, depicting Carol from behind. It has now again focused on Carol, upfront and mid-length, as she is speaking and is surrounded by people. Carol continues:

> just that I really hated myself before I came here and uhm.. so I'm trying to see myself hopefully uhm more as I am, more uhm.. positive like seeing the plusses. Like I think it's slowly opening up now, people's minds, like uhm educating and uhm aids and uhm and other types of diseases cause, cause.. and it is a disease cause it is out there and we just have to be more aware of it, with uhm.. make

> people aware of it and uhm even ourselves like going.. reading labels and going into buildings.. (*Safe* 1995: 1:50:20-1:51:56)[1]

Having said this last word, Carol stops speaking. She slowly raises her head and looks up, glancing at the camera indistinctly. Her look is now more elusive than her speech. The camera shifts to her audience, watching her attentively. The community leader raises a glass and proposes a toast "To Carol." They all repeat.

It is the first and only time in the movie that the viewer hears Carol speak for longer than a few short sentences. Even now, her sentences are incomplete. They are fractured, fragmental, repeating parts of what her community has told her about the importance of positive thinking and how her illness is a result of her self-hatred. When she is asked to speak up, the illness that has happened to her emerges as something that's 'out there' and that can catch you when you're not aware. People have to be made aware of it, but they also have to watch out because it can happen to them, too. Nowhere is safe except in your own mind, where positive thinking can help you overcome your illness and heal yourself.

Safe was read as being about many things, and Carol's indeterminate illness has been analyzed as a metaphor for different cultural conditions, such as Whiteness in US-American culture, gender dynamics, and ecocriticism (Scherr 2009; Kollin 2002; Lessy 2006; Barnett 2017; Seymour 2011). Haynes himself characterizes the film as a story of the burden of individual responsibility of illness in late capitalist US-American culture. Haynes notes how *Safe* dealt with the blame laid on individuals for conditions for which there is no clear explanation ("Todd Haynes Q&A | Safe" 2015). It is a story of the force of narrative wanting to find a way over the body and a story of the fierce wish for control. Control over the environment that makes you sick, but also the illusion of control of the mind over the body, lays an enormous and politically charged responsibility on the individual. According to Haynes, the central concepts of the film are identity and

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[1] In an interview published on *YouTube*, Haynes notes that when researching *Safe*, he had interviewed women with environmental illness in Texas. Carol's speech at the end, including the way in which she loses her train of thought, is based on words from the interviews he conducted. Where Haynes notes the speech in the scene sounds like Julianne Moore is improvising, she is, in fact, following the script "to the comma." See "Todd Haynes Q&A | Safe" 2015.

immunity (“Todd Haynes Q&A | Safe” 2015).[2] Carol’s flimsy voice and fragmented sentences betray an absence of both. In a commentary on the role, which was one of Moore’s first, she stated how she spoke “above her vocal cords” to “create the sense that Carol’s voice was body-less” (Tougaw 2011: 44). Her body is sick, and her character is constructed as a void. Throughout the film, she struggles to express herself, as she says in conversation with Wrenwood leader Peter, “I am still learning, you know, the words” (*Safe* 1995: 1:28:20).

The film and Carol’s final speech, in particular, provide an opening for this dissertation in multiple ways. Carol’s struggle for words and her inability to express herself offers a first entrance into thinking about unexplained illness in medical knowledge. It poses the problem of unexplained symptoms for expression and exposes the obstruction they form to the realization of a common understanding of the self that is afflicted by illness. Carol’s difficulty to speak is related to the lack of words that she has for her illness, but also to the fact that she is made to speak by her social environment, even though she obviously doesn’t want to. She is singled out and held accountable for her own experience, although it is not of her own making. She is still, you know, “learning the words.”

Perhaps surprisingly, my treatment of this central problem, although it provokes the question of how to speak about symptoms of an illness unexplained by medical science, does not concern itself principally with the troubled relation between language and body or world; that is, with language as signification. The issue is rather the conditions of a subject relating to the body and the world in which it is entangled. And, consequently, the issue is the different routes that language and explanation take for a subject to relate to a felt bodily “thing” that needs to be expressed.

This dissertation traces and identifies four of these different “routes” which I have characterized as *nervous routes*. The first concern, when looking at ways in which unexplained illness is understood, is accountability, the concept around which this chapter

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[2] Both were pressing in their 1987 setting in the midst of the AIDS crisis in the US, and both have again turned disconcertingly urgent at times of COVID-19. Hayes had deliberately set the film in 1987, right in the middle of the AIDS crisis in the US. In an interview, Haynes notes how he felt a strong desire to find a metaphor for it that was at the same not directly related to the AIDS pandemic context, addressing issues of identity and immunity in a White, upper-middle-class suburban ho

me (“Todd Haynes Q&A | Safe”).

is centered. Carol is held accountable in a system that is not of her own making. She struggles while she learns the words handed to her by male patriarchal figures in her life, and she ends up merely repeating them. When she is made to speak, the film stages a confrontation between a forceful expectation of individuality and the void of her character. Rather than giving an explanation for the appearance of Carol's symptoms, Haynes presents a trajectory in which Carol's symptoms and the meaning of her illness change shape. Emerging out of what seems like nowhere at the beginning of the film, her symptoms are first disregarded by the patriarchal figures in her life: her husband and her physician, who say she might be stressed, who both hint at her symptoms being a form of hysteria. She then runs into a flyer at her gym aerobics class, which says "Do You Smell Fumes" and "Are You Allergic to the 20th-Century?" and she learns of an illness called multiple chemical sensitivity, or environmental illness. This leads her in the direction of a support group. After a seizure at the dry cleaner's, she ends up at the hospital, where she sees a TV commercial for the Wrenwood Center, where the last and third act of the film takes place.

The film leaves the physical explanation of her seizures, rashes, nose bleeds, convulsions, and hyperventilation in the open but presents instead a chronology of events that lead to different explanatory models. Carol herself remains the empty and inarticulate subject of them all, unable to master their different languages, yet traveling through them and continuing to become more and more isolated until, at last, she ends up in a sheltered igloo all by herself, repeating the words "I love you" to a mirror in one of the film's rare close-ups.

Instead of focusing on the patient ("Carol"), this dissertation stays with the different routes along which unexplained symptoms are nonetheless explained or are struggling to find an explanation and how these different languages work to produce or fill subjectivity. Thinking about how bodily sensations of discomfort are translated in hospital settings, doctor-patient encounters, intimate relations, and artistic presentations, I aim to address the structure of bodily sensation itself. Here, my entrance into what counts as sensations will be to read for it in different cultural contexts and with regard to "texts" that vary from medical texts and illustrations to internet memes, video art, films, or classificatory systems. What Eugenie Brinkema has called "reading for form" in *The Forms of the Affects* (2014) allows me to address the affective dimension of the "symptoms themselves" not as already given within a dualist language that splits experience from translation, but as that which only emerges as apprehensible through the practice of cultural analysis.

For instance, the wide shots in *Safe* place Carol in the margins. Long takes show her sitting still in her house while the housemaid and painters work in the background. Carol remains frozen in a single isolated spot devoid of action. These formal elements work to create a sensation of alienation and provide the affective background against which Carol's eventual isolation with unexplained illness is understood. Such a reading for form allows me to account for the affective dimension of physical symptoms and avoid the trap of already foreclosing them within language myself.

I just described the affective qualities of the film in terms of the experience of the viewers of *Safe* as they watch Carol's body awkwardly moving about or being still in her house. Referring to affect as such immediately calls up problems of access. While the form of the scene might be analyzed, the type of sensations it produces will forever remain opaque, inaccessible to academic scrutiny. They are not the object of analysis here. Still, this problem of access goes right to the heart of this dissertation, where similarly, the type of reading proposed is not one of unexplained symptoms but of the different forms through which they emerge as apprehensible, to the doctor encountering them, to the analyst writing on them, or to the patients sensing them, having to account for them, having to live with them daily. Writing about unexplained illness thus places the problem of accessibility on both sides, ranging from the language with which the body is mediated to the symptoms themselves being transformed through the act of thinking about them. This transformation does not involve a former "true union" of body, language, and sensation but instead points to the material-discursive process in which the body is understood throughout different structural contexts.

When I speak of unexplained illness, I refer to the translation of medically unexplained but felt things that emerge through the problematic encounter captured in the attempt to speak of bodily sensations for which no dominant medical language exists. It concerns symptoms outside the realm of dominant medical explanation, whose existence in speech becomes fractured, fragmented, or broken, where parts of other languages have been incorporated or repeated, and others are lost. Such forms of speech are attempts to make bodily sensations legible or to communicate them to others. My attempt is to read for such bodily sensations and interpret how they have been given form, to remain with their potentiality, and to critically reflect on what their forms do for the speaking subjects themselves.

Carol's trajectory in *Safe* moves from being perceived as a hysteric to finding comfort and recognition in a support group to ending up in a new-age community that tells her that her illness is the result of her self-hatred. The medical establishment in *Safe* is represented through the figure of one older White male doctor. In line with her husband, he tells her she is "just stressed" and sends her to a psychiatrist. When she is not helped here, Carol seeks relief elsewhere and moves through an alternative circuit. The route presented is one along which different understandings of physical symptoms intersect. Different notions of the self in relation to the symptoms, the influence and meaning of environmental factors, the conceptualization of "stress," or the different roles of class, race, and gender all interfere with how Carol's symptoms gain different meanings. These notions shape how, in the end, Carol ends up literally isolated at the film's daunting ending.

In Carol's case, her status as a White upper-middle-class suburban housewife results in an all-white and privileged seclusion from the world that is "making her sick." Carol's character is so thin as to be hardly there. She is presented as a void filled with the language of her surroundings that she nevertheless never fully embodies as she stutters to give the speech at her birthday party. In the end, she succumbs, all alone, and repeats the self-love mantra to her sick reflection in the mirror. *Safe* shows a trajectory through which the subject is formed by the different routes along which unexplained illness is mediated and how this subject eventually disappears under their weight.

"Unexplained" by no means carries the literal meaning that no explanations are given. The consequence of the fact that the cause of Carol's physical sickness remains unexplained in contemporary medical terms is that there is no consensus for her symptoms. To understand, from a scholarly perspective, what is at stake in the concept of unexplained illness is to look for the conceptual travels that are made in making sense of the sensations themselves. These routes are what I have identified as nervous routes, that is, *the lines of thought along which different formulations of unexplained illness are given* *shape and act to shape physical sensations themselves*. For instance, the changing notion of hysteria, as it traveled from antiquity to Galenic medicine, the nineteenth-century neurosciences, and the present, can be considered as such a route to which already existing gender constructs come to be attached.

These routes are nervous because they change course. They move, merge, and shift but stubbornly stay on track, unable to shake themselves off. This nervousness has close ties to hysteria, which was recast as a nervous disease in the nineteenth century. The term hysteria derives from the Greek *hystera*, which means womb and is the prime locator for the illness up until the nineteenth century. The (in)famous nineteenth-century neuroscientist Jean-Martin Charcot spearheaded an interest in the nervous system through his research on hysteria. Hysteria was no longer localized in the uterus but in the brain and was understood as a disease of “the nervous system.”

Nerves are fibers that transmit impulses or sensations through the body. The diagnosis of nervous illness thus identified a malfunction in sensations. To have too many sensations or to exhibit the wrong ones could be considered signs of illness. To get on one’s nerves usually involves something aggravating. To have a nerve or to hit one is not commonly perceived as pleasant, but to keep it is admirable. To be troubled by nerves, to live on them, or to be a bag of them comes closer to the illness associated with it. As a nervous disease, hysteria encompassed a range of symptoms: from anxiety or shortness of breath to vomiting, seizures, or the temporal loss of control over one’s movements or one’s ability to speak, but also pain or paralysis.

The nervousness of the nervous routes followed in this dissertation pertains to at least three meanings. My use of nervous routes signals nervous disease. It thus opens a relation to a wide spectrum of thinking on illness as being related to psychological or psychiatric factors beyond the mere physicality of the body, as it was conceptualized around the turn of the nineteenth century. Before the term nervous attained its psychological meaning, the Latin *nervosus* indicated something sinewy or vigorous, strong or robust. This etymology also signals the form of the path itself as long and thin but stubborn. Nervous routes are like stringy fiber-like paths that transmit certain information and withhold others. They go a long way back historically. They are often subtle, used in speech, or referred to by way of underlying assumptions but are nevertheless stringy and hard to shake. They need very little context to refer to certain ideas and thus transmit information merely by being invoked. And last, these routes are nervous in the sense that they are anxious. They are called upon when any other explanation is missing and are thus often used as a seemingly innocent form of last resort, something to call upon when commonly used physical explanations are lacking.

The word route derives from the old French *rute*, via the Latin *rumpere* or *via rupta*, which means broken way or path. This meaning possibly goes back to the wheel breaking into the surface of the ground that it travels on. The etymology of route points to a trail, a physical presence that the route leaves behind. The route breaks into that on which it travels. Not only does it offer a trail and often moves along those trails that come before it, but the route also leaves a marked trace on its surface. The route partly overlaps with the trail that travelers – the wheel, the foot, the vehicle – leave behind. Whereas the traveler remains a conceptual notion, and the route creates the conditions for it, the trail is the physical trace left behind. These traces, or the physical consequences of the different explanations given for unexplained illness that remains outside of the dominant realm of knowledge over the body, are the object of this dissertation. The access to them is through the forms they leave behind.

This means that my use of nervous routes distinctively turns away from metaphor. They are not meant to be representative of something else. The nervous routes traced in this dissertation are the traces of the forms that the routes leave behind. This is done through a close analysis of cultural objects that span (documentary) film, literary writing, internet memes, medical texts, or illustrations. Inasmuch as they are not used metaphorically, they do qualify as a method through which unexplained illness becomes attainable. By focusing on the routes along which unexplained illness is understood, I am able to describe the problem of unexplained illness as patients live it. My analysis of these forms, or the traces of the routes, eventually aims to contribute to an understanding of the problem that the unexplained symptom poses for the sensed body and thus seeks to map the consequences of their unexplainedness for the understanding of the bodily sensations for the patients themselves.

The relation of the patient to their unexplained symptoms is complicated. I trace the theoretical reverberations of this relation back to feminist discussions on the (biological) body and processes of subject formation. The material body Judith Butler writes about in *Bodies that Matter* neither precedes nor follows the process of subject formation but emerges through a social process. Materiality is thus understood as "the effect of power, as power's most productive effect" (2011 [1993]: xii). Around the same time that Butler's *Gender Trouble,* originally published in 1999 (2002) became influential in the 1990s, the then-new and emerging field of transgender studies exposed and discussed how Butler's theories around gender and sexuality became canonical. Mainly, it discussed ways in which Butler was "misread," such as proposing a voluntary and antimaterialist account of the body that replaced performativity with theatricality or seeing gender as something that could be chosen of free will.[3] Butler themselves carefully opposed such readings, highlighting repetition or citationality in *Bodies that Matter*. They argued for gender's materiality as being always already discursively defined and definitely not as something towards which the individual possesses any kind of "free" non-discursively defined relationship.

The emergence of the body through such discursively defined processes has received little attention in relation to unexplained illness, even though unexplained illness exposes both the failure and the limits of (medical) discourse. The unexplainedly ill body falls outside the domain of medical explicability, which in turn fails to account for these, who have now become liminal, lived physical experiences. Butler described such a failure in relation to gender and what they call *compulsory heterosexuality*, which operates in a similar all-encompassing manner, leaving all whom it excludes vulnerable and exposed.[4] Butler writes how "Compulsory heterosexuality sets itself up as the original, the true, the authentic; the norm that determines the real" (1993: 312). Showing the relevance of Butler's arguments around gender to describe the experience of bodies failing to incorporate an able-bodied norm, Robert McRuer transposes their arguments, stating that "if anything, the emphasis on identities that are constituted through repetitive

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[3] This misreading, or what Kendall Gerdes has called a "rhetoric of performativity stripped from its theoretical heritage […] reduces performativity to performance […] and so forgets the historical chain of repetitions that makes each instance possible." See Gerdes 2014: 148-149. See also Stryker 2006. On the way in which performativity is often misunderstood in relation to transgender issues, see Andersen 2016: 12.

[4] The link established here between Butler's notions around compulsory heterosexuality and the failure of some bodies to confirm such compulsory and normative constellations is largely indebted to Robert McRuer's *Crip Theory*. I partly follow but also add to the passage by Butler, which McRuer quoted.

performances is even more central to *compulsory able-bodiedness*" (2006: 9; emphasis added).

The unexplainedly ill body further adds to this complication of norms, as it does not only not comply with able-bodied standards but can also not be reconciled with common normative medical knowledge and explanations of illness and etiology. Unexplained illness exposes the inevitable failure of complete explicability: the failure of positions that are, in Butler's words, "intrinsically impossible to embody" (1999: 155). I thus look critically at exclusionary mechanisms. Doing so shows how bodyminds are confronted with normative surroundings that require and expect a particular kind of comfort, such as identifying with the assigned sex at birth, being generally able-bodied and healthy or at least ill in a way that is physically visible on the body or through tests or scans. This confrontation means that people not included in these compulsory identities have to nevertheless mediate these forms in which they are already inscribed. One of the central claims of this dissertation is that this mediation of a failure already inscribed in a system of physical explicability happens along nervous routes.

Discussing this particular kind of failure means that this dissertation is located mainly within crip theory and intersectional materialist feminism. Rosemarie Garland Thompson's theories of the misfit, Margaret Price's expansion of the term bodymind, and Eli Clare's explorations on disability and queerness have served as essential touchstones that allowed these routes to be theorized and critically addressed. Equally vital in developing this thought has been work by disability activists, artists, and writers such as Johanna Hedva, Leah Lakshmi Piepzna Samarasinha, Carolyn Lazard, and Mia Mingus.

In his 2006 monograph *Crip Theory*, McRuer develops crip theory alongside his concept of compulsory able-bodiedness, which produces the crip like compulsory heterosexuality produces the queer. McRuer specifically ties the formation of queer and crip identities to a system of neoliberal capitalism, in which "free" meant to be "free to have an able body but not particularly free to have anything else" (2006: 8). Located within queer and crip approaches to normativity, a critique on the dominant neoliberal notion of able-bodied and productive individuality lingers on the background in my various analyses. Especially in Chapter Five, I will focus on how the notion of a self-contained individual who presents a gendered type of mastery and control over their body is central to the accountability framework that negatively impacts patients with unexplained illness.

This neoliberal, self-contained, and supposedly free individual is closely tied to a capitalist logic that ideologically promotes individuality and productivity. Such an overarching notion is a factor in my analyses and mentions of cultural objects that capitalize on stereotypical narratives surrounding unexplained illness, such as in Chapters Two and Four.[5] However, the pervasive structure of capitalism itself, which makes it, in Mark Fisher's words, "easier to imagine the end of the world than the end of capitalism" (2009: 1),[6] is never made central, as I am more concerned with knowledge practices that emerged in this system than with formulating a thorough critique of neoliberal capitalism itself. However, it is in reference to a neoliberal, arguably capitalist individualist notion of self that McRuer and other crip theorists or disability scholars and activists claim crip as an affirmative term and propose a reappropriation of terms. It is in this sense that I keep returning to capitalism as it emerges as the opposite of means of care, for instance, in the work of Silvia Federici or Johanna Hedva.

The affirmative move claimed by crip theory resists exclusionary norms and rallies to form a crip identity. In the introduction to *Feminist Queer Crip* (2013), Alison Kafer discusses who is included in the claiming of the crip identity and how to deal with those people who want no part in such names. She states that the hardest group to include would be the largest proportion of disabled people: people with hearing impairments, asthma, or diabetes, who, "for a whole host of reasons, would claim neither crip identity nor disability" (2013: 14). Kafer notes that although the question of crip affiliation is not easily solved, the term is meant as both expansive, provocative and fluid.[7]

Even so, the inclusion of chronic illness in a crip identity remains a complicated issue. By crip theorists like Kafer or Clare, chronic illness is explicitly included in

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[5] I specifically refer to my discussion of a lawsuit filed by a group of patients against their depiction in Netflix's *Afflicted* (2018), section 4.2, 184-188, and to my mention of the case of the drug called Lyrica, pushed as treatment for fibromyalgia by Pfizer, section 2.2.1, 68-69.

[6] Fisher attributes this quote, which is also the title of the first chapter of *Capitalist Realism*, to Frederic Jameson and Slavoj Žižek (2009: 1).

[7] Kafer refers to work by Robert McRuer and Carrie Sandahl, who both prefer Crip and Crip Theory above disability studies. Kafer cites McRuer and Sandahl saying that crip "is more contestatory than disability studies, more willing to explore the potential risks and exclusions of identity politics." See Kafer 2013: 15; McRuer 2006; Sandahl 2003.

statements on crip or disability theory, politics, or rights.[8] However, on a more general level, the relationship 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” (2005: 593). This difference between groups that may or may not want to be implicated in a specific term is also related to differences in bodily experience within a very large and diverse group. Disability theory and the disability rights movement have predominantly defined disability as a social construction. Disability scholar James Charlton characterized this social construction, stating that “if a particular culture treats a person as having a disability, the person has one” (2000: 8). This means that disability is often used as a broad term – also evidenced by the deliberately comprehensive definition it received in the legal terminology of the Americans with Disability Act (ADA) in 1990.[9]

Not everybody with a disability leads a life characterized by pain. Within such a large and diverse group, pain knows many forms. Disability theorist Tobin Siebers has pointed out that in thinking about pain in disability theory, pain is rarely physical. That is, pain is often described as being created by society and described in terms of guilt or social repression. Yet, pain also “hovers about innumerable daily actions” in the sense of bodyminds having to physically navigate their environment, having to get out of bed, or meeting a “well of pain” in the evening (2011: 62). Elsewhere, Siebers described how the strong discursive links that exist between pain and disability have resulted in violence against people with disabilities. Siebers argues that the fear of pain is “one of the most pervasive and insidious justifications of disability oppression,” in the sense that the wrongful assumption that someone must be in pain can lead to involuntary treatments, or even the ending of someone’s life (2021: 184). Disability and crip theorist Eli Clare also commented on this in his explorations of the violence administered on people with disabilities in the name of cure, love or wellbeing.[10] Such critique has led to the importance of stating that not all lives of people with disabilities are characterized by

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[8] Kafer 2013: 7; Clare 2017: 60-61.

[9] For a history of the passing of the ADA, see Pelka 2012: especially 474. See also Siebers 2011: 69.

[10] See Clare 2017, especially Clare’s discussion of the famous case of the patient known as “Ashley,” also known as “Pillow Angel,” as dubbed by her parents, who underwent a series of medical treatments (“The Ashley treatment”) chosen by her parents and designed to keep the child permanently small. The case attracted a lot of media attention from 2007 onwards, when “The Ashley Treatment” was published in a medical journal and became controversial, after which the parents publicly shared information on a blog, telling their side of the story. See “Pillow Angel” n.date; n.pag; Pilkington 2012; Clare 2017: 152-156.

pain, culminating in a movement of queer and crip affirmation that has been described as disability desire.[11]

Insofar as people with chronic illness, however, can be considered a group, their bodyminds are united by their experience of discomfort or pain. *Unexplained illness*, as described in this dissertation, is often chronic. I emphasize the specific unexplained character of many chronic illnesses to call attention to the intensification of pain that emerges in the attempt to account for bodily sensations for which no biomedically accepted medical language exists. These sensations are not only characterized by bodily pain or discomfort, a lack of treatment or cure, but also by a socially felt exclusion based on an epistemological framework of organic explainability.

Alyson Patsavas argued for a *cripistemology* of pain that situates pain within "discursive systems of power and privilege" (2014: 205). In the coining of this term, Patsavas refers to prominent disability scholar or crip theorist Carrie Sandahl's use of *cripping*, in the form of a verb. Cripping involves a spinning of mainstream representations which "reveals able-bodied assumptions and exclusionary effects" (2003: 37). Patsavas combines Sandahl's method of cripping with an insistence on standpoint epistemology which centralizes experience and acknowledges the subject position from which knowledge is produced (2014: 205).[12] Patsavas' *cripistemology* "traces the discursive systems that materially produce and structure experiences of pain" (2014: 203) and largely overlaps with this dissertation's attempt to identify, formulate, and analyze different nervous routes.

The difference lies in the way in which my focus on nervous routes is specifically attuned to illness that counts as unexplained. This concerns my emphasis on defining unexplained illness as a problem: patients whose experiences significantly differ from those whose illnesses are biomedically legitimized and recognized struggle to give an account of their pain and struggle to be heard. These patients deserve – and are especially

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[11] For a collection of articles that discusses disability desire within the context of queer and crip theory see a special issue of *GLQ,* McRuer and Wilkerson 2003. For a discussion of disability desire in relation to pain see Price 2015. See also section 3.2 to this dissertation.

[12] For Patsavas, this means that her own experiences with chronic pain and the socio-political mechanisms through which care and medication were denied to her – the doctors treating her at the clinic deemed her unwilling to participate in her recovery following her refusal to join experimental treatment – are included in her understanding of chronic pain.

served by – a theoretical framing of their own. Second, I identify, formulate, and analyze at least four distinct nervous routes along which this dissertation is structured.

These routes partly overlap and intertwine but can be individually pinpointed. First, I present *the case* as a nervous route in the form of stepping stones on which a path going forward is formed, by which generalized knowledge is produced that leaves patients with unexplained illness unattended. Second, I map out the circular movement of *classification* in terms of the mentalization of unexplained symptoms within psychiatry as a continuous and failed attempt that eventually disadvantages people with unexplained illness. Third, I show how the disciplinary travels of the term "psychosomatic" have led to a nervous route in the form of an *impasse:* getting stuck in a dualist framework that works to create a pejorative figure that attributes blame to the individual who is unexplainedly ill. Fourth, I discuss the back and forth of psychosomatic contagion, or the idea of illness imitation, by critically discussing the potential for an affirmative understanding of unexplained illness in terms of *transference,* that is: exploring the potential to frame transference between bodyminds as relationality instead of contagion.

Although this dissertation centralizes experience, I address this experience *in tandem with* and *through* a theoretical reading in the sense that I aim to analyze the forms through which experience gains shape. The activist, queer and subversive qualities of the sick body have received ample attention in artistic representations such as Dodie Bellamy's *When The Sick Rule The World* (2015), Amy Berkowitz's *Tender Points* (2019), Alice Hattrick's *Ill Feelings* (2021) or Johanna Hedva's "Sick Woman Theory" (2022a). Reimagining and appropriating the figure of the "Sick Woman," Hedva's work politicizes illness by formulating a critique of a capitalist ideology that invalidates and dismisses the lived experience of people living with chronic conditions. In this context, Hedva explicitly rethinks chronic (unexplained) illness as a sensitivity and reaction to regimes of neoliberal, White-supremacist, imperial-capitalist, and cis-hetero-patriarchal oppression. The productive potential of these works hides in a reconceptualization of illness not as a singular individual temporality but as an entangled social and political state of being for which collective responsibility must be carried.

The queer and the crip and their relation to illness offer an invaluable counterweight to the privileged role of the able body in late capitalist neoliberal societies.

Building on this, one of the central aims of this dissertation is to steer clear of creating a new metaphorical typology of symptoms. This also means that I take seriously how patients themselves want to fit into dominant medical modes of explanation. The routes that I identify function to trace the explanations that are given to symptoms that count as medically unexplained and thus aim to engage with how people have had to make sense of themselves or have been made sense of in words that are not their own when medical science failed to provide an answer. This means that both the wish to fit into a dominant medical mode of explanation as well as the formulation of a queer sick person as the deviant relation to the norm form a response to the malfunctioning of the norm: the *failure* that this dissertation describes.

To take this seriously also means that I aim to engage with how medical explanation is done in practice. This practice emerges in different ways throughout this dissertation but will most often be looked at through textual or visual representation. This means that my analysis concerns the cultural form in which the unexplainedly ill bodymind is mediated rather than the people who come to live with unexplained illnesses themselves. This involves a methodological choice further discussed in the next chapter. The practice of medicine is thus not engaged with through the mundane. However, looking at unexplained illness in its myriad of forms does not mean that I take what Annemarie Mol has called and problematized as a perspectivalist approach, where the perspective of, or the meaning that both patients and doctors attribute to the body and illness is studied, and “doctors become the social scientists’ objects” (2002: 10). This approach, which is perhaps more common within mainstream medical humanities, risks to again bypass the body’s physical and material reality itself.

The intersection of different fields of research, or, in the case of this dissertation, a mapping of a problem that involves medical science, social science, and the humanities, requires particular attention to detail and particularity. Close reading, as a method that zooms in on the particular and aims to scrutinize detail without drowning in generalizing claims, thus proves a critical, slow counterweight to fast and simplified claims that either dismiss medical knowledge altogether or fully ascribe to ultimate explicability. Thus, I aim to stay with the problem as lived by the patient with unexplained illness.

Within the humanities, (chronic) illness is mostly discussed in the broad, interdisciplinary field of the medical humanities. What has come to be known as "mainstream" or "first-wave" medical humanities was defined by Whitehead et al. in their 2016 *The Edinburgh Companion to the Critical Medical Humanities*. Their edited volume provides an intervention into common practices within the medical humanities. In the introduction to the volume, Whitehead and Woods comment on the emphasis placed on the patient-doctor encounter. The authors note how mainstream medical humanities attributed much importance to the role of literature as a form of self-understanding. Drawing attention to how dimensions of gender, class, race, sexuality, and debility have been sidestepped in mainstream medical humanities, Whitehead and Woods have characterized this field as follows: "The humanities are looking at medicine looking at the patient" (2016: 2). This focus on the way in which medicine looks at the patient runs the risk of too much respecting a division of labor in which medicine has authority over the body, and the humanities have authority over matters of meaning without critically reflecting on the contexts in which medical knowledge is produced. Moreover, such a focus leaves little space to understand materiality in its discursive or performative reality.

Within the humanities, there exists a further division of labor, where the (critical) medical humanities have been mostly concerned with illness and its representation, and disability studies or crip theory has mainly focused on a queer critique of exclusive ableist normative structures. My way around both levels of separation will be to read for forms in which meaning is constructed, less than to stay simply with the different takes on "meaning" that leave – in Mol's words – the physical body "untouched" (2002: 12). Often, this involves looking at specific medical classifications for certain conditions and being attentive to the knowledge practices that emerged from those, both within and outside of what counts as medical discourse. Staying with the form of the object itself, engaging with objects that are rarely limited to literature, and inquiring into how these objects shape reality in specific ways, I remain critical of the gap between meaning and the body, theory, and practice.

The chapters of this dissertation are organized around different concepts. Each chapter opens with a reading or close analysis of a cultural object with which the concept is brought into conversation. The central concept of each chapter describes a particular nervous route that I trace in medical discourse and popular culture. The objects under analysis are taken from medical texts and popular culture, in traditional media like literary form or (documentary) film, and internet culture. My analysis of the nervous routes through my reading of these objects focuses on the effects of these particular routes on the lived reality of patients with unexplained illnesses. Following these analyses, the overarching movement of this dissertation goes from accountability to affirmation. My analysis of nervous routes results in an exploration of a view on unexplained illness that prioritizes care and collectivity over an emphasis on individual blame and responsibility.

The blame that the patient, "Carol," is made to believe, laid on her by the patriarchal figures in her life or by the self-help community that she ends up in, attributes her illness to her own negative feelings or unconscious will. It holds her accountable for the creation of her illness in the sense that if organic explanations fail to answer for the appearance of the symptoms, her character or individuality must. Accountability, which Judith Butler discussed as being inextricable from the social condition in which the "I" is addressed, involves an interpellation of sorts by a system of power (2005). In a general sense, holding an individual accountable usually involves an accusation against a person instead of against a system that has been formative for the creation of the subject. Holding an individual accountable for creating one's illness singles a patient out in reference to a system of organic explicability of illness against which their bodymind has failed to comply. The system in which the patient is held accountable is at the center of this dissertation and is addressed by identifying four different nervous routes.

The structural conditions at the center of my analysis of nervous routes also affect the terminology used in reference to what is sometimes called "the somatic." That is, the theoretical background of this dissertation within Crip Theory and Materialist Feminism means that I use bodymind to denote the inextricability of the terms often separated as body and mind. This term was developed as a materialist feminist concept for disability studies by Margaret Price (2015).[13] The term bodymind does not just combine two separate entities but describes the overlap and mutual implication of body and mind. Whenever I use the term bodymind in this dissertation, I explicitly use it to address this mutual implication. To highlight the fact that mind and body are culturally perceived and often referred to as separate entities, Eli Clare uses a hyphen and refers to

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[13] I further elaborate on the concept in section 3.2, 131-132.

"body-minds" or the "body-mind" (2017: xvi). Turning this phrase around, I refer to mind-body dualism to call attention to the unevenly distributed hierarchy enmeshed within this dualism, which places the mind above the body. The separation of mind and body and placing the mind on top of a hierarchy greatly contribute to the idea that patients can be held accountable for creating their symptoms. This hierarchy implies that the mind should be in charge of the (feeble) body that is subordinate to it.

Before I return to the theoretical implications of this account of materiality, in the next section, I want to first get into the (medical) routes and definitions for symptoms that count as medically unexplained.

1.2 Trajectories

In this section, I discuss different trajectories. I first discuss the trajectories offered by different systems of naming unexplained illness: the different names that have been given and the effects of those names. I then discuss the trajectories of the nervous routes alongside lines of gender, race, and class and how such structural conditions intersect with unexplained illness. Next, I will discuss the medical trajectories for unexplained illness that branch out into different illnesses and diagnoses.

The fact that this dissertation is concerned with discourse analysis affects the terms I use. Names for unexplained illness vary between the disciplines in which they are encountered. Above, I have referred to symptoms and illnesses with no found organic cause as unexplained illness. The "right" terminology is contested. However, names that are used vary from "medically unexplained (physical) symptoms," also abbreviated as MUPS or MUS (Greco 2012: 2363) in medicine and social sciences, to "functional disorder" or "functional somatic syndromes" (Barsky and Borus 1999; Henningsen et al. 2007) or "somatoform disorder" in medicine and psychiatry (Brown 2007: 772). Far into twentieth-century medicine and psychiatry, a wide range of symptoms were still often referred to as "hysteria" or "Briquet's syndrome."[14] Within the *Diagnostic and Statistical*

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[14] Paul Briquet (1796-1881) was a French physician/psychologist who published his *Traité Clinique et thérapeutique de L'hystérie* in 1859, and who became the name-giver to what was known in psychiatry as Briquet's syndrome, a disorder which later changed name to somatization disorder. Briquet worked at the Salpêtrière, the Paris hospital that later became famous under Jean-Martin Charcot's rule. Not much is written on Briquet himself, although the syndrome named after him was still used in twentieth-century

Manual (hereafter DSM)[15] used in psychiatry, earlier editions, in use up until 2000, mention that somatization disorder was previously referred to as hysteria, establishing a historical line between previous diagnoses of hysteria and present-day psychiatric diagnoses (APA 1994: 445; APA 1987: 255).[16] Depending on the field or context, syndromes with no found organic cause can be referred to as "psychosomatic," "psychogenic," or "nonorganic."

On Betterhelp.com, the world's largest commercial online therapy service, the entry on psychosomatic symptoms opens by saying, "No one likes to be told their symptoms are psychosomatic. That's because, for many people, the term has come to mean imaginary. Being told your symptoms aren't real makes you feel brushed off and disrespected" (Faubion 2022). This view is confirmed in a study on the terms that patients themselves prefer for unexplained illness. The study made use of a questionnaire, in which the term psychosomatic was not included. However, it was found that patients preferred terms that included the word "physical": the most popular term being "Persistent Physical Symptoms" (Picariello et al. 2015: 423). It shows the strong wish amongst patients with unexplained symptoms for demonstrable causality. Another study by Marks and Hunter that looked at preferred terms for unexplained illness amongst lay and otherwise healthy people included the term "psychosomatic/psychogenic." The study showed that the term scored low on popularity, whereas, similar to the preferences of people with unexplained illness, "Persistent Physical Symptoms" was also found to be most popular (Marks and hunter 2015: 111-112).

The term "invisible illness" is often used online by patients or advocacy groups, for instance, as #invisibleillness. In many cases, this hashtag refers to chronic conditions

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psychiatric literature, in which it was often used interchangeably with hysteria or somatization disorder. DSM-III mentions that Somatization Disorder was previously referred to as hysteria or Briquet's syndrome (APA 1980: 241). See also Maggio et al. 2020. On the differences between research on hysteria by Briquet, Janet and Freud, see Meares et al. 1985.

[15] In accordance with common practice, I do not italicize the abbreviation DSM, which refers to the different revisions to the *Diagnostic and Statistical Manual of Mental Disorders* published by the APA between 1952 and 2013.

[16] This concerns the third and fourth editions, DSM-III (APA 1980), DSM IV (APA 1994), up until the text revision of the same manual: DSM IV-TR (APA 2000). The name "somatization disorder" was in use from DSM-III up until DSM-IV. In DSM-5, the most recent revision of the manual, somatization disorder was reconceptualized as "somatic symptom disorder," a different formulation of similar complaints that removed the necessary existence of a medically unexplained symptom for diagnosis with a psychiatric disorder (APA 2013). See also this dissertation, Chapter Three, especially section 3.5.

such as ME/CFS or fibromyalgia.[17] Invisible illness is also maintained in Megan O'Rourke's critically acclaimed and partially personal account called *The Invisible Kingdom: Reimagining Chronic Illness* (2022) or in the patient-activist publication by Austin et al. called *But You Don't Look Sick: The Real Life Adventures Of Fibro Bitches, Lupus Warriors, And Other Superheroes Battling Invisible Illness* (2021). This invisibility refers to the lack of visual clues of illness, such as a broken leg in a cast, but also to the medical invisibility of many illnesses in the sense of scans or lab tests. It also calls to mind the social and political invisibility in the sense of a social environment that questions if the illness is real. The title of the last-mentioned publication by Austin et al. plays with the often-quoted saying in patient communities: "Oh, but you don't look sick." It features in memes and blogs and is used by patients to show how the daily reality of being ill is undermined in social contact.[18]

Within social sciences or cultural studies, names vary from "contested illness" (Groenevelt 2022; Groenevelt et al. 2022; Armentor 2017; Swoboda 2006), "emergent illness" (Dumit 2006), "hidden illness" (Philips and Rees 2018), or even "enigmatic illness" (Franssen and van Geelen 2018). The more medically oriented term "MUS" or "MUPS" is used by medical sociologist Sarah Nettleton (Nettleton 2006; Nettleton et al. 2005) but also by Jenny Slatman (2018) and Monica Greco (2012), both researchers on the intersection of social sciences and philosophy. In arguably the most extensive discussion on nomenclature around unexplained illness, Monica Greco discusses how nomenclature and classification feed into the conflictual dynamic around unexplained illness from a performative perspective, paying attention to what certain representations or descriptions do. From this perspective, her use of the term MUS is maintained as a placeholder: "in the sense that its referent is not fixed to a single concept but shifts according to context, taking on different connotations each time" (2012: 2363).

My choice to specifically refer to the unexplained character of these illnesses and not to a placeholder of sorts is informed by my insistence on the discourse in which

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[17] See for instance the blog founded by Christine Miserandino, called "butyoudontlooksick." Miserandino has lupus herself, and became famous with her essay "the Spoon Theory," which offers a widely used metaphor for the limited energy resource – expressed in the form of "spoons" that, in the words of Miserandino function as a "code word for what I can and cannot do" – that people with (unexplained) illnesses possess. For the essay see Miserandino n.date, for a discussion of the essay see Latifi 2023.

[18] For an exhibition on how the phrase is used in reference to a wide variety of illnesses on social media, see Rocketto 2021.

these conditions are formed. I explicitly refer to *unexplained illness* because my focus is on the problem of the unexplained character of specific physical symptoms. Within current medical discourse, the lack of organic markers or explanations for the experience of the symptoms is central to the problem of unexplained illness as it is lived by patients. Also, highlighting that these illnesses are unexplained carries the potential for resituating this burden within medical science itself.[19] This means that my use of terminology and the focus on the unexplained nature is in line with the general move that I propose. That is to emancipate unexplained illness from blame within a structure focused on individual accountability and to think about what an affirmation of unexplained illness in terms of collective care and responsibility can mean.

1.2.1 Trajectories of structural conditions

The explicit need for a move towards affirmation of unexplained illness is related to its delegitimization. This is all the more important since unexplained illness predominantly and disproportionally affects women and already marginalized groups. In a study that analyzed the number of reported medically unexplained symptoms in primary care practices in Germany, it was concluded that two-thirds of all reported symptoms involved unexplained illness and that women, younger persons, and non-native German speakers had the highest rates (Steinbrecher et al. 2011: 263). Such numbers already show how race and gender are among the markers of bodily unexplainedness. In these primary care settings, medical unexplainedness is counted as those physical symptoms for which there is no structural physiology or underlying physical disease that can be identified in relation to the experienced symptom. Among the group of symptoms that commonly remain medically unexplained are back pains, severe fatigue, abdominal pain, and bloating, but also partial paralysis and severe pains in muscles and joints.

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[19] I have highlighted this potentiality for affirmation elsewhere, in a chapter included in *Science Fiction and the Medical Humanities*, edited by Gavin Miller and Anna McFarlane. In the chapter for the edited volume, I referred to patients with unexplained illness as “the unexplainedly ill,” in an explicit attempt to place the burden of unexplained illness with the structure of medical explicability as a whole (Hommes forthcoming “Going with ‘the crowd’”). In this dissertation, I maintain a larger scrutiny of such framing in terms of groups of people, as my main aim is to work towards a description of the problem of unexplained illness as it appears along nervous routes.

The gendered and racialized aspects of such symptoms go a long way back. Unexplained symptoms have historically been linked to femininity, and these complaints have been feminized: they have gotten a lesser degree of credibility, tainted by the lack of conclusive objectifiable evidence. Critique of the feminization of certain types of illness goes at least back to Ehrenreich and English's analysis of the medical system as being "strategic to women's oppression" in their 1973 manifesto *Complaints and Disorders: The Sexual Politics of Sickness* (2011 [1973]: 31). Tracing back the view that women are sick to the expulsion of paradise, Ehrenreich and English state that "medicine's prime contribution to sexist ideology has been to describe women as sick, and as potentially sickening to men" (32). Class and race differences are made explicit in their 1973 manifesto, to the extent that the authors note that "it was as if there were two different human species of females" (41). Upper- and middle-class (mostly White) women were described as "sick," while working-class women, Black women, and immigrants were described as "sickening," honing in on the idea of women as being frail and weak or classist and racist fears of being infected and polluted (45).[20]

These different categories relate to different notions of feminization that can be traced back to negative stereotypes of unexplained illness today. The more privileged form of female invalidism culminated in notions around hysteria, still resonating in stereotypes of female malingerers out for attention or fears by patients of not being heard and taken seriously. At the same time, neglect of the hard living conditions that less privileged working-class people and people of color had to endure led to stereotypes of being healthy and robust while being feared as a potential carrier for disease at the same time. Stereotypes of marginalized people as being more robust than upper- to middle-class White people or being polluted still resonate today. They can be traced back to present-day beliefs that "Blacks feel less pain" (Trawalter et al. 2012), in women of color being over- or under-diagnosed for certain conditions, such as fibromyalgia (Pryma 2017: 68) and endometriosis (Farland and Horne 2019), or being denied pain medication on suspicion of being an addict (Hirsh et al. 2020).

Sander Gilman has shown that the nineteenth century knew a "clear 'feminization' of the male Jew," linking the notion of hysteria not only to gender but also

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[20] A more in-depth analysis of fears of contagion as connected to unexplained illness is given in Chapter Five.

to the racialized other who was seen as being out of place (2020: 45). In her brief historical rendering of gender in relation to unexplained illness, Susan Johnson notes how some symptoms, especially fatigue and muscle weakness, were historically associated with White upper-class women and were characterized as hysteria or neurasthenia, a name for an illness coined around 1880 (2008: 14). In working-class people, similar symptoms were not absent but often "unrecognized, untreated and underreported." Johnson notes how this situation returned in the contemporary case of ME/CFS, which was initially labeled the "yuppie flu" until research showed that cases were more prevalent in non-White minority groups (2008: 15).

A similar case is found in endometriosis, which has historically been described as a disease that affects only wealthy White women and thus resulted in late or sometimes wrong diagnoses for Black women and women of color in the US at present (Farland and Horne 2019: 1115). Different conditions are linked to different sets of gendered, racialized, and classed stereotypes. The risk involved is that both people falling within this stereotype and people outside it – those people who do not conform to the typical risk group – are negatively affected. The former group risks being stigmatized, and the latter group risks not being adequately diagnosed or recognized as ill.

In 2020, researchers updated an earlier study done in 2016 and looked at the relationship between disease burden and research funding in the US. The update showed that ME/CFS is more underfunded with respect to burden than any other disease funded by the United States National Institutes of Health (NIH), (Mirin et al. 2020: 277). Although ME/CFS is more debilitating than many chronic illnesses, it receives far less funding than most, certainly when the numbers are adjusted to prevalence and disease burden, as this study has done. The authors concluded that "to be commensurate with disease burden, NIH funding would need to increase roughly 14-fold" (279). Research by Arthur Mirin alone (the lead author of the 2020 update on the study on ME/CFS funding) concluded that the NIH applies a disproportionately large share of funding to diseases that primarily affect men. Mirin shows that illnesses that are far more prevalent in women, such as ME/CFS, migraine, headaches, anorexia, endometriosis, and digestive diseases, receive the least funding when compared to disease burden (2021).

In research on functional neurological disorder (FND) published in 2023, fifty-two authors, of whom most were medical professionals, medical scientists, neurologists, or psychiatrists, argue that the condition is a feminist issue (McLoughlin et al. 2023). FND is an umbrella term used for a wide variety of symptoms, such as weakness, involuntary movements, and sensory changes. It predominantly affects women – with most large studies presenting a range of seventy percent – and is viewed skeptically by many medical practitioners based on its poorly known causation (McLoughlin et al. 2023; Barnett et al. 2022). In their discussion on the position of women in healthcare, as it becomes apparent in the controversy around FND, McLoughlin et al. note how women are considerably underrepresented in research. Women are excluded from medical trials due to hormonal differences. Having to account for hormonal differences compared to men would lead to extra costs (McLoughlin et al. 2023: 5). On a more general level, McLoughlin et al. draw a line between illnesses that predominantly affect women and the little funding allocated to research on those illnesses. They conclude that "the history of FND mirrors the history of women in society" (2023: 5). It shows how a particular type of (presumably cis-gendered) man is taken as a model person from which to develop medical knowledge.

Many studies that look at gender disparity in medical research or funding do not separate between sex and gender and hold on to a binary model, thus being limited to describing cis-gender women and cis-gender men. In this dissertation, I have tried to be explicit about such gaps and have used the term "women" as an inclusive term open to those wishing to identify with it. I refer to Hedva's choice of subject position in their "Sick Woman Theory."

> Though the identity of 'woman' has erased and excluded many (especially women of color and trans/nonbinary/genderfluid people), I choose to use it because it still represents the un-cared for, the secondary, the oppressed, the non, the un-, the less-than. (2022a: n.pag.)

Hedva refers to women as a general category for the oppressed, partly because of their own experience of being "feminized" because of their illness, disability, and vulnerability (2022a: n.pag.). This means that in the context of Hedva's manifesto, the Sick Woman also includes, and explicitly so, "a homeless person, especially one with any kind of disease and no access to treatment, and whose only access to mental-health care is a seventy-two-hour hold in the county hospital," or "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" (2022: n.pag.).

My focus on nervous routes means that I do not propose a new term that explicitly frames unexplained illness in terms of identity, as outlined by Hedva. My use of the term woman thus signals such an inclusive term, yet is more limited in its reach, mainly to denote a gendered category. I have used male or female whenever biological sex needs to be emphasized.

Not only has the White cis-gendered male body long remained the standard for medical study, but also women, people of color, trans*,[21] non-binary, and intersex people struggle to be heard and to be taken seriously by medical professionals.[22] Qualitative studies within social sciences have explored how different cultural vectors intersect with unexplained illness in response to cultural discourses. Research has been done on unexplained illness in relation to gender and disease (Werner et al. 2004), gender and class (Mik-Meyer 2011), or casting a wider intersectional view, considering the specific difficulty of non-White working-class women to claim chronic pain and credibility (Pryma 2017). The last mentioned study by Jane Pryma was done in the context of welfare retrenchment in the U.S., which has given rise to a discussion on the deservingness of care and welfare that disproportionally affects those already vulnerable. Pryma conducted interviews with twenty-four women who were diagnosed with fibromyalgia. The study concluded that intersectional stigma significantly shaped how these women presented themselves when trying to claim chronic illness (2017: 72). In accord, social science and psychology research found that women's pain was generally more often psychologized than men's (Zhang et al. 2021). Medical research showed that racial and ethnic disparities affect pain management in medical settings (Lee et al. 2019). Such studies show that

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[21] The use of the term "trans*" refers to Jack Halberstam's reflections on naming in his recent *Trans*: A Quick and Quirky Account of Gender Variability* (2018), in which he argues that the use of trans* (rather than merely "trans"), "puts pressure on all modes of gendered embodiment and refuses to choose between the identitarian and the contingent forms of trans identity" (xiii).

[22] For women, this results in having to wait longer to get treated in the emergency room, being more likely to be sent home in the middle of a heart attack, or experiencing considerably longer diagnostic delays, see Dusenbery 2018, 4. For a systemic review of the safety of healthcare for ethnic minority patients, see Chauhan et al. 2020. On specific issues of the transgender community in relation to healthcare and medical education, see Giffort and Underman 2016, for a more theoretical discussion that includes personal experience with trans-healthcare, including how to speak to healthcare professionals, see Spade 2006.

medical research, medical science, and medical practice are not exempt from marginalization along the lines of sex, gender, race, and class.

Medical research itself knows a fraught history of racism, as shown in scholarly work on medical experimentation on Black Americans in the U.S. (Washington 2008; Cooper-Owens 2017). This history can be traced to ongoing present-day health disparities experienced by Black Americans (Roberts 2011; Hatch 2016), and racial disparities have only increased during the COVID-19 pandemic (Wright et al. 2022; Laurencin and Walker 2020). Black women experience a specific type of medical racism in relation to reproductive care (Davis 2019). Another effect of racism was pointed out in reference to lupus, a condition that is commonly framed as either unexplained or contested and which predominantly affects Black American women. Spears et al. have shown that anticipatory racism stress leads to worse disease outcomes amongst Black American women as compared to White Americans (2021). Unexplained illness is intimately tied to already marginalized groups and their complicated relationship with medicine. On top of this, unexplained illness itself has a further marginalizing effect on the people affected.

1.2.2 Named Medical Trajectories

Among those syndromes that are often referred to as “medically unexplained” are irritable bowel syndrome (IBS), fibromyalgia and myalgic encephalomyelitis, otherwise known as chronic fatigue syndrome or better, ME/CFS, but also vulvodynia, and interstitial cystitis, a syndrome characterized by bladder pain. Let me be very clear on the fact that I do not characterize any particular condition as a condition that is, by any essentialist framework, ultimately “medically unexplained.” I will not make any claims on the causation of the specific conditions and syndromes I discuss. Instead, when I discuss particular conditions, I do so to show the context in which they have been discussed as unexplained. What I thus bring up for discussion is how the uncertainty about the biomedical status of certain conditions or complaints has resulted in negative frameworks and stigmatization of patients based on poorly understood biomedical etiology.

IBS can cause mild to severe stomach and abdominal pain and bloating. It is a syndrome of which the symptoms range from mild to severely debilitating and which is estimated to affect roughly twenty percent of people worldwide (O’Mahoney et al. 2017).

Being quite prevalent, IBS is among those medically unexplained syndromes whose patients can count on the greatest acknowledgment and support from their doctors. Although no cure exists, treatment takes place in gastroenterology, which has developed specific diets by which patients often improve. Patients with fibromyalgia or ME/CFS are seen by Rheumatologists, or sometimes within infectious disease, in the case of ME/CFS. Patients with ME/CFS encounter much more disbelief and stigmatization within medical institutions (Johnson 2008: 38; Blease and Geraghty 2018: 393). According to a memoir by Sarah Ramey, who was herself ill with multiple undiagnosed conditions, the disbelief in the case of fibromyalgia goes to the point where fibromyalgia is seen as simply "code for crazy" (2020: 13).

ME/CFS often develops as a post-infection disease. This is seen more often in unexplained illness, and is also the case with chronic Lyme disease (CLD), or Long Covid.[23] CLD is a contested syndrome in which symptoms after infection with the bacterium *Borrelia burgdorferi*[24] linger or become chronic. Lyme disease is an uncontroversial illness that follows after bacterial infection, from which most patients recover after antibiotic treatment. CLD, sometimes also referred to as post-treatment Lyme disease syndrome (PTLDS), refers to a state from which patients do not recover. Instead, symptoms linger and become chronic. The symptoms experienced by CLD patients bear a close resemblance to symptoms seen in patients with ME/CFS or fibromyalgia. They linger and vary wildly, from mild to severely debilitating (Wong et al. 2022: 267). The newest post-infection illness is Long Covid. Long Covid emerged amongst patients infected with COVID-19 during the worldwide pandemic that started in 2020. Symptoms that are often experienced in post-infection disease are debilitating fatigue, post-exertional malaise, and brain fog. In cases of post-infection illness, the infectious agent can be (but is not always) known or visible in the body. The cause for the long-term effects of the symptoms is unclear. It is unknown why certain people suffer from long-term effects, and others do not.

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[23] Although, in accordance with common practice, I do not capitalize names of disorders in general, I capitalize the term "Long Covid" to follow Felicity Callard and Elisa Perego's coining of the term. See Callard and Perego 2021.

[24] *Borrelia burgdorferi* is the most common species of the bacteria in the United States, although more diversity is found in Europe and in other parts of the world. See Marques et al. 2021.

Chronic Lyme Disease counts as contested amongst doctors. According to the information on the US-National Institute of Allergy and Infectious Diseases website, the fact that patients in whom the bacteria was never found also claim the illness leads to confusion and poor clinical support for the term ("Chronic Lyme Disease" 2018). Chronic Lyme often significantly affects the patient's daily life and involves a myriad of symptoms like severe fatigue, brain fog, painful muscles, impaired vision or motor coordination, and abnormalities in the regulation of body temperature. These symptoms are often unpredictable, and patients experience flare-ups that alternate with longer stretches of symptom-free periods (Iliopoulou and Huber 2010: 416; Baarsma et al. 2022: 4). A focus group study on the experience of patients with CLD showed that negative experiences with healthcare professionals were "near-universal" and that these patients often felt abandoned by the medical system (Baarsma et al. 1).

According to Philip J. Baker, the executive director of the American Lyme Disease Foundation, "There is no better example of a relentless attack on evidence-based biomedical research and the integrity of outstanding scientists than that associated with the treatment of a poorly defined condition called "chronic Lyme disease" (2010: 4175).[25] He notes that patient groups "relentlessly" promoted the use of antibiotics even though medical evidence on positive effects was scarce. According to Baker, the use of antibiotics as treatment for CLD could be potentially dangerous. He states that doctors he refers to as "Lyme-literate-physicians" (a phrase that he mockingly places in between quotation marks) profit immensely from prolonged treatments (2010: 4176). His viewpoint presents a controversy: patients feel they are not taken seriously by the medical establishment; they organize themselves in advocacy groups and cling to the few treatment options available. The medical establishment hesitates or even opposes providing treatment when no proof is available. It shows the complexity of the various positions of the situation that unexplained illness results in for patients, healthcare professionals, and general medical science. Just as much, such controversies show the importance for healthcare professionals to take their patient's symptoms seriously.

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[25] Similar claims have been made by researchers who developed treatments for ME/CFS, which focused on behavioral or mental aspects of the illness. See my discussion of the controversy around ME/CFS in section 4.3, 204-211.

With the emergence of Long Covid during the global COVID-19 pandemic, hope for more public acknowledgment and research funding has been revived amongst patient groups with ME/CFS. The similarities between Long Covid and ME/CFS were soon visible and publicly recognized by Anthony Fauci, then chief medical advisor to the president of the United States, during the global pandemic of 2020-2023 (Wise 2022: n.pag.). Patient advocacy groups such as #MEaction and Action For Me hoped that this new form of post-infectious disease would lead to more understanding and more research on both conditions ("Coronavirus and ME/CFS" n.d.; "Long Covid" n.d.). At the time of writing, research on the social effects that patients with Long Covid or post-COVID syndrome experience is still young, but researchers found that patients, amongst whom women are in a sound majority, report social stigma and a lack of belief from their medical practitioners, and feel they are taken not seriously (Ladds et al. 2020; Pantelic et al. 2022).

The term Long Covid was first used online in May 2020 as #longcovid by Elisa Perego. She lived in Lombardy, an especially hard-hit early hotspot in the pandemic. Already in October 2020,[26] Perego, a health humanities researcher, published a paper with medical humanities scholar Felicity Callard in which they reported on Long Covid as a patient-made disease. Both write from personal experiences with long Covid. They emphasize the importance of it being the first illness formulated by patients who found each other online. The speed of publications and consolidation of knowledge around COVID-19 meant that, in such an early stage, patients and their first-hand experience had the potential to become important actors in how the post-infection illness was defined. Callard and Perego map the routes of the formulation of the illness through various media to formal clinical and policy channels in "just a few months." They highlight the importance of the patient-led formulation because it allowed them to marshal "epistemic authority" (Callard and Perego 2021: 1).

Such epistemic authority matters because patients with unexplained illness frequently experience what can be called epistemic injustice. This concept was coined by Miranda Fricker in 2007. It denotes a situation in which someone is wronged specifically in their capacity as a knower (Fricker 2007: 1). The concept was applied in the context of

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[26] The paper was received by *Social Science & Medicine* in revised form on October 3, and published online on October 7 2020, by then only seven months in the global pandemic, which was declared by the WHO in March 2020. The article was published in the journal in January 2021, volume 268.

unexplained illness and used to make sense of a patient's lack of agency. For instance, in relation to ME/CFS (Byrne 2020; Blease et al. 2017) or Long Covid (Byrne 2022; Ireson et al. 2022). The epistemic injustice that patients with unexplained illness are confronted with concerns a lack of epistemic authority (accounts of patients are not believed by their doctors).

Epistemic injustice can also be linked to what Fricker has called *testimonial injustice*, a prejudice on the hearer's part that means that the speaker, in this case the patient, is attributed less credibility. Eleonor Byrne is a philosopher of medicine and psychiatry who has applied the concept of epistemic injustice to cases with ME/CFS and Long Covid. She identifies and recognizes testimonial prejudice in encounters of patients with unexplained illness with healthcare professionals. She notes that such testimonial injustice follows negative stereotypes along the lines of sex/gender, race, or class. She also states that one's status as an "ill person" provides a negative stereotype that leads to lesser testimonial credibility (2020: 372). The analyses by Byrne and other researchers show how Fricker's concept gives voice to the experience that follows from the delegitimization of unexplained illness.

Another form of epistemic injustice concerns hermeneutical injustice, which Byrne characterizes as "a structural problem that arises as a result of a collective shortfall in conceptual resources" (2020: 372). In response to ME/CFS, Byrne notes that the lack of knowledge or conceptual impoverishment about the illness leads to a lack of framework in which patients and medical professionals can make sense of the condition. Byrne points out how these two injustices "are closely linked and work to sustain one another" (2020: 373): a low degree of sustainability is both an effect and a consequence of a lack of knowledge of unexplained conditions. For instance, the little funding for research on the physical causes of unexplained illness can be explained within the context of testimonial injustice (patients' accounts are not taken seriously, so the need for medical research is not acknowledged) as well as hermeneutical injustice (a lack of knowledge on these conditions, both medically and socially/politically, further discredits patients' credibility and discourages further endeavors for medical research).

As an overall framework, epistemic injustice and its particular effects on the testimonial credibility and hermeneutical context of patients with unexplained illness helps to explain the various discriminatory effects that unexplained illness has on patients. In terms of this dissertation, these forms of injustice continuously linger in the background. They are described through my focus on the various routes along which unexplained illness are understood. My tracing of the nervous routes thus provides a cultural, epistemic, and sometimes (medically)historical context for these injustices, often resulting in blame and stigmatization.

The effects of this blame are aptly described by Jameisha Prescod, a Black writer and chronically ill disability activist who states that "to believe yourself, your body, and that your pain is real is a radical act of self-care" (2021: 125). Prescod is diagnosed with lupus. The condition is widely known through its reference in the long-running series *House M.D*, in which a Sherlock Holmes-type of doctor is on a quest for the right diagnosis for "mysterious illnesses" and repeatedly, as a form of running gag, says, "it's never lupus." In the series, it is never lupus because the illness is notoriously hard to diagnose. The illness is far more prevalent in women than in men and is shown, in the U.S., to predominantly affect Black American- (Amsden et al. 2018: 1088) and Latin American women ("Lupus CDC" n.d.).

Lupus is a chronic autoimmune disease, meaning that the immune system sees the body's own cells as invaders and attacks them. Writer and artist Carolyn Lazard, who has autoimmune disease herself, described autoimmunity as "the immune system is perplexed and is driven to hyperactivity" (Lazard n.d.: n.pag). The overactivity of the immune system causes inflammation and a range of wildly varying and hard-to-diagnose symptoms. In the case of lupus, these symptoms vary from fatigue to skin rashes, fever, and joint pain or swelling (CDC "Lupus" n.d.). In 2008, science journalist Donna Jackson Nakazawa published *The Autoimmune Epidemic*, in which she stated that forty-five percent of patients with autoimmune disease had been labeled as hypochondriacs during their search for a diagnosis. Nakazawa attributes this to the fact that most people with autoimmune conditions are women (75).

The importance of having physical symptoms diagnosed by a doctor is huge. Research has shown that the path to diagnosis is different for marginalized groups and that this can lead to receiving late or wrong diagnoses for physical conditions.[27] A diagnosis identifies an illness or condition, gives it a name within an existing framework, and provides a path towards treatment or cure when possible and wished for.[28] Apart from possible treatment, a diagnosis also legitimizes patients' experienced symptoms, both medically and socially. A common topic of concern for patients with undiagnosed symptoms is the degree to which their experience of illness is accepted amongst their health professionals and their social circle (Glenton 2003; Zavestoski et al. 2004; Nettleton 2006). At the same time, some diagnoses come with their own stigmatizing effects and do not necessarily provide the form of relief that patients are after. For instance, patients with psychiatric diagnoses such as somatic symptom disorder, diagnoses under the umbrella term "functional disorder," or patients diagnosed with fibromyalgia often suffer from further delegitimization because of the low status of their diagnosed condition. I expand on this tension in chapter three, called "Classification."

The list that I give here is far from exhaustive. Other conditions that count as unexplained are multiple chemical sensitivity (MCS), mold sensitivity, Gulf War syndrome, or Morgellons. These conditions tend to be even more controversial within medicine. In a 1996 workshop held in Berlin by the World Health Organization, MCS was not recognized as a clinically defined disease. The suggestion was made to drop the name because it "makes unsupported judgement on causation" (Bold and Kiesswetter 2002: 100). MCS, or idiopathic environmental intolerance (IEI), as the WHO prefers, was seen not to be causally related to chemical exposure, but to fear of that very exposure (Bolt and Kiesswetter 2002: 105). This effect, sometimes called the "nocebo effect," continuously hovers about unexplained illness. The status of the condition is dependent on the extent to which the symptoms are seen to have their origin either in the mind or in any identifiable physiological cause. The notion that illnesses can be transferred socially,

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[27] Racial disparities leading to late or wrong diagnoses have been well documented, especially in relation to cancer, as shown in studies by Fry et al. 2023 and Virnig et al. 2009. The effect of social class on diagnosis is less well-researched. It is established that poorer patients and people who received a lower education are generally in poorer health than patients with a higher socio-economic status or higher education and that poorer patients die up to ten years earlier, see Al Alwan 2019; Meara et al. 2008. This is largely attributed to structural conditions, such as a lack of access to healthy foods and lifestyle, see Nandi et al. 2014; Meara et al. 2008. Patients with lower socio-economic status also report lower satisfaction in their encounters with health professionals, see Becker and Newsom 2003.

[28] Not all diagnoses require treatment, and not all conditions require cure. For a discussion of cure in relation to disability politics see: Clare 2017.

via suggestion, or the more dauntingly formulated notion of an infection of the mind, is further worked out in Chapter Five, called “Transference.”

Except for MCS and Gulf War syndrome, all of the conditions mentioned above are found to be more prevalent in women, making the problem of unexplained illness also very much one of continuing gender disparities in health care.[29] When unexplained illness is described in men, it is often connected to war, as shown in the case of Gulf War syndrome, or in historical cases of shell shock and “war hysterics.” In his history of hysteria, historian Andrew Scull describes the discourse around male hysteria as one that understood “the males who shared these traits […] as weak effeminate creatures bereft of the qualities generally seen as appropriately masculine,” also bearing close proximity to homophobic fears around homosexuality (2011: 55). In an analysis of medical and literary discourse around male hysteria in nineteenth-century France, historian Jan Goldstein describes the almost inextricable conceptual links between femininity and hysteria as also having potential for gender subversion of these stereotypes, as shown in Flaubert’s self-characterization as “hysterical” (1991: 134). The feminization of unexplained illness is not only related to women but also shows in characterizations of (historical) cases of unexplained illness in men who were seen as vulnerable, weak, or too much affected by traumatic experiences such as war.

Within present-day healthcare, the notion that hysteria is related to unconscious structures or unfulfilled fantasies has stuck in the imaginary connected to psychosomatic symptoms. In this case, the situation is entirely indebted to Freud. In 1897, Freud made his infamous switch from the trauma-induced seduction theory of hysteria, where the illness was believed to be related to early experiences of childhood sexual abuse, to the

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[29] On the prevalence of fibromyalgia in women an article by Yunus notes a proportion of 9:1. A systemic overview on the prevalence of ME/CFS by Lim et al. concluded that ME/CFS is more common in women than in men. Lee et al. provided an overview of gender differences and the prevalence of IBS in women, see Lee et al. A study by Pearson et al. stated that among the afflicted patients with Morgellons, seventy-seven percent were White women. Research on MCS seems to be the exception to the gender bias of unexplained illness. A national population study on the prevalence of MCS in the US by Caress and Steinemann concluded that chemical hypersensitivity is widely distributed throughout the general American population “cutting across racial/ethnic, age, and gender groupings.” A study by Steinemann alone even found a male bias in diagnosed patients with MCS. Gulf War syndrome is a condition connected specifically to the veterans of the Gulf War, who are mostly men, and thus predominantly affects men, presenting with similar symptoms as found in ME/CFS, such as fatigue, muscle/joint pain, headache, difficulty concentrating, memory loss and sleep disturbance. See: Yunus 2001: 129; Lim et al. 2020: 4; Lee et al. 2001: 2184; Pearson et al. 2012: 1; Caress and Steinemann 2004: 304; Steinemann 2018: 154; Kang et al. 2003: 141.

fantasy model that placed the origin of the illness in the unconscious desires of the patient. This allowed Freud to expand his psychoanalytic theory, firmly placing the cause of the physical symptoms in the patients' minds, which could be uncovered and treated in analysis (Bernheimer and Kahane 1985: 14-15). The fantasy model of hysteria saw the illness no longer as a result of wandering wombs or direct reactions to sexual trauma and abuse. Instead, it conceptualized hysteria as originating in the unconscious fantasies of patients. This created a (medical) distrust of women's experience of their own bodies that continues to influence their credibility within the healthcare system today.

Perhaps unsurprisingly, the history of hysteria will be continuously returned to throughout this dissertation. The nineteenth-century female body was a point of departure for linguistically or discursively oriented feminist theory, calling attention to hysteria around the 1970s and 1980s and continuing in the 1990s. Feminist theorist Elaine Showalter described hysteria as a form of protolanguage "communicating through the body messages that cannot be verbalized" (1993: 286). Within the group that Showalter called the "New Hysterians," hysteria was understood as a cultural condition and seen as reactive to patriarchal oppression of women (Devereux 2014: 20; Showalter 2020: 28). The cultural history of hysteria studied illness as a metaphor, or conceptualized it, in the work of Hélène Cixous and Luce Irigaray as a language of feminist protest.[30] Also, the imagery, theatricality, and performativity of the hysterical body have been the subject of much scholarly attention, among others, by Georges Didi Huberman, Sander Gilman, Jonathan Marshall, and Felicia McCarren.

Around the same time that hysteria had been established as a paradigmatic point of reference with which to discuss the female body, Elaine Showalter formulated what she called contemporary forms of hysteria, or *Hystories,* in 1997 (2013). It turned out to be a controversial monograph on which she received much critique, even to the point of death threats, from patient organizations and advocacy groups for her conceptualization of conditions like ME/CFS as a modern form of hysteria (Showalter 1998).

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[30] Irigaray speaks of a power that is always repressed in hysteria in *This Sex Which is Not One*. Cixous states that "Silence is the mark of hysteria. The great hysterics have lost speech, they are pushed to the point of choking, nothing gets through. They are decapitated, their tongues are cut off and what talks isn't heard because it's the body that talks, and man doesn't hear the body." See: Irigaray 1985: 138; Cixous 1981: 49.

In the original monograph, Showalter speaks of these "modern-day day hysteria's" as an "infectious epidemic" that spread by "stories circulated through self-help books, articles in newspapers and magazines, TV talk shows and series, films, the Internet, and even literary criticism" (2013: 5). Showalter's account of hysteria emphasizes the outsider's status of unexplained illness, and does not account for the experience of the patients themselves, nor for the structural conditions under which these symptoms come to materialize. It thus risks laying the blame on the individual patient who is stigmatized for producing symptoms that are not perceived as "real."

Her account fits the notion of a twentieth-century resurgence of the routes along which hysteria travels: routes that have traditionally failed to include the patient's position and have marginalized their experience of their body and their pain. By contrast, this dissertation aims to stay with the problematic nature of the symptoms' existence outside of what counts as dominant medical science, yet as having a firm presence in the lived and felt body.

1.3 Dissertation Structure

These conditions under which individual physical sensations occur are discussed in different instances. In the next and second chapter, called "Cases," I engage with the problematic relationship between the individual case and generalized knowledge, especially concerning (medical) care for unexplained illness. I question the construction and use of the medical case that functions by generalizing particular personal information, a movement that I discuss in reference to the lack of care that unexplained illness often implies. This chapter can be read as a reflection on methodology. It sets out my approach to writing about cases in the coming chapters. I start by looking at the specific narrative structure of a case description used as a "model case" for somatization disorder in psychiatry. Reading this case, I ask how the case subject itself is constructed to come to bear the weight of an explanation beyond their individual situation alone.

My methodological focus thus aims to avoid the appropriation of the individual personal account of physical sensations and sets out to find an entrance into the writing of individual cases. In line with Brinkema's *reading for form*, which I referenced earlier in this introduction, this chapter argues that this entrance is found in an analysis of cultural objects, or: the form that constructs the medical case. This involves close reading and attentiveness to the particularities in which unexplained illness gains shape. As I argue in this chapter, this is of special importance in relation to a discussion of unexplained illness. The nervous route that I identify in this chapter is one moving from the personal to the public/political, or the singular to the general, but also from case to case to construct knowledge along the way. In tandem with the third chapter ("Classification") and the fourth chapter ("Impasse"), the second chapter works to map and define the fields throughout which I operate.

Firmly located within the humanities, I engage with a range of disciplines, from medicine and psychiatry to subdisciplines like psychoanalysis and psychosomatic medicine, as well as the history of (neuro)science and psychiatry. The interdisciplinarity of this dissertation thus lies in the approaches that I take to analyze different cultural objects in which unexplained illness gains shape in the present. In the third chapter, called "Classification," I trace the concrete medical route laid out for unexplained physical symptoms that lead into psychiatry. Until the latest revision to the *Diagnostic Statistical Manual of Mental Disorders* in 2013, the existence of a medically unexplained symptom automatically meant that such physical symptoms were psychiatrically explained. The route I identify in this third chapter is one of classification; the trace of the diagnostic history that continues to shape the psychiatric diagnosis of physical symptoms. This nervous route is operational in the DSM-5 today and determines the medical route with which unexplained illness is encountered at present.

The fourth chapter, "Impasse," addresses a nervous route of impasse; getting stuck and not moving forward. Specifically, I address the impasse that occurs within psychosomatic definitions of unexplained physical symptoms that remain stuck within mind-body dualism and that continue to stigmatize patients. Reading a case description from the *Psychosomatic Case Book* (Grinker and Robbins 1954), I focus on how mind-body dualism is worked with in the psychosomatic tradition. After discussing a particular instance in which a patient resists a diagnosis because it implies psychosomatic illness, I present a short genealogy of the psychosomatic tradition within Western medical knowledge. I discuss the development of psychosomatic medicine as a field that has failed to provide a positive framework for unexplained illness. I show how the psychosomatic tradition continues to remain shackled to a form of mind-body dualism that lays responsibility with the individual patient and obstructs a view of the structural conditions in which the patient's symptoms are lived. In the last section of this chapter, I mobilize Sara Ahmed's notion of "stickiness" to argue that the psychosomatic definition of illness works as a "sticky concept" that attributes blame to the individual patient.

This personal responsibility is related to a particular kind of integrated healthy bodymind. In effect, the integration proposed in psychosomatic medicine obstructs attention to the formative effects of relations of power and the material conditions that shape how the body is lived. Despite the initial attempt of psychosomatic theory to overcome the mind-body dualism, this chapter argues that psychosomatics as a field participates in a persistent narrative of unexplained illness in which material conditions are ignored in favor of a (possibly neoliberal) notion of individual responsibility of healing that ignores the relationality of care.

The fifth chapter is no longer concerned with a particular field or domain of knowledge on unexplained illness but focuses on the concept of transference in relation to unexplained illness. This chapter, called "Transference," particularly looks at fibromyalgia, a physically unexplained syndrome that causes severe and widespread muscle pains. The idea of psychosomatic contagion implies that an idea or cultural notion can make you ill. Psychosomatic contagion particularly travels around fibromyalgia. In this chapter, I question the notion of psychosomatic contagion by looking at specific cultural objects in which fibromyalgia is mobilized, referred to, or classified. Following my reading of these cultural objects, I identify two opposing ways of conceptualizing transference in relation to illness, either as a contagious movement between closed individual spaces or as a relationally sensitive notion of how the body is inhabited. I argue that the notion of the contagious body is at risk of creating a narrow space that again lays the blame for the illness on the socially vulnerable individual. By contrast, a view on transference of illness that moves between different bodyminds constructs a relational view of the body. Such a framework simultaneously works to avoid a limited and stigmatizing understanding of unexplained illness.

1.4 Accounts of Materiality and Contained Selves

The individual on whom power operates is not singled out in this dissertation. Instead of working with personal stories of bodily distress, I have chosen to focus on texts, images, or classificatory definitions. There are multiple reasons for this, which are grounded in a materialist feminist framework. The personal stories I present in this dissertation are those presented through cultural objects. As cases, they become stories and examples for diagnosis; as told in memoirs, they become textual translations of what is bodily felt, and when visualized, their expression has to be read for. In my analysis of them, I focus on the forms in which individual experience takes shape. This allows me to look at the conditions that set the possibility to relate to one's physical symptoms. This is also done because I see this as one of the scarce ways of accessing the problematic relation between physical symptoms and discursive structures overall.

Where theory is able to conceptualize bodily felt sensations as signs of different cultural vectors, it holds a problematic relation to the materiality of the symptoms. Theory involves the problem of access. Although my attention on nervous routes means that I focus on discourse, my materialist feminist lens makes me attentive and ultimately concerned with the consequences of this discursive setting on the experience of unexplained illness for people who suffer from it. In accordance with materialist feminist theory, I maintain a focus on material reality as being entangled with meaning-making processes. This means that these experiences themselves are not singled out and are only described through the forms in which they materialize. These forms are found in different cultural objects.

In the introduction to *Material Feminisms*, an anthology on material feminist theory, Stacy Alaimo and Susan Hekman state that the long-standing difficulty of feminist theory with materiality has resulted in a "refuge within culture, discourse and language" (2008: 1). Thinking and theorizing about illness within the humanities always has had to balance the slippery terrain between the body and discourse. Here, illness is in danger of being turned into metaphor, and the body is at risk of being smothered or disappearing through language. The medical humanities have focused largely on the narrative forms in which the experience of illness is expressed without attending to the structural possibilities and constraints in which an expression of bodily sensation takes place. In short, it has ignored the question of power.

The linguistic and discursive turn that I described in my brief discussion on feminist theory on hysteria in the last section (and which is also described by Alaimo and Hekman above) has been very much concerned with power. Yet in its address of this body under power, feminist theory has often constructed "figures," "hystories," that left the aching body itself untouched. Or, feminist theory has failed to account for the material conditions under which a patient's lived experience takes shape and under which it has consequently gotten no voice.[31]

The gap that persists between the lived experience of patients' physical symptoms and the theory that tries to come to terms with it manifests in the experience of unexplained illness. Medical science has failed to account for these patient's experience of illness, as shown in studies in which patients report feeling neglected and left out.[32] Critical theory has done much to account for how power materializes in the body and how it produces subjectivity with it. Yet patients often find themselves up against such power, up against a medical system that fails to include them, and up against a body that hurts. This dissertation does not literally give patients a voice but looks at the structures through which their voice is shaped, possibly muddled, or denied existence at all.

In response to this ongoing struggle, my inquiry into the meaning that has been attributed to the manifestation of medically unexplained illness addresses how these "meanings" shape subjectivity along the way. These meanings are structured alongside the power of authorities. The nervous routes that I identify in this dissertation aim to expose the way in which concepts are invested in the production of certain subjects. Through looking at the ways in which unexplained illness comes to be defined as unexplained, my analyses of different cultural objects work to problematize the relation between knowledge and the body directly and do so by staying with the formative effects of power.

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[31] I refer to my comments on Showalter's work above (40). Other such figures can be found in the feminist work on hysteria in the 1980's such as in Irigaray and Cixous, who mobilized their version of "the hysteric" as a metaphor for a language of feminist protest. See 40, note 30.

[32] See my discussion of ME/CFS as the "Yuppie Flu" (29), my discussion of research by Pryma (2017) (31), or my discussion of research by Nettleton et al. (2005) in section 3.1, 124.

In 2004, Elizabeth Wilson addressed the difficult relationship between feminist theory and materiality in *Psychosomatic: Feminism and the Neurological Body*. This monograph specifically addressed the biology behind unexplained illness, in her case, nineteenth-century biological accounts of hysteria. Wilson called attention to the lack of critical interest in biology within feminist theory (2004: 13). Her attention to biological detail in her 2004 monograph and later in *Gut Feminism* (2015) acknowledges the importance of antibiologism for feminist theory. Wilson also argues that paradoxically, this antibiologism constitutes its own conceptual limitations, as it restricts which feminist arguments can be made (2015: 4). In a sense, my inquiry into the problematic of unexplained illness follows Wilson's reading of biology or the method she describes as *gut feminism*: "a feminist theory that is able to think innovatively and organically at the same time" (2015: 17). Following Wilson, I am concerned with the way in which biology is mobilized. The objects discussed in this dissertation continuously refer back to the question of how organic matter is conceptualized and how this conceptualization works to formulate a particular kind of subject.

This issue of the organic matter of unexplained symptoms comes back to the persistent notion that symptoms of unexplained illness are less "real" than symptoms belonging to explained conditions like a broken leg or cancer. In an essay on Morgellons, a mysterious condition in which patients find fibers coming out of their body, Leslie Jamison writes that the difference between "real" and "unreal" symptoms is not only related to a physical versus a mental condition but that it also implies a difference in the way in which suffering is perceived: it matters if the suffering is produced by a force outside the self, or if it comes from a "force from within." Reflecting on the strange condition that is Morgellons and the notion that patients have created their own illnesses, Jamison writes:

> these explanations place the blame back on the patient and suggest not only that the harm inflicted is less legitimate but also that it's less deserving of compassion or aid. Parasites and bacteria are agents of otherness; easily granted volition as some sinister they or them, and – in holding this power – they restore the self to a victimized state. (2014: 41)

Jamison notes how the presence of an "external agent of damage," like a wrong movement in the case of a broken leg or a found physical marker like rapidly reproducing cells in the case of cancer, confirms and keeps in place the self as a unified entity. It is in line with the strong wish for a physical explanation and demonstrable causality: patients often want a physical agent. It legitimizes their pain and forms a shield against the notion of the self as a non-contained, "leaky," conflicted, fractured, or destructive entity. Contrary, Jamison writes that she experiences her body as "much more discordant and self-sabotaging, neither fully integrated nor consistently serving its own good" (2014: 41). Yet this view presents a theoretical privilege that easily vanishes with the manifestation of unexplained illness. Once confronted with unexplained illness, it is difficult to fully embrace this notion when dominant discourse implies the likelihood that, however "mysterious" it may be, these patients made themselves sick, are, as a consequence, themselves to blame, and are, thus, less deserving of care.

Of importance is the link between the notion of the self as a contained entity and the association with "real symptoms" as coming from the outside. In the case of Morgellons, this produces an extra confounding situation, as the fibers found by patients are physical entities. Contrary to most unexplained conditions that are invisible to the outside, Morgellons is often visible on the skin. However, this visibility does not seem to help Morgellons in becoming a more recognized condition. Even more so than other unexplained conditions, its patients are seen as delusional. In medical terms, Morgellons is characterized as "delusional parasitosis" (Dovigi 2010: 603).

When viewed skeptically, the fibers lose their status as "real" specimens from the patient's body. These fibers are, for instance, explained as being "environmental," as is done, for instance, on morgellonswatch.com, a blog dedicated to proving Morgellons is not "real." The Morgellons-skeptical blog states that the fibers come from a piece of clothing or furniture instead of a parasite (West 2006: n.pag.). Even though the fibers are physical entities, and the lesions on the skin are visible, they are not seen as "real" because they have not been connected to a parasite or to bacteria. The general explanation becomes that the manifestation of the fibers is not related to some kind of "real," legitimate form of infectious "other" but to a force from within.

This force has been called many things and has been most famously characterized as the “Id” or “das Es” in the psychoanalytic/psychosomatic tradition.[33] The revolution of the neurosciences of the nineteenth century gave a new meaning to the age-old belief that personality, demons, or other types of internal factors could lead to physical illness. With Freud, the starting point for certain physical symptoms is found in unconscious processes, which then convert into bodily symptoms. Georg Groddeck, a contemporary of Freud, is usually credited with coining the notion of the “Id,” although the notion goes back to Nietzsche (Freud 1961 [1923]: 23). In one of his last theoretical works, *Das Ich und das Es*, translated as *The Ego And The Id*, Freud characterizes Groddeck’s work, saying that his colleague is “never tired of insisting that what we call our ego [ich] behaves essentially passive in life, and that, as he [Groddeck] expresses it, we are ‘lived’ by unknown and uncontrollable forces” (Freud 1961 [1923]: 23).

It is a tradition that lingers. It is difficult to overestimate the influence of the notion of unconsciousness on the way in which unexplained illness is understood. In the fourth chapter of this dissertation, I engage specifically with the psychosomatic tradition and its relation to psychoanalysis. Here, I call attention to the effect that the concept of psychosomatic symptoms has on patients’ experience of their symptoms. The relation between mental and physical states was once described by Freud as “that mysterious leap from the mind to the body.”[34] This phrase became a common way to describe the conversion from mental processes to physical symptoms.

In practice, patients are often held accountable for the presentation of this “mystery.” Following Jamison, amongst others, this often results in blame and in the notion that these patients are less deserving of aid and compassion. Victimization and the lack of care and compassion need not be necessarily tied to physical and causal

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[33] “The id” is the latinized version of the German “das Es,” which would be “the it” in English. James Strachey, the translator of Freud’s works into English, maintains the latinized version throughout the *Standard Edition*. He stated that the choice was made “so as to be parallel with the long established ‘ego’” as translation for “das Ich,” instead of “the I.” See Freud 1961 [1923]: 7.

[34] Greco notes that the original German *rätselhafter* used by Freud was translated differently as “mysterious” by Stanley Hall, and as “puzzling” by James Strachey. The original phrase in *Vorlesungen zur Einführung in die Psychoanalyse* (Freud 1916–17) is “jener rätselhafter Sprung aus dem Seelischen ins Körperliche.” Greco notes that the phrase “mysterious leap” was “reactivated” by Felix Deutsch, and then worked with in a series of papers produced in 1959 by a group of the Boston Psychoanalytic Society under the title *On the Mysterious Leap from the Mind to the Body – A study on the Theory of Conversion*. According to Lilian Furst, this book “naturalized the phrase in the United States.” See: Greco 2019: 107, 113; Freud 1966 [1916-17]: 265; Furst 2003: 37.

demonstrability of illness. Yet, the persistent nervous routes, which are the object of this dissertation, make that they are, and implicitly or explicitly hold the patient accountable for the creation of their own symptoms when other explanations are lacking.

Within evidence-based medicine, quantitative methodologies gained the upper hand over descriptive language and subjective knowledge. The emphasis of illness etiology has come to be on bodily processes instead of the subjective experience of the body.[35] While this has done much to progress Western medicine, evidence-based medicine has been under critique from fields such as the medical humanities. A formulation of such critique is that evidence-based medicine "does not *increase* objectivity but rather *obscures* the subjective elements that inescapably enter all forms of human inquiry" (Goldenberg 2006: 2621; emphasis original).

Studies centering around the medical humanities have often turned to phenomenology to conceptualize the difference between the objective body, or *Körper*, and the lived body, or *Leib* (Wirth 2019: 346). In Jenny Slatman's work on what she calls medically unexplained illness (MUS), she has argued for a revision of phenomenology in such a way that this *Leib* also includes the subject's experience of their physical and material existence. The idea is that this would avoid the psychologization of unexplained symptoms that is so often prevalent (2018: 103). While this dissertation is concerned with making an emancipatory move for patients, or in Slatman's words, to "reclaim the body" (2018: 103), this work sets out to do so by attending to the nervous routes of unexplained illness, that is, the ways in which unexplained illness is understood.

On the whole, the following chapters are concerned with the processes in which the cause for unexplained illness is either placed inside or outside the self and with the effects that both conceptualizations of illness can have. In general, within evidence-based Western medical science, an external cause for illness, such as an infection or a broken bone, is epistemologically preferred over an internal cause. External causes present a clear cause and effect. Something happens, or the body is attacked, and it becomes sick. Internal causes are more complicated. There can be a myriad of malfunctions happening in the body, some of them known and understood, like cancer, and others less so, like a range

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[35] For a genealogy of evidence-based medicine see: Hanemaayer 2016.

of autoimmune disorders. These conditions are more at risk of being explained alongside various nervous routes.

The body with unexplained illness is not easily reclaimed. Such an endeavor involves a greater understanding of the concepts in place and the conditions in which they are embedded. To be able to reclaim this body for the patients themselves also means to be careful not to write too much into it myself. Not to make, so to speak, a similar move as is done by the predicate of unexplained given by medical knowledge, in which (non)explanations are given which do not fit with the body as experienced by the patient. In the next chapter, I further engage with the consequences of foreclosing patient experience in scholarly research and reflect on ways in which this can be avoided. This involves a reflection on the use of the case (study) and a practice of care towards it. Ultimately, it is such care that can help patients forward. Care for bodyminds that hurt. A care for bodyminds that do strange things sometimes, and a careful rendering of those bodyminds that need looking after.

2. Case

2.1 Blackout

I start with a case of a 50-year-old woman living alone with her son. She has had abdominal pains since she was seventeen, but even after exploratory surgery, no specific diagnosis was found. She has been pregnant several times, each time difficult, experiencing extreme nausea, vomiting, and pain in her belly. After delivering a son and after another pregnancy that she lost, her uterus was removed because it was "tipped." She lives with her son, with whom she travels from hotel to hotel. She divorced at 32 and has had no other relationships since then. She is not very interested in that anymore. She works as a secretary, but there are long periods of time when she does not feel strong enough to work and has to stay in bed.

Her dizziness started after she turned 40. Sometimes, she experiences what she calls a blackout. Her doctors told her these blackouts could be related to multiple sclerosis or a brain tumor, but nothing has been diagnosed. A few years later, she found herself intolerant to a number of foods. Her belly was significantly bloated, but no physical cause or intolerance was found. Her vision is not always clear. She feels confused sometimes and feels her heartbeat is irregular. She thought it might be due to kidney failure because she had heard that sometimes results in similar symptoms. She went to the hospital, but the doctor who examined her there had found nothing wrong with her kidneys.

Who is this woman? Her name is not mentioned, nor whether she even lived, and how she is doing now. Her story does have a name – it is called "Blackout." It was published along with 214 other stories that exhibit a knack for alliteration, like "Edgy Electrician" (Spitzer and APA 1981: 166), "Apathetic Accountant" (168), or "Stuporous Student" (13). These titles are not only reminiscent of Agatha Christie novels – "Blood is Thicker than Water" (32), "Too Far From Home" (35), "Unrecognized Genius" (37), but also give off a vaguely misogynist odor: "Wicked Young Lady" (195), "Triple Divorcee" (154), "Worthless Woman" (17), "The Suffering Lady" (201); or they carry a combination of the three: "Sad Sandy" (185), "Wealthy Widow" (6), "Tiny Tina" (178).

As it turns out, "Blackout" was written in order to answer a different set of questions. Her story is taken as a test case for clinicians, who are meant to diagnose her with somatization disorder. This woman's story has, in fact, become the model case for somatization disorder, drawn from the storybook of psychiatric diagnosis, the *Case Book: A Learning Companion to the Diagnostic and Statistical Manual of Mental Disorders (third edition),* (hereafter *Case Book*), which was published by the American Psychiatric Association in 1981. The DSM itself is also referred to as the "psychiatric Bible" and is used to diagnose people with mental disorders in clinical practice. The *Case Book* accompanied the third edition of the DSM, published in 1980.

According to the authors, the information contained in these model cases is the necessary information needed for a diagnosis. The discussion that follows "Blackout" states that "the chronic, polysymptomatic disorder of physically unexplainable symptoms involving multiple organ systems" clearly points to somatization disorder (Spitzer and APA 1981: 260). "This clinical picture, far more common in women than in men, in the past referred to as hysteria or Briquet's syndrome, is now called Somatization Disorder" (261). With that, this woman's unexplained symptoms have been given a name as well as a gendered history. With this name, it is learned that the story is not a story but a case.

In this case, the story was written for a specific purpose. The third edition of the *Diagnostic Statistical Manual* (DSM-III) revolutionized classification systems for psychiatry. Contrary to earlier editions, which included rather broad descriptions and occasional psychoanalytic slips, DSM-III aimed to formulate concise and clear formulations. It included a multiaxial classificatory system and introduced diagnostic flowcharts to smoothen the now professionalized psychiatric diagnostic endeavor. Part of this operation was the introduction of the *Case Book,* which bundled 214 cases.[36] Every case description aims to give only the information that is relevant for diagnosis, simultaneously providing the critical reader outside psychiatry with a reading guideline for analysis. For the authors of the *Case Book,* however, the fact that these case descriptions are brief allows for the most "effective (and painless) way for clinicians to get experience in applying the principles of DSM-III to a wide range of patients" (Spitzer

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[36] See my analysis of the evolution of the DSM and the DSM-based criteria for psychiatric diagnosis of physical symptoms in Chapter Three. In section 3.4, I describe the (supposed) psychoanalytic orientation of DSM-I and DSM-II. In section 3.5, I discuss the widened reach of the diagnostic revolution of the DSM-III, which now describes particular individuals as disordered.

and the APA 1981: 1). This raises the question: what might be painful about making a diagnosis?

Among the 214 cases published, thirty-five cases are designed as "test cases" to train the aspiring psychiatrist. Students will, on average, "complete the 20 adult test cases easily within an hour" (252). *Blackout* is one of these. In the discussion that follows the case, the authors discuss other possible related diagnoses but state that, in this case, "the full clinical picture of Somatization Disorder is present" (261). Symptoms like nausea, abdominal cramps, vomiting, bloating, food intolerance, seizure, blurred vision, and dizziness are all symptoms that point to somatization disorder. The test case argues that should these symptoms occur in a similar fashion, the same diagnosis can be made in a different case. More than other cases, the test case has a point to make. Not only does it frame the patient who models for it in a particular way, but the test case also becomes a model for other cases. To function in a teaching setting, the test case adds an extra layer to how the patient is framed.

I start with this case with the intention of turning the use of the case by the American Psychiatric Association's *Case Book* into a case to be reviewed itself. Above, I have turned the situation around by presenting the case as a story and the story as a case. In the introduction to the *Case Book*, the authors note that they had collected the case vignettes from their own experience; "from the perspective of many well-known experts in particular areas of diagnosis and treatment" (1). The information presented in the case is thus "based on a real story," written from second-hand experience. The blurring between story and case performed at the start of this chapter thus serves multiple purposes. This is not only to avoid reproducing the way in which the woman's story is taken from her but also to map out the entangled situation between the two. How was her story turned into a case in the first place? What kind of story elements were used to do so? How important, for instance, is her non-conventional lifestyle for the diagnosis? How do such story elements, so to say, *make the case*?

Problems of appropriation continuously hover about the usage of the case within psychiatry, in which cases are constructed to extract and communicate medical knowledge to provide medical care. In this chapter, I address the medical case with a focus on care, or carelessness. I focus on the way in which the patient who stands at the center of the case is constructed to serve a particular goal, namely of the medical ability to “care”. Such a goal is defined in terms of knowledge construction within the medical setting. Ultimately and ideally, the knowledge derived from the analysis and interpretation of the case results in medical care. The ideal of medical care is that a case can be framed in such a way that it leads to diagnosis and can thus offer an appropriate form of care. The lack of a physical explanation for medically unexplained illness complicates diagnosis and care. The framing of a case that happens nevertheless and extracts knowledge from a patient should thus be done carefully. It does not necessarily result in a form of care.

In a general sense, care is operative on at least three levels as it relates to this medical case. The first is a medical practice in which unexplained symptoms are lived and encountered as a case that has to be made sense of. This is where the confrontation between care and unexplained symptoms first takes place. The second is the case as it exists in medical scientific knowledge and education, which is always evolving and always involved in the production of the patient's lived experience. The third level is the case insofar as it becomes an object of concern in critical cultural analysis. Lauren Berlant has described the case study as a machinery that makes individuals into normative units; it creates a “walking exemplar” (2007: 666). On this level, the problem facing those working with unexplained illness (and how to care for those who suffer from it) is equally pressing but becomes methodological.

This chapter approaches care by focusing on two types of questions. First, I ask what kind of form care might take faced with *unexplained illness.* This question shifts attention away from the knowledge extracted from the case and focuses on the way in which the case is approached and on the case subject itself, which has been removed from the center of it as a subject of care. It is this subject, who is in the process of being turned into a medical case, that this chapter eventually cares about. Second, I ask how care can be practiced as methodology. A careful methodology by which to approach unexplained illness within the humanities is important to not reproduce the same cycle in which unexplained illness is made sense of in ways that usually either neglect or smother the patient. This careful methodology is pivotal in my insistence on nervous routes. I theorize these nervous routes as reactions to the problem posed by unexplainedness.

The case functions as a nervous route in that it can be understood as a movement (a sequence) by which the patient becomes an exemplar for something else. The patient who modeled for the medical case remains visible yet in a liminal way. The construction of this patient in the form of a case is done within a particular framework of knowledge, oriented on biomedical science. I consider this framework constructive for a patient, who, as a result, only remains visible through different frames. This leaves the subject who modeled for it out of view. Nevertheless, being turned into a case can still result in care for a patient with an objectively identifiable disease. However, in cases of unexplained illness, this framework, or the orientation of medical science on biomedical explanations, leaves the patient with unexplained illness exposed and uncared for. Their condition does not fit into a framework of biomedical knowledge. This leaves not only the patient who modeled for the case invisible but also the condition. It creates the patient as a vulnerable subject: one whose subjectivity is framed in a liminal space, a void to be filled.

Medical knowledge, like the study and practice of law, is historically based on cases. The case is constructed orally or in written form by physicians in response to a malady experienced by the patient. The case is also taught as a diagnostic method: it organizes information with which to think through patients' symptoms (Hunter 1992: 164). The difference between a medical case and a patient's story is that the case is not meant to be a story. Though both are narrativizations of events of illness that occurred in a patient, the medical case has a clinical objective: "detached, impersonal, unemotional about death and loss and limitation" (164). Seeing the case as a representational narrative, the isolated and objective character of the case in medicine has attracted critique since the 1980s. The critique focused on the marginalization of the voice of the patient and the resulting dehumanization of medical care (Tierney 2004: 272), while the very possibility of the clinical objective was also considered in relation to power hierarchies and narrative construction.

In unexplained illness, a patient's own account of their symptoms cannot be easily translated into a conclusive medical case that results in diagnosis, treatment, and care. Here, care is not the intended outcome of the construction of a medical case but a problem: it is unclear how it can be given or even imagined. This lack of clarity exists on the side of medical care, which lacks treatment to provide healing for the patient's symptoms, but also on the side of case construction, where it is unclear how to make sense of and attend to unexplained symptoms.

In psychiatry, unexplained symptoms are referred to as *somatizations*, like in the *Case Book* case that opened this chapter. In practice, this often means that the unexplained nature of the case is offloaded onto patients, who come to bear a double burden: the pain of their illness and the burden of being undiagnosed and, therefore, a "problematic patient."[37] The inherently vague diagnoses that are given to unexplained illnesses do not destabilize the authority of medical diagnosticians but only enlarge the burden and insecurity for the patient.

In terms of medical care, this means that there is often no cure. Instead, these patients are offered controversial therapies focused on behavior or the mental aspects of physical illness,[38] are referred to psychiatric counseling for physical pain, or are left with no therapy at all. In such cases of unexplained illness, medical care is problematic and not easily located. Unexplained illness thus results in an outsider's status for patients. Following this outsider's status, the case that the presentation of unexplained symptoms in medicine results in effectively places the patient outside the dominant frame of medical knowledge and expertise.

The patient presented at the beginning of this chapter functioned within a particular psychiatric framework. She became a model case of somatization disorder. I want to return to this patient and close-read the text in which this patient is constructed in order to see how this woman is turned into a case for a discipline. The DSM story told above was taken from the *Case Book*, and slightly rewritten for present purposes. The original DSM *Case Book* version starts with the following paragraph:

> A perplexed internist asked for a psychiatric consultation on a 50-year old divorced and unemployed secretary. When first encountered the patient was lying in bed in a contorted position, with occasional jerking movements of her arms, one every few seconds. Within minutes she was sitting up and explaining that she had been having "a seizure" that was "still there, in my spine. At any minute it can break out and overwhelm me again." Her present difficulties began

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[37] In this chapter, I discuss this double burden in terms of the construction of the case. In another, forthcoming publication, I have made a similar point, looking at the problem of unexplained illness in relation to shame and pride, see Hommes forthcoming "Towards a Theory."

[38] Examples are graded exercise therapy (GET), or Cognitive Behavioral Therapy (CBT), often prescribed for ME/CFS, but removed from the UK-based National Institute for Health and Care Excellence (NICE) guidelines for treatment of ME/CFS (2023). See also section 4.3, 206-209.

> two-and-a-half months previously with nausea, abdominal cramps, and pain in the extremities that kept her bedridden for several days. (Spitzer and the APA 1981: 260; quotation marks original)

I want to begin by looking at the first three words. The very first character on the stage is a generalist so specialized that they can be seen as a personification of medical science as a whole. An internist does not specialize in a certain organ, a certain process or technique, but takes the whole of the human body as their field of study. If a problem is especially perplexing, if multiple problems exist in relation to each other, in short, if singled out physical explanations do not hold, you go see an internist. And so, the suggestion seems to be, when even an internist is perplexed, there is probably no explanation at all.

By opening the description with the perplexity of the internist, the reader is already primed to understand what is to come in terms of unexplainability. Enter the patient. Their gender is not made explicit but implied by the mentioned employment as a secretary, a gendered and feminized profession. The first thing the reader hears about her is that she has no job, no husband and that she is well above fertile age. Where the mention of her former employment is linked to her gender, her marital status and current unemployment set up subtle links to unexplained illness: failing and falling between societal norms.

The next line takes a more descriptive approach and seems to describe the situation as the internist encountered the woman. Yet here, the subject of the encounter is missing, just as other pre-existing knowledge. As the internist is referred to in the opening line, they are not implied to be the author of this case; someone else was asked, probably a psychiatrist, who also encountered this woman. The mention of the occasional jerking of the woman's arms implies that someone counted the seconds as the woman's arms were moving. The next line tells that she sits upright within minutes after the jerking seems to have stopped. Here, the authors of the *Case Book* directly quote the woman herself: it was she who called it a seizure, not the internist or the authors of the case, who referred to what was happening with the rather more understated "occasional jerking movements."

Usually, direct quotes are used to present a version of reality in its most reliable form. Apart from giving details that make a text more realistic, this quote provides the psychiatrist with direct “proof,” as these words are not spoken by the authority of the text but by its subject. The next part of the quote, where the woman states that “it” can happen any minute now and “overwhelm” her again, serves another purpose. To use this verb outside the quote would have been far too dramatic a word choice, while the placement in the quote shows both the dramatic speech of the woman and also the extremity of her symptoms.

Direct quotes are given twice in the story: here and in the last of the three paragraphs, where she is quoted as stating that “sex never turned me on”. In the introduction to the *Case Book*, the authors note that they had collected the case vignettes from their own experience; “from the perspective of many well-known experts in particular areas of diagnosis and treatment” (1). The story is constructed through second hand, by hear-say, making it more unlikely that these are the woman’s own words. As the *Case Book* gives her a voice to speak in the first person, it may well be putting words in her mouth.

The story continues with an account of her medical history, reporting – in that order – the abdominal pain, various complications during multiple pregnancies, dizziness, hiatal hernia, weakness, blurred vision, difficulty urinating, complaints of bloating, and an intolerance to a variety of foods. The authors write that “She also had additional hospitalizations for neurological, hypertensive, and renal workups, all of which failed to reveal a definitive diagnosis.” The last paragraph recounts her personal situation:

> She has been divorced since age 32 and has worked very sporadically. She lives with her only child, an adult son. They lead a rather vagabond life, settling for a few months at a time in a residential hotel, then moving on to another city. They have no significant relationships other than each other. She avoids heterosexual encounters, explaining that “sex has never turned me on.” (260)

It is not difficult to write a story with these personal elements. The difficulty, instead, seems to be not to write too much into it; not to make up a story about how it scared her when her belly bloated again, after her previous pregnancies, how the harsh lighting in the hotel perhaps triggered her dizziness, and to think of how she might fear that her son might one day start to suffer from similar symptoms.

The lack of any clear-cut physical explanation asks to be filled up on multiple levels. Perhaps the most important and least discernible desire for interpretation lies with the interpreter of the text, the cultural analyst—us, me, you—who is furthest removed from the situation but, yet again, has to make a story of it. Without clear physical explanation, this interpreter shall have to use interpretive skills, tempted but also wary of the fact of *having to tell* a story themselves. In the opening story to this chapter, I have tried to perform this temptation, this need to narrativize, not by going wild with speculation, but by staying, by and large, with the story of the *Case Book*, yet slightly altering its order, rephrasing it just a bit. *Doing so was an attempt to reflect on case construction and on the effect of telling a certain story a certain way.*

2.2 Case-Study Machinery

This section provides a theoretical framework for my discussion of case-based forms of knowledge. Following various analyses and with the help of Berlant, I characterize the case as a machinery that produces a particular type of subject. I first draw attention to gender in relation to unexplained illness by close reading a sampled sentence by Jane Austen. Second, and more generally, I discuss the organization of medical knowledge along the lines of the medical gaze that intersects with a male gaze. I then again provide an analysis of an argument made in a medical article that discusses the gender dimension of fibromyalgia, a condition that is often stigmatized based on a poorly known etiology. I follow by turning to theorists like Berlant and Agamben to discuss the case as a normative unit. Being turned into a case suspends the person who modeled for it. This is all the more problematic in cases of unexplained illness since this suspension does not result in a form of care.

In 2022, writer and editor Meghan O’Rourke blended memoir and research to describe what she calls “invisible illnesses”: chronic illnesses that are poorly understood and frequently marginalized. O’Rourke was a recipient of a Guggenheim fellowship and editor of the Yale Review. Her book, *The Invisible Kingdom: Reimagining Chronic Illnesses,* made O’Rourke a *New York Times* bestselling author. On the first page of a chapter called “The Woman Problem,” one-third into the book, O’Rourke writes the following:

> One of the punitive fantasies – to borrow Susan Sontag’s phrasing – society has long held about women who are ill is that their unwellness is mainly in their

> heads. The stereotype of the sickly woman whose disease is strictly psychological still holds today when examples in medical literature of ‘problem patients’ are nearly always women. And so it is a truth universally acknowledged among the chronically ill that a young woman in possession of vague symptoms like fatigue and pain will be in search of a doctor who believes she is actually *sick*. (2022: 103; emphasis original)

The attentive reader well-versed in English literature will recognize one of the most famous first lines of Western literary history: “It is a truth universally acknowledged that a single man in possession of a good fortune, must be in want of a wife.” O’Rourke does not mention the opening sentence from Jane Austen’s *Pride and Prejudice* (1972 [1813]) but samples it to make a point on the marginalization of women within present-day healthcare.

The sentence by Austen is one of the most famous in literary history and one of the most reused, rewritten, and mashed-up literary lines in general. An article by *the Telegraph* on the (mis)use of famous quotes plays with this fact in its title: “It is a Truth Universally Acknowledged that Great Words will be Misquoted” (Dodds 2017). O’Rourke’s quote goes further than the version in *the Telegraph*. She stays with the structure of Austen’s sentence, which mentions a particular type of person with a specific set of attributes, which makes another set of people suspect that this type of person will probably be in want or search of x.

The sentence by O’Rourke adds to Austen’s construction by starting with “and so.” O’Rourke thus uses Austen’s famous opening line in a conclusionary tone, first having mentioned Sontag in a reference to a harmful discourse that holds the individual accountable for their illness, then moving on to defining the stereotype that the sentence critiques: the sickly woman whose illness is psychologized, and who is seen as a “problem patient.” This “conclusion” is given after two previous sentences. Contrary to Austen, O’Rourke first sets the scene and then uses the trope of the “universally acknowledged truth” to make a point on the medical marginalization of women.

Jane Austen’s opening line gave a voice to a popular cliché at the time. The sentence proclaims that this “truth” exists and is universally acknowledged. It does not provide clarity on the part of the narrator or the author. In *The Cambridge Companion to Pride and Prejudice*, literary scholar Thomas Keymer points out that the “grandiose, generalizing formulation is punctured by the shallowness and parochialism of the point that follows" (2013: 1). His point is that there is nothing universal about this statement. The statement resembles a social attitude or belief within a – now historical – particular upper-class social circle. This attitude resembles the needs and desires of middle- to upper-class women who want to marry their daughters off well. The little agency attributed to women within this social setting was limited to the choice around marriage: whom to marry or not to marry at all. This social position shows that there is more than parochialism to be found in Austen's irony. Austen's sentence can be read as a critique of the limited options for women at the time. This critique can be read favorably in terms of women's reactions to their position in society (an oppressive context constitutes this "silly" or "shallow" behavior) or less favorably (these women should rather resist their limited options and should not be so concerned with marriage at all).

The ambiguity of the position of the narrator's voice is lost in O'Rourke's sampling of the sentence by using it in a conclusionary way rather than as an opening statement. Nevertheless, she samples the sentence in a chapter concerned with the gender dimension of unexplained illness. In doing so, O'Rourke references how a culturally specific trope works. A social attitude and popular cliché are shallowly seen as a "universally acknowledged truth." However, when closely read, this "universal truth" is revealed never to hold any universal pretense.

Another vital difference between Austen's sentence and O'Rourke's version is that O'Rourke gives the reader a specific group for whom this universally acknowledged truth holds. She states that the belief that young women with unexplained symptoms must want their symptoms acknowledged by a doctor exists amongst people who are chronically ill themselves. O'Rourke emphasizes the word "sick" to show that the verity of this sickness is what is commonly denied: these women with vague symptoms are troubled by pain and fatigue. However, they are commonly not seen as "actually being sick."

The links to patriarchal oppression are present in both sentences. O'Rourke focuses on *women* who present unexplained symptoms, which must be legitimized by medical science through being granted the institutional belief that these women are, in fact, ill. Like the women with little agency besides marriage who are referred to in

Austen’s line, the women who are chronically ill cannot do much but seek this type of legitimization. Yet while Austen’s sentence presented the single man as the subject talked about by an unknown set of people – but presumably middle to upper-class mothers wanting to marry their daughters to them – O’Rourke presents the group that talks about the subject of the sentence as the chronically ill themselves. It thus counts as a “truth” within groups of people with unexplained symptoms that you will want and seek this type of legitimization. Outside of this group, the unexplained symptoms are viewed differently. There, the “truth” held is opposite from the “truth” maintained amongst the chronically ill. Outside this group, the belief that is generally held is that these women are not actually sick. Certainly not when the medical institution does not recognize their symptoms.

O’Rourke points out the present-day gender dimension of unexplained illness by referencing a historical Regency novel. The reference fits well within the historical context often given to unexplained illness and traces the gender disparity that exists for the experience and evaluation of unexplained illness back to nineteenth-century hysteria. O’Rourke’s use of the quote already references unexplained illness, which is talked about and presented in different contexts by which a statement about it appears as truth. The fact that this “truth,” described by O’Rourke, concerns only women hints at a problem of representation in a historically White, upper-class, and male-dominated medical science.

A critique of the limited view that this form of science results in can be found in feminist scholarly work that has theorized the female body as one that has become an object constituted by the male gaze. In the following sub-section, I first turn towards a discussion of the intersection of the medical gaze and the male gaze.

2.2.1 Gendered Subjects of Medical Science

The way the female body is looked at has been central to feminist discussions, at least since Laura Mulvey’s “Visual Pleasure and Narrative Cinema,” published in 1975. The concept of the male gaze, which constituted female subjects as objects of the gaze, gained much traction, also outside of strictly scholarly attention.[39] Another and earlier

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[39] See a recent (2023) article by Lauren Michele Jackson in *The New Yorker*, also pointing to how: “uses of the ‘gaze’ today—be it the male gaze, the White gaze, the straight gaze, and so forth—seem more invested in matters of identity than in the project of aesthetic analysis.”

formulation of a particular gaze in relation to power is Foucault's formulation of the medical gaze, although much more contained within the scholarly sphere. Whereas the male gaze went back to psychoanalytic theory and the (Lacanian) act of looking as being constitutive for one's sense of self, the medical gaze is characterized by a distance of the self in reference to that which is looked at. Foucault's medical gaze objectivizes by maintaining an institutionalized form of distance.

Foucault developed the medical gaze in his 1963 *Naissance de la Clinique.* Foucault describes the onset of modern medicine at the end of the eighteenth century as a development in which medical knowledge starts to make a separation between the normal and the abnormal. Where medicine had been more concerned with "health" as a place to restore up until the end of the eighteenth century, it now starts to study the individual who is not sick. Foucault describes how, within medicine, a definition starts to emerge of the "model man" (1994 [1973]: 34). This gendered description – Foucault mentions "the healthy man," "the non-sick man," and "the model man", and uses the pronouns he/him – shows that the model described by Foucault is male-dominated. Although he himself does not highlight the gender dimension of modern medicine as such, it is intricately tied up with the normative power formations he describes.

> in the ordering of human existence it [modern medicine] assumes a normative posture, which authorizes it not only to distribute advice as to healthy life, but also to dictate the standards for physical and moral relations of the individual and of the society in which he lives. (1994 [1973]: 34)

The organization of modern medical knowledge around – now-established – normative standards allowed for the expansion of normative views beyond the practice of healing alone. Foucault describes how normative notions of what constitutes a normal and healthy body were formulated according to an idea of standard functions and deviations from that standard. The medical gaze is an institutionalized way of looking supported by modern medicine as it was developed in the modern clinic, born around the end of the eighteenth century.

Communication scientists Amanda Friz and Marissa Fernholz argue that the medical gaze was always a male gaze. They support their claim with an analysis of a 1971 medical textbook, which uses pinup pictures to illustrate human anatomy. Friz and

Fernholz closely read the pictures and their textual embedment to argue that the images depict femininity as an object that exists in relation to the male viewing subject. Friz and Fernholz cite the textbook authors, who state that they included pin-up pictures and maintained a "tongue-in-cheek tone" to offer a textbook that was both educational and entertaining. In constructing the textbook, the authors had simply held "the student in mind" (2020: 8). Friz and Fernholz show that the student who was held in mind was presumably a White, male, heterosexual student. They write that the performances of femininity "are deeply rooted in the logics of White supremacy that valorize White women's bodies and gendered performances of heterosexual availability" (7-8).

The analysis shows that the images, which are meant to illustrate and present human anatomy, perform a sexualized and racialized version of "model femininity" instead. Friz and Fernholz analyze this structure as one in which "female models [pose] as model females" (7). This construction of the model female goes one level further than that of Foucault's "model man." Foucault has shown that power is constitutive of the subject upon which it acts. The model man is constituted based on a formulation of the normal as opposed to the deviant. The model female is secondary: constructed by a male gaze grounded in the "model man."

This construction does not only have meaning within a theoretical framework. A male-dominated contemporary Western medical culture can have very concrete consequences for women, both as women patients and as women medical personnel. A large body of studies has shown how women patients, especially in the context of unexplained illness, feel disbelieved and disrespected by their (mostly male) doctors.[40] Analyses by Kirsti Malterud and Malterud et al. have connected this disbelief to a medical gaze, critically discussing the privilege of the latter in reference to the voice of the (woman) patient (Malterud et al. 2004: 8). Here, the separation of "objective" findings, observable by the doctor, and the "subjective" matter of the experience of the patient is crucial. Malterud contextualizes the ability of the objective gaze to produce "facts,"

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[40] For a specific discussion of disrespect or delegitimization in relation to gender and unexplained illness, see, for instance, Cheston 2022; Dickson et al. 2007; Nettleton et al. 2005; Werner et al. 2004; Werner and Malterud 2003; Åsbring and Närvänen 2002; Johansson et al. 1996. For a more general discussion of gender in relation to the clinical encounter, see Hoffmann et al. 2022; Hoffmann and Tarzian 2001.

stating that they emerge from a gendered form of interaction instead (Malterud 1999: 276).

Although not directly referring to them, Malterud's analysis is in line with feminist debates on science and technology that, in Donna Haraway's words: "unmasked the doctrines of objectivity" in favor of "'embodied' accounts of the truth" (1988: 578). Malterud concludes that since medical theory and practice have "for a long time, been constructed by men, with the clinical gaze of men, the cultural templates of men, and the perception and language of men," unsurprisingly, clinical signs presented by women are not always "adequately embraced within the scope of contemporary medical epistemology" (1999: 283).

At the same time, scrutiny of a broader male-dominated medical culture exposes that gendered stereotypes and objectification of women can also negatively impact women medical personnel. Elizabeth Evens writes how yearbooks from medical schools in the U.S. during the 1960s and 1970s included imagery of sexualized female nurses and showed images of a "sport" called "hunting." This involved male students attempting to grab female nurses and practitioners with their backs turned (Evens 2019: n.pag.). Research done more recently at the British Medical Association (BMA) reported a sexist discriminatory culture in which "women were undermined, bullied, and in some instances sexually harassed" (Rimmer 2019: 1). These examples are a result of a culture in which gendered stereotypes were maintained as the standard which was acted upon, sometimes resulting in violent, sexist behavior. Medical culture, medical knowledge, and medical care were and are not exempt from views on women that sexualized women and measured patients along a male gaze.

The woman subject exists in an extra vulnerable position in relation to a medical gaze. She is constructed normatively not only in relation to a model person but in relation to a gendered model in which she is placed at a passive level, summarized by John Berger as one on which: "men act and women appear" (2008 [1972]: 47). Passive, in the sense that she is secondary and responsive: constructed by a male gaze grounded in the "model man." The passivity implied in this notion of femininity is also illustrated in the functioning of the woman who modeled for the test case featured in the DSM *Case Book*. This woman was written about as a case and framed in a way in which her gender was linked to her former profession and in a way that linked her outsider's status as a single mom, as being unemployed and unmarried, to a lesser degree of credibility. It resulted in the construction of this woman as a model case for unexplained illness. A model case that was given shape in the DSM-III-based classification with somatization disorder, which framed a particular instance of illness, physically experienced, as something that exists "all in the head."

The intersection of the medical gaze and the male gaze means that the subject of unexplained illness is at a double risk of delegitimization. Unexplained illness escapes objectification: no clear-cut objective sign can be related to the subjectively experienced symptom. While unexplained illness is exposed to the medical gaze that looks for disease, the objectification of the illness does not result in a precise formulation of illness, i.e. a deviancy in relation to model man cannot be unequivocally established. Instead, this medical gaze produces an objectified subject with an outsider's status. This is where the intersection with the male gaze becomes especially pernicious: the lack of biomarkers is easily related by the medical gaze to lessened credibility on the part of the patient, something which the male gaze has historically attributed to women. The secondary role that women have been accorded in a patriarchal discursive ordering of medical knowledge entails a lesser status: not corresponding to the "model man." Pairing the effects of both gazes with the higher prevalence of unexplained illness amongst women means that unexplained symptoms run a high risk of being feminized. That is, unexplained illness becomes linked to subjectivity, lesser credibility, and general dramatization on account of the patient's unstable mind. The feminization of unexplained illness means that experiences connected to unexplained illness are at higher risk of overall delegitimization.

The high prevalence of unexplained illness amongst women has been commented on in recent publications by journalists and popular science writers, like the already mentioned Meghan O'Rourke (2022), Maya Dusenbery (2018), Elinor Cleghorn (2021), and Sarah Ramey (2020), who are writing on the position of women in contemporary medicine. In her "medical history of misogyny," Cleghorn gives an account of how "medicine has inherited a gender problem" (3). O'Rourke and Dusenbery have more concretely linked the prevalence of unexplained conditions in women to a lack of research and a lack of funding accorded to research into illnesses that are feminized in reference to the "model male."[41] The prevalence of unexplained illness amongst women is easily linked to the marginalized position that women have historically held in relation to a patriarchal form of medical science, as is done by these writers. The intersection of a medical and a male gaze is then seen as creating a female-shaped blind spot in which unexplained illness hides and becomes a problem. Studies showed a present-day gender disparity in the allocation of research money, where generally less funding was distributed to illnesses predominantly affecting women (McLoughlin 2023). Such results fit within a discursive (patriarchal) history that has negatively influenced attitudes to illnesses that are considered and stigmatized as "female conditions." At the same time, the large number of missed diagnoses of cardiovascular disease among women shows that illnesses seen as "stereotypical male" also negatively impact women at present.[42]

Easy as it is to make the connection between a male-dominated medical science and a female-dominated body of "unexplainedly ill" patients, this link must not automatically be tied fast and tidy by way of the explanatory statement that unexplained illness is a direct effect of patriarchy. Saying so would be to follow a line of reasoning that ultimately repeats the tying of femininity to unexplained illness. On the one hand, this does locate causation within structural conditions instead of within essentialist and individualist notions of identity that tie unexplained illness to a particular version of femininity. Such an emphasis on structural conditions could be positive for patients with unexplained illness because it circumvents the problem of putting blame on the individual. On the other hand, there is a potential danger in creating a new politically informed figure that merely becomes a new kind of essentialism: reducing unexplained illness to a patriarchal construct, not a feminine essence, but an essentially feminized concept nonetheless.[43] The lived experience of unexplained illness is much more complex than that and calls for a thorough intersectional and interdisciplinary analysis, where gender is significant but a limited framework on its own.

Writers like O'Rourke, Cleghorn, and Dusenberry can be seen as contemporary voices responding to Barbara Ehrenreich and Deirdre English's seminal work on women

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[41] See Dusenbery 2018: especially 23-59; O'Rourke 2022: 105-108.

[42] See my mention of the discussion on heart disease in women in the next section 2.2.2, 75. See also den Ruijter 2024.

[43] Here, I refer back to my argument on 1980's feminism that created an anti-patriarchal figure around hysteria, section 1.2.2, 40, note 30.

in relation to a medical system of power, described in the first introductory chapter of this dissertation.[44] Most notably in *Complaints and Disorders* (2011 [1973]), but also in *Witches, Midwives and Nurses* (2010 [1973]), and *For Her Own Good* (2005 [1978]), Ehrenreich and English write a history of the medical system as a powerful instrument of social control in the context of women's oppression. Especially *Complaints and Disorders* provides a thorough exploration and critique of race and class dynamics that is ahead of its time – a time when (White) feminism often ignored the implications of race in issues of gender, as pointed out by Susan Fauldi in the introduction to the new edition (13). The works must be understood within the context of second-wave feminism, written, according to the authors in an introduction to the second edition of *Witches, Midwives, and Nurses,* "in a blaze of anger and indignation" (2010 [1973]: 7). What Ehrenreich and English did was to pave the way for an intersectional critique that linked women's oppression to larger political structures that are still relevant for an analysis of unexplained illness today.

Going back to the feminization of unexplained illness in the contemporary setting, an example of feminization and the importance of a broader framework not limited to gender alone can be found in a marketing campaign for a drug for fibromyalgia called Lyrica developed by Pfizer. The campaign involved direct-to-consumer advertising in the form of TV commercials and was immensely important in shaping public opinion on fibromyalgia.[45] Kristin Barker, a sociologist who had earlier published a monograph on fibromyalgia called *The Fibromyalgia Story* (2005), cites patient reports posted online that celebrate the drug, such as: "I think that Lyrica commercial is going to be one of the best things that ever happened to us…whether the med helps or not. It somehow validates us as human beings that have a debilitating illness not just the hypochondriacs they thought we were!" (2011: 839; ellipsis original). The drug was solely marketed to women,

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[44] I have left out Sarah Ramey's memoir, mentioned two paragraphs earlier, in this mention because although Ramey's work is framed as a critique on the position of woman in contemporary medicine, it largely sticks to personal experience and eventually remains within the limits of a memoir, whereas the works mentioned here also crossover to journalism and incorporate a more extensive and intersectional form of critique. For my earlier discussion of Ehrenreich and English, see section 1.2.1, 28.

[45] For another analysis that analyses the Lyrica advertisements as "narratives of gendered domestic normalcy to which women with fibromyalgia are encouraged to aspire through pharmaceutical intervention," see Violet 2022.

and the campaign specifically tied into notions of validation, emphasizing that fibromyalgia is “real” because now there is a drug that can cure it.

Barker analyzed the campaign in terms of feminization. Barker argues that aspects of the commercials, such as showing only bright, thin women while a common side effect of the drug is significant weight gain, or pairing a possible disclaimer that the drug could lead to suicidal thoughts with a vision of a bright sunny background, are “troublingly manipulative given the desperation for relief among chronic pain sufferers” (2011: 838). Explicitly targeting women and their feelings of delegitimization and common mentalization of fibromyalgia symptoms, the commercials play in on feelings of neglect, countering the stereotype of the female malingerer. Barker notes how the legitimization by way of the marketing of the drug that sells fibromyalgia as a “real thing” is fundamentally tied to the feminization of the disorder (838). Barker analyzes these ads as an aggressively feminized marketing campaign that shaped the public opinion of fibromyalgia as a female illness.

The drug proved immensely profitable for Pfizer. Barker points out that around 2009, there was only one drug with higher revenues than the fibromyalgia drug Lyrica and that its sales were even higher than those of Viagra, the company’s “blockbuster” (838). It shows the cynical merging of (a lack of) medical knowledge with cultural stereotypes in a capitalist setting, where a marketing campaign is able to offer public knowledge on fibromyalgia, creating more awareness and legitimization by building on exactly those stereotypes, further feminizing the condition in the process of making a profit. Though the existence of a drug was marketed as a legitimization for people with fibromyalgia, the feminization of the drug and the disease relied on heavily stereotyped figures that further tied the illness to femininity in public knowledge, likely having a further delegitimizing effect. Here, gendered stereotypes merge with capitalist structures. Feminization of unexplained illness is not solely linked to gender but must be understood within a broader framework that shows the interconnectedness of structural conditions. In this case, the intersections include negative gendered stereotypes within a dualistically, biomedically oriented medicine, intertwined with existing pharmaceutical companies that capitalize on exactly those stereotypes within the logic of the market.

2.2.2 The Female Risk Factor

To further reflect on what feminization of unexplained illness entails, in this section, I focus on a 2001 medical article by Muhammad Yunus that examines gender differences in fibromyalgia diagnosis. Yunus has a long-standing career in research on fibromyalgia, even being referred to as the "father of our modern view of fibromyalgia" (Winfield 2007). The 2001 article discusses possible causes for the found prevalence of fibromyalgia in women and the more severe symptoms experienced by women with fibromyalgia (more fatigue, pain all over the body, and greater pain severity). Yunus states that the mechanisms of gender differences in fibromyalgia and related syndromes (he mentions ME/CFS, Irritable bowel syndrome, and headaches) are not fully understood but that "they most likely involve an interplay of biology, psychology, and sociocultural factors" (132). As regards the biological factors known at the time of writing, Yunus only gives a few hints at genetic differences and physiological mechanisms. Genetic differences were found in animal testing, which showed differences in the experience of pain between animals of the male and female sex. In terms of physiologic mechanisms, Yunus mentions the possible role of hormones like estrogens and androgens in the experience of pain (131).

The way in which the sociocultural and psychological factors are described deserves some further scrutiny. The sociocultural factors for the gender differences are described in terms of cultural differences. According to Yunus, they are influenced by "cultural background, upbringing, gender role, ethnicity, religion, education and socioeconomic status." At the start of the article, Yunus explicitly states that he does not separate sex and gender but will refer to them interchangeably. His reasoning is that "the biologic and psychosociocultural aspects of being a man or a woman interact and overlap and cannot be teased out easily in studies of a given illness or disease" (129). Needless to say, this statement simply ignores the many people (and theories) for whom sex and gender explicitly do not overlap for the sake of simplicity. About the cultural differences that can account for the high prevalence of women among patients with fibromyalgia, Yunus states that "pain behavior and pain response to a stimulus have been reported to be influenced by gender" (132). Because Yunus uses sex and gender interchangeably, I assume that he refers to a cis-gendered norm.

Another reference to a default of a cis-gender heterosexual, patriarchal framework in which the gender disparity of fibromyalgia diagnosis is described is made by Yunus' use of the following example.

> The gender of the examiner or a caregiver also affects a patient's attitude and tolerance to pain. In one study, males reported less pain during a cold pressor test when the experimenter was an attractive, young woman. (132)

Not maintaining a distinction between sex and gender here means that the word male is used to refer to cis-gendered men, who are also automatically assumed to be heterosexual and to conform to the gender-conform behavior of responding to an attractive female-gendered person – who is also young – in a masculine way: not showing pain or not allowing the experience of it. On the one hand, Yunus seems to only report studies that show dominant gender-stereotypical behavior. On the other, the fact that Yunus includes these assumptions shows that his study, which links femininity to fibromyalgia, operates within this dominant framework, thus giving it further credibility.

Yunus ends the section on sociocultural factors of the gender dimension of fibromyalgia with his reference to research that found that women "catastrophize" accounts of pain (132). In many accounts of patients themselves who write of their experience with unexplained illness in the encounter with healthcare professionals, they refer to the thin line on which they have to balance in order to have their symptoms taken seriously.[46] This suggests that the negative stereotype of "catastrophizing women" could well have a catastrophizing effect: of women having to exaggerate their symptoms even to be taken seriously at all. On top of these stereotypes, Yunus' refusal to distinguish sex and gender results in the implicit maintenance of a heterosexual norm. Further referencing gender stereotypes in the context of socio-cultural factors without taking the social and cultural influence on these stereotypes into account results in the reinforcement of gendered stereotypes, such as the catastrophizing woman.

The psychological factors of the gender differences in fibromyalgia and related syndromes are described in terms of statistics. Yunus states that "recent studies have demonstrated that gender is a risk factor for psychological distress." This risk factor is

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[46] See, for example, Prescod 2021: 126; Ramey 2020: 10; Hirsch 2018: 123; O'Rourke 2022: 62; Dusenbery 2018: 62-63; Khakpour 2018: 21.

attributed, amongst other reasons, because "women endorsed more psychosomatic symptoms than men and reported greater dys-function in daily life" (132). "Psychosomatic symptoms" is a term used to refer to physical symptoms without identifiable organic markers that have a presumably mental cause.[47] There is a particular logic at work here that I want to unpack because it presents a prime example of a normative account of science: one based on a "model man" and one that produces the subject that it describes.

The stated risk factor is supported by statistical proof that shows that women present more psychosomatic symptoms than men. Thus, while the causes for the gender disparity remain unclear and are looked at through different (biological, psychological, and sociocultural) lenses, Yunus suggests that gender – in this case, being a cis-gendered woman – is in itself a risk factor for the experience of symptoms labeled psychosomatic. While, in a sense, attributing this risk factor might be seen as a way to show that these women constitute a vulnerable group, what this article does instead is link a particular view of femininity to a type of illness that is already at risk of stigmatization on the basis of poorly known etiology. Fibromyalgia becomes a condition that coincides with a lesser version of the "objective real." Fibromyalgia patients become dramatizing and catastrophizing women. Yunus makes this link without further reflecting on the vulnerable position that women are thus placed in while continuing to build on gendered stereotypes, such as the heterosexual active man and the catastrophizing woman.

The risk-factor statement is based on existing research that consisted in the analysis of statistical data published between 1990 and 1999. Yunus does not provide a direct source for his claim but gives examples by referring to four different studies in the remainder of the paragraph in which he makes this statement. The studies that Yunus refers to were not related to fibromyalgia specifically but to general psychological distress, found more in women. The statistical data were mainly acquired via research questionnaires. These questionnaires were used in order to evaluate behavioral avoidance in headache sufferers (Lacroix and Barbaree 1990), gender differences in psychological symptoms (Gilbar et al. 1998), or the impact of gender on the appraisal of pain and coping

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[47] See my extensive discussion of the psychosomatic concept in Chapter Four, especially section 4.2.

strategies (Unruh et al. 1999). Of these three studies that Yunus mentions, only the study by Unruh et al. explicitly mentions sex-gender differences.[48]

Yunus' refusal to distinguish between sex and gender, mentioned at the start of the article, is based on the belief that it would be too difficult to account for this difference in research into particular illnesses. This decision results in the reinforcement of a cis-gendered norm. Two of the four studies on which the conclusion is based do not separate sex and gender.[49] The statistical data that Yunus refers to includes gendered information alongside a binary logic and a cis-gendered norm, where the term "women," who are at risk, is used as a trans-exclusionary term referring only to cisgender biological females. While this in itself does not directly translate into a negative stereotype of this limited use of the term "woman," not being explicit about this difference risks essentializing notions of femininity based on biological features, equating female sex with certain types of characteristics. Contrary to this line of reasoning, I contend that the prevalence of unexplained illness must be seen exactly the other way around: having a particular class of symptoms is a high-risk factor for being feminized in a male-dominated medical science.

According to Kristin Barker, the feminization of fibromyalgia includes cultural stereotypes about women's "emotionality and irrationality" (2011: 833). For Barker, the vagueness of the fibromyalgia diagnosis and the "nagging question about whether fibromyalgia is "real" (i.e., has organic biological origins)" intersects with these stereotypes. Barker states that "consequently, for millions of women, living with fibromyalgia requires managing a constellation of chronic symptoms while coping with medical and public skepticism" (833-834). This context means that the attribution of the female risk factor and the inclusion of normative gendered notions does not stand on its own but must be viewed critically in what it does in relation to the subject that it describes.

Yunus' article presents an overview of research based on inductive statistics: empirical research that is an evidence-based method within medical science. Within

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[48] The studies by Lacroix and Barbaree (1990) and Gilbar et al. (1998) do not mention a distinction between sex and gender. Unruh et al. state that they focused on gender to include a broader and more complex framework that includes a psychological, sociological and political framework that is relevant for their research. See Unruh et al. 1999: n.pag.

[49] I was able to review three of the four studies mentioned by Yunus: Lacroix and Barbaree 1990; Gilbar et al 1998; Unruh et al. 1999. For Yunus reference to and use of the studies see 2001: 132.

evidence-based science, the subjective observer involved in producing the data forms a risk. A subjective observer is not able to account for all cases. This risk is often compensated for by only drawing conclusions in terms of statistical significance and probability. The above example demonstrated how inductive statistics includes normative standards based on a “model man.” The “high risk” attributed by Yunus follows from an objectivizing approach that does not account for the researcher’s position in relation to the object of research. This objectivizing approach does not make the subjective, implicit normativity that hides in the organization and collection of the research data explicit. Furthermore, such an objectivizing approach cannot and does not strive to account for how it is an agent in the construction of a particular subject. In this case, Yunus’ use of a limited set of data constructs a gendered subject as someone who is at higher risk of psychological distress and experiencing psychosomatic symptoms. It produces particular types: a feminized version of fibromyalgia and a dramatizing, feminized fibromyalgia patient.

On a larger scale, this example calls into question what counts as medical evidence and what does not. The present-day golden standard of evidence-based medicine, based on randomized controlled trials (RCTs), is discussed by Malterud et al. as having a limited effect on the types of knowledge produced (2004). It limits the type of questions that can be asked and considers any clinical strategy that has not been proven invalid. The authors, who are medical practitioners themselves, point out that this significantly limits knowledge of relationships in clinical practice because they are especially difficult to control, manage, and reproduce in a clinical setting (12). Relationality is not easily accounted for in the framework of evidence-based medicine, thus limiting the possibility of taking experience (patients’ experience of their symptoms or practitioners’ in terms of their earlier encounters with similar symptoms) into account.

A counterpoint to evidence-based medicine is experience-based or patient-centered medicine. Such an approach would potentially be more able to draw from a wider area of factors during the clinical encounter, such as the patients’ knowledge of their symptoms and power dynamics within the medical examination. When viewed on their own, both evidence-based medicine and experience-based medicine have their limitations, leaving patients within an experience-based approach potentially more vulnerable to the whims of the practitioner. However, Malterud et al. point out that the significant privilege of evidence-based medicine today means that it has become more unlikely that cultural preferences hiding in the data are recognized and reflected upon, whereas that is more likely done within an experience-based, patient-centered medicine in which the potentiality of biases is addressed much more upfront (13).

Evidence-based medicine should not be quickly supplanted by a solely patient-centered approach but should, like its staged counterpart, also reflect on its biases and limitations. A famous and striking result of these limitations in relation to sex differences is the failure to include female patients in research on heart failure. Cardiovascular disease has been considered a problem mainly affecting male patients, thus leading to a poor representation of female patients from randomized control trials and poorer knowledge of the presentation of cardiovascular disease in female patients. Results have been translated to female patients without “specific consideration or correction” (Deidda et al. 2017: 156), while cardiovascular disease presents so differently in females that it can be seen, according to Malterud et al., as “almost a different disease.” This can result in dangerous situations where physicians do not recognize the disease in time (Malterud et al. 2004: 14). Here, being a woman indeed presents a risk factor for heart failure, not in terms of etiology, but based on a poor inclusion of women within evidence-based medicine that is based on a model man.

2.2.3 Case, Care, and the Individual

Having zoomed in on Yunus’ study in relation to gendered stereotypes and conventions within a broader range of evidence-based medicine based on statistics, I will now continue on the particularity of its opposite mode of knowledge division, that is, knowledge production from a specific case. The difference between inductive statistics and a case study is that the latter zooms in on a particular situation more closely. The case study, therefore, involves a different inductive movement. Instead of analyzing a set of data and inducing a careful generalization, the case-study analysis moves from the individual case to generalized knowledge based on individual characteristics. The complicated use of the case study for science poses different questions on the use, appropriation, and interpretation (read: the knowledge production) of the singular in reference to the universal or the general rule.

In 2007, *Critical Inquiry* dedicated a special issue to these questions, called “On the Case.” In the introduction to the issue, entitled “What Does it Matter Who One Is?” the co-editor Lauren Berlant states that the case is a “problem-event that has animated some kind of judgment.” Berlant follows by laying out the questionable uses for case studies in different disciplines, most notoriously law, medicine, and psychiatry. The formation of these disciplines was historically based on case studies, where the case study was not only formative for the discipline but vice versa; case study subjects become subordinate to disciplinary power. For Berlant, the case study becomes the “primary machinery for making individuals into normative social units” (2007: 664-665). The case not only takes from individual situations but also becomes the basis for measuring those situations. In Berlant’s words, in their article “On The Case,” “the marked subject is a walking exemplar” (2007: 666).

This “exemplar” or example, into which the individual situation is transformed, therefore, functions as a bearer of meaning beyond the individual situation alone. Exemplars are the standards used in textbooks. They are the examples used to train someone new to a discipline (Forrester 2016: 7). One of the most sustained critical discussions of the functional form of the example and its relation to biopolitics can be found in Giorgio Agamben’s *The Signature of All Things* (2009), which combines three essays on method. In the first essay, Agamben discusses the conceptual figure of the paradigm (with reference to Foucault and Kuhn) and the paradoxical type of movement that defines it. Where induction moves from the particular to the universal to produce knowledge, and deduction from the universal to the particular, the paradigm “intervenes in dichotomies of logic” (Agamben 2009: 20) and works by way of analogy, that is, it moves from the particular to the particular. This “peculiar form of knowledge,” in Agamben’s formulation, thus calls into question the dichotomy between the particular and the universal. In a way comparable to how Agamben connects the paradigm to the Foucaultian *Epistèmè*, I want to see how the case, which dwells on a similar plane of interconnected particularities, can be examined according to the logic of analogy.

Through what Agamben calls “paradigmatic exhibition,” the normal use of a thing is suspended. He explains this by way of the linguist, who, in order to explain the class of performatives, utters the example “I swear.” Insofar as the listener is aware that the linguist is giving an example, the listener knows that the linguist did not “really” swear an oath. “To be capable of acting as an example, the syntagma must be suspended from its normal function, and nevertheless it is precisely by virtue of this nonfunctioning and suspension that it can show how the syntagma works and can allow the rule to be stated” (2009: 24). Where Agamben’s notion of the example (which suspends) works to explain something about the nature of the paradigm, unexplained illness presents a different formula. Here, the cases that remain unexplained do not simply perform knowledge production by linking the particular to a general rule, but rather acquire their case status by falling precisely between these two. They occupy a liminal space such as was characterized by Doris Bachmann-Medick: a “fragile intermediary existence outside social structures” (2016: 82).

Such cases are not cases of a rule but of an exception. They repeat a situation of suspension: not only by their exemplary function, but doubly so, as falling short of a rule that would, for other cases, at least provide some kind of safe comfort by means of an adequate, or accepted diagnosis. In the DSM-test case, the internist sends for the psychiatrist since the general rule for unexplained symptoms is that there is no physical explanation. The patient is thus confined to what in Western (bio)medical thought remains abstract: the workings of the mind. Thus, unexplained illness is created as a new category, called somatization, which connotes an exception that comes to carry its own markers and explanations.

The question arises as to why some situations are turned into cases and how they become examples. It is at this point that Berlant’s discussion of the case is especially helpful:

> […] to ask the question of what makes something a case, and not a merely gestural instance, illustration, or example, is to query the adequacy of an object to bear the weight of an explanation worthy of attending to and taking a lesson from; the case is actuarial. It raises questions of precedent and futurity, of canons of contextualization, of narrative elucidation. This is what’s disciplinary about the normativity of caseness. Its operations are ethical, referencing the vicissitudes of conventionality, of what kind of thing, event, or person has come to be associated with what kind of exemplarity. (2007: 666)

Berlant calls to question the methodological and epistemological problems with the weight of an explanation and its disciplinary function, adding politics to it: the strategic choices of associating certain things with a certain exemplarity. To again return to how the nameless woman who modeled for the DSM-test case functions as a case, two things are important. First, thinking with Berlant, it becomes apparent how the woman's story is constructed to bear the weight of an explanation and how her personal situation is made into a lesson for the discipline. This is to say, firstly: *The case extracts and appropriates*.

Second, Berlant notes the importance of attending to the question of what kind of event or person has come to be associated with what kind of exemplarity. This is where the different story elements come to matter. The case's protagonist is a divorcee; she is a single mom, unemployed, does not stay put, and lives in a hotel. Not only is her accountability taken from her and all agency removed by way of the suspension that follows her functioning as an example, but the inclusion of these unruly details also calls into question their importance. The question is whether these are the typical qualities of a patient with somatization disorder. Yet, adding them produces what Mieke Bal has called "the effect of the real,"[50] as a result of which, secondly: *The case works as an agent to construct normativity*.

Complementary to the extraction of – and normativity pertaining to – the subject that models for the medical case, unexplained illness adds complexity that affects care. Their unexplained nature defines medical case constructions of physical symptoms without physical explanations. The lack of care for patients is thus not only found in an absence of treatment but, on a more general level, in being relegated to the outside of the medical domain itself. The normativity of caseness that Berlant brings forward becomes only more problematic in the face of unexplained illness, as the structure of the medical case extracts agency from individual patients whose symptoms do not fit in a medical mold. My analysis of the model case for somatization shows how the woman at the center of it is absent. She has come to embody a certain kind of caseness and exposes at once the problem of it: she is not cared for.

While the case is the route that this chapter follows, care thus functions as a concept to discuss the effects of the nervous route on patients and the ways in which their symptoms are encountered within the medical system today. Focusing on care, which "remains ambivalent in significance and ontology" (Puig de Bellacasa 2017: 1) allows

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[50] Bal refers to the term (*l'effet de réel*) used by Roland Barthes, see Bal 1992: 559.

me to draw attention to the *effects* of becoming a case; the neglect of the individual and the process of knowledge construction.

The politics of care, or care as a form of work, has been addressed by feminist theories that point to the moral and normative structures that tied specific groups to the caretaker role: women, mothers, and people of color. Here, I refer to the body of essays written over more than thirty years by Silvia Federici on housework and women's struggles in relation to the domestic, as bundled in *Revolution at Point Zero* (2020) or Joan Tronto's *Moral Boundaries: A Political Argument for an Ethic of Care* (1993). More recently, Leah Lakshmi Piepzna-Samarasinha writes how it is the poor and the "working class disabled femmes" who are doing care work as a form of feminized and invisibilized labor (2018: 28). In describing the efforts of forming a care collective by and for disabled queer and trans people of color Piepzna-Samarasinha writes how

> All of us were eager to offer care; receiving care, not so much. It was so much easier to offer care to other people than to ask for what we needed, for so many reasons. Many of us had been raised as immigrants and/or women or femmes of color to always jump up and feed people first, do all the dishes, and help without being asked, while serving ourselves last. (24)

To care, or the role of caring for people, as Piepzna-Samarasinha shows, has been unevenly distributed alongside roles divided across gender, race, and class. Care has historically been attributed little economic value, although, as Federici has shown, care has been the motor and the invisibilized labor that keeps the capitalist system going.[51] The people whom Piepzna-Samarasinha describes jumping up first are those people who have historically embodied the role of carer. Piepzna-Samarasinha describes how especially challenging it is for this group of people to ask for care themselves, a difficulty which the lack of legitimization that follows from unexplained illness only adds to.

The politics of care, or the reimagining of the role of very practical and hands-on care in present-day neoliberal societies, has received a wave of critical attention in recent years (Piepzna Samarasinha; Puig de Bellacasa), acquiring new urgency around the COVID-19 pandemic which exposed the undermining of care and care work (Chatzidakis et al. 2020: 13). The care webs that Piepzna-Samarasinha writes about

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[51] See Federici 2020; Hedva 2022a; Eales and Peers 2021.

function as important self-organized networks founded in sick, queer and trans people of color communities. These care collectives can be a survival strategy in a place where the state refuses to fund attendant care. Care then becomes a "site of community and political organizing" (Piepzna-Samarasinha 2018: 21). This relationality of care is also worked with in Puig de Bellacasa's monograph *Matters of Care*, in which care is addressed as a web in the ontological sense of an interdependency in which humans and non-humans live "in spite of the aversion to "dependency" in modern industrialized societies that still give prime value to individual agency" (2017: 4). Care implies a relation and is, as a concept, both explicitly hands-on as well as integral part of the sustainment of relationality itself.

While these aspects of care are mobilized to forward the political aims of crip theory and disability justice, there is also a darker side to care. Not only can care be denied, devalued, and underfunded, but it can also mean control. Lindsay Eales and Danielle Peers write how care is a "dirty word" in disability, queer activist communities and is often used euphemistically to refer "to precisely those unpleasant, embarrassing, or violent arrangements where (the best versions of) care rarely flourishes" (2021: 170). Such care takes the shape of a relationship in which the caregiver controls what care looks like, often without considering the expressed desires of disabled and ill people. Piepzna-Samarasinha writes how sick and disabled people are told that their care needs "are a pain in the ass and a burden – to the economy, the state, our families" (2018: 17). Accepting care can mean being declared incompetent, and it sometimes includes "accepting queerphobia, transphobia, fatphobia or sexphobia from our care attendants" (2018: 19). This kind of care, which does not attend to its subject but is practiced as something empty soon to be filled with already existing normative structures, is what I presently aim to deconstruct as well as avoid in this chapter.

The politics of care are inextricably bound to the problematics of care for unexplained illness. The lack of biomedical explanation further complicates the access to care, which is already limited for marginalized groups. To address this difficulty, my interest in care in this chapter moves towards method: of care, in the words of Maria Puig de Bellacasa, as a form of *thinking-with* (Puig de Bellacasa 2017: 71). As a relational way of thinking, care involves an approach that tries to resist forms of labelling that often go hand in hand with knowledge production. This means, concretely, to stay attuned to the particularities of the subject of care, or the person at the center of it.

The question then becomes how to find such persons and how to care for them. *Critical Inquiry* dedicated a second issue to questions around the case, which was titled “Missing Persons” and which focuses on the “person” as the substance of caseness (Berlant 2007). In the introduction to the issue, Berlant focuses on the person, the idea of a person, a kind of person, or a norm of personhood at the center of the case. Berlant’s central question is what happens when a different model of a person is used for the conventional way of describing something. Would this result in a radical difference in what the case produces or, as Berlant questions, “just a slight perturbation?” (2007: 2). These questions relate to the subjects that knowledge is organized around and to the archives that are used to describe and understand particular events. Berlant also mentions the possibility that the person “we expect to encounter was *never* there” (2007: 3). This possibility refers to the notion of a person being constructed in the making of the case but who is themselves missing and made invisible through its construction. To what extent is the case subject always a fiction? Is their story reframed and extracted from its particularities?

Going any further would lead to questions of authentic personhood or what counts as true accounts of self-narration. Instead, my discussion of the person as the substance of caseness aims to steer attention to the production of the subject. I focus on this process of subject formation instead of on notions of “authenticity” or simple “narration” as such. Berlant notes how “the instance that becomes a case of *x* is an event that verifies something in a system: a symptom is named, an occurrence is adjudicated, or a cluster of activities or objects are reframed, solidified and transformed through explanation” (2007: 1). Going back to the case of unexplained illness, the model case of somatization verifies that symptoms which cannot be explained physically can be seen as bodily manifestations of mental distress. The test case also correlates the characteristics of the woman’s gender, joblessness, homelessness, divorced status, and position as a single mom to somatization, casting them as the markers of unexplainability.

While the woman who makes up the test case is directly quoted, the reader of the case is given information on what the woman herself supposedly expressed to her doctors: calling her attacks seizures and stating that sex never turned her on. The verity of the seizures for medical doctors reviewing them is questioned by marking the statement with quotation marks. In one claim that is directly quoted and that concerns sexual activity, the quotation marks work to show that this woman herself dismisses sex as such, giving the impression that she has a voice in the story. However, the case description allows no space for an encounter between the woman and the reader of the case. The reader is given no name to identify this woman but is merely presented with a list of characteristics associated with somatization disorder – that is, in the case that the test case is completed successfully. At the heart of this case exists a missing person. A person who functions as an example in the sense that Agamben has described it: being suspended by way of their functioning as an example and dwelling in a liminal space.

In the next section, I pick up on the particular type of absence of the person who remains at the case's center. This next case stars another woman who lived almost precisely a hundred years earlier. Both women became model cases of conditions not easily understood in their time. While they expressed physical symptoms, these were understood as an expression of mental states or their gender or social status and non-conformity. The DSM-test case involved a case vignette, a short textual description produced within a specific discipline to perform the function of training diagnoses. The case I will consider next is made up of so many different layers that the woman originally standing at its base is smothered by a different kind of case production machinery. This case, which concerns nineteenth-century views on hysteria, also proved constructive of cases to come: the history of hysteria shaped understandings of unexplained illness to such an extent that it formed into a nervous route of unexplained illness.

Moving to the next case, I thus discuss both the problematic history of hysteria and the way in which this history continues to linger in the nervous route that I describe in this chapter: one that molds patients' stories, transforming particularity into deviation along stereotypes that are already present and are largely informed by the history of hysteria.

2.3 Seeing, Writing Hysteria

The image of the painting is well known; lesser known is the size and original in its full 2,9 by 4,3 meters. The painting has been reproduced many times. It depicts 31 people, of whom 28 are men, dressed in black, looking at one woman, painted on the right. She is held by someone as she leans back, unconscious, in the arms of the man looking down on her. Light falls on her chest, and her loose corset and low neckline reveal her shoulders. Two other women are painted on her right, one of whom the viewer is only given a face within the frame of the picture. She also looks at the woman at center stage. The other, who is dressed in what seems to be a nurse's clothing, holds out the woman's hands as though to help her. A man on her left is the only one whose eyes are directed elsewhere. He points his finger. Calm as he stands there, he seems to be explaining something. The gazes on the painting seem to be directed at them both: the woman painted in the bright light and the man pointing his finger. Coming from the window, the light shines on her chest and reflects into the room. Her eyelids seem to have closed, only a hint of them is discernable, slightly open and directed towards the viewer who knows her to be the object of the man's speech.

Contrary to the anonymized woman in the *Case Book* that accompanied the DSM, the name of the woman immortalized in this painting is known. The painting is titled *Une Leçon Clinique à la Salpêtrière*, painted by Pierre Brouillet in 1887, and currently belongs to the Université Paris Descartes in Paris, where it is located near the entrance to the Musée d'histoire de la Médecine. The woman painted here is known as Blanche Wittmann, and at the moment, as depicted in the painting, she had been hypnotized by the man painted on her left, the one pointing his finger. His name is Jean-Martin Charcot, and he is shown while teaching a lesson at the Salpêtrière, a Paris hospital where he was conducting research on hysterics. The discussion of the DSM *Case Book* pointed out that somatization disorder, of which I reviewed the test case, was "previously referred to as hysteria, or Briquet's syndrome" (Spitzer and the APA 1981: 262). In the nineteenth century, hysteria, the condition Blanche Wittmann was diagnosed with, was a condition of the "nervous system" that mainly afflicted women. Both Wittmann and the anonymous woman became model cases for medical diagnosis.

It was not only the painting that made Blanche Wittmann famous. During her confinement at the Salpêtrière, Charcot's patients performed hysterical attacks for a large audience of male students. These performances were not limited to the Tuesday lectures at the Salpêtrière or other public demonstrations but also stretched the performance of symptoms to inside the hospital, where the women were kept and studied. Outside the hospital, Wittmann became a "star hysteric" and was featured in newspaper columns, magazine articles, plays, and novels (Hustvedt 2012: 49; Stephenson 2001: 27). Georges Didi-Huberman points out how the exhibition of the hysteric shows an "extraordinary complicity between patient and doctors." Their relationship was theatricalized and, in Didi-Huberman's words, one of "desires, gazes and knowledge" (2003 [1982]: xi). These psychiatric theatrics are what the painting emblematically depicts. The performative or theatric nature of hysteria in the nineteenth century, particularly in its guise at the Salpêtrière under Charcot, has attracted ample critical attention in the last decades of the twentieth century, among others by Didi-Huberman, Ulrich Baer, Felicia McCarren, and more recently by Jonathan Marshall and in an edited volume by Johanna Braun.[52]

Being emblematic, the painting was often reproduced, on postcards, book covers, and illustrations of publications discussing nineteenth-century hysteria.[53] However, the apparent subject of the painting, Blanche Wittmann, is strangely hard to pin down. Looking at her, at the center of the show, and as she attracts attention, one cannot fail to notice that she is not fully present, in a sense other than her being unconscious. Why is her neckline so low, or what is on display here? Her painted presence shows the performative qualities of the illness. The painting represents the Tuesday lectures at the Salpetriere and the extreme visibility and presence of a "star hysteric." But what it presents is an absence at the center: an absence at the place where the viewer apparently

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[52] For an analysis of the interplay between and the performative character of photography at the Salpêtrière, see Didi-Huberman (2003 [1982]), but also Ulrich Baer (1994). Felicia McCarren has focused on dance and hysteria and emphasizes the effects of Charcot's medical gaze that measured the body's movement at the Salpêtrière (1995). More recent work by Jonathan Marshall has focused on Charcot's neurology, specifically through a theatrical lens (2016). The edited volume by Johanna Braun *Performing Hysteria: Contemporary Images and Imaginations of Hysteria*, highlights how the rebranding of hysteria in psychiatry to histrionic personality disorder "diagnoses the hysteric as a performer" (2020: 12) and traces historical performance practices in what the volume names as contemporary "'hysterical' discussions" such as "migration hysteria," "Trump-" or "Anti-Trump hysteria" but also "trans-bathroom hysteria," "Black Lives Matter hysteria," and "COVID-19 hysteria," to name a few (2020: 11).

[53] Forbes Morlock (2007) explores the image in relation to (re)production: the production of knowledge, reproduction of the image in various forms, such as postcards, and hysteria's links to reproduction.

sees a woman. At the same time as it shows a painted woman, a patient, a "star hysteric," and a model case, the painting hides from view its own complicity in the complete and utter disappearance of the subjectivity of this woman. She has never been important and has only ever appeared as a case. The real subject of the painting is a look, a look that becomes a medical gaze that constructs a subject who appears as a star hysteric.

Patients like Wittmann did not have much to say about their treatment or how they were represented. In an essay titled "The Hysteric's Discourse," Gérard Wajcman states: "if hysteria is a set of statements about the hysteric, then the hysteric is what eludes those statements, escapes this knowledge" (2003: n. pag.). A particular focus of the twentieth-century scholarly attention to the nineteenth-century construction of the hysteric was precisely this complicity between patients and doctors described by Didi-Huberman, where the knowledge constructed went hand in hand with their patients' manifestation of strange physical symptoms. These patients continue to embody a liminal form of presence. The presence of a body that performs, a body that is exposed, and of a body on which power is exerted. Like the woman who features in the DSM-test case, or the character of "Carol" in *Safe* analyzed in Chapter One, the patients themselves are at the center of attention, yet appear as voids to be filled by the environment in which they gain shape. The historical construct of hysteria is not only a paradigmatic reference point for the position of women in medicine but also exposes how knowledge, case-construction, and the removal of the patient's agency work together to produce a particular type or figure.

According to her case history, published in *Iconographie Photographique de la Salpêtrière vol.3* (1879-1880 hereafter *Iconographie*), Wittmann was "admitted" to the Salpêtrière on May 6th, 1877, then eighteen years old. The *Iconographie* is a three-volume book produced by Jean-Martin Charcot and his staff as a description of the cases and treatments at the Salpêtrière. It is most famous for being illustrated with many photographs of the women confined there. As Daphne de Marneffe notes, the emphasis that was placed by Charcot on the photographs as "proof" of hysteria as illness is striking since photography, at first glance, seems "so comparatively ill-equipped to capture the subjective information conveyed by their words" (1991: 71). However, photography was more than just a new and exciting medium. For Charcot – who embraced it as a way of documenting the various induced poses by the hysterics and hired professional photographers to document them – it had a greater meaning.

In a famous quote by Freud from an obituary to Charcot, whom he studied with and greatly admired, Freud writes about Charcot that he "was not a reflective man, not a thinker: he had the nature of an artist he was, as he himself said, a 'visuel,' a man who sees." A few sentences later, Freud describes how Charcot was troubled about what it is to study.

> He used to look again and again at the things he did not understand, to deepen his impression of them day by day, till suddenly an understanding of them dawned on him. In his mind's eye the apparent chaos presented by the continual repetition of the same symptoms then gave way to order: the new nosological pictures emerged, characterized by the constant combination of certain groups of symptoms. (1962 [1893-1899]: 12)

The classification of disease is explicitly described by Freud here as taking place in the "mind's eye" of the *visuel*. At the same time, Freud described how Charcot struggled with the possibility of seeing "new things" in the order of things that he himself ascribed to them:

> He might be heard to say that the greatest satisfaction a man could have was to see something new – that is, to recognize it as new; and he remarked again and again on the difficulty and value of this kind of 'seeing.' He would ask why it was that in medicine people only see what they have already learned to see. He would say that it was wonderful how one was suddenly able to see new things – new states of illness – which must probably be as old as the human race; and that he had to confess to himself that he now saw a number of things which he had overlooked for thirty years in his hospital wards. (1962 [1893-1899]: 12-13)

It seems that Freud's characterization of Charcot as a *visuel* lies not in Charcot's visual methods but in his determination to *see*. Seeing is to perceive visually, but also to understand, to experience, or to witness. Looking at something, as Charcot did "again and again" he brought his attention towards something until it became visible: until he *saw*, as a *visuel*. Looking at the repetition of symptoms, he was not satisfied to understand them in ways already given. Instead, he looked to see something new. In Felicia McCarren's description of Charcot's method, she describes this *seeing* as the first step to understanding (1995: 769). Seeing thus required the special insight of the "mind's eye" to recognize what the combinations of symptoms added up to.

Charcot himself devoted a more direct, yet not less ambiguous statement to what it is to see, as he described the photographic medium, used by him as an instrument of proof, as nothing less than his very methodology. He saw no difference between his actions and that of a photograph: "I inscribe what I see."[54] While this "methodology" is in itself questionable in all its purported neutrality, I want to briefly stay with this method of inscription.

Making a brief detour in the next subsection, I move to discuss the historical patient known as "Blanche" in more detail. I do so to, first, more firmly demonstrate how this patient appears as a construction; second, to emphasize how this construction has material consequences, in the form of it literally being inscribed on a body; and third, to explicate the dangers of constructing cases as such. Making this detour, I work towards the definition of a method of care. This method is driven by my definition of the nervous route of the case as one that transforms subjects into something else, and it ultimately aims to practice a form of theory that is responsive to that which is theorized.

2.3.1 Blanche, Inscribed

Upon arrival at the Salpêtrière, "Blanche Wittmann" does not yet exist. The woman I have been referring to is listed in the *Iconographie* as "W…. Marie," who is referred to as "W" for Wittmann throughout her case history (1879-1880: 5). Information from her life before she arrived at the Salpêtrière has been recorded by her doctors. The woman who came to be known as "Blanche" was the oldest child of a Parisian working-class family. Her father was an unemployed Swiss carpenter and a violent man who, for example, according to the available information, attempted to throw his oldest daughter out of the window (Hustvedt 2012: 39) and, strangely, had once put her in a coffin alive (Alvarado 2009: 25). Later, Wittmann's father ended up at the Sainte-Anne asylum for the insane

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[54] The original quote by Charcot from "L'Hystérie Féminine" in *L'Hystérie: Textes Choisis* reads: "Mais à la vérité, je ne suis absolument là que le photographe; j'inscris ce que je vois." (qtd. In Baer 1994: 48, note 32). In English language academic work the "j'inscris" in this quote is translated as "to inscribe" by Ulrich Baer (1994: 48), "to describe" by McCarren (1995: 768) or – as the perhaps more neutral – "to register."

where he was institutionalized (Hustvedt 2012: 39; Alvarado 2009: 25). Her mother worked as a laundress, which was, according to Asti Hustvedt's research into the lives of the women confined at the Salpêtrière published as *Medical Muses*, "one of the lowest-paid and least-respected jobs available at the time" (2012: 38), working fifteen to eighteen hours a day (2012: 40).

Wittmann experienced convulsions from a very young age, and at times was unable to walk or speak (Alvarado 2009: 25). Five of her eight siblings died, one of them having had possible epilepsy (Hustvedt 2012: 38; Alvarado 2009: 25). A surviving younger sister was described to suffer from "weaknesses" (Hustvedt 2012: 40). When Wittmann was around fourteen years old she worked and lived with a furrier who sexually harassed her. Here Wittmann suffered from more tremors and convulsions. Eventually, after more unhappy sexual experiences and violence, she ended up as a ward girl at the Salpêtrière, a job which Hustvedt describes as a last resort for poor women at the time and which held horrendous working conditions (2012: 40-41). During one of her attacks, having convulsions at the job, she was admitted at the Salpêtrière as a patient (Hustvedt 2012: 42). According to Hustvedt, the dire conditions under which Wittmann ended up at the Salpêtrière were no exception: the institution "functioned as a warehouse for the women Paris no longer wanted" (Hustvedt 2012: 38).

The first time the case history in the *Iconographie* mentions the name "Blanche" is in a description of a *Periode dé Délire* at 14 may 1877, eight days into her stay at the Salpêtrière. Her case history in the *Iconographie* quotes her directly:

> More frequent breathing; dilated pupils; small moans; lip movement; the patient speaks low without being heard at first, then she cries "Blanche! Blanche!" (that is the name of her sister) "Ah! they have fallen! Blanche! Blanche!" She comes back to herself; with a surprised look "So I was ill" She complaints of a headache, blurry sight and of being tired. (1879-1880: 8)[55]

Contrary to the quoting style in the DSM case book, the quotations in the *Iconographie* make it clear that her voice is not used to make up a story, but that her utterances,

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[55] Translation from the French original by the author. The quotation marks belong to the French original. The original reads: "Respiration plus fréquente ; pupilles dilates; petites plaints ; mouvements des lèvres ; la malade parle bas, sans qu'on l'entende d'abord ; puis, elle appelle : « Blanche !... Blanche ! » (C'est le nom de sa sœur). « Ah! Ils sont tombés! Blanche!... Blanche!... » Elle revient à elle ' regarde d'un air étonné : « J'étais donc malade… » Elle se plaint d'avoir mal à la tête, la vue embrouillée et d'être fatiguée."

movements and gestures are eagerly studied by the hospital staff. Where the previously cited *Case Book* reads as an Agatha Christie novel, by contrast, the *Iconographie* reads more like exquisite gothic horror.

Hustvedt writes that Wittmann had many siblings, of whom the only living one at the time was named Suzanne (2012: 43). For Hustvedt it remains unclear why Marie came to be known as Blanche. As the *Iconographie* also makes no mention of it apart from the quote above, Hustvedt notes how it is hard to resist the temptation to read more meaning into the name than the *Iconographie* provides. Blanche, whose translation is "too appropriate to have been merely fortuitous" according to Hustvedt, translates as "white" or "blank": ready to receive any identity the doctors might give to her (Hustvedt 2012: 43). In this context, Hustvedt's reading of Wittmann's case history in the *Iconographie*, also recounts peculiar experiments done with the women at the hospital called "dermographism" in which words were inscribed on the women's bodies while they were sedated with chloroform after a hysterical attack.

In August 1878, fifteen months into Blanche's stay at the hospital, the *Iconographie* mentioned that her doctors used the point of a pen to trace the name of the patient on her skin (1879-1880: 19). Because of the extreme cutaneous sensitivity that sometimes occurred on the skin of hysterics, this tracing turns, as Hustvedt explains, into a sort of relief on the skin (2012: 55). The doctors at the Salpêtrière literally wrote the place of her confinement on her body, together with her name. It is not mentioned which name, that is, if it was written Blanche or Marie Wittmann. Hustvedt notes that "Blanche Wittmann, Salpêtrière" was written on her body (2012: 58), but the *Iconographie* only speaks of "le nom de la malade et sur le ventre, le mot Salpêtrière" (1879-1880: 19). Since the *Iconographie* also mentions "Marie" as her name upon entry, it is unclear which name was written on her, although the character inscribed, by the writing on her body, is one that came to be known as "Blanche."

The actual inscriptions can only be described and reconstructed, they can never be fully attained. Yet the fact that the *iconographie*, which was made as a document to portray the treatment of patients at the Salpêtrière, speaks of literal inscriptions of the name of the disease on patients is telling and adds to the performative element of hysteria that ruled under Charcot. Hustvedt traces the startling technique of dermographism and its use at the time and recounts other examples where a doctor inscribed his own name on a patient who was instructed to bleed from the letters so that his name remained visible for more than three months (2012: 57). The *Iconographie* itself does not mention bleeding, yet the horrid literacy of view the name of a disease on the patient places Charcot's saying, "I inscribe what I see" in a different context.

The "inscribing" of the doctors' view on their patients sometimes took place quite literally. Janet Beizer comments on the dermographic practices at the Salpêtrière. She states that any reading of the hysterical body is wholly produced and constructed by the physician, who used the body of the hysteric as a blank page on which he was free to write (1994: 24). With Blanche, the viewer looks at *a woman who has been written on*. It is not that Blanche herself is invisible. The viewer sees her quite clearly, as she is painted, photographed, and written of, again and again, in a light that is not her own. What the viewer looks at, with the woman on the painting, is not any blank page, but one so filled that it is unclear where to look at present.

It seems that writing on women cast as hysterics is doomed to reproduce a cycle of appropriation of some sort. Wittmann became a case among cases. So many has been written "on" her body, not only in the Salpêtrière but also in later scholarly work that addresses the conditions at the Salpêtrière and again mobilized her case. All this commentary has become part of what it is to discuss a medical case. This body of writing shows how a person is made into some kind of exemplar who appears as a liminal subject. In Wittmann's case, there was a heavy production machinery behind the construction of the model hysteric that is well-documented and well-studied. To address Wittmann within the context of what has been written on her is to address this machinery.

In other cases, in which the writings on the body are less literal, it seems less obvious how the case is produced. There is no big body of text on the anonymous woman of the DSM, for instance. Wittmann's story shows what it might look like if there had been. The task is then to find a way to approach the case that does not reproduce it by means of appropriation and to look for a form of care instead. This chapter locates this form of care in a careful methodology.

Before returning to care as a methodology in section 2.5, I first turn to define the problems of care for unexplained illness in a more practical present-day medical setting in section 2.4. In what follows, I provide a close reading of a video work by a contemporary artist and patient with chronic illness to question the risk of a lack of care in an institutionalized hospital setting. This shows the ways in which care can be absent. In this sense, I move towards a better understanding of how care for unexplained illness can be practiced and how a methodology of care can assist in overcoming care obstacles.

2.4 An Attempt at Care

In a videowork from 2019 titled "NOT BETTER YET," Black American artist Panteha Abareshi addresses the chronically sick body as it exists in US-American medical institutions. The work was shown at an exhibition called *Crip Time* at the MMK in Frankfurt between September 2021 and January 2022. The work is shot on video, super 8 mm color negative. This specific medium does more than carry the images but is also investigated as medium itself. As I will show, using it enables Abareshi to draw attention to the effects that (medical) documentation has on the person who is examined.

The video opens with an image of a flickering black and turquoise screen and electronic noise. The screen shows a black bar with a flickering square on the left side. The square is an effect of an 8 mm recording but is sometimes also added to digital recordings to create a vintage effect. The black bar and the square on the left remain visible for most of the work, which is 5.58 minutes long, only to disappear briefly in the middle. The work shows a body in the hospital setting, superimposed with text and images. This creates the impression that digital methods supplement the 8 mm film and that the square on the left is not only an effect of the analog recording but is deliberately shown. Abareshi emphasizes the analog recording as the frame through which the viewer sees that which is represented. When a body first appears on the screen, the viewer understands this to be a body that is looked at from a deliberately chosen perspective and knows that this act of looking is part of what is addressed.

Words appear on the flickering screen within the set frame. "Something is clearly wrong," they say. The words flicker and reappear while zoomed-in images of a Black body in white bandages appear (00.07). The viewer sees battered feet with what look like wounds on them, a wrist with a hospital tag wrapped around it, and legs covered in bandages. The zoomed-in images are filmed unsteadily, making the viewer aware of the camera's searching view. The images of the body parts are interspersed with moving particles that look like images of cells viewed under a microscope. The camera starts zooming out while the microscopic images partly overlap with the body. The viewer is now shown the body in full, lying in a fetal position, dressed only in white bandages and the face covered by a surgical mask. The words on the screen disappear and reappear in abbreviated versions: "clearly wrong" and "wrong," it now says (00.13). A hospital beep sounds, and the camera's view starts to hover over the body, which lies uncomfortably and alone in the sterile hospital room.

The image then returns to the turquoise screen of the opening shot. There is another hospital beep, and the viewer sees the same body in a different position. Text overlaps with the image. The text is shown in braille (presented on the screen so it cannot be read in relief) and in English subtitles for deaf people and people who are hard of hearing. The subtitles state that the "high pitched tone signals morse code S.O.S." The body is now shown in what is known as a child's pose: upper body folded forward over the legs, exposing the bare back. Slowly, a large red target appears over the image of the back. While the image on the screen flickers, the word "DISEASE" appears in its middle, all-caps, overlapping with the target shown on the exposed back.

Figure 1: Still from Abareshi, "NOT BETTER YET" (2019).

The work continues to present the body with superimposed images and text. The text states, "wrong," "disease," and "S.O.S," signaling a body that does not function properly according to medical norms. Hospital staff are heard talking in the background.

At the same time, the body is shown in different positions, presumably still alone in the hospital room but watched by the camera, measured by the instruments, and discussed by the voices in the background (01:36-2:08).

In the next scene, the mechanic drone grows louder, and the S.O.S pattern of the beep morphs into the sound of a heart rate monitor. Images alternate between the body and the microscopic particles. A beep sounds each time the image returns to the body, then shown in different contorted positions. The following scene is presented in slightly different lighting, now more clearly referencing the analog recording: the image flickers, the coloring is different, and a clicking sound is heard in the background, emphasizing its documentation on film. With every beep, a frame on the screen shows the body in a new position. Next, the sequence repeats but is shown from a different perspective, now filming the various positions from the right side, positioning the viewer at the body's feet. Like the analog recording that is accentuated by showing the square on the left, this repetition demonstrates that this work addresses how this body is looked at.

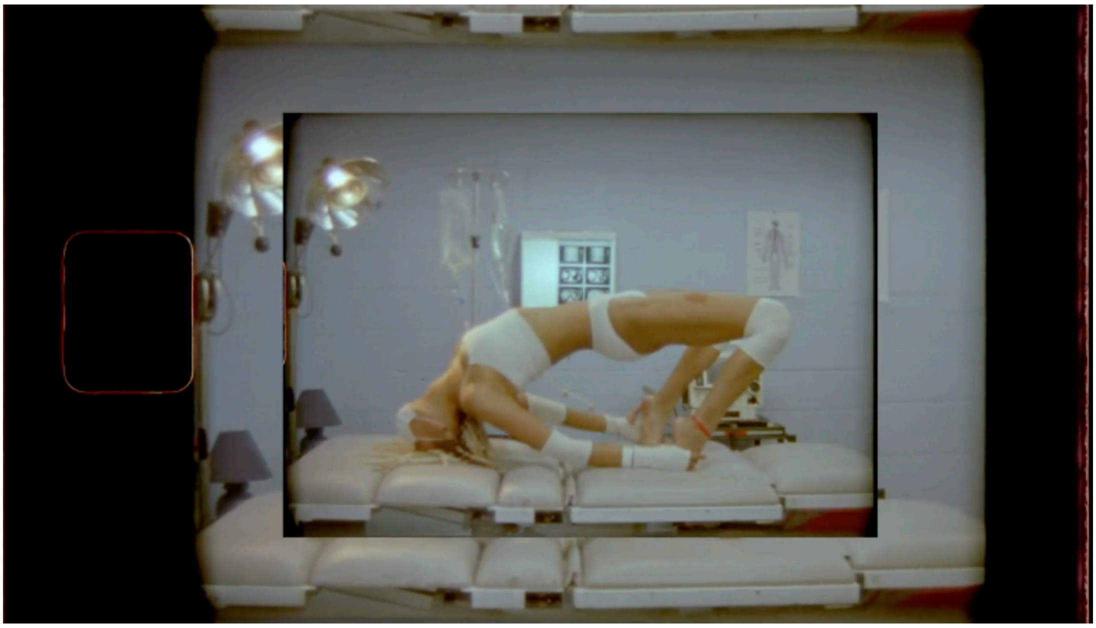

Figure 2: Still from Abareshi, "NOT BETTER YET" (2019).

The first of these positions that this body moves in in this series presents the inverted arch, a position also known as the Hysterical Arch, or *L'Arc hysterique*, first illustrated in 1885 by Paul Richer in *Études cliniques sur l'hystéro-épilepsie ou grand hystérie*. Richer's illustration is also visible on the wall in the background of the painting by Brouillet that immortalized Blanche Wittmann. The analog recording, the new positions that the body twists in every time a beep sounds, and the inverted arch all reference the photography of the women at the Salpêtrière and the practices whereby they were documented. The references invoke the troubled history of women diagnosed with hysteria, who were (often) not helped but studied and not cared for but confined in a hospital.

Abareshi's work presents a layer of frames through which the sick body emerges. The sequence from which the still shown in Figure 2 was taken freezes the body with each new position, as though in a photograph, establishing another link with the Salpêtrière. The frozen images create a pause that highlights the uncomfortable positions that this body twists itself in. The sequence shows that this body is uncomfortable and it underlines its strangeness. Even more so, the pauses in this sequence create frames within this image. These frames intensify the viewer's awareness that this body is looked at and that being looked at is what forces this body in these positions. The body is filmed, photographed, and layered with text and microscopic images, as though they contain some authority over this body. Like the women at the Salpêtrière, this body is documented, talked about, and measured. The body is center stage and the object of attention. I consistently refer to it as "the body" because both the person it might represent and the person who models for it are absent. Abareshi shows the frames and practices that centralize this body in an objectifying manner.

The viewer never gets to see the face of the body that is shown. The face is blocked by a blue rectangle (figure 3) or a surgical mask, or it is not shown because the body is filmed from a different angle. Thus, the work shows the body as an object of medical care in the institution of the hospital and presents this care as having an objectifying effect. The body is shown naked, apart from the bandages and white underwear that highlight their illness. It is devoid of any social cover and is shown all alone. The body twists and turns itself in contorted positions, as though to answer to some kind of call or fold itself into some mold. It is to no avail: the body is discharged by the hospital staff, who is heard to say they expect patient MRN 4187871 soon to be back. The work closes with a crossing out of the title's last word, leaving only "NOT BETTER" to remain (05.29). Ultimately, the illness is not solved and the patient is not better.

Figure 3: Still from Abareshi, "NOT BETTER YET" (2019).

There are obvious visual references to theoretical concepts. Abareshi plays with spectatorship, objectification of the body, and medical settings, as it exemplifies this objectification further by turning the body into a number. The body is not only looked at but the frames in which this looking happens are intensified and addressed. The opening image presenting a turquoise background with a black square is the first frame: the first image shown. The body appears later, within this frame that remains visible. The lingering of the frame makes explicit that this frame affects how this body is looked at. A new frame appears when the body twists into different poses, as though summoned to by someone, and the image is temporarily frozen (Figure 2). Furthermore, the instrumentalization of unsteady camera work represents a gaze that searches for its object. At the same time, this camera work presents the body to the viewer. This implies that it is a type of spectatorship that does the framing, a *medical gaze*, so to say.

Abareshi presents this gaze as one that practices control over the body, which consequently does not seem to move according to its own will. This gaze works to objectify the body within the medical setting. The microscopic images that are shown to overlap with the body and are visually merged with it, reference the biomedical gaze on the body. Overall, the work presents a body that is looked at and studied but not necessarily cared for.

The body that modelled for Abareshi's work is their own. Abareshi lives with a chronic illness known as sickle cell zero beta-thalassemia. It is a condition that is medically explained but chronic. It cannot be cured but can only be managed by avoiding complications and providing pain medication. Abareshi's condition has the privilege of being medically explained in terms of possessing an identifiable biomarker and is thus incorporated within the system of biomedical legitimization. Even so, Abareshi's work shows the effects of the objectification of medicine when it fails to provide medical care by which a disease is cured. It presents a separation between care in the form of a cure and care directed toward the person. Abareshi's condition causes debilitating pain and bodily deterioration, which increases with age. Connecting this personal experience to the representation of their own body in this work, I take Abareshi's work to be a reflection on what is left in terms of care in the case of chronic illness: an illness that cannot be cured within the US medical system and thus must be focused on the person who remains ill.

By presenting their own body in this setting, Abareshi goes further than just addressing their personal experience with healthcare. Referencing spectatorship and objectification, they confront the structural conditions that have shaped their experience with chronic illness. In an article accompanying their art, published in *The Massachusets Review*, they explicitly link their experience as a patient with chronic illness to experiences of marginalization.

> Being a chronically ill body has shaped my experience into one that is extremely, and highly isolating. The nuances of disability and chronic illness are lost on the average able-bodied individual, and the marginalization, erasure and violence that I have endured from it alone is devastating. In combination with my personal notions of gender, racial and sexual identity, I am fully immersed in otherness. (Abareshi 2022: 682)

Having experienced marginalization, "erasure," and violence in their own experiences with health care, Abareshi shows an isolated body that seems to find no comfort and is eventually dismissed without getting better. The use of the term "erasure" implies that they felt they had modeled in a system that erased the person it was supposed to care for. Even though Abareshi is cared for by nurses and doctors, the system in which this care is given shape is structured in such a way that Abareshi experiences it as isolating.

The difference between Abareshi's case and the women who were represented in the DSM-test case, in the painting by Brouillet, and the discourse around hysteria is that Abareshi uses their own body. They use their body as a vessel by which their representation in the US-medical system can become visible. They own their representation to form a critique on how the person who models for a medical case is produced by a medical system. This type of production is shown to happen through frames in which the body becomes apprehensible. Abareshi highlights the means of documentation that leave the body isolated and uncared for by explicitly showing the frames in which they are represented. These frames can be read as means of looking that are structured by gender, race, and sex, as mentioned by Abareshi themselves. Abareshi's body is confronted with a system that cannot cure their disease but nevertheless attempts to care for their body. Abareshi addresses this care as one that fails because of a way of looking that isolates a patient. A way of looking that frames them, makes them uncomfortable and dismisses them without being better.

Criticism of the isolation of the patient and the objectification of the body in Western medicine as something that stands in the way of a different vision of "good medical care" is not new. Abareshi's critique is related to a general political ideal that resists "the system" because it is unable to account for a diverse range of bodies. In a more general sense, this fits within the critique of "objectification, commodification and standardization," addressing the general effects of neo-liberalization, which in the particular setting of the hospital merged with a biomedical view of the body, leaving little attention to the individual patient and the particularity of their illness (Timmermans and Almeling 2009). In cases of unexplained illness, this lack of attention to the particular or individual patient creates a more pressing situation because it means that the experience of the patient cannot be matched with or explained within the general rule of biomedical explicability.

Abareshi's critique of the isolation of the medical gaze thus proves relevant when discussing the individual experience with unexplained illness. Yet it is also in danger of throwing the baby out with the bathwater when it presents "the" medical system as an adversary to the patient and thus incapable of individualized care. The specific difficulty of medical care in relation to *unexplained* illness is that the lack of biomarker denies care focused on the illness's physical aspect. In this case, it is not a generalized version of a "system" that fails to care for patients. The failure of care is due to a specific flaw located within this system that cannot accept unexplainedness and thus fails to account for the experience of illness without an identifiable biomarker. The unexplained status of their illness means that a layer of complexity is added. Their body is not only in danger of being objectified, but the risk is that their experience of illness is delegitimized as well.

This delegitimization can be further explained by considering the particular type of outsider position of the patient with unexplained illness by contrasting it to that of someone with a disability, as I do in the next section. Laying out the differences, I point to the centrality of epistemological exclusion of unexplained illness. The exclusion of unexplained illness is based on systems of knowledge that have practical use in the organization of medical care. As I will argue next, this considerably complicates the possibilities for the emancipation of unexplained illness.

2.4.1 Cripping Unexplained Illness

Disability is defined as dis-abled, or as the opposite of being abled. It is thus grounded in a concept of able-bodiedness, which the last decades of disability studies have addressed as a sociohistorical concept that can be analyzed. Disability studies, therefore, maintain a social model of disability, looking at disability as a social construction instead of a medical problem. The social exclusion of disability can be resisted on social and political terms.

The patient with unexplained illness, however, is excluded not only *by means of* but also *on the basis of* biomedical knowledge instead of social norms. Patients with unexplained illness are outsiders in reference to epistemological concepts and a system of biomedical explanation more than they are to a normative system of social making. They are up against a different system. Next to the social stigma of not conforming to an able-bodied or healthy norm, people with unexplained illness can also not count on at least having their experience of physical illness legitimized (albeit negatively). The type of case that the sick body becomes in an institutionalized version of medicine as it was drawn out by Abareshi – as a medical handling of a body that leaves it uncared for in the absence of cure – is thus intensified in cases of unexplained illness.

The difficulty of resisting the exclusion of unexplained illness in a political way can also be understood when looking at the type of affirmation of disability within disability studies and activism. The notion of disability as a social category has also exposed the politics of disability and allowed for a counter-movement of affirmation or the rise of disabled people advocating for their rights. This was already described in 1999 by prominent disability scholar Lennard Davis as a movement in which “Crips Strike Back.”[56] Academic attention to disability and growing disability activism have turned attention to disabled people as a minority within a capitalist system that values and idealizes able-bodied productivity and works to oppress people who do not live up to an able-bodied norm and a capitalist, arguably white notion of wellness.[57]

The activist, subversive politics of disability studies, such as in the work of Robert McRuer, Carrie Sandahl, Alison Kafer, or Eli Clare, have been collected under Crip Theory. Kafer writes how crip theory explicitly employs the harshness of the sound of *crip,* which includes a “desire to make people wince” and to “shake things up” (2013: 15). Clare writes how *cripple* makes him flinch: how it “too often accompanied the sticks and stones on [his] grade school playground.” Yet he writes that he loves the audacity of turning it into a word of pride and that this word, like queer, feels like his word, whereas *freak* does not. “[F]reak has a hurtful, scary edge, it takes *queer* and *cripple* one step too far; it doesn’t feel good or liberating” (2015: 83). He, too, refers to *crip* or *cripple* as a name to shock, “to infuse with pride and self-love,” to “resist internalized hatred” and to “help forge a politics” (2015: 84).

Although crip has etymological connotations which relate the term to being unable to walk and thus implies physical disability, it is employed widely as an explicitly inclusive and flexible term for people to identify with.[58] The reappropriation of crip is a liberating move against the hate and violence that has all too often been inflicted on

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[56] “Crips Strike Back” is the title of Davis’ article. See Davis 1999.

[57] This argument on disability in relation to capitalism was already made by Charlton (2000) in his seminal work on disability politics in 1998, which turned the phrase “Nothing About Us without Us” into a famous disability activist slogan. More recently, the link between disability oppression and capitalism in relation to a notion of wellness was described by Johanna Hedva in their “Sick Woman Theory” in which they argued that “‘wellness’ as it is talked about, and sold, in America today, is a White and wealthy idea.” According to Hedva, Whiteness allows for an “oblivious neutrality: it is the premise of blankness, the presumption of the universal” (2022a: n.pag.). See also Charlton 2000.

[58] There is discussion on the reach of the term crip, and on crip affiliation in general. Carrie Sandahl defines crip along the fluidity that is included in the notion of the queer, and includes not only people with physical impairments but “those with sensory or mental impairments as well.” Sandahl also leaves the possibility open for a nondisabled person to claim crip, similar to heterosexuals claiming queer. Robert McRuer builds on Sandahl’s work, weighing the solidarity of “coming out crip” against risks of appropriation following a nondisabled claim to crip. See Sandahl 2003: 27. See McRuer 2006: 34, 36-37. See also Kafer 2023: 16. For a discussion of mad studies in relation to crip theory see Thorneycroft 2020. For a discussion of the term neuroqueer in relation to crip or crip theory see Egner 2019.

people with physical or mental disability. It works as an affirmative term because it can be reappropriated. Cripping, in the verb as it was proposed by Sandahl, thus involves an affirmation in the sense that it exposes able-bodied assumptions and claims an identity of its own.[59] It offers a tool to, in Sandahl's words, "disarm what is painful with wicked humor" (2003: 37). Claiming crip thus means to reappropriate the outsider's position in reference to a normative framework.

Such an affirmative move is more complicated for patients with unexplained illness. First, it would involve claiming an identity that contests a system of knowledge rather than a view of normality. And second, because unexplained illness does not inhabit an outsider's position that is similar to crip (in reference to a norm) but is better described as a limbo instead. Unexplained illness lacks a defined field in which its problem is specifically discussed in terms of oppression.[60]

The difference between unexplained illness and disability has not been specifically discussed at length within the humanities. The difference between chronic illness and disability, however, and the *cripping* of chronic illness in particular has received recent critical attention (Pieri 2023; Sheppard 2020; Smith 2021). The chronic illnesses discussed by these authors mostly count as medically explained, such as in Abareshi's case, but also include illnesses such as ME/CFS and fibromyalgia. Mara Pieri highlights the problematic status of conditions such as ME/CFS and Fibromyalgia and mentions the dismissal or stigma associated with these conditions (2023: 28). However, the problem of unexplainedness as such is not made central and has scarcely been central to theoretical scrutiny. I will briefly draw out the way in which Pieri has made a crip analysis of chronic illness and point out where the aspects described by Pieri are intensified in cases of unexplained illness.

Pieri's *cripping* of chronic illness involves three things: a problematization of the (in)visibility of chronic illness, a valuation of pain, and a contestation of medicalization. I consider all three points Pieri highlighted to be all the more relevant in relation to unexplained illness. On the first point, Pieri argues that the separation between

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[59] See the first introductory chapter of this dissertation, section 1.1, 16.

[60] In the context of a special issue of *Shame and Medicine*, I attempt to bridge the various attempts that have been made in different fields to engage with unexplained illness and specifically work towards a theory of unexplained illness that is framed in terms of marginalization and epistemological oppression. See Hommes forthcoming "Towards a Theory."

the normal and the deviant is all too often made on the basis of visibility, although many chronic illnesses are not always visible from the outside or are only present in the form of flare-ups (2023: 27). I would add to this that in *unexplained illness*, the problem of visibility is even greater, as these conditions also escape tests, scans or other kind of physical proof.

The second way in which Pieri proposes to crip chronic illness is by providing a valuation or acknowledgment of pain. She refers to physical pain but also social pain of exclusion, dismissal, and violence. Again, the acknowledgment of pain as “an important standpoint of knowledge and a political resource” (2023: 28), such as Pieri argues in relation to chronic illness, only wins in importance when applied to unexplained illness, where the lack of a biomedical indicator of pain sometimes directly denies the existence of any pain at all. Pieri’s third deployment of crip in relation to chronic illness involves a critique of medical science and proposes to review the power that medical authority has over disabled persons (2023: 28). For patients with unexplained illness, this authority has far-reaching consequences. It can implicate that what these patients experience as physical is seen as mental instead, thus denying legitimization to the experience of these physical complaints.

These three meanings of cripping of chronic illness highlighted by Pieri set the critical discussion of chronic illness apart from disability. I add to Pieri’s employment of crip that the unexplained character of illness brings further complexity to that which is already negatively experienced by patients. Thus, Pieri’s cripping of chronic illness cannot simply be transposed to unexplained illness because of the more complicated nature of epistemological exclusion. The epistemological constellation from which unexplained illness emerges is not easily problematized, contested, or re-evaluated. This means that this contestation of medical science that Pieri proposes in relation to chronic illness must take place on a much deeper level to be relevant for unexplained illness. Such a contestation needs to go further than addressing the authority of medical science over the body and must confront the type of knowledge upon which this authority is based.

This is a level that concerns the organization of medical science on the basis of mind-body dualism and modern evidence-based science. The stigmatization of mental illness is one of the markers of the unevenly distributed hierarchy between mind and body.

The distinction between mind and body usually privileges the mind over the body socially, politically, and epistemologically speaking. At the same time, physical explanations for illness are valued over mental causes. A result is that physical symptoms with a presumed mental cause are stigmatized. Unexplained illness has no place within evidence-based medicine and falls somewhere within the separation made by dualism.

The mind-body dualism ingrained in Western medical care complicates a patient’s own experience of complaints in reference to a normative system in which the body should behave in a specific way and is otherwise deemed a “defect” or “failure.” Yet patients with unexplained illness often long for a cure for an unknown pathology. They commonly wish for their symptoms to go away and are thus disabled in relation to a notion of health defined within a dualistically oriented medical setting. As part of medical care, these patients are often exposed to psychiatric treatment for symptoms experienced by them as physical or treatments which are resisted by patient groups because they either do not help or even impede their recovery.[61] Treatments, in short, try to fit unexplained illness into a discourse in which mind and body are separated, in which the mind is placed at the top of a hierarchy, and in which biomedical evidence prevails.

Within such a discourse, care for unexplained illness presents a problem and is in danger of trying to fit patients into limiting molds. My analyses of the representations of the two women who stood as models to embody a specific view on a type of unexplained illness have shown the limitation of those molds. At the same time, they have exposed that there is no simple, ready-made solution. Must the only relation between care and unexplained symptoms then take place outside institutionalized Western medicine as a whole?

In the next subsection, I reflect on this question by turning to another artistic account, this time in the form of a written letter, reflecting on experiences with unexplained illness within institutionalized medicine. The letter addresses care as opposed to healing and politicizes the latter by linking it to a notion of justice: a form of healing that can be brought about by acknowledging different forms of knowing beyond

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[61] See my discussion on cognitive behavioral therapy and graded exercise therapy in relation to ME/CFS and the fierce resistance to these forms of therapies maintained by patient advocacy groups in section 4.3.

an institutionalized medical form alone. Reading this text, I discuss and also problematize the extent to which this can be seen as a way forward for people with unexplained illness.

2.4.2 In Search of Healing

Concluding this section, I read Johanna Hedva's "Letter To A Young Doctor," published online in *Triple Canopy* in 2018. Johanna Hedva, a Korean-American genderqueer multidisciplinary artist, became famous with their influential essay "Sick Woman Theory" (2022a). "Sick Woman Theory," originally published online in *MASK* magazine in 2016, was widely read in queer and crip art communities around the world and addressed the marginalized position of the sick person in late capitalist societies. In the piece discussed here, Hedva voices their experience with the US-American and German medical systems and writes of their experience of being confined in a Berlin psychiatric hospital to reflect on the notion of care in relation to healing.

The piece is written in the form of a letter. The letter is written as a response to one that Hedva purportedly received from a person called Erica. The original letter has not been published, but Hedva's response gives a version of the questions that were in it. Hedva writes how Erica approached them, saying she is someone "who will soon be a physician attempting to care for people" but still doesn't know what healing means (2018: n.pag.). Hedva responds by saying that it meant a lot to them that Erica had used the word "attempting." The letter provides a reflection on the relationship between patient and doctor and the authority vested in medical science from Hedva's view: chronically (unexplainedly) ill themselves and having spent large parts of their life in hospitals and psychiatric wards.

It opens as follows.

> Dear Erica,
>
> You wrote me asking if I can think of a way, any way, that healing might happen within the current institution of the medical-industrial complex and its attendant oppressions, of which you are currently a student, set to begin your residency this year. (2018: n.pag.)

The repetition “a way, any way” highlights the urgency expressed in Erica’s question to Hedva. The opening of the letter refers to medical practice but does not use the word care. It couples medicine with industry and describes it as an oppressive complex. Healing comes in as a concept to perhaps replace care because care in this system, as Hedva describes it, is absent.

The letter is written in the context of the success of Hedva’s “Sick Woman Theory.” Hedva writes how it still shocked them that this unexpected success, which they refer to elsewhere as being an “underground band who has an unexpected hit on the radio” (2022b: n.pag.), made they were seen to be in a position of authority to answer Erica’s questions about healing. This authority felt strange to them, as Hedva writes:

> It made me ask myself what kind of knowledge I have about healing that you, trained and educated in the field of medicine, do not. What would I have to teach you? (2018: n.pag.)

Reflecting on their previous essays – “Sick Woman Theory” (2022a) and “In Defense of De-persons” (2016) – Hedva writes that they see how they might have come across as an authority: “The voice I was able to construct in those essays was empowered in its sickness” (2018: n.pag.). Yet, the kind of knowledge that they have about healing, Hedva writes, is only the knowledge from a patient who is the recipient of attempts at care from institutions and practitioners, and, as one who often concludes that “none of us really know what healing means” (2018: n.pag.).

Hedva’s writing is thoroughly positioned. They refer to themselves as a patient, as a Korean-American – just like “Erica,” so they know about “the kind of family pressure that probably existed […] around choosing the right career” (2018: n.pag.) – as genderqueer and as chronically ill. These positions are explicitly laid out and are the place from which Hedva carefully moves towards linking healing to justice. From these positions, Hedva openly thinks, writes, and exchanges thoughts about what healing might entail instead of forcing a particular type of “care” upon someone when a notion of healing is undefined.

Separating the two concepts of healing and care already implies that care does not always lead to healing: that there is not necessarily a causal connection that links care to healing. The importance of the word *attempt,* for Hedva, is because it acknowledges that a relationship is needed for care (2018: n.pag.). This imagined relationship goes both ways: back and forth between patient and practitioner. Instead of being forced into an existing framework, Hedva pleads for a vision of medicine in which doctors are not the only people with authority over the body but that the patient is heard and given agency.

> What if, instead, the presumption went both ways—that the patient was *also* a specialist, like you, in possession of a set of knowledges, a vision of a world we'd like to build, that is different from this one, and so by collaborating as equals, utilizing each person's skills, we might together build a world that contains multiple parts, a world that is not only one part—your part? (2018: n.pag.; emphasis original)

These multiple parts would then combine to form a version of medicine that incorporates multiple views, similar to the merging of the differences described in terms of the opposition of evidence-based medicine in opposition to experience-based or patient-centered medicine. For Hedva, the thought experimental form of medicine would acknowledge the existence of perspectives beyond a (bio)medical one alone. This would be a version of medicine that does not smother patients with authority, ideology, or versions of events in which the patients do not recognize themselves.

The devil, however, is in the details and is concerned with the specifics of the collaboration, the utilization, and the *building* that this vision proposes. Eventually, Hedva's proposition involves a particularly destructive account of Western medical discourse, in the sense that it denies or even wishes to overthrow some of the concepts upon which Western medicine heavily relies: the separation between body and mind, the importance of and difference between objectively verifiable knowledge and subjective experience and the hierarchy this implies between patient and doctor.

Hedva's vision is presented as a "what if": it seems to be only a thought experiment, which is powerful because it is so radical. However, particularly when the vision is applied to unexplained illness, one sees why Hedva keeps insisting on the need for a revolution now. The revolutionary notion would come down to the idea that if a system fails a patient, this system must be brought to a halt. The patient is a specialist in the knowledge that follows from the experience of pain or discomfort. The medical practitioner is a specialist in knowledge based on a learned and interpreted set of experiences, coupled with a personal experience of handling other people's pain or complaints in a certain way. Hedva's proposition to bring these two together is thus, at first glance, not so radical at all. For unexplained illness, it would mean that the delegitimization that patients experience would be reduced since the legitimization of illness is not dependent on the type of knowledge held by the medical specialist. However, the strong and hierarchical separation between different knowledges is so deeply ingrained within medical science that it is radical to imagine otherwise.

Institutionalized medical care, as described by Hedva and shown by Abareshi, is a type of care that is focused on disease and cure less than on the subjective experience of illness. This relates to medical care that involves a medical gaze that is coupled with a male gaze and has historically marginalized women. (The history of) institutionalized medical care has also resulted in practices that are hard to think of in terms of care at all: confinement in a nineteenth-century hospital, the inscription of the disease on a patient, literally or metaphorically, or a present-day objectification of the body as represented and experienced by Abareshi.

Insofar as the patient coincides with disease, the patient can be cared for in terms of treatment for objectively verified symptoms. Whenever there is no treatment, in the case of chronic illness, or when the (objective) disease behind the (subjective experience of) illness cannot be verified in cases of unexplained illness, care becomes more complex. Insofar as the patient coincides with disease, the disease-focused approach to care is also one that focuses on the patient. At the moment when disease cannot be cured, or when the illness cannot be objectively verified in terms of disease, it results in a lack of care that is twofold: care does not exist for the illness and not for the patient who suffers from it.

For Hedva, healing is connected to, or even the same as, justice (2018: n.pag.). This means that healing for them becomes a process of reimagining a political future. Taking Hedva's vision seriously would lead to a far-reaching revolution that includes overthrowing all binaries and authorities and the medical-industrial complex related to global capitalism. Apart from having little practical applicability or traction in the world at large, it is unsure what this vision would mean for people with unexplained illness.

Having laid out the difference between disability and unexplained illness, I tried to show the difficulty of politicizing unexplained illness: the oppression of unexplained illness is not solely connected to social norms but to epistemological frameworks, which have a marginalizing effect. Thus, a better understanding of the epistemological movements that have resulted in a lack of care is needed to overcome this marginalization. The next part addresses this question by looking at the modes of production by which the case is made.

2.5 Isolation, Case Production

In the above, I have first briefly laid down some of the qualities of the case and focused on two exemplary cases to question the use of the case and its formative function for disciplinary formation. Next, I have close-read a videowork and literary fragment pointing to the absence of care in chronic or unexplained illness cases. What was left untouched is how the case can be approached in a way that tries not merely to take from it to box, to label, and put it away again, that is, to appropriate an individual story and turn it into a case for a discipline, but to engage in conversation that leaves room to resist this labeling. This is of particular importance when discussing unexplained illness that lacks a label that matches the patient's experience of their complaints as physical.

Questioning how to approach cases of unexplained illness raises the methodological problem of addressing that which falls between different domains of knowledge, the medical and the experiential. In her introduction to *The Practice of Cultural Analysis*, Mieke Bal discusses the tension that exists between "the need to account for difference and specificity and the desire to construct global comparative frames" (1999: 14). Instead of solving this issue, she calls for keeping a productive dynamic alive and to work with the tension. Let me briefly consider what this means.

In the preliminary consideration of both case women, who have come to be known through their case representation, I have shown how details are either extracted from their lives, highlighted, or made up in order to make the case. They became, as Foucault described in the *Birth of the Clinic*, "isolatable events whose form of solidarity was of the order of the series" (1994 [1973] 97-98). The woman in the DSM *Case Book* is made anonymous. The reader is given only certain facts of her life, yet learns some private details. Wittmann was written on more than one can remember and escaped from view at the same time. She is exposed and, at the same time, concealed by the ones exposing her.

Within the practice of cultural analysis as laid out by Bal, exposure carries an important double meaning. An exposition makes something public but is also always an argument (1999: 5). Expository agency, however, is not limited to individual intention but also encompasses its situatedness: “what a community and its subjects think, feel or experience to be the consequence of the exposition” (10). This widened use of what it means to expose and what is complicit in the act of exposing can be connected to the dynamics at work in the production of a case and what it produces in turn. In exposing the women as test cases for a diagnosis, they were turned into a living example, and their agency was suspended. As examples, they became isolated events and came to embody their illness. This happened at the level of their case production for medical practice and in their reproduction to function as a case within the argument of scholarly texts like this one.

I have tried to be explicit about this. The production of a case is not limited to the construction of knowledge within a discipline but produces subjectivities that I have reproduced here in order to reflect on the exposition of these women within medical research or knowledge. A similar cycle of appropriation was described by Hélène Cixous when she states that the feminine construct possesses the power of producing the other that “never returns to her” (1981: 47). In a classical sense, the case can be seen to produce such a construct, as it produces the woman on the painting, Blanche, or the woman who came to be known as a model case for somatization. Both Hedva and Abareshi heavily critique these constructs at present. This woman, or this figure, is endlessly produced but does not return; she does not “recognize herself in the images she has been given” (Cixous 1981: 47). The figure of the hysteric, produced in the nineteenth century and exposed by feminist literature in the 80’s, became a classic example, a classic case.

Likewise, the psychiatric case as a genre of writing is intimately linked to hysteria and the development of psychoanalysis through the case descriptions written by Freud. The case I will consider next is closely connected with the development of psychoanalysis and the construct of the hysteric. The case, hysteria, and psychoanalysis can be understood as a dynamic interplay in which the boundaries between knowledge and its subjects are nowhere near stable and sometimes dissolve.[62]

Freud's first case history, published as "Fragment of an Analysis of a Case of Hysteria" in 1905, is one of the best-known case descriptions.[63] It recounts Freud's main interpretations of his analysis of a patient he called Dora, who was in his analysis for only three months. According to Maria Ramas, who wrote about the Dora case in 1980, the Dora case is not only considered a "classic" but also has "the first or last word in almost every psychoanalytic discussion of hysteria."

> Dora's frigidity, so haunting to Freud and to us, is still considered a cornerstone of hysteria and its most profound symptom. And the meaning Freud attributed to it is still considered to be "truth" by psychoanalytic theory and by popular culture. (Ramas: 1980: 473)

The frigidity that Freud read in Dora's resistance to the advances made on her by a person called Herr K. was read as a sign of hysteria.[64] Writing in 1980, Ramas saw this truth, tying frigidity – a term which carries itself a misogynistic undertone and is only used for women – to hysteria, to be very much alive: it refers to the patriarchal and misogynist idea that all women must want sex with men, that they should behave responsively, and are "crazy" or "hysterical" if they do not. It refers to commonly held notions that tie one's personality, behavior, or personal preferences to the manifestation of illness. It usually only does so when this personality, behavior, or preference deviates from societal, often gender-based norms.

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[62] See also the introduction by Claire Kahane to Bernheimer and Kahane's edited volume *In Dora's Case Freud-Hysteria-Feminism* (1985: 19-32).

[63] See Freud 1953 [1901-1905].

[64] Herr K. was a friend of Dora's father, whose wife Dora's father himself was in sexual relations with. Herr K.'s declaration of love and multiple attempts at sexual engagements with Dora were met with resistance from the young girl, which Freud describes as follows. "He then came back, and, instead of going out by the open door, suddenly clasped the girl to him and pressed a kiss upon her lips. This was surely just the situation to call up a distinct feeling of sexual excitement in a girl of fourteen who had never before been approached. But Dora had at that moment a violent feeling of disgust, tore herself free from the man, and hurried past him to the staircase and from there to the street door." A paragraph below, Freud further engages in interpretation of the scene stating that "In this scene […] the behaviour of this child of fourteen was already entirely and completely hysterical. I should without question consider a person hysterical in whom an occasion for sexual excitement elicited feelings that were preponderantly or exclusively unpleasurable; and I should do so whether or no the person were capable of producing somatic symptoms" (Freud 1953 [1901-1905]: 28). In the second introduction to Bernheimer and Kahane's edited volume, Claire Kahane states that readings of the Dora case around the 1980's suggests that "as brilliant as Freud was in constructing a narrative of Dora's desire, he essentially represented his own" (1985: 20).

The Dora case recounts the emerging sexuality of an adolescent girl, whom Freud describes as portraying unhealthy sexual behavior when experiencing disgust when being kissed by Herr K., a much older friend of her father, whom she instead slaps in the face at the age of fourteen.[65] In feminist engagements with the Dora case, Dora's experiences with the person whom Freud anonymized as "Herr K." have instead been turned to as a "familiar shape of what is now called sexual abuse" (Robinson 1988: 610).

Not surprisingly, Freud's case analysis attracted much feminist criticism around the 1980s.[66] More recently, Cecily Devereux argued that the reclaiming of hysteria in feminist theory around the 1980s "is the logical obverse of its removal at the same moment from the medical discourse of the *DSM*" (2014: 21). An edited volume by Bernheimer and Kahane focused specifically on the "conflictual field" that is the relation between hysteria, psychoanalysis, and feminism in response to the Dora case (1985: 1-2). Not only did the Dora case – which was based on a patient whose identity was later revealed and is widely known – become a classic case for hysteria, but it also became a classic case of all that was wrong with case studies roughly eighty years later.

In his prefatory remarks to his Dora case, Freud wrote how, "revolting though it may seem," some of his colleagues may choose to read the case history "not as a contribution to the psycho-pathology of the neuroses, but as a *roman à clef* designed for their private delectation" (1953 [1901-1905]: 9). That this case reads as a novel is because it includes intimate information, that is, for Freud, vital to understanding hysteria. It is intimate information that the patient would never have shared, Freud notes if they had known that it might be put to scientific use and publication (1953 [1901-1905]: 8). He devotes around three pages to the betrayal of these secrets, as he calls it, and the precautions he has taken for the patient to remain anonymous; the patient's personal circumstances being unknown in their milieu in Vienna, the treatment that remained a secret and the prolonged time between the treatment and publication (1953 [1901-1905]: 8-10). Overall, his rationale for eventual publication was that the physician does not only have duties towards patients but towards science as well and that when one believes to

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[65] For the description of the slap in the face see: Freud 1953 [1901-1905]: 46.

[66] See for instance: Bernheimer and Kahane 1985; Bronfen 1998; Ramas, 1980.

know the causes of hysteria, it is their duty to publish, as long as they can avoid direct personal injury to the patient concerned (1953 [1901-1905]: 8).

There are at least two assumptions at work in this line of reasoning. First is the notion of the case description as a contributor to science that elucidates something about cases that are deemed similar. This means that a transfer of knowledge is implied from one situation to the next. The second is Freud's assumption that his interpretation of the case contains truth on hysteria beyond a mere reading or interpretation alone. I am not suggesting that there is no scientific value in the type of knowledge produced in the case. However, the specifics of the move from the individual event or story to the individual story-as-case-to-function in a discipline require clarity. Berlant described this lack of clarity in their address to the disciplinary and normative effects of caseness.

Next to disclosing personal information, the physician who publishes a case also has to overcome what Freud calls technical difficulties of drawing up the report of a case history when it is conveyed orally to the listener. This concerns the problem of note making, about which Freud writes he tries to avoid it during a session for fear of shaking the patient's confidence, and the problem of having little time for making notes in between treatments, when Freud sometimes conducted as much as six or eight psychotherapeutic treatments a day (1953 [1901-1905]: 9). The record can never be "absolutely – phonographically – exact," and shall always be, to some extent, written from memory. In the Dora case, Freud writes how two aspects came to his help. The treatment only lasted for three months, and the material he was interested in was mainly centered around two dreams, whose wording he recorded immediately after the session. Although the case was partially written from memory, Freud concludes that "it can claim to possess a high degree of trustworthiness" (1953 [1901-1905]: 10).

While Freud went to great argumentative lengths to present his work as science, his writing, especially his case histories, has been reviewed as a great work of literature. Steven Marcus writes of the Dora case that "it is both an outstanding creative and imaginative performance and an intellectual and cognitive achievement of the highest order" (1985: 57). According to Marcus, Freud's written account of the substance of the case history takes all of Freud's "immense analytic, expository, and narrative talents to bring into order" (1985: 58-59). The narrative of the Dora case is not organized around chronology of the events occurred, but according to what Marcus calls an "inner logic" and follows a general form that bears "suggestive resemblances to a modern experimental novel" or "a series of Ibsen plays" (1985: 64). The difference is, as Marcus notes, that Freud is not only the writer, the creator and playwright, but also "one of the characters in the action" (1985: 65).

This reading of Freud as writer, creator, playwright, and character at once bears a resemblance to how Charcot, Freud's teacher in all matters hysteria, is encountered in scholarly work; as a dramaturgist or stage director guiding the performance of hysteria at the Salpêtrière.[67] Didi-Huberman refers to the theatrics at the Salpêtrière under Charcot as a form of stage direction:

> a strategic letting-be, a response that feigns to allow the word of the other to spin out at its own rhythm, but a response that is always already interpretive, and thus oracular. It is hypocrisy as method, a ruse of theatrical reason as it presumes to invent truth. (2003 [1982]: 8)

Charcot is described as someone foreclosing anything other than his interpretation of events and physical symptoms displayed at the Salpêtrière. His vision was always already interpretive, and thus, for Didi-Huberman, oracular: both ambiguous and enigmatic but holding authority at the same time. The effects of this authority were that the women confined there started to portray the physical symptoms that were expected of them. This, in turn, leads to hypocrisy (etymologically going back to theatrics, playing a part, or pretending) as described by Didi-Huberman: it is an authoritarian method that presumes to invent truth as something discovered or "new" but sees only what it proclaims as see-able. It "invents truth."

In the creation of hysteria by Freud and Charcot, observation, interpretation, and description resulted in a form of reinvention, a staging that isolated and produced the case subject as new. The difference between the story and the case, or in this sense, the case in relation to fiction or play, is that the interpretation of the case makes a claim on reality. Whereas fiction can be based on real-life experience, the case description made in the

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[67] Jonathan Marshall specifically refers to Charcot as "stage manager of the Salpêtrière" (2016: 20). For scholarly work which considered the performative qualities of hysteria at the Salpêtrière under Charcot, section 2.3, 84, note 52.

name of science has a more direct entrance into the formation of bodily experience and the creation of the true meaning of the symptoms. The case description exerts power. Not only is its knowledge extracted from isolated, individual events, but it also directly claims them and produces a specific character: the hysteric.

Seeing as this dissertation concerns unexplained illness, I do not present such a character. That is to say, I am not fleshing out a new version, figure, or construct. The figure of the hysteric is already too much in place. I attempt to follow the routes laid out by the existing constructs, thus providing a formulation of a problem. Unexplained illness confronts the production of knowledge in medical practice. However, instead of becoming a true confrontation between medical science and bodily experience, new figures have created a negative image of the patient. The unexplained symptom is not a blank space but is filled with many associations, stigmatizations, and other cultural connotations. It is a phenomenon that escapes while it is pinned down at the same time. The case or the form in which this pinning down takes place creates a subject which, at the same time, escapes from its center.

In these cases, the lack of explanation becomes the basis for a (non)diagnosis: a disease that remains unexplained. The danger of the (non)diagnosis is that the disease consequently becomes suspect. It labels in a way that is vulnerable to already existing notions to attach to it. In the case of unexplained illness, these notions have often been shaped around cultural imaginations around hysteria. These cultural imaginations are embodied in narratives, called *Hystories* by Showalter, that have been directly linked, by some working on (the representation of hysteria), to contemporary conditions with controversial biomedical status, such as ME/CFS (Showalter 2013; Hustvedt 2012: 7), but can also be traced in medical/psychiatric literature (APA 1952: 32-33; APA 1980: 377-378; Merskey 2004: 649), or popular discourse in which women have to mediate a stereotypical account of the “crazy, lazy, illness-fixed or weak-woman patient” (Werner et al. 2004: 1043).

With such strong cultural connotations attached to unexplained illness, I propose that the construction of the case of unexplained illness requires extra care. This can be made extra clear by again drawing on the difference between cases generally described in medicine and cases of medically unexplained illness. According to Monika Class, who edited a special issue of *Literature and Medicine* on the issue of "the" medical case, there are three interrelated functions of cases explored in scholarship on medical case histories. The medical case represents an empirical foundation for the induction of knowledge; the case is bound up with the relation of the particular and the universal, and the case might also expose a situation in which the particular and the universal do not coalesce. According to Class, cases as such point "to a singularity that may trigger modification of a system or a new hypothesis" (2014: xi). Cases of unexplained illness, however, present a different situation in which the singularity of the case does not trigger such modification but is filed under a new header, that of the medically unexplained.

This strange category of exception does not result in modification of knowledge but is often offloaded onto the individual. The case of unexplained illness does not represent an empirical foundation for the induction of knowledge, as maintained in reference to general medical cases by Class, because it is an experience in which the particular and the universal do not coalesce. Nevertheless, its particularity deviates in such a way that it does not result in modification. Instead, the individual is held accountable for the experience of something that does not fit into a system of universality. In order to not reproduce the stigmatizing effects following its exclusion, it means that the case of unexplained illness presents an exception that needs to be handled differently.

A second aspect relevant to the discussion of a (medical) case is described by historian of medicine Gianni Pomata, who focuses on what cases produce. He writes how the case is not an isolated event. However, he contends that the case "is related, explicitly or implicitly, to a set of rules, the case is always part of a frame story" (2014: 1). This set of rules, embodied in medical practice, determines how the interpretation of the case gains shape. Pomata argues that the medical case should be viewed as an epistemic genre with a deliberate cognitive purpose aimed at knowledge production. The exceptional status of the case of unexplained illness, coupled with the production of knowledge, results in the danger of producing a particular figure or subject, as was done by Freud and Charcot. A subject in which the patient who presents with physical symptoms in the first place does not recognize themselves. A subject position that Hedva and Abareshi critiqued.

The exceptional status of unexplained illness results in a particularly difficult situation in relation to care. It raises the question of how to carefully address the case in a way that makes it possible for individuals to feel that they are accounted for instead of being held accountable or being transposed into something they feel they are not. This process involves care in a hands-on medical way and pertains to writing and thinking of unexplained illness and its status as an exception. This rendering of care relates to how Puig de Bellacasa understands care as an "ethico-political attitude in the everyday doing of knowledge practices" (2017: 18). She notes that thinking and knowing are "essentially relational processes that require care" and that thinking with care is a "noninnocent requisite of collective thinking in interdependent worlds" (2017: 19). In relation to unexplained illness, I take such an ethico-political attitude as one that scrutinizes knowledge (production) based on what and whom it excludes. For Puig de Bellacasa, care involves an attitude that acknowledges or even emphasizes relationality and interdependence. Considering this in my discussion of unexplained illness means that a careful rendering of unexplained illness must include an analysis of the structural conditions under which it comes into being.

2.6 Conclusion

Insofar as this section has reflected on methodology, it has argued that unexplained illness requires extra care when it is molded into a case to extract knowledge from because the transformation into a case is in danger of producing a particular subject. Making a case of unexplained illness transforms the person with unexplained illness into someone who fits stereotypes of unexplained illness, such as were produced in the discourse around hysteria and survived in contemporary thought. The nervous route of the case in relation to unexplained illness transforms the particularity of unexplained illness into merely a deviation from the norm. This is a move that leaves the unexplainedly ill body unattended and reduces the patient's access to care.

This chapter describes this movement as a nervous route that reduces particularity and transforms it into generalized knowledge that leaves the unexplainedly ill body unattended. In the case of biomedically explained illness, this is a medical route that results in care directed towards objectively verifiable disease. In the case of unexplained illness, this is a *nervous route* that leaves the patient unattended. From my analysis of the use of the test case discussed in the first section of this chapter, I showed how the case extracts, appropriates, and constructs normativity. By turning to another model case of unexplained illness in the available information on Blanche Wittmann, I addressed the production machinery behind the construction of “the hysteric” in the nineteenth century and succeeding scholarly work and the invasive, sometimes violent consequences for the hysteric’s body. The lived body that is acted upon is again at the center of Abareshi’s work. However, here, the artist themselves possesses the representation of this body, now addressing the lack of care they themselves experienced in medical institutions. Hedva’s discussion of healing involves a vision of medical care that acknowledges the authoritative effect of medical language on the patient.

Eventually, Hedva ends the letter by referring to their own experience in the German psychiatric hospital, where there was one doctor with whom they could build a relationship of trust. This was possible because, Hedva writes, he had treated them as an equal and had spoken to Hedva about the colors in a Van Gogh painting at a time when they had desperately needed to be addressed as a person on a topic that was dear to them. Hedva writes that they trusted him because he trusted them (2018: n.pag.). The setting is not radical; it is a doctor who talks to them in a human way during a particularly difficult moment of Hedva’s hospitalization, and it results in care. During the moment that Hedva describes, they have not been turned into a case. They had felt seen, taken seriously, and talked to, not as a patient but as a person, and to them, it had made a difference.

A case of unexplained illness carries the risk of removing the patient at its center, reducing the possibilities for care. A way to avoid the appropriative, extractive, generalizing, and normative dimensions of the case can be to maintain a method of care as set out in this chapter: to be responsive to that which is theorized. I have elaborated upon and practiced this methodology in this chapter by focusing on how these cases are constructed. I will maintain this methodology in the chapters to come. Tracing different nervous routes along which unexplained illness is understood, I mean to practice a methodology of care, as the only ethical form of access to defining the problem of unexplainedness as such. The goal is not to speak in terms of cases that are already or need to be interpreted and explained, but to focus on the structures through which the subject of unexplained illness appears.

3. Classification

3.1 What can Diagnosis Do?

In the 2019 Netflix series called *Diagnosis*, a patient named Ann narrates the onset of her unexplained paralysis. Her symptoms started to appear gradually. First, the right side of her jaw had been painful for a couple of months. Then, one morning, she woke with a headache at the back of her head, which extended into her right shoulder. When she tried to call her dentist because of a pain in her jaw that had now spread to her head and shoulder, she noticed it was difficult to speak. Seeing her face in the mirror, she barely recognized it: the right side of her face drooped, and she could not move it. When she went to her doctor, he told her she had full facial paralysis and sent her to the ER. On the way to the hospital, her right eye closed, and she was unable to open it, even though she was driving on the highway and could barely see. When no physical cause was found at the hospital, where both a CAT scan and MRI were performed, a neurologist came in and told her he thought her symptoms were psychosomatic. In the episode of *Diagnosis,* which represents Ann's story, Ann narrates the doctors' phrasing directly, mockingly raising her eyebrows to repeat his words. "Well you know I think you're just stressed, I think all of this is just stress, you're just, it's just psychosomatic" (*Diagnosis* 2019: E07 09:18).[68]

Ann's account of her symptoms and the encounter with the doctor is told in the seventh episode of a new medical mystery series that aims at helping patients find a medical diagnosis for various unexplained ailments. *Diagnosis*, a seven-part US documentary series, was based on a popular column by Lisa Sanders, a medical practitioner at Yale New Haven Hospital and a writer. The column always only presented "solved" cases. Those are cases that eventually receive a successful diagnosis by a doctor. In 2018, Sanders tried something new and started writing about unsolved cases, asking "the crowd" for possible diagnoses. Sanders' column becomes the basis for a

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[68] The description of Ann's case is partly based on Lisa Sanders' description of Ann's case as published in *The New York Times Magazine*. See Sanders 2018: n.pag. In this dissertation, I discuss Ann's case in the context of classification, as explained in the next pages. In another, forthcoming publication, I discuss Ann's case in the context of what I call "scientific fiction" of complete explicability. Some fragments of this section, strictly concerning descriptions of the material, may overlap, while the analysis differs distinctly. See Hommes forthcoming "Going with 'the crowd.'"

crowdsourcing experiment central to the series: the general readership of *The New York Times* – explicitly open to lay people and personal experiences – is invited to upload their diagnosis onto an online platform. Each episode follows a different patient along their diagnostic process. The episodes are hosted by Sanders, who also functions as a patient-crowd "mediator" throughout the series, presenting the responses and filtering through different diagnostic options. The seventh and last episode of the documentary series features Ann, a patient with a "mysterious paralysis."

"Ann" is represented by the Netflix series, and the present account is based on this representation. I focus on the clash I discern between Ann's hunt for a diagnosis and how the series represents her symptoms. In the original column that presented Ann's case to the crowd, Sanders writes that Ann "asked that we use an abbreviated version of her name to protect her privacy" (Sanders 2018: n. pag.). The series and my following account follow this naming. Yet my tracing of Netflix's dramatized version of Ann's quest for medical diagnosis does specifically not attempt to lay any claim on the patient who modeled for the episode. Instead, I focus on the representation of the symptoms and the confrontation between their presentation by Ann and their representation, both by the series and by the medical profession that is equally represented in the series. In doing so, I aim to set up my discussion of classification, which is central to this chapter.

The Netflix series presents the quest for a diagnosis as its central theme. Sanders, who published two books on the search for medical diagnoses and whose column also inspired the long-running series *House, M.D.* (2004-2012) for which she was a consultant, approaches medical diagnosis as a detective-like quest. In the optimal situation, diagnoses present themselves in the series as concrete names of diseases that relate to a physical structure in the body – for instance, carnitine palmitoyl transferase type 2, or CPT2-deficiency, in the case presented in the first episode (*Diagnosis* 2019: E01 40.48). Of the eight cases presented in the series, there are two – Ann's presented in episode seven and a patient whose story features in episode five – where patients resist their given diagnoses (*Diagnosis* 2019: E05; *Diagnosis* 2019: E07). Both patients are not presented with a clear-cut physical explanation for their symptoms in these episodes. Instead, the characterization of Ann's symptoms as being a "psychosomatic" reaction to stress lingers in the episode when Ann receives the possible diagnosis of a "functional disorder": a medically vague term for an illness that is characterized "more by symptoms, suffering and disability than by consistently demonstrable tissue abnormality" (Barsky and Borus 1999: 910). Ann refuses to accept the classification as the explanation for her symptoms for fear that it will disqualify her in the eyes of medical professionals.

I start this chapter with the representation of Ann's quest for diagnosis because it puts into relief the problem of classification of unexplained illnesses. This problem is related to the way in which unexplained illness is classified either as a physical or a mental entity and how both characterizations of illness have different effects. First of all, the popular representation of Netflix's quest for diagnosis plays in on the importance that is accorded to finding a name for an ailment. Obtaining a diagnosis is often a central aim and a desired status for the person experiencing symptoms that are yet unexplained. It offers what Sarah Nettleton has called "the permission to be ill," which undiagnosed patients often seek (2006: 1167). A diagnosis that fits a medical classification of illness legitimizes the illness experience. An example of relief following such legitimization is found in an essay on diagnosis by Esme Weijun Wang. Describing her own experience with a diagnosis of schizoaffective disorder, Wang writes that she finds comfort in preexisting conditions: "I like to know that I'm not pioneering an inexplicable experience" (2019: 5).

At the same time, Ann's story shows how not every diagnosis grants this kind of relief. Ann's expressed reluctance to accept the diagnosis she is handed shows that for her, disease classification and the cultural notions that are attached to it determine how physical symptoms can be lived. This chapter identifies and traces the nervous route of classification as one that patients travel as they move through the medical system when no organic cause for their illness can be found. This route forms a concrete path upon which patients travel in the medical system, but it is also a nervous route in the sense of an epistemological movement. Medical/psychiatric classification is a knowledge practice determining how unexplained illness is treated in psychiatry and popular culture. Tracing this route, the subsequent sections of this chapter pay particular attention to the classification of unexplained physical symptoms in psychiatry because it is there that symptoms run the risk of being denied a physical entity, something that is feared by Ann. In the following, I will stay for a bit longer with Ann's quest for diagnosis and her resistance to being classified as a patient with a functional disorder. Her story and the representation by Netflix provide the background against which to read my discussion of the psychiatric classification of unexplained illness in the sections to come.

In Ann's case, the crowdsourcing experiment central to Netflix's *Diagnosis* results in two possible diagnoses for her unexplained paralysis. Lyme disease and a functional disorder are most frequently mentioned by the crowd and presented by Sanders as the main contesters for diagnosis. When Ann is handed the possibility of the diagnosis of "functional disorder" through the crowdsourcing experiment, it results in a conflictual situation. She feels that the implication of this diagnosis runs contrary to institutionalized medicine's beliefs and refuses to accept the name as an explanation for her paralysis. Her refusal comes down to the expectation that the medical profession itself will think she is crazy. When she rephrases the doctor's answer to her symptoms during the ER visit, when she was told she was "just stressed," she mimics her doctor's words: psychosomatic. She makes it sound dirty. It is clear that Ann did not feel that her ailments had been taken seriously with this term.

In what is arguably the most emotional scene in the episode, Ann has just returned from seeing another specialist, who told her that her paralysis could not be explained as Lyme disease. Sitting on her couch at home, Ann says the following:

> Once again, no answers. […] If you don't have a diagnosis… I can't go into a hospital if something goes wrong, like it did before. 'oh and they don't know what it is'… They automatically assume that you're just crazy and trying to seek attention. It makes me afraid to go to the doctor. I don't want to see a new doctor. I don't want to have to justify myself to somebody else. I'm tired of it. (*Diagnosis* 2019: E7 26:30–27:35)

For Ann, neither functional disorder nor the word "psychosomatic" offers more understanding. They make her feel as if she has to justify herself. In the first episode of the series, featuring a different patient, the moment of diagnosis results in an emotional and narrative climax in which both patients and doctors are immensely relieved and share their happiness (*Diagnosis* 2019: E01). The moment of diagnosis is often used in films about illness, where it functions as a moment of transformation or a device to construct a narrative (Jutel and Jutel 2017). A diagnosis steers one in a clear direction. By contrast, Ann's illness remains unresolved. Ann does not accept the notion of functional disorder as the explanation for her symptoms, and the episode closes her story with a black shot with superimposed text stating rather dramatically that Ann “continues to look for answers on her own” (*Diagnosis* 2019: E07 44:54).

Ann has her particular reasons for not wanting to accept functional disorder. Of the seven episodes in the series, the last episode featuring Ann is the only one presenting not one but two patients, Ann and Joe. Both from the state of Connecticut, Ann and Joe maintain different approaches to their unexplained paralyses. Joe is described by the makers of the Netflix series as the textbook “good patient.” He is a White, middle-aged male dentist, himself part of the medical community, and stays very positive and in good spirits while treated by his doctors. On the other hand, Netflix describes Ann as being “more skeptical.” The audience sees Ann struggling with the medical community. In the first scenes, Joe, a self-proclaimed “firm believer in Western medicine,” praises the “brilliant doctors” who are helping him (*Diagnosis* 2019: E07 04:45), while Ann is shown expressing frustration about having seen over 30 medical specialists who do not know what is wrong with her. Ann expresses a fear of doctors and explicitly frames her position as a woman of color as having a negative influence on the measure in which she is being taken seriously by medical science.

Throughout the episode, Ann hints at the difference between her, as a woman of color, and a hypothetical patient like Joe, whom she is presented next to.

> Really, being a person of color people tend not to take you seriously. In fact, I feel like every woman in this country knows what it’s like to be pooh-poohed by a doctor, cause it’s happened to I would say... and I don’t think I am exaggerating when I say every woman in this country at least once. This is the reason why I don’t trust doctors. (*Diagnosis* 2019: E07 09:34–09:52)

While including her comments on racial bias against women of color and therefore acknowledging them, the series presents Ann’s issues with the medical community as an individual problem without giving attention to the complex social and political hierarchies between doctor and patient or the history of medical racism that makes her position towards the medical community different from Joe’s.[69]

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[69] For an overview of a U.S. history of medical racism and the way in which this continues in present-day healthcare practices in terms of unconscious bias and microaggressions, see Martin et al. 2019, specifically the chapter by Brummer et al. 2016 (published in an earlier edition).

After Ann is shown speaking these words, the editing cuts to a suburban surrounding, showing the façade of a big house in which Sanders is getting ready for work. The image cuts to Sanders sitting in front of a camera, saying that when she came to know Ann and Joe, it was very clear to her that their attitudes about the medical community were very different (*Diagnosis* 2019: E07 10:12). Sanders carefully broaches the possibility “that Ann’s distrust of the medical community would affect her ability to accept observations from that community” (*Diagnosis* 2019: E07 10:40). The wording is chosen carefully and describes the difficulty of Ann’s distrust in a seemingly neutral manner. Yet, placing emphasis on Ann’s distrust frames the problem as being Ann’s attitude and glosses over the structural role of Ann’s race and gender, which are stressed by Ann herself.

The above quote given by Ann emphasizes the way in which women of color are marginalized as a community. Going even further, Ann states that all women in the U.S., in general, have at some point faced belittling approaches from medical practitioners. Making sure to add that she does not think this is an exaggeration, she reflects on how she understands the severity of this claim. It seems that she wants to be understood correctly. Or, mentioning the possibility of her claim being perceived as an exaggeration shows her concern with how her comment is perceived. She seems to fear the effect that her position as a woman of color has on the type of diagnosis she is able to receive. At the same time, she thereby points to the accumulating effect that a diagnosis of functional syndrome will have: how it will further marginalize her. When Ann discusses the possibility of a functional disorder, she states the following.

> I have issue with functional disorder, and the reason why is because [pauses] functional disorder, the term functional disorder is still associated with a psychological condition, and they are both interchanged. […] and it’s just like, there is going to be an awful lot of medical people who come in and they look at that and they just think: Nutty. Crazy. Hysterical. (*Diagnosis* 2019: E07 34:06–34:34)

Ann directly links her reservations about functional disorder to a tradition of the oppression of women and minority groups in medicine by referring to the fear of being called hysterical. Placing functional disorder in a direct line with the notion of and the reception of hysteria, Ann shows how she fears the cultural traditions that are attached to unexplained illnesses and shows that they are not easily shed.

The trace of hysteria being present in the contemporary term “functional” is confirmed in medical literature, where functional symptoms are described as “the contemporary term for what was ‘psychosomatic’ 50 years ago and ‘hysterical’ a century ago” (Edelberg 2012: 306). Monica Greco notes that while the term “‘functional’ literally refers to disturbance in function, […] the term has a long history of being used among doctors as code for ‘psychogenic’” (Greco 2012: 2366). Although names have changed, the fact that functional disorder is defined by a lack of demonstrable tissue abnormality or known physiology results, for Ann, in a fear of stigmatization as a result of a cultural imagining that is attached to physical symptoms without identifiable physical cause.

The term functional disorder refers to the class of functional somatic syndromes (FSS), defined as physical syndromes without known underlying organic causes. Conditions such as ME/CFS, fibromyalgia, and IBS are often linked to this category (Joustra et al. 2015: 94). The overall prevalence of functional somatic syndromes is high (or the category is wide), seeing as thirteen percent of patients older than 65 years present symptoms which are classified as functional somatic syndromes when visiting their general practitioner (Ko et al. 2022: 1). Ann’s possible diagnosis is a *functional neurological disorder* when it is first presented to her by Sanders (*Diagnosis* 2019: E07 24:14), but referred to by Ann as *functional disorder* throughout the episode.

A study from 2022 that looked at attitudes from health care professionals towards patients with functional neurological disorders reported an “overwhelming” number of negative attitudes from doctors towards patients, such as “attention seeking,” “manipulative,” “annoying,” “difficult to manage,” “impossible to help” or “troublesome” (Barnett et al. 2022: 1807). These terms were used to describe their colleagues’ negative feelings towards these patients or to voice their own. The study mentions that a possible explanation for these negative attitudes might reside in how this patient group makes healthcare professionals feel incompetent or uncertain about how to manage these symptoms, leading to frustration, anxiety, and discomfort. It was also found that some practitioners questioned whether functional symptoms were real and described these patients as malingerers, confirming, in at least some cases, Ann’s fear of not being taken seriously. The overarching themes the study identifies in the practitioners’ attitudes are uncertainty and fear (1802). The uncertainty relates to the diagnosis, their professional role, and the management of the symptoms (1806). Most common fears of medical practitioners centered around saying the wrong things, giving the wrong diagnosis, making patients worse, or labeling them with a stigmatizing diagnosis (1806), showing that the struggle around the classification of functional neurological symptoms also affects medical practitioners in their attempt to care for patients.

Ann's reservations towards functional disorder as an explanation for her physical symptoms convey the wish for her symptoms to have a place in medical knowledge, that her symptoms would fall within the dominant range of organic explicability. A qualitative study on the narratives of people with unexplained illness confirms this wish as a common theme amongst patients, who felt frequently marginalized by doctors, and refers to the term "medical orphans" to describe people with unexplained illness (Nettleton et al. 2005: 206). The term "medical orphans" is taken from an article by medical doctor Robert Aronowitz, which describes an increased importance that is accorded to clinical or laboratory specificity. Aronowitz speaks of a "relentless push to define disease at ever 'deeper' levels (from subjective experience to organ derangements and then to cellular derangements)" (2001: 803). This push laid increasing emphasis on objective signs in relation to the now perceived subjective symptom and resulted in a medical classification that left patients who were previously diagnosed with symptom-based or clinically based diagnoses to become what Aronowitz describes as medical orphans: left out of the medical system with no care available.

Ann's reservation is not a resistance to medical science – on the contrary, it might be better described as an exaggerated or inflamed dependence on its classifications. She fears doctors' reactions and fears being excluded from medical explicability as a result of accepting the diagnosis of functional disorder. Ann's resistance is directed towards the notion of functional disorder itself precisely because it disrupts the clear boundaries between physical and mental symptoms that medical knowledge maintains. The crossing of these boundaries and the lacuna of knowledge connected to the term conveys to Ann that what is actually being implied is that she behaves in a way in which she should not, by normative standards, and that she can be held, in some way, accountable for the creation of her own symptoms.

Looking at one scene more closely, it becomes apparent that Ann is not unjustified in thinking this. When reviewing the crowd's results, Ann and her husband are filmed sitting at their living room table at night. They are hunched over several pages with statistics, presumably showing the results from the crowd. The scene cuts between Sanders explaining the possible diagnoses to the viewers and the homely scene. A voice-over by Sanders states that:

> The other possibility is that Ann has a functional neurological disorder. That is, it is not an infection, not a tumor, it's not some pathology, which comes from the outside to attack you, it is instead something that your body is doing wrong. (*Diagnosis* 2019: E07: 24:11)

As Sanders' voice-over speaks, the audience is shown the images of Ann and her husband. At the moment when Sanders utters the word "wrong," Ann directs her gaze upwards, looking at her husband as if she is alarmed by something. Immediately after Sanders' voiceover has finished, Ann says, "It's not a functional disorder. That's not it. It's not [pauses] that's not it. So…" Leaving the viewer ignorant of whether the sentence was finished, the scene cuts back to Sanders, who explains to the audience that

> When some patients hear the diagnosis: a functional disorder, it has a really bad connotation. What they hear is that it's all in your head. That they are crazy. But of course, that is not what it means. (*Diagnosis* 2019: E07: 24.41)

Next, the camera switches back to Ann's home, where she tells her husband that she has been saying it from the beginning and thinks it is Lyme (*Diagnosis* 2019: E07: 24.48). In effect, the sequence's switching back and forth between Ann and Sanders presents an alternation between explanations from the medical community, represented by Sanders as the series' host, and Ann's individual feelings and intuitions. Where Sanders speaks from a position of knowledge and speaks carefully finished sentences that explain what she thinks medically is going on, Ann's speech is chaotic and halts. Although Sanders ostensibly refutes the notion that functional disorder is similar to being "crazy," what she effectively does is invoke the possibility by refuting it without providing justification or an alternative explanation. Furthermore, both of Sanders' quotes above imply that Ann is wrong: first, her body is doing something wrong, and second, she wrongly takes functional disorder as something that it simply "is not."

Ann's reluctance to accept a diagnosis that she fears might not bring her much good is steered by the immense power that diagnosis wields. In his monograph *Brilliant*

Imperfection, Eli Clare writes of diagnosis as having many “incarnations” that can be read (2017: 42). Some diagnoses carry almost no stigma, he writes, yet others “come freighted with discrimination and self-loathing; still others bring both relief and sorrow” (2017: 42). For patients with unexplained illness, diagnosis is a double-edged sword. On the one hand, diagnosis with a condition like ME/CFS, IBS, or fibromyalgia might offer some support in the form of a framework for experience, a community of fellow patients, and (albeit often limited) options for treatment. On the other hand, the diagnosis comes with many things attached and frames the illness experience. Clare writes how diagnosis holds a history and predicts the future (2017: 41): it places a patient in a certain narrative and predicts how life with the condition will be. In the case of unexplained illness, both the narrative in which the patient is placed as well as the predicted future, in which often no clear course of illness or treatment is known or available, often hold no positive outcome for the patient.

The importance of the moment of diagnosis emphasized by the Netflix series hints at the formative effects of a diagnosis on the subject. For people with unexplained illnesses, these effects are ambiguous in the least. Clare writes how “Diagnosis can become a cover for what health care providers don’t understand; become more important than our messy visceral selves; become the totality of who we are” (2017: 42). Diagnoses of unexplained illnesses are often those of exclusion, meaning that the diagnosis is not made based on medical tests but by process of eliminating other possible diagnoses. Somatic symptom disorder, IBS, and also Long COVID, for example, are among such diagnoses. These, what Clare calls “covers” for what cannot be objectively verified, then become names that structure a bodily experience that is in itself often messy but now becomes ordered according to a certain classification. Diagnoses of exclusion offer a way to group patients according to similar syndromes and provide a common framework by which to measure experience. The formative effects of this narrative framing can be seen positively in providing a common framework and possible recognition in other patients and negatively in becoming a totalizing “cover” for an experience that is often more ambiguous and unclear.

Such classification is not necessarily a bad thing but can have serious consequences. A diagnosis determines material realities, which are dependent on different social and legal contexts that differ across countries and nationalities. In the case of the diagnosis “mental retardation” in the US, for instance, Clare mentions how it shapes and determines where people receive education and of which kind, how it influences the unlikelihood of paid work and independent living of one’s own choosing, increases the probability of having one’s children taken away and landing in prison, a group home or an institution (2017: 42). In the case of a functional disorder that Ann so resists, the negative connotations of the diagnosis are most often described in medical literature in social terms such as perceived and experienced stigma and the invalidation of their symptoms (Ko et al. 2022), of identity loss or transformation (Asbring 2001: 316), social isolation (Joustra et al. 2015: 94), and an overall perceived “low quality of life,” a term used to describe all “emotional, social and physical aspects of the individual’s life” (Mönnikes 2011: 98).

The more material dimensions of a diagnosis with a functional syndrome mentioned in the medical literature are related to indirect costs for the patients, mainly because of productivity loss at work, early retirement, health-related job loss, and work disability (Joustra et al. 2015: 95), although here it is difficult to separate the impact of the physical toll of the experienced symptoms and the consequences of the naming of the disease. In Ann’s case, narrated by the series, the physical consequences of the disease experienced before the search for a diagnosis have already resulted in financial struggles for her and her family. She is a writer and editor but states that she cannot take contract work anymore because of the unpredictability of her illness. She also cannot afford health insurance, so she and her family struggle financially (*Diagnosis* 2019: E07 21:34). The fear of not being taken seriously by medical professionals can also result in people disengaging from health services because they no longer wish to feel invalidated (Stone 2014: 192). At the same time, a given diagnosis can also provide a “cover” in a more positive sense. Depending on the country and social context, a diagnosis allows some patients diagnosed with functional disorders to benefit from access to health care and benefits that would not be granted to them should their condition remain undiagnosed. Even so, functional disorder is still associated with high levels of stigma.

In a systemic review of literature on perceived stigma in patients diagnosed with functional somatic syndromes, Ko et al. define stigma as “a social process, in which social groups or individuals accept, endorse or enact negative attitudes, characterized by exclusion, rejection, blame and devaluation,” in this case against people with functional somatic syndromes (2022: 2).[70] The authors distinguish different kinds of stigma, that is: a perceived, an experienced and an internalized stigma. The conclusion of the review confirms the higher perceived as well as experienced stigma for patients with functional somatic syndromes as compared to patients with similar but medically explained conditions (2022: 6).[71] People diagnosed with a functional somatic syndrome often feel that their symptoms are not validated, either by their social surroundings or by healthcare professionals, and often note that their condition is "dismissed as an emotional problem" (2022: 2). Ko et al. also conclude that higher stigma as perceived by the patient resulted in more negative health outcomes (2022: 6), thus resulting in a possible worsening of the symptoms and overall lack of betterment. This shows how the measure of social acceptance of a diagnosis can affect the severity of the symptoms, which in turn can spiral into material consequences such as job and financial loss, loss of independent housing, the need for more care, and resulting financial struggles.

The stigma that is related to functional syndromes is directly related to the association between functional syndromes and mental illness and, thus, to the stigma that comes with mental illnesses in general.[72] As Ann pointed out, she feared that when diagnosed with a functional disorder, her doctors would look at her and think "Nutty, Crazy, Hysterical" (*Diagnosis* 2019: E07 34.34). In medical literature, it is even suggested that the desire to avoid the stigma of mental illness can lead to patients presenting their symptoms in physical rather than mental terms (Looper and Kirmayer 2004: 377). All of the twelve participants whose narratives of their illness were analyzed in a study by Nettleton et al. described that at some point, they felt that their practitioners and social surroundings saw them as a "'fraud,' a 'timewaster,' a 'hypochondriac,' a 'malingerer,' a 'fake' or a 'hysteric'" (2005: 207). The authors point out that these concerns are related

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[70] Much scholarship on stigma goes back to the work of Erving Goffman, who characterized stigma as a socially discrediting attribute. See Goffman 1986.

[71] The systemic review by Ko et al. looked at three different diagnoses which are characterized as functional somatic syndromes, namely IBS, Fibromyalgia and ME/CFS. The authors conclude that in people diagnosed with Fibromyalgia or ME/CFS, they could report of a significantly higher perceived or experienced stigma, while the results proved more ambivalent in the case of IBS, when compared to a comparable explained condition, where patients also perceived and experienced stigma and invalidation related to their diagnosed condition. See Ko et al 2022: 5-6.

[72] For scholarly work on shame and stigma in relation to illness and disease, see Dolezal 2022a; 2022b, or Lyons and Dolezal 2017. For scholarly work on stigma in relation to mental illness, see Rüsch et al. 2005; Corrigan and Kleinlein 2005.

to the notion that the symptoms exist all in the mind and are, therefore, not legitimate conditions.

Functional syndromes fall in between different modes of classification, presenting physical symptoms that cannot be physically explained. Within psychiatry, up until the latest revision of the DSM, the presence of a physical symptom that remained medically unexplained was one of the criteria that could land a patient a diagnosis with somatization disorder (Mayou 2014: 418). With the revision from DSM-IV to DSM-5, which dropped the Roman numerals and was published in 2013, the distinction between medically explained and unexplained was dropped, and the emphasis of the revised disorder, now called somatic symptom disorder, came to lie on the "excessive thoughts, feelings, or behaviors related to the somatic symptoms or associated health concerns" (APA 2013: 311). I turn to the specifics of the classification of bodily symptoms in psychiatry in the last two sections of this chapter. For now, I want to stress the importance of the link between a lack of organic medical explanation and psychiatric classification, which is what so bothers Ann. After the revision in classificatory psychiatry that removed the direct link between the existence of unexplained illness and a diagnosis of mental illness, the association between the two has not been dislodged for a general audience.

The representation of Ann's diagnostic struggle by the Netflix series shows the difficulty of the classificatory struggle to deal with unexplained symptoms in medical science and popular culture. Medical practitioners are shown to struggle to come up with explanations for the experienced symptoms, while Ann struggles to protect herself from her suspected further marginalization. Both struggles are directly related to the overall stigmatization associated with unexplained conditions. Ann's emphasis on structural factors like her race or gender and the general attitudes maintained by medical practitioners are glossed over by the episode's narrative, which ends with a disappointing note to the audience that leaves her story unresolved: Ann has decided to search for answers on her own. She has not reached out to the specialist in functional disorders shown in the series as an option and remains without medical care. Joe, on the other hand, the patient whose story Ann's was presented next to, and who attributed great confidence in the medical system, is stated to still receive medical care at Yale Hospital, where "he and his family remain hopeful that he will continue to show signs of improvement" (*Diagnosis* 2019: E07 46:16). In the end, it is Ann, a patient who already feels marginalized and attempts to protect herself from further marginalization while having little financial means, who draws on the shorter end of the diagnostic quest.

In discussing the effects of diagnosis, Clare invites his readers to think about what diagnosis does. It is a system, he writes, that not only describes certain people as "defective, deficient, or disordered" but also helps shape how the world treats those people (2017: 42). Having opened this chapter on classification with an extensive discussion of a popular representation of one patient's diagnostic quest, I have wanted to point to the double-edged sword that diagnosis presents for unexplained illness. On the one hand, it is a much sought-after status for people with unexplained illness, but on the other, specific diagnoses seldom bring the relief these patients are after. Ann's resistance to her being qualified in terms of functional disorder is precisely because it does not bring the comfort of physical explicability but leaves the causes for her symptoms in the open; open, in this sense, for the stigma of mental illness to be associated with the symptoms and to be held accountable for the creation of her illness.

In the following sections, I trace how unexplained illness has been classified and understood as illnesses of either body or mind. In those conceptualizations, the separation of the bodymind conflicts with the union's inextricability. Focusing on how these classifications struggle with the conceptualization of bodyminds, the main body of this chapter traces the formulations of unexplained illness maintained in the different versions and revisions of the DSM, where symptoms of unexplained illness are classified in psychiatry. It is mainly in the diagnostic formulations of physical symptoms *as mentally steered* conditions that the separation of bodyminds becomes one that is experienced as problematic for the patient.

3.2 Mapping Bodyminds

The classification of unexplained illness faces the problem of conceptualizing symptoms as belonging to either the body or the mind or a curious interaction between what are perceived as separate entities. In her 2015 monograph called *Gut Feminism*, Elizabeth Wilson argues that the interpretation of biological data in biomedical research "often splits mind from body, locates mind only in the brain" (2015: 16). Wilson shows how, when biological data is read critically, which she does with a regard to biomedical studies of abdominal migraine, the split between both perceived entities as well as the localization of the condition in one place are far from resolved. Her suggestion is not to resolve this situation by way of more empirical studies that aim to localize the condition – in this case either in the brain or the gut – but to see, instead, that "the character of migraine is truly open and distributed" (2015: 15). This argument, which follows from a feminist engagement with biological data, instead of the often maintained antibiologism within feminist theory, shows how the conceptualization of biological data directly invokes deeper concerns related to mind-body dualism.

The term bodymind is increasingly used to denote the imbrication of the entities often separated as body and mind. 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, addressed what is at stake in maintaining or departing from different dualisms, gendered ones, but also related to nature/culture, mind/body, and even self/other. Here, I draw on work by Judith Butler, Karen Barad, Rosi Braidotti, and Elizabeth Wilson, but also on work on affect, such as Brian Massumi's Deleuzian re-reading of Spinoza (2002; 2015). Materialist feminist theory scholarship has theorized the relation between matter and meaning, discussing it in terms of contingency, intra-action, or entanglement (Barad 2003), as a result of which "personhood" or identity is understood as something that emerges through those interactions. Feminist theory that merged with disability studies, like in the work of Margrit Shildrick, questioned embodiment in relation to boundaries (2015) or constructions of the "leaky" body that is feminized (1997). The term bodymind, as it gained traction following work by Margaret Price, similarly follows this line of thought, putting to task different dualisms in light of normative structures and political oppression of marginalized groups.

In her influential article, "The Bodymind Problem and the Possibilities of Pain," Price developed the term bodymind as a specific materialist feminist concept (2015: 270). In her specific use, the term has a political value for disability studies or crip politics that defines the bodymind as "a sociopolitically constituted and material entity that emerges through both structural (power- and violence-laden) contexts and also individual (specific) experience" (Price 2015: 271). Price calls upon the notion of the misfit, as theorized by Rosemarie Garland-Thomson as a central concept to think the notion of bodyminds with. Garland-Thomson's use of the misfit aims to reframe dominant understandings of disability. It emphasizes disability as a dynamic, shifting special and temporal relationship where things either "come together in harmony or disjunction" (Garland-Thomson 2011: 592).

> When the shape and substance of these two things correspond in their union, they fit. A misfit, conversely, describes an incongruent relationship between two things: a square peg in a round hole. The problem with a misfit, then, inheres not in either of the two things but rather in their juxtaposition, the awkward attempt to fit them together. (Garland-Thomson 2011: 592-593)

Price takes from this that fitting is generally a function of relations of power (2015: 271). She is, however, critical of how Garland-Thomson develops the concept only in relation to physical and sensory disability and that, apart from a brief mention, she does not further engage with mental illness (Price 2015: 272). Both Price and Garland-Thomson explore the misfit to describe a general position of disability in society, where disabled people have historically been considered outcasts.

The misfit is a dynamic concept which does not stand on its own. It is only in the "awkward attempt" to fit something where it doesn't that the misfit is produced. The misfit depends on the spatial or temporal contexts that constitute it and thus calls attention to disability as a construct. Fitting involves spatiality as well as a "proper" or "suitable" relationship with an environment that satisfies the requirements of a specific situation (Garland-Thomson 2011: 593). Significant about the misfit is, for Garland-Thomson, that it exposes disability as a dynamic that is grounded in the materiality of the world: the specifics of the spatial setting in which disability comes into being. As Price notes, "the claim that identity emerges interactionally is incomplete if one overlooks the fact that not everyone can access interactions equally" (2015: 271). This difference in access, so prevalent in disability, is ultimately grounded in an able-bodied or able-minded norm.

One of the differences between disability studies and a study of unexplained illness is that in disability studies, disability is defined by the conditions of oppression that give rise to the category of disability. I commented on the politics of disability when introducing crip theory and setting apart chronic illness from disability and experiences of unexplained illness in section 2.4.1. Within disability studies, the oppression of people with disabilities is rallied against by the turn that Price defines as "disability desire": an affirming movement that strives towards a world of multiple corporalities that "pisses on pity" (Price 2015: 275) and that "values difference and resists dualisms such as straight/queer or abled/disabled" (Price 2015: 274). For Price, this turn, which she describes as valuable, is at the same time in danger of overlooking the problem of pain, undesirability, impairment, and physical conditions that are sometimes unbearable (2015: 275). In disability studies, the undesirability of disability is a complicated notion since the affirmative movement of disability directly follows from defining disability discursively.

Looking critically at unexplained illness results in a different discussion. In Chapter Two, I separated chronic illness from both disability and unexplained illness by focusing on a form of normativity that pertains to a version of a model man, having a formative effect on a subject. Focusing on classification in this chapter, I frame the difference between unexplained illness and disability in terms of the physical experience of the patient. These different physical experiences are constructed as a misfit based on different systems. Whereas the physical experience of disability is often confronted with an ableist construction of space, the misfit of unexplained illness is grounded in a classificatory logic that separates the body from the mind.

The separation of body and mind has consequences for the definition of the problem of unexplained illness as it is opposed to disability. Unexplained illness involves a suffering of some sort that is not always part of a disability and is itself a term not preferred by disability scholars and activists. On the contrary, unexplained illness is first known through suffering that is, in the first instance, physically felt and only later related to mental states. Unexplained illness often involves symptoms such as abdominal pain or bloating, head or muscle aches, or (severe) fatigue, which can vary from mild to severely debilitating and is often defined by an immediate and directly experienced bodily discomfort or pain. Where both disability and unexplained illness are up against an able-bodied and able-minded norm, the misfit of unexplained illness holds a more direct conflict with knowledge construction. That is, unexplained illness is confronted with a version of medicine that does not incorporate, include, and legitimize the illness experience of people with unexplained illness.[73] This marginalization, described in the case of Ann, is what then spirals into material consequences, where people with a

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[73] See also my discussion of unexplained illness in relation to disability theory and politics in another, forthcoming publication, Hommes forthcoming "Towards a Theory."

disability or an unexplained illness find themselves equally up against oppressive structures.

The failure to connect physical yet organically unexplained symptoms to the commonly held structure of medical explanation defined by physical determinants labels people with unexplained illnesses as outcasts or misfits. Where the ill or disabled bodymind does not fit into spatial or temporal settings that are designed according to able-bodied/able-minded standards, people with unexplained illness are also produced as a misfit in terms of medical classification, which determines and shapes the illness experience and leaves these patients without discursive backing and/or material support.

This chapter is organized around my critique of knowledge practices that define unexplained illness. In this section, my critique is twofold and directly related to this problem. First, it relates to maintaining a mind-body dualism that makes a separation between two entities co-implicated in each other. This dualism is maintained in the different disciplines of medicine and psychiatry and their respective classifications of unexplained illness. Second, I am concerned with the specific knowledge practices that emerge from this separation and which define unexplained illness as either a mental or a physical condition. I locate and engage with these knowledge practices via a tracing of the different classifications of unexplained illness in psychiatry, more specifically in the different publications and revisions of the DSM.

Pointing to knowledge practices, I refer to the foregrounding of the practices in which objects, illnesses, situations, or people are handled. Here, I take my cue from Annemarie Mol, who emphasizes how objects come into being with the practices in which they are manipulated in *The Body Multiple* (2002). She understands knowledge not as a "matter of reference, but as one of manipulation" (2002: 5). This means that her focus shifts from finding "truth" to questioning how objects are handled in practice. In her case, this involved specific ethnographic work done at a local Dutch hospital. Here, Mol looked at the knowledge practices that defined a specific, commonly held to be quite medically explained condition called atherosclerosis, which, when looked at closely, emerged in many different guises. In my current inquiry, I locate the knowledge practices that define unexplained illness in the criteria for classification, which determine how unexplained illness is lived.

Psychiatric classification, and the history of the DSM in particular, has been a contested subject whose problematics largely play out around the notions of truth versus manipulation, as pointed out by Mol. A recurring discussion centers around the extent to which mental disorders can be classified as natural phenomena or are ever-shifting, more elusive, or even culturally defined phenomena, similar to, as Wittgenstein remarked, the shape of clouds.[74] Where to separate pathology from normal variation? How to observe and measure what is defined as abnormal or pathological human behavior in a consistent manner? Here, it might help to consider classification as an act similar to that of drawing a map: as an abstract ordering of a world that calls representational relationship into question.

In an article from 2010 by Valérie November, Eduardo Camacho-Hübner, and Bruno Latour, the authors distinguish between a mimetic and a navigational use of maps. They signal the problem of the territory described by the map being substituted by the representation of it. This separation refers to the problem of the practical use of the map being all too easily translated into a mimetic use: the idea that the map represents reality and is not merely a tool for its navigation. The authors state that there is nothing "obvious, necessary nor natural" about engaging with maps in a mimetic way and that it is striking how little a two-dimensional map "resembles the world it is supposed to 'reflect'" (November et al. 2010: 589). Here, the problem of the mimetic use of a map relates to the difficulty of classification, especially when it concerns physical symptoms classified in psychiatry. The practical need for a map – a navigation of some sort – is in danger of resulting in a mimetic use.

November et al. trace the mimetic understanding of the map back to being an art-historical way of looking that goes back to perspective painting or Dutch painting of the seventeenth century. This, what they call the "one-copy – one-model mode" of realistic painting, was transferred to maps, which in turn were aestheticized. The authors note, however, that this understanding of mimetic representation has no use for understanding science (2010: 590).

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[74] Here I refer to Assen Jablensky's reference to Wittgenstein's *Philosophical Remarks* in the opening to his discussion on the validity and utility of psychiatric classifications. See Jablensky 2016: 26.

A classification of physical symptoms in psychiatry results in a similar effect. The effect of classification is that it provides a practical map with a clear navigational use. This navigational use is often overshadowed by the notion of the map as mimetic: the idea that this map reflects the reality of unexplained symptoms as they are lived. In practice, this often comes to mean that physical and mental symptoms are separated as an either/or. This navigational effect has practical use in determining a focus for treatment but becomes problematic when it is understood in a mimetic way; it leaves the person who is diagnosed with physical symptoms as expressions of mental states open to the stigmatization that is related to the organic unexplainedness of these symptoms.

This problem can be traced back in psychiatric classification to the conflict around the use and meaning of the DSM as either a practical manual meant to assist diagnostic reliability or as a textbook of psychiatry.[75] In the latter use and meaning, the DSM is at risk of being treated mimetically: its descriptions are open to being understood as representing lived symptoms in a certain way. In the former use, the DSM is treated merely as a tool for navigation: as a manual used in clinical practice that helps to assist in treating lived experience, which it does not ultimately represent. When used as navigation, the separation made between symptoms, either mental or physical, only refers to the practical needs for classification, finding common ground and means of communication amongst practitioners, and giving a direction for treatment, amongst others.

Taking the insights of November et al. back to the problem of classification, it becomes apparent that, without claiming the mind-body separation necessary for classification as having any traction in reality, psychiatric classification need not pose a problem for unexplained illness per se. Thinking of classification as an act that is similar to mapping and that produces similar effects then helps to remind one of the practical need for classification. Classification does not necessarily have to result in a claim on reality – which is where the terrain gets muddy.

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[75] In an overview-article discussing different revisions from DSM-I to DSM-5, Blashfield et al. state how a lack of clarification on the part of the DSM concerning its mission, as either aiding researchers or practitioners, results in criteria which are “too specific for clinicians and not specific enough for researchers” See Blashfield et al. 2014: 44. See also: Sadler 2013; Kendler and Parnas 2012: xiii.

In a discussion on psychiatric classification, psychiatrist Assen Jablensky states that the current discussion within psychiatry has not resulted in very different answers than in what he refers to as the earlier periods of scientific psychiatry. He suggests that this is due to shortcomings in the nosological classifications that were adopted since the beginning of the twentieth century (2016: 26). These shortcomings have been referred to in reference to the "atheoretical" claim that characterized revisions of the DSM from 1980 onwards (Aragona 2013: 166; Demazeux 2015: 7). This "atheoretical" nature included implicit philosophical assumptions on psychiatric classification which psychiatrist and philosopher Massimiliano Aragona describes as neo-positivist (2013: 167); a starch emphasis on observable facts and experimentation in favor of a "purely" descriptive approach to reality that at the same time overlooked its own theoretical assumptions. Both Jablensky and Aragona state that these shortcomings continue all the way to the present versions of the DSM (Aragona 2013: 166) and the International Classification of Diseases (hereafter ICD), issued by the WHO (Jablensky 2016: 26). Writing in 2016, Jablensky refers to the currently in-use DSM-5, which went into effect in 2013 and ICD-10, which dates from 2014. In order to set up my tracing of psychiatric classification of physical symptoms in the following sections, I first contextualize how psychiatric classification of physical symptoms continues to move between a mimetic and navigational function.

The first issue of the DSM was issued in 1952 and was a relatively small publication, including only 128 categories listed in a mere 132 pages that cost $3,- at the time (APA 1952; Blashfield et al. 2014: 28). By contrast, the DSM-5 lists 541 diagnostic categories, described in 947 pages and costs around $199,- per hardback copy (APA 2013; Blashfield et al. 2014: 41). The rising numbers, in extensiveness, size, and cost reflect the growing importance of the DSM within the ever-increasing professionalization of psychiatry and psychology, in which the DSM is not only used as a clinical manual to diagnose patients with, but also as textbook for the discipline.[76] According to the preface to DSM-5, the manual is a "tool for clinicians, an essential educational resource for students and practitioners, and a reference for researchers in the field." In this description,

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[76] The rising number of diagnoses, that grew steady with every revision, also points to a movement of expanding diagnostic reach towards mental states previously considered normal. This medicalization is one of the leading critiques of psychiatry today, also addressing conflicts of interest and the entanglement of psychiatry to the pharmaceutical industry's gains in formulating diagnosis for which a drug can offer "cure." On this subject, see *Medicating Normal* 2020; Burston 2018.

the difference between tool, resource, and reference is not made specific. However, the claim is made that “fortunately, all of these uses are mutually compatible” and were considered when revising the manual (APA 2013: xli). Depending on the context and manner in which the DSM is used as either a resource or reference, the latter two uses of the classification made in the DSM risk shifting the diagnostic criteria from having a navigational to having a mimetic function.

The immensity of the DSM’s ambitions and its wide reach outside the mere clinical diagnostic setting has been a returning point of critique in literature commenting on the manual, noting that it “has fallen victim to its success” (Marecek and Gavey 2013: 4) or that it is “too powerful for its own good” (Frances 2013a: xiv). The process for the revision resulting in DSM-5 started in 1999 and included what was called the “Prelude Project,” a website that provided, according to a news article from psychiatry online in 2004: “an opportunity for all DSM users to participate in the earliest stages of the revision process by submitting comments and suggestions” (Sirovatka 2004: n.pag.). In response to the first draft, which was posted in 2010, 8000 comments were submitted, followed by 2000 comments in response to the second draft the next year (Blashfield et al. 2014: 41). The opening of the discussion, which took place in the then new and rapidly developing online spaces is described by Blashfield et al.: a resulting “staunch opposition” which the leaders of the DSM-5 had not anticipated (2014: 41).

The revision of the manual was organized into different work groups, 13 in total, which contained around 500 health professionals (Blashfield et al. 2014: 41). In a preliminary report written by the workgroup on somatic symptom disorders, the authors emphasize their dedication to expand the classificatory process by offering wide opportunities for feedback. They hoped to “embrace” the wide public health implications of classification, “including issues relating to gender, culture, life span, and the psychiatric/general interface”: issues beyond etiology alone (Dimsdale and Creed 2009: 473). The difference between the DSM-IV and DSM-5 somatoform disorders (DSM-IV) and somatic symptom disorder (DSM-5) was immense compared to earlier revisions and resulted in fierce critique from prominent psychiatrists such as Allen Frances (chair of the DSM-IV task force) and Richard Mayou (Emeritus professor of Psychiatry at Oxford University).

Allen Frances goes as far as to say in an interview for *WIRED* Magazine in 2010 that "there is no definition of a mental disorder. It's bullshit. I mean, you just can't define it" (Greenberg 2010). Here, Frances refers not just to the specific revision towards somatic symptom disorder but to the task of psychiatric classification overall. While the workgroup hoped to incorporate thinking of public health implications of defining physical symptoms in psychiatry, also in terms of sociopolitical factors, Frances' critique on the revision towards somatic symptom disorder boils down to how DSM-5 risks mislabeling people with a general medical illness as being mentally ill (Frances 2013b), a risk that he identifies in the general layout of DSM-5.[77] According to Frances, even "seemingly minor changes [in diagnostic criteria] could have a disastrous impact" on people's lives (2013a: xiv). His solution is to set the bar for diagnostic criteria high (2013a: xiii), as was done in the DSM-IV criteria for somatization disorder that required a specific age and experienced length for the onset of symptoms that remain medically unexplained and at least eight symptoms spread around different specified body parts (APA 1994: 446, 449; APA 2000: 486,490). The workgroup leading the revision stated that clinicians found this specificity cumbersome, and diagnosis was "extremely rare" because of its stringent nature (Dimsdale et al. 2013: 224). The revision was hoped to be more useful and to better reflect the frequency with which these symptoms are seen in clinical practice (Dimsdale and Creed 2009: 474).

The main difference between the DSM-5 classification of somatic symptom disorder as opposed to the DSM-IV somatoform disorders was the latter's reliance on medically unexplained symptoms, thus maintaining a strong mind-body dualism in the way somatic symptoms were defined in psychiatry. In DSM-IV, the existence of a symptom that could not be explained in medical terms was a prerequisite for psychiatric

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[77] After his early retirement from a successful career in psychiatry, Frances published a popular non-fiction account of his experiences called *Saving Normal: An Insider's Revolt Against Out-of-Control Psychiatric Diagnosis, DSM-5, Big Pharma, and the Medicalization of Ordinary Life* (2013a), which was met by much media attention outside of psychiatry. Written in a compelling narrative fashion and in a personal tone, Frances describes his own temptation to make his mark on the DSM, as well as his colleagues career-driven pet projects. After hearing he was to chair the task force for DSM-IV he describes being very much excited during a long walk on the beach, only then to realize that in every problem he would correct he would be creating new ones, and that there was no reason why he, or anyone else should trust their "pet ideas." "All changes to the diagnostic system should be science driven and evidenced based, not influenced by my personal whims or anyone else's" (2013a: xiii). Frances' personal warning note on psychiatric classification calls on feelings of responsibility of psychiatrists themselves: to not value their own wishes and "naïve enthusiasm" for reform over science-driven, evidence-based data (2013a: xvi).

diagnosis. This criterium was removed in DSM-5 to make way for a wider and more positive basis of diagnosis based on psychological criteria, not on what was lacking medically. The main criterion for somatic symptom disorder was “the patient’s difficulty in tolerating physical discomfort and in coping adaptively with bodily symptoms” (Dimsdale and Creed 2009: 474).

A commonly voiced critique towards the DSM-IV-based criteria for somatoform disorder had been that it perpetuated mind-body dualism, which the DSM-5 work group now wanted to avoid (Dimsdale and Creed 2009: 473; Creed et al. 2010: 6; First 2011: 594). According to Mayou, in his commentary on the revision, the text of the DSM-5 class for somatic symptom disorders remains, however, “firmly dualist” in its references to “somatizing individuals” (2014: 419).[78] Even so, the attempt to remove the dualist basis of the classification is an important goal for the workgroup and also applauded in the critique by Mayou, both thereby recognizing the difficulty of separating mind from body and body from mind (Dimsdale and Creed 2009; Mayou 2014). However, the practice of classification and the use of the manual beyond its function as a navigational tool makes it more difficult to shed the dualism that these prominent psychiatrists are so ill-contented with. The very structure of medical science, being separated into different specialties of medicine and psychiatry, already restricts the conditions under which bodyminds can be referred to in an integrated way. A possible way out of this may be found in a field-wide reconsideration of the theoretical foundations upon which DSM classification is based, steering away from mimetic claims and towards a classificatory use as mere navigation.

In clinical terms, the effects of mind-body dualism can also be described as the functional-organic dichotomy that separates between conditions that are either based on organic structures or functional disturbances whose organic cause is unknown. According to Kenneth Kendler, a prominent psychiatrist who also published on the philosophy of psychiatry, such dualistic thinking causes a conceptual impediment to the work of psychiatry itself. He notes how psychiatric research has shown that biological,

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[78] I turn to the specifics of the text of the revision in section 3.5, which discusses the formulations of somatic symptoms in DSM-III, IV and 5.

psychological, and socio-cultural spheres should be integrated and that this effort is yet held back by a “deeply entrenched dualistic thinking” (Kendler 2012: 385).

> most modern psychiatrists and neuroscientists when pressed will deny being dualists, insisting that they are ‘eclectic’ and/or fully recognize that psychiatric disorders are ‘multifactorial.’ Yet, their actions belie their words. In the ways that we think about patients and their treatments, and the etiology of our disorders a strong tendency remains for us to emphasize either a mentalistic mind-based or a biological brain-based view of illness.” (Kendler 2012: 378)

This tendency to refer to illness as either “mentalistic” or biological/organic has further consequences in terms of etiology. Kendler notes that the term “mental,” as used in the *Diagnostic and Statistical Manual for Mental Disorders*, does not only reflect the psychological nature of the symptoms that are classified there but also carries connotations towards their origin. Again, such connotations imply a mimetic use of the mapping that is classification that at the same time shapes its territory. In this way, the listing of somatic symptoms in the DSM implies that the origin of the symptoms lies in the mind instead of the body.

According to Kendler, this is mainly a problem of vocabulary and ways of thinking that has little trace in nature (2012: 378). This problem of vocabulary and ways of thinking is located in the conceptualization of classification as having a mimetic function: mapping certain groups together and separating between others in a way that can never fully do justice to the complexities of lived reality. Taking into account Frances’ critique on the far-reaching consequences of psychiatric diagnosis today, in which he identifies multiple factors like pharmaceutical gains and psychiatrists’ ambitions beyond the strictly knowledge-related part of psychiatric classification (2013a), this manipulation of a territory, or what Mol calls objects of knowledge, is one to take seriously.

The history of critiques of psychiatry, sometimes summarized as anti-psychiatry, shows that similar issues have been long addressed, most notably by Michel Foucault, R.D Laing, and Thomas Szasz. In a review addressing psychiatry, anti-psychiatry, and anti-anti-psychiatry, Daniel Burston notes that all three of these theorists resisted the anti-psychiatry label (2018: 6) and that the term today is mainly used as a derogative term by psychiatrists: “to lump many cogent and thoughtful critics of psychiatry together indiscriminately, and to silence, ignore, or drastically oversimplify their individual contributions in the process" (2018: 4). Burston identifies a way in which anti-psychiatry becomes a useful term for psychiatry to disregard critiques as being empty or merely "anti" without attending to the practical need for psychiatric care, diagnosis and classification. In my present inquiry, I am not so much concerned with a critique of psychiatry overall but with the effects of the psychiatric classification of bodily symptoms. Attending to classification as knowledge practices circumvents an oversimplified account of all that is wrong with psychiatry in general in favor of an analysis of how classification is done and how it shapes illness experience as an effect.

The stubborn pervasiveness of mind-body dualism within the psychiatric classification of bodily symptoms is key to this endeavor. Kendler traced the origins of the functional-organic dichotomy within psychiatry to the early development of psychiatry in the nineteenth and early twentieth centuries. In this period, the developing discipline separated between neurology and psychiatry, where the former became concerned with disorders that produced consistent neuropathological findings, and psychiatry got, in Kendler's words, "what was left" (2012: 378).

In this period of disciplinary formation, two weighty figures, both born in the year 1856, were at work around the same time: Sigmund Freud and Emil Kraepelin. Where Freud slowly moved away from his early physiologist neurological work, dissecting fish in the lab of Ernst Brücke and developing what is now known as psychoanalysis, Kraepelin similarly began his career doing lab work and would later write a classification of psychiatric disorders whose legacy was celebrated widely within a medically oriented psychiatry, leading him the reputation of a "tough-minded, brain-focused, hard-nosed nosologist" (Engstrom and Kendler 2015: 1190). The reputation of both men in terms of their legacy has come to stand for radically different strands in post-war US psychiatry, the time when the classificatory system that psychiatry is based on today was developed.

In the following section, I trace the two different tracks associated with the different figures. Both Kraepelin and Freud worked to map bodyminds in different ways. I describe these two tracks as separate yet being part of the same nervous route of classification that eventually works to mentalize symptoms that are part of unexplained illness. In doing so, I aim for three things. First, the next section provides a limited yet necessary medical history that contextualizes and explains the attempts to provide a medical classification of unexplained symptoms. Second, this shows ways in which the classification of unexplained illness became embedded in psychiatry, a discipline still in the making at the turn of the twentieth century. Third, presenting both a Freudian and Kraepelinian track of the nervous route of classification shows the limitations of the classificatory act, which I argue, is in this case, especially *nervous* when it tries to map symptoms experienced within "the body," but viewed as originating within "the mind."

3.3 Freud, Kraepelin, Kraepelinians

The dominant reception of the first two editions of the DSM, published in 1952 and 1968, is of them being manuals with a strong psychoanalytical focus (Decker 2013: xvi; Cooper and Blashfield 2016: 449; Greco 2016: 5). The revision of DSM-III, led by Robert Spitzer and published in 1985 reoriented itself around the work of Kraepelin, who then got attributed the reputation of being a great "classificatory separator of the psychoses" (Decker 2013: xvi) and whose work became the basis of the neo-Kraepelinian revolution in psychiatry. Freud's legacy, psychoanalysis, only dominated psychiatry for a brief postwar period (Decker 2013: xvi; Blashfield et. al 2014: 32; Greco 2016: 5) and was largely removed from DSM-III, where the neo-Kraepelinian revolution found no place for etiology or notions of disorders having a basis in early childhood experience or unconscious structures. Instead, it focused on providing clear descriptions and explicit diagnostic criteria. This approach constituted the general "atheoretical claim" of DSM-III cited earlier.

Where Kraepelin today is associated with brain-based research and classification, and Freud with the muddier terrain of unconscious structures that was therefore deemed unscientific and banned from neo-Kraepelinian psychiatry, Freud's thinking has especially stuck to those symptoms that fail to be classified under present-day classificatory systems. Notions like "psychosomatic" and "hysterical" both have close ties to Freudian psychoanalysis, which originated as a treatment for nineteenth-century hysteria, a condition largely characterized by physical symptoms. Present-day psychiatry, oriented around Kraepelin's legacy, formulated clear and demarcated criteria that established how physical symptoms are described as mental disorders.

This section considers the legacy of both men as routes that map the interaction between body and mind differently and as both having a lasting impact on how unexplained illness is perceived today. Both routes partly intersect and overlap yet end up in different, more and less desirable places for patients with unexplained illness. Where the neo-Kraepelinian interpretation of symptoms separates, maps, and classifies, it leads to a place of in/exclusion, resulting in consequences for the patients concerned. What can be seen as a more Freudian-oriented interpretation of bodily symptoms as having a mental origin is one that is more directly associated with the stigmatization of the patient and the experienced symptoms based on their (unconscious) mental origins.

In 1907, in one of his letters to Carl Jung, Freud wrote of a patient they had both examined. Freud expresses his eagerness to hear Jung's opinion on his diagnosis.

> Now his attack looks like this: He is standing in front of a door, screaming, roaring, racing and spitting. When you look at the scene, you notice at first glance – *but a real psychiatrist is not allowed to see what is not in the Kraepelin* – that he puts two fingers of his right hand into a groove in the door (so I saw it) and moves up and down, i.e. he imitates coitus! (Freud, 2013 [1907]: 1746; emphasis added).[79]

Freud's diagnosis of the patient is an early form of compulsory hysteria and not dementia praecox (Freud 2013 [1907]: 1745), a condition classified by Kraepelin as a degenerative psychiatric illness (Adityanjee et al. 1999: 439). At the time, Kraepelin had just published one of his versions of what Freud mockingly referred to as "the Kraepelin": an eight-volume textbook of psychiatric classification. Freud's interpretation of the attack is that the boy is a spectator of a sex scene to which he reacts with rage. He is both a bystander and participant in the scene at once, for his spitting is interpreted by Freud as ejaculation. Freud mentions that the boy slept with his parents until he was ten so that "one can guess which couple he is eavesdropping on" (1746). In the interpretation of the symptoms,

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[79] Translation from the German original by the author. The original reads: "Jetzt sieht sein Anfall so aus: Er steht vor einer Türe, schreit, brüllt, rast und spuckt. Wenn man sich die Szene ansieht, merkt man auf den ersten Bück – aber ein richtiger Psychiater darf ja nicht sehen, was nicht im Kraepelin steht –, dass er mit zwei Fingern der rechten Hand in einer Rinne des Türflügels (so sah ich es) auf und ab fährt, d.h. er imitiert einen Koitus!" (Freud 2013 [1907]: 1746).

Freud includes information on the boy's family life and early experiences to read the signs of the attack. His diagnosis is that it is a form of compulsory hysteria, a sexually driven diagnosis, rather than a degeneration of the mind. While doing so, Freud connects the name Kraepelin to a classification model that he mockingly refers to as "real psychiatry," one that only sees what is already classified. His approach to this case is to *read* the symptoms, not to classify them, and to connect them to early life experiences to make a diagnosis.

In today's terms, dementia praecox – the Latinized version of the French *démence précoce* – cannot be described as a neutral term. Its translation refers to a premature deterioration process and is used to describe "mental weakness" or "defect" (Sarteschi 2014). Throughout his eight-part *Lehrbuch*, Kraepelin develops what will be known as the Kraepelinian dichotomy in psychiatry: a radical simplification of the nineteenth-century classification of mental disorders between dementia praecox and manic-depressive disorders. The division is broadly between major mood disorders and psychotic illness. In recent psychiatric research, the dichotomy is broadened to a distinction between affective and non-affective psychoses (Compton and Guze 1995: 197). Although, according to Hannah Decker, towards the end of his life, Kraepelin said that there was "nothing holy about his nosology," the Kraepelinian dichotomy became his biggest legacy in modern psychiatry (2007: 340). Later, dementia praecox would be renamed as schizophrenia by Eugen Bleuler and, according to Zilboorg and Henry, "within fifteen years after Kraepelin stated that there was a definite disease 'dementia praecox,' the whole concept was changed" (1941: 502).

In Kraepelin's time, his contemporaries met the nosology with skepticism (Palm and Möller 2011: 318). Today, references to the dichotomy are made, stating that it "has been enshrined in Western psychiatry for over a century and continues to influence clinical practice, research, and public perceptions of mental illness" (Craddock and Owen 2010: 92). A study published in 2002 by Möller et al., a group of prominent psychiatrists, presents a fifteen-year follow-up study in which the authors assessed the present place of the dichotomy in psychiatry. According to their preliminary findings, the authors state that from their assessment of the data, the dichotomy can still be supported (2002: 93). In a sense, the study confirms a closed feedback loop in which an implicitly neo-Kraepelinian approach is used to validate and support the Kraepelinian dichotomy. The maintenance of the dichotomy, and more so, the interest of contemporary psychiatrists in the present form of the dichotomy, gives an insight into Kraepelin's central role in psychiatry today.

Kraepelin's *Lehrbuch*, which was looked forward to as avidly as present-day revisions of the DSM (Shorter 2015: 60), was described as "a summary of the many classificatory systems proposed during the nineteenth century" (Blashfield 1984: 8). Important to late twentieth-century commentaries that celebrated Kraepelin's work was his view on mental disorders as representations of underlying disease states, which could be grouped according to similarities among patients whose disorders had a similar course (Blashfield 1984: 8). Gerald Grob, a historian of mental illness and medicine, wrote of Kraepelin's approach as follows.

> Dealing with a large mass of data, he sorted out everything that individuals had in common, omitting what he regarded as purely personal data. In this respect he diverted attention away from the unique circumstances of individuals toward more general and presumably universal disease entities. (Grob 1991: 423)

In the later celebration of Kraepelin's work, the attention away from the individual circumstances towards a generalized notion of illness made Kraepelin such a suitable figure on which to base psychiatric classification. However, the omitting of personal data, as described by Grob, can be seen just as much as a reading of the material at hand as Freud's interpretation of the attack: it exposes a choice of focus.

It is, however, unclear whether and with what particular interest the historical Kraepelin was focused on universalizing principles, as described by Grob. In an article evaluating Kraepelin's reputation against the historical person and his writings, Engstrom and Kendler quote the sixth edition of Kraepelin's *Lehrbuch*, where Kraepelin states that "Nowhere does the specific individuality, the sensitivity of the patient in question, play a greater role than in the causation of insanity due to mental factors" (Kraepelin, qt. in Engstrom and Kendler 2015: 1192). In an adapted and translated version of the seventh edition of the *Lehrbuch* in English, published in 1912, Kraepelin discusses methods of examination and stresses the importance of close and detailed questioning that should include a patient's family history and personal circumstances (Kraepelin 1912: 97). He explicitly states that "general questions are wholly inadequate" and that examination requires close and detailed questioning (Kraepelin 1912: 98). However, the focus on the specifics of the individual patient is directed at creating an image of the illness that is as scientifically exact as possible, which can later be analyzed in relation to other presentations of illness in order to create a general classification of different forms of mental illness. It is understood as a reality that is, in theory, mappable in relation to other manifestations of illness.

Where the theory underlying psychoanalysis has led it to be banned from present-day evidence-based psychiatry, the theory underlying a Kraepelinian form of classification is less conspicuous. The Kraepelinian approach is now seen as part of psychiatry – or even as an origin that psychiatry returned to in order to establish a reliable field. Kraepelin taught his students not to interpret but to describe (Decker 2007: 340) and was devoted to empirical research. However, in her review of the historical Kraepelin, historian Hannah Decker argues that by today's standards, but also to his own contemporary critics, Kraepelin's deductions and his record keeping were not scientifically sound in terms of preconceived notions and observer bias and that "his legacy is balanced on shaky empirical foundations" (2007: 341). According to Paul Hoff, a psychiatrist who published extensively on Kraepelin and the Kraepelinian tradition in psychiatry, there exists a specific lack of unbiased histories of Kraepelin (2000: 2). Such accounts point to the strategic way in which Kraepelin's name serves to support a neo-Kraepelinian claim on psychiatry as a reliable science. Freud also aspired to clear and distinct scientific brain-based explanations for psychological behavior, but only Kraepelin's name has come to be associated with what is now called "scientific psychiatry."

According to Engstrom and Kendler, the historical Kraepelin did not "entirely share the brain-based, antipsychological approach to psychiatry that we have come to associate with his name" (2015: 1193). He was critical of the far-reaching brain-focused ambitions of psychiatry in the nineteenth century, for which Theodor Meynert was a central figure (1833-1892). Although Kraepelin was perhaps not as brain-based in his etiological views on mental illness as he was later celebrated for, he did maintain an approach to mental illness as something that could eventually be related back to organic states.[80] This approach was central to his classification. Even so, he became a

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[80] On Kraepelin's opposition to Meynert, see Engstrom and Kendler 2015. On Kraepelin's views on the organic orientation of mental illness, see Noll 2011; 2007.

spokesperson for psychiatry as a science: an empiricist, realist, brain-based, anti-Freud version of it. In the seventh edition of his *Lehrbuch*, Kraepelin writes that:

> Judging from our experience in internal medicine, it is a fair assumption that similar disease processes will produce identical symptom pictures, identical pathological anatomy, and an identical etiology. If, therefore, we possessed a comprehensive knowledge of any one of these three fields, – pathological anatomy, symptomatology, or etiology, – we would at once have a uniform and standard classification of mental diseases […] Cases of mental disease originating in the same causes must also present the same symptoms, and the same pathological findings. (1912: 117)

The nervous route associated with a Kraepelinian approach is one in which mental illnesses could be, ultimately, described as physical entities and organic states. A Kraepelinian classification is predominantly grounded in the belief that all mental states would eventually be traced back to organic structures that produce similar effects in different bodies. Mental illness is not only something that can be observed and described but also pinned down in different parts of the body. For unexplained illnesses, which are, in today's psychiatry, labeled as mental illnesses that present themselves as bodily pain or discomfort, the emphasis on an organic basis of these conditions seems to comply with how the condition is lived, in the first instance by the person experiencing it: as a bodily phenomenon. Yet, the neo-Kraepelinian approach to psychiatric classification includes an emphasis on a "medical model" that maintains a "skeptical" approach and clear, evidence-based observations (Compton and Guze 1995: 199), precisely those that remain absent in the case of unexplained illness. From this perspective, the skepticism of the emphasis on evidence opens the view of the patient experiencing unexplained symptoms as a malingerer: someone who presents symptoms that cannot be verified through objective observation.

The other route that explanations of unexplained illness follow is part of the same territory in which the neo-Kraepelinian path dwells. The Freudian route partly overlaps but eventually leads in a different direction: one in which unexplained illness is further removed from having an organic basis and is thus removed and excluded from dominant evidence-based medical explanations. Like Kraepelin's case, the extent to which the Freudian route directly relates to the historical Freud remains up for discussion. The main characteristic, however, is that in the Freudian interpretation of unexplained illness, it is understood as a manifestation of repressed feelings or desires, which manifests as physical symptoms. An interesting and complicated matter is how this transference, or "mysterious leap" from mind to body, was understood and conceptualized, both in Freud's original research and in later Freudian interpretations.

Writing on the role of biology in Freud's writings as well as in feminist commentaries on Freud, Elizabeth Wilson stated that "oddly enough, it is the very mechanism of conversion (of psyche into soma) that has been the least explored aspect of conversion hysteria" (2004: 5). Wilson addressed the way in which feminist interest in Freud and Freudian research on hysteria engaged with the illness as ideational or culturally defined. Here, she points to the neglect of the biology behind Freud's claims. Freud's work at the Salpêtrière with Charcot that set him on to research hysteria is well known, but less often mentioned is his time as a scientific researcher with physiologist Ernst Brücke between 1876 and 1882, investigating the spinal cord of the lamprey, as well as his time with the then famous neurologist Theodor Meynert in 1883.[81]

In her 2015 monograph *Localization and its Discontents: a Genealogy of Psychoanalysis and the Neuro Disciplines*, Katja Guenther argues against the common mode of referencing Freud's neurological work within the humanities as an early "hindrance" to the development of psychoanalysis. Instead, she states that Freud's career can be seen as the "result of an internal criticism and reformulation of the neuropsychiatric tradition" (70). As psychiatry re-oriented itself from a brief post-war psychoanalytically oriented period towards the work of Kraepelin, it further pushed Freud's legacy out of psychiatry into the realm of literature and the humanities. According to Guenther, however, the story of a clean break between Freud's neurological work and his analytic career is not as simple as is often believed, and psychoanalysis and neurology would be better considered as having the same heritage.

Freud's study of hysteria's bodily symptoms, such as bodily paralysis, loss of speech, or gastric pains, set him on track to understand the causes of these ailments as conversions. That is, as an effect, or deferred action, *Nachträglichkeit* in German, of mental processes. Although the concept is not yet mentioned in the *Studies on Hysteria*

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[81] For a brief account of Freud's time at Brücke's lab, see Wilson 2004: 2-3. For an overview of Theodor Meynert's research into neurology, and its influence on Freud, see Guenther 2015.

that Freud wrote together with Joseph Breuer, traces of the notion are already present when Freud and Breuer speak of hysteria as being related to "psychical trauma," the memory of which "acts like a foreign body which long after its entry must continue to be regarded as an agent that is still at work" (Freud 1955 [1893-1895]: 6).

Important to the understanding of the causes of hysteria for Breuer and Freud is the notion of energy and affect. If there has been an energetic reaction to an event that provokes an affect, the affect disappears as a result. "If the reaction is suppressed, the affect remains attached to the memory" (1955 [1893-1895]: 8). The treatment that Breuer and Freud suggested consisted of what they call an *abreaction*, or a discharge of sorts that is offered through the cathartic method of what would later become psychoanalysis.

James Strachey, Freud's translator and editor in English, notes that key to understanding the necessity of the abreaction is the principle of constancy, which forms the theoretical basis for the hypothesis (Freud 1955 [1893-1895]: xx). Strachey's observation eventually places the general understanding of the etiology of hysteria in what Freud understood as being physiological processes. The notion of the principle of constancy refers to the idea that affective energy, later also called libido by Freud, strives to maintain a balanced state. Freud described the charge of this energy as *Besetzung*, which was translated as *Cathexis* by Strachey.[82]

According to Strachey, "there can be no doubt that at the time of the publication of the *Studies* [*on Hysteria*] Freud regarded the term 'cathexis' as a purely physiological one" (Freud 1955 [1893-1895]: xxiii), a use which changed in Freud's later writings.[83] A few months after the publication of the *Studies on Hysteria* with Breuer in 1895, Freud started to write the *Project for a Scientific Psychology* (Freud 1955 [1893-1895]: xx), which he later abandoned and which was only published in unfinished state in 1950

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[82] The translation was subject to a wave of criticism from the 1980's onwards, pointing to the difference between the colloquial use of the German *Besetzung* and *Cathexis*, having a Greek origin and having more direct connotation to the notion of charge, which Strachey considered central to Freud's use of *Besetzung*. See Hoffer 2005.

[83] General psychoanalytic understanding of *Cathexis* described it as a process that attaches energy, or libido, to an object. In Freud's later writings, the emphasis on physiological energy shifts to *cathexis* as a process that is related to the affects. According to the *International Dictionary of Psychoanalysis*, "A feeling not cathected with energy, or loaded with a certain quantity of affect, does not become fixed in memory" (Denis 2005: 259).

(Freud 1962 [1893-1899]: 62).[84] The attempt was to describe the workings of psychic processes like memory, perception, consciousness, affect or symptom formation in neurobiological terms (Glucksman 2016: 70).

What does it mean that the early Freud believed in the physiological/neurological basis of mental states? First of all, the shared heritage of psychoanalysis and neuroscience exposes a continued focus on the same object: the description of the interaction between what is perceived as separate yet present as inextricable states: the mental and the physiological. In both later disciplines, the interaction between either brain and physiology or mind and body remains a central notion that eventually leads to different conceptualizations. This leads me to my second point. Freud's notion of physiology, which could not be proved at the time through fMRI or EEGs, remained merely a theorization on etiology without demonstrable facts. With the neo-Kraepelinian revolution in psychiatry, etiology no longer occupied a prominent place in psychiatric classification according to the "medical model," in which only observable empirical facts counted. With the disappearance of Freud's neurological work from the history of psychiatry, emphasis was placed on Freud's described psychological aspect of the symptoms or the "psychogenic" origins of physical disease, whose understanding is now stripped of its physiological underpinnings. At present, when no organic cause for physical symptoms is found, this opens the way to conceptualize unexplained physical symptoms as being originated in the mind, a route that is now understood as a Freudian one and which has potentially marginalizing effects on people with unexplained illnesses.

For conditions with symptoms that present as predominantly mental states, the neo-Kraepelinian state of present psychiatry classifies such symptoms based on their presentation without needing to state a presumed etiology. The current classificatory system provides a more complicated situation for conditions with symptoms that present as bodily pain or discomfort without identifiable organic cause. Their classification as

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[84] According to Wilson, it remains a contested issue amongst readers of the early Freud whether he "abandoned, or simply sublimated, his neurological ambitions" (2004: 97). Myron Glucksman states that the abandonment of the project was due to Freud lacking the information and technology that became available in the following century (2016: 69). Mark Germine mentions the effect that Freud's cocaine use might have had during the time he worked on the project (1998: 80), but it remains guesswork to speculate on the reasons for his abandonment of the project. Whatever reasons there might have been for the abandonment, the start and the ambition of the project shows how Freud was concerned with grounding observations on mental states in physiological reality.

mental illness would automatically include an implication on the psychogenic origin of the bodily symptoms. Although unexplained illness as a criterion for psychiatric diagnosis was removed from the latest revision of DSM-5 in 2013, it left medically unexplained conditions open for a different kind of explanation, not based on classification but on the description of mental processes that go back to Freud.

Having laid out the separation between different traditions that yet merge in the context of unexplained illness, I will move to discuss the formulations used to describe bodily symptoms in the first two editions of the DSM in the next section. In these early editions, particular attention is paid to their conceptualization as reactions to the environment. Discussing the early formulations of unexplained illness within classificatory psychiatry shows the continued struggle that the different traditions result in, a struggle that I ultimately trace to the current classification for physical symptoms within psychiatry within DSM-5.

3.4 Names and "Reactions" in DSM-I and II

In 1949, a master's degree student in industrial psychology from Pennsylvania State University caused an uproar in the American psychiatric community. In *The Journal of Abnormal and Social Psychology*, the student named Phillip Ash published an article called "The Reliability of Psychiatric Diagnoses." Ash studied the psychiatric diagnosis of 52 White males who were under the "official cognizance" of a government agency. The agency is not named, but it had a clinic connected to it, where the men were to be diagnosed "to screen out the psychotic and mentally defective" (Ash 1949: 272). Three psychiatrists were employed by the clinic that used a diagnostic system that included five major categories, the first of which was "mental deficiency." This category was subdivided into four grades of mental deficiency: "High-grade moron, Middle grade moron, Low grade moron and Imbecile" (Ash 1949: 272).

Psychiatry has come a long way since then. Within three years, these subdivisions were deleted from the psychiatric vocabulary.[85] With his study, Ash had wanted to show how psychiatric diagnosis might not be as reliable as previously thought.

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[85] In DSM-I the terms, "moron," "idiot" and "imbecile" have been eliminated in the development of the manual (APA 1952: 10).

The three psychiatrists working in the clinic used the same diagnostic system but only agreed on the same specific diagnostic category in twenty percent of the cases (Ash 1949: 273). The diagnostic system used in the study followed the American Psychiatric Association which had issued different diagnostic systems over the years. Ash does not mention the specific system, meaning it is impossible to review its functioning or evaluate how remarkable the diagnostic agreement actually was. Three years after the publication of Ash's study, the American Psychiatric Association issued the first version of the DSM.

Before 1952, the American Psychiatric Association used at least four systems. Commenting on this, the authors of DSM-I point out that "practically every teaching center" made modifications for their own use (APA 1952: vii). Ash's study partly set in motion a wave of reliability studies on psychiatric diagnosis around the 1950s to the 1970s (Matarazzo 1983; Mehlman 1952). Setting out on a path towards clearer and stricter guidelines to objectify the moment of diagnosis, these studies were concerned with finding agreements among clinicians, thus wanting to establish some kind of consensus on what constitutes (mental) disease. DSM-I and DSM-II, however, still reserved relatively little space for descriptions of the diagnosis, leaving much open to the interpretation of individual clinicians.

In DSM-I and II, mental diseases are referred to as *reactions*, such as affective reactions, schizophrenic reactions, or psychophysiological gastrointestinal reactions (APA 1952: 5-6). In secondary literature, this formulation is attributed to the heritage of Adolf Meyer (1866-1950), an influential psychiatrist in the early half of the twentieth century (Decker 2013: 133; Lamb 2014: 21; Blashfield 1984: 126). For Meyer, clinical syndromes represented behavioral reactions to experienced changes in one's internal environment. His conviction that psychiatric disorders must be seen as reactions meant that Meyer saw little use in classification since diseases/mental disorders were direct outcomes of a person's unique "biology and experience."

In a monograph on Meyer, historian of science and medicine, Susan Lamb writes of Meyer's far-reaching influence on American psychiatry in the first half of the twentieth century. Meyer held a specific view on psychobiology, a distinctive approach that saw psychiatry as a branch of biology (Lamb 2014). Lamb describes the fundamentals of Meyer's psychobiology as the belief that mental disease is not seen as an "ontological disease but as *a failure to adapt*, resulting from multiple and interdependent anatomical, physiological and mental variables" (2014: 21; emphasis added). According to Lamb, Meyer had an "intolerance for all forms of reductionism and dualism" and eventually held to the idea that "biological adaptation" was key to understanding psychopathology (2014: 66). Vaguely echoing Darwinist tendencies, this meant that disorders were seen as a deterioration of some sorts, or, in Lamb's interpretation of Meyer, as a "dismantling of evolutionary upgrades" (2014: 68).

Although the formulation of mental disease as reactions, so characteristic of especially the first edition of the DSM, is often attributed to Meyer's influence, the first two editions themselves cannot be characterized as Meyerian publications. Meyer himself was rather critical of the use and function of such a system. In Gerald Grob's influential article on the origins of the DSM, Meyer is described as "the major opponent" to adopting a uniform psychiatric nosology (1991: 426). Yet Meyer's influence on the conceptualization of illness as reactions and the normative claim that is attached to the reactions being either fitting or failed is found throughout the manual. The main division of the manual is of mental disorders that are associated with "organic brain disturbance" and of those occurring without "such primary disturbance of brain function" (APA 1952: 12), thus maintaining a separation based on presumed etiology. The section titled "Disorders of psychogenic origin or without clearly defined physical cause or structural change in the brain" opens with the following description of psychotic disorders.

> These disorders are characterized by a varying degree of personality disintegration and failure to test and evaluate correctly external reality in various spheres. In addition, individuals with such disorders fail in their ability to relate themselves effectively to other people or to their own work. (APA 1952: 24)

The different diagnostic classifications described in this section are called reactions, such as involutional psychotic reaction or manic-depressive reactions. "Schizophrenic reactions" also fall within this category (APA 1952: 26-28). The language of failure clearly indicates a normative conception of illness, where reactions to the environment can either be right (healthy) or wrong (diseased). In this scheme, individuals presenting the wrong reaction have failed to relate to the environment in the right way. Thinking back on Ann, the patient whose diagnostic quest opened this chapter, this notion of failure that is offloaded to the patient has not completely been removed from the implications of the psychiatric diagnosis of bodily symptoms today. In her case, it still stuck to the way she feared she was perceived by her healthcare providers. While the DSM mutates and changes along with culture, a tracing of this route exposes the stubborn implications of presumed etiology for people with unexplained illnesses. It is here that a valuation of mental vs organic causes, an emphasis on the organic explainability of physical symptoms, a notion of unconscious structures, and a stigmatization of mental illness collide.

In DSM-I, symptoms that present as bodily complaints are listed as "Psychophysiologic autonomic and visceral disorders." The authors prefer this term above psychosomatic disorders because psychosomatic has connotations on the medical discipline of psychosomatics as a whole (APA 1952: 29), which was influential around the publication of the first DSM. The class of listed "reactions" is described as follows.

> These reactions represent the visceral expression of affect which may be thereby largely prevented from being conscious. The symptoms are due to a chronic and exaggerated state of the normal physiological expression of emotion, with the feeling, or subjective part, repressed. Such long continued visceral states may eventually lead to structural changes. (APA 1952: 29)

Strikingly, the description specifically addresses the causes for these experienced symptoms, which are placed in the exaggerated state of what is considered "normal physiological expression of emotion." The affect is described as visceral: a more bodily than conscious state. The implication is that if the consciousness or a feeling towards something is repressed, it manifests itself in visceral states that may eventually have lasting consequences on the body itself. The idea is that when an event is not adequately addressed, and the individual fails to meet an appropriate reaction to it, it can eventually culminate in physical illness for which the individual can be held accountable.

Accountability is not a term used in the DSM but comes to the fore with the explicit mention of emotions that are seen to play a causative role in the etiology of the symptoms. All ten reactions listed under "psychophysiologic autonomic and visceral disorders" specifically mention the "causative role of emotional factors" for the formation of the condition. In the case of "psychophysiologic cardiovascular reaction" for instance, the formulation is as follows.

> This category includes such types of cardiovascular disorders as paroxysmal tachycardia, hypertension, vascular spasms, migraine, and so forth, in which emotional factors play a causative role. (APA 1952: 30)

The descriptions are pretty straightforward and include relatively little information, let alone criteria for diagnosis, as they are known from later editions of the DSM after DSM-III, published in 1985. In the 1952 manual, reactions are listed along with their presentation in the body. The only further characterization of the reactions is that they have an origin in the mind. The means of specifying in what way the causative function of the mind is determined is not given: it is deduced from the fact that the symptoms are not further medically explained. The second edition of the DSM, published in 1968, keeps to the same formulation, stressing that emotional factors are causative factors. In DSM-II, the class of disorders describing physical symptoms is shortened to "psychophysiologic disorders," leaving behind the autonomic and visceral characterization in naming. It specifically defines these disorders as having a "presumably psychogenic origin" (APA 1968: 46).

The foreword to DSM-II includes a paragraph in which the authors discuss the effects of naming different disorders and their approach to them. They note that their emphasis has been on selecting terms that would facilitate maximum communication within the profession and that they wanted to avoid confusion and ambiguity in the chosen names (APA 1968: viii). More interestingly, they include a note on the act of naming itself in the psychiatric setting.

> Rationalists may be prone to believe the old saying that 'a rose by any other name would smell as sweet'; but psychiatrists know full well that irrational factors belie its validity and that labels of themselves condition our perceptions. The Committee accepted the fact that different names for the same thing imply different attitudes and concepts. It has, however, tried to avoid terms which carry with them *implications* regarding either the nature of a disorder or its causes and has been explicit about causal assumptions when they are integral to a diagnostic concept. (APA 1968: viii; emphasis added)

In the case of bodily symptoms, the authors' causal assumptions form the basis for their inclusion in a diagnostic manual in psychiatry, hence the explicit mention of it. Regarding the different attitudes and concepts attached to a name, the term *psychophysiologic* stands out: it establishes a causal relation (from mind to body) that conditions how this term is perceived. The emphasis on the practical use of communication that the authors deemed most important to the early DSM points to its navigational use: as a manual that enables one to find a way in an otherwise undetermined landscape. Furthermore, the acknowledgment of the effects of naming and the way in which it conditions perception points to a recognition of its mimetic function, which should be reduced to a minimum.

A name that carries an assumption on the nature of a disorder is a name that holds a claim to that disorder and shapes it at the same time. In constructing the manual, the authors recognize that a mimetic use cannot be avoided, although, for them, the manual has, first and foremost, a navigational function. Although the intention is for the manual to be used in a navigational manner, the mimetic effects of classification seem hard to avoid, and the solution offered is to reduce the potentially harmful sides of the mimetic effects by choosing names to navigate within the most neutral manner possible. Overall, the first two editions of the DSM can be seen to be rather self-conscious of their responsibility as providing a manual for psychiatric classification. In later revisions of terms used to describe physical symptoms within psychiatry, this discussion returns, and classificatory naming is adapted according to shifting cultural meanings.

The term *psychophysiologic* was removed in DSM-III in favor of somatization disorder, which presented a large shift from the previous names in terms of reactions. The authors of DSM-III comment on the use of *psychophysiologic* for bodily symptoms within psychiatry by referring to a paper by Looney et al. (1978) that listed the shortcomings of the term.[86] In this paper, Looney et al. note that, amongst other factors, causation is much more complicated than a strict mind-body dichotomy allows and that social and interpersonal factors, such as organic vulnerability, might all interact in the onset of illness and should be included (1978: 305). Overall, the name "psychophysiologic disorders" and the conceptualization of these disorders as reactions can be seen to overly emphasize the mental causation for physical symptoms. Such an emphasis plays into notions of failure on the side of the individual patient and borders on an implication of the patient's accountability in terms of its mental causation.

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[86] This paper is based on mid-twentieth century psychosomatic research by Frances Dunbar and Franz Alexander, both important figures in psychosomatic theory from that period. Looney et al. note that the term psychophysiologic, like psychosomatic, seems to imply a dichotomy which psychosomatic research exactly wanted to avoid (304). The dichotomy that is inherent to, but tried to be overcome in psychosomatic research and thinking is of central focus in Chapter Four of this dissertation.

In turning to consider the formulations in place in DSM-III to DSM-5 in the next section, I will discuss how, in the case of bodily symptoms classified in psychiatry, roses with different names do, to a certain extent, smell just as sweet: although names have changed, their connotation with failure of the individual patient, and the accountability for the creation of the physical symptoms in mental states continues to stick.

Different names do different things. Yet a constant factor in the names for unexplained illness I have thus far described is the stigma that attaches to the term based on the symptoms not being organically explained. This holds for the case of functional disorder, a medical classification resisted by Ann, for the concept of hysteria, as defined by Freud, or for the early DSM classifications as *psychophysiologic*. In the latter two historical formulations, but similarly so in the present use of functional disorder, all three concepts imply a physical presentation of the symptoms that, even though it could not be verified by objective observation, formed an integral part of the conceptual notion of the formulation. Yet, the diagnosis nevertheless places people with unexplained illness outside the realm of medical explicability and leaves them vulnerable to what I have characterized as the Freudian route: the notion that the symptoms are psychogenic, a route that often goes hand in hand with a language of failure on the part of the individual patient and their unconscious, vulnerable mental states for which they are nevertheless held accountable.

In the next section, I further develop the established link between psychiatric classification, the individual as a subject of it, and the Freudian route laid out in the previous section in my discussion of DSM-III to 5.

3.5 The Birth of the DSM – III to 5

In this section, my previous focus on the effects of naming and the classificatory formulations that stood at the center of my discussion of the classification of physical symptoms in DSM-I and DSM-II shifts toward the political and performative nature of classification in DSM-III onwards. The 1980 manual revolutionized psychiatry's focus toward an observable objective approach to knowledge and science. What was born with DSM-III was a paradigm change in psychiatry, in which symptoms were not only listed but meticulously described. Practitioners were given the tools for a far more totalizing practice of psychiatric classification that now not only described a mental state but diagnosed the whole person. This "birth" follows a Foucaultian description of a psychiatric practice that gains territory over the patient, in which the patient is not only classified and described but medicalized to a degree in which psychiatric diagnosis determines and shapes subjectivity through the exertion of power. The act of naming, described as having an effect on patients by the authors of DSM-II, is now expanded as the reach of the DSM widens.

The use of the term paradigm shift to describe the revision of the DSM-II to DSM-III is contested by Monica Greco, who states that the DSM operated precisely not as a paradigm around the time of the early editions. Moreover, the state of psychiatry around 1952 was better described by the absence of a paradigm (Greco 2016: 3). The paradigmatic shift that happened with the introduction of DSM-III must not be looked for in the revision but in the introduction of a comprehensive system, that according to Greco, did come to function in a paradigmatic way (2016: 4). The paradigm shift occurring with the introduction of DSM-III was one in which the DSM and its character as the "bible" of psychiatry, complete with its authoritative and reality-shaping status was born. DSM-III expanded the reach of psychiatric diagnosis, having the effect that psychiatric diagnosis of bodily symptoms become further institutionalized as mental illness. Further establishing the grounds of diagnosis, DSM-III included descriptive text and criteria that established the nature of what was now called somatization within psychiatry.

The modern clinic, as described by Foucault, came into being through the medical gaze: a specific mode of looking organized around a theoretical notion of physiological normality and a standard functioning of organic structure. In section 2.2, I commented on the medical gaze in relation to normativity. In this section, I call upon the medical gaze again to describe a particular change in classificatory logic that came about with the introduction of DSM-III. The construction of DSM-III follows a similar path from Foucault's modern clinic: it organized and standardized knowledge on what constituted (in this case, mental) illness and the place of bodily symptoms in reference to normal functioning and has done so to a degree formerly unknown. This section traces the formulations in place from DSM-III to DSM-5 to describe their effects on people with unexplained illness.

DSM-III introduced the name somatoform disorders as an umbrella term, which would remain the same until the change to somatic symptoms and related disorders in DSM-5. The group of disorders includes five disorders, separated into somatization disorder, conversion disorder (or hysterical neurosis, conversion type), psychogenic pain disorder, hypochondriasis, and atypical somatoform disorder (APA 1980: 241-252). The DSM-III section of somatoform disorders opens with a descriptive text, of which I quote the first paragraph at length.

> The essential features of this group of disorders are physical symptoms suggesting physical disorder (hence, Somatoform) for which there are no demonstrable organic findings or known physiological mechanisms and for which there is positive evidence, or a strong presumption, that the symptoms are linked to psychological factors or conflicts. Unlike Factitious Disorder or Malingering, the symptom production in Somatoform Disorders is not under voluntary control, i.e., the individual does not experience the sense of controlling the production of the symptoms. Although the symptoms of Somatoform Disorders are "physical," the specific pathophysiological processes involved are not demonstrable or understandable by existing laboratory procedures and are conceptualized most clearly using psychological constructs. For that reason, these disorders are not classified as "physical disorders" (APA 1980: 241)

The DSM-I and DSM-II classifications of bodily symptoms emphasized the autonomy of the visceral reaction. The DSM-III text references the lack of demonstrable evidence in a more implicit manner that describes the physical symptoms as part of the workings of the mind. Starting in the first sentence, the text states that the essential feature that characterizes the group of disorders is a physical symptom that only suggests physical disorder, but for which no organic evidence can back up this suggestion. The phrasing in terms of suggestion is a removal from a more neutral description in terms of the absence of organic findings and instead hints at the symptoms themselves being an actor of some sort. In this formulation, the physical symptoms are the actors of the suggestion. These symptoms, however, are no longer described in terms of the patient's unconsciousness but as a production over which the patient experiences a lack of control. In a sense, this removes the accountability attached to earlier formulations, placing the production of unexplained symptoms in the unconscious while at the same time emphasizing the individual lack of control on the side of the patient.

A lack of voluntary control over the production of symptoms is an important aspect of organic illness that is, presumably, unwanted by patients. Yet, in unexplained illness, the link between physical symptoms and psychological factors or conflicts places the lack of control in a different light. Here, the lack of voluntary control refers to how the mind operates: it involuntarily produces physical symptoms "linked to psychological factors or conflicts."

The opening paragraph on somatoform disorders in DSM-III describes that the most clear conceptualization of the symptom is, therefore, found in psychological constructs, which means that the symptoms themselves lose their physical status. In this formulation, the etiology of the symptoms is not specifically mentioned, yet the link to mental causation is made. Furthermore, the symptoms are not only described as having no organic cause but are attributed to a mental status by the removal of the attribute "physical," which is put in quotation marks by the authors of the text, thereby giving way to the impression that these symptoms, which are not classified as physical disorders, exist only "in the mind." Although the notion of unconsciousness is removed from the now neo-Kraepelinian DSM-III, the involuntary mental processes clearly refer to a similar process. The notion is removed, but its function is intact and necessary for the classification to hold. In the classification of physical symptoms within psychiatry, psychoanalytic implications on the etiology of the symptoms, seen as taking place somewhere across the "mysterious leap from body to mind," are hard to shake.

The descriptions of the disorders in DSM-III include not only a name and a short sentence but all kinds of more personalized information on the essential features of the disorder as well. These are associated features such as other disorders frequently seen together, the age of onset, the typical course of the disorder, prevalence and sex ratio (somatization disorder is stated to be rarely diagnosed in males), and familial pattern (APA 1980: 242). In these aspects, the DSM widens its reach and does not only provide a means of communication on the names of different phenomena but maps a particular individual as a disordered one. In the case of somatization disorder, this individual presents their complaints in a "dramatic, vague, or exaggerated way" or has a "complicated medical history in which many physical diagnoses have been considered" and has received medical care from a "number of physicians, sometimes simultaneously." It is someone who is out for medical attention. "Although most people without mental disorders at various times have aches and pains and other physical complaints, they rarely bring them to medical attention" (APA 1980: 241). It is someone who needs this attention where others do not.

Research on attitudes amongst medical practitioners in relation to functional syndrome by Barnett et al. shows that when presented with patients with unexplained medical conditions, a strategy maintained by physicians to manage the uncertainty surrounding these patients was to pass them along to a colleague (Barnett et al. 2022: 1808). This handling by medical practitioners then leads to the situation in which patients with unexplained illness often see many medical practitioners. Seen next to each other, the situation described by Barnett et al. and the description of a patient with DSM-III-based somatization disorder[87] exposes the difficulty of the separation between medicine and psychiatry. It shows how a *strategy* maintained by medical practitioners to not have to deal with unexplained symptoms within medicine becomes a *symptom* within psychiatry. As such, the inability to adequately respond to unexplained illness within a medical setting results in a situation in which responsibility is offloaded onto the patient in psychiatry.

The diagnostic criteria for somatization disorder include a history of physical symptoms of several years duration beginning before the age of 30 and a list of complaints that are gender specific. For women, at least 14 symptoms are required, whereas for men, the criteria count is only 12. The criteria give a specific list of 37 symptoms. They are separated as *pseudoneurological symptoms,* such as difficulty swallowing, paralysis, or muscle weakness; gastrointestinal symptoms, such as abdominal pain or bloating; female reproductive symptoms, such as painful or irregular menstruation; *psychosexual symptoms,* such as sexual indifference or lack of sexual pleasure; pain symptoms, such as back pain or pain on urination, and *cardiopulmonary symptoms,* such as shortness of breath or palpitations (APA 1980: 243-244). The criteria mention that a symptom counts as a symptom when it is acted upon by the patient, such as when the patient has taken medicine, made changes in their daily life, or has seen a physician. It also mentions that

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[87] The mention of the number of physicians seen by the patient in the descriptive text accompanying the disorder in DSM-III was slightly altered in the descriptive text in DSM-IV, where it mentions that patients "often seek treatment from several physicians concurrently, which may lead to complicated and sometimes hazardous combinations of treatments" (APA 1994: 446).

a symptom is assessed based on the patient's report of it, so that it does not matter whether the clinician was convinced that the symptom was present, further emphasizing the patient's behavior over the physical symptoms themselves.

To reiterate: for the psychiatric classification of physical symptoms, what matters is how the patient acts and reports on their physical symptoms rather than assessing if these actually occurred. This is also echoed in the mention of the symptom "Sickly": the patient's "belief" that "he or she has been sickly for a good part of his or her life" (APA 1980: 243). Speaking on the subjective feeling of being sick in terms of belief makes the symptoms suspect in terms of a physical determination. Having to speak to doctors can mean that patients adjust their vocabulary or how they present their symptoms to be believed or taken seriously by medical practitioners.[88] The psychiatric classification of physical symptoms includes not only information on a particular type of individual (age, gender, and familial pattern) but also a list of behavioral traits, such as exaggerated speech, acting according to felt physical symptoms, and a way of reporting on it. At this point, the classification of somatization disorder goes further than describing symptoms for classificatory purposes; it links these symptoms in a Foucaultian fashion to a particular individual at risk of becoming the disordered subject itself.

An account of the formative effect of classification on patients can be found in an essay by filmmaker and digital content creator Jameisha Prescod. Prescod, a young Black person with chronic illness, has a popular social media account called *Youlookokaytome*, on which they share their experiences with chronic illness. Their essay was published in a volume called *On Being Ill*, which included writings by young women and genderqueer artists and writers to accompany Virginia Woolf's original essay. Prescod was diagnosed with lupus, a chronic autoimmune disease that disproportionally affects Black women (Chae et al. 2019).[89] In Prescod's essay, they narrate their own experiences with chronic illness and comment on the fears and tension they experience when going to a doctor.

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[88] I refer back to section 2.2.2, in which I discussed the thin balance patients feel they have to walk to be believed by doctors, sometimes altering how they speak and present their symptoms. This also relates to debates in trans* communities on how to speak to doctors in order to receive the necessary treatment. On this last point, see also Spade 2006.

[89] See my short description of lupus in the introduction to this dissertation, in section 1.2, 37.

> There’s a reason why it feels like you’re sitting in the headmaster’s office when you’re waiting for your appointment. You desperately try to remember all of your symptoms and the dates on which they appeared. You attempt to speak clearly and quickly before your five minutes are up. You try your best to communicate well, but not too well in fear that you will look too healthy, but you also want to be honest so that they don’t accuse you of malingering. You try to be the perfect student or patient – or both. (Prescod 2021: 126)

The use of the second person perspective, often used to immerse the reader into the narrative, here places the implied reader on opposite sides of the mentioned “they”: the archetypical doctor who holds power over the patient who is only trying their best. The reference to the headmaster’s office and the mention of the accusations are both related to power: the possibility that the you of the text has done something wrong for which they will be punished. The “wrong” implied here is the experience of physical symptoms and acting on it by seeking medical help. There are only five minutes in which this “you” can speak of their symptoms. Not only having the symptoms or reaching out and seeking medical help but also wasting the little time granted is feared here. Prescod fears that their symptoms will not be viewed as physical ones but labeled as a mental disorder instead. The desperation that they report is in their attempt to come across as coherent. It remains, however, an attempt of which the assessment is in the hands of an unnamed “them” who hold the power of how the patient, the “you” of the text’s physical symptoms are classified, and thus how they are labeled, medically speaking. Since this label, as it was introduced to psychiatry in DSM-III, includes notions of behavior and personality, it is in danger of classifying not only illness but the person itself.

The descriptive text used to diagnose somatization at the time of use of DSM-III explicitly mentions dramatic, vague, or exaggerated means of presenting physical symptoms as a marker of somatization disorder. Prescod’s essay, written some 40 years after the introduction of DSM-III, echoes this text, which emphasizes the patient’s behavior around the experience of the symptoms. Prescod writes that they resort to a certain vocabulary to receive medical care that treats these symptoms as serious, physical ones.[90] To be referred, to get a scan, and to be medically examined according to the symptoms they themselves report, instead of being prescribed antidepressants, Prescod

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[90] I refer to the quote given above (2021:126). See also note 88.

has to present their symptoms in a particular way. The experience described by Prescod relates to a common feeling amongst people with unexplained illness: that they are not taken seriously or that their practitioner or social surroundings might see them as fraudulent, malingering attention seekers (Nettleton et al. 2005: 207). In Prescod's text, the separation between what is assessed as either physical or mental symptoms influences the type of care they receive and disciplines them into certain behaviors.

In DSM-IV, issued in 1998, the descriptive text for somatization disorder is slightly altered but still mentions a particular way in which patients present their symptoms. In a sense, the text goes even further.

> Individuals with Somatization Disorder usually describe their complaints in colorful, exaggerated terms, but specific factual information is often lacking. They are often inconsistent historians, so that a checklist approach to diagnostic interviewing may be less effective than a thorough review of medical treatments and hospitalizations to document a pattern of frequent somatic complaints. (APA 1994: 446)

Here, the patient's narrative as a reliable source is further drawn to the background, and medical documentation is valued over the patient's account of their own complaints. In contrast to malingering or factitious disorders, the physical symptoms that occur with somatization disorder are not seen as intentional. The colorful or exaggerated terms mentioned are thus not seen as being used to disguise an intentional deceit. Instead, how this kind of speech is described paints a picture of a particular type of personality who exaggerates without them knowing it themselves. This type of speech is called exaggerated in relation to a normative view of symptom presentation that presumes a moderate (not colorful) individual that more easily resembles normative standards. Only with the significant change issued in DSM-5 did the emphasis on exaggerated speech change shape.

The unconscious nature of somatization disorder is an important aspect of the diagnostic criteria. It sets somatization disorder apart from malingering and factitious disorder, where an individual deliberately and knowingly feigns illness. The difference between malingering and factitious disorder is the motivation of the patient. Both names are used to denote a patient who feigns physical or mental symptoms intentionally. Malingering is mentioned in the DSM-III as a focus of clinical attention but is not listed as a disorder (APA 1980: 19). The intentional feigning of illness in malingering serves an external goal, such as avoidance of work or obtaining financial gain (APA 1980: 246; APA 2013: 326).

Factitious disorder is listed as a mental disorder from DSM-III to DSM-5 (APA 1980: 285; APA 2013: 324) and requires the absence of such obvious rewards. It is understood to be motivated by internal factors, such as sympathy for being ill or receiving care from loved ones (Van Impelen et al. 2017: 342).[91] The DSM-III definition of factitious disorder states, "In the past, some of the disorders classified here would have been subsumed within the category of Hysteria" (APA 1980: 286). The same is said of somatization disorder (APA 1980: 241). Although a separation is made between the two based on an unconscious/conscious presentation of symptoms, both are tied to a cultural discourse around hysteria.

The unconscious nature of physical symptoms in somatization disorder means that the presentation of physical symptoms by the patient must be screened for hints of which the patient themselves is not conscious. This difficulty greatly contributes to how the patient is assessed. The feeling described by Prescod of having to thread on thin ice when presenting their symptoms fits within this framework, in which it matters how patients present their symptoms to a medical practitioner. Due to the individual assessment of what could constitute an unconscious creation of physical symptoms, it is impossible to know how to act in "the right way."

Having revolutionized psychiatric classification with the introduction of close descriptions that linked certain personality types to specific disorders, the introduction to the DSM-IV, which followed fourteen years after DSM-III, dedicated a section of text to the question of the definition of mental disorder. First, the authors state that the separation between physical and mental disorders is a "reductionistic anachronism of mind/body dualism," which they name as unfortunate. However, although they note that much literature points to the imbricated nature of both, they have not found an alternative for

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[91] The inclusion of malingering and factitious disorder in psychiatry opens up a different range of questions concerning the reliability of patients in medical settings. More recent attention in popular media has been given to factitious disorder imposed on another, also known as Munchausen syndrome by proxy. See, for instance, *Believe in Magic* 2023. The scope of this dissertation limits the attention that I can give to these formulations of illness, but this conflictual field deserves a critical review within the humanities that looks beyond a dramatization of the deceit.

the use of the term “mental” in mental disorders, so they decided to stick to the term (APA 1994: xxi). They further note that “a common misconception is that a classification of mental disorders classifies people, when actually what are being classified are disorders that people have” (xxii). Here, the authors of DSM-IV refer to the way in which classification is not geared towards disciplinary power but to finding a general common ground amongst practitioners that assist in making diagnoses that ultimately assist in providing care for patients. Similar to the question of naming raised by DSM-II, DSM-IV tries to account for the responsibility that comes with psychiatric classification. Since mental disorders are described in terms of certain types of behavior, a classification of it necessarily concerns the person involved.

Although disciplinary effects of classification are not aimed at by the DSM, Prescod’s account shows how the criteria for classification of physical symptoms within psychiatry are echoed in the feeling of having to watch out when presenting a certain set of physical symptoms in a way that can be perceived as exaggeration. This is both due to the separation made between mental and physical illness and the emphasis on a particular type of dramatic, exaggerated behavior associated with psychiatric diagnosis of physical symptoms, as listed in the DSM. Prescod writes that they wished their family doctor had believed them sooner, “Maybe then, I wouldn’t have so much trouble believing myself all these years later” (2021: 125). Not being believed and being steered towards psychiatric classification also has an effect on the experience of illness for the patients themselves. Prescod writes how the suggestion that their severe physical pains were due to depression became associated with the idea of being dismissed (126). They write how psychiatric diagnosis following physical pain does not only “completely invalidate the lived experience of the patient” but also “further stigmatizes and underestimates the severity of mental health conditions” as it separates the two “as if they are not often born intertwined” (126).

The separation between physical and mental symptoms in psychiatric classification already bothered the authors working on DSM-IV and was even explicitly rejected. Yet the manual continues to rely on the separation when it classifies somatization disorder. Working towards DSM-5, multiple suggestions were made for a classification of somatic symptoms within psychiatry that would avoid this maintained dichotomy. According to Michael Sharpe, who was part of the workgroup on somatic symptom disorders in charge of the revision towards DSM-5, one of the main reasons for revising the diagnostic criteria was that the old definition (under the name of Somatization Disorder) was based on a version of mind-body dualism that the revision wanted to dilute. Sharpe notes that “if no disease is found in the body, it is [in DSM-IV] assumed that the disease is all in the mind” (2013: 320). The main characteristic of DSM-5 diagnostics for physical symptoms, therefore, becomes the *experience* of a large amount of stress *associated with* physical symptoms.

The introductory text to the chapter on somatic symptom and related disorders states, “A distinctive characteristic of many individuals with somatic symptom disorder is not the somatic symptoms per se, but instead the way they present and interpret them” (309). This new method of classification means that generally, every type of illness (also very “medically explained” ones like types of cancer) that incites a large amount of stress can be labeled under DSM-5-based somatic symptom disorder. The name change, from *somatization* to *somatic symptom disorder,* also signifies removal from viewing unexplained physical symptoms within psychiatry as a result of a process that is unconsciously or involuntarily constructed by the patient towards a formulation that focuses on the *existence* of the symptoms.

Allen Frances was the chair of the task force that worked on DSM-IV. In section 5.2, I commented on his fierce general critique of psychiatric classification, which he made public at the time of the work that led to DSM-5. Commenting on the proposed DSM-5 revision, Frances calls to mind how psychiatric diagnosis of physical symptoms has to balance between being overly descriptive or being too loose. Frances’s critique is that the new, looser criteria maintained in DSM-5 risk mislabeling millions of people as being mentally ill. He claims to have suggested to the workgroup to include a reminder to rule out medical explanations before concluding that a mental disorder is present and that clinicians should consider whether the health concerns are completely unrealistic or possibly related to an underlying medical disorder (2013b: 1). The workgroup reviewed and rejected the suggestions, and focused on diagnostic criteria that were not dependent on the existence of medically explained illness. The introductory text to the DSM-5 class of somatic symptom and related disorders mentions that grounding a diagnosis on the absence of an explanation is “problematic and reinforces mind-body dualism” (APA 2013: 309). It even suggests that because of the predominant focus on the lack of medical explanation, “individuals regarded these diagnoses as pejorative and demeaning, implying that their physical symptoms were not ‘real’” (APA 2013: 309).

The fear that is connected to the doctor’s visit, as described by Prescod, was both related to a mind-body dualism resulting in physical symptoms not being taken seriously and to the way in which excessive thoughts on physical symptoms qualify for psychiatric diagnosis that inhibits a patient from receiving further physical medical care. DSM-5 makes a big step in avoiding dualism. Yet, the emphasis comes to be on the excessive thoughts, feelings, or behaviors related to physical symptoms, the assessment of which is placed with the clinician. According to Frances, this disproportionately places women at risk of misdiagnosis “because they are more likely to be casually dismissed as “catastrophizers” when presenting with physical symptoms” (2013b: 2). This sentiment is echoed by Prescod, who states that they feel that their “race and gender are on trial too” (2021: 128) as well as in Ann’s story in the opening of this chapter, who emphasized her position as a woman of color, and emphasized how it affected the extent to which she is believed.

The text accompanying the diagnostic criteria for somatic symptom disorder in DSM-5 explicitly mentions that “The individual’s suffering is authentic, whether or not it is medically explained” (APA 2013: 311). Although an important statement, it is in danger of becoming a disclaimer, removing classificatory responsibility from the idea that psychiatric diagnosis could potentially delegitimize a person’s suffering and, in turn, result in it being perceived as less authentic. It is also a statement that forecloses the possibility and the responsibility for the way in which suffering by specific groups is valued differently from others.

The experience of fear of psychiatric diagnosis when presenting so far undiagnosed physical symptoms was central to Ann’s quest for a diagnosis, as narrated by Netflix as well as in the passage from Prescod’s essay. In this section I have read Prescod’s text next to a more elaborate discussion of the revolutionized third edition of the DSM. From DSM-III onwards, psychiatric criteria included a previously unseen emphasis on the way in which patients act and report on their physical symptoms. This created a framework that holds the patient accountable for illness, either consciously or unconsciously. This framework is formative of the subject, who starts to question the nature of the symptoms, and the possibilities for these symptoms to be taken seriously within the medical/psychiatric context that is dependent on these frameworks led by classification.

3.6 Conclusion

The main part of this chapter has reviewed the specific texts in which psychiatric classification of physical symptoms has been made. This shows the continued discomfort of the discipline in supplying a classification for physical symptoms. Psychiatric classification of physical symptoms knows a particularly tormented way of handling the distinction between the body as a measurable entity and the mind as a more complex, less measurable, but yet classifiable reality.

With the introduction of the neo-Kraepelinian DSM-III, the notion of a (Freudian) unconsciousness is avoided, while the text simultaneously speaks of involuntary processes that maintain a similar implication on etiology. Every revision since the third mentions a discomfort around the dualism that is nevertheless maintained. The significant change in DSM-5 is a big step in the direction of removing mind-body dualism from psychiatric classification. All the same, the widened criteria and increased emphasis on individual behavior in relation to physical conditions continue the risk of stigmatizing and delegitimizing unexplained illness and continue to contribute to a cultural discourse in which patients are held accountable for experiencing unexplained illness. In all cases, people with unexplained illnesses draw on the shorter end.

The attempt to classify physical symptoms in psychiatry is to create some form of clarity, of devising a concrete path along which physical symptoms are met within psychiatry. Yet the route that I have traced throughout these classificatory formulations is particularly nervous in its attempt to escape a Freudian view on unexplained physical symptoms as results of unconscious activity: it continues to deny as well as to establish it at the same time. The classificatory path travels in circles, or at least continues to bump into the same construct in which the distinction between mind and body is made and denied. The circular movement is symptomatic of the character of the DSM itself, an eliminatory process that forges a path through medical science and psychiatry that classifies what escapes at the same time. Here, the maintenance of mind-body dualism serves a classificatory logic, whereas an integrated, fused, or even entangled understanding in terms of bodymind would not.

In the next chapter, I further engage with the resilience of mind-body dualism. Yet, here, it takes a different shape: not of a circle but of the unlikely route of impasse, in which the understanding of unexplained illness does not progress in any direction but remains simply stuck. Here, I focus on psychosomatics as a field of research and as a dominant cultural notion connected to unexplained illness. The impasse presents itself in the conceptualization of the mysterious interplay between body and mind. The same maintained distinction that is grappled with in the psychiatric classification of unexplained illness remains little understood in origin and continues to stigmatize people with unexplained illness.

4. Impasse

4.1 A Case of Psychosomatics

I take another case, this time described in a casebook outside of psychiatry and paraphrased for this purpose. The patient is a 45-year-old married man who works as a business executive. He consulted a psychiatrist because of frequent gastrointestinal problems and respiratory infections, from which he suffered for many years. He had seen doctors about these over the years, but they had been unable to cure or prevent the recurring ailments with any treatment. During the week, he worked very hard, but when he tried to relax on weekends, he often suffered from watery nasal drippings. He then wrapped himself up in blankets and stayed indoors. His runny nose often developed into rhinitis or laryngitis. He had no friends or confidants, and he often took on the most difficult tasks at work without receiving any extra praise. After being in his job for quite some time, he demanded a higher salary, which was refused. At his own initiative, he quickly found another job that paid much better.

He developed his first severe upper respiratory infection during his time in the military, where he served during the Second World War.[92] As with his other respiratory symptoms, these symptoms often became worse over the weekend. They were also more severe whenever he felt angry. He felt angry a lot and did not know how to express it. He had not had a very happy childhood. His mother, who had been very strict and demanding, had often expressed the importance of financial security, which pressured him and the family. His father had been a salesman and had started a failed independent business. This was often used as a warning by his mother, who stated that she did not want her son to fail or be weak like she thought his father was. The patient received psychiatric treatment, during which his abdominal pain intensified. He was sent to an internist, and a peptic ulcer was identified, treated, and removed at the hospital. Still, during the weekends, his stomach aches often reappeared.

Contrary to the case that opened Chapter Two, in this case, I will not focus on the identity and agency of the man whose story serves to construct a case-in-point. This case was not taken from a diagnostic manual in psychiatry but from a case book

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[92] The specific war is not mentioned but considering that this case was published in 1954 in the United States, I take this to be the Second World War. See Grinker and Robbins 1954: 5-7.

introducing the field of psychosomatic medicine: *Psychosomatic Case Book*, written by Roy Grinker and Fred Robbins and published in 1954. To open this chapter, I comment on the construction of the case as a case of psychosomatic illness. I focus on how this field situates itself, concerning the complicated relation that psychosomatic medicine holds to disease causation. When not physically explained within general medicine, unexplained physical symptoms are often "explained" (away) as somatizations: physical manifestations of psychological distress. In doing so, medical discourse itself sustains the rift between mind and body, locating the problem precisely in between: the problem experienced in the body is, at the same time, a problem of the mind. The conditions of the patient's experience of the disease as a physical entity are thereby considerably reduced. Still, the painful experience itself is enlarged by offloading the responsibility for the lack of explanation onto the patient. This patient comes to bear a double burden: the experience of physical symptoms and the blame for being held responsible for the creation of these symptoms in the realm of the mind. Here, mind-body dualism presents itself as a painful impasse.

Within psychosomatic theory, as presented in Grinker and Robbins' *Psychosomatic Case Book*, this impasse is further complicated by partly suspending this dualism and attempting to think of mind and body as being, in some way, integrated. In the case book, this patient's physical symptoms, watery nose, respiratory infection, and abdominal pain, are presented next to a description of his personal life, presenting the two as intertwined. On the one hand, this offers more space to review the entanglement of mind and body as captured in the term bodymind. On the other, the specific psychosomatic approach that approaches physical illness as being caused by a mental or emotional factor creates an impasse in the understanding of body and mind, where they are first separated and then intertwined. Dualism is maintained but denied simultaneously, and the common understanding of the bodymind is brought to a halt.

Much like the case that opened Chapter Two of this dissertation, the case from the *Psychosomatic Case Book* is used to make a point: the man's story (the first case discussed) is described as an "Illustration of the complexity of etiology and relationship between somatic and psychological symptoms and of the problems of therapy" (1954: 5). The problem at hand is the interrelation between mind and body in relation to disease and how to treat it. In the mid-twentieth century, psychosomatic medicine was in its heyday as a relatively new approach to medicine. It intended to revolutionize the separation between mind and body by reviewing disease etiology, that is, by looking at the origins of disease in a more integral fashion.[93] At present, however, the term psychosomatic bears predominantly negative connotations amongst lay people as well as health practitioners (Herrmann-Lingen 2017: 5), and patients often feel that it delegitimizes their physical experience as imaginary or not real.[94] There clearly exists a mismatch between a field wishing to integrate mind and body to work towards a better understanding of their entanglement that better matches how a bodymind is lived and treated and a common understanding of the term that, when used to describe physical symptoms, is seen as derogatory. It is here that the impasse is lived: as one in which the status quo that maintains a mind-body dualism is brought to a halt, exposing the conditions of the attachments by which people live, yet without offering a way forward.

In referring to the impasse, I call upon Lauren Berlant's development of the impasse of the present in relation to their notion of *cruel optimism*. Berlant's 2011 monograph, by the same name, was written in the context of the failure of capitalism to protect people against precarity. It describes the continuous fantasy of the good life (American dream) as something to aspire to as a cruelty because this life often remains a fantasy that is never reached. Berlant reads a wide range of cultural objects to show the cruelty of this optimism amidst precarity, contingency, and crisis. The term impasse is offered by Berlant to analyze the contemporary state in liberal-capitalist societies.

To describe the present in terms of impasse also means that it opens, to this present, a way out or that it enables one to review the conditions under which the impasse has been created. Berlant describes the impasse as a "holding station that doesn't hold securely but opens out into anxiety, that dogpaddling around a space whose contours remain obscure" (199). An impasse is not a happy place to dwell. As well as possibly opening possibilities to review its conditions and to recognize the place one is in, it first connotes a holding station that is not secure. In Berlant's formulation, this holding place is often one that is not of one's own making but refers to the conditions under which one lives and of which one is unsure how to get out. It is a place in which one is inhibited

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[93] See Dunbar et al. 1939, or section 4.2, 189, 195.

[94] See Ann's resistance to the word psychosomatic, as commented on in Chapter Three, or my discussion of the term in section 1.2, 25.

from going any further, of “dogpaddling” without direction, and of being, to a certain extent, trapped. For Berlant, the impasse is “a space of time without a narrative genre”: an interruption of norms and, therefore, unsecure.

Such lack of security comes into play at the moment in which the dualism is suspended. Thinking of body and mind in an integrated way is a clear interruption of norms connected to an epistemological and Cartesian framework. The impasse at work in common psychosomatic understandings of mind and body is one in which the mind-body separation is suspended, but no way out is offered. The impasse exposes the way in which dualism can no longer be maintained and results in a place that knows little discursive backing, or at least of a different sort: one that does not follow dominant, physically-oriented explanations.

In this insecure place of suspension, mind and body are not understood as entanglement or bodymind, nor as separated. Instead, they are understood as *integrated* in the sense of two separate entities brought together. In this sense, it is the mind that is seen to be able to produce symptoms in the body, and bodily symptoms are understood as having a mental or emotional origin. Precisely, this connotation of the term “psychosomatic” is bothersome to patients who wish for their physical symptoms to be understood as such: physical. The notion of integration is key to the impasse created by the term psychosomatic. It maintains the dualism that it at the same time wishes to overcome and creates a situation in which the patient with psychosomatic symptoms is left to dwell in an unsecured space: one of neither body nor mind.

Berlant describes the impasse in terms of a lack of narrative genre. In the impasse that results from an integration of mind and body, a narrative genre is not completely lacking. The integrated understanding of mind and body within psychosomatic research follows along different routes that I trace in this chapter. With this case, I first focus on the way in which the complexity of the etiology of illness is described by the *Psychosomatic Case Book*. The next section addresses the different connotations of the term and pays attention to the mismatch between the psychosomatic approach that is established in the field and the connotations of the term psychosomatic in popular discourse. This difference is a marker of the way in which the field has failed to establish an approach in which bodyminds are addressed in a way that alleviates the stigma associated with unexplained illness and has, instead, become a word with which to denote the stigma itself.

From there, I move to discuss the impasse that comes to the fore in the psychosomatic integration of both body and mind as a problem that asks to be, in Harawayian terms, *stayed with* or asks to be deepened when an understanding of unexplained illness is concerned. Overall, central within this chapter is the impasse in the conceptualization of the interaction or integration of mind and body and how it travels to the cultural understanding of unexplained illness. As much as this chapter centers around the nervous route of the impasse, in which an understanding of unexplained illness remains stuck within different integrations of mind and body, the term, and the different travels of the term “psychosomatic” is a second center of gravity. The term “psychosomatic,” as well as the medical sub-discipline or field that developed around it, is central to the creation of the impasse because it denotes different versions of how the integration is understood.

These particular integratory constellations differ greatly depending on their context. In the more historical formulation of the psychosomatic concept, the lack of organic explicability of illness has not been a necessary indication. In the contemporary use of the term, however, “psychosomatic” is often equated with a pejorative understanding of unexplained illness, as well as with implied notions of blame or responsibility or even “secondary gains” for the patient, such as care or attention. In sections 4.2 and 4.4, the contemporary and predominantly negative use of the psychosomatic concept is looked at through an analysis of the discourse around the Netflix series *Afflicted* (2018), in which seven patients with unexplained or contested physical illnesses were followed. Here, the recurring implication is that these conditions are due to mental illness rather than having a physical origin. Again, it is a version of an interaction between body and mind that creates doubt around physical conditions where the patients, in this case, represented by the series, draw on the shorter end.

To review one such specific formulation of this interaction, I want to go back to the case of the *Psychosomatic Case Book* described above. It was written by psychiatrists Roy R. Grinker and Fred P. Robbins. Of these two authors, Grinker was more influential as a psychiatrist and psychoanalyst. He was one of the last patients of Freud (in 1933) and published a number of books on the psychological effects of war on men (Holinger 2010: n.pag.). The cases described in the *Psychosomatic Case Book* clearly resemble this psychoanalytic background. The description of the case as an "illustration of the complexity of etiology," such as described above, is more accurate than a first glance would presume. The authors emphasize complexity and interpretation over clearly presenting "facts." Contrary to the cases used as examples in the DSM *Case Book*, the *Psychosomatic Case Book* does not give definite diagnoses or other labels to the stories about these patients. Instead, the cases in the *Psychosomatic Case Book* are described or analyzed in terms of etiologic complexity.

The case described here is the first case of the *Psychosomatic Case Book* and has a specific function as an illustration of etiologic complexity. In the other cases, the function of the case is made less explicit by the authors, such as in: "Case 23. A case of frigidity with associated recurrent eye symptoms of hysterical character" (128-130) or "Case 33. Hypertension in a childlike dependent female unable to express her intense oral cravings or her rage at their frustration" (151-155). The cases take up a big part of every chapter of the *Psychosomatic Case Book*, sometimes with longer descriptions, sometimes by presenting multiple cases with shorter descriptions. The presentation of the cases does not seem to follow any general rule and differs per case. The *Psychosomatic Case Book* uses these stories as *illustrations* for the presented theory. That is, it depicts or sketches knowledge on how body and mind interrelate rather than directly proving it by way of a language of analogy in the case of the DSM-test case discussed in Chapter Two. Here lies the big difference between the *Psychosomatic Case Book* and the use of cases in the case book that accompanied the DSM. Whereas the DSM presents these cases as a clear example of a particular diagnosis, the *Psychosomatic Case Book* uses these cases to illustrate a form of complexity, which is open to different interpretations.

Grinker and Robbins literally refer to the case discussed here as "a *story* which raises many important questions" (6; emphasis added). This comment also stands in stark contrast to the DSM-test case in Chapter Two, which was written with a clear storyline (complete with catchy alliterating titles) but firmly presented itself as a *medical case* to train the aspiring psychiatrist.[95] In my discussion of the DSM-test case I discussed the

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[95] See section 2.1, 53.

relation between a medical case and a story, and have worked to blur that distinction. Closely reading the DSM-test case, I have shown that the case description that is made in the name of science resembles a general creation of a story. As such, in Chapter Two, I raised awareness of the authoritative nature of such a "story" and its claim on its subjects. In the case from the *Psychosomatic Case Book*, the blurred distinction is already made explicit by Grinker and Robbins. Much of what is written in the case description is not gotten back to nor made explicit through analysis. It *illustrates* instead of describes.

The use and the effects of this loose type of illustration can be further exemplified by turning to the way in which the mention of this patient's military service functions in this case. Grinker himself has published extensively on the effects of military service on (male) psychology.[96] In this case, this patient's military service is mentioned and listed along with this patient's unhappy childhood, stressful job, and poor social circle. Like these other biographical facts, they are mentioned, but not further worked out in relation to the causation of disease. This case is the only one featured in this dissertation that describes a male patient whose condition is represented as an example of unexplained illness. All the other patients discussed in this dissertation are women. This resembles the high gender disparity that exists in relation to unexplained illness. It also resembles how nervous routes are structured around gender and shows how, in men, unexplained illness is often linked to traumatic experiences of war.

Male hysteria received widespread attention during the First World War. Although male hysteria was discussed in medical literature much before the recognition of shell shock,[97] the traumatic experiences of men returning from the First World War led to a new attention to hysterical men. In accordance with general gendered stereotyping, these men were often seen as hypochondriacs who failed to do their duty properly (Link-Heer and Daniel 1990). This history can be traced to the present, for example, in the casting of Gulf War Syndrome, an unexplained condition that only occurs in (predominantly male) veterans of the Gulf War, as a psychosomatic illness originating in

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[96] See Grinker 1945; Grinker and Spiegel 1944; 1945.

[97] Mark Micale has argued against the idea that male hysteria was first discussed in relation to shell shock and traumatic war experiences in the First World War, and states that male hysteria was discussed in medical literature since the seventeenth century, when new ideas about causation included the brain and the nervous system, instead of organs, locating hysteria exclusively in the uterus. See Micale 2008: 16, 47.

the mind. Gulf War Syndrome was listed by Showalter quite literally as a modern version of hysteria (2013).

The mention of this patient's military service is done without further notice. It depends on the link that exists between war neuroses and psychosomatic illness. The authors depend on a unifying reader experience where the onset of somatic symptoms cannot be separated from an unhappy childhood, a lack of appreciation at work, and social isolation. What this case does, as an illustration, is to argue that disease cannot be separated from the person who is suffering from it. Ultimately, it suggests a definite and causal link between the patient's unhappy childhood, his time in the military during the Second World War, his demanding mother, and his peptic ulcer.

In the text itself, this link is drawn by already announcing the case as an illustration of the complexities following the understanding of mind and body as a unity. When this unity is maintained, the determination of the onset of illness – which is in (dualistic) medical practice principally based on the evaluation of physical symptoms – becomes a more complex matter. Do his respiratory symptoms originate from a lack of love from his mother? Did his mother's strong reaction to his father's failures (she saw his father as physically and financially weak) lead this patient to work more than he could, and is the patient's body giving him signs to slow down, to take care of himself? Or are his physical symptoms a cry for help, a call for the mother that he never had? The *Psychosomatic Case Book* does not go so far as to ask these questions or even speculate on the exact relation between the different factors presented.

Instead, the case book poses different questions, which seem to be less concerned with the link that is established between psyche and soma on the level of the life events portrayed and are more focused on the possible causations derived from their unity. These questions, such as "Did his personality problems 'cause' his somatic symptoms or were both relation to some common process?" or "Was there some constitutional defect within a central neural regulatory center?" and "Were his attacks of discomfort primarily precipitated by the invasion of an external infectious agent or by an internal emotional agent" (1954: 6-7), oscillate between psychological and medical questioning, and address the mechanisms that cause the physical effects. At the same time, the authors do not discuss the links that are being made in the text. The illustrative character of the man's case is thus given in the fact that the case is not used to directly prove a point but rather to depict a problem that remains central to the psychosomatic endeavor and is difficult to make explicit through language.

The *Psychosomatic Case Book* gets at this complexity by means of an interwoven presentation of facts and events where the authors switch between giving an account of physical and psychological factors. The writing style of the case differs between these different tracks. I have paraphrased the case above for this present purpose – the case presented in the book is much longer and spans almost three pages. I quote two small passages from it.

> The patient worked long hours after school and greatly envied the freedom and sociability of other children and the material things that they accepted as a matter of course. He developed compulsive habits of self-driving, hard work, and strict attention to details. In time he became a cold, methodical, machinelike person, never permitting himself relaxation or gratification. (1954: 5)
>
> A cooperative study of this patient's daily urinary excretion of pepsinogen was made under the direction of Dr. Arthur Mirsky. It was shown that whenever the patient was in a situation in which his anger seemed to be justifiably mobilized, but did not come to the surface, his pepsinogen excretion increased. If quantity of pepsinogen is an index of hunger, the increase in gastric secretions could mean that threatening eruption of violent rage intensified his need to eat, or in psychological terms, his need to be loved. (1954: 6)

The first quote describes the patient's relational life. The authors refer not only to his direct family but to his social context in school and his feelings of envy. They describe both his relationship to the outside world and his relationship to himself. Revealing the plot of the passage in the last sentence, the authors present a causal chain leading toward the cold, methodical, machinelike person described. He envied, he developed, and *in time*, he became cold. This last phrase, "in time," hides an implicit notion of causality. It places the origins of his cold attitude towards himself and others within his lack of warm social surroundings. Whereas this quote expresses his lack of social connections at school, the larger case presented in the case book depicts a general lack of love at home. Overall, the authors write a story of the patient's distorted relationality and link it to the patient's physical symptoms.

The second quote is taken from the next page of the two-and-a-half-page case description. It comes in from a different angle, presenting the findings of one dr. Arthur

Mirsky, who is not mentioned before in the text. Mirsky was an internist, physiologist and psychoanalyst who conducted seminal research on the interaction of psychological and biological processes.[98] Mirsky's research focused on pepsinogen, a protein digestive enzyme made in the stomach that, when turned into its active form (pepsin), helps to break down proteins in food during digestion. Following Mirsky's findings, the authors correlate the various observations of pepsinogen to this patient's anger, an intensified need to eat, and his need to be loved. The writing style of the second quote focuses less on the causal relations between various events but emphasizes the correlation between the various presented facts. While the first lines are written in a positivist objectifying manner (the study under the direction of dr. Mirsky showed the pepsinogen to increase under certain circumstances), the authors use a less objectifying argumentative style (this could mean that) to correlate these events to each other.

The difference between the argumentative style in these two lines can be explained by further drawing out *causation* in relation to *correlation*. Sociologist and anthropologist Nissim Mizrachi analyzed the difference between these two in the context of the mid-twentieth-century development of psychosomatic medicine as a field. Mizrachi describes causation and correlation as two modes of explanation of disease. Looking at four decades of publications in the journal *Psychosomatic Medicine*, founded in 1939, he identifies a general trend within psychosomatic medicine towards correlation. According to Mizrachi, the initial aim of the journal to explore mind-body interaction was slowly substituted by correlation models that measured psychological and somatic phenomena (2001: 319). Ironically, Mizrachi notes, this move to correlation presupposed the split again, thus re-establishing the dualism that the journal founders originally set out to overcome (2001: 320). For Mizrachi, this change is essentially an epistemological one that moves away from focusing on *explaining* the mind-body interaction towards a mere *description* of it. This descriptive focus fits a general trend in medicine towards standardized, evidence-based knowledge and was, according to Mizrachi, essential to legitimizing the journal and, by effect, the psychosomatic approach within medicine (2001: 320).

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[98] Arthur Mirsky's research focused predominantly on peptic ulcer disease and looked at pepsinogen which was understood as a physiological marker of psychological distress, as is also described in the case in the *Psychosomatic Case Book*. See: Wise 2014.

Within a focus on correlation, explanatory models are relegated to the background and remain open to suggestions. The case used as an illustration in the *Psychosomatic Case Book* is not analyzed or otherwise accounted for in any conclusory tone and is used merely as a vehicle for questions. While shaping a more integral approach to mind and body, the authors aim to portray complexity, thus refraining from labeling the case and giving a clear-cut definition or diagnosis. Instead, they gesture to it by presenting an illustration that demonstrates the complexity of a psychosomatic view with this patient's story. While this can be seen as only a gesture – contrary to the firm move made in the DSM case discussed in Chapter Two – in this case, it could be argued that the openness of the gesture invites a much stronger lingering of its effect.

This less clear distinction between the symptoms and their cause, and the type of signs that the symptoms come to stand for, is in danger of instating an implicit worldview where body and mind definitely influence each other, but in unknown ways, open for interpretations following culturally dominant routes. When traced back to the original coining of the term psychosomatic to a developing field and the colloquial contemporary use of the term, the interpretation of the interaction of mind and body that is captured in the psychosomatic concept often shows to have negative consequences for patients with unexplained illness. In the next section, I address different travels of the concept "psychosomatic," and the effects of the openness that results from the suspension of mind-body dualism within psychosomatic thought.

4.2 Psychosomatic Travels

The term "psychosomatic" is generally attributed to the nineteenth-century alienist and psychiatrist J.C. Heinroth in 1818.[99] Heinroth was a professor of psychiatry in Leipzig and used the German term "psychisch-somatisch" with a hyphen that disappeared in later uses of the term in English (Margetts 1950: 403). After first being used by Heinroth, the term fell into disuse, to be later picked up by Felix Deutsch, a student of Freud (Aisenstein 2008: 104). At present, the term carries many connotations that differ widely from

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[99] The paper by Edward Margetts was the first who wrote a history of the use of the term psychosomatic and who attributed it to Heinroth, this is also reported in later accounts of the history of the term or the discipline. See Lipowski 1984: 155; Aisenstein 2008: 103; Wise 2014: 65.

context, use, and discipline. These connotations can be separated into negative and positive ones. The term's negativity predominantly revolves around a meaning of illness that is "all in the mind" and that lays the blame and responsibility for its creation with the patient. In the words of Monica Greco, the term can be in danger of "adding insult to injury" (1998: 2). The term's positive use can be found in striving for a more comprehensive outlook on illness and disease. This would be a view of disease that uses physiological facts and incorporates a wider vision of the patient concerned (Greco 1998: 2).

A psychosomatic approach to illness differs from the action of simply labeling symptoms as psychosomatic. A *psychosomatic approach* relates to a treatment of illness in general, whereas the usage of the term in relation to physical symptoms implies a statement on etiology that can have a stronger effect on how a particular illness is perceived. Ambiguity and controversy continue to exist in the use of the term, of which a clear or at least coherent definition cannot be given (Lipowski 1984: 153; Greco 1998: 4). Instead, a refusal of a definition of "psychosomatics," as maintained by Greco in her extensive (Foucaultian) discussion of psychosomatics in her monograph *Illness as a Work of Thought*, might be the most productive way to address its ambiguity and point to the various uses of the term. This section traces the travels of the concept "psychosomatic" and pays specific attention to the mismatch between the negative and positive uses cited above.

First, I trace these uses in a colloquial, negative use of the term by focusing on the discourse around the representation of a group of patients in the Netflix series *Afflicted* (2018). From there, I trace the concept in a review of the medical sub-discipline that developed around the positive meaning of the term in psychosomatic medicine in the late eighteenth and early to mid-twentieth century. Starting with how the term is used at present provides a context to the original intentions within the discipline and the way in which it allowed for the term to travel towards a predominantly negative colloquial use.

The insult that the term adds to injury is very real in patient communities and popular speech, where "psychosomatic" is mostly used to denote how illness is delegitimized. A group of patients wrote a collective statement against the way in which they were represented in the Netflix series *Afflicted*. The statement was published on medium.com, an open online publication platform. The statement repeatedly uses the word "psychosomatic" to denote how they were grossly misrepresented by the series' editing and portrayed narrative. The patients who agreed to feature in the series collectively report that they were misled by the production team that had promised them a compassionate lens on their struggles and illness but instead portrayed their illness as "psychosomatic" ("The Truth Behind" 2018: n.pag.).

Next to the collective statement, the five patients and some of their partners also wrote personal stories of their experiences with their participation. Several of them reported participating in the series because they hoped it would offer a greater understanding of often misunderstood and stigmatizing diagnoses. Instead, in accounts of their personal stories, they write that the series opened them and their communities to further ridicule and disbelief (Sidwell 2018; Edelstein 2018; Olave 2018), and they filed a defamation lawsuit against Netflix.

In April 2022, this lawsuit was reported to be allowed to proceed according to a state appellate court (Cho 2022). A news article from the *Hollywood Reporter* cites part of the panel's statement, saying that the misrepresentations:

> were reasonably susceptible to an interpretation that defendants were portraying [their] illnesses, and accompanying physical symptoms, as not the result of any underlying, diagnosable medical condition, but rather as either the product of [their] imaginations or some mental disorder. (Cho 2022: n.pag.)

The statement cited in the article separates physical and mental symptoms and describes the confusion that arises when physical symptoms are seen to have a mental origin. Apart from the fact that the last sentence hints at a form of disdain towards mental illness, (falsely) attributing physical symptoms to the imagination or to the realm of the mind is ruled to be offensive and something that can be legally fought by the people concerned. The dramatized narrative made by Netflix and the case made by these patients show the serious pejorative connotations that stick to the notion of psychosomatic symptoms today.

The collective statement given by the patients reports that physical markers of their illnesses, in the shape of lab results, scans, and doctors' reports', as well as their conventional doctor's opinions, were ignored and excluded from the series editing and that they were instead portrayed as people who were not “really” sick, whose illness was a product of their imagination, or who were simply out for attention. They write that:

> The most serious and central flaw of *Afflicted* is the way it frames our conditions — which impact millions of people around the world — as psychosomatic or psychiatric disorders. It does this in part by carefully excluding facts, which show that yes, while there is a lot that science does not understand about our conditions, they have an ‘organic’ basis. (“The Truth Behind” 2018: n.pag.)

In this use of the term, “psychosomatic” stands in contrast to an illness as having an organic basis, something which these patients were denied by the series editing. They collectively state that most of them have, at some point, undergone psychological or psychiatric treatment or taken antidepressants and that they would gladly pursue treatment in this direction, but that it did not work, and their psychiatrists or psychologists have never told them that their physical symptoms have a psychiatric cause. The patients state that the framing of the series was a result of careful editing techniques and the exclusion of medical data in order to create the “most sensationalist narrative possible” (“The Truth Behind” 2018: n.pag.). The patients show how the notion of their illnesses as psychosomatic is not enforced by the medical establishment but by a media company trying to capitalize on a dramatized version of events that has entertainment value. The group of patients emphasized the setback that the series’ representation caused in terms of cultural understanding of people with unexplained or chronic illnesses. Overall, the cultural understanding of the term “psychosomatic” as a negative one stands central.

Along with the collective and personal statements by the patients, an open letter was published that was signed by five of the seven patients who featured in the Netflix series, as well as a list of influential people such as professors of biochemistry and genetics, molecular biology and biology from Stanford and Cornell University, disability activists, documentary makers, but also writer, actress and producer Lena Dunham and anti-bullying activist Monica Lewinksy. The letter starts with stating their disappointment with and concern about the unethical treatment and the factual errors and omissions by the series, and lists the severe material consequences that this representation can cause for the group of patients with unexplained illnesses. The fact that the series can be viewed on Netflix and thus potentially reaches millions of viewers worldwide, the group writes, can “reinforce barriers to appropriate medical care or disability benefits, dampen the support of vital research, and add to the stigma and social isolation of an already profoundly marginalized group of people" ("Open Letter" 2018: n.pag.). Not only is the implication of their illnesses being psychosomatic hurtful to the patients, it also contains a strong narrative that has material consequences in terms of how the illnesses are managed.

The letter emphasizes both the unethical treatment of these patients in the production of the series and the deliberate omission of knowledge of the patients' conditions from the editing that described the illnesses in organic terms. The unethical treatment includes the pressuring of participation on the basis of access to free medical care, the setting up of meetings with alternative care practitioners, which were found questionable by the patients but pushed by the producers, and the encouragement of unnecessary medical procedures with serious risk of infection for the sake of producing footage which was eventually never used ("Open Letter" 2018: n.pag.; Hill n.d.; n.pag.). The open letter's authors identify the production company's deliberate framing of these patients. They were treated as people with mental illness who imagined strange things that were not really there. According to the open letter, this provided a narrative that was apparently found to have better entertainment value: it played in on a sensationalist story of "seven people suffering with bizarre chronic illnesses" ("Open Letter" 2018: n.pag.).

Such a framing capitalizes on a general notion that is attached to the word psychosomatic: mysterious, self-absorbed malingering. These people suffer from illnesses and thus can be sympathized with, but at the same time, they do not fully deserve this sympathy, for they have potentially played their part in the creation of their illness. As Jill Edelstein, one of the patients who features in the series states in her account of her participation, "I shouldn't blame the haters on social media, though, because *Afflicted* makes me look like a bad person. If I were them, I would hate me too" (Edelstein 2018: n.pag.).

In Edelstein's case, she reports she was portrayed as taking advantage of her partner, both in material and emotional terms. In Edelstein's own words, her and her partner's representation on the series makes it look as though her partner "is being fleeced by a selfish whiner who does little more than take vitamins, make her own hand-crafted suppositories, and drink afternoon cocktails" (Edelstein 2018: n.pag.). In the way in which Edelstein was represented, the sensationalist narrative plays in on a notion of people with psychosomatic illnesses being self-absorbed people who take advantage of their loved ones and extort them both financially and emotionally. By both Edelstein as well as her partner, who wrote a story of her account as well, this framing is fiercely opposed and countered by pointing out Netflix's factual omissions (Edelstein 2018: n.pag.; Feczko 2018: n.pag.).

The importance of organic basis for physical symptoms to countereffect the negative image that is sketched of these patients' illnesses is emphasized in the open letter by calling upon medical history. I quote the paragraph at length.

> The history of medicine shows that until illnesses are better understood, they're often considered psychosomatic. The consequences can be devastating. Multiple sclerosis was once called "hysterical paralysis" until the invention of the MRI revealed lesions in the brain. As late as the 1980s, ulcers were thought to be caused by the "wish to receive love" before the discovery of H. pylori. Breast cancer was attributed to holding onto negative emotional states until effective chemotherapeutic treatments dispelled the myth. Tuberculosis, epilepsy, and rheumatoid arthritis were all at one point in their history thought to be psychosomatic disorders before science elucidated their mechanisms. In the interim, untold numbers of patients were institutionalized, given inappropriate treatments, and died as a result. ("Open Letter" 2018: n.pag.)

Again, the letter holds to a predominantly negative use of the term, which, when enforced, can have "devastating consequences." Here, "psychosomatic" is used as a temporary term: a placeholder for what is not yet explained in organic terminology. The words used to describe the eventual explanation, "revealed," "dispelled," and "elucidated," all signal a view of organic explanation as a liberatory move out of the presumed darkness of inexplicability. Emphasizing how previously unexplained conditions were eventually explained in organic terms portrays a trust in the progression of medical science that will eventually find biomedical markers for an ever-growing range of experienced physical sensations. This trust is based on an understanding of science that goes back to the Enlightenment. It refers to the idea that something is only real once it is proved by scientific methods.

On this note, the letter also points to the progress that science has made regarding the organic understanding of conditions like ME/CFS, mold and chemical sensitivities, and Lyme disease, which were amongst the subject's diagnoses ("Open Letter" 2018:

n.pag.). While this progress in medical understanding is something to applaud, the emphasis on medical science as something that will lead to an ever-progressing understanding of illness continues to privilege physical pathology. As such, it will not lead to a better understanding of the marginalization that people with unexplained illness experience. In a sense, it thus contributes to a delegitimization of people who experience symptoms that fall between the separation made between mind and body.

According to the open letter, the producers were handed information on the physical findings of the patients' illnesses. They attended a symposium at Stanford University on the molecular basis of ME/CFS and even interviewed a geneticist and immunologist. However, the authors of the open letter state that the producers chose to exclude the information and footage from the editing. Less controversial diagnoses like common variable immunodeficiency disorder or Hashimoto's thyroiditis, which two other subjects were diagnosed with, were either omitted or de-emphasized in the series' portrayed narrative ("Open Letter" 2018: n.pag.). This handling, as the patient group and advocates report it, describes how the placeholder in the form of "psychosomatic" is exploited by the makers of the series, playing into a dominant cultural discourse that sketches a negative stereotype of unexplained illness. The fact that this is done as part of a documentary series for a major entertainment platform shows that the trope of unexplained illness as psychosomatic functions as an attractive story for a wide audience that can be exploited for entertainment value.

In the discourse around the series, "psychosomatic" is thus used in multiple ways that all signal negative notions for the patients concerned. Patients use it to state what is wrong with their representation, and, according to the patient's statements made after the series airing, it is used to portray doubt about the represented conditions. It is used as a term that refers to illnesses as having a mental etiology, as a term that signals a self-absorbed malingerer, or as a placeholder for yet-to-be-explained conditions for which medicine has no answers. Across these various connotations, the main player is the lack of organic explicability of physical symptoms. This lack of explicability sticks negatively to the notion of illness being psychosomatic and often leads to negative effects for the patient and their perceived symptoms.

Ironically, in the initial coining of the term and the medical field that developed around it, the focus on the lack of organic explicability is much less central than in the above-cited present-day meaning of the term. In the following, I now turn to review the development of psychosomatic thought and the medical sub-discipline. Focusing on the development of the field, I will highlight some of its influential scholars and scientists from the late nineteenth century to the mid-twentieth century period. Within psychosomatic medicine that developed in the U.S., the term psychosomatic is institutionalized as an exciting new approach to illness that not only looks at the organic, physical side of illness but also incorporates attention to the social and psychological environment of the patient. The case described in the opening section of this chapter gave an example of such an outlook of illness, in which mind and body were integrated to create a wider outlook on illness in general.

The establishment of the first journal of psychosomatics was an important moment for the formation of the medical sub-discipline. According to Mizrachi, the origin of psychosomatic medicine in the U.S. was the foundation of the journal by the same name in 1939 (2001: 317). Three years after the journal was founded, the leading people behind it started what was then called the American Society for Research in Psychosomatic Problems (Mizrachi 2001: 317). Both the journal and the foundation still exist, be it that the latter's name has changed to American Psychosomatic Society (APS). The foundation was created to give institutional backing to the journal, as well as to "attempt to organize and direct or subsidize research in psychosomatic medicine or in any of the allied disciplines" (Herrmann-Lingen 2017: 2). The current mission statement, as published on their website in 2022, remains formulated along the same lines: "to advance and integrate the scientific study of biological, psychological, behavioral and social factors in health and disease." (APS n.d.).

In the introductory statement of the journal in 1939, its first editors stated that they wanted to "study in their interrelation the psychological and physiological aspects of all normal and abnormal bodily functions and thus to integrate somatic therapy and psychotherapy." (Dunbar et al. 1939: 3). The journal and the foundation worked to establish credibility for the psychosomatic approach in the eyes of medicine. Where the foundation has the practical goal of supporting the journal, the journal functioned as a forum for the exchange of research on the integration of somatic therapy and psychotherapy, thus attempting to develop new and integrative forms of therapy.

The introductory statement was written by the first editors and founders of the journal, of whom Helen Flanders Dunbar was the most influential figure. The editors start by stating that "psychosomatic medicine is an expression which has not yet obtained citizenship." The use of the term citizenship signals the way in which the recognition of the discipline as a form of science also leads to a certain status and protection. By 1939, psychosomatic medicine was coined but was not yet mentioned in medical dictionaries and was not clearly defined. The editors also mentioned that the term had various connotations among different physicians. The introductory statement starts out by pointing to the need for a clearer definition of the term. The journal firmly presents itself in terms of all the things that it is not: "psychiatry," "medicine," and not "restricted to any specific field of pathology" (Dunbar et al. 1939: 3). Commenting on this framing, Mizrachi points out that the editors of the journal thus focused on identity by exclusion, and that the differentiation of psychosomatic medicine from psychiatry seemed to be their main concern (2001: 328).

Psychosomatic thought developed earlier in German-speaking countries and stood at the basis of the field and the later connotations of the term. This German tradition is closely connected to psychoanalytic theory, which goes back to Felix Deutsch, Sándor Ferenczi, and Georg Groddeck (Aisenstein 2008: 104). The early German-speaking psychosomatic interest had close ties to romanticism as well as early psychoanalysis. Anne Harrington reports that before Freud, Romantic-era thinkers like Goethe and Schelling were already involved with a version of the body as a whole that had implications on how a person was to be viewed in medical terms.[100]

The romanticism that clung to the early German tradition of psychosomatic thought is most visible in the work of Georg Groddeck, who is later referred to as one of the most radical proponents of psychosomatics in the sense of psychogenesis (Lipowski 1984: 165).[101] For Groddeck, illness was an expression of the It (or *das Es*), which he saw

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[100] See: Harrington, 2009: 82; 1996; Alexander 1962: 13–24.

[101] Groddeck is forcefully attacked in Susan Sontag's essay *Illness as Metaphor* for the notion that illness is a manifestation of some kind of unconscious wish or inner state. I turn to Groddeck and Sontag in more detail in the next section.

as a mysterious, strong, and unconscious force of which our identity and behavior are mere manifestations. Groddeck saw illness as a vital expression of the It, which made him conceptualize illness as a purposive internal process. Groddeck held a close friendship with Sándor Ferenczi, to whom Freud introduced him (Poster 2009: 199). Not only were they close friends, and both men had complicated and intimate relationships with Freud, [102] but their ideas on psyche and soma, which they both conceptualized in terms of unity, also closely overlapped (Mészáros 2009: 209).

Felix Deutsch moved from Vienna to the United States and became part of the advisory board of the Journal *Psychosomatic Medicine*, established by Dunbar (Herrmann-Lingen et al. 2019: 694). Next to having been Freud's personal physician, Deutsch was an influential figure for early psychosomatic thought and published extensively on the topic. Around 1956, he organized a workshop with members of the Boston Psychoanalytic Society on the "mysterious leap from the mind to the body." This workshop revolved around questions about the process of conversion and also resulted in a publication in 1959. According to Franz Alexander, a Hungarian-born psychoanalyst who had also moved across the Atlantic, Deutsch was, along with Groddeck, a fierce proponent of the view that organic illness must be understood in a symbolic fashion in terms of repressed ideas (Rosenbaum 1990: 476). For Deutsch, conversion (from mind to body) was not only a mechanism in place in hysteria but was believed to be a factor in the etiology of all illnesses in general (Rosenbaum 1990: 476; Lipsitt 1989: 599). In these early German meanings of psychosomatic illness, the concept was thus closely tied to notions around personality and unconscious will that, in Groddeck's thinking, even went as far as understanding all illnesses as a purposive internal process.

With the transfer of psychoanalytic and psychosomatic thought to the United States, psychosomatic theory was further institutionalized. First in creating a journal and then in the foundations of research societies. Two important figures in psychosomatic medicine were Helen Flanders Dunbar and Franz Alexander, who together stood at the

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[102] Ferenczi came to be known as a relational psychoanalyst who emphasized interpersonal and intersubjective theories. The relationship between Ferenczi and Freud is often described in terms of father and son, Ferenczi having the role of the latter. See: Szekacs-Weisz and Keve 2012. Groddeck's relationship with Freud was characterized by a more combative nature. They inspired and admired each other's work, but were also critical of each other, and Groddeck was not amused by Freud's use of the Id, for which Groddeck's notion of the It had been of great influence. See: Ávila 2003: 87; Poster 2009: 198.

basis of the journal. Alexander was critical of the early German interpretations of psychosomatics. He did not abandon the idea that there was a relationship between repressed emotions and disease but inserted another step into the process. For Alexander, emotions would affect bodily functions in the sense that chronic repression of emotions could activate the body's organs in a way that eventually would lead to specific diseases (Harrington 2009: 91). In this way, mind and body were not understood in terms of a unity or of an It which led to the notion of illness as manifestation of will or character, but seen in terms of inseparable influence in which emotional states have physiological concomitants. Such a view also allowed Alexander to integrate Freudian methods with physiological data (Harrington 2009: 92).

The development of psychosomatic medicine in the U.S. became less concerned with giving holistic concepts of mind-body unity. Instead, it worked to attribute etiological specificity to specific diseases. In this vein, Alexander and Dunbar linked specific psychological factors to specific disease states. Dunbar's book *Emotions and Bodily Change* (1954) was first published in 1935 and reviewed all literature on the topic that was available at the time. It is widely seen as having launched psychosomatic medicine in the United States (Powell 1977: 133; Herrmann-Lingen 2017: 1).

In 1939, Dunbar published an article in the *Psychoanalytic Quarterly* describing the role of character in symptom formation. She reports a study that interviewed patients hospitalized with conditions like cardiovascular disease, diabetes, and fractures, but also ulcers, allergies, and skin lesions over a period of four or nine years, which looked for reaction patterns amongst patients with the same physical symptoms (1939: 20). Differences between the patient groups and similarities across patients with similar physical symptoms were found in terms of major conflicts or character traits. For example, Dunbar reports that "Most fracture patients, like hypertensive patients, have a focal conflict over submission to authority and marked hostility" (1939: 44). By bringing the etiological specificity to the attention, Dunbar calls for further research on the way in which character and specific physical symptoms interrelate. Presenting two cases of patients with anginal syndromes, one with known organic disease and the other without, Dunbar argues that there are important similarities in personality and history, such as their position in the family, the type of mother they had, their compulsive nature and the situations that preceded their attacks (1939: 42). The link between physical symptoms and character traits is thus made less on the basis of known or unknown organic illness, but in relation to physical symptoms themselves.

Going perhaps further than Dunbar, Alexander explained the etiology of certain illnesses in terms of personality traits, linking specific traits to specific illnesses. Greco notes that it is often assumed that Alexander's work "allegedly supplanted Dunbar's" in the sense that where Dunbar had merely described and observed certain personality traits and their links to certain illnesses, Alexander's work focused on finding etiological accounts. These etiologic accounts were seen by Alexander to be able to "explain the psychodynamic origin of the personality traits Dunbar had merely described" (Greco 1998: 99). Robert Powell, who extensively studied Dunbar's work, describes a general distinction made within psychosomatic history between "specificity theorists" Dunbar and Alexander, where Dunbar's focus was on the specificity of personality, and Alexander was concerned with specific types of conflict as the determinant of psychosomatic disorders (Powell 1977: 135). What is important is that, overall, Alexander maintained a multifactorial etiology in the sense that certain conditions are not exclusively psychogenic but that he saw specific psychological factors as necessary causes of certain diseases (Greco 1998: 100).

For Alexander, *specificity* means that "different emotional states have their specific vegetative tonus" (Alexander 1943: 209). Alexander clearly separated hysterical conversion symptoms from vegetative neuroses. He understood hysterical conversion symptoms as substitute expressions or *abreactions*,[103] which cannot otherwise be expressed and thus turn into physical symptoms (1943: 206). Hysterical conversion symptoms were understood as symbolic, as having meaning, and as being an attempt at relief (207). However, they never bring full relief as physical symptoms and must, therefore, be treated in psychological treatment such as psychoanalysis.

By contrast, vegetative neurosis is not symbolic or an attempt to express emotion but a physiological accompaniment of recurring emotional states (Alexander 1943: 207). Alexander notes that it is "most improbable, however, that internal organs such as the liver or the small arterioles of the kidney can symbolically express ideas." However, if

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[103] Abreaction, a discharge of sorts, is a term used by Freud. See for a discussion of the Freudian abreaction section 3.3, 150.

emotional stimulation becomes excessive, it can influence what Alexander calls vegetative function (1950: 41). This is a mechanism described above in terms of specificity, where emotional states are seen to have a physiological accompaniment. When certain emotional states are experienced for a longer period, they will eventually become physical symptoms corresponding to this emotion. Alexander also makes a third separation in the term "psychogenic organic disorder," which develops in two phases; first, an emotional disturbance affects a vegetative organ, which then "gradually leads to tissue changes, and to an irreversible organic disease" (1950: 44).

Alexander famously described what came to be known as the "psychosomatic seven": duodenal ulcers, ulcerative colitis, asthma, essential hypertension, rheumatoid arthritis, thyrotoxicosis or Graves' disease, and neurodermatitis.[104] Gastric neuroses were connected to the need to be loved because "The wish to be loved is deeply associated with the wish to be fed since the nursing situation is the first one in which the child enjoys parental love and care" (Alexander 1943: 207). What Alexander calls "vegetal innervations," or physical symptoms, are not substitutes for the wish to be nursed but "inseparable physiological sequelae" of emotional states. Thus, they are, in Alexander's words, merely "physiological concomitants of a chronic or periodic emotional tension" (1943: 207). Asthma, on the contrary, is described by Alexander as having components of a hysterical conversion symptom because he saw it as a direct expression of a suppressed emotion "such as the wish to cry" (208).

Where Groddeck thought of psychosomatic illness in terms of the It, and thus conceived of illness as an almost purposive process, with Alexander, the term psychosomatic becomes an approach to medicine that is concerned with the influence of psychological factors on the functions of the body (Alexander 1950: 11). In the early days of the discipline that developed in the American context, the approach was not concerned with determining differences between organically explained and unexplained illness, but more so with understanding physiological disturbances in terms of emotional states.

This latter part is one that still lingers in the discourse around *Afflicted*, where the represented patients report that their illnesses are portrayed as having an emotional cause, such as a need for attention or love or an unconscious wish. In response to their

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[104] See: Alexander 1950; Alexander 1962: 20.

(mis)representation, patients and their advocates have shown how the existence of an emotional cause for illness has a delegitimizing effect that leads to their illnesses not being taken seriously. The emphasis that is laid on the existence or absence of organic illness that determines whether or not a condition is perceived as psychosomatic shows how, at present, the psychosomatic approach to medicine has not led to a colloquial meaning of the term as signifying a more comprehensive outlook on illness. Instead, the idea of illness as having an emotional component has lingered in a negative way.

When Alexander and Dunbar stressed how certain personality types and emotional states were prone to develop certain diseases, they did so because they wanted to understand the relationship between illness and emotional states. While Alexander's notion of a vegetative neurosis merely describes a vision of the workings of physiological accompaniments for emotional states, it can, to a certain extent, be seen as moving away from the blame around the creation of one's own disease that stands more central in Groddeck or in, for example, Alexander's notion of conversion symptoms. At the same time, these notions have not been contained in psychosomatic medicine alone. Harrington gives examples of how Alexander's approach to psychosomatic medicine traveled to the popular press and popular culture, appearing, for instance, in the 1950 Broadway musical *Guys and Dolls*, in which a female character suffers from respiratory symptoms that are hinted at to be caused by frustration over her unmarried status.[105] The basic idea that physical symptoms have emotional components or causes has become popular culture. At the same time, the original intentions towards a better understanding of mind and body and a wish to overcome the separation were left behind or had, as shown in the discourse around *Afflicted*, predominantly negative consequences for the patient concerned.

According to Greco, the heyday of psychosomatic medicine was around the mid-twentieth century, when it was celebrated as a new science of mind-body relations that would transform medicine as a whole (2019: 107). In a review of the development of the American Psychosomatic Society from 1942 to the present, Herrmann-Lingen cites a presidential address held by Eric Wittkower in 1960, in which psychosomatic medicine was already declared as being in crisis. The synthesis between psychoanalysis, psychiatry, and medicine had not taken place. Wittkower pointed to a study that showed the

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[105] Harrington cites the text of "Adelaide's Lament" a 'hit-number' of the musical "just from waiting around – for that plain little band of gold – a person can develop a cold" see: 2009: 93.

percentage of neurologists or medical specialists published in the journal had dropped from 22% to only 7% (Herrmann-Lingen 2017: 3). The goal of an integrated and multidisciplinary approach towards health and illness that acknowledged the relevance of emotional factors for the onset of physical disease seemed only further removed. In the following years, the number of medical specialists amongst the authors of the journal, as well as the membership of the society, kept declining. Herrmann-Lingen quotes a presidential address ten years later, stating that "realistically we must face the fact that the psychosomatic approach has not as yet had the sweeping, revolutionary impact on medicine of which it appears capable" (2017: 3).

One of the problems that was continuously faced within psychosomatic medicine was how the term itself implied a mind-body dualism. The field, therefore, dealt with an intrinsic complexity at the heart of it. Herrmann-Lingen points out continuous pressure from within the field and from outside "to conform to scientific methodologies basically mechanistic and reductionistic in conception and inappropriate for many of the problems under study" (3-4). As a field intended to be multidisciplinary and bring together disciplines like psychoanalysts, internists, neurologists, and psychiatrists, psychosomatic medicine thus continuously had to mediate a mind-body dualism that was part of the medical specialties involved in the psychosomatic endeavor. According to Greco, "the impulse of psychosomatic medicine has therefore itself been reabsorbed and reconverted into the dualist mainstream" (2019: 108). This is why, in the next section, I discuss mind-body dualism and its problematic relation to unexplained illness in more detail.

4.3 Mind, Body, Problem

A famous formulation of the dangers of integrating mind and body is found in Susan Sontag's *Illness as Metaphor* in 1978. In her polemic essay, Sontag attacks the idea that "the sick man creates his own disease" (1991: 47). In this formulation, Sontag refers to Groddeck, who becomes, in her account, the personification of all that is wrong with metaphoric thinking. Sontag quotes Groddeck, who states that it is "'because it is not pleasant to look within ourselves' that doctors prefer to 'attack the outer causes […]' rather than address the real, internal causes" (Sontag 1991: 47). For Sontag, Groddeck becomes a blameful figure: someone exemplary of a nineteenth-century outlook on disease that places the blame for the illness with the patient.

Her essay is, first of all, an attack on metaphors in relation to illness. Sontag repeatedly stresses the way in which language on illness has an effect in reality. Describing different historical relations to illness, she identifies a shift taking place in the nineteenth century, which no longer viewed disease as a punishment from the gods (Greeks) or a punishment that fits the sinner (Christianity) but as something that "fits the patient's character" (1991: 44). More so, Sontag notes, illness is now seen to express a patient's character. Such – in her words – "preposterous and dangerous views" (1991: 48) manage to put the responsibility, or weight of the disease, on the patient, who is then, by effect, also discouraged from an outlook on healing – a character is not easily changed.

Most of all, Sontag warns of speaking of illness in terms of metaphor. She is not very specific on the direct consequences of metaphoric language in relation to illness. However, she warns against the type of metaphoric speech that equates illness with the personality of the person suffering from it. Sontag herself does not seem to link the influx of metaphor to either identity, feeling, or character in any particular sense but rather to a general notion of personhood altogether. These notions seem to bleed into each other in the general flow of her argument, which is mainly focused on resisting the mentalization of disease, which, for her, distorts the physical cause of disease and obscures the origin of disease for the person suffering from it. For Sontag, these origins can be found only in physical processes. Her critique focuses on presenting illness in common expressions and public discourse. Here, the problem she is getting at is precisely the unspecified use of identity, character, and feelings regarding disease. People do not make themselves sick, and disease should not be seen as the result of an excess of feeling. For Sontag, "the most truthful way of regarding illness – and the healthiest way of being ill – is one most purified of, most resistant to, metaphoric thinking" (1991: 3).

It matters how one speaks about disease. However, taking Sontag's claim seriously is not an easy task. It is often unclear how to avoid metaphors hiding in unexpected places. Commenting on Sontag's claims against metaphor, Peter Rudnytsky, a scholar of psychoanalysis who writes of its relation to the field of narrative medicine, argues that Sontag's refusal to speak of illness as metaphor in effect leads patients into the hands of “supposedly godlike physicians” (2004: 255). Sontag warns of the stigmatizing effects of illness metaphors in society and thus steers clear from any meaning that is attached to illness. Rudnytsky, however, hints at how Sontag thus fails to recognize how physical illnesses are often already given unconscious meanings by the person suffering from them. Following Rudnytsky, these metaphors, or ideas attached to the meaning of illness, might already be unknowingly turned to by patients and affect the outcome of healing.

The two positions that can be discerned here are one in which disease is seen as a consequence of a force that is equated with a notion of character, or individual, non-physical factors, as opposed to the notion that disease has nothing to do with one’s character, but is merely something that appears in the body, following a physiological process that, in itself, is devoid of meaning. As maintained by Sontag, this second position is formulated as a critical response to the first. Rudnytsky seems to fit in neither of these two and seems to take up a third, one that sympathizes with an understanding of mind and body as being somehow intertwined and that stresses the therapeutic possibilities of an integral approach. Yet this third position stays away from epistemological consequences and does not engage with the dualistic problem inherent in it.

Rudnytsky refers to the interplay between mind and body as a psyche-soma, to which he attributes a capacity for self-healing (2004: 255). He cites a story of a woman whose own understanding of her physical symptoms as psychosomatic and her doctor’s refusal to label her illness in physical terms allowed her to investigate her symptoms and regain her health (257). Rudnytsky uses the account as an example of the power of narrative and its potentially healing quality. Rudnytsky mentions his admiration of Groddeck’s appreciation for “the unconscious dimensions of illness” and maintains that every patient attributes some meaning to their illness (255). However, for this healing to occur, the narrative connected to psychosomatic theory must be positive. In taking up Sontag’s arguments against Groddeck, Rudnytsky does not manage to free Groddeck completely from Sontag’s visceral attack: it is undeniably true that Groddeck’s way of thinking makes use of an all-explaining inner cause which potentially stigmatizes patients’ physical symptoms as manifestations of their character. The question is how the interplay between mind and body can be accounted for in a way that does not violate personal illness experience or place the blame for the creation of illness on the patient.

The problem eventually culminates in how mind and body are relationally understood. That is, as always already entangled, as two separated or as two integrated aspects. Different approaches to the problem spread in different directions, fields, positions, and disciplines. As shown in the previous chapter of this dissertation, the separation in the form of mind-body dualism holds a particularly unwanted resilience within psychiatry, where it is referred to as a relic from the past that psychiatry is nevertheless unable to shed.[106] Mind-body dualism is often characterized as being at the root of all problems and, implicitly, its eradication as the solution to most, if not all, problems.

When mentioned, mind-body dualism is simply referred to as a sort of Cartesian hangover: a Cartesian shadow or “Philosophical mistake” (Hopkinson 2015) or referred to as “Descartes’ ghost” (Novick and Ross 2020: 328). Being an unwanted requisite of the past, it seems all too easy to discard it as such. Without being able to overcome this impasse, a mention of Cartesian dualism often serves as an easy reference to a problem that is itself too big to solve. In the humanities, twentieth-century attention to the body in scholarship turned to the body in terms of discourse determined by gender, sex, race, or class, which further removed itself from the idea that mind and body can be separated and widely discarded a Cartesian form of dualism.[107] As Ian Hacking wrote in 2005, “Descartes is absolutely out of fashion,” and “Cartesianism is wholly rejected” in contemporary philosophy and thinking. However, in Hacking's words, this does not necessarily mean that “no one is a dualist anymore” (2005: 155).

Within disability studies and crip theory, the term bodymind offers the most far-reaching reconceptualization of the dualism known from Descartes. It does explicitly not refer to a form of integration but insists on the inextricability of body and mind. The term bodymind, therefore, moves beyond the mere mention of a problem, summarized in the name of Descartes, and does, in Schalk’s words, “theoretical work” itself in highlighting forms of oppression that have been based on the separation (2018: 5). Different from the connotations of the term psychosomatic, discussed in the last section, bodymind is a term

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[106] See section 3.6, 170.

[107] The edited volume by Lock and Fraquhar (2007) *Beyond the Body Proper: Reading the Anthropology of Material Life* can be seen as a comprehensive anti-Cartesian manifesto that collects essays from philosophy throughout the twentieth century, from Friedrich Engels, Walter Benjamin and Maurice Merleau Ponty to Judith Butler, Bruno Latour and Anna Tsing.

used in a positive sense in disability activism.[108] It is used to refer to the conceptual realm that aims to overcome the negative connotations that stick to the integration of body and mind. In that sense, Schalk refers to the term doing “theoretical work”: the use of the term bodymind refers to a state in which dualism is overthrown altogether.

Perhaps a new term was needed. Outside the humanities, psychosomatic theory has dealt with dualism in theoretical terms, often by speaking of the inseparability of physiological and emotional states, such as in Alexander’s psychosomatic theory. Historian Theodore Brown describes how psychosomatic theory as a field has engaged with dualism in a commentary on the central role given to Descartes. In a 1989 article on the Cartesian heritage of dualism, Brown reviews the way in which literature on psychosomatic research suddenly refers to Descartes with an “uncommon frequency.” Brown mentions how these references regularly repeat stock phrases and “offer minor variations of identical interpretations.” By contrast, his own aim is to present a nuanced version of the historical Descartes, balancing between the mythological and the historical figure and providing a “fresh reading” of the primary historical texts. Brown asks:

> If the true historical Descartes and the mythic Descartes differ substantially, what purpose – not necessarily conscious – does this mythological reconstruction serve for American psychosomaticists? Why are they so attracted to a particular, antiheroic version of medical history? What ideological and emotional needs does it serve? (1989: 322)

Brown considers the way in which psychosomaticists have found themselves stuck and referenced Descartes to formulate it. Focusing on the figure of Descartes and his place in this contemporary debate, Brown brings to light some of the central problems in twentieth-century psychosomatic research. Most importantly, there is the central problem of both upholding a belief in “ultimate biological realities” and maintaining a broader overview of the interplay between organic and mental factors. The multidisciplinary endeavor of the psychosomatic approach itself ties it to disciplinary contexts such as psychiatry and medicine, in which the mind-body dualism remains especially resilient. Feeling compelled to account for Descartes himself, Brown states that “Rather than

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[108] See: Price 2015; Piepzna-Samarasinha 2018; Schalk 2018. In *Brilliant Imperfections* (2017), Eli Clare sticks to body-mind, while Alison Kafer, in *Feminist, Queer, Crip* (2013), speaks of the body/mind in a similar way.

looking at themselves and their own complex, confusing, and conflict-laden circumstances, American psychosomaticists wagged their critical fingers at a distant and distorted Descartes" (330). Brown thus signals how the name "Descartes" is used as a name for a problem without going into the problem or the original formulation of the dualism within the historical texts themselves.

This necessity, or wish to create a figure, a straw man, in order to avoid facing a conceptual haziness within a disciplinary, practical, or professional context, can perhaps be productively reviewed through the context of the suspended reserve, as formulated by Penelope Deutscher. In the introduction to her 2017 monograph on reproductive life in the work of Foucault, she reflects on the nature of critique. Her notion of suspended reserves is taken from Derrida and describes a certain movement or relation to a text. Usually, a critique of a given text or tradition expresses itself accusingly or negatively (in this case, a mere reference to a Cartesian notion), or, differently put, it uses "a language of failure." Rather than performing a similar cycle of critique by pointing out what a text fails to do, addressing a text's "suspended reserves" supposes that one tries to stay with the possibilities it offers. As much as this is a methodology for theoretical critique, Deutscher's way of reading provides an opening. Not only for a greater generosity in relating to theoretical texts or frameworks but also to become attuned to the potentially transformative ways hiding in theoretical or philosophical texts: to those possibilities that might, at first glance, be absent.

I am citing Deutscher not to propose to maintain a suspended reserve towards Descartes's texts. In fact, I propose to leave Descartes himself out of the equation. Instead, her reading methodology shows multiple ways in which creating a figure for critique can sidetrack the problem at hand. As much as Brown identifies a movement in which Descartes becomes a central figure, a type of placeholder for a problem that cannot be easily solved, Brown's focus on rectifying historical material again results in a situation where the problem remains absent. His focus on the historical facts of the texts themselves inhibits a clearer vision of the life of the problem for the present. Justified as this consideration may be, it makes and deepens another problem, which, although interesting in its own right, is not the problem at hand.

The problem is that the issue is not nearly problematic enough. A problem is usually seen as something to be gotten out of the way, if not solved. Identifying and refuting or critiquing a "Cartesian dualism," a problem is being experienced, felt, and addressed. However, is it not thereby also immediately removed as a problem and replaced by a rather annoying paradox or contradiction: there is a unity which is a duality, or there is a separation which is actually one. Framed in this way, and especially in combination with a tendency to "localize" something in terms of a "here" (for instance, in the mind) or a "there" (in the body) or everywhere (in some sort of "whole"), means to lose sight of the particular habits, characteristics, environment of the problem.

If a problem is seen as something not be gotten out of the way but as the only possible way of getting anywhere, it also means to cherish and deepen that problem into veritable engines of change. What does it mean to deepen a problem? First, it must be formulated and looked in the eye. Blaming Descartes is sloppy formulating at best: the eyes of a straw doll never look back. How to find, write, magnify the problem? Looking at what is unexplained in different explications of the body may well contribute to one of the most concrete manifestations of the problem so often caught in the slipshod net of "medical dualism." Naming Descartes could conceivably help formulate the problem but may never give it life, motion, reality.

A more productive way of addressing the dualism, or putting into use the suspended reserve, might be found in centering the resilience of mind-body dualism, as Monica Greco did in 2019. She writes of the state of psychosomatics today as a problematic and states that the resilience of dualism in the field should be taken as the point of departure to address it. Instead of starting at the formulation of dualism as a philosophical problem, she approaches it as an "*empirical and historical datum*, a given" (2019: 108). Greco's proposition is to formulate questions not in abstraction from the dualism but by starting from recognizing the dualism as an achievement, something to which its stubborn endurance testifies.

Greco links the modern form of mind-body dualism to the "bifurcation of nature," as formulated by Alfred North Whitehead, and to a specific form of scientific materialism, a system of thought whose assumptions Greco notes to be thoroughly embedded in our institutional as well as social and personal life (2019: 109). The "bifurcation of nature" was formulated by Whitehead to criticize the distinction that modern science makes between scientific knowledge and subjective experience or intuition. Greco argues that an awareness of the "bifurcation of nature" allows one to understand it in the context of scientific materialism. This also shows its historical contingency (109). Starting from the dualism as an empirical datum or epistemic configuration in the present, Greco draws on Whitehead and Foucault to argue that dualism has itself a "functional utility (or value) in the context of liberal political economy and biopolitical forms of governance" (112). Placing the notion of values at the center of the modern problem of psychosomatics, she argues for the importance of looking at disease/illness in critical ways.

Such critique will not come from psychosomatic medicine itself, and Greco notes that it is equally unlikely that this dualist or scientific materialist mentality will be transformed through the reform of medicine as a whole (112). She proposes to look at the places where the dualism fails: "not epistemologically but pragmatically – and where other forms of thought and practice are prompted into existence" (113). The existence of medically unexplained illness within the current medical system can easily be seen as a pragmatic failure of modern medicine's insistence on dualism, which excludes patients without organic markers for their illness. Yet this failure is instead offloaded to the patient, who comes to bear the burden of the lack of clear-cut organic explanation. This offloading of the burden is a result of the impasse that mind-body dualism results in and a clear formulation of the problem of dualism lived at present.

Sontag's writing on the dangers of conflating metaphor and illness resonates strongly here. As also seen in the discourse around *Afflicted*, the idea that illness is in some way an expression of repressed frustrations is indeed presented as a failure on the side of the patient rather than of medicine's lack of explanation. My discussion of the representation of patients with unexplained illness in *Afflicted* also showed how this failure is capitalized on by having entertainment value in the form of a recognizable cultural trope. The integrative model, or the link between entities generally conceived of as separate, keeps this problem in place. Attempts to reformulate or reform this dualism within psychosomatic medicine have continuously resulted in similar effects and an eventual negative connotation of the term.

Greco's argument, tracing mind-body dualism back to the "bifurcation of nature," works well on its own. It clearly establishes the dualism and its resonance in the present-day status of psychosomatics as a problem. However, it gets significantly more difficult when Greco's analysis is applied to the contemporary controversy around ME/CFS, as she does in an article written together with prominent psychiatrist Michael Sharpe, which was published in the same year. In a sense, the article by Sharpe and Greco engages with a practical reverberation of mind-body dualism in the form of medical care for unexplained illness. Their article focuses on the maintained distinction between illness and disease and the effects of this distinction in the management of ME/CFS. However, the publication of their article resulted in a dispute that illustrates how an analysis of the problem of mind-body dualism on a conceptual level is in danger of ignoring the real-life manifestation of this problem, which plays out in the form of stigmatization and neglect of patients' physical conditions.

Sharpe and Greco draw out the relationship between disease (as an objectively verifiable reality localized in bodily pathology) and illness (as a subjective experience told in narrative version). In cases of ME/CFS, they maintain that *disease* cannot be found, but *illness* is present. They thus characterize ME/CFS as a form of illness-without-disease. Similarly, as Greco did in her article that she wrote as a single author in the same year, Sharpe and Greco also refer to Whitehead's "bifurcation of nature" and Foucaultian theory. Doing so, they map out the epistemological framework of bifurcation in which patients and medical practitioners navigate a controversial situation.

Departing from this epistemological context, Sharpe and Greco discuss the resistance of patients with ME/CFS to forms of therapy that focus on illness instead of disease. In cases of unexplained illness, an illness-focused approach to care centralizes patient experience instead of identifiable biomarkers. As treatment options, an illness-focused approach to care includes, for instance, cognitive behavioral therapy (hereafter CBT) and graded exercise therapy (hereafter GET) (2019: 183). Both therapies aim to reframe patients' beliefs about their symptoms and target patients' behavior instead of the symptoms themselves. The fact that Sharpe and Greco rely on a model for ME/CFS as illness-without-disease, as well as their general endorsements of these therapies, led to fierce resistance, not only from patients but predominantly from their fellow scholars.

Their argumentation on the relevance of the “bifurcation of nature” for the understanding of the controversy around ME/CFS goes as follows. It departs from the separation between objective and subjective realities. This separation means that subjective reality derives from the objective (measurable, visible) reality of disease. The separation of objective and subjective realities is made on a hierarchy that values objectivity and distrusts subjective experience. This hierarchy creates a paradox in which experienced reality “can be dismissed as merely delusion, unless it corresponds with objectively known reality.” Sharpe and Greco note that because of this bifurcation, the two notions, “‘this is a real illness/this is not a disease’” cannot be simultaneously true (2019: 185). Tracing the distrust of patients with ME/CFS towards illness-focused approaches to care back to the “bifurcation of nature” shows not only the historical contingency of epistemological frameworks but also the structural conditions that determine how physical complaints are both experienced and met with.

Yet their article did not only describe a current controversy but also became highly controversial itself. On the one hand, Sharpe and Greco identified the operation of an epistemological framework that has real-life consequences for patients. They contextualized patients’ resistance and recognized the need for them to resist these therapy forms. They acknowledged how an “absence of a disease diagnosis can make an illness appear morally ambiguous” and stated that the rejection of illness-focused forms of care by patients with ME/CFS “can consequently be seen not as irrational, but as entirely understandable” (2019: 184).

On the other hand, Sharpe and Greco endorsed CBT and GET as illness-focused forms of care, while scientific evidence for their effectiveness was contested, and these forms of therapy were criticized, mainly because they departed from a model that implied mental causation for ME/CFS. Endorsing them thus was controversial, seeing as that patients, as well as medical scientists, had been rallying against them. These patient groups have argued that a focus on the mental aspects of ME/CFS led to a neglect of the physical side of their illness. A painful example of this argument can be found in accounts of patients who reported that GET, which focuses on physical exercise, had even made them worse (Kindlon 2011).

Sharpe and Greco formulate carefully, and their article focuses on the symptoms of fatigue instead of on ME/CFS itself. They do not state that ME/CFS can be cured but mention that research has stated that illness-focused forms of therapy (CBT and GET) have lessened fatigue in cases of ME/CFS, which is why the authors support these forms of therapy.[109]

The current UK-based National Institute for Health and Care Excellence (that goes by the acronym NICE, used hereafter) guidelines for ME/CFS reflect the shifting attitude towards CBT and GET as treatments for ME/CFS. They no longer unequivocally endorse them. In reference to CBT, the guidelines state that this form of therapy could be used to better cope with the signs of illness but that it does not cure ME/CFS.[110] The NICE guidelines include a separate box that states the following.

> The committee wanted to highlight that cognitive behavioural therapy (CBT) has sometimes been assumed to be a cure for ME/CFS. However, it should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness. (2021: 42)

The NICE guidelines state that although CBT could be used as support, it must not be seen as a cure. The need to mention that CBT is sometimes assumed to be a cure shows the confusion around offering this form of therapy. It easily implies an assumption of a mental origin for the illness. The explicit mention of *support* in reference to *cure* shows how the guidelines take care not to implicate that ME/CFS has a mental origin and cannot be treated and cured as such. Sharpe and Greco's reference to the fact that fatigue has lessened as a result of CBT leaves this in the open. Since fatigue, to a severe and debilitating extent, is the main characteristic of ME/CFS, it could be read in a way that suggests that a focus on behavior could be used in a curative way.

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[109] Sharpe and Greco's specific formulation is as follows: "the fatigue in both these cases [fatigue related to cancer and fatigue related to ME/CFS] has been found in research studies to be lessened by illness-focused rehabilitative treatments that include a talking treatment called cognitive–behavioural therapy (CBT) and a behavioural treatment called graded exercise therapy (GET)." A source listing the research that is mentioned is not given. See Sharpe and Greco 2019: 183.

[110] The guideline includes a separate box which explicitly states that CBT has "sometimes been assumed to be a cure for ME/CFS. However it should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness" See NICE guidelines 2021: 42.

The NICE guidelines are clear in reference to GET: “do not offer people with ME/CFS any therapy based on physical activity or exercise as a cure for ME/CFS” (2023: 33). The authors of the guidelines warn against this form of therapy, and state that these therapies are based on a theory that assumes that ME/CFS is due to an avoidance of exercise. Thus, the guidelines hint at the way in which GET can implicate that the origin of ME/CFS lies in behavior for which the patient can be held accountable. The guidelines also mention that physical activity can cause a worsening of symptoms in the form of flare-ups, which “usually occur as part of post-exertional malaise” (2023: 57).[111] In a section that explains why the committee made various recommendations, the authors of the guidelines state that qualitative evidence has reported that people with ME/CFS were harmed by GET, and that physical exercise should be approached most carefully and individually in cases of ME/CFS (2023: 78). On the whole, the guidelines are clear to not endorse GET as a form of cure, and are very careful in reference to GET as form of support.

Research in social psychology has discussed the negative stereotype that illness-focused approaches to care resulted in and attributed the main factor for this stereotype to what they call the “cognitive behavioral model” for ME/CFS (Geraghty et al. 2019; Froehlich 2022). The study by Froehlich et al. argues that the causal attributions for the stigma of ME/CFS are mainly due to the introduction of cognitive behavioral therapy as a viable treatment. The analysis by Geraghty et al. focuses on the history of the cognitive behavioral model, which they conclude to be primarily an idealized narrative model with “stark weaknesses, inconsistencies and contradictions” (2019: 10). Most importantly, it ignores biological, sociological, and psychological factors, and focuses on individual behavior and illness-belief, that could be overcome with the right behavioral and mental treatment (Geraghty et al 2019: 9). The focus on mental and behavioral aspects has led to a view of ME/CFS *as mental illness*. This has not only led to stigma but also implied that the patient was in some way a factor in the creation of their own symptoms.

The focus on the management of these symptoms and the attempt to gain more control over the thoughts that a patient has about their symptoms in therapies like CBT and GET risks implicating that these symptoms have, in fact, an origin in the mind, and

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[111] For a discussion on (an earlier publication of) the NICE guidelines in relation to graded exercise therapy see also Torjesen 2020.

that they could be alleviated by practicing a better mental control. The patients' side could thus look as follows. The patient experiences physical symptoms and experiences that are not taken seriously. This patient has to accept a form of therapy that will not cure but only manage the symptoms and which does this in a way that suggests mental causation on multiple levels. This patient thus has to deal with debilitating symptoms but also with managing the implication that part of their illness is due to exhibiting the wrong type of behavior or feelings and that better management of these could, or would have, prevented a part of their illness.

The journal that published Sharpe and Greco's article published at least three articles in which other scholars argued against Sharpe and Greco's claims (Wilshire and Ward 2019; O'Leary 2020; Lubet and Tuller 2020). All three articles point out that Sharpe and Greco's characterization of ME/CFS as illness-without-disease is not backed up by research, which now acknowledges ME/CFS as a biomedical disease that is supported by biomedical data. All three articles also point out that Sharpe and Greco endorsed GET and CBT, while evidence supporting their positive effects on patients is scientifically flimsy and highly controversial. Moreover, the fact that Sharpe himself was personally and professionally invested in CBT and GET treatments further problematizes the fact that research that contradicts the positive effects of CBT and GET for patients with ME/CFS was not cited by the authors.[112]

The dispute points out how easily a focus on an epistemological framework is in danger of ignoring and sidetracking the voices of patients, who have advocated for the recognition of their experience of physical illness for years. Almost nowhere is the problem of mind-body dualism for the understanding of unexplained illness so clearly and acutely present as in the battle over the causation of ME/CFS. It does not only show how the impasse of mind-body dualism is often offloaded onto the patient, it also illustrates how an analysis of this problem is in danger of ignoring the real-life manifestation of it. For unexplained illness, mind-body dualism is not only a theoretical problem but one that results in a very real form of stigmatization and neglect of the

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[112] Sharpe helped to develop CBT and GET for patients with ME/CFS, and published extensively on the usefulness of these forms of therapy in his professional career. See Wilshire and Ward 2019: 1; Lubet and Tuller 2020: 2.

physical side of patients' conditions. Or, to come back to an earlier formulation: a continuous focus on mind-body dualism risks to sidetrack the problem at hand.

Multiple patient advocacy groups for ME/CFS have organized themselves to advocate for the recognition of ME/CFS as a distinct somatic disease. Such patient organizations have continuously argued that an overemphasis on psychological aspects (such as is maintained in the endorsement of CBT and GET as a treatment for ME/CFS) leads to serious neglect of the physical aspects of ME/CFS and that more biomedical research on ME/CFS is acutely needed.[113]

This argument is also made by philosopher of science Diane O'Leary, in response to specifically Sharpe and Greco's analysis. According to O'Leary, "It is no longer safe to assume that patients with ME/CFS suffer from illness-without disease." ME/CFS was recognized as a somatic condition by national institutes in the U.K. and the U.S. O'Leary points out how this recognition means that this debate is no longer held between patients and professionals but between professionals themselves, who can no longer ignore biomedical evidence. However, Sharpe and Greco still refer to ME/CFS as illness-without-disease and thus emphasize a patient's coping behavior instead of their physical condition. O'Leary states that it is "vitally important to determine how error of this kind could prevail for so long" (2020: 5). According to O'Leary, Sharpe and Greco represent the long-standing perspective of psychosomatic medicine, which presents the "worrisome possibility that disease in patients with ME/CFS has been rejected on the basis of conceptual positioning, without adequate regard for medical risk." (2020: 5).

The controversy around ME/CFS goes a long way back. It often got very heated, not only within scholarly work. Patient activism has long targeted what they call the "Wessely school," of which Sharpe was a prominent member.[114] In 2019, Michael Sharpe was interviewed by *the Guardian* author Andrew Anthony for an article on internet

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[113] The patient organization #MEaction writes on their home page that their "movement fights for recognition, education, and research, so that, one day, all people with ME and CFS will have support and access to compassionate and effective care" (#MEaction n.date; n.pag). For an analysis of online communities and support groups organized by patients with ME/CFS see Lian and Grue 2017; for an analysis of the stigmatization of patient groups as "militant" see Blease and Geraghty 2018; for an analysis of the dangers of neglecting the somatic aspects of ME/CFS see O'Leary 2020.

[114] On the website *#MEpedia*, a project founded by the MEAction Network, an entry is dedicated to the "Wessely School," describing the biopsychosocial model of ME/CFS as promoted by psychiatrist Simon Wessely. See "Wessely School" 2023.

activism by patients with ME/CFS. *The Guardian* reports that, in 2019, the same year that Sharpe and Greco published their article, Sharpe announced that he had withdrawn from research on ME/CFS "because the field had become 'too toxic.'" Sharpe states that ME/CFS activists are "absolutely set against any implication whatsoever that there could be any aspect to their illness which isn't rooted in biological disease." Any small implication that does not depart from biological data becomes the equivalent of, says Sharpe to *the Guardian*, "'saying it's not real, it's imagined, you've made it up'" (Anthony 2019: n.pag.).

The subtitle of *the Guardian* article states that "research into [ME/CFS] may be stalling because of online criticism and abuse."[115] The tone of the article fits within a general pattern of media reporting on ME/CFS, which was pointed out by patient activist Naomi Chainey. According to Chainey, a writer and experimental filmmaker who was diagnosed with ME/CFS herself, the tone of newspapers that report on ME/CFS can be characterized into two categories. The first describes patients as just "lazy," discrediting ME/CFS as being "real." Chainey describes this category as falling under the general headline saying something alongside the statement that, "Scientists Reveal People With ME/CFS Are Just Afraid Of Exercise." The second category plays with a sensationalist surprise based on initial disbelief and discrediting of the illness. It says something along the line of: "Have Scientists Finally Proven That ME/CFS Is A Real Disease?" Chainey described that a third category was added when patients started advocating for themselves: "Chronic Fatigue Extremists Are Harassing Scientists!" (Chainey 2016). The tone of *the Guardian* article in which Sharpe was interviewed fits this last category. The trope of militant patients was scrutinized in a scholarly article by Blease and Geraghty (2018), who discussed and refuted that ME/CFS patient activists behave "militantly." They concluded that negative mischaracterizations are dangerous because they could stand in the way of important exchanges between patients, medical researchers, and primary care physicians (2018: 400).

Amongst many things, the clash between Sharpe and patient advocacy groups shows the extent of pain that the idea of psychosomatic illness results in for patients. This is deeply personal for patients: their physical experiences are delegitimized, and it is

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[115] Without omissions, the full subtitle reads as follows: "Research into the chronic illness, which affects 250,000 people in the UK, may be stalling because of online criticism and abuse." See Anthony 2019.

suggested that they are due to mental illness. The fierce clash shows the high stakes of the pain of the delegitimization, the helplessness, and the desperation that these patients experience. Sharpe's statement in *the Guardian* that the tiniest hint of the implication of unexplained illness is not based in biological data becomes the equivalent of saying that these patients "made it up" is true: these patients with ME/CFS become extremely sensitive for spotting the denial of a biological basis, and the implication that their experience of illness is not real. The denial of a biological basis can have serious material consequences, which Sharpe and Greco also mentioned and acknowledged.[116] Disability benefits can be denied in the absence of disease, leaving patients without any financial support whilst they are unable to work due to illness. Patient activists have even reported the threat or risk of involuntary psychiatric hospitalization (Chainey 2019; Harding 2010). Taking this into account, it is no surprise that patients exhibit great sensitivity. These patients are often severely ill, while support in the form of medical care, social acceptance, and financial means is often lacking.

In the case of unexplained illness, mind-body dualism emerges as a great and greatly problematic cluster. This cluster does not need to be untangled but rather asks to be understood as a complexity that needs to be carefully approached. The difficulty lies in an overemphasis on both sides of the controversy: either only wanting to focus on the mental or the physical aspects of illness for which biomedical evidence is contested. In the case of ME/CFS, patient advocacy groups have shown that the "cognitive behavioral model" of ME/CFS has long resulted in an overemphasis on the mental aspects of the condition.

Staying with the problem at hand first means identifying the main characteristic of the problem. Patients with ME/CFS have shown that the main problem of mind-body dualism for them has been the neglect of physical aspects of their illness in favor of an overemphasis on mental ones. Mirin et al. reviewed the small amount of funding that was attributed to biomedical research on ME/CF and attributed it to stigma (2020:278). Addressing this problem has to at least involve compensation in the form of research on the biomedical aspects of ME/CFS.

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[116] Sharpe and Greco mention that the rejection of illness that is not seen as "real" has implications for acceptance, care and financial support (2019: 184).

In the next section, I stick to the pragmatic existence of the problem of mind-body dualism for unexplained illness by going deeper into the notion of secondary gains. The idea that illness offers some kind of advantage for the patient in the form of the "sick role" has been central to some of the most problematic discourses around unexplained illness. It attributes an unconscious motivation for the creation of physical symptoms to the patients. In turn, these patients are at risk of being held responsible for the creation of their own illness. Describing the discourse around secondary gains allows me to flesh out how patients with unexplained illness are made into a problem themselves. The notion of secondary gains is supported by the psychosomatic conception of mind and body and provides a clear example of a negative framing of not only unexplained illness but also of the patients who suffer from it.

4.4 Perverted, Psychosomatic Gains

One of the patients represented in Netflix's *Afflicted* has particularly attracted a lot of hate and negative attention in reaction to how she was portrayed in the series. Pilar Olave, who suffers from multiple chemical sensitivity (MCS), has given her account of the representation in an article called "The Truth About the Most Hated 'Character' In Afflicted" (Olave 2018: n.pag.). She describes how the series created a drama that portrayed her character as the villain who takes advantage of and abuses her husband.

> They created a soap opera with a husband who was made into a hero, fighting hard, doing all the right things until the end, despite an extremely unsupportive father and a mentally ill wife who used him to her advantage, perhaps even entirely faking her so-called illness in order to leave the marriage. (Olave 2018: n.pag.)

Olave writes that this is "not the real story at all" and that the reality was that she got sick after being exposed to a two-year gas leak from an undetected gas pipe that ran underneath her bedroom. Her symptoms then appeared gradually. First as occasional headaches and food allergies, then in being unable to breathe or speak, palpitations, nerve pain, and physical numbness (Olave 2018: n.pag.). From there, her health deteriorated further, and she started to be severely ill, being in constant pain and also losing her vision and cognitive functions. Eventually, in order to avoid all kinds of exposure that trigger her symptoms, she lives an isolated life between four walls and uses a breathing mask to receive enough oxygen. As much as she can, she limits exposure to natural gas fumes, petrochemicals, solvents, cleaners, pesticides, perfumes, fragrances, cleaning products, car exhaust, and other kinds of incitants.[117] This also results in her keeping away from public buildings or maintaining her distance from people whose clothes have not been sanitized according to her needs, including her husband.

She received multiple diagnoses from medical specialists, who confirmed the long-term gas leak as being the cause of her physical symptoms and did multiple lab tests that gave clear indications of physical illness due to chronic exposure. In the blog post recounting her story, Olave includes excerpts from the medical reports written by specialists she has seen before filming the series. These reports confirm that there were organic findings. In her blog post, these excerpts function as proof of the physicality of her illness to contrast Netflix's framing of her condition as being predominantly a mental one, made up because it would provide her certain advantages.

On Reddit, a user called egorman9 posts the following in reaction to the episode in which Pilar Olave is introduced.

> There is nothing more despicable than taking advantage of someone for their kindness by leading them on, not caring if you put them in a position that could ruin their life just for your own personal gain. Sick or not (which I question at this point), there's no excuse for that type of selfishness. It's sociopathic. (Egorman9 2018: n.pag.)

The post is placed on a Reddit called "Confessions," and is titled "Netflix Series Afflicted: I Want To Punch Pilar In The Face." The blog post written by Olave herself also gives examples of the different kinds of hate messages she received personally, such as: "You're a piece of shit. You deserve to die for the way you treated your husband, only taking and never giving back" (Olave 2018: n.pag.). Apart from the severe aggressiveness and hateful tone, the commentary on Reddit and the example of the hate messages received by Olave describe her physical illness in terms of taking advantage, leading someone on for personal gain, selfishness, or "only taking and never giving back." The general idea

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[117] Olave included medical information provided by various healthcare professionals in her blog post. See Olave 2018.

is that Olave has created her own illness in order to gain care from her husband without needing to be close to him physically.

Different patients who featured in the Netflix series and wrote accounts of their misrepresentation published on medium.com stated that the series' makers have gone to great lengths to frame unexplained illnesses in terms of such secondary gains. This narrative framing is resisted by the group of patients who rallied against Netflix (Sidwell 2018; Olave 2018; Edelstein 2018; Feczo 2018). Jake Sidwell, another patient who volunteered to be part of the series, writes that "it's no small thing to add another voice to the mob which says we want to be sick, that we find some benefit in relinquishing our dreams in favor of a bed" (Sidwell 2018: n.pag.).

Olave's own story counters the series' representation on multiple accounts. She notes that interview techniques were used to make her say certain things that were later edited together and that scenes in which her husband is shown caring for her were scripted by the producers. She writes how their marriage of seven years had been in a fragile state at the start of filming the series because of her husband's neglect of her condition, his refusal to accept that her symptoms were due to physical illness, and his temper issues (Olave 2018: n.pag.). Her account is that she did not trust him anymore but that he would not accept a divorce. The constructed narrative, however, paints a picture in which Olave uses her illness to maintain a distance from her husband, also physically, while she, at the same time, extorts him financially. A similar narrative trope is at work in the representation of the relationship between Jill Edelstein and her partner.[118] They report that their relationship was depicted in terms of financial extortion and emotional abuse, a representation that is firmly countered by them both (Edelstein 2018; Feczo 2018).

The idea of secondary gains, or the idea that an illness would provide a certain benefit in maintaining the patient's sick role, goes at least as far back as Freud, who made a distinction between primary and secondary gains of illness.[119] A primary gain, according to Freud, is described as a "flight into illness," where illness is seen as the result of an

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[118] See also section 2.4, 186-187.

[119] The distinction is most elaborately mentioned by Freud in a footnote that he added later as a correction to a passage in 1923 to his Dora case, "Fragment of an Analysis of a Case of Hysteria." As pointed to elsewhere (Hommes forthcoming "Towards a Theory."), the inclusion of the footnote in a case of hysteria already says much about the gender dynamics in the formulation of the concept. See: Freud 1953 [1901]: Freud 1963 [1917]: 384.

inner conflict (Freud 1953 [1901]: 43). Secondary gains are related to the social surroundings in which the sick person finds themselves as a result of their illness. The illness might offer the patients not to have to work again, to gain attention, or to keep their families close. The notion is also well-known from nineteenth-century literature, such as Jane Austen's novels, in characters like Mrs. Bennet, the mother of the protagonist in *Pride and Prejudice* (1972 [1813]), or Anne Elliot's sister in *Persuasion* (2003 [1817]), who both use feigned conditions, or their "nerves," to get out of situations that displease them or to receive care and attention from their family.

Jane Schmidt's analysis of Marianne Dashwood's illness, the main protagonist in Austen's *Sense and Sensibility* (2003 [1811]), is a more positive one. Schmidt describes Austen's portrayal of Marianne's illness as an exercise of power: as something with which the heroine negotiates her position within the limited options available to her (Schmidt 2019: 436). This interpretation of nineteenth-century "female maladies" comes back in twentieth-century feminist reappropriations of hysteria that retrospectively analyze the reported physical symptoms as forms of protest against patriarchal societies.[120] There are two interpretations of illness found here. The more cynical one is shown in the first two mentioned Austen novels. The more positive one is given to Austen's portrayal by Schmidt and in the feminist interpretations of hysteria as a form of protest. However, both interpretations hold on to an idea of physical illness that is, in some ways, created because it is instrumental to the patient.

A similar instrumentalization of illness is at play in the portrayal of Olave and Edelstein's illnesses in *Afflicted*. It is done in such a way that both Olave and Edelstein report not to recognize their own life or relationships in the representation. Edelstein's partner reports that instead, a recognizable sensationalist narrative was scripted (Feczko 2018: n. pag.). This narrative is carried by the idea that conditions that are only partly physically understood or remain contested within medicine – such as MCS, which both Edelstein and Olave struggle with – are unconsciously created by the individuals themselves, who are then vilified. In *Afflicted*, the doubt around the physicality of the

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[120] See section 1.2.2, 40, note 30. For a review of Irigaray and Kristeva's engagement with hysteria, see Summers-Bremner 1998.

represented patient's illnesses stands at the basis of the implication of there being secondary gains.

In what follows, I will briefly pause at how this is done by looking at the opening sequence of the fourth episode of *Afflicted*, titled "Chapter 4: The Mind," which first introduces the character of Pilar Olave to the series. The episode opens with a black screen and the sound of a low rumble. Over it, the voice of Jake, who was already introduced in episode three, speaks the following. "Saying that everything feels like a dream where I feel high all the time. [pause] Just saying nothing seems real to me [pause]" (*Afflicted* 2019: E04 0:09). While these words are spoken and the rumble continues, flickering camera images appear of Jake standing in front of a mirror, with tubes in his nostrils and tubes attached to the back of his head. When the edits switch to the opening credits that state this is a "Netflix original series," Jake's voice continues, and speaks: "You sound like a crazy person" (*Afflicted* 2019: E04 0:19). This sets the main theme of the episode's narrative, which is titled "The Mind."

Next, the rumble continues, and the sequence switches to include more featured patients named Carmen and Bekah, also introduced in earlier episodes. Carmen is shown sitting in her house while her voice-over says, "A lot of people think this is all made up." The edits then switch to Bekah, shown lying down and sitting in her van, stating, "It's a head fuck, and it's alienating. A lot of chronically ill people, we [pause] are each other's doctors. It's cause we are just used to being called crazy. Even when something is easily diagnosable." After Bekah, medical specialist Otto Yang, a physician specialized in cellular immunology, is shown in a more formal setting, stating that "Some cases of unexplained chronic illness can originate from the mind" (*Afflicted* 2019: E04 0:55).

In this narrative sequence, the patient's voices, in the form of voice-overs, are presented over shot images of them in their house or surroundings. Lying in bed, putting on oxygen masks, sitting in their living room, or staring at the ceiling. The images are of patients who either do nothing or are preoccupied with their illness. The images are presented in grey tones and stark contrasts, creating an unhealthy picture of their skin and surroundings. The camera work is flickering and unsteady, zooming in and out on the various positions. It creates an unstable image of the patients shown. When the edits switch to the image of the specialist Yang, shown in an upright, talking head interview style, the lighting is brighter, and the camerawork is steady. This allows the viewer to focus on the words that are spoken. The clear difference between the two types of camerawork indicates the valuation given to the represented patients and the specialist's dry remark. Where the specialist is shown in a neutral position, giving a general statement directly at the audience, the patient's voices are edited over their unsteadily filmed images, shown in unflattering positions and overall grey tones, giving the impression that their voices, in general, should be considered as having a lesser level of trustworthiness.

The next specialist shown directly after Yang's statement is Richard Friedman, professor of clinical psychiatry at Weil Cornell Medical College, but also contributing op-ed writer at *The New York Times*. While Friedman speaks, the editing shows images of the different featured patients, over which his voice states the following.

> After all, the brain is a very, very powerful organ and can cause all kinds of mischief. We have a saying in medicine that when you hear hoofbeats, the first thing that should come to mind is a horse, not a zebra. Statistically it's more likely that the cause of the problem is a common psychiatric problem, more than it is an unknown or uncatalogued physical illness. You can be deluded that you are sick. Meaning that you can believe that you're sick when in fact you're not sick and have a false belief about anything. (*Afflicted* 2019: E04 0.59-1.34)

Matching Friedman's voice with the images of the patients implies that they are the ones who are deluded that they are sick when they are, in fact, not and have what Friedman calls "a false belief." He alludes to the common saying in medicine about horses and zebras used to justify making a diagnosis based on common causes rather than to look for rare diseases, which are less common from a statistical view. In a medical article on the diagnosis of rare diseases, James Dickinson states that "until one [a zebra] arrives in the office, most doctors consider their existence to be as likely as unicorns or hippogriffs" (2016: 620). Dickinson states that the rare disease, metaphorized in the form of the zebra, is seen as a myth (like hippogriffs, who do not actually exist). Friedman, who speaks of horses and zebras first and then of the statistical unlikeliness of unknown illness and the possibility of delusion, almost uses the zebra as a hippogriff: not as an unlikely creature, but as one who probably does not exist because statistics tell a different story. Friedman's notion of statistics presents a limited framework. The commonness of the horse is tied to localized factors, not universal truth. Yet the zebra, an exoticized creature, is made into a hippogriff: unlikely to appear to (doctors like) Friedman.

Some of the patients, as well as their loved ones, as stated in their versions of their believed misrepresentation by the Netflix series, especially saw the edits overlapping Friedman's statements with shots of the various patients as problematic, dangerous, and manipulative (Edelstein 2018; Hill n.d.; n.pag.; Olave 2018; Feczko 2018). Janine Feckzo, the partner of Jill Edelstein, who was also filmed for the series, states that especially Friedman's statements "led the audience to the conclusion that whomever they were speaking of wasn't physically ill but mentally ill … and, therefore, cast doubt on any other person suffering from the same illness" (Feczko 2018: n.pag.; ellipsis original). Olave also comments explicitly on how the editing used statements by Friedman to discredit the physicality of her illness. She points out that she has never met Friedman and that he is not familiar with her case (Olave 2018: n.pag.). Nevertheless, Friedman's words are edited over a scene in which she is shown leaving her apartment together with her husband while she covers her nose. Shown under Friedman's voice-over, who speaks of certain symptoms only occurring under specific contexts, it creates the impression that her symptoms are an emotional reaction to her husband instead of, as she writes herself, "a reaction to cleaning products in the building, fragrances in the elevator, and car exhaust in the parking area" (Olave 2018: n.pag.).

The opening sequence of the series episode is one in which the images of the patient's conditions are explained through the words of the specialists who refer to the statistical likeliness of unexplained illness being caused by psychiatric problems. The comment on the horses and zebras shows that for Friedman, unexplained illness as a function of the mind is more likely than there being a physical cause. For him, patients who hold onto physical symptoms without clear organic cause are possibly deluded or have what he calls "a false belief" created by a "mischievous brain." Friedman here simultaneously infantilizes these patients and their brains, as well as the described process of conversion–something to which the tone of voice and the repetition in the first sentence also contribute. Apart from altogether ignoring the fact that some of these patients have received diagnoses and present various lab findings to back up their medical diagnoses, the way in which Friedman's comments are edited over the images of patients in vulnerable states indicates that something else is going on: that they are not really sick, and that the clue to their illness lies somewhere else.

In the constructed narrative of the series, Friedman functions as a specialist whose words are not contradicted by a counterargument. In his statement, Friedman argues that the belief of illness on the side of the patients can be real but does not necessarily need to correspond with what he sees as "real" illness, which is here implied to be physical illness. The way in which the idea of "real belief" but a lesser "real" illness is portrayed in *Afflicted* corresponds to the idea that secondary gains are created unconsciously.

A present-day Groddeckian example of such secondary gains that sees such gains as a result of an unconscious force that maintains physical illness is given by Lazslo Ávila. In a case study analysis published in the *American Journal of Psychoanalysis*, Ávila reads a father's illness as a means to keep his family together. He describes the process of identifying secondary gains as a "delicate mosaic" of which the patient is "the author of a complex, original and unknown 'product': his illness" (Ávila 2011: 287). In an earlier 1995 review on the secondary gains concept in medicine, David Fishbain notes that the concept has infiltrated different medical specialties yet is poorly defined by then. Fishbain states that one of the main problems around it is whether secondary gains are consciously or unconsciously motivated (1995: 264). In contemporary medical diagnostics, only somatoform disorders[121] are considered "truly unconscious" and, therefore, correspond to the idea of secondary gains (Fishbain 1995: 266-267).

Unexplained illness is thus often seen as an unconscious act and understood in terms of providing a certain gain for the patient. A frame that is thus established can explicitly bypass the patient's own agency or idea of their illness. In a memoir by Sarah Ramey, a writer and musician with a background in political campaigning, the more sneaking aspects of the idea that unexplained illness is created according to unknown and unconscious motivations come to the fore. Her memoir, published in 2020 as *The Lady's Handbook for Her Mysterious Illness,* recounts her chronic experience with multiple unexplained conditions.

Her story starts with a urinary tract infection, which was treated and then slowly worsened. Her first symptom after the treatment was a feeling of peeing broken pieces of

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[121] Somatoform disorders are listed in the DSM-III to DSM-IV (APA 1980; APA 1987; APA 1994). These diagnostic criteria were significantly changed with the revision to somatic symptom disorder in DSM-5. See Chapter Three of this dissertation, especially section 3.5.

glass, which then developed into extreme pain and spasms. She experienced pain in many parts of her body. In "all of the pelvic floor muscles, including those in the whole of the vagina, the rectum, the sacrum, the groin, the hip flexor region, the urethra, the bladder, the uterus, the cervix, and the left ovary" (2020: 35). Sometimes, this pain would spread through her abdomen and legs. She developed severe bowel and stomach problems, extreme fatigue, brain fog, radiating pain throughout her spine, unexplained fevers, frequent yeast infections, bacterial vaginosis, incapacitating menstrual cramps, vomiting during menstruation, and multiple other symptoms. At large parts of her story, she is completely bedridden and unable to do even the simplest things. She was repeatedly told that what was wrong with her was "all in her head" (2020: 40-42, 101).

Some of her diagnoses include ME/CFS, fibromyalgia, postural orthostatic tachycardia syndrome (PoTS), and Complex Regional Pain Syndrome (CRPS). Her memoir describes how she, before receiving these diagnoses, went through years of medical examinations in which no doctor could tell her what was wrong with her. Halfway through her memoir, she describes how, finally, after years of walking away from doctor's offices with yet another prescription for an antidepressant, Ramey finally received a name for her illness. *Strongyloides stercoralis*, a roundworm she had "probably picked up as a teenager in Costa Rica." (2020: 88). This type of infection can cause all kinds of symptoms like abdominal pain and a cough, but is often asymptomatic. It can lay dormant for many years until some event triggers the infection. After she received this diagnosis, she did not get better and eventually turned worse, as the lack of improvement from the treatment after the diagnosis made her desperate. She then writes the following.

> I really had no idea what I could possibly do to change this situation. I had done absolutely everything. This must be what I want, I conceded. *I accept I may have created my own illness*, I wrote on a sticky note and attached it to my mirror. *Take responsibility*, I wrote on another. *What you resist, persists*. I decided I just needed to accept that I was the attention-seeking malingerer those emotional healers had hinted at – the parasitic woundologist obsessed with being a victim, […] I didn't have a parasite – I was the parasite. Something was so perverted and so buried inside of me, no one could dig it up. I must not want them to, I reasoned. The hidden secondary gains were too, too great. There was no explanation.
>
> *I am a monster*, I thought. (2020: 109; emphasis original)

At this point in her story, she was lost. The narrative that was repeated to her so often got stuck in her head. In this passage, she, too, turns against her body, describing herself as a parasite and a monster. The sticky note that she attached to her mirror literally places the idea of secondary gains on her perception of self. Moreover, it is described as a concession. In her description of her desperation, the idea that eventually, at some darker level, she must want this illness is described as a fight she is no longer able to maintain.

It is a common and gendered narrative: women blaming themselves rather than other people or the larger society because that is the "feminine" thing to do. In 1985, Paula Caplan famously coined the phrase *The Myth of Women's Masochism*, in her monograph by the same name, writing a cultural history of the misogynist idea that women were in terrible situations because they “unconsciously *enjoyed* being there” (1993: xiii; emphasis original).

With the mention of the “emotional healers,” Ramey refers to alternative medicine scenes as being the primary instigators of the idea. Not only did she experience disbelief from medical professionals, but the notion that she must be at some level at fault in being unexplainedly ill also came from “the other side”: the more dogmatic alternative medicine practitioners hinting at the idea that not getting better is, as Ramey framed it in an online interview published on *Experience Life* website, “a choice” (Dulude n.d.: n.pag.). The hidden secondary gains, in Ramey’s description, are a perversion: a distortion of a perceived “normal” organic cause for illness that is now turned around, not originating in the body but in the mind.

The idea of secondary gains as a perversion of a normal illness etiology is widespread. It is a cultural notion as much as it is part of medical discourse. Within medical discourse, the secondary gains concept is used in general medicine, psychiatry, and psychology (Fishbain 1995: 264). The concept is explicitly mentioned as playing a part in the DSM-III-based formulation of conversion disorder, although this was removed in the fifth edition of the manual (APA 1987: 257; APA 2013: 320). Within popular culture, the way in which the Netflix series taps into the trope of secondary gains in order to create a sensationalist narrative shows the cultural traction of the idea that illnesses not explained in clear-cut medical terms must offer the patient some kind of advantage. In tandem, Ramey’s described concession brings to light not only the pervading aspects of the idea but also the force of the notion on Ramey's own perception of her illness. In addition to Sontag's critique that warned against thinking of illness as the result of repressed frustrations, the persistence of the notion of secondary gains exposes a second negative connotation that sticks to viewing illness as psychosomatic: it places the burden for the creation of the illness with the patient and attributes an unconscious, but nevertheless convenient motivation to it as well.

The perversion mentioned by Ramey hides in the turnaround of the dominant organic model of illness. Perversion, which comes from the Latin *pervertere*, or to turn around, here means that physical symptoms are not being created in the body but in the mind. Again, the way in which the idea of secondary gains relies upon a mind-body dualism is what results in it being problematic for the patient. The monster that Ramey speaks of is created at the moment when she concedes to the idea that she may have created her own illness. She has not experienced her illness as being something parasitic but when at a loss and being close to breakdown, she starts to accept the notion that is repeated to her so often.

Ramey's account, as well as the stories told by the patients of *Afflicted*, all resist the idea of secondary gains and instead experience their illness as a physical matter, something of the body, rather than their minds. Not only do Ramey and the patients of *Afflicted* report that the various undertaken psychological treatments did not help, but they also stress various organic findings, like lab tests and diagnoses, to maintain a physical status for their illness. Within the secondary gains concept, the consequences of a view on the integration of mind and body intersect with the dominance of organic explanations for illness and create an overall negative tone: that, at some level, the patients themselves are at fault.

The next section turns to Sara Ahmed's mobilization of the concept of stickiness to further enlarge on the psychosomatic impasse that unexplained illness results in for patients. Here, I argue that not only does the psychosomatic concept stick to unexplained illness in a negative way but that the liminal, in-between place of psychosomatics as existing somewhere between the separated body and mind allows for the patients themselves to become "sticky." Their illness is in danger of not being viewed as something to be understood and hopefully cured but as a jumble of different factors. This liminality, which characterizes the impasse of unexplained illness, eventually is a dangerous place that implies not only blame but also negatively impacts treatment options, medical diagnoses, and societal acceptance of experienced physical symptoms without organic explanation. I thus turn to Ahmed to describe how this danger "sticks" to patients and how these patients become liminal themselves as a result of the psychosomatic impasse described in this chapter.

4.5 Sticky Concepts

Certain things stick. In *The Cultural Politics of Emotion*, Ahmed explores emotions in relation to relationality, bodies, language, and performativity. Throughout Ahmed's monograph, the question of "what sticks" is continuously present. It questions social transformation, relations of power, and the way in which people become invested in social norms (2004: 12). Ahmed develops the concept of stickiness in a chapter on disgust. She does so in such a way that it incorporates a view on the interplay of corporeality, psyche, and emotions not based on separations, dualisms, and/or unities but on points of contact, viewing these as an aspect of relationality. As such, thinking with stickiness addresses the edges of contact or specific fringes of discourse.

For psychosomatics, and how it implies a particular integration of psyche and soma, or mind and body as previously separate entities, thinking with stickiness helps formulate the implications of this integration in at least two ways. The integration that results in a liminal space is one of being between two things and incorporating neither side fully. At the same time, both sides of the separation are linked, or, in other words, stick to each other. Considering the difference in the valuation of physical and mental illness, and especially the way in which physical symptoms without organic explanation are prone to stigmatization, a certain idea of "psyche" sticks to "soma" in a negative fashion. Going even further, the liminality of the psychosomatic impasse does not only imply a sticky relation to each other but is expanded to the patients with unexplained illness, who now become sticky themselves.

Such a description of a negative transfer of concepts onto things, people, or emotions makes Ahmed's use of stickiness useful for my present purposes. Thinking about disgust, Ahmed asks "how stickiness becomes a quality of some surfaces, objects and signs" (2004: 89). In posing this question – which refers to surfaces as the outsides of bodies, objects, or things that are exposed to contact – Ahmed asks about the ways in which relationality comes to be embodied and lived. Discussing why some things are considered sticky and disgusting (slimy things) and others are not (glue), Ahmed thinks of borders of things and how something is seen as disgusting when it threatens to cross or override that border. The in-betweenness of slime (neither solid nor liquid) makes it disgusting. It clings, is not firm, nor does it flow. But of this in-betweenness, it is not the slime itself that incites the disgust. Rather, it is the fear of being absorbed into something liminal, something borderless and unknown, that Ahmed describes as being seen as threatening or disgusting (2004: 90).

Queer and feminist theory and the more recent trans* studies explored how borders are perceived as a threat in connection to politics of oppression or patriarchal and colonial structures. Anne McClintock's *Imperial Leather: Race, Gender and Sexuality in the Colonial Contest* (1995) is an example of an analysis that shows the interconnectedness of race, gender, and class as being tied to Western imperial modernity. McClintock shows how, in the colonial context, borders were feared and feminized by sailors, settlers, or soldiers, placing female figures "like fetishes at the ambiguous points of contact," calling unknown land "virgin territory," or marking the parts indicating blank seas on maps with images of mermaids and sirens (24). McClintock speaks of women as the boundary markers of empire. The feminization of borders is thus described as a strategy by McClintock in order to compensate for what she calls "male boundary confusion" in terms of fear for the racialized, classed, or gendered other (24).

Critical queer and trans studies created an entrance to think with fluidity to counter a solid state of self that creates an outside figure, exposing the politics of the practice of bordering and the fear of the other or the unknown. These scholars have connected White, straight, male, imperialist, and ableist notions of normativity to the (feminization of the) imagined "other."[122] Although not always working with the concept

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[122] See, for instance, Jasbir Puar's critique of U.S. exceptionalism in *Terrorist Assemblages* (2017), originally published in 2007. Puar analyses U.S. exceptionalism in terms of homonationalism, a concept by which she describes, amongst others, how an Islamophobic outside figure is created in defense of empire and heteronormativity. See also: Jack Halberstam's critique of naming and classification and his insistence on using the term "trans*" as a refusal to deliver certainty through the act of naming (2018: 3); Halberstam's more recent exploration of the concept of the wild (2020); or Cathy Cohen's earlier critique of a limited form of queer theory and plea for resistance to normalization and stabilization (1997).

of borders or liminality explicitly, critical queer and trans theory have been invaluable as a critique of forms of power based on separations and the creation of stable identities: those normative constructions exposed by critical queer and trans theory as an illusion, instead proposing resistance to norms, fluidity, and a destabilization of stable, single identities.

Circulating around such a queer political context, Ahmed refers to Mary Douglas and the notion of dirt as matter-out-of-place. In *Purity and Danger,* originally published in 1966, Douglas writes that "where there is dirt there is system." Meaning that the notion of dirt, or, in this case perhaps, disgust, is "the by-product of a system"; a way of ordering things neatly into their right places (2002 [1966]: 36). Similar to how Rosemarie Garland-Thomson's *misfit* as a concept for disability studies has meaning in a social context, as discussed in section 3.2, Ahmed takes Douglas's work on purity to mean that something is not inherently disgusting, or sticky, but only becomes so by its moments of contact, the disordering of things outside of their own bound places.

> Rather than using stickiness to describe an object's surface, we can think of stickiness as an effect of surfacing, *as an effect of the histories of contact between bodies, objects, and signs*. To relate stickiness with historicity is not to say that some things and objects are not 'sticky' in the present. Rather, it is to say that stickiness is an effect. That is, stickiness depends on histories of contact that have already impressed upon the surface of the object. (Ahmed 2004: 90)

For Ahmed, stickiness is an effect intimately tied to relationality, or what she calls the historicity of contact that has impressed the object and has left their mark. This impression that is left on that which becomes sticky is important when taken back to psychosomatics and how the notion is transferred onto patients in a negative way. Ahmed notes that it is not entirely possible to clearly separate the literal and the metaphorical: a sticky sign and a sticky finger are not two completely different things (2004: 91). Certain notions, concepts, or words can become sticky. They can attach to certain objects or people associated with them. In the stories of the patients and the open letter that reported the mishaps of Netflix's *Afflicted*, notions of blame and responsibility were attached to the understanding of their illness as psychosomatic and stuck to the people concerned. As the notion of psychosomatics is itself a sticky sign, it becomes transferred to the people who are associated with it.

Asking how things or signs become sticky, Ahmed gives an obvious answer: things become sticky as an effect of encountering other sticky things. Stickiness is transferred from things to people, to signs and bodies, or in any different order in any sticky situation. These gatherings, this travelogue of contacts, become part of the object's surface, thing, or of a person, and for Ahmed, this accumulation often puts their integrity in question (2004: 91). Clear boundaries are dissolved, and the individual is no longer contained but too open, vulnerable or "leaky." The stories by the patients of *Afflicted* clearly report feeling such a loss of integrity. The misrepresentation is described by Olave as a "soap opera" that was created or as "sensationalized," according to Feczko (Olave 2018: n.pag.; Feczko 2018: n.pag.). Both patients point to the way in which the created narrative painted a picture in which they themselves and their partners did not recognize their own lives. As they report collectively, this misrepresentation exposes them all to ridicule and disbelief ("The Truth Behind" 2018: n.pag.).

The stickiness of psychosomatics is related to the concept's in-betweenness. The liminal aspects of the idea of psychosomatics as existing somewhere between body and mind call into question the person's illness. This liminality, captured in psychosomatics, turns it into a sticky concept and allows its stickiness to be transferred to people whose illness or physical conditions become associated with it. As an effect, they themselves become sticky.

Important to this constellation is that the stickiness of something is not a property of something itself but a property of its relationality. Ahmed gives an example of a sticky sign in the word "Paki," "which speaks to other words that are not spoken: immigrant, outsider, dirty, and so on." The associations between these words are concealed in the word "Paki" alone, and the way in which they are concealed is what allows such signs to accumulate value (2004: 92). That which is unspoken sticks to the sign and transfers its meaning to the person who is called by it. Where the word "Paki" functions as a sticky sign in that it is associated with negative and stigmatizing views connected to immigrants and outsiders, "psychosomatic," as I have shown, implies blame, responsibility, and being less deserving of care.

4.6 Conclusion

The liminality as a result of the particular integration of mind and body in the psychosomatic concept results in an impasse insofar as the dualism within medical discourse and popular culture holds it in place. This impasse becomes unbearable for people with unexplained illnesses.

The previous sections have shown how the negative associations of the psychosomatic concept function as a sticky sign instead of a promising new field within medicine. By contrast, the use of bodyminds in contemporary disability scholarship and activism aims at overcoming this stickiness by virtue of not existing in a liminal space of integration but by viewing mind and body as being always already entangled. On the one hand, the term can be seen to do "theoretical work,"[123] in the sense that it allows one to move beyond dualism conceptually. As such, it offers a promising turnaround of the problems maintained in dualism and creates more conceptual space for patients to understand unexplained illness beyond the mind-body schism. Theoretically, this would offer a conceptual route out of the impasse. On the other hand, translating the theory captured in the term "bodymind" into practical applicability requires a grand revolution of the organization of medicine that will not be easily accomplished.

One can only hope that this theory will find a way into practice. However, my discussion of mind-dualism has drawn out the practical limitations of the revolutionary theory captured in the term bodymind. Following Greco's and Sharpe and Greco's analysis of the problem of dualism in the present, I have argued that, especially when unexplained illness is concerned, it is first of utmost importance to draw out the complexities of mind-body dualism. It exists as an epistemological framework that is deeply engaged in Western knowledge. Unexplained illness is a theoretical problem that is necessarily interdisciplinary. First and foremost, however, it is a problem that patients experience at present. In this present, the problem is lived as an impasse—an impasse in diagnosis, treatment, recognition and care for these patient's symptoms.

This chapter addressed the travels of the psychosomatic concept and the negative consequences for people with unexplained illness, such as maintained in the idea of secondary gains. I did so by focusing on the consequences of mind-body dualism and

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[123] See Schalk 2018: 5; Price 2015; but also section 4.3, 199.

placing the origin of unexplained illness in the mind. The next chapter goes further in this direction by addressing not only the idea that illness is created in the mind but that this mind is somehow susceptible to contagious ideas. I will discuss the idea of psychosomatic contagion and the idea that the transfer of contagious ideas can be an instigator of physical illness. Similar to the negative fashion in which the psychosomatic concept is understood, the idea of contagion implies a negative view of relationality, which I will review in the next chapter.

5. Transference

5.1 Fibromyalgia and the Infectious Idea

A Reddit user starts a thread. The sub-thread in which it is posted is called “Confessions.” The description goes as follows: “Get that nasty secret off your chest or simply use this as a place to vent. See the unfiltered opinions of strangers.” A user who posts under the name @Fenniganisalive vented the following.

> I don’t believe there is a disease called fibromyalgia. I worked for the board of examiners for the state and federal agencies to determine whether someone was disabled or not. Every instance there is some type of mental disorder or drug abuse, attention craving fat 40 year old house wives that are lazy as fuck. There are men that claim that they have it too, but not nearly as many women. I think it’s fake and everyone knows it. (@Fenniganisalive 2012)

The responses to the post vary greatly. Some wholeheartedly agree, saying that they, too, know a “lazy lady,” siding with the misogynist tone of the comment. Others share their own stories or stories of family members. They state how their lives, or the lives of their loved ones, have been ruined because of fibromyalgia, pointing to the hurt the user inflicts. “Fuck you and fuck all the people who don’t believe. I’ve stared it in the eye and it’s there” (@Daydreamer99 2012). One thing that both comments have in common is their emphasis on believing. You either believe or don’t believe that fibromyalgia is real.

Fibromyalgia is a chronic condition that causes severe and widespread pain in muscles and joints. Other symptoms include severe fatigue and cognitive difficulties, often called “fibro fog” by patients. It involves difficulties with concentration, memory loss, and general confusion. As a diagnosis, fibromyalgia refers to a collection of symptoms that are often seen together. Fibromyalgia symptoms group around joints and muscles and are often treated in rheumatology. Fibromyalgia is much more common in women than it is in men. The numbers differ, but some reports note a ratio of nine to one (Johnson 2008: 4; Yunus 2001: 128; Robinson et al. 2012: 1367). Fibromyalgia’s ambiguous medical status means that patients often feel that they have to work hard for their pain to be taken seriously and that it often is not, both in the medical setting and outside (Hellström et al. 1998; Åsbring and Närvänen 2002; Åsbring and Närvänen 2003). There is no cure or treatment for fibromyalgia. Getting a diagnosis does not mean that patients will eventually improve.

The issue of belief whether the disease exists as such or not is not limited to this Reddit thread. In 2008, *The New York Times* published a front-page article by journalist Alex Berenson: “Drug Approved, Is Disease Real?” The article cited Frederick Wolfe, a researcher who helped define the criteria for fibromyalgia issued by the American College of Rheumatology in 1990. Wolfe was the lead author of the paper that formulated the first widely used and accepted diagnostic criteria for fibromyalgia (Wolfe et al. 1990). As *The New York Times* reported, he regrets formulating the diagnosis. He argues that the formulation of the condition encouraged people to think of themselves as sick. “Some of us in those days thought that we had actually identified a disease, which this clearly is not. […] To make people ill, to give them an illness, was the wrong thing” (Berenson 2008: n.pag.). This statement goes further than denying fibromyalgia’s existence by not believing in it. It is inferred here that the illness was created by providing a medical name.

The article in *The New York Times* states that Wolfe has become “cynical” about the diagnosis. Almost twenty years after the publication of the initial diagnostic criteria, he considers fibromyalgia a “physical response to stress, depression and economic and social anxiety” (Berenson 2008: n.pag.). The article does not dive further into why these causes do not qualify for the term disease. It also does not inquire how Wolfe comes to the conclusion that fibromyalgia is “clearly not a disease.” Instead, the article leaves a definition of disease, as well as a definition of fibromyalgia, quite in the dark. In the meantime, the reality of fibromyalgia is questioned: the researchers had only “thought” they had “found” a disease, which now has no claim on reality. Certainly not, since the man who first helped formulate the official criteria now looks back with regret.

The above-quoted comment by Wolfe in *The New York Times* implicitly refers to fibromyalgia as the result of imitation. Fibromyalgia has become a name that can be used as a model for people’s experiences of pain. Imitation has a complicated relationship to notions of “reality” and “disease.” In the article, neither the author nor the medical specialists quoted seem to directly deny that the experiences are real. Yet, the statement that “to give them an illness, was the wrong thing” means that the experiences might not qualify as being the cause of disease but are merely the result of imitation. If so, the reality of these symptoms becomes a more complicated question: one that does not take place in the physically identifiable realm of the body but in the experience of it by the individual patient who has copied illness behavior from someone or something else.

Fibromyalgia has frequently been discredited in medical literature. A 1999 article in *Annals of the Rheumatic Diseases* calls it a "pseudoscientific label" that provides an "official medical stamp of approval for failing to cope with the consequences of minor road traffic accidents, tripping over loose curbstones, or having a stressful occupational or domestic environment" (Reilly 1999: 325). The quote shows how patients are blamed for the experience of illness: failing to cope with life(style) experiences in a certain way must have led to their chronic pain. In 2003, an editorial in the *Journal of Rheumatology*, titled "Pain Is Real; Fibromyalgia Isn't," referred to the chronic pain that is part of fibromyalgia as a "lifestyle mix" and stated that "all manner of associated symptoms or nonsymptoms become prominent when the individual focuses on herself and her discomfort" (Ehrlich 2003: 1666). Here, the pain that fibromyalgia patients experience is also coupled with lifestyle and behavior (too much focus on themselves). It also genders the condition by the use of the pronoun "her." Both quotes illustrate the controversy around fibromyalgia, whose patients are amongst the most stigmatized group of people with unexplained illnesses.

I have so far referred to fibromyalgia as it is discussed on Reddit, as it is written in medical literature, and published in established media. In these different places, the notions of the "reality claims" of the disease, as well as fibromyalgia's gendered aspects, are negotiated differently. Blatantly, by the sexist tone on Reddit that denies that fibromyalgia even exists, or less obvious, in the referral to fibromyalgia by the pronoun "her" that links fibromyalgia to lifestyle and behavior in a commentary in a medical journal. The article by *The New York Times* greatly contributed to a popular perception of fibromyalgia as "not being real." It did so by citing an important name in fibromyalgia research, claiming that the disease was *created* by medical science and *imitated* by patients. The view presented in this article represents the fourth nervous route that I identify in this dissertation: that of transference.

The notion of transference stands at the center of this chapter. It relates to the common belief that does not only hold patients with fibromyalgia accountable for the creation of their own illness but also sees this illness as being the result of a form of imitation or even as social contagion. In medical terms, this means that fibromyalgia is seen as being *iatrogenic*. That is, the origins of the existence of fibromyalgia in patients are traced back to the medical definition of "fibromyalgia" within medicine. The term "iatrogenesis" comes from the Greek *iatro*, meaning healer, and the Greek *genesis*, or origin. In general terms, iatrogenesis is used to refer to medical activity that causes disease. This could mean that the administration of specific medicine or treatment makes patients ill. The term can also refer to bad hospital hygiene. In the case of fibromyalgia, it is the existence of the name "fibromyalgia" as a specific medical diagnosis that is believed to have created an idea of illness that is imitated by patients. By renowned rheumatologist George Ehrlich, the idea was formulated as follows: "Giving a name to the pains has spawned the very symptom amplification and imitative behavior the rheumatologic profession should be combating" (Ehrlich 2003: 1666). Casting fibromyalgia as iatrogenic thus involves a concern with the *formulation of illness* and involves a particular preoccupation with the spreading of this name as a possible diagnosis for complaints. This name is considered to be dangerous.

Links drawn between fibromyalgia and hysteria are not uncommon in medical publications. Similarities are noted between the location of the pain that is experienced in the body in fibromyalgia – these are called "tender points" – and in hysteria, as they were defined by Charcot (Brigo 2014). A link between a historical case of hysteria is made via an argumentation that this patient would be diagnosed with fibromyalgia at present (Pinals 2009). A study from 2019 looked at differences in personality and psychopathology in patients with fibromyalgia as compared to patients with rheumatoid arthritis, a condition with similar symptoms but which counts as medically explained. The study used a self-administered inventory, which they analyzed on eight clinical scales, one of which was called "Hysteria" (Gonzales et al. 2019: 261). Hysteria itself is not a recognized disease in contemporary medicine, but it serves as a point of reference whenever an illness lacks biomedical markers and is predominantly identified in women. In the case of fibromyalgia, the overlap between the type of pain experienced in patients with hysteria and patients with fibromyalgia further adds to the analogy. The connection that is easily drawn between fibromyalgia and hysteria greatly contributes to the stigmatization of fibromyalgia patients.

The analogy between fibromyalgia and hysteria is also used by people outside medical science to formulate a critique of how fibromyalgia patients are treated. In 2015, artist and writer Amy Berkowitz wrote a memoir in which she narrates her own experiences with fibromyalgia. She writes that the more she read about her condition after she was diagnosed, the more she was "surprised and amused to diagnose myself with hysteria" (37). Berkowitz did not feel taken seriously by the doctors that she saw and uses the reference to hysteria to implicate that she felt wronged by medical science in a similar way as the women who were labeled as hysterics during and around the nineteenth century. The comparison is also often made on patient blogs (Land Quant 2020; "Hysterical Women" n.date).

By some medical historians, sociologists, and cultural scholars, however, the comparison between fibromyalgia and hysteria was made in a different tone. Here, the comparison is not used to state that these patients are in any way wronged by a system. Instead, it is used in a way that diagnoses contemporary patients with fibromyalgia as modern-day hysterics and effectively discredits their legitimacy. A subtle example of this can be found in sociologist Kristin Barker's 2005 monograph on fibromyalgia. Although Barker's monograph largely focuses on describing "the human suffering that is fibromyalgia" (3) and emphasizes that women with fibromyalgia are often not believed as a problem (161), Barker also risks characterizing fibromyalgia as a modern-day version of what was previously called hysteria by linking the two, writing that:

> The most straightforward explanation for the sudden and dramatic rise of FMS would be that the tools of medicine have only recently discovered or revealed what has historically eluded the medical gaze or had been crudely captured in accounts of 'vapors,' 'nerves,' 'hysteria,' or 'neurasthenia.' (2005: 4)

Although she immediately after states that "such a scientifically deterministic account of the emergence of FMS is impossible to maintain," she states that medical science "has yet to make FMS visible" (4), thus linking medical unexplainedness to a stigmatized state, described in the referral to hysteria. Emphasizing general symptomatic and epidemiological similarities later on (55), and here speaking of a "sudden and dramatic rise" of fibromyalgia diagnoses right at the beginning of her monograph risks inferring that these patients are modern hysterics instead of creating more understanding of the social context in which these conditions were described as such.

In a footnote, Barker explains that "it is a very tricky matter" to compare nineteenth-century conditions to contemporary conditions like fibromyalgia and ME/CFS. "Nevertheless," she states, "exploring the ways the typical hysteric […] was like or unlike the average patient with CFS or FMS [fibromyalgia syndrome] can be instructive" (215). On the one hand, Barker's monograph was influential in its specific attention to fibromyalgia and how its poorly understood etiology negatively affected women. On the other, writing of "the typical hysteric" in relation to the average patient with fibromyalgia, who is also compared with a generalized person with ME/CFS, can indeed be "tricky" because it risks further establishing a link that effectively works to discredit lived experience. Establishing this link is especially problematic in the light of social contagion, discrediting the "real" of fibromyalgia by casting it as a mere imitation of age-old tropes.

Less subtle, more blatant examples of an established link between fibromyalgia and hysteria that argue for an understanding of fibromyalgia as a form of imitation can be found in writings by prominent medical historian Edward Shorter and feminist theorist Elaine Showalter. In *From Paralysis to Fatigue* (1992), Shorter establishes a clear link between hysteria as a historical diagnosis and present-day conditions like fibromyalgia and ME/CFS. Feminist theorist Elaine Showalter also does this in her controversial monograph *Hystories* (2013), originally published in 1997, in which she presents a similar argument.[124] In these accounts, fibromyalgia is referred to as a modern resurgence of hysteria, which spreads by inciting an idea. When Shorter discusses a news report on fibromyalgia, he states that "thousands of readers must have been suggested into coalescing their inchoate bodily symptoms into fibromyalgia as a result of this story. Television has spread this plague of illness attribution even more rapidly than the print media" (1992: 316). What it says is that fibromyalgia is caused by an idea. In such accounts, attention is paid to individual behavior and character in a way that deems some people, predominantly women, too susceptible to certain ideas. It redirects attention away from physical symptoms and the pain that these people experience and instead presents a negative version of the effects of social and discursive reality.

In recent years, medical attention for fibromyalgia is growing. A review article from 2020 states that there was considerable dissent among medical professionals about the cause of fibromyalgia for decades but that this view is now outdated (Bair and Krebs 2020: 34). Seven years earlier, a news article cites a U.S neurologist from Boston who states that there has been an "absolute explosion of papers" on fibromyalgia since 2013

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[124] For further scrutiny of Showalter's arguments around unexplained illness, see section 5.2, 246-249.

(Weintraub n.date: n.pag.). Recent research concludes that there is significant biomedical evidence to support claims that fibromyalgia is an autoimmune disease (Goebel et al. 2021). An editorial from *Clinical Rheumatology* closes with the words that the discipline is “transiting from an era of misogynistic disbelief of fibromyalgia structural underpinning to a time of innovative research based on well-structured scientific evidence” (Martínez-Lavín 2021: 3866). However, the history of fibromyalgia that is connected to misogynistic disbelief is not easily shed, and the surge in research does not mean that the discourse around fibromyalgia is easily changed. In a sense, this process shows that the acceptance of complaints of pain predominantly made by women is dependent on a biomedical marker to be taken seriously.

In this chapter, I address this problem by focusing on claims that fibromyalgia is merely an idea that creates illness in certain people. This group of people was characterized by rheumatologist and immunologist Nortin Hadler as people whose “individual personality traits and vulnerability predispose them to learning to lead a life of somatizing” (1997: 176). This view states that a combination of a certain personality type and a particular idea or environment leads to somatization: the conversion of mental symptoms into physical symptoms. Although Hadler does not mention the gender aspect of somatizing behavior, I argue that this vulnerability is feminized in this chapter. From my analysis of different cultural objects, I show how the discourse around fibromyalgia and related disorders makes use of a cultural stereotype of women as being overly sensitive, being too much focused on other people, being “leaky” (not contained as an individual) and generally too relationally focused. This feminized person is contrasted with a strong, rational, and self-contained individual who is stable and not susceptible to imitative, somatizing behavior.

Fibromyalgia’s poorly understood etiology also has the effect that there is generally little known about this condition. A 2017 study looked at attitudes toward fibromyalgia among undergraduate medical students and found that they had a limited understanding of fibromyalgia and were skeptical about its existence (Silverwood et al. 2017). The authors concluded that these attitudes were influenced by what they call the “hidden curriculum.” That is, the communication of a medical culture from teacher to student implies that the medical establishment does not take fibromyalgia seriously. These students also took the lack of a formal curriculum to mean that fibromyalgia was not serious and that it was a low priority. Amongst the general population, however, fibromyalgia has a similar prevalence as type two diabetes (Silverwood et al. 2017: 6).

Although biomedical research on fibromyalgia may be more accepted than it was, this does not mean that the connotation of it being a psychogenic illness is easily removed. In 2018, Häuser and Fitzcharles published a paper on fibromyalgia in which they also mentioned the surge in research but pointed out that there are many parties involved in the recognition and legitimization of fibromyalgia as a "real disease." They argue that the dispute around fibromyalgia largely exists because of the different interests of the parties involved rather than in reference to current scientific knowledge. These interests are, for example, different in patient support groups or for the pharmaceutical industry, who push a specific drug for fibromyalgia patients for financial gain. Academic and medical researchers may side on one particular side of the "fibromyalgia war" to advance their careers (54). Häuser and Fitzcharles do not take up a particular position in this debate. Frederick Wolfe, the same researcher who was the lead author of the 1990 American College of Rheumatology criteria for fibromyalgia diagnosis who later expressed his regret in helping to formulate the illness, does take up a clear position and writes that fibromyalgia is an illness that is actually a social construction (2009).

Wolfe departs from the idea that fibromyalgia may be an illness but that it is definitively not a disease in the sense that it lacks known pathology. When he tries to answer what fibromyalgia is, if not a disease, he resorts to theories of social construction. He refers to a concept by David Morris, a writer and literary scholar who published extensively on pain and wrote on "postmodern illness" as a biocultural phenomenon. Following Morris, Wolfe writes that although illness may originate in the mind, these minds operate in a cultural context. His next step is to warn society and medical researchers about which illness is supported and legitimized and which is not, stating that "A society can actively choose which illnesses are to be supported" (2009: 672). Taken back to fibromyalgia, the idea is that these complaints can only exist because of an idea that has created them. Consequently, these ideas must not be granted existence. If they would, they would only further spread ideas that lead to illness.

It is a very complicated terrain with implications on ontology. The question is whether the complaints, characterized under the header of fibromyalgia, would have existed had they not been named. For Wolfe, they clearly would not have. He states, "None of this could have happened without the Smythe-Moldofsky definition and the scientific hypothesis as to etiology" (2009: 673). The Smythe-Moldofsky definition was the first scientific paper that characterized fibromyalgia in 1977. This paper was also used by Wolfe et al. in their definition of the 1990 criteria that established fibromyalgia as a workable diagnosis. The idea that fibromyalgia would not have existed had it not been "invented" heavily depends on the acceptance of biomedical evidence as something that represents an undeniable truth.

In *The Body Multiple* (2002), medical anthropologist Annemarie Mol has shown that reality is more complicated and that even in the case of a very accepted medical diagnosis of atherosclerosis, the condition does not exist as a clear single entity. Instead, it emerges through different practices: a disease is enacted in medical settings in different ways that depend on the specific, local context. Going further, a broken leg emerges as something that is known as a "simple," very medically explained malady because of the socially accepted nature of bone fracture as a clear etiology. It says much that the book by Morris, which describes a wider view of illness as a biocultural phenomenon, resorts to using ME/CFS and PTSD as examples instead of conditions with a clear physiological etiology. This effectively contributes to a view in which some pain is granted recognition and legitimization, and others are not. While the idea of social construction may be used to create a wider view of illness in general, in practice, it often comes to the fore in the explanations of illnesses with poorly understood physiological etiology. What this results in, eventually, is a neglect of physical characteristics of these illnesses: a neglect of the pain that is just as real as a broken leg.

This chapter centralizes this movement by maintaining a focus on transference. As a nervous route, transference denotes understanding unexplained illness as something that can be transferred from person to person. Like the nervous route of impasse described in Chapter Four, transference is a nervous route that attributes the existence of unexplained illness to the realm of the mind. In a negative interpretation, the nervous route of transference holds the patient accountable. Like the nervous route of impasse, with transference, the confusion about unexplained illness is caught between different entities. In the previous chapter, I discussed the impasse in understanding unexplained illness as a result of the separation and subsequent integration of mind and body. In this chapter, I go one step further and discuss transference in reference to a maintained separation between the self and the other or the individual in reference to a discursive structure.

I have chosen to use the term transference rather than imitation or contagion because I explore the possibility of discussing such a movement in a positive as well as in a negative sense. That is, as a negative account of relationality, in the meaning of contagion, or as a positive account of relationality that views any transference between individuals as an inevitable aspect of being alive as a human bodymind. Even though the term transference itself is barely neutral in the sense that it comes with different cultural connotations, I use it as a more neutral term in the sense that transference allows for a discussion of both the action by which something is transferred and the process of transference. Transference is not necessarily hierarchical. Unlike contagion, it is not contaminated with pejorative connotations or medical/physicalist metaphorics. Also, it is implicated in psychoanalytic discourse on the unconscious structures of mind and body, which constantly hovers over the notion of illness transference as it is discussed in this chapter.

Transference can be understood in at least three ways in relation to unexplained illness. First, it is used as a concept to refer to the movement in which mental thoughts are believed to be transferred to physical symptoms like pain. This scheme holds onto a dualistic notion of mind and body as separate entities that influence each other in some mysterious way. Second, there is the transference of ideas from one mind to another, which subsequently transfers into bodily symptoms. The dualism implied in both of these processes is one in which the mind is believed to create physiological changes in the body. In both cases, the movement from mind to body is seen to take place on an unconscious level. The third meaning is related to the psychoanalytic connotation of transference, which indicates a certain redirection or substitution of emotions. In psychoanalysis, transference is a relational process between analyst and analysand, which can be made productive to work towards a cure for the unconscious thoughts that “created” symptoms. In this third meaning, the psychoanalytic understanding of transference is instrumentalized to cure the “illness transference” of the first two transference moments.

In the psychoanalytic sense, *Übertragung*, or transference, was first mentioned in 1895 by Freud and Breuer in their "Studies of Hysteria" (1955 [1893-1895]: 302). Some years later, in Freud's analysis of the Dora case, he describes transference as a process in which "some earlier person" is replaced by "the person of the physician," read analyst (1953 [1901]: 116). The classic example of psychoanalytic transference is that in the analysand's unconsciousness, the analyst takes the position of the analysand's father. A successful psychoanalysis will then uncover this movement; it "does not *create* transferences, it merely brings them to light" (Freud 1953 [1901]: 117; emphasis original). The psychoanalytic connotation of transference thus invokes the relation between analyst and analysand that can be made productive in working towards a "cure" for the symptoms for which the patients consulted the analysand.

In my present uptake of transference, I first park the psychoanalytic connotations in the sections to follow and instead stage an opposition between notions of transference-as-contagion and transference-as-relationality. The following section first focuses on the negative interpretation of transference in the sense of psychosomatic contagion.

5.2 Transferring/Contagion

Within medicine, the contraction of an illness through a contagious idea is known as "medical student syndrome" or "medical student disease." Students studying medical textbooks were believed to be influenced and affected by what they read and would diagnose themselves or their loved ones with all kinds of (imagined) diseases as a result.[125] In 1999, neurologist Stephen Ross wrote an article that worked with the idea of contagious ideas, now defining them as "illness-memes" that can operate as an "infectious agent." He opens his article by asking if "a mere idea [can] cause medical pathology?" (867). Ross speculates that illnesses like fibromyalgia, Irritable Bowel Syndrome, and ME/CFS are iatrogenic. He writes that conditions such as the ones named above, but also eating disorders (868), repressed memory syndrome, multiple chemical sensitivity disorder, and silicone breast implant illness are *psychosomatic memes* (868): ideas packaged in cultural units that wait to be picked up by vulnerable individuals. Ross speaks

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[125] See also Waterman and Weinman 2014.

of psychosomatic contagion as a “mimetic” condition that “involves imitative behavior” (867). I will start this section by looking at Ross’s article in more detail because it so clearly presents the negative view of illness transference that stands central to this chapter: transference that is understood as contagion of vulnerable individuals.

In describing this process, Ross coins the term “psychosomatic meme.” The concept was not entirely new, but the formulation as such was exceptional. The idea of psychosomatic illnesses as being iatrogenic was much more widespread (Hadler 1997; Ehrlich 2003; Reilly 1999; Ablin 2012: 587). Ross, however, specifically introduces the meme, which he deems to be an adequate concept to describe the origins of psychogenic illness (867). Ross’s use of the meme was written before the term meme became known as the internet meme, which pairs text and visuals as it is known today. The concept of “meme” was coined by Richard Dawkins in 1976 as a “unit of culture” that is disseminated and changes shape in the process of dissemination (2016). In Ross’s pairing of the meme with illness and infection, it becomes a negative concept that departs from a view that maintains a normative standard of a contained and rational individual. On this basis, only “vulnerable individuals” are susceptible to the psychosomatic meme.

Ross questions if “a mere idea” can cause medical pathology. He redirects etiological attention of illnesses without clear biomedical etiology to “social surroundings” and to something that Ross calls a “socially constructed script” (867). He defines psychosomatic memes mainly by mentioning similar concepts, such as “disease conceptions” or “infectious agents.” Ross borrows from an epidemiological vocabulary, speaking of “virulent ideas” and “transmissible templates,” mixing them up with social concepts to define the psychosomatic meme as an agent of disease. He also refers to the psychosomatic meme as a “narrative fragment.” Notably, the words that are used to define the illness meme, such as “virulent ideas,” “infectious agents,” and “socially constructed script,” are all negative terms. This negativity that is associated with the meme does not concern the effects of the meme (illness – as a non-desirable state of the body) but the way in which memes operate across individuals (social contagion that induces illness is non-desirable).

The negativity of the meme associated with “social contagion” goes back to the original coining of the term by Dawkins. Dawkins coined the term in close relation to his particular notion of social influence. In his book *The Selfish Gene* (2016), originally published in 1976, he defined the meme as a unit of cultural transmission or imitation. "Meme" was chosen as an abbreviation of the word mimeme, and was shortened not in the least because it "sounds like gene," according to Dawkins. Just as genes leap from "body to body," memes leap from "brain to brain via a process which, in the broad sense, can be called imitation" (2016: 249). The original conception of the term meme is thus directly related to the concept of the gene, the hereditary unit transferred from biological parent to offspring. Presenting the term in this context, the meme is used by Dawkins as a Neo-Darwinian model of social interactions from which to theorize the transmission of cultural concepts, ideas, and stories. Those who are picked up and transferred the most will be most fit for survival and last the longest.

The type of infection imagined is presented rather dauntingly. The language that Dawkins uses to speak of cultural transmission is war-like and aggressive. Dawkins writes of the meme as something that is planted in the mind and "literally parasitize[s] … [the] brain, turning it into a vehicle for the meme's propagation in just the way that a virus may parasitize the genetic mechanism of a host cell" (249-250). The idea, however, of a viral "unit of culture" was picked up by many scholars as a model of explanation for maladaptive social behaviors. The meme as a unit of culture was used to explain phenomena such as suicide contagion but also suicide bombings, and alcoholism as outcomes of a process of "memetic attraction" (Robertson 2017: 354-355). Dawkins's wording compares the workings of the unit of culture to an infectious disease in which a viral intruder or parasite comes to attack the host cell. The language with which the term meme is used by Dawkins presents a negative view of social influence, not as an inescapable aspect of what it is to live together as human beings, but as something that needs to be fought and contained.

Another aspect of the use of the meme is the way in which it makes use of the concept of contagion. The concept of contagion is not necessarily tied to a medical context and has always been used in a wider cultural context. According to digital media scholar Peta Mitchell, it is difficult to draw a line between "literal" and "figurative" uses of the term. She notes that "contagion proves impossible to quarantine in this way" (2012: 5). Mitchell writes that contagion slowly disappeared from medical texts, which now prefer to speak of "communicable disease" instead (6). Mitchell speaks of contagion as a "limit case" for metaphorical language and states that the notion of contagion has fostered epistemological anxiety as it "unsettles clear distinctions between the physical, the medical, the cultural and the affective" (6). Contagion is a prime example of a traveling concept that is used in different ways across disciplines. Even though the etymological roots of contagion go back to the Latin *con* (with) *tangere* (touch), it perceives this touching, or coming together, as the root of something bad (disease) or harmful (a contagious idea).

A similar argument about the travels of contagion as a concept has been made by science historian Margaret Pelling in her intellectual history of the use of contagion. She shows that the concept was already widely used before it "became scientific" in the nineteenth century (2001: 15). Concepts like "germ," "species," or "virus" go back a long way in European culture. Pelling shows that an intellectual history of these terms demonstrates that they are "not single concepts but many" (Pelling 2001: 16). Literary scholar Priscilla Wald notes that "contagion is more than an epidemiological fact" (2008: 2). As a foundational concept for the study of human relationships and society, it has a long history that tells different stories about the "necessity and dangers of human contact" (2). Studying contagion can be a productive way to inquire into the way in which relationality has been given shape in Western thought.

Contagion as a concept has a far richer history than the newly coined meme, be it only due to its place within cultural theory. Two important figures in the history of the concept in relation to mental or social processes within cultural theory are Gabriel Tarde (1843-1904) and Silvan Tomkins (1911-1991). For Tarde, contagion and imitation are not metaphors or matters of speech that describe how certain things spread from person to person but the fabric of the society itself. Silvan Tomkins's work has been introduced to critical theory by Eve Kosofsky Sedgwick and Adam Frank, most notably, who collected his writings (1995). They emphasized the circulations of affect as something that is not confined to single individuals but as moving in between bodies. For both Tarde and Tomkins, the process of contagion is central to being relational and social beings. Viewing the individual not as a single entity but as part of a social construction of networks or flows of affect allows for a less pejorative view of social influence overall.

The valuation of the notion depends. It varies from a general conception of relationality or as a possible threat to individuality. According to Mitchell, it is especially in the late nineteenth century that the notion of contagion was connected to the social as a "conceptual handle" to explain crowd behavior and social influence (2012: 60). While the "handle" itself might have been relatively neutral, the uses of it were less so, as for example Daniel Beer demonstrated when describing how contagion was linked to morality in the political context of late Imperial Russia. Beer describes how, in Imperial Russia, biomedical theories of social decline and individual deviance were used to portray society as an organic body that has to be guided by biological and psychological laws (Beer 2007: 534). This "biologisation of the social" gave scientific legitimacy to a form of moral panic and used the idea of contagion to do so. In the nineteenth century, the words "moral" and "social" were used in reference to contagion in the social sciences. This shifted to speaking of "mental," "affective," and "social" contagion in late twentieth-century sociology, anthropology, and psychology (Mitchell 2012: 7, 59-63).

In relation to illness, social contagion is also described as mass hysteria or mass-psychogenic illness. Its history is often traced back to stereotypical descriptions of instances of choreomania in Europe in the fourteenth and seventeenth centuries in the wake of the Black Death, in which groups of people danced according to a collective impulse, often violently, or resulting in death by exhaustion (Gotman 2018: 44; Bartholomew 1994: 301). The history of mass hysteria has also been described by giving examples of "hysterical fits" and "demonic possession" or even "biting nuns" in cloisters (Balaratnasingam and Janca 2006: 171; Bartholomew and Wessely 2002: 300; Wessely 1987: 109).

In 2002, sociologist Robert Bartholomew and prominent psychiatrist and former president of the U.K.-based Royal College of Psychiatry Simon Wessely, who became a controversial figure because of his work on ME/CFS and Gulf War Syndrome, placed the phenomenon of "mass sociogenic illness" in a broader historical and cultural context. The authors make a distinction between "motor hysteria" and "anxiety hysteria." The former refers to abnormal movements and neurological complaints. Bartholomew and Wessely characterize the latter as having concerns over environmental factors such as "food, air, and water quality." This form has a more rapid onset and recovery. Motor hysteria was seen to be more prevalent in religious contexts between the fifteenth and nineteenth centuries or during the industrialization in the eighteenth to early twentieth centuries. According to Bartholomew and Wessely, during industrialization, outbreaks of motor hysteria were typically reported in factories. Outbreaks of anxiety hysteria were often reported in close community settings like schools or workplaces (2002: 300-302).

Although Bartholomew and Wessely note that mass sociogenic outbreaks predominantly affect women, they state that there is "no particular predisposition to mass sociogenic illness, and it is a behavioral reaction that anyone can show in the right circumstances" (2002: 303). Research found that when satisfaction at work was the least, the workers' symptoms tended to be more severe. This research was conducted in the seventies and looked at workplaces such as a shoe factory (Murphy and Colligan 1979: 136), an electronic plant (Colligan et al. 1979: 305), or a data center in North America (Stahl and Lebedun 1974: 45). In the extensive study on the link between job-related stress and mass-psychogenic illness that was done by Colligan et al., the work-environment at the electronic plant is described as having "poor supervisory support and an authoritarian management style," where "boredom, unwanted overtime, and noise" were frequent experiences from the predominantly female workforce (1979: 298). The results of these studies can be used to support claims on the "secondary gains" that were created with these symptoms, as I described in the previous chapter. That is, psychosomatic symptoms are created because the patient benefits from it in certain ways, such as no longer having to work in a harsh environment.

At the same time, the dismissal of these symptoms as psychogenic also carries an obvious risk. The search for a physiological cause may be abandoned because of the psychogenic label. The possible dangers of the lack of attention to the etiology of symptoms in cases of collective outbreak of physiologically unexplained illness are addressed in a study by Halley Faust and Lawrence Brilliant. In 1981, Faust and Brilliant maintained a more critical stance towards the believed etiology of the contagious symptoms in these different collective outbreaks in workplaces. They question whether the diagnosis is not an excuse for an incomplete investigation of the toxins present in the affected environments. They state that in specific cases, the levels of toxins and their interactions with other possible factors of influence (i.e., weight of affected women and food intake prior to the onset of the symptoms) were under-researched (1981: 25). They also comment on the use of the term hysteria itself, saying that it is "obviously a pejorative term" and that a diagnosis of mass hysteria should not be made simply because other causes cannot be found. Faust and Brilliant's study argues for greater caution concerning the diagnosis of mass hysteria. It also describes how causation is not easy to determine. In any case, etiology is not sufficiently explained through the concept of mass hysteria. According to Faust and Brilliant, mass hysteria becomes an excuse not to search for other explanations instead of a form of causation itself (1981: 26).

Apart from the risk of misdiagnosis, the term "mass hysteria" also is at risk of discrediting the symptoms and the people who experience them. The idea holds a certain implication of a "copycat," like it is described in reports on suicide contagion (Sudak and Sudak 2005: 459; Ortiz and Khin Khin 2018: 246): of someone whose symptoms imitate someone else's "original" symptoms. Imitation presupposes a separation between two things or individuals in which one is considered the original. Imitation has carried a negative connotation since ancient Western philosophy and the banishment of the poets from Plato's Republic. When something is said to be an imitation, it usually implies that it is lesser than the presumed authentic original.

Without going into the depths of theory on mimesis, imitation, and contagion, it can be claimed that these concepts carry negative connotations within modern Western philosophy that values originality, authenticity, rationality, and individuality. In contrast, relationally oriented behavior, emotional and social behavior, "feeble-mindedness," and general social susceptibility have been seen as "lesser-then." Such behavior or personality traits have been gendered and feminized. A relational orientation has been viewed as a liability that contributes to low self-esteem or as a vulnerability for greater emotional distress and depression, for example (Do Couto and Hennig 2015: 137). Paula Caplan's 1985 monograph *The Myth of Women's Masochism,* also mentioned in Chapter Four, described how the commonly held idea that women enjoy pain and abuse contributed to the pathologization of women as masochists. This pathologization inhibited a clear view of the structures in which women endured abuse. Having to nurture children, practice care and patience, and self-denial are not essentially female traits. Caplan argued that the notion of women as masochists inhibited a view of these traits as a means of survival in a patriarchal society. These feminized traits have then been pathologized instead of understood in a gendered discursive context.

The negative view of social influence as contagion and the (sometimes violent) effects that this potentially has on patients with unexplained illness can be made clear when turning to an influential yet controversial 1997 monograph by literary scholar Elaine Showalter. In *Hystories* (2013), Showalter traces what she takes to be hysteria itself, all the way from the nineteenth century to what she believes are late-twentieth-century resurgences of the disease. She classifies a number of wildly variating twentieth-century illnesses and phenomena such as ME/CFS, Gulf War syndrome, recovered memory, alien abduction, and multiple personality syndrome as modern versions of hysteria, calling them hysterical epidemics. Placing these massively different illnesses and phenomena under one header called modern hysteria was a controversial move to say the least, even in the 1990's. In a preface to the paperback edition, she writes how she had expected that the monograph would upset special interest groups but that the intensity of the reaction, including assassination threads and a bombardment of hate mail, was beyond what she expected. She also states that the "inflammatory reaction to the book from some quarters has only confirmed my analysis of hysterical epidemics of denial, projection, accusation and blame" (2013: x).

Showalter does not only speak of modern hysterical epidemics, but also states that in the 1990s, hysteria is "more contagious than in the past" (5). Showalter attributes this fact to the fast spread of ideas through contemporary media, especially to the then new and just developing online world. She contends that hysteria is a mimetic disorder: "It mimics culturally permissible expressions of disease" (15). In framing hysteria as a contagious disease, she uses a language of viral disease throughout her monograph. She loosely uses notions of infectious disease to describe a complicated social and cultural reality.

> Infectious diseases spread by ecological change, modern technology, urbanization, jet travel, and human interaction. Infectious epidemics of hysteria spread by stories circulated through self-help books, articles in newspapers and magazines, TV talk shows and series, films, the Internet, and even literary criticism. The cultural narratives of hysteria, which I call *hystories*, multiply rapidly and uncontrollably in the era of mass media, telecommunications, and e-mail. (2013: 5)

Spreading, multiplying, and doing so rapidly through mass communication, Showalter frames modern hysteria as something that is primarily "caught" by catching a story – a specific one she calls *hystory*. These cultural narratives are then seen to infect individuals, something for which Showalter blames the media as they continue to spread the danger.

Showalter's position towards the ontological status of the symptoms experienced by patients remains ambiguous. On the one hand, she states that it is an oddity that "A century after Freud, many people still reject psychological explanations for symptoms; they believe psychosomatic disorders are illegitimate" (4). Here she seems to imply that she wishes that mental disorders would be more widely recognized and understood. At the same time, she displays contempt for the way in which patients often resist psychological explanations for their illness and keep searching for a physical cause. She states that "contemporary hysterical patients blame external sources – a virus, sexual molestation, chemical warfare, satanic conspiracy, alien infiltration – for psychic problems." (4). In general, Showalter's monograph maintains a tone that considers illnesses without clear etiology as "panics fueled by rumors" (5). This did not land well with patients who sought general recognition for symptoms that they themselves experienced otherwise.

This becomes especially problematic when Showalter discusses ME/CFS. ME/CFS is the first illness on her list of "modern hysterias" that she discusses in the third part of her monograph. Similar to the medical editorial that referred to fibromyalgia as a result of a "lifestyle mix," Showalter speaks of the self-organization of patients who fight for their illness being taken seriously as a "way of life" (125). She plays in on a narrative of delegitimization by referring to activities such as coffee hours and self-help groups without acknowledging the activist aims according to which they are organized. She criticizes the "media hystory of chronic fatigue" (117) and frames these patients as modern hysterics whose "symptoms are genuine" (116) but whose problems are mainly caused by the fact that they live in a culture that "looks down on psychogenic illness, that does not recognize or respect its reality" (117). She thus frames these symptoms as psychogenic and then states that the real problem is that society looks down on such symptoms.

However, Showalter resorts to the framework of the hysteric as a context for these symptoms. This is a framework that is highly gendered and that is part of a history of medicalized and institutionalized violence against women. Referring to these symptoms as “psychogenic,” in the same way as hysterical symptoms were perceived to have a mental origin, even calling these patients “modern hysterics,” shows that Showalter participates in the continuation of the “real problem”: looking down on people with symptoms which lack physical explanation in a way that feminizes them, discredits them, and does so in a way that is at risk of becoming violent. The strong emotions that patients felt and expressed in reaction to the views contained in the monograph, which sometimes also became violent, show that the stakes are high. Patients feel that they have to protect themselves from such views because they are at risk of delegitimizing their condition.

Apart from participating in this problematic narrative, Showalter emphasizes individual responsibility instead of discursive structures in which this individual operates. Showalter’s account of modern hysteria was characterized by Susannah Radstone as a “fundamentally Enlightenment,” rational emphasis on individual responsibility, evidence, and truth (1999: 247). This emphasis on individual responsibility is shown when Showalter describes individual actions, like doctors who validate patients’ complaints and journalists who report on these illnesses, as acts that perpetuate the hystories that should be avoided. Showalter notes that the discourse around these unexplained conditions is what prevents “us from claiming our full humanity as free and responsible beings” (206).

In contrast to this statement, I claim that there exists no “free” or “non-discursive place” and that responsibility is something that must be practiced with attention to discourse: to the structures that determine us and in which this responsibility matters. Here, I would like to call upon Butler’s remark in *Senses of the Subject* (2015), where they state: “Of course, many people do act *as if* they were not formed, and that is an interesting posture to behold.” For Butler, to posit the capacity to act as what they term “a fully independent feature of one’s individuality” is a form of disavowal (2015: 8). With regards to Showalter’s account of individuality and contagion, I maintain that instead of calling attention to individual actors, the attention should be on the type of story that is created and the effects that it has on the people affected.

One of the effects of the continuation of the discourse around hysteria is that people with unexplained illness are not taken seriously. The consequences of this are enormous: these patients doubt themselves and their own experience of their body, experience social isolation, and cannot always count on disability benefits while suffering from conditions that are underfunded and for which there are often no effective treatments. Showalter's account of relationality and materiality is one in which discourse has an effect on people's physical condition. At the same time, it perpetuates a discourse that has a negative effect.

Noteworthy is that this view comes from someone working within feminist theory. Elaine Showalter is an influential American feminist literary critic who published her main works during the 1970s and 1980s. She became famous for her concept of "gynocriticism," which refers to a female-centered approach to women's literature. Her work has paid attention to the female voice in nineteenth-century literature and to the historical links between madness and constructions of femininity. At the same time, Showalter's negative view of relationality, viewed in terms of social contagion, resulted in her eventual neglect of discursive structures and their lived effects on bodyminds in light of emancipatory movements. With *Hystories*, Showalter essentially contributed to the figure of the contemporary unexplainedly ill (and predominantly female) person as a modern-day hysteric, whose complaints could be, in good conscience, ignored as serious physical complaints because they were merely caused by suggestion in people who had been too susceptible for contagious ideas. As such, Showalter's monograph presents a prime example of how not only medical views but also literary theory can contribute to reinforcing the nervous routes of unexplained illness.

The idea of psychosomatic contagion is not only maintained in medicine but certainly also endorsed outside the clinic. Contagion itself cannot be and has never been solely a medical concept. Contagion is a traveling concept whose interpretation discloses something about how relationality is perceived in a particular context. Across these meanings, the prime characteristic of contagion is that it conceives of that which is transferred as something harmful or negative. Contagion highlights the negative influences of the fact that no human exists in isolation.

"Psychosomatic contagion" adds another concept and depends on the idea that illness can be created in the mind. By calling symptoms "psychosomatic," the separation and simultaneous integration of body and mind, described in Chapter Four, results in a liminal space that is often filled with negative stereotypes that are already available and are often gendered. They are of women as being out for attention, wanting to be cared for, financially and otherwise. When coupled with contagion, "psychosomatic contagion" pairs this understanding with a negative interpretation of relationality. This negative interpretation is gendered, seeing as that a relational orientation is historically associated with women. Being susceptible to social influence is seen as a feminized and less desirable trait. Psychosomatic contagion refers to the gendered idea that unexplained illness essentially is a contagious idea that is most easily picked up by vulnerable women.

In the next section, I move back to the concept of the meme and closely read a present-day manifestation of an illness meme in the form of an internet meme that is shared online. Closely reading the text that is paired with an image, I argue for the importance of paying attention to the social context in which this meme circulates. An illness meme does not always operate as a meme. In some cases, the meme does not incite illness but is only recognized as an illness meme by people who are already ill. In those cases, the meme does not bring illness. Instead, it offers recognition and support for people within a certain illness context.

5.3 The Meme and the Mimetic Stall

"What would you call a person who has no body and no nose?" is a bad joke, a "dad joke." The answer to the question is usually given by the person telling the joke and is usually met with a shrug from their audience. Maybe a laugh sometimes. "Nobody Nose," says the answer. The joke is translated into a meme and is circulated on the internet. This involves a surprising amount of huskies and images of Voldemort (a villain without a nose). Most of these memes follow the joke's storyline, where the conclusion (nobody nose) is portrayed at the bottom of the image. The question is portrayed on top. The background of these memes is often taken from famous meme types such as "Condescending Wonka" or "Bad Joke Eel."[126] Other memes evolve and add a layer of irony to the joke itself. These memes make fun of the joke itself, asking, "Where did

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[126] These images, a still of actor Gene Wilder starring in *Willy Wonka & the Chocolate Factory* (1971) and one close-up of a Moray-eel, are famous meme-types that have been used for various purposes. *Condescending Wonka* is often used to sarcastically question something, while the *Bad Eel Joke* is often used because: "Eels always look like they just told a joke and are waiting for a reaction." See Tibbets 2017 n.pag; "Bad Joke Eel Images" n.date; n.pag.

Voldemort go? Nobody Nose." Another meme shows an image of a family dining table, dad laughing so hard he is close to tears, his kids all banging their heads on the table out of boredom. Dad Jokes are bad jokes.

Only in some rare cases of the meme is the joke reversed, and an extra layer is added. In these memes, the conclusion of the joke is now portrayed at the top of the image. "Nobody Nose," it says again. The background shows an image of Voldemort; at the bottom, the text: "What's going on," referring both to the noseless villain and to the popularity of the bad joke itself. The joke has been doubled, but its humor is limited to the people who know about the bad joke: it is for them that it gets extra meaning. This meme refers to the larger body of memes. Together, they construct a language of humor, of inside jokes, and references. The humor lies in the repetition: the repetitions of jokes, images, and their different combinations.

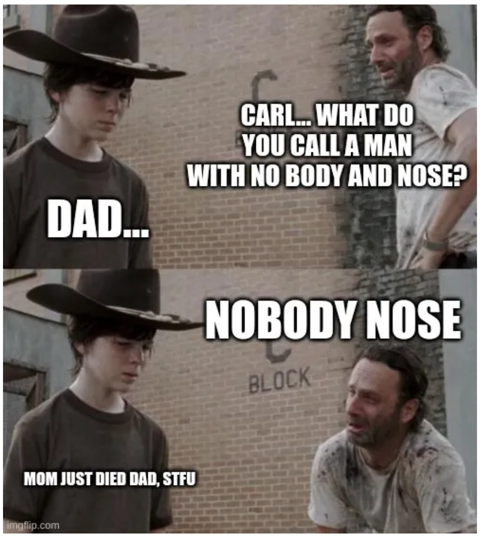

Figure 4: Making fun of the dad-joke, @Meme_hoarder (n.d.).

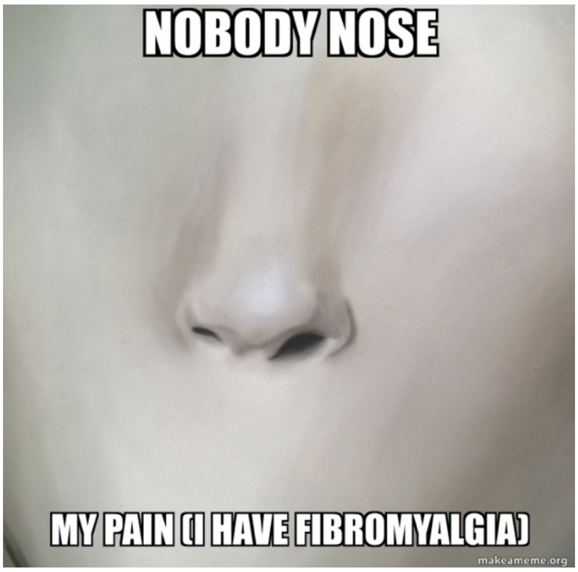

Figure 5. "Nobody Nose My Pain," created by anonymous user (n.d.).

Another meme then. The same words, "Nobody Nose." This time, the image is not familiar. At the same time it is clear what it shows. The onlooker sees a grey surface, out of which a long stretched nose emerges. At the place where one would expect a mouth there is a blank. At the bottom of this image it says "My Pain (I have Fibromyalgia)." The letters are in white, with black lining, in all caps. The meme type.

It is not just a nose, though. The shape of the grey surface faintly follows the form of a face. The colors alternate between light and dark in grey-blueish tones that mimic White skin color. In the bottom left corner, easy to miss, two darker stripes suggest a rounding, which creates the shape of a face. Seeing the assembly of colors, the missing mouth and eyes, the viewer knows they are not looking at a complete face or a real nose but at a computer-generated image. This gives the words “Nobody Nose” a different context. Yet the image is read as relating to somebody’s pain. The “I” referred to in the text at the bottom seems to be the entity that narrates. At one glance, the viewer is confusingly confronted with a nose, a nonexistent face, and a narrator with fibromyalgia.

Fibromyalgia usually has nothing to do with noses. It is a chronic condition that causes widespread pain throughout the whole body. Seeing the slim nose on the memed image, and the soft lining at the side of the face, the viewer might assume the disembodied nose is from a woman. The knowledgeable viewer might think it’s a woman because most patients with fibromyalgia are women. Most viewers will understand that the woman in question feels misunderstood because “Nobody nose her pain.” Nobody knows it because it is only she who feels it. And nobody knows because the physical cause of the disease remains unexplained. Patients with fibromyalgia often feel a lack of support from their health professionals and often report that they long to feel understood (Briones-Vozmediano 2013: 20).

In the large pool of nobody-nose memes, this one clearly stands out: it is not funny. Without knowing the nobody-nose joke and its memed history, it is obvious that this is not even a joke at all. It’s something radically different; it is a call for empathy. However, what this meme does, at first glance, seems to be rather the opposite. It might not speak to its viewer at all and might easily not incite an emphatic response to its plea. Many other memes on fibromyalgia address fibromyalgia’s invisibility more directly, such as a meme of a person sitting calmly in a fire while somebody asks how they are, and they respond: “I’m fine, thanks.” The viewer knows that they are not “fine” through the visual contradiction. Another meme visualizes a shattered back with bruises, swollen veins, and lightning-like lines that portray the traces of pain. “If you could see my invisible illness, would you finally believe I’m in pain?” it says. This meme does not contain the same directedness. Yet, the referential nature of its text, accompanied by the singularity of the image, hints that a different kind of invisibility is at stake: one that depends on whether the nature of the reference is understood by its onlooker.

Memes are not always read the same way. In the case of this meme, it is probably not. The meme is an expression by somebody (the "I" who hides behind the image) and visualizes the inexpressibility that is connected to their experience with Fibromyalgia. The fact that it is shared online hints at the way in which online patient blogs or social media accounts function as safe spaces that allow for this meme to be shared. In this context, this meme loosely references the unknowability of fibromyalgia. In that sense, the meme expresses something about the difficulty of speaking about an illness that remains unexplained by medical science.

While the meme might speak to some about the experience of dealing with an unknown pain, this reference might not come across to others. The measure of its referentiality is related to the unexplained nature of the illness. Fibromyalgia is often called an "invisible illness": it is not only invisible in the appearance of the patient – who often "looks fine" – but also to the medical gaze which is extended to scans, x-rays and blood tests that show nothing, that says everything looks "normal." The meme, on the contrary, is all about visibility. It is a one-liner made visual, a text amplified, or recast in an image. This play between making the invisible visible works in several memes on fibromyalgia. These "fibro-memes" are popular amongst patients on online forums.

In the one with the nose, it seems that something else is at stake. The visual reference is unclear, just like its cryptic text.

> Nobody Nose
> My Pain (I have Fibromyalgia)

Without the image, the first four words read like poetry, expressing an intense feeling through form, continuing the sentence beyond the line. Accompanied by the image, the viewer assumes that its grammatical error is implied. The question thus is what this different spelling does for the understanding of the narrator's pain. (Can one know pain differently? What is it to nose, instead of to know?) It is halfway through the second line of the text that something happens. Here, the text leaves the wordplay behind and draws the viewer in, maybe unwantedly so. Here, the viewer becomes not only part of a pain they cannot know or *nose*, but of an "I" with an illness: a condition called fibromyalgia. This viewer might have heard of the illness, or they might have not. In any case, the name might be strange to them, excluding them even more from the scene in which they suddenly feel misplaced. In this case, it is the name connected to the ”I” that excludes them. The mention of fibromyalgia removes this viewer from the grammatical play and the image of the nose. They might wonder why the nose is there and might not see the joke anymore.

Another viewer might know very well of the disease. This might be exactly why they look at the image. This viewer might be suffering from the same pain and might even be looking for support. This viewer long knows that nobody nose their pain. They might shrug or might even think this meme is funny. For this viewer, the brackets do not exclude. They know what fibromyalgia is and feel included by the use of the “I” to recognize another patient. In the best case, the meme might offer a moment of comfort, something lighthearted. It doesn’t matter whether this viewer thinks it is funny or not. In this case, the mere recognizability of a pain that is shared is enough for this meme to work.

For the first group of viewers, unbeknownst of fibromyalgia, the meme is not a meme. It is not funny, not recognizable, and it makes nothing visible. Instead, it might be better described as a *mimetic stall*. As a noun, the stall refers to an individual compartment. A market stall, or the place to keep horses: the stall refers to a place that is fixed. The stall keeps something put in a single spot. As a verb, “to stall” refers to a standstill, to bringing something to a halt. The *mimetic stall* is not recognized, passed over, and repeated. It is not imitated but rather left to be. It does not incite movement but stops it instead, impeded by whatever cause. The mimetic stall is not the opposite of a meme but a description of the same object from a different position. It speaks about the same thing, yet it has different effects. *The mimetic stall is an effect of an object which could also be seen as a meme.*

In the case of this particular visual, there are multiple elements that contribute to the mimetic stall. First, there is a nose that looks strange without the common elements of a face: eyes, mouth, ears, or hair. Only the facial contours are present. Then the common joke might be recognized by way of the nose, only then to realize that the joke is now related to pain. This makes that the nature of the joke changed. When the memed text draws the viewer in, using the brackets to make it even more intimate, the viewer is not part of the story anymore. This is not an image they would share, slightly alter, and pass on. They might rather *stall it* to be able to move on and look at other things. The joke is not recognized, the visual is not understood, and the meme is not shared. The meme under discussion here has not been very popular. It was generated by an anonymous user on make-a-meme.org and has disappeared from social media by the time of writing in 2021. It has not generated many comments and was not shared widely. The meme was, literally, brought to a standstill. While the reasons for this standstill can be manifold, the disappearance of this particular meme is perhaps apt.

In bringing forward the difference between the *meme* and the *stall*, I want to show that a meme is not always a meme. A visual image with superimposed words does not always do its mimetic work: it is not always recognized, picked up, altered, and spread. In his monograph *The World Made Meme*, Ryan Milner speaks of the meme in the adjective or adverbial form to emphasize the social process essential to the creation of memes. He states that “an individual tweet or image or mashup or video isn’t in and of itself a meme, though it may be memetic in its connection to other tweets, images, mashups, and videos, and it may memetically spread along with others in kind.” (2016: 3). A meme is heavily dependent on context to be picked up or even be understood as a meme.

Although the idea of mimetic culture is as old as culture itself, the internet meme is a more recent phenomenon that attracts interdisciplinary scholarly attention under the header of meme studies. Within meme studies, there is much attention on the meme in different social contexts. This relates to the sharing of certain content that is specifically geared to particular social communities. A reading list compiled by the Meme Studies Research Network tentatively groups topics of interest such as art and aesthetics, linguistics and semiotics, feminism and gender, and meme and capital (Meme Studies Research Network). Meme studies is an interdisciplinary field that exists somewhere between media studies, sociology, and cultural studies. Memes are specifically studied in relation to alt-right movements (DeCook 2018; Tuters and Hagen 2020), sexism often seen in certain meme cultures (Harlow et al 2020), or rather on the memed feminist protest against sexism (Brantner et al 2020; Rentschler and Thrift 2015). Across these different research interests, the meme itself is often mentioned as being important to a sense of community building (Rentschler and Thrift 2015; DeCook 2018; Tuters and Hagen 2020). This aspect of the meme is specifically relevant when looking at illness memes.

The importance of online spaces in sharing personal experiences or other types of information about (chronic) illness has been long acknowledged (Eysenbach et al. 2004; McArthur et al 2006; Kingod et al 2017). Illness memes are memes that are often shared on patient fora and online support groups, as well as individual social media accounts, where people gather and share stories. I take these online spaces to function as safe spaces for people with chronic or unexplained illness, where it is possible to share stories of illness and relate to others. The invisible aspect of many unexplained (and/or chronic) conditions is then transformed by way of what Tarryn Philips and Tyson Rees have called "visibility work" (2018). According to Philips and Rees, this visibility work allows for "alternative forms of recognition beyond the clinical gaze" (2018: 214). When shared in similar groups, these memes do the trick of constructing and maintaining a language of shared understanding. They possibly spread moments of relief, in which patients no longer find themselves alone with their pain.

By critics, online spaces have been labeled dangerous. The fear is that these spaces would expose vulnerable people to explicit content. A social science research paper from 2022 described this fear and studied the effect of memes in the context of mental health (Akram and Drabble 2022). The "mental health memes" that were described were mostly about depression. The UK-based Royal College of Psychiatrists deemed mental health memes a threat to public health due to mechanisms of social contagion. Akram and Drabble write that this claim was an assumption that was not supported by empirical evidence. However, they note that this assumption was widely picked up by the press "where vilification of internet memes continues despite diminutive evidence" (Akram and Drabble 2022: 2). Both authors were involved in an earlier study that showed that the most popular memes related to anxiety and depression that were posted on Reddit did not demonstrate any encouragement to "adverse behavior" (Akram and Drabble 2022: 2; Akram et al. 2020). They conclude that there is no evidence to demonstrate that mental health memes lead to harmful behavior or further decline in illness. Instead, Akram and Drabble state that it appears that these memes rather facilitate emotion regulation strategies and social bonds and that they are generally perceived as supportive (2022: 4).

In an online space that functions as a space for patients to share similar symptoms and or diagnoses, the meme's "contagious" working is put to use to spread relief instead of illness. In a different context, however, this meme might be read as a mimetic stall. In this latter scenario, the meme may only contribute to a process of "othering" that lacks an understanding of living with unexplained illness. My analysis of this particular meme and my coining of the *mimetic stall* review the readability of the meme for different audiences. Closely reading a meme in its context might show that it is not a meme but rather a mimetic stall instead.

This section has focused on a close analysis of one particular illness meme with which I have asked what is transferred through its communication. Looking at this meme, I have argued that what is transferred depends heavily on the contexts in which the meme is encountered. Illness is often already shared amongst people who participate in online support groups. In this context, contagion is not the right word to describe the effect of the meme. Instead, it is recognized and offers support for something that is already there. Outside of illness communities, the meme is not recognized and works as a mimetic stall instead, effectively also forfeiting its "contagious" nature.

In the next section, I return to the diagnostic criteria of fibromyalgia, and look more closely at the 1990 paper, which established fibromyalgia as an illness and was also mentioned at the beginning of this chapter. After first discussing the context of the study, I provide a close reading of a visual that is used to define the prime locations of pain in fibromyalgia patients. In this visual, the disciplinary boundaries of medicine are crossed by making a reference to a neoclassicist painting that portrays idealized femininity. My analysis focuses on the contextuality of the image. I analyze this context in order to discuss the implicit gender ideology that is incorporated in the 1990 criteria and to discuss the way in which cultural discourse travels to medical diagnostics.

5.4 Fibromyalgia: Tender Points, Tender Echoes

In 1990, the American College for Rheumatology published criteria for the classification of fibromyalgia. The criteria were worked on by twenty-four authors, led by Frederick Wolfe as the main author, and were published in *Arthritis and Rheumatism.* The twenty-four authors of the article came from different institutions that worked together to formulate the diagnostic criteria for fibromyalgia. The criteria were twofold: first, the experience of widespread pain in combination with, second, tenderness at 11 or more of the 18 specific tender point sites (Wolfe et al. 1990: 171). These tender point sites are specific places on the body in which pain often groups for fibromyalgia patients.

The study examined 558 patients, of whom 265 belonged to a control group, which was made up of patients whose ailments could be confused with fibromyalgia symptoms. The control patients also mainly reported pain. The complaints of the people in the control group varied from patients with neck pain, lower back pain, or trauma-related pain syndromes (1990: 162). The study shows significant differences in the location and the extent of pain complaints for patients with fibromyalgia, as well as the concomitance of returning symptoms for fibromyalgia patients, such as fatigue, sleep disturbance and morning stiffness in seventy-three to eighty-five per cent of the patients (165). Overall, the study found the tender points to be the "most powerful discriminator between fibromyalgia patients and controls" (166).

Fibromyalgia is characterized by pain. This makes it difficult to find "objective" abnormalities. To avoid a circular study, the authors used blinded examiners, who were unaware of the diagnosis held by the investigator, as well as a device called a "dolorimeter" to examine a patient's tender points. A dolorimeter is used to apply pressure in order to measure pain. Investigators were told to advance the pressure and to instruct patients to let them know when it became painful (Wolfe et al. 1990: 162). These methods were put in place in order to ensure a method of falsification. The aim was to try and see whether the distinction between the fibromyalgia patients and the separated support group holds.

There had existed previous research on fibromyalgia, such as the early 1977 paper by Smythe and Moldofsky. This was the first study that established diagnostic criteria and thus established fibromyalgia as an illness.[127] Smythe and Moldofsky also first formulated the notion and the location of the tender points on the body. The same locations for the tender points also remain central in the criteria published by Wolfe et al in 1990. However, it was only with the 1990 paper that fibromyalgia got wider recognition as an illness with diagnosable symptoms (Wolfe 2020: 647; Galvez-Sánchez et al. 2020: 1219-4). Wolfe et al. comment on the 1977 paper in their paper from 1990. They point

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[127] The Smythe-Moldofsky criteria were also mentioned by Wolfe, who suggested that these criteria were the instigator to the whole fibromyalgia concept. See section 5.1, 237.

out serious methodological problems, such as imprecise definitions and poor testing that rarely went beyond the center in which the study was defined. The most problematic, however, according to the authors, was that these criteria tended to be circular; "that is, the criteria confirmed the definition of fibromyalgia that was held by the investigators who developed them" (1990: 161). The 1990 paper hoped to do better and hoped to provide clear and objective criteria.

The construction, the definition, and the history behind the locations of the tender points were left unspoken by the 1990 paper, even though the existence of tender points on a patient's body is the main aspect that qualifies fibromyalgia as a distinct diagnosis. In 2004, two medical doctors, Fatma Inanici and Muhammad Yunus,[128] published a short historical overview of fibromyalgia from a medical perspective. They state that the study by Wolfe et al. used the tender points that were defined in 1972 by Hugh Smythe, who was himself the second author of the 1990 study (Inanici and Yunus 2004: 373).[129] Seeing the centralized role of the location of the tender points for the diagnosis, the absence of a further reference to the origin of the location of the tender points is striking. Fibromyalgia becomes defined on the basis of a sensitivity that is experienced on particular tender points, but a justification for the location of these tender points is missing.

The tender points themselves are portrayed in two ways. The first is a schematic figure with which the authors visualize the locations of the tender points on the body. The second is a textual description of the exact physical locations using medical terminology. The tender points themselves are all bilateral; that is, they are located on both sides of the body: at "the suboccipital muscle insertions" or at "the anterior aspects of the intertransverse spaces at CS X7" (171). In the following, I provide a close reading of the schematic drawing by which the tender points are visualized.

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[128] Muhammad Yunus was discussed earlier in section 2.2.2 as the author of the paper on fibromyalgia discussed there. He was also one of the authors connected to the 1990 study discussed here.

[129] Inanici and Yunus (2004) refer to Smythe as the "grandfather of fibromyalgia" as his chapter in *Arthritis and Allied Conditions (8th edition), A Popular Textbook of Rheumatology,* was one of the first publications describing fibromyalgia as a generalized pain syndrome.

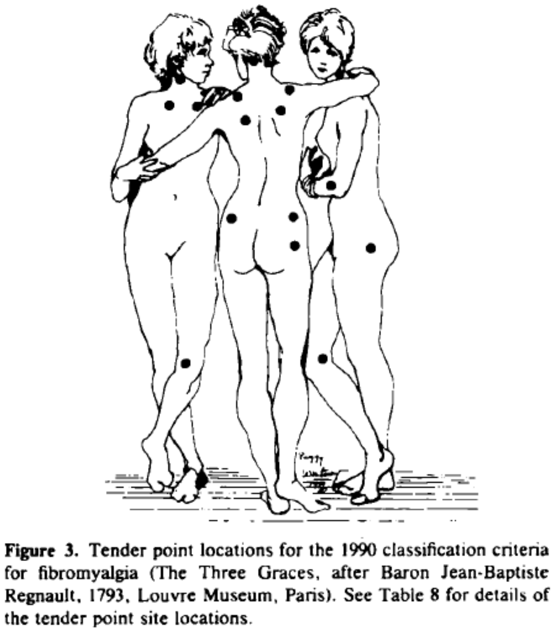

Figure 3. Tender point locations for the 1990 classification criteria for fibromyalgia (The Three Graces, after Baron Jean-Baptiste Regnault, 1793, Louvre Museum, Paris). See Table 8 for details of the tender point site locations.

Figure 6. Tender Point Locators. Included in Wolfe et al. 1990.

Figure 7. Jean-Baptiste Regnault (1793-1794). *The Three Graces.* Paris: Louvre

The visual representation might be one that readers recognize. It shows three naked women standing in classical postures. The woman in the middle has her back directed towards the viewer and holds both other women in her arms. The woman on the left has her gaze directed at the one on the right, who looks directly at the viewer. The description accompanying the figure says:

> Tender point locations for the 1990 classification criteria for fibromyalgia (the Three Graces, after Baron Jean Baptiste Regnault, 1793, Louvre Museum, Paris). See Table 8 for details of the tender point site locations. (Wolfe et al. 1990: 169)

The three graces embody a common image, not only from the eighteenth-century painting here referenced by Regnault but also from Greek/Roman mythology. It was a recurring Renaissance theme such as depicted in Raphael's *The Three Graces* or Botticelli's famous *Primavera* (ca. 1480), in the neoclassical style by Regnault, or in Canova's nineteenth-century sculpture. Not much is needed to reference the three graces: three naked women, usually adorned with flowers, standing in specific postures. In many cases, the title explains the depiction, just as it does here. In this case, the 1990 article provides a figure caption. This is the only place in the text that mentions the visual reference. This figure caption goes even further than the references made to other paintings in the Renaissance. The 1990 depiction of the three graces refers to a specific work as well.

The three graces are included in a medical study that legitimized fibromyalgia as a disease. In my analysis of the schematic drawing I take the reference to the three graces seriously. I consider the drawing as a modern-day interpretation of an age-old theme. Because of the absence of a title to the drawing, I will refer to the drawing by its function, that is: as the tender point locators. Taking the visual reference seriously means that two immediate questions arise. What is its place in the 1990 medical study, and what is its relationship to the iconography of the three graces?

The schematic drawing of the three graces in the article departs from Regnault's painting in many ways. First of all, the three women have been drawn considerately thinner, with different modernized haircuts, and the flowers are eliminated. There is no frame or background. The white nondescript place in which the figures stand easily blends in with the white of the 1990 article's margins. Not painted in elaborate fleshy taints accentuating their figure, the drawing merely consists of a few simple lines. It only presents their contour and posture. On it, the different tender points mark their bodies as big black dots.

At first glance, it might seem like an apt anatomical image that is suited for this purpose. It highlights where the centralized points of pain in fibromyalgia are located. The image portrays a woman's body from the front, the back, and from the side, showing the locations of the tender points through different postures and in motion. It simply takes the drawing as an anatomical study, in which the eighteenth century excelled, to be an illustration of a medical case. At the same time, the drawing makes the tender points hard to locate. The black and white of the hairlines, as well as the lining, which suggests the shadows to highlight the complicated positions of the feet, clearly overlaps with the black of the dots. Seeing this, it seems that the author's willful sticking to the reference of the three graces rather blurs the exact location of the tender points instead of clearly locating them on the women's bodies. For instance: is there, or is there not one positioned at their feet?

The drawing is copied by an artist who is not mentioned by name in the study and only gives the viewer their posture. In the Renaissance, this posture, in which the woman in the middle has her back directed at the viewer and is accompanied by two women at her sides, of which one gazes at the audience, was known from antiquity and copied as a reference. Being here included as a figure of illustration, with no mention of the artist, it is at first hand unclear what the viewer looks at and why the reference is made. But while the text does not make a note of the artist of the drawing, the drawing itself speaks something different. It clearly is signed. However, the name of the signature is not readable due to the size of the print. Yet its presence speaks a different story. The signature shows that this drawing, included in a 1990 scientific paper that defines a disease, is, in fact, a modern interpretation of an age-old theme.

The graces served different allegories over time. Seneca described them as smiling virgins who symbolized three forms of generosity: giving, receiving, and doing well.[130] Later interpreters in Renaissance Italy saw in them the three phases of love: beauty, desire, and satisfaction. In other descriptions of the theme, they are called chastity, beauty, and love (Hall 2006: 90-91). The theme of the three graces carries all these attributes (love, beauty, chastity, giving) and ascribes the different qualities to the women depicted. They become individual personifications of these collective notions of womanhood, and all portray a single ideal. In the current 1990 interpretation, there is no difference discernable between the women. No individual features can be recognized in the two faces, nor by the style of their hair or the looks of their naked bodies. They are merely grouped together. As a group of women, as a whole, these tender point locators reference the attributes given to them through the ages.

The difference hiding in the 1990 interpretation lies in its abstraction. In all concrete manifestations of the three graces in art, there are found different instances of specificity that together compose an image of womanhood in a specific time, bound to a specific canvas or piece of marble. In those visualizations, it is the different strokes of brushes, the light in the studio, or the model that partly guides the composition. A contemporary might recognize a woman from the scene, as she has come to embody beauty in the depiction of it. Together, these elements construct an image of the three graces specific to a time and place as the different interpretations of a theme. The interpretation comes with its own notions of womanhood, drawn from the eyes of men

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[130] The original quote in Latin, cited in Hall’s iconographic handbook reads: “ut una sit quae det beneficium, altera quae accipiat, tertia quae redat” (Hall 2006: 90-91).

and for men to watch. As works of art, they each narrate their own story of the three graces. They have the particularities of each moment in history ingrained in them and tell stories of the male gaze and of idealized femininity. The neoclassical style in which Regnault takes up the theme brings with it its own references, just as the stilled painting by Raphael does, where all three graces hold a golden-red apple as a reference to Venus/Aphrodite with whom they are associated.

But as these paintings tell their own stories, the stories are constructed by way of specific visual elements; the slight alterations in their postures, lavish backgrounds, scarce pieces of clothing, or iconographic attributes. In the specific story told in the 1990 interpretation, these specific elements are exactly what the viewer is deprived of. For the purpose of this scientific publication, the specificities of the visualization are left behind. It presents merely an abstraction. It provides only the remains of the reference to the theme. Its contours are copied from a given original; the Regnault painting, as it hangs at the Louvre in Paris. Everything that is specific to it is removed for its purposes as an illustration of the study, and all specific characteristics of the graces are stripped of their flesh, colors, and particularities. As a concrete manifestation of the three graces, it shows a pure, stripped instance of a male gaze, one that gives only the contours of these women. What remains is an even stronger feeling of a male gaze on femininity. Except that what is constructed through this image is not an idealized version of female beauty, chastity, or generosity but a localization of an illness, which is predominantly identified in women.

This particular image carries its own instances of specificity, be it that these are now located in the context rather than the visualization of the theme. Although the article itself does not attribute authorship or another type of information to the image, a comment on a blog on fibromyalgia reveals the circumstances behind the image. On the platform, the lead author of the 1990 study, Wolfe himself, reacts to a question that asks whose choice it was to include the three graces, saying that they expect it to be a “portly middle-aged male.” Wolfe then replies.

> The 3 Graces! I was looking for a way to be able to use human figures to display the tender points. The 3 Graces seemed to be the only way to do it because the positions of the figures showed all of the possible sites. I found these particular Graces in reproduction from the Louvre. A friend, Peggy Whitney, copied the Louvre figure. I put the dots on myself. I figured the attractive figure would bring

> attention to the subject. I was right. And, no, I was thin in those days. (Wolfe 2013: n.pag.)

This quote shows at least three things. Ironically, the 1990 drawing might be one of the rare visualizations of the three graces drawn by a woman. This woman was a friend of Wolfe called Peggy Whitney. Wolfe then added the black spots signaling the tender points himself. Furthermore, Wolfe looks back on the process of the paper with a certainty that this “was the only way.” Not mentioning Regnault, the artist of the picture, Wolfe twice names its institutional backing at the Louvre, referencing a rich cultural tradition rather than individual artistry.

While the quote mentions Wolfe’s individual considerations to include the image, it would be wrong to think of him as an individual instigator of it. Even besides thinking of the other twenty-three authors of the article, this image speaks of a tradition in which individual motives are not easily discerned. Particularly, it opens a wide discursive field of knowledge that is written on the female body in a “rich” tradition.[131] It is exactly this tradition that becomes visible in the image while it is concealed at the same time. The image invokes a tradition of constructed femininity, while it appears to be an objective representation of it in unison.

With fibromyalgia’s physical cause remaining unknown, it is not surprising to find a cultural context incorporated in the article. This is a structure that operates alongside nervous routes: the 1990 study incorporates already existing stereotypes of femininity at the moment in which biomedical evidence for illness is lacking. The explanation that is hinted at in the visual reference to the three graces is “femininity,” which becomes an important aspect of fibromyalgia. The 1990 study gave fibromyalgia credibility and recognized it as a diagnosable illness. Yet, its physical causes remained unknown. Meaning that in constructing knowledge on the illness, there was a gap to be filled on the physical nature of the disease. Rather than including a more neutral-looking sketch of a genderless human figure, the tender point locators served to fill part of this gap. With their inclusion in the study’s findings, fibromyalgia’s physical unknowability was partly substituted with an already-known cultural image of femininity. The image of

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[131] See my discussion of hysteria as an illness that was inscribed on female bodies, sometimes literally, in the nineteenth century in section 2.3 of this dissertation.

the three graces effectively imports cultural discursivity into the knowledge construction of fibromyalgia. The tender point locators were included to provide physical markers for a contested illness and objectively pinpoint them on the body. It did so by importing an image of idealized, naked femininity. By firmly placing the tender points on the three graces' bodies, it inscribed fibromyalgia onto a notion of femininity, more than creating a clear not-to-be-contested physical marker for illness.

The lived consequences of the gender stereotypes that are inscribed in the construction of fibromyalgia come to the fore in a 2015 memoir by Amy Berkowitz, to which I now turn. Berkowitz was diagnosed with fibromyalgia herself. Her memoir is titled *Tender Points*. On the first pages of her memoir, she writes that fibromyalgia is often referred to as a "mystery." Berkowitz voices how damaging it can be to insist on fibromyalgia as something mysterious. Were fibromyalgia a condition primarily affected by men, she speculates that the words "'mysterious' and 'unknown' [would] drop from the literature, replaced by the findings – however incomplete – of research done thus far" (27). For Berkowitz, fibromyalgia does eventually not emerge as a mystery but is inextricably linked with trauma and experiences of the uneven power balance experienced by female patients in the hands of male doctors.

For Berkowitz, this uneven power balance is even more pressing because of her own experiences with sexual abuse. She narrates that she was raped in a medical setting. She writes that she tucked the memory away but that it came back to her years after the abuse had taken place. Trauma is not linear, she states, and neither is her memoir, which consists of fragmented prose. The book is constructed of short fragments, which sometimes take the form of a listicle ("4 Events You Miss Because Of Fibromyalgia Pain") or a single quote that takes up its own page (22-23, 19). Other times, she writes in a more essayistic style (31), reflecting on other authors' views on feminism, fibromyalgia, or gender. I read Berkowitz's experimentation with form as a search to narrate experiences that are denied words. Words for experiences that were lost to Berkowitz herself in her forgotten and recovered memory. But also to find words for experiences that were denied by her social surroundings: her pain, which was filed under the header of fibromyalgia.

Many of the things she writes about – the nature of the disease and her memories recovered at a later stage in her life – are marked by uncertainty. In response to this, she states that she wants to write clear sentences, to let there be no question about what is exactly written. She writes that "poetry fails me because it's not written plainly" and refers to Anne Carson's observation that women have been associated with disorderly speech and uncontrolled sounds, like shrieks, wails, and sobs, since the classic literature of ancient Greece (25).

> That is why I so firmly want prose here. Sentences. Periods. Male certainty. These are facts. No female vocal fry. No uptalk. No question about what I tell you. No metaphor. Go ahead. Fact check. 'Did I stutter.' Fuck off.
>
> I'm writing about the violence of patriarchal culture. I'm writing about the uneven balance of power in female-patient/male-doctor relationships. I'm aware of a certain home-team advantage, and I will not dare write this in anything that can't pass for straight masculine prose. It's not that this isn't *écriture féminine*, but it's *écriture féminine en homme*.

Her play with form also is a way to master authority. She uses the form of the listicle to "get people to listen" (21) and simultaneously mocks the simplicity of the form of the listicle itself. The challenge is to find the words for an experience that is often denied existence: her illness and her recovered memory of sexual abuse. Berkowitz maintains that "*écriture féminine en homme"* is needed in order to be taken seriously when writing about her subject matter. The words used by Berkowitz are not a metaphor for something else. She wants to be clear about her view on fibromyalgia as a highly feminized condition and about the repercussions of this gendered discourse in a patriarchal society.

Her writing makes a clear point on the absence of metaphors in her text. Yet, unlike many patients with unexplained illness who advocate for their condition to be perceived as a physical disease, Berkowitz explicitly describes her illness *as metaphor*. "Where is Sontag on psychosomatic illness? Any psychosomatic illness, including mine, is essentially and inextricably a metaphor." (100). For Berkowitz, her fibromyalgia is a metaphor for the traumatic abuse that she experienced.

The pain started right after she recalled the rape (71). Viewing her illness as a reaction to, or even going as far as to say it is a metaphor for, a traumatic event, she moves attention away from individual accountability for the creation of illness and towards discursive structure, or the environment that allows for this illness to exist. This argument is central to the politics maintained in crip theory and literary activist work, such as by

Johanna Hedva, Carolyn Lazard, or Alice Hattrick.[132] For unexplained illness, this means that nervous routes that imply individual blame and accountability are circumvented and offered a different path.

Berkowitz not only addresses her physical pain itself but also the lack of place that her pain has in a patriarchal, capitalist society, in which she is denied credibility and is expected to be a productive body. She writes about her experience in a workplace in which she was not allowed to be sick and by which her short-term disability claim was rejected twice (35). She writes about how HR maintained a radio silence on the terms of her sick leave, but she could not work and had to stay home for two weeks. Coincidentally, she got back to work the same day as a coworker who had broken his ankle during a snowboarding accident. His cubicle was decorated with get-well cards. Hers was not. "A get well soon card would have acknowledged the fact of my illness, and as far as the world's largest market research company was concerned, I was faking it." (36). She takes this as an example of how female pain is treated.

Overall, Berkowitz's play with form shows the struggle to give voice to experiences of pain. Although the sentences are written in clear prose, the experimental form of the different fragments reveals an investigation of the role of writing in response to physical experience. In the first pages of her memoir, Berkowitz gives a list of the criteria for fibromyalgia. The reader has first read that the narrator feels like she is run over by a bus every morning, that she hates riddles, suffers from unexplained pain, and that there exists a diagnosis called fibromyalgia, which is, according to the narrator, related to trauma. On the next page, the reader finds the following:

> 2 at the bottom of the neck just above the collarbone
> 2 just below the center of each collarbone
> 1 on the crease inside each elbow
> 2 more on the inside of each knee
> On the back of the body, 2 at the bottom of the neck
> 1 above each shoulder blade and just inside each shoulder blade
> 2 on either side of the lower spine
> 2 more on the outer part of each hamstring

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[132] I discuss Hedva's work in section 2.4.2, 103-106. I discuss Hattrick's work at length in section 5.5. See also: Lazard n.d.

> In order to be diagnosed, the patient must experience discomfort in at least 11 or 18 tender points designated by the American College of Rheumatology.
>
> (Berkowitz 2015: 16)

These are nine lines showing the location of the tender points on the body. The last line explains what the reader has just read. These are not just locations on the body but painful sites. Moreover, these sites carry a particular weight: in order to be diagnosed with fibromyalgia, these places need to hurt. Berkowitz mentions the American College of Rheumatology as a source: they have designated these points.

The American College of Rheumatology was the organization behind the 1990 paper by Wolfe et al., which included the schematic drawing that visualized the tender point locators. Berkowitz's lines bear a striking resemblance to the text used by Wolfe et al. to describe the locations of the tender points on the body. There, the locations are described as follows:

> Pain in 11 of 18 tender point sites on digital palpitation.
>
> Definition. Pain, on digital palpation, must be present at least 11 of the following tender point sites:
>
> Occiput: bilateral, at the suboccipital muscle insertions.
>
> Low cervical: bilateral, at the anterior aspects of the intertransverse spaces at CSX7.
>
> Trapezius: bilateral, at the midpoint of the upper border.
>
> Supraspinatus: bilateral, at origins, above the scapula spine near the medical border.
>
> Second rib: bilateral, at the second costochondral junctions, just lateral to the junctions on upper surfaces.
>
> Lateral epicondyle: bilateral, 2 cm distal to the epicondyles.
>
> Gluteal: bilateral, in upper outer quadrants of buttocks in anterior fold of muscle.
>
> Greater trochanter: bilateral, posterior to the trochanteric prominence.
>
> Knee: bilateral, at the medial fat pad proximal to the joint line.
>
> Digital palpation should be performed with an approximate force of 4 kg.
>
> For a tender point be considered "positive" the subject must state that the palpation was painful. "Tender" is not to be considered "painful."
>
> (Wolfe et al. 1990: 171)

The text of the 1990 paper is presented in a separate box containing the criteria for fibromyalgia diagnosis. The first criterion is a history of widespread pain. “Widespread” is defined as pain on the left and right sides of the body, above and below the waist, and in the spine, chest, or lower back (Wolfe et al. 1990: 171). The second part of the criteria for fibromyalgia is cited in full above.

The lines by Berkowitz and the lines in the 1990 paper mirror each other, almost like the two depictions of the three graces do in their visual shape. This time, it concerns a textual reference instead of an iconographical one. Again, the subject of the reference is the location of the tender points on the body. Again, the difference between the two versions depends on their specificity and context. In the textual reference, the formulation of Berkowitz is the artistic interpretation of a scientific “original”: the text of the 1990 paper. In the visual reference of the tender point locators, a scientific interpretation presented a seemingly objective “interpretation” of an artistic “original.” This time, in the text cited here, Berkowitz, the artist, the writer, sticks to a sober description, calling the locations by their common names instead of the Latin descriptors used by the scientists in the 1990 version. The 1990 text is the more lyrical one of the two. It uses lavish Latin openers for different sentences and can be seen as a written analogy to the eighteenth-century Regnault painting. The 1990 text is the institutional version, not hanging in a museum but published in a scientific article. It is the original of the two texts, an interpretation of a theme explored by others before them, much like Regnault’s interpretation of the three graces.

Berkowitz’s version plays with the neutrality and objectivity implied in the American College of Rheumatology text. Like the schematic drawing of the tender point locators, Berkowitz’s text is stripped of specificity and gains meaning by its context. Here, not in a medical article but in a memoir expressing difficulty narrating the physical pain of something defined by this medical article. Her dry description of the localization of these points makes the reader all the more aware of the physicality of these tender points. They point to a particular location on a body. Berkowitz’s formulation works like an echo, repeating the same words, yet softer, with a stronger lingering of its effect on the reader. Encountering the dry, factual description of Berkowitz’s text in her memoir, a reader may realize that this is not merely a description of the tender points on any body but a display of how the tender points mark places of pain as Berkowitz suffers it.

Berkowitz's text discloses the intimacy of what is pressed upon in these points. She describes the tender points as "frustratingly vague" (40). "Press here and I'll tell you if it hurts. Now press here. Now press here. / All I have to do is tell you. All you have to do is believe what I tell you." By her dry description, she plays with the supposed objectivity of these criteria. In real life, the fact that the measurement of these tender points depends on subjective pain experience presents a problem. Her description of the tender points obscures the objectivity implied in the language used to describe them and exposes a vulnerable body instead.

Reading Berkowitz's text, I want to show that the gender stereotypes that are imported and ingrained in the 1990 criteria *are lived by Berkowitz*, who struggles to find words for them. Her writing tries to convey that these criteria deal with flesh and bodies that hurt. The "suboccipital muscle insertions" are located at the bottom of her neck, and the "lateral epicondyle" is her elbow. She references the supposed objectivity of the medical language but shows that her body is at stake. She writes about the system in which this knowledge takes place and shows that she is discredited and suffers from it. Reading the tender point locators next to Regnault's painting has shown how the criteria for fibromyalgia include an idealized version of femininity that fills part of the gap left by the lack of physical explanation. Reading Berkowitz's text next to the original 1990 criteria shows how she is burdened by the gendered history of fibromyalgia today. Berkowitz's repetition of the 1990 criteria localizes the tender points and exposes them as being truly tender: painful sites on her body.

These are two different repetitions of the tender points. The tender points were drawn and formulated to give a conceptual shape to hurtful places on the body. The 1990 study imported gendered discourse on idealized femininity into supposedly objective criteria. Berkowitz' text moves the other way around by importing objective criteria into a personal narrative of illness experience.

Although I have wanted to expose and critique the gendered and idealized femininity of the 1990 criteria, let it be clear that my aim is not to purge scientific studies from discursiveness (let alone the fact that this would be a contradiction). Neither do I propose to strictly define and narrow the form with which personal experience should be conveyed. By presenting these two repetitions of the tender points next to each other, I hope to think of a way to bring these different formulations of tender points together.

A concrete proposition would be that objective scientific criteria explicitly attempt to reflect on the assumptions they include. As such, the inclusion of the three graces into the 1990 criteria could also be seen as an opener or as a first attempt to discuss the gendered aspect of fibromyalgia: a condition that is predominantly diagnosed amongst women. In my discussion of these three interpretations of the tender points, the schematic drawing based on the three graces, and the two textual lists, I have shown that all of these versions bear a relation to each other that cannot be denied. In fact, to understand these tender points, these relations have to be made explicit and have to be acknowledged. The original visualization of the 1990 criteria relates to idealized femininity, and Berkowitz's experience of pain in her body relates to the formulation of these points by medicine. These medical formulations shape Berkowitz's experience, while these medical formulations are shaped by implicit gendered assumptions. Mapping these relations can help to disclose some of these assumptions.

In the next section, I turn to another memoir and return to the author's self-characterization of the illness as a metaphor, which already came to the fore in Berkowitz's text. Berkowitz has no trouble describing her illness as psychosomatic and goes as far as saying that her illness "is essentially and inextricably a metaphor." As pointed out above, this is done in the context of Berkowitz's critique of discursive structures: capitalism and patriarchy and the way in which patriarchal structures played out in medical encounters as she experienced them. Thus, relocating her illness away from individual accountability allows her to affirm the illness within a larger, relationally-oriented version of the present. Turning toward the next memoir, I further discuss the movement of this characterization of unexplained illness as metaphor as I work towards a possible reinterpretation of the nervous route of transference in terms of relationality.

5.5 Transferring/Relationality

This section focuses on a view of transference as relationality instead of as contagion. I explore the possibility of understanding transference in relation to illness in such a way that it does not discredit patients with unexplained illness. This means that transference is not understood as something that only happens to particular vulnerable people who are predisposed to create illness. Instead, transference would be understood as an unavoidable and ever-present aspect of being an embodied subject. Such an understanding eventually works towards an affirmative approach to unexplained illness that would address unexplained conditions as part of a present for which a collective responsibility must be practiced. A view of bodyminds as inextricably connected to their discursive surrounding contributes to such an affirmative view because it challenges clear binaries such as body and mind or self and other.

The overthrowing of these binaries is explored in feminist literature on (unexplained) illness, such as in the recent surge in illness memoirs from a feminist perspective. In *Ill Feelings* (2021), a blend of memoir, medical history, and non-fiction by Alice Hattrick, the author writes of her mother's and of her own history with ME/CFS. Like Berkowitz, whose memoir of fibromyalgia I commented on in the previous section, Hattrick herself does not shy away from writing of her own illness in terms of metaphor. By Berkowitz, the dichotomy between body and mind is called into question when she writes of her illness as a result of a certain form of trauma. Berkowitz did not perceive body and mind as separate. Hattrick's memoir describes that the author and her mother were both diagnosed with ME/CFS. Hattrick writes of the shared illness between her and her mother as something unavoidable and a consequence of their social bond. She describes how the boundaries between herself and her mother's illness dissolved. By both authors, the dissolving of these boundaries is not perceived as something negative. By moving beyond these maintained dichotomies, my reading of Hattrick focuses on the way in which this makes her able to focus attention on discursive structures instead of on individual accountability.

Hattrick writes how she and her mother both have symptoms of illness without any known cause. The unexplainedness of their symptoms, writes Hattrick, meant that their symptoms were accorded "the status of feelings." These feelings were confined to their bodies and resulted in their sense of their bodies being ill. "Ill – bad, sick, wrong – is also how I learned to feel about my diagnosis," Hattrick writes, because society "deemed people with ME/CFS as fakers, scroungers, lazy and privileged, and indeed all chronically ill and disabled people as less-than-human, deserving of fewer rights, less pay, and less security and care" (17). By referring to "ill feelings," Hattrick denotes both the way they felt as how they were taught to feel about their illness because of the negative way in which ME/CFS is commonly perceived. These ill feelings were shared between mother and daughter.

Hattrick's mother was diagnosed with ME/CFS earlier, and Hattrick's health became a matter of concern for their social surroundings at around age ten. Amongst the medical doctors who treated them, suspicion arose around whether Hattrick's mother was making her sick.

> Sometimes it is impossible to find an origin for ill feelings. I had contracted Giardia aged two, and my mother says I verbalized my persistent symptoms from when I could first speak, but it seemed my ill feelings were all read through my mother's: they even sounded like the symptoms of atypical pneumonia, the trigger for her chronic illness. It was as if I had watched and learned how to be ill from my mother. (Hattrick 2021: 28)

Hattrick's memoir switches between narration from a first-person perspective and a more reflective tone, which discusses how events seemed to the outside rather than how Hattrick experienced them. Her illness was stigmatized and seen as "ill feelings" by her social surroundings, to whom Hattrick's symptoms sounded awfully much like her mother's.

Doctors started to be worried, and by their surroundings, Hattrick's symptoms were understood in terms of imitation. On this, Hattrick writes: "as if I was another symptom of my mother's confounding health" (2021: 28). By Hattrick herself, her illness is not presented as being the fault of Hattrick's mother, or her ten- or two-year-old self. Rather, Hattrick herself writes about it as an unavoidable aspect of the influence from mother to daughter. Her brother did not experience any symptoms. By their environment, this influence was not seen as unavoidable, and Hattrick's mother is blamed for making her daughter ill.

"'They told me we had a shared hysterical language," Hattrick's mother says to her daughter, reporting back what her doctors had told her upon a medical visit (2021: 16-17). Hattrick's symptoms started roughly after she had seen her mother collapse on the floor. After this event, she started to develop symptoms like having to sleep during school times and feeling pain in her arms and legs after sports or after regular movement during the day. She also experienced mood swings and emotional symptoms (16). It was decided that separation was the only solution, and Hattrick was sent to a boarding school that was funded by charity (2021: 18).

She describes her pain not as something that was contagious – which was the language used by their doctors and the rationale behind their separation – but instead speaks of it in terms of sharing. "It was the way I could share my pain with my mother and share my mother's pain" (51). She writes that her grandmother blamed her for what she believes is mimicry because she thought that Hattrick's symptoms reflected badly on her mother. Hattrick was the one who appeared to have created "the conditions in which the mimicry occurred," and she needed to give her mother a break (49). Hattrick says she does not know why her grandmother thought she was faking her symptoms and that she herself has always known that her illness was "a form of love" (50):

> The shared hysterical language between my mother and me, our ways of speaking to one another, was incomprehensible to others for a reason. It was a potentially powerful means of resistance, of subversion, even, to the structures that deemed us sick, and therefore worthless, something to be feared. Our anger, our rage, threatened to demolish discourse. If we couldn't speak then we couldn't relate to one another; sustain the shared hysterical language that protected us and gave us power. If we were silenced long enough, we might even forget how to speak altogether. (Hattrick 2021: 50)

Hattrick writes how her illness made her feel closer to her mother. The illness that had no place in discourse became a way to subvert this lack of place and became the language of the subversion itself. It became a *shared language*, something that was theirs and theirs only. The boundaries between their bodies had blurred. What emerge are at least four different terms by which Hattrick's illness is described. Sharing, imitation, mimicry, and love. "Sharing," and "love," here indicate Hattricks's own feelings towards their symptoms, while the implication of imitation, or Hattrick's use of "mimicry" is used to signal their surroundings' negative take on their both being ill.

Hattrick's writing is different from other memoirs of unexplained illness in that the more personal reflections so easily gloss over the search for an identifiable cause. In this passage, Hattrick is not concerned with finding a definite organic cause for her illness. She is more interested in the relationality that was exhibited in their shared symptoms. If she has to, she fully embraces the fact that their unexplained illness is not discursively accepted and works with their illness as something subversive. She does not stress herself to prove that their illness was, in fact, physiological. Instead, Hattrick moves away from a negative understanding of her illness within a language of contagion and thinks of her illness, however hurtful in itself, as a form of relationality instead.

This form of relationality can be paired with what Teresa Brennan theorized in 2004 as the *transmission of affect*. Brennan tries to think beyond the physical separation between self and other and does so in a way that allows further thinking on transference and relationality. Her monograph, also titled *The Transmission of Affect*, was published posthumously and was an ambitious project that she was not able to completely finish due to her unforeseen death. Brennan was a feminist scholar with a background in psychoanalytic theory. In the monograph, Brennan focuses on communication as something that is continuously going on between bodies. She describes this communication in terms of affect: a pre-emotional state that resides “in the flesh” and manifests as thoughts, sensations, or emotions. She takes physical communication between bodies seriously and theorizes it as the transmission of affect.

Brennan describes that in non-Western and nonmodern theories of mental illness, emotions and “energies” can cross over from individual to individual. By contrast, modern and Western notions of mental illness hold on to the notions of boundaries and maintain that the individual is an “energetically self-contained entity, whose affects are his or hers alone” (24). At issue is thus a view of subject formation. Brennan considers this process to be thoroughly discursive and relational, but instead of focusing on language and signification, she turns to the body and to what she understands as the transmission of affect.

Brennan’s project is a response to the structure of the Western psyche that gives people the sense that they are contained individuals whose affects and feelings are their own. Her book sets out to explore whether the transmission of energy and affects can be seen as “the norm rather than an aberration at the beginning of psychical life” (24). Here Brennan refers to psychoanalytic theory that presumes that a healthy human being will learn to be self-contained. This is not contained to psychoanalysis alone. Common developmental theories hold that the child will slowly realize that the mother is a separate person. The separation between the self and the other is maintained as the standard, healthy individual.

Where Dawkins and Showalter spoke of contagion in an attempt to conceptualize effects of relationality between human beings, Brennan refers to “simple affective transfer.” These affective transfers are not seen as something dangerous that can incite illness or allow the stranger a dangerous entrance into ourselves but as an inescapable quality of life as a human being. These affective transfers happen in crowds, but also in shared rooms or in proximity to someone, when individuals act according to what Brennan calls “rhythmic identification” (2004: 49). Brennan’s different conceptualization of transference as an inescapable aspect of embodied life thus enables her to formulate a positive notion of transference in terms of relationality.

Brennan does not stand alone in her attention to relational life as a starting point for theory. Her 2004 monograph appeared the same year as Butler’s *Precarious Life*, which theorized violence and mourning in the face of vulnerability and interdependence and can be seen as a more politically informed inquiry into the nature of (bodily) relationality. Some ten years later, in *Senses of the Subject* (2015), Butler further reflects on the primacy of the senses in relation to subject formation, or, if you want, Brennan’s relational subject. Butler claims that when one says that “I am already affected before I can say ‘I’ and that I have to be affected to say ‘I’ at all,” one does not take into account the narrative delay that is involved in making that statement. That is, in Butler’s words, the “I” involved in this statement speaks much later than the process it seeks to describe (2). Taking the question of embodied, sensed relationality thus philosophically further, Butler asks if it is possible to try to give a narrative sequence for the process of being affected, or the emergence of the “I” (3).

For Hattrick, who perceives her own illness as a form of being affected, having learned to be ill from her mother, there is no such narrative sequence. Their shared language developed as Hattrick developed, “verbalized from when she could first speak.” There is no before, as far as Hattrick’s narrative goes. The narrative delay involved in having to make sense of her senses means that her and her mother’s illnesses are shared, and that the boundaries between them are blurred. In the absence of an explanation that narrativizes the experience of illness in organic terms, Hattrick resorts to affect, or, a pre-emotional state of embodied relationality.

This embodied relationality stands in a complicated relation to language. In this pre-emotional state, defined in terms of affect because it describes the doings of the body before it was conscious, Hattrick does locate a form of subversion and resistance. She even describes the doings of her body in terms of *language*, literally described as a "shared hysterical language" (50). The way in which the body, language, and relationality intertwine and overlap in Hattrick's account gains further meaning when looking at her seemingly contradictory statements on metaphor. On the one hand, she writes

> I know that feeling, of every sound or touch hurting. There is no metaphor for everything hurts. (56)

But she also states that

> Pain lends itself to metaphor, welcomes it, even – like illness in general. If pain is a web that holds me inside it, it also unravels me. It is possible, sometimes, to unravel it – the mysteries of my nervous body – in turn. (131)

The distinction between these two statements is one between a *feeling* – that everything hurts – for which there is no metaphor and the narrative act of having to describe pain. The first statement thus describes a bodily felt thing that has to gain shape in language. The second describes the already narrativized translation of a feeling: "pain," a word in itself being a translation of a bodily felt thing that simultaneously feels incomplete in doing justice to that which is felt, to the extent that it is supplanted by metaphors to fill its meaning.

Here, the narrative delay, as described by Butler, comes in as a useful concept to describe the difficulty of having to account for the self in language. Having to do so involves an obvious problem of temporality: "To say that I am affected prior to ever becoming an "I" is to deliver the news by using the very pronoun that was not yet put into play" (Butler 2015: 4). Butler asks what it means that the subject, in the Foucaultian sense, is produced by norms, and states that these norms are plural and arrive in clusters. This means that norms act in "multiple and sometimes contradictory ways; they act upon a sensibility at the same time that they form it" (5). The first essay collected in Butler's 2015 *Senses of the Subject,* engages with Cartesian thought and discusses the relationship between the body and language. For Butler, it is possible to discuss the body as being *given through language* without immediately stating that the body is nothing other than the language by which it is known (20). In relation to this "I," inextricably and simultaneously connected to this body and language, this means that this "I" comes into being through an *embodied self that is given through language*.

The inextricability between body and language means that language itself cannot escape how it is implicated in bodily life and that the body cannot be thought of without language. Butler writes that "just as the effort to determine the body linguistically fails to grasp what it names, so the effort to establish that failure as definitive is undermined by the figural persistence of the body" (22). How does this relate to metaphor, simply and implicitly taken by Hattrick as the figure of speech that applies a word or phrase to something to which it is not literally applicable? Used as such, body metaphors exist in a strange situation, for if one is to follow the simultaneous coming into being of body and language, naming a leg or naming pain simultaneously shapes that which it describes, thus already subverting the "literal" qualities of the signifier to some extent.

In the above description, I stick to the "simple" or "traditional" definition of metaphor as describing something (here taken as "the literal") in terms of something else ("the metaphor"), as it is referred to in Hattrick's text and also used as such by Berkowitz. This simple definition results in a contradiction when it is applied to the body when it is understood as a discursive process. Where this description concerns the already complicated matter of describing the body through language, it also becomes clear how the situation is further complicated in cases of unexplained illness. In the context of unexplained illness, the already strange situation of body metaphors becomes stranger, as any "literal" description of that which needs to be described is exactly that which lacks. Within this context, both Hattrick and Berkowitz's preoccupation with the way in which their experiences must not, or simply cannot, be defined in terms of metaphor is telling. It shows both something about the way in which metaphors work, in terms of creating what has been called "surplus meaning," as well as Hattrick and Berkowitz's fear of what is included in this surplus meaning: how, when unexplained illness is concerned, these surplus meanings are in danger of becoming negative.

The way in which metaphors work to create "surplus meaning," mentioned above, has been described by literary and cultural scholar Greta Olson in the context of a view of metaphorization as an "affective, embodied, and generative meaning-making process (2023: 124). Giving examples of metaphors used in anti-immigration rhetoric, Olson shows that words like *Flüchtlingskrise*, or *Flüchtlingswelle* in German, "highlight metaphors' liminal status between the verbal and the visual" but also their "haptic qualities" and "emotional resonances" (131). Olson notes how these metaphors deindividualize refugees, and that simultaneously, these metaphors work as vehicles to easily communicate ideological viewpoints (131-132). These slippages of meanings have affective resonance and can have, as Olson describes, "disastrous effects" (123).

The working of metaphor to create a slippage or surplus meaning is closely linked to the operation of nervous routes as laid out in this dissertation. I have worked with nervous routes as epistemological movements that depart from the core problem of unexplainedness and then branch out on paths that are already well-trodden and primed by cultural stereotypes. Nervous routes thus "slip into" meanings that are already available for unexplained illness, thereby filling in the gap left by biomedical unexplainedness. Nervous routes do not themselves create a surplus but are moved by what is already created. Exactly here, the slippages of meanings that are easily created in metaphorical imagining become more dangerous and can have potentially disastrous effects.

Thinking of metaphor as an affective process thus helps in understanding Hattrick and Berkowitz's resistance and their ultimate description of their illness in terms of metaphor. In the first quote given above, Hattrick refers to hurt, here becoming the "literal" word for a sensation, a feeling, in the attempt to bring it across as directly as possible without further intermediaries. In the second quote, the experience of pain and the act of having to communicate this experience is described through metaphor, here closely resembling etymology in the Greek *metapherein*, or *to transfer*. Pain is explained in the form of a web: one that holds but also unravels, one that has formed Hattrick as a subject but that has also unraveled a sense of self: exposing her failure to exist as a singular being and simultaneously writing up a sense of her pain in terms of relationality.

Similarly, Berkowitz, in her memoir *Tender Points*, as discussed in the previous section, also explicitly turns away from *describing* illness or her sensations in terms of a simple definition of metaphor. She states that she does not want to turn to metaphor and firmly wants prose and clear sentences. Berkowitz's refusal to describe her illness in metaphorical terms relates to the status of what is called "ill feelings" by Hattrick: "Ill – *bad, sick, wrong*," related to negative stereotypes of people with unexplained illness as "fakers, scroungers, lazy and privileged" (17). At the same time, when Berkowitz narrativizes her illness, and places it in the context of her experience with (patriarchal) medicine and sexual abuse, she eventually states that her illness itself is "essentially and inextricably a metaphor" (100), thereby similarly exposing herself as not singular being, and instead as being formed by norms and experiences that have impressed on her.

In both instances, metaphor is resisted insofar as it supports the narrative drive that is contained in and pushed by the nervous route. Metaphor is resisted insofar as it supports a negative view of transference-as-contagion, understanding their illness as mere copy and cry for attention. Metaphor is maintained, or even followed, when it supports a positive view on transference-as-relationality, insisting on the inseparability of self and other and emphasizing the way in which the self is never contained but always imbued with discourse.

When the cause for Hattrick's illness was not found, it was assumed by her doctors that her mother was responsible for creating the conditions in which the illness would be transferred, making her daughter ill as well. Not thinking of it in terms of contagion but speaking of the sharing of their illness instead allowed Hattrick to reconceptualize their illness, away from the notion of blame, and towards an explanation that emphasized the way in which the body is lived as a relational entity. Doing so opens up a possible affirmation of unexplained illness: not in the sense of finding necessary biomarkers that provide proof of disease as it exists in a single individual, but in the sense of practicing a form of care that acknowledges experiences of bodyminds as they are lived in relation to one another.

Hattrick thus moves away from a language of contagion and thinks of her illness as a form of relationality instead. Doing so simultaneously exposes that discourse around unexplained illness often maintains a negative attitude towards transference. The transference of mental symptoms into bodily complaints, but also the transference of ideas between people, is seen as something that the healthy and contained individual should be able to resist. Going back into this chapter, Dawkins' war-like language used in the formulation of the concept of the meme showed that relationality is often viewed as a dangerous concept: as parasites or intruders that need to be contained. The individual needs to be held in place. Hattrick's and Berkowitz's memoirs question the relation between language and the body. They thereby also undo the separations that are maintained in the negative view of transference-as-contagion that involves a normative concept of a self-contained individual in reference to their environment. This self-contained individual is susceptible to blame, while the relational individual described by Hattrick and Berkowitz invites us to care.

5.6 Conclusion

What I have done in this chapter is explore the notion of unexplained illness as a contagious idea: a nervous route of transference-as-contagion that attributes blame to vulnerable "leaky" individuals. I have started out with a Reddit thread that showed the misogynistic disbelief attached to fibromyalgia and followed with presenting the regret voiced by the doctor who played a major role in defining the illness for having a part in "inventing" this diagnosis: giving people an illness, effectively "making them ill."[133] Thus I have first established fibromyalgia as a contested condition whose unexplainedness results in ideas of social contagion. Focusing further on describing a view of transference-as-contagion, I have shown how closely connected fibromyalgia is to ideas of social contagion and that contagion itself is a traveling concept that has never been contained within a medical setting alone.

In the close readings that followed, I have argued, first, that the specific meme under analysis does not always operate as a meme but sometimes operates as a mimetic stall instead: not transferring anything, but rather putting understanding and shareability to a halt. Contrary to the negativity part of the coining of the term meme by Dawkins, online illness memes often offer recognition and support for existing experiences rather than creating them, while, in other cases, outside illness communities, the meme is not

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[133] See section 5.1, 230.

shared and understood, thus does also not work in a contagious way. Second, I have provided a close reading of four connected objects, echoing each other, to show how fibromyalgia's physical unknowability was partly substituted with an already-known cultural image of naked, to-be-looked-at femininity while defining tender points on the body. These tender points hurt; in more ways than strictly physical, and there is a need for an acknowledgment of this hurt, something to which the idea of fibromyalgia as contagious, aided by a feminized version of the illness such as shown in my analyses, does not contribute.

Finally, I have read two illness memoirs next to theoretical accounts of relationality to show that illness transference does not have to be thought of in negative terms such as contagion. Thinking with relationality can help work towards an affirmation of unexplained illness in terms of collective care and acknowledgment of pain that is already there.

6. Conclusion: Cracks, Practice and Affirmation

6.1 Flowcharts, Paths, and Nervous Routes

In 2022, a urinary tract infection (UTI) was the most common diagnosis made upon a visit to a primary doctor in the Netherlands (Heins et al. 2023: n.pag.). The Dutch Association of Primary Care Doctors (Nederlands Huisartsen Genootschap, hereafter NHG) published a flowchart that shows how such a diagnosis is made.[134] Upon the presentation of symptoms by the patient, the doctor asks further questions relating to the symptoms. In the case of a possible UTI, this involves whether the patient experiences pain, difficulty, or changes in frequency and amount of urination. When the answers indicate the presence of an infection, for instance, when the patient experiences burning pain during urination or has to go more frequently, the doctor might undertake a physical examination (inspecting or touching the belly or genital region). When there is a suspected UTI, a patient is asked to provide a urine sample on a stick, which, depending on the doctor's office, can be checked right away. When nitrite is found in the patient's urine, a UTI is diagnosed. When no nitrite is found, the flowchart spreads out into a more difficult path.

In the absence of nitrite found in the patient's urine, the patient can still be diagnosed with a UTI. It only presents a longer route on the flowchart. The diagnosis now also depends on whether or not the doctor has a persistent suspicion of a UTI, even though the initial test did not indicate one of the biomedical markers that is often associated with it. When there is such a persistent suspicion, the doctor can look for further biomarkers via another urine examination, either checking the urine for bacteria under a microscope (seen as less reliable) or via what is called a dipslide; growing a culture of the urine, which can take up to a day (seen as preferable and more reliable).[135]

This short description summarizes one of the most common proceedings in Dutch primary care. It also shows that the medical route towards diagnosis and treatment

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[134] The flowchart is published on the website of the NHG, as part of the NHG-Guidelines for diagnosis for specific conditions. See Bouma et al. 2020 n.pag. The flowchart, as referred to here, is presented within the summary of the guidelines published on the website. A more extensive 129-page version of the guidelines can also be downloaded.

[135] For further explanation of the specific methods mentioned in the flowchart, see Bouma 2003.

is significantly simplified by the privileging of a simple biomarker to identify disease. Even in a case of a very "medically explained," and arguably "straightforward" case of infection,[136] this route is complicated by a lack of initial biomarker. In this case, the routes of the flowchart spread out in multiple possibilities, where a "persistent suspicion" plays a crucial role in the process but where, ultimately, the identification of a biomarker still determines the outcome of the diagnosis. A UTI can be treated. This means that the most common diagnosis made in Dutch primary care often results in care, eventually relieving the patient of their symptoms.

A problem arises when pain is not explained or given a name in the form of a diagnosis. When the encounter between patient and doctor does not result in a recognizable sequence of events in which the symptoms gain meaning, care becomes much more complicated, and other explanations will follow. This dissertation formulates four main theses in response to this problem. The first is that such explanations can be seen and traced as specific knowledge practices. Second, that they often end up making patients accountable for their symptoms. Third, the act of tracing these practices exposes the cracks in a system of knowledge and, finally, offers an entry point to look for care in the form of an affirmation of pain that is felt.

In this dissertation, I have argued that when illness is not explained in biomedical terms, the lack of physical markers leaves patients vulnerable to explanations that follow what I have called *nervous routes*. I have worked towards a definition of a problem – the problem of unexplained illness, which is not sufficiently taken seriously as such within medical science and popular culture at present. This problem results in nervous behavior. This nervous behavior follows from the powerful narrative drive to give meaning to physical sensations, regardless of a lack of obvious causal grounds, so that unexplained illness is commonly explained by falling back on nervous routes. As a consequence, bodyminds failing to conform to biomedical explicability are excluded and become a marginalized group, often within already marginalized communities.

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[136] The scare quotes serve to signal Annemarie Mol's *The Body Multiple* (2002), a medical ethnography of day-to-day hospital practices, diagnosis, and treatment of atherosclerosis, showing that in practice, localized in the specifics of the hospital, what looks at first glance as a very medically explained and straightforward condition appears as many things: a body multiple.

I have closely read and analyzed medical texts or illustrations, artistic work, and representations of unexplained illness in popular culture. Doing so has enabled me to identify and formulate nervous routes and their productive effects. I have defined nervous routes as lines of thought along which formulations of unexplained illness are given shape, and I have simultaneously described how these routes act to shape physical sensations themselves. By giving shape, I mean the cultural discursive process through which unexplained illness becomes apprehensible and is understood in various contexts. The route laid out in the flowchart used for UTI diagnosis presents a concrete path along which general practitioners measure patients' symptoms. Yet, when this chart does not lead to a diagnosis when completed, and other flowcharts fail as well, the path is less certain. Here, I argue that the path becomes a route, and the route becomes nervous. In these cases, the problem, which is initially one of medical professionals having to solve a case, is often offloaded to the patient, who becomes problematic.

People with unexplained illnesses are confronted with two kinds of struggle: first, they have to get their conditions diagnosed; then, when such a diagnosis fails, they have to struggle with the lack of social acceptance and validation that comes with the status of having an unexplained illness. Such a lack of discursive backing creates a breeding ground for negative attitudes around bodies that fail to operate according to medicine's standards of wellness and disease. Patients often internalize this failure.

My study of nervous routes of unexplained illness has shown the desire for, and necessity of, explanations for illness that will always be given in some form or another. My study also shows that the absence of a conclusive biomedical explanation usually results in a negative interpretation of unexplained illness associated with blame and responsibility. Nervous routes tend to follow or are structured alongside culturally dominant lines of division such as gender, sex, race, and class. In this context, nervous routes risk further marginalizing already marginalized groups. When an organic cause for an illness cannot be biomedically identified, patients are often told that "it's all in their heads." They are prescribed antidepressants, sent to a psychiatrist, and held accountable by others for creating their symptoms. I describe marginalization as a result of three different processes, which continuously return in my description of the various nervous routes: *delegitimization*, *feminization*, and *psychologization,* of symptoms, complaints, and the patient that presents with them.

I have set two main limitations in this project. The first is that I have singled out and limited myself to the problem that arises when illness is unexplained. The second is that I have provided a cultural analysis of this problem, defined as “unexplained illness,” through various close readings of cultural objects. This means that I have concerned myself with a theoretical exploration of a problem based on an analysis of cultural objects read as text. At the same time, both limitations mean that this analysis has the potential to extend beyond the localized analysis of cultural representations of unexplained illness itself. Unexplained illness continuously invokes the structure of medical explanation as a whole and, taken as a problem, eventually exposes the cracks of a system. In that sense, focusing on unexplained illness and on the forms of this exclusion provides an exemplary entry point into an analysis of biomedical explicability and of what and who it leaves behind. Although I have focused on cultural objects, it is the people who are at the other end of the door or who find themselves still in the waiting room that this analysis is for. The formulation of nervous routes is vital to understanding the shape in which their bodyminds are molded. In this place of limitation and exclusion, it is vital to imagine which other shapes can be possible: what emancipation from nervous routes might look like.

With this in mind, I have traced these routes in the preceding chapters. I have identified four: “the case,” “classification,” “impasse,” and “transference.” All four routes involve a specific movement in which the symptoms, experienced by the patient as physical, attain another markedly negative shape and result in a negative framing of unexplained illness in medical science and popular culture. Due to the nervous routes, unexplained illness, as an issue of medical science and practice, extends beyond the clinic. These nervous routes penetrate daily life and experience, not only of patients with unexplained illnesses themselves but also within a general understanding of bodyminds within a dualist structure.

Identifying these routes, I specifically call upon the *trace* that they leave behind. I have thus paid attention to the route that is followed by medical/cultural discourse in an attempt to solve the problem of non-explanation of physical symptoms at present. At the same time, I have also focused on the mark that this route makes on the patient. I have argued that this patient becomes marked by unexplainedness and is at risk of eventually becoming a liminal subject without discursive backing. As mentioned above, the thrust of this dissertation has been to show how the nervous routes of unexplained illness are underpinned by a a dualistically organized form of medical care and practice, how they result in a delegitimization, feminization, and psychologization of unexplained illness, and how they ultimately lead to a marginalization of patients. I shall unpack this critique in the section below, and close with a reflection on what affirmation might look like within this context.

6.2 Accountability: Liminal Individuals, Dualism and Marginalization

Throughout this dissertation, I have shown how a lack of discursive backing often results in holding the patient accountable for the creation of their symptoms. The first introductory chapter laid out the problem of unexplained illness in terms of accountability. Attitudes and practices that hold the patient accountable for the creation of their symptoms could lead to the isolation of patients with unexplained illness, who are relegated to a place outside of dominant (medical) discourse. In response, I have identified and described four different nervous routes which link unexplained illness to individual accountability, in order to loosen this bond and resituate unexplained illness in a collectively experienced present.

What emerged from my various analyses was how unexplained illness is closely related to issues surrounding credibility in the face of (medical) authority. This credibility has historically been denied to women and minority groups. I show this in Chapter Two, in which I discuss cases constructed of women with unexplained illness. These cases include personal information that was taken from these patients, creating a version of their illness and personality that they themselves did not recognize. The issue of credibility also comes to the fore in Chapter Three, in my presentation of a patient's resistance to a particular diagnosis because she felt this would discredit her in the eyes of medical science, towards which she felt even more vulnerable as a woman of color. In Chapter Four, the issue of credibility is present in the lawsuit filed by a group of patients who criticized the dramatized and sensationalist presentation of their symptoms as "psychosomatic" as a form of delegitimization. In Chapter Five, I discuss illness memoirs by writers who had their own account of their illness denied by coworkers or in encounters with medical professionals. Such discussions and close readings exposed the way in which patients with unexplained illness have limited agency in response to a discursive structure in which they have become liminal subjects.

I have deliberately not investigated specific illnesses in order not to fall into essentialist-type categories, such as myself classifying some conditions as unexplained. Part of my aim to diagnose the problem of unexplained illness is that I have not contributed to the construction of a new figure, in the sense of the construction of a name that can be claimed as identity (like for instance the 80's feminist figure of the "Hysteric," or more recently, Johanna Hedva's "Sick Woman.") Even though such a figure could potentially serve an emancipatory function, my aim is to be found elsewhere in my focus to describe the consequences of people being ill without a biomedical explanation. To do so, I discussed various conditions in which biomedical evidence for disease is lacking or contested. As mentioned before, without biomedical evidence, explanations often shift towards the mental domain, following the idea that if disease does not exist in the body, it must reside "in the mind." This psychologization is intimately tied up with the delegitimization of the patients' reality of being ill and a feminization of the patient and their condition.

With delegitimization, I point to the process in which the symptoms gain a status of less "real" as they are understood to emerge within the fuzzily defined domain of "the mind." Unexplained illness results in a scene of tension between two types of legitimacy that are both important pillars of medical science. The first is the type of legitimacy of the patient, etymologically connected to the one who suffers or undergoes. This patient is the subject who presents an experience that holds legitimacy in the sense that it is the basis upon which validation is built. Second, is the type of legitimacy of the experiences insofar as they are reducible to an object of medical science. This concerns pain or complaints (symptoms) that can be verified by biomedical markers ("the real"). In unexplained illness, the lack of legitimacy of the second type means that the first is damaged. In practice, the lack of biomarkers means that the legitimacy of the patient is affected in a negative way.

With feminization, I point to a cultural framework that starts to see these patients as being vulnerable, "leaky," non-contained subjects: too open or susceptible to social influence – a "feeble mind" in a "feeble body." Feminization can also be seen as a concrete historical form of delegitimization that is closely connected to historical formulations of hysteria, most notably in the nineteenth century. Examples of this connection have been shown throughout this dissertation in the form of the continuous reference to hysteria in contemporary psychiatric classifications of unexplained illness in the DSM, explored in sections 3.4 and 3.5, or in the self-characterizations of patients with unexplained illness in terms of hysteria, shown in section 3.1, and in the memoirs analyzed in Chapter Five.

Throughout my various analyses, delegitimization, feminization, and psychologization of symptoms appeared as a cluster. This was shown, for instance, in my theoretical discussion of the intersection of the male gaze and the medical gaze in section 2.2, but also in my reading of the medical illustration used in the 1990 criteria for fibromyalgia in section 5.4 or in my discussion of illness memoirs in which authors themselves describe their experience with this cluster as a system of oppression, as shown in section 5.5. In all of these examples, delegitimization, feminization, and psychologization of unexplained illness can hardly be untangled. Ultimately, the inextricability of this cluster greatly contributes to the way in which unexplained illness is characterized by, and results in marginalization.

This cluster of exclusionary structures is underpinned by a conceptual separation of mind and body. In the case of unexplained illness, mind-body dualism continues to contribute to notions of blame that hold individual patients responsible for *creating* their symptoms. In response, I have used the materialist feminist term *bodymind* throughout this dissertation to indicate that I instead depart from the inextricability of what has often been separated as two entities. As a term, bodymind aims to escape the dualist framework of body and mind.

Medical explainability is defined almost exclusively on one side of the dualism: that of the body. Illness that has no obvious physical marker is a theoretical problem for the organization of medical care and for medical knowledge at the basis of this organization. This theoretical problem manifests itself in a very concrete, practical, and painful way. Because physical conditions without known organic markers are presented as unexplained, this results in a situation in which patients are denied basic forms of care. This care is missing medically, in the form of a lack of research and funding that acknowledges the seriousness of patients' conditions, and it is missing socially in the form of their being denied the status of being ill. Care is also missing financially, in patients' being denied disability benefits in the absence of biomedical proof for disease. All the same, these patients are ill and need various forms of support. They are often unable to work or perform basic daily tasks. They often cannot afford the consequences of the delegitimization of their condition. My aim has been to emancipate unexplained illness from notions of blame and draw attention to the material consequences of the delegitimization of unexplained illness.

This also means that inasmuch as this dissertation has focused on theory, it has done so to specifically address the gap between both medical and cultural theory and practice that manifests itself in the existence of unexplained illness. To emancipate unexplained illness from nervous routes, it is first necessary to provide a clear formulation of the problem that unexplained illness poses. Focusing on nervous routes allowed me to draw attention to explanations commonly given to illnesses that lack a proper biomedical explanation. Importantly, these nervous routes are not meant as metaphor but constitute a methodology. I have developed this concept as a point of departure for the tracing of the discursive process that contributes to the meaning of unexplained illness in the present. Coining the concept of nervous routes has allowed me to map the discursive structures through which unexplained illness is understood, both medically and culturally. This means that I have been able to analyze different cultural instances that have contributed to this understanding. In doing so, my aim has been to expose the various forms of blame and delegitimization of unexplained illness and discuss their effects.

My focal points imply, first, that I have bracketed what can be called "the symptoms themselves" and have been cautious not to ascribe names to what emerges as "unexplained." As said, I have been methodologically careful not to construct a new figure of the unexplained. Second, I have focused on closely describing the figures already there by analyzing cultural objects such as (documentary) films, illness memoirs, internet memes, and medical texts. I have addressed these cultural objects as actors in the construction of unexplained illness. A close reading of these objects allowed me to trace how unexplained illness gains shape.

A discussion of unexplained illness is needed within the humanities, which have rarely centralized the problem of unexplainedness in relation to structural conditions. Such a discussion shows the need for a theoretical insistence on discourse. This lack of theory around (un)explainedness is all the more glaring, as an unexplained illness is, first of all, an experience that often directly clashes with theoretical authority. Unexplained illness results in a situation in which the experience of the body stands in direct conflict with a medical authority closely tied up with a(n often implicit) theory of the body. It exerts this authority in order to provide care but also to legitimize it. Unexplained illness does not match medical discourse and, as a result, may signal a lack of care. To care for people with unexplained illnesses, I have argued that unexplained illness needs to be examined in close connection with the discourse through which it occurs and which has created it as a problem.

The organization of medical science along the persistent and hierarchically organized mind-body dualism tends to privilege bodily explanations. This enables a mentalization of physical symptoms that lack an identified biomarker. The way in which this dualism is ingrained within medical theory, practice, and popular culture has concrete negative consequences for patients with unexplained conditions. Firstly, unexplained illness either implies a complete absence of explanation or a negative interpretation of explanation. The absence of explanation leaves the patient to dwell in a liminal space, somewhere between mind and body. Secondly, the negative form of explanation links the illness to identity. It implies blame and holds the patient's character, habits, or even their unconsciousness responsible for creating physical symptoms. I have traced both the lack of explanation and a negative explanation back to the origins of psychoanalysis and its interpretation of hysteria as an unconscious repression that manifests itself in physical symptoms.

6.3 Working Towards Affirmation

In Chapter Two, I presented historical cases made in the name of patients diagnosed with hysteria who were abused in medical settings. Apart from showing the sometimes violent history of hysteria diagnosis and treatment, I have focused on hysteria throughout this dissertation to argue how, at present, the illness and the patients who were diagnosed with it only appear to us as a construction. This construction follows the first nervous route as I have identified it: one of case construction that extracts knowledge from the patient and creates a figure of unexplainedness that removes the patient's agency, delegitimizes their bodily experience, and leaves them uncared for. This delegitimization is explained through the second nervous route: that of classification, which, as I argued in Chapter Three, plays out in psychiatry, mentalizing symptoms that are experienced as physical. This maintained separation is further explored in Chapter Four, which focuses on the nervous route of impasse. In this context, I discussed the integration of mind and body that was attempted in the psychosomatic effort. Here, I argued that this effort failed due to its remaining stuck in a dualist framework and eventually contributed to the characterization of patients with unexplained illness as liminal subjects themselves.

These problems and the resultant limitations on speech and expression that are part of these nervous routes can be partly circumvented by paying greater attention to relationality. I have done so in Chapter Five by identifying the nervous route of transference, drawing out how the negative interpretation of relationality is voiced as psychosomatic contagion, playing into the notion that vulnerable, often feminized individuals become sick from imitation of an idea. I have argued that psychosomatic contagion drives home the stereotype of unexplained illness being less "real" and these patients being malingerers. Pointing to relationality as a central concept in Chapter Five, I describe the existence of bodyminds as inextricable unity, as well as the contact between different bodyminds within discursive reality. My move in this chapter towards a positive interpretation of illness transference works towards the overarching route proposed by this dissertation. This is a movement away from a model of accountability towards a model of affirmation. In such a model of affirmation, the need for legitimization of unexplained illness is nullified and replaced by an affirmation of the need for care and support between relational beings.

My analyses of different cases, diagnoses, and means of representation reveal that patients with unexplained illness have to mediate between their physical complaints and the shape they have gotten in the present, often in the form of negative stereotypes. I have discussed different instances of feminist artistic, activist, or literary works in which patients with unexplained illnesses themselves formed a critique of how they were represented in medical settings or popular discourse. This was the case in my discussion of video work by Panteha Abareshi (2019), literary work by Johanna Hedva (2018) in Chapter Two, and memoirs by Hattrick (2021) and Berkowitz (2019) in Chapter Five. In these artistic and activist accounts, affirmation of unexplained illness is continuously sought, emphasizing relationality. By focusing on the intricate entanglement of entities – ostensibly separated into body and mind – as bodyminds, and on discursive forms of subject formation, dominant hierarchies and separations are questioned and undermined. This is an important movement for unexplained illness because these patients have experiences that are at odds with such separations and do not fit in the mainstream classificatory logic based on these separations.

An affirmation of unexplained illness must be looked for in a theoretical insistence on discourse. Here, the term bodymind helps formulate a problem contained in dualist medicine, both in terms of knowledge (etiology and classification) and in practice (the organization of medical care based on mind-body dualism). The problem, however, is greater than can be solved with a formulation or proposition for a new term. Unexplained illness dwells on the limits of discourse. Addressing it, therefore, “shakes things up.” In its dwelling on the limits of discourse, unexplained illness exposes the cracks of a system. The oppression of patients with unexplained illnesses is not simply turned around by embracing the notion of the bodymind or by (re)appropriating a certain identity.

For people with unexplained illness, the uneasy consequence of their illness dwelling on this limit of discourse, exposing a crack, is that zooming in on these cracks also exposes the failure of a system by which many wish to be legitimized. In this sense, my tracing of nervous routes can be seen in the context of what Butler has called “disclaiming” which is, according to them, “no simple activity” but what they have to offer as a “form of affirmative resistance to a certain regulatory operation” (308). To emancipate those who suffer from unexplained illness from the discursive context by which they are delegitimized, it will not do to erect a legitimate identity category for them to claim (e.g. “the unexplainedly ill”), because this only uncritically extends the dominance of a cracked discourse. In this sense, my argument takes the form of a disclaimer. The only affirmation of unexplained illness I have to offer is a record of how the absence of biomedical explanation results in a kind of regulatory operation nevertheless: “other explanations” in the form of nervous routes.

My analysis of unexplained illness *crips*, in the uneasy connotation of the word as it was defined by Carrie Sandahl (2003). It subverts mainstream representations and practices around unexplained illness and exposes the failure of Western dualist medicine to account for lived experience. In a sense, such a cripping can be seen as an affirmative move: it exposes and addresses the conditions under which unexplained illness comes into being while making space for the lived experience of those suffering from it. Simultaneously, this is a cripping that is more ambivalent, more complicated, and perhaps too destructive to be unequivocally positive or to even pass as affirmation at all. Exposing the failure of Western medicine does not mean that one gets any closer to bettering the lives of people with unexplained illness themselves. Because of the complicated existence of unexplained illness on the limits of discourse, any attempt to resituate necessarily involves a destructive move that does not offer immediate help to patients who wish to be legitimized within a dualist system. The danger is that for patients with unexplained illness, without medicine, even a dualist organization of it, all that would be left is pain, of which affirmation alone is not enough.

Not only do many patients with unexplained illness wish to be legitimized by biomedical standards, but biomedical knowledge also holds the potential to improve the lives of patients with unexplained illness or even cure some of the conditions that are poorly understood at present. It would not be safe to discard this system as such. This does not mean that I automatically subscribe to a model that strives towards the ultimate biomedical explicability of the body, or its ultimate potency to cure everything. It does mean that affirmation of unexplained illness must partially be sought *in a careful approach*, more than in an immediate queer and crip subversion of a complex and intertwined system of knowledge, belief, and practice. Being attentive to nervous routes provides a *practical* path that could eventually create more space to practice care for patients with unexplained illnesses.

The two main concepts of this dissertation, accountability, and affirmation, must therefore be understood not as routes but as positions from which unexplained illness is understood. The four routes that are described, “the case,” “classification,” “impasse,” and “transference,” are located in between these positions. The last of these four, “transference,” I describe as a dual track: two interpretations of a similar concept, one negatively voiced in terms of contagion, one positively voiced in terms of relationality.

In this scheme, relationality is not described as a route but as a possible reinterpretation of the nervous route of transference that works towards affirmation. What remains to be seen is whether this affirmation can or even needs to take the shape of the flowchart shown at the beginning of this conclusion. That is, whether ultimate biomedical explicability can provide relief.

Identifying four nervous routes, the case, classification, impasse, and transference, I have wanted to trace how unexplained illness takes shape. The historical formulations of unexplained illness that predominantly revolved around hysteria have informed the present understanding of unexplained illness. Tracing these routes results in a need to resituate unexplained illness, not in terms of dualisms or hierarchies, but in a present that affirms the existence of pain instead of only holding patients accountable for it. By focusing on the productive effects of knowledge – shaping bodyminds as it goes along – this dissertation has also shown that the acknowledgment of these effects is often sorely lacking in medical encounters; be it in medical texts, cultural representations, or in the doctor’s office. Unexplained illness is not only characterized by pain but also by the discursive gap in which this pain grows louder and yet is hidden. This pain must be acknowledged. Eventually, this might help to emancipate unexplained illness from nervous routes, to stop turning patients with unexplained illnesses into problems themselves, and to start caring.

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Illustrations:

Figure 1: Still from Panteha Abareshi (2019). *NOT BETTER YET.* Vimeo <https://vimeo.com/433272648> (3 July 2024).

Figure 2: Still from Panteha Abareshi (2019). *NOT BETTER YET.* Vimeo <https://vimeo.com/433272648> (3 July 2024).

Figure 3: Still from Panteha Abareshi (2019). *NOT BETTER YET.* Vimeo <https://vimeo.com/433272648> (3 July 2024).

Figure 4: @Meme_hoarder (n.d.) "Carl What Do You Call a Man with No Body and Nose? Dad…" Pinatafarm. Web. <https://www.pinatafarm.com/p/79e487b9-fa49-43da-9115-502c7e8bca87> (5 July 2024).

Figure 5: "Nobody Nose My Pain (I Have Fibromyalgia)" (n.d.) Makeameme.org. Web. <https://makeameme.org/meme/nobody-nose-my> (5 July 2024).

Figure 6: Wolfe et al. (1990). "Figure 3." "The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia. Report of the Multicenter Criteria Committee." *Arthritis and Rheumatism* 33.2: 160–72.

Figure 7: Jean-Baptiste Regnault (1793-1794). *Les Trois Grâces.* Paris: The Louvre. Oil on Canvas.

German Summary

In der medizinischen Praxis fasst der Begriff "medizinisch unerklärtes körperliches Symptom" sämtliche Beschwerden zusammen, für die keine strukturelle physiologische Ursache oder zugrundeliegende körperliche Krankheit im Zusammenhang mit dem Symptom identifiziert werden kann. Dieses Defizit, das zunächst auf der Seite des medizinischen Wissens auftritt, wird häufig auf die Patient*innen abgewälzt. Patient*innen, deren Erfahrungen nicht biomedizinisch legitimiert und anerkannt sind, bereitet es Mühe, über ihre Schmerzen zu berichten, und kämpfen darum, gehört zu werden. Diese Patient*innen verdienen eine eigene theoretische Rahmung. In dieser Dissertation wird diese Rahmung geschaffen durch die Identifizierung und Formulierung dessen, was ich als "*Nervous Routes"* bezeichnet habe: die Gedankengänge, entlang derer verschiedene Formulierungen unerklärlicher Krankheiten Gestalt annehmen und die körperlichen Empfindungen selbst formen.

Auf der Grundlage verschiedener "*close readings*" kultureller Objekte, die von medizinischen Texten und Illustrationen bis hin zu Fallbeschreibungen, Internet-Memes, literarischen Memoiren und (Dokumentar-)Filmen reichen, identifiziere ich vier verschiedene Wege, auf denen sowohl Wissen als auch affektive Erfahrung reisen, zusammenfließen und kollidieren und damit einen konfliktreichen konzeptionellen Raum entstehen lassen, in dem man sich auf den ungeklärten kranken Körper bezieht.

Ungeklärte Krankheiten sind durch Marginalisierung im medizinischen Diskurs und in der vorherrschenden Populärkultur gekennzeichnet. Wenn sie nicht biomedizinisch erklärt werden können, macht das Fehlen physischer Marker die Patient*innen anfällig für Erklärungen, die *Nervous Routes* folgen. Ich definiere diese *Nervous Routes* als erkenntnistheoretische Bewegungen, die vom Problem der Ungeklärtheit ausgehen, aber auf bereits ausgetretenen und durch kulturelle Stereotypen geprägten Pfaden weitergehen. *Nervous Routes* sind entlang kulturell dominanter Trennlinien wie Geschlecht, Gender, Rasse und Klasse strukturiert. Sie bergen die Gefahr, dass bereits weiter marginalisierte Gruppen an den Rand gedrängt werden. Das Kernproblem der Marginalisierung besteht darin, dass Menschen mit ungeklärten Krankheiten individuell für die Erfahrung einer ungeklärten Krankheit verantwortlich gemacht werden.

Jedes Kapitel folgt einer anderen *Nervous Route*, d.h. Fälle (Case), Klassifizierung (Classification), Sackgasse (Impasse) und Übertragung (Transference), mit der ich die Art und Weise nachzeichne, in der ungeklärte Krankheit konzeptualisiert wird. Indem ich die erste *Nervous Route* des Falls verfolge, betrachte ich die Konstruktion von Fällen als eine Bewegung vom Einzelfall zum verallgemeinerten Wissen. Die zweite *Nervous Route* zeichnet die Ablage und Klassifizierung von medizinischem/psychiatrischem Wissen nach. Die dritte *Nervous Route* zeichnet die Versuche der Integration von Geist und Körper nach. Schließlich verfolge ich die Krankheitsübertragung oder die Idee, dass Krankheit auf eine ansteckende Idee zurückgeführt werden kann. Alle diese *Nervous Routes* erweisen sich als kompliziert, weil es keine physischen Marker für Krankheiten gibt, wie es bei verschiedenen Symptomen und Zuständen der Fall ist, die als unerklärlich gelten oder als solche erlebt werden.

Ungeklärte Krankheiten haben viele Namen erhalten, die je nach disziplinärem Kontext und emanzipatorischem Potenzial für die betroffenen Patient*innen variieren. In der angelsächsischen medizinischen Fachliteratur wird dafür häufig der Begriff "medizinisch unerklärliche (körperliche) Symptome" verwendet, der meist mit MUS oder MUPS abgekürzt wird, wodurch eine leicht erkennbare Figur geschaffen wird, mit der ein breites Spektrum von Erkrankungen in Verbindung gebracht werden kann. Noch im 20. Jahrhundert wurde häufig auf Hysterie als historischer Kontext für das, was heute als MUS oder MUPS verstanden wird, verwiesen. Eine andere medizinische Terminologie, die im Zusammenhang mit ungeklärten Krankheiten kursiert, ist der englische Begriff "functional disorder", der sich wörtlich auf eine Funktionsstörung bezieht, aber sowohl bei Patient*innen als auch bei Ärzt*innen eine negative Konnotation erhalten hat.

Der Begriff "psychosomatisch" setzte sich um die Mitte des 20. Jahrhunderts durch, ursprünglich um den Geist-Körper-Dualismus[137] in einem psychoanalytisch orientierten Umfeld zu überwinden. Gegenwärtig wird er vor allem von Patient*innen als pejorativer Begriff wahrgenommen. In dem Versuch, eine neutrale Beschreibung zu formulieren, oder genauer gesagt, sich in Richtung einer politischen Emanzipation dessen

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[137] Obwohl der geläufigere Ausdruck "Körper-Geist-Dualismus" lautet, habe ich diese Spaltung stattdessen als Geist-Körper-Dualismus bezeichnet, um die ungleich verteilte Hierarchie zwischen den beiden hervorzuheben, bei der der Geist den Körper auf negative Weise beeinflusst.

zu bewegen, dem medizinische Glaubwürdigkeit vorenthalten wird, werden die englischen Begriffe "contested illness", "hidden illness" oder "invisible illness" verwendet. Der letztgenannte Begriff wird von den Patient*innen selbst oder von Aktivist*innen verwendet, die die Stigmatisierung überwinden wollen, die mit der Unerklärlichkeit verbunden ist.

Meine Entscheidung, in dieser Dissertation den Begriff "unerklärte Krankheit" beizubehalten, um speziell auf den unerklärten Charakter von Krankheiten hinzuweisen, beruht auf meinem Beharren auf dem Diskurs, in dem diese Krankheiten entstehen. Ich beziehe mich ausdrücklich auf *unerklärte Krankheit*, weil ich mich auf das Problem des ungeklärten Charakters bestimmter körperlicher Symptome konzentriere. Im gegenwärtigen medizinischen Diskurs ist das Fehlen organischer Marker oder Erklärungen für das Erleben der Symptome von zentraler Bedeutung für das Problem der unerklärten Krankheit, wie es von den Patient*innen erlebt wird. Daher birgt die Hervorhebung des unerklärten Charakters dieser Krankheiten das Potenzial, diese Belastung innerhalb der medizinischen Wissenschaft selbst neu zu verorten.

Eine solche vorgeschlagene Neusituierung steht im Einklang mit dem allgemeinen Ansatz, den ich in dieser Dissertation vorschlage. Unerklärte Krankheit von der Verantwortlichkeit (accountability) hin zur Affirmation zu verfolgen, bedeutet, dass ich darauf abziele, unerklärte Krankheit von der Schuld innerhalb einer Struktur zu emanzipieren, die sich auf die individuelle Verantwortlichkeit konzentriert, und darüber nachzudenken, was eine Affirmation ungeklärter Krankheiten im Sinne einer kollektiven Fürsorge und Verantwortung bedeuten kann. Die beiden Hauptkonzepte dieser Dissertation sind also nicht als Wege zu verstehen, sondern als *Positionen*, von denen aus unerklärte Krankheit verstanden wird. Meine Identifizierung und das Aufspüren der vier Nervous Routes geschieht letztlich mit dem Ziel, unerklärte Krankheit von eben diesen Nervous Routes zu emanzipieren und einen Weg zu finden, wie eine Affirmation von unerklärter Krankheit möglich werden kann. Eine solche Affirmation würde die Tatsache anerkennen, dass diese Menschen wirklich krank sind, ohne auf Erklärungen zurückgreifen zu müssen, die den Patient*innen selbst die Schuld zuschieben, und stattdessen nach einer Form der Pflege suchen.

An dieser Stelle muss auch gesagt werden, dass ich bewusst keine spezifischen Krankheiten untersuche oder bestimmte Zustände als ungeklärt einstufen möchte. Ich habe keine Behauptungen über die Verursachung der von mir besprochenen spezifischen Erkrankungen und Syndrome aufgestellt. Wenn ich bestimmte Krankheiten anspreche, so tue ich dies, um den Kontext aufzuzeigen, in dem sie als unerklärt diskutiert wurden. Ich stelle also zur Diskussion, wie die Ungewissheit über den biomedizinischen Status bestimmter Erkrankungen oder Beschwerden zu negativen Rahmenbedingungen und zur Stigmatisierung von Patient*innen auf der Grundlage einer schlecht verstandenen biomedizinischen Ätiologie geführt hat.

Zu diesem Ziel gehört, dass ich nicht zur Konstruktion einer neuen Figur im Sinne der Konstruktion eines Namens beitrage, der als Identität beansprucht werden kann. Auch wenn eine solche Figur potenziell eine emanzipatorische Funktion haben könnte, liegt mein Ziel an anderer Stelle, nämlich in der Beschreibung der Folgen des Krankseins von Menschen ohne biomedizinische Erklärung. Ich klammere also das ein, was man als "die Symptome selbst" bezeichnen kann, und versuche zu vermeiden, dem, was sich als "unerklärt" herausstellt, einen Namen zu geben. Das bedeutet, dass ich mich darauf konzentriere, die Figuren, die bereits existieren, genau zu beschreiben, und zwar in verschiedenen *close readings* von (Dokumentar-)Filmen, Krankheitserinnerungen, Internet-Memes und medizinischen Texten. Ich betrachte diese kulturellen Objekte als Akteure in der Konstruktion ungeklärter Krankheit. Das *close reading* dieser Objekte ermöglicht es mir, nachzuvollziehen, wie ungeklärte Krankheiten Gestalt annehmen. Mit Gestaltwerdung meine ich den kulturellen diskursiven Prozess, durch den ungeklärte Krankheiten in verschiedenen Kontexten verständlich werden und verstanden werden.

Dennoch sind die Bedingungen, die in den Vordergrund treten, wenn es um ungeklärte Krankheiten geht, oft dieselben und betreffen ME/CFS, Fibromyalgie, chronische Borreliose oder die erst kürzlich aufgetretene postinfektiöse Erkrankung, die als Long Covid bezeichnet wird. Noch umstrittener in der Medizin sind Morgellons, Multiple Chemikalien-Sensitivität oder multiple Chemikalienunverträglichkeit (abgekürzt MCS von englisch Multiple Chemical Sensitivity) oder das Golfkriegssyndrom. Mit Ausnahme der beiden letztgenannten sind alle diese

Erkrankungen häufiger bei Frauen anzutreffen.[138] Neben den geschlechtsspezifischen Unterschieden in der Prävalenz weist auch die Tatsache, dass die Bezeichnung "Hysterie" in der psychiatrischen Literatur noch bis ins 20. Jahrhundert hinein als Bezugspunkt für verschiedene ungeklärte Zustände verwendet wurde, darauf hin, dass sich das Problem der ungeklärten Krankheit in einem geschlechtsspezifischen Rahmen darstellt, auch in kultureller Hinsicht.

Diese Dissertation stellt das Geschlechterproblem ungeklärter Krankheiten in den Vordergrund, indem sie auf die Feminisierung dieser Erkrankungen hinweist. Diese Krankheiten und die Menschen, die an ihnen leiden, haben ein geringeres Maß an Glaubwürdigkeit erlangt, das durch das Fehlen schlüssiger, objektivierbarer Beweise getrübt wird. Mit der Feminisierung weise ich auf einen kulturellen Rahmen hin, der diese Patient*innen als verletzliche, "undichte" (*leaky*), nicht geschlossene Subjekte zu sehen beginnt: zu offen oder anfällig für soziale Einflüsse – ein "schwacher Geist" in einem "schwachen Körper". Die Feminisierung kann auch als eine konkrete historische Form der Delegitimierung gesehen werden, die eng mit den historischen Formulierungen der Hysterie verbunden ist, vor allem im 19. Jahrhundert. Die Feminisierung ungeklärter Krankheiten bezieht sich nicht nur auf Frauen, sondern zeigt sich auch in der Charakterisierung von (historischen) Fällen ungeklärter Krankheiten bei Männern, die als verletzlich, schwach oder zu sehr von traumatischen Erfahrungen wie dem Krieg betroffen angesehen wurden.

Ich beschreibe die Feminisierung ungeklärter Krankheiten als Teil eines Clusters, das auch Prozesse der Psychologisierung und Delegitimierung der Patient*innen und ihres Zustands umfasst. Ohne biomedizinische Beweise verlagern sich die Erklärungen oft in den psychischen Bereich, nach dem Motto, wenn die Krankheit nicht im Körper existiert, muss sie "im Kopf" sein. Mit Delegitimierung bezeichne ich den Prozess, in dem die Symptome einen weniger "realen" Status erhalten, da sie als in der unscharf definierten Domäne "des Geistes" entstehend begriffen werden. Ungeklärte Krankheit führt zu einem Spannungsfeld zwischen zwei Formen von Legitimität, die beide wichtige Pfeiler der medizinischen Wissenschaft sind. Die erste Form ist die Legitimität des Patienten, etymologisch verbunden mit demjenigen, der leidet oder sich

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[138] Siehe Anmerkung 24 in der Einleitung zu dieser Dissertation.

unterzieht. Diese Patientin ist das Subjekt, das eine Erfahrung macht, die insofern legitim ist, als sie die Grundlage für die Validierung bildet. Die zweite Form der Legitimität bezieht sich auf die ist die Legitimität der Erfahrungen, insofern als sie auf ein Objekt der medizinischen Wissenschaft reduzierbar sind. Dies betrifft Schmerzen oder Beschwerden (Symptome), die durch biomedizinische Marker ("das Reale") verifiziert werden können. Bei ungeklärter Krankheit bedeutet das Defizit an Legitimität des zweiten Typs, dass der erste Typ beschädigt ist. In der Praxis bedeutet das Fehlen von Biomarkern, dass die Legitimität der Patient*innen beeinträchtigt wird.

Diese drei Hauptkonzepte – Psychologisierung, Delegitimierung und Feminisierung – erweisen sich als zentral für das in dieser Dissertation beschriebene Problem der ungeklärten Krankheit und tragen letztendlich zur Marginalisierung ungeklärter Krankheiten bei. In meinen verschiedenen Analysen tauchten Delegitimierung, Feminisierung und Psychologisierung ungeklärter Krankheiten als ein Cluster auf. Dieses Bündel ausgrenzender Strukturen wird durch eine konzeptionelle Trennung von Geist und Körper untermauert. Im Fall von ungeklärten Krankheiten trägt der Geist-Körper-Dualismus weiterhin zu Vorstellungen von Schuld bei, die den einzelnen Patient*innen für die *Entstehung* seiner Symptome verantwortlich machen. Als Antwort darauf verwende ich in dieser Dissertation den materialistisch-feministischen Begriff *Bodymind*, um zu verdeutlichen, dass ich von der Untrennbarkeit dessen, was oft als zwei Entitäten getrennt wurde, abweiche. Als Begriff zielt *Bodymind* darauf ab, dem dualistischen Rahmen von Körper und Geist zu entkommen.

Ich habe also vier Wege beschrieben, auf denen unerklärte Krankheiten verstanden werden, die dazu führen, dass ein Cluster negative Folgen für Menschen mit unerklärte Krankheiten hat. Ich beschreibe diese *Nervous Routes* im Rahmen von zwei Positionen, die im Sinne von Verantwortlichkeit (*Accountability*) oder Affirmation formuliert sind. Ich behaupte, dass diese *Nervous Routes* von einer Position gegenüber ungeklärter Krankheit abweichen und zu einer Position führen, die Patient*innen zur Verantwortung zieht, und schlage schließlich vor, die Position in Richtung Affirmation zu ändern, d. h. in Richtung eines relationalen Denkens, das die Notwendigkeit der Anerkennung von Krankheit und die Notwendigkeit von Pflege betont.

Ausgehend von einer Definition der Form der Verantwortlichkeit, die häufig mit ungeklärten Krankheiten in Verbindung gebracht wird, befasst sich das erste Einführungskapitel mit dem Titel "Accountability" mit der Frage, wie Menschen mit ungeklärten Krankheiten oft so gesehen werden, als hätten sie ihre Krankheit selbst verursacht. Hier führe ich zunächst das Konzept des *Nervous Routes* als eine Methode ein, die es mir ermöglicht, die verschiedenen Formen der Verantwortlichkeit in der Gegenwart nachzuzeichnen. Ich eröffne das Kapitel mit einer Lesung von Todd Haynes' *Safe* (1995), die zeigt, dass der ungeklärte Charakter ungeklärter Krankheiten nicht bedeutet, dass es keine Erklärungen gibt. Anhand der verschiedenen Erklärungsansätze, die der Hauptprotagonistin von ihrer Umgebung – ihrem Mann oder ihrem Arzt – angeboten werden, die an der Realität ihrer Krankheit zweifeln und andeuten, dass es sich um eine Form der Hysterie handelt, zeige ich, dass eine ungeklärte Krankheit einen bereits vorgezeichneten Weg darstellt und nicht ein unbestimmter Zustand ist. Carol, die Hauptprotagonistin des Films, wird dazu gebracht, für ihre Krankheit zu sprechen, sie wird für ihre Erfahrung verantwortlich gemacht, obwohl sie diese Erfahrung nicht selbst gemacht hat.

Von hier aus gehe ich dazu über, den theoretischen Rahmen dieser Dissertation in Bezug auf die materialistische feministische und *Crip Theory* und die Theorien zur Subjektbildung im Gefolge von Foucualt zu definieren, die die diskursiven Bedingungen aufgedeckt haben, unter denen das Subjekt und die Beziehung des Subjekts zu seinen physischen Bedingungen zustande kommt. Judith Butlers Theorien zu Geschlecht haben auf das Verständnis von Materialität als Effekt von Macht hingewiesen: Geschlecht ist immer schon diskursiv definiert. Normative Vorstellungen von Geschlecht bilden einen begrenzten und ausgrenzenden Rahmen, in dem der Körper gelebt und verstanden wird. In Anlehnung an Butlers Theorien über Geschlecht argumentiere ich, dass der ungeklärte kranke Körper nicht nur mit einem normativen Rahmen in Konflikt steht. Das heißt, Menschen mit ungeklärten Krankheiten werden nicht nur aufgrund ihrer Nichtübereinstimmung mit normativen Standards für gesunde Körper ausgeschlossen, in diesem Fall das Vorhandensein eines identifizierbaren Biomarkers, der eindeutig auf eine Krankheit hindeutet, sondern sie werden auch aus epistemologischen Gründen ausgeschlossen. Ihre Krankheit passt nicht in ein biomedizinisches Erklärungssystem. Ein wesentlicher Teil des Problems im Zusammenhang mit ungeklärten Krankheiten besteht darin, dass dieses Versagen eines Wissenssystems dann soziokulturell als Versagen der Patient*innen ausgelegt wird. Im Gegensatz dazu vertrete ich die Auffassung, dass ungeklärte Krankheiten das unvermeidliche Scheitern der (vollständigen) Erklärbarkeit aufzeigen müssen.

In meinem theoretischen Verständnis entsteht der Körper in einem diskursiven Prozess. Diesem Ansatz folgend, konzentriert sich meine Analyse auf die Formen, durch die körperliche Symptome wahrnehmbar werden. Dabei beziehe ich mich auf die *Form im Sinne von* Eugenie Brinkemas Arbeit über den Affekt (2014), die argumentiert, dass der einzige Zugang zum Affekt immer über die Form erfolgt, die er hinterlässt. Ungeklärte Krankheit zeigt sich als problematische Körperempfindung, die mit der diskursiven Praxis kollidiert. Um die problematische Existenz des Ungeklärten zu thematisieren, frage ich, welche Formen das medizinische und kulturelle Verständnis von ungeklärter Krankheit in der Gegenwart angenommen hat. Ich analysiere diese Formen in meinem close reading von kulturellen Objekten und spüre diesen kulturellen Objekten als Teil verschiedener Nervous Routes nach und diskutiere sie.

Ein hartnäckiger und letztlich sehr komplizierter Gedanke im Zusammenhang mit ungeklärten Krankheiten betrifft der Begriff des eigenständigen in sich geschlossenen Subjekts. Ohne einen identifizierbaren Biomarker werden die Symptome ungeklärter Krankheiten oft als weniger "real" angesehen als Symptome, die zu erklärbaren Krankheiten wie einem Beinbruch oder Krebs gehören. In dieser Dissertation argumentiere ich in verschiedenen Kontexten und anhand von unterschiedlichen Fällen, dass die Art und Weise, in der ungeklärte Krankheiten konzeptualisiert werden, stark von einer aufrechterhaltenen Differenz zwischen einem Selbst und einem vermeintlichen Anderen abhängt. Es macht einen wesentlichen Unterschied, ob Krankheit und das damit verbundene Leiden durch eine Kraft außerhalb des Selbst hervorgerufen werden oder ob sie von einer "Kraft aus dem Inneren" herrühren. Wenn sie mit etwas zusammenhängen, das aus dem Selbstgefühl herausgelöst werden kann, wie z. B. ein äußeres Ereignis wie ein Sturz, der zu einem Knochenbruch führt, oder Bakterien, die zu einer Infektion führen, ist es einfacher, dieses Selbst intakt zu halten. Wenn weniger klar ist, worauf die Krankheit zurückzuführen ist, wird das Feld schlüpfriger, und es besteht die Gefahr, dass die Grenzen zwischen dem Selbst und dem Anderen aufgehoben werden oder das Selbst sogar als eine destruktive oder konfliktbeladene Entität betrachtet wird, und als im Stande, sich selbst krank zu machen.

Wenn ungeklärte Krankheit in diesem Sinne als innerer Konflikt betrachtet wird, so führt das dazu, dass diese Menschen sich selbst die Schuld für die Krankheit geben und daher als weniger pflegebedürftig angesehen werden. Dieses Spannungsverhältnis zwischen ungeklärter Krankheit und dem Gefühl eines eingeschränkten Selbst, das nicht aufrechterhalten werden kann, wird schließlich in Kapitel fünf erörtert, wo ich argumentiere, dass ein Denken mit Relationalität diesen Konflikt überwinden kann und somit auf eine Affirmation ungeklärter Krankheit hinarbeitet, die die Krankheit innerhalb eines gemeinsamen sozialen Kontextes anerkennt.

Im zweiten Kapitel, "Case", wird die Methodik der *Nervous Routes* weiter ausgeführt, indem die Beziehung zwischen dem Einzelfall und dem verallgemeinerten Wissen hervorgehoben wird. Ich erörtere das Thema des Falles, indem ich mich auf eine anonyme Patientin konzentriere, die zu einem Testfall gemacht wurde und deren Erfahrungen exemplarisch für eine Somatisierungsstörung wurden. In meiner Lesung dieses Falles lasse ich absichtlich die Grenzen zwischen der Konstruktion eines medizinischen Falles und der Konstruktion einer Erzählung verschwimmen, um zu zeigen, dass die Patientin mit ungeklärter Krankheit in diesem Prozess vereinnahmt wird und nur als Konstruktion erscheint. Mit Hilfe von Giorgio Agambens Arbeit über Analogie (2009) und Lauren Berlants Schrift über den Fall (2007) argumentiere ich, dass der medizinische Fall als eine normative Maschinerie gesehen werden kann, die eine verallgemeinerte soziale Einheit produziert.

Diese Konstruktion ist häufig von geschlechtsspezifischen Strukturen innerhalb einer historisch patriarchalischen Form der Medizin abhängig. Ich beschreibe die Überschneidung des *medical gaze* mit dem *male gaze*, um zu argumentieren, dass sich das weibliche Subjekt in einer besonders verletzlichen Position befindet, da es an einem männlichen Modell gemessen wird. Die hohe Prävalenz ungeklärter Krankheiten bei Frauen lässt sich leicht mit der marginalisierten Position in Verbindung bringen, die Frauen in der Vergangenheit in Bezug auf eine patriarchalische Form der medizinischen Wissenschaft innehatten, wie dies von populärwissenschaftlichen Autoren wie Meghan O'Rourke (2022), Maya Dusenbery (2018) und Elinor Cleghorn (2021) dargestellt wurde.

Gleichzeitig bleibe ich jedoch vorsichtig, ungeklärte Krankheiten nicht als eine Auswirkung des Patriarchats zu definieren. Erstens würde dies ungeklärte Krankheiten gleichermaßen mit Vorstellungen von Weiblichkeit verknüpfen, wie es in problematischen Darstellungen geschieht, die letztlich eine stigmatisierende Wirkung auf die Patient*innen haben. Zweitens behaupte und argumentiere ich in dieser Dissertation, dass die gelebte Erfahrung ungeklärter Krankheiten viel komplexer ist und eine gründliche intersektionale und interdisziplinäre Analyse erfordert, bei der das Geschlecht zwar eine wichtige Rolle spielt, aber nur einen begrenzten Rahmen darstellt.

Die in diesem Kapitel besprochenen medizinischen Fälle werden von Männern konstruiert und konstruieren spezifische Arten von Weiblichkeit, die als Modell für ungeklärte Krankheiten dienen. Nach dem *close reading* des Testfalls, mit dem das Kapitel eingeleitet wurde, und meiner anschließenden, eher theoretischen Erkundung des Geschlechts in Bezug auf ungeklärte Krankheiten, erörtere ich die Vielzahl der Fälle anhand einer einzigen historischen Patientin. Diese Frau hat viele Namen erhalten, wurde aber vor allem als "Blanche Wittman" bekannt, eine Starhysterikerin unter Jean-Martin Charcot (1825–1893) an der Salpêtrière in Paris. Ich zeige, dass diese Frau fast ausschließlich als Konstruktion erscheint, und zwar als eine, die so verworren ist, dass es heute völlig unklar ist, wo sie zu suchen ist. Dennoch wurde diese Konstruktion exemplarisch für die Hysterie, die noch heute das Verständnis von ungeklärter Krankheit prägt.

Die medizinische Wissenschaft ist auf fallbasiertes Wissen ausgerichtet und funktioniert daher nach der Logik der Analogie. Indem sie eine lange Kette von analogen Fällen aufbaut, macht die medizinische Diagnostik aus einer individuellen Erfahrung einen *Fall von etwas*. Gibt es keine fallbasierten biomedizinischen Indikatoren, wird ein Einzelfall zu einem Fall von Unerklärlichkeit. Fallbasiertes Wissen kann insofern als Weg betrachtet werden, als es den Weg ebnet, auf dem Krankheit verstanden wird: Medizinisches Wissen wird von Fall zu Fall aufgebaut. Die Interpretation von ungeklärten Krankheitsfällen führt oft zu einer Figur, in der sich die Patient*innen ("Blanche") nicht wiedererkennen. Bei der Nervous Route *des Falles* (Case) wird den Patient*innen Wissen entnommen und führt dieses Wissen nicht zu Pflege. Stattdessen werden die Patient*innen entlassen und eine Figur des Ungeklärten geschaffen, die den Patient*innen die Handlungsfähigkeit nimmt, ihre Körpererfahrung delegitimiert und sie unbeachtet lässt.

Im Anschluss an den Fall konzentriert sich dieses Kapitel auf die Pflege. Das bedeutet, dass ich die Möglichkeit auslote, über Fälle von ungeklärter Krankheit auf eine Weise zu schreiben, die sich die persönliche Erfahrung nicht zu eigen macht. Ich bin stets bestrebt, einen delegitimierenden Schritt zu vermeiden, indem ich selbst einen medizinischen Fall von Ungeklärtheit konstruiere. Ich suche daher nach einer sorgfältigen Methodik, die ich im Nachzeichnen von *Nervous Routes* verorte, anstatt eine neue Version dessen zu schreiben, was unerklärte Krankheit ist, sein kann oder bedeuten muss. In diesem Sinne ist dieses zweite Kapitel auch als eine weitere Reflexion über die Methodik und eine Erkundung dessen zu lesen, was das Schreiben über ungeklärte Krankheiten sein kann und was es ungewollt in Bezug auf die Subjektbildung bewirkt. Ich schließe das Kapitel, indem ich nach einer sorgfältigen Methodologie suche: nach einer anhaltenden Aufmerksamkeit für die Strukturen, durch die das Thema der ungeklärten Krankheit erscheint.

Das dritte Kapitel mit dem Titel "Classification" befasst sich nicht mit dem Thema der ungeklärten Krankheit, sondern mit der Bewegung der Klassifikation. Der Hauptteil dieses Kapitels zeichnet die diagnostische Geschichte der körperlichen Symptome in der Psychiatrie von den ersten Ausgaben des DSM bis zur Gegenwart nach. Das Kapitel beginnt mit einem *close reading* der Suche eines Patienten nach einer Diagnose in Netflix' *Diagnosis* (2019). Ich analysiere den Widerstand der Patientin gegen eine Diagnose, die sie aufgrund fehlender biomedizinischer Beweise als stigmatisierend empfindet. Dies zeigt, wie eine Diagnose den Patient*innen einen (heiß ersehnten) Rahmen für ihre Krankheit bietet. Die Diagnose von Krankheiten, die als ungeklärt gelten, kann jedoch stattdessen zu einer Stigmatisierung führen. In meinem *close reading* der klassifikatorischen Formulierungen körperlicher Symptome vom DSM-I (1952) bis zum aktuellen DSM-5 (2013) diskutiere ich die Trennung von Geist und Körper in Bezug auf die psychiatrische Klassifikation. Mein *close reading* führt zu der Schlussfolgerung, dass jede Überarbeitung des psychiatrischen Diagnosehandbuchs seit der revolutionären dritten Auflage mit dem Dualismus, den es dennoch beibehält, nicht zurechtkommt. Ich diskutiere die Trennung von Geist und Körper in Bezug auf die psychiatrische Klassifikation, indem ich die klassifikatorischen Formulierungen von körperlichen

Symptomen vom DSM-I (1952) bis zum aktuellen DSM-5 (2013) *close read*. Meine *close reading* führt zu der Schlussfolgerung, dass jede Überarbeitung des psychiatrischen Diagnosehandbuchs seit der revolutionären dritten Auflage mit diesem Dualismus kämpft, ihn aber trotzdem beibehält.

Ich erörtere hier die praktische Notwendigkeit einer Klassifizierung und die gleichzeitige theoretische Unmöglichkeit, etwas diskursiv so schwer fassbares wie Krankheit und Erfahrung festzulegen. Ich zeige dieses Problem auf, indem ich die Klassifizierung als eine Form des *Mappings* betrachte. Mit Hilfe eines gemeinsam von Valérie November, Eduardo Camacho-Hübner und Bruno Latour (2010) verfassten Artikels kommentiere ich den Unterschied zwischen der Karte als Navigationsinstrument und der Karte als mimetische Darstellung der Realität. Aufbauend auf ihrer Argumentation zeige ich, wie das praktische Bedürfnis nach psychiatrischer Klassifikation – eine Art Navigation – die Gefahr birgt, zu einem mimetischen Gebrauch zu führen. Ein mimetischer Gebrauch der Klassifikation nimmt die Klassifikation in ontologischen Begriffen wahr. Daraus ergibt sich für die Patient*innen das Problem, dass sie mit den mimetischen Implikationen der Beschreibung ihrer Krankheit feststecken, während sie die Möglichkeit verloren haben, in einem nun besetzten Terrain zu navigieren. Die auf dem DSM basierenden Klassifikationen haben ungeklärte Krankheiten in der Psychiatrie etikettiert und wesentlich zu der populären Vorstellung beigetragen, dass ungeklärte Krankheiten "nur im Kopf" existieren.

Neben einem theoretischen Überblick über den Akt der Klassifikation erörtere ich die diagnostische Geschichte der körperlichen Symptome in der Psychiatrie und vertrete die Auffassung, dass sie sich in zwei Richtungen aufgespalten hat: einen kraepelianischen bzw. einen freudianischen Kurs, der entweder zu einer zeitgenössischen (neo-)kraepelianischen, auf Klassifikation basierenden Psychiatrie geführt hat, die mit dem Geist-Körper-Dualismus kämpft, oder zu einer hartnäckigen (freudianischen) Vorstellung, dass körperliche Symptome ihren Ursprung im Geist haben. Die (neo-)kraepelianische Auffassung geht davon aus, dass die Klassifizierung psychischer Symptome möglich und sinnvoll ist. Der Freud'sche Weg meidet die Klassifizierung völlig und lehnt sogar ihre Navigationsfunktion ab. Der Kraepelin'sche Weg war besonders nervös, weil er die Freud'schen Konnotationen, die unerklärliche körperliche Symptome mit unbewussten Strukturen in Verbindung bringen, zwar vermeiden, aber niemals loswerden konnte. Beide Richtungen kämpfen mit Formen des Geist-Körper-Dualismus, dessen ungleich verteilte Hierarchie Patient*innen stigmatisiert, bei denen ungeklärten Krankheiten diagnostiziert werden.

In diesem Kapitel wird der Vorgang der Klassifizierung als eine zirkuläre Bewegung theoretisiert, bei der immer versucht wird, das festzulegen, was sich gleichzeitig entzieht. Es zeichnet die diagnostische Geschichte der körperlichen Symptome in der Psychiatrie nach und entlarvt die Klassifizierung als eine ausgrenzende Form von Wissen/Macht, die sowohl negative als auch positive Folgen für die Patient*innen hat, aber unweigerlich zur Benachteiligung von Menschen mit ungeklärten Krankheiten tendiert. Die Klassifizierung eröffnet insofern einen Weg, als sie bestimmt, wie Fällen ungeklärter Krankheiten begegnet wird. Eine medizinische Klassifikation setzt das Wissen, das aus der Analyse eines Falles gewonnen wird, in eine standardisierte Praxis um. Wenn die Symptome nicht durch eine bekannte körperliche Pathologie erklärt werden können, besteht der vorherrschende medizinische Weg darin, sich dem "mentalen" Bereich zuzuwenden und körperliche Symptome innerhalb der Psychiatrie zu klassifizieren und zu diagnostizieren. Die Nervous Route *der Klassifizierung* (Classification) mentalisiert Symptome, die als körperlich erlebt werden, auch wenn es selbst nervös ist, diese Unterscheidung beizubehalten. Dadurch läuft diese *Nervous Route* jedoch Gefahr, die Körperlichkeit dieser Symptome zu vernachlässigen und trägt zur Delegitimierung ungeklärter Krankheiten bei.

Das vierte Kapitel mit dem Titel "Impasse" baut auf der Konzeptualisierung der Körperlichkeit unerklärlicher Symptome auf, indem es Probleme im Zusammenhang mit dem Geist-Körper-Dualismus und seiner vermeintlichen Alternative, dem psychosomatischen Konzept, erörtert. Die Psychosomatik hat ihre Ursprünge in der Psychoanalyse. Ich eröffne dieses Kapitel mit einer Diskussion des ersten Falles des *Psychosomatic Case Book* (1954), dessen Wurzeln auf die psychoanalytische Theorie zurückgehen. In einer für die Psychosomatik spezifischen Weise integrieren die Autoren des Fallbuchs eine bestimmte Interpretation der unbewussten Wünsche und Sehnsüchte des Patienten (nach Liebe und Anerkennung) mit einer Darstellung der physiologischen Krankheitsmerkmale. Der Fall stellt diese Faktoren lediglich nebeneinander, während er das eigentliche Problem ausklammert und einen "komplexen Fall" präsentiert, der für persönliche Interpretationen offen ist. Von diesem Fall bewege ich mich zu einer Klage, die Patient*innen einreichten, die sich von der Netflix-Serie *Afflicted* (2018) falsch dargestellt fühlten. Damit will ich nachzeichnen, wie der psychosomatische Begriff in der Gegenwart überwiegend negativ verwendet und von diesen Patienten als pejorativ wahrgenommen wurde. Die Komplexität, die der Begriff vermitteln sollte, erwies sich als Sackgasse und wurde auf negative Weise auf die Patient*innen abgewälzt.

Ich schließe dieses Kapitel, indem ich Sara Ahmeds Konzept der *stickyness* aufgreife, das sie in *The Cultural Politics of Emotion* (2004) entwickelt hat. *Stickyness*, oder Klebrigkeit, beschreibt eine negative Übertragung von Konzepten auf Dinge oder Menschen. Das Denken von Klebrigkeit beschreibt also Orte des Kontakts. Die Negativität klebriger Dinge (in der Regel schleimiger Dinge) bezieht sich auf ihre Unverortbarkeit. Anstatt mehr Verständnis zu schaffen, wurde "psychosomatisch" zu einem klebrigen Begriff, der diese Patient*innen selbst "klebrig" machte. Dieses Klebrig-Werden lässt sich letztlich auf die psychosomatische Integration von zwei zuvor getrennten Entitäten, "Körper" und "Geist", zurückführen.

Nachdem ich mich hauptsächlich auf *d*ie Sackgasse konzentriert habe, die der Geist-Körper-Dualismus für Patienten mit ungeklärten Krankheiten gegenwärtig darstellt, zeichne ich den Geist-Körper-Dualismus als ein allgemeines Problem der Gegenwart. Um diesem Problem zu begegnen, beschäftige ich mich mit Versuchen, wie z. B. von Monica Greco (2019), die Widerstandsfähigkeit des Dualismus näher zu beleuchten, anstatt einfach zu versuchen, ihn ganz abzuschaffen. Es ist offensichtlich, dass der Dualismus in der medizinischen Forschung, Theorie und Praxis einfach zu tief verwurzelt ist, als dass man sich seine radikale Auflösung vorstellen könnte. Obwohl der Geist-Körper-Dualismus in der Theorie immer wieder diskreditiert und verworfen wurde, zeigt die gegenwärtige Situation von Patient*innen mit ungeklärten Krankheiten, dass er in der Organisation der medizinischen Versorgung und ihrer Praxis sehr lebendig ist.

Anstatt einen breiteren konzeptionellen Raum zu schaffen, in dem die Interaktion zwischen Geist und Körper verstanden und theoretisiert werden kann, hat die psychosomatische Medizin zu einem besonders negativen und engen Rahmen geführt, innerhalb dessen ungeklärte Krankheiten verstanden werden, wie meine Erörterung der Genealogie des Feldes der psychosomatischen Forschung oder meine Erörterung der Klage von Patient*innen gegen die Darstellung ihrer Krankheiten als psychosomatisch durch Netflix zeigt. Für ein besseres Verständnis von ungeklärten Krankheiten ist zumindest eine klare Formulierung des Problems erforderlich. Ich lokalisiere Aspekte dieses Problems in der Organisation der Medizin entlang eines hartnäckigen Geist-Körper-Dualismus und im gegenwärtigen Zustand der Psychosomatik als einer Sackgasse.

Die psychosomatische Medizin hat sich vorgenommen, die Medizin zu revolutionieren, indem sie die zuvor getrennten Konzepte von Geist und Körper integriert. Trotz dieser Absichten kann der gegenwärtige Stand dieser Integration besser als ein Durcheinander beschrieben werden, das im dualistischen Denken stecken bleibt und ein weiteres Verständnis ungeklärter Krankheiten behindert. Die psychosomatische Medizin bietet einen submedizinischen Weg für ungeklärte Krankheiten, der nicht ganz Medizin und nicht ganz Psychiatrie ist. *Die* Nervous Route *der Sackgasse* (Impasse) ergibt sich aus dieser Grenzsituation und trägt folglich zur Charakterisierung von Patient*innen mit ungeklärten Krankheiten als Grenzsubjekte selbst bei.

Das fünfte Kapitel, "Transference", befasst sich mit einem anderen Aspekt des psychosomatischen Konzepts, nämlich mit der weit verbreiteten Vorstellung von psychosomatischer Ansteckung. Der erste Abschnitt dieses Kapitels befasst sich hauptsächlich mit der Verbreitung dieser Begriffe im Zusammenhang mit der Fibromyalgie. Diese Krankheit ist durch weit verbreitete Schmerzen gekennzeichnet. Sie wird vor allem bei Frauen diagnostiziert und ist stark stigmatisiert. Ich kommentiere einen Artikel der *New York Times* aus dem Jahr 2008, in dem suggeriert wird, dass Fibromyalgie "nicht real" ist, von der medizinischen Wissenschaft geschaffen wurde und von Patient*innen nachgeahmt wird. In diesem Zusammenhang diskutiere ich die Übertragung von Krankheit in Bezug auf benachbarte Konzepte wie Ansteckung (contagion), Nachahmung (imitation), *Meme* und Metapher. Im Diskurs über die Fibromyalgie wird Ansteckung als erklärender Begriff für einen Prozess verwendet, bei dem Ideen übertragen werden, von denen man annimmt, dass sie bei Menschen Krankheiten hervorrufen. Nachahmung wird in einer Weise verwendet, die die Krankheitserfahrung als weniger realitätsnah diskreditiert.

Der Begriff *Meme* bedarf einer näheren Erläuterung. Er wurde geprägt, um eine kulturelle Einheit zu beschreiben, die aufgegriffen und weitergegeben werden kann. Das

Aufkommen des *Meme* in Form des Internet-Memes hat auch das "Krankheits-Meme" hervorgebracht, das häufig von Patient*innen geteilt wird, die online nach Unterstützung und Anerkennung suchen. Ich analysiere ein solches Krankheitsmeme und zeige, dass diese Art von Meme mehr als andere stark von einem Kontext abhängt, der nicht allgemein geteilt wird. Ich schlage vor, dieses Meme als das zu betrachten, was ich einen *mimetic stall* (mimetische Box) genannt habe, ein Begriff, mit dem ich einen gegensätzlichen Effekt zu einer Ansteckung beschreibe: Das Meme verbreitet keine Krankheitsidee, sondern kommuniziert eine Bedeutung, die nur für eine kleine Gruppe von Menschen verständlich ist, die bereits krank sind.

Während Ansteckung, Nachahmung und Meme im Zusammenhang mit ungeklärten Krankheiten negativ verwendet werden, schließe ich das Kapitel mit der Lektüre zweier zeitgenössischer feministischer Memoiren von Alice Hattrick (2021) und Amy Berkowitz (2019), in denen ungeklärte Krankheiten im Sinne von Metaphern diskutiert werden. In diesen Memoiren wird die Metapher als positiver Begriff zur Beschreibung von Krankheit durch Patient*innen mit ungeklärte Krankheiten selbst verwendet. In Kapitel vier erörtere ich Susan Sontags bahnbrechendes Argument gegen das metaphorische Verständnis von Krankheit, das ihrer Meinung nach Krankheit negativ mit dem Charakter verknüpft und somit zu Schuldzuweisungen führt. Im fünften Kapitel lege ich bei der Lektüre dieser beiden Lebenserinnerungen mit ungeklärter Krankheit die Neutralität offen, die in den etymologischen Wurzeln der Metapher steckt, die auf das griechische Wort *meta* zurückgeht*,* das über oder quer bedeutet, und *pherein*, das tragen oder ertragen bedeutet. Etwas wird von einem zum anderen getragen. In Berkowitz' Fall von einer traumatischen Erfahrung auf ihren Körper; in Hattricks Fall von ihrer Mutter, von der sie sich nicht getrennt fühlt, auf sich selbst. Wenn man die Metapher in Begriffen der Relationalität denkt, können sowohl Berkowitz als auch Hattrick sie als einen positiven Begriff beanspruchen, der im Wesentlichen besagt, dass das Denken an ihre Krankheit in Begriffen der Metapher eine Bestätigung der Krankheit sein kann und nicht eine diffamierende Annäherung.

Der Begriff "psychosomatische Ansteckung" (*psychosomatic contagion*) wird oft in einer Weise verwendet, die Patient*innen mit ungeklärten Krankheiten als "schwache" Individuen darstellt und den angeblich irrealen oder imaginären Charakter ihrer Symptome unterstreicht. Der Begriff der psychosomatischen Ansteckung basiert auf einer normativen Vorstellung vom Individuum als rational und in sich geschlossen. Psychosomatische Ansteckung wird daher als abnormales Verhalten wahrgenommen. Folglich werden Ideen, die ansteckende Vorstellungen von Krankheit hervorrufen, als gefährlich angesehen. Auf die Spitze getrieben, könnte dies zu einem Rahmen führen, in dem die Formulierung eines Namens für bestimmte körperliche Erfahrungen gefährlich wird. In einem solchen Rahmen werden die Patient*innen davon abgehalten, gemeinsam über diese Erfahrungen zu sprechen. Wie ich zu Beginn des fünften Kapitels erörtere, sind Frederick Wolfes Bedauern über seine Beteiligung an der Formulierung der Diagnosekriterien für Fibromyalgie und die Vorsicht und Zurückhaltung, mit der sich Kritiker Patientenforen und Blogs genähert haben, Beispiele für diese wahrgenommene Gefahr.

Der Diskurs über psychosomatische Ansteckung ist auch geschlechtsspezifisch, was bedeutet, dass Frauen im Allgemeinen als anfälliger für soziale Einflüsse oder, in Bezug auf Krankheiten, für "Massenhysterie" angesehen werden. Indem ich mich in diesem Kapitel auf die Bewegung der Übertragung konzentriere, kann ich aufzeigen, wie der Begriff der psychosomatischen Ansteckung eine negative Interpretation der Relationalität beinhaltet. *Die* Nervous Route *der Übertragung* (Transference) ist die negative Interpretation der Relationalität, die als Ansteckung zum Ausdruck kommt. Indem ich Übertragung als Ansteckung und Übertragung als Relationalität erörtere, untersuche ich die positiven und negativen Interpretationen der Krankheitsübertragung. Das Denken in Relationalität bietet einen theoretischen Ausweg aus der Sackgasse des Geist-Körper-Dualismus. Es ermöglicht einen Rahmen, in dem der im materialistischen Feminismus und in der *Crip Theory* geprägte Begriff des *Bodyminds* als kollektiv geteilte Antwort auf diskursive Praktiken erscheinen und produktiv gemacht werden kann. Dieser materialistisch-feministische Begriff, so behaupte ich, umgeht die Einschränkungen, die der Dualismus mit sich bringt.

Abschliessend stelle ich in diesem Kapitel zwei historische Fälle von Patient*innen mit der Diagnose Hysterie vor, die in medizinischen Einrichtungen missbraucht wurden, wobei ich mich darauf konzentriere, wie die Krankheit und die Patient*innen, bei denen sie diagnostiziert wurde, uns nur als eine Konstruktion erscheinen. Diese Konstruktion folgt der ersten *Nervous Route*, wie ich sie identifiziere: eine Fallkonstruktion, die den Patient*innen Wissen entzieht und eine Figur der

Unerklärlichkeit schafft, die ihnen die Handlungsfähigkeit nimmt, ihre Körpererfahrung delegitimiert und sie unbeachtet lässt. Diese Delegitimierung wird durch die zweite *Nervous Route* erklärt: den der Klassifizierung, die, wie ich in Kapitel 3 darlege, in der Psychiatrie zum Tragen kommt, wenn sie Symptome, die als körperlich erlebt werden, als geistige Phänomene definiert. Diese aufrechterhaltene Trennung wird in Kapitel 4 weiter untersucht, das sich auf die *Nervous Route* der Sackgasse konzentriert. In diesem Zusammenhang diskutiere ich die Integration von Geist und Körper, die im Rahmen der psychosomatischen Anstrengungen angestrebt wurde. Hier argumentiere ich, dass diese Anstrengungen daran scheiterten, dass sie in einem dualistischen Rahmen stecken blieben und schließlich dazu beitrugen, dass Patient*innen mit ungeklärten Krankheiten selbst als grenzwertige (*liminal*) Subjekte charakterisiert wurden.

Diese Probleme und die sich daraus ergebenden Einschränkungen von Sprache und Ausdruck, die Teil dieser *Nervous Routes* sind, können teilweise umgangen werden, indem man der Beziehungsfähigkeit mehr Aufmerksamkeit schenkt. Dies geschieht in Kapitel Fünf durch die Identifizierung der *Nervous Route* der Übertragung. Indem ich auf die Relationalität als zentrales Konzept verweise, beschreibe ich die Existenz von *Bodyminds* als untrennbare Einheit sowie den Kontakt zwischen verschiedenen Körpergeistern innerhalb der diskursiven Realität. Mein Schritt in diesem Kapitel hin zu einer positiven Interpretation der Krankheitsübertragung arbeitet auf den übergreifenden Weg hin, der in dieser Dissertation vorgeschlagen wird. Es handelt sich um eine Bewegung weg von einem Modell der Verantwortlichkeit hin zu einem Modell der Affirmation. In einem solchen Modell der Affirmation wird die Notwendigkeit der Legitimierung ungeklärter Krankheit aufgehoben und durch eine Bestätigung der Notwendigkeit von Fürsorge und Unterstützung zwischen Beziehungswesen ersetzt.

Anhand von vier *Nervous Routes*, dem Fall (*Case*), der Klassifizierung (*Classification*), der Sackgasse (*Impasse*) und der Übertragung (*Transference*), zeichne ich nach, wie ungeklärte Krankheit Gestalt annimmt. Die Verfolgung dieser Wege führt zu der Notwendigkeit, ungeklärte Krankheit neu zu verorten, nicht im Sinne von Dualismen oder Hierarchien, sondern in einer Gegenwart, die die Existenz von Schmerz bejaht, anstatt nur die Patient*innen dafür verantwortlich zu machen. Aufgrund der komplizierten Existenz ungeklärter Krankheiten an den Grenzen des Diskurses ist jedoch jeder Versuch einer Resituierung notwendigerweise ein destruktiver Schritt, der den

Patient*innen, die innerhalb eines dualistischen Systems legitimiert werden wollen, keine unmittelbare Hilfe bietet. Die Gefahr besteht darin, dass den Patient*innen mit ungeklärter Krankheit ohne die Medizin, auch wenn sie dualistisch organisiert ist, nur der Schmerz bleibt, für den die Affirmation allein nicht ausreicht.

Was diese Patient*innen brauchen, sind Formen der Betreuung. Ich sehe Pflege nicht nur in einer praktischen Betreuung, die dringend benötigte Hilfe bietet, sondern auch in einem Ansatz, der das Problem der Ungeklärtheit auf eine sorgfältige Weise angeht. Ich hoffe, dass eine sorgfältige Darstellung der formalen Struktur verschiedener Repräsentationen ungeklärter Krankheiten zu einem besseren Verständnis der Strukturen führen kann, die zur Delegitimierung und Marginalisierung ungeklärter Krankheiten beitragen.

Acknowledgements

I am so happy to have been given the chance to work on this. I want to thank the GCSC for providing not only the material conditions for me to do so but also an institutional embedding and research environment in which this dissertation could be developed. I remain ever grateful for the institute's continued support in times of need, something that is unfortunately rare in our times.

For giving me even more space and academic room to develop this thought, for the nudges that brought me back when this thought was too much off (disciplinary) track, for the drawings included in your edits, for your enthusiasm, for Christmas parties with hats that make me look stupid but make everyone look stupid, which is nice, but of course even more for your guidance throughout these years and the invaluable support for the need for emancipatory interdisciplinary theoretical work, I thank you, Greta Olsen, the supervisor without whom this dissertation would not have existed.

I thank Frans Willem Korsten for coming in late to this project but immediately starting to think *with me*, which can always only be done in a clear voice of one's own. I thank you for not being subtle, for your incredible energy, your reading pace and thoroughness, for saying yes and no, for taking me on, for the work that you do for students in all phases of their work, and for enjoying it in the process. This really helped strengthen my hope in the academic endeavor, something for which I cannot thank you enough.

Thank you to everyone who participated in Greta's colloquium and who has read my work during this process, especially to Melanie Kreitler, for turning out to be a true co-conspirator in the town that is Giessen, for all your help with so much and for drinks, and to Birte Christ, for reaching out to me when I needed a pep-talk and for saying all that needed to be said. Thank you to the IPP, for the support offered during the colloquia and for their support of my conference travels. Thank you to all my teachers, spread out across universities and contexts, some of whom deserve particular mention for their support very early on. Thank you, Murat Aydemir, Jules Sturm, Niall Martin, Mireille Rosello, and Eugenie Brinkema. And thank you to my now colleagues at Leiden University, who may not have played a part in the creation of this work but have so positively reminded me that this is what I want to do, always, and that it can be done.

Thank you, Merlijn Olnon, not only for your incredible work to keep thought alive in a public setting but also for already thinking with me about what this book could look like beyond an academic form and for seeing this potential.

Thank you to my friends and loved ones, for being with me and for shaping my life as this was written. Thank you Andreas Zangger, Anne Wijn, Daniela Solano, David Bos, Gwen van der Zwan, Hans Roodenburg, Heleen Wabeke, Hester van Woudenberg, Ilios Willemars, Margriet Minnema, Niels Springveld, Nina van Oort, Pablo Kamsteeg, Peter Huijzer, Rosa de Jong, Rosie Voorthuis, Salomé Roodenburg, Sjoerd Scheffer, Sylvie de Kubber, Tess Korthout and Tristan Knelange.

Thank you, Tom and Hanneke, for being a gang ever since we lost and for being a part of me.

Christiaan, for a long time I thought that this work was for you, as are so many of my thoughts and so much of my being. But it is you who can show me that it is not and that this work is the part of me that extends beyond our being together, and I thank you for that.

Thank you, Rijmpje, for slamming your little hand on my keyboard and showing me that my focus is with you, always, and for being everything that you are. And to the person we are yet to know, thank you for keeping me company and being in my body during this final process.