REPORTABILITY AND CREDIBILITY
IN NARRATIVES OF CONTESTED ILLNESSES: A TEXTUAL ANALYSIS

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ABSTRACT

Reportability and Credibility in Narratives of Contested Illnesses: A Textual Analysis

Doctor of Medical and Health Humanities Dissertation

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This dissertation is concerned with illness narratives or memoirs (Couser 1997, 2012; Frank 1995; Hawkins 1999) of contested illnesses (e.g., Hart 2014; Quinn Schone 2019; Swoboda 2005, 2006) written by patients/memoirists. Because contested illnesses are characterized by a disputed disease status, this study explores how constructing doctorability may constitute a narrative/reportability problem for patients. A total of twenty-two memoirs, eighteen memoirs about contested illnesses and four about non-contested illnesses, are analyzed from the interdisciplinary perspective of the medical/health humanities drawing on narrative analysis (Labov 1997, 2008, 2013) and stancetaking (Aikhenvald 2005; Chafe and Nichols 1986; Hunston and Thompson 2000).

This study argues that narratives of contested illnesses amplify the credibility dilemma (Halkowski 2006) that all patients face in their doctors' offices: we are socially expected to tell out-of-the-ordinary stories within the 'ordinary cast of mind' (Sacks 1984, 1995). Patients/narrators with contested illnesses are particularly challenged by the narrative demands of the reportability paradox: as more eventful a story sounds the more reportable, but the less credible it will be. It is speculated that in personal interactions, narratives of contested illnesses are likely to become *contested narratives* by virtue of the

vague, subjective, and out-of-the ordinary nature of their realities that seems to push further the conventional boundaries of what we can afford to accept as rational and medically possible. The hesitancy in believing these patients' accounts may be explained by the oscillation between the belief in the existence of certain symptoms that have a conventional reference to the actual, experiential world (e.g., headaches) and the disbelief in the patients' emplotment of those symptoms reporting unconventional syndromes, as that emplotment challenges conventional diagnosis. Memoirists' strategies to construct credibility are summarized in three main narrative strategies: (1) constructing credibility by challenging reliability, that is, by drawing on discursive devices of ambiguity and contradictions; (2) constructing credibility by means of "reported evidentials" that assert the narrator's visceral knowledge as complementary to the knowledge of medical science; and (3) constructing credibility by displaying figurative linguistic devices as ontologically valid conceptual tools to represent experience. Writing memoirs plays a legitimization function in asserting patients' conditions as existentially real, transforming contested narratives into *ontological narratives*.

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In the early 2000s, I was a doctoral student in linguistics at the University of Pittsburgh, Pennsylvania. One assignment in my discourse analysis course was to conduct an interview, transcribe it, and analyze it drawing on some of the theories we have been studying. At the time, I was living in an apartment building in the neighborhood of Shadyside, in Pittsburgh. Some of my neighbors were graduate students like me, and others were professionals. One of those neighbors was a woman named Lindsey. A pediatric nurse, Lindsey was always at home, though. She was not working due to a chronic condition (chronic fatigue syndrome) of which I was unaware but intrigued. I took the risk and one day asked her if I could interview her for my class assignment. I told her I was interested to listen to her story of illness. She was welcoming.

Lindsey's story took me by surprise. Lindsey told me a story about a heated exchange with a physician in the emergency room who had denied her Ibuprofen, despite her complaints of pain and distress. The doctor, she said, did not believe that the symptoms she was reporting were real. The physician said that she was hysterical, so Lyndsey told me. Given that I knew Lindsey to be a nurse, it troubled me that her physician could be so adamantly skeptical about her account. Soon I learned that Lindsey was not the only neighbor who happened to suffer from chronic fatigue syndrome (CFS) in my building, or to tell me about stressful experiences with doctors as well as with family members who disbelieved their stories as "complainers." My other door-to-door neighbor, Janet, was also diagnosed with CFS. Jane told me that she lost her job as a cashier in a bookstore, given that her extreme fatigue forced her to be in bed when she needed to be at work. I was perplexed, but I truly did not know anything about CFS at that time. I wondered though about the odds that two females in their early forties, living in a small apartment building, had the same “weird” (to me) diagnosis. For them, CFS was a hidden epidemic that had been neglected by the medical authorities in the United States because of the mysterious lack of organic evidence and because of the medical and social crisis triggered by the HIV/AIDS epidemic in the 1980s and 1990s, which overlapped with the CFS epidemic.

The day I gave my presentation about Lindsey’s interview in my discourse analysis class, I cannot forget the question that my distinguished, sociolinguistic professor asked me: “Didn’t you feel manipulated?” she said, with a suspicious tone. I was conflicted by my professor’s question. Like Lindsey’s doctor, my professor had the impression that Lindsey’s illness was not real, but rather “in her head.” Personally, it had not occurred to me that Lindsey was “manipulating me,” exaggerating, or lying. I assumed that Lindsey’s story was her own version and whether true or fabricated, my position was to analyze her narrative as her subjective construction, instead of the “truth.” However, my professor’s comment opened a question for me about the problem of how credibility is constructed in discourse, which I had not thought about before.

Almost two decades later, in New Jersey, I learned about the lasting effects that chronic Lyme disease can have on a person’s health, even after the acute infection has been treated successfully with antibiotics. That was the story of my late, dear friend Georgia, who started with symptoms associated with chronic Lyme in the mid- 1980s, when Lyme was not well known. Georgia’s doctors also thought that her symptoms were "all in her head." Like Lindsey's doctor, Georgia's doctor did not believe her symptoms were organically based; she was referred to a psychiatrist, and her condition remained undiagnosed for more than a year with serious, long-term lasting implications for her health.

Soon after my interviews with Lindsey and Janet, and after I completed my course work in my program, I started working on the prospectus for my dissertation in linguistics. I could have continued working on patients' stories with CFS, but other dramatic witnessing experiences in a hospital in Buenos Aires led me to focus on patients with HIV/AIDS and to study the types of verbal exchanges that took place between HIV/AIDS patients and their doctors in Uruguay, Latin America.

Now, at the end of this dissertation in medical/health humanities, I feel I have returned to those initial stories of my neighbors in Pittsburgh, but with a better frame of mind and preparation; that is, from the interdisciplinary frame of the medical/health humanities. The path to this topic was not clear to me from the beginning, though. Rather, it was a long journey of exploration which started in Dr. Piehler's course "Joy of Scholarly Writing" and her gentle feedback to the several papers we wrote to refine our interests. It was, at that time, when the stories of people like Lindsey, Janet, Georgia, and the HIV/AIDS patients I met at the hospitals in Buenos Aires and later in Montevideo, came back to me with a conviction, leading me to this topic.

This current research may seem far away from linguistics, but it is not. My passion and curiosity remain in these people's narratives and the discursive construction of their experiences. In the present study, I expect to have unified my analytic skills in linguistics with the wide humanistic frame of the medical/health humanities borrowing from medical anthropology, sociology, literary studies, narratology, sociolinguistics, and the history of medicine.

I dedicate this study to the memory of Georgia, and to the Lindseys and Janets, as well as to the memoirists studied here, whose suffering tends to remain unacknowledged because it is seen as not real, thus, as not credible. I also dedicate this study to my loving husband Joe for his support, and to the memory of my grandfather who taught me with his example about the “good life.” Last, but not least, this dissertation and my studies in the medical humanities would have not been possible without the financial support of my late father Dr. Delbene, who was not aliened to contested illnesses.

I also want to express my gratitude and appreciation to my Drew University professors for their dedication and for the trust they conferred in me: Dr. Liana Piehler, Dr. Laura Winters, Dr. Kate Ott, and Dr. Merel Visse. Most of the bibliography included in this study was facilitated by the Drew University Library collection. I am thankful to the librarians for their help in scanning, finding extra materials through interlibrary loan, and for providing me with access to valuable texts, especially during the closure of the university due to the Covid-19 pandemic. Finally, the following friends, mentors, and healers have been great companions and a source of support throughout this period. I thank Richard Morehouse, Nancy Gross, Nakaweese Kantongole, Geraldine Lucignano, and Colette Hayes.

INTRODUCTION

This dissertation is concerned with illness narratives; that is, autopathographies or memoirs (Frank 1995; Hawkins 1999; Couser 1997, 2012) of contested illnesses (e.g., Hart 2014; Quinn Schone 2019; Swoboda 2005, 2006) written by patients who became authors in the process of narrating and publishing their stories with contested illnesses. A total of twenty-two memoirs, eighteen memoirs about contested illnesses and four about non-contested illnesses, are analyzed. Because contested illnesses are characterized by a disputed disease status given that biomarkers are not easily found, most of the authors who write about their illness experiences report having had their symptoms disputed, at least in the onset of their illnesses during consultations with their healthcare professionals. All these patients/memoirists ended up being diagnosed with a contested illness, for instance, post Lyme disease, chronic fatigue syndrome, and multiple chemical sensitivity among others, but in their memoirs they tell us about their struggles in having their conditions recognized as real. On the one hand, their struggles were to identify a diagnosis for their afflictions, and on the other, the skepticism they encountered with respect to the ontological reality of their conditions. Often, they were told by their healthcare professionals that their conditions were psychologically motivated or “all in their heads,” as we will see in the analysis (see chapters seven and eight).

In order to call the attention of their audience, narrators need to construct credibility according to Labov’s (1997, 2013) theory (see chapter six). Thus, I argue that in writing their memoirs, memoirists construct credibility about their stories and, in so doing, they also construct credibility about their conditions; they socially transform their memoirs into a credibility claim about the reality of their conditions (Berger and

Luckmann 1966). By means of narrative analysis (Labov 1997, 2008, 2013), stancetaking and evaluation in text analysis (e.g., Aikhenvald 2005; Englebretson 2007; Hunston and Thompson 2000), this study is mainly concerned with the rhetorical and discursive strategies that memoirists employ to construct narrative credibility about their conditions.

1. Contested Narratives and Contested Diseases

Diseases need to be nosologically recognized by medicine as an institution to be deemed doctorable (Halkowski 2006). When new diseases emerge, such as the infections caused by HIV/AIDS or SARS Covid-19, scientists deploy all their resources to identify the biological markers (in these cases the respective viruses and their variants) responsible for triggering illness reactions in human beings. However, the identification of biological markers and effective treatments is plagued with scientific, social, financial, and ethical challenges. Not all conditions—despite people's suffering—are automatically inscribed into a recognized, legitimate, nosological category. Yet, the construction of certain conditions as holding a disease status is as much a scientific as well as a social endeavor, according to the normative position on the construction of disease, which I adopt here (Aronowitz 2001; Engelhardt 1981; Komarroff 1990; Rosenberg 2002, 2007). The dramatic tension between the voice of medicine and the voice of lifeworld (Mishler 1984) can be observed in the memoirs or pathographies studied in this dissertation. This struggle is expressed, I argue, in the patients'/memoirists' rhetorical and narrative attempts to construct credibility.

Because contested diseases are typically symptom-based illnesses rather than sign-based (Aronowitz 2001), the patients' report of symptoms associated with these conditions (e.g., myalgia, fatigue, general malaise) are highly subjective and patients' illness stories difficult to corroborate, according to biomedical expectations (Malterud 2000). In other words, patients' descriptions of their conditions and illness experiences tend to make reference to their internal realities rather than to verifiable realities in the external world. Thus, their illness stories cannot be easily quantified, made visible, or objectively verified by their physicians, especially at the onset of the disease.[1] The following excerpt by Diane Crumple (1994), a multi-chemical sensitivity sufferer, whose memoir is included in this study, illustrates the subjective dimension of language in describing her symptoms:

> I was profoundly thankful that there was no tumor yet chastened, that such pain and debility could be self-inflicted because of some character flaw and my inability to cope with the stress of life.… [However] *Weird sensations* came and went. Food would suddenly *taste vile*. *Pains would stab up my legs as if steel rods were being hammered up my bones*. My throat was forever sore, my lymph glands tender and swollen. *Tingling, burning, and numbness* developed in my hands and feet, and my skin crawled as if invaded by a million ants. Strangest of all was *a crazy feeling, like ice melting and trickling deep into my brain.* (24-25) (emphasis added).

We observe that symptoms like tingling, burning, and numbness can only refer to the person's inner world and subjective, sensory experience; thus, patients with contested illnesses raise the following question: Can the patient's illness narrative be taken as sufficient evidence of a pathological condition?

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[1]. This clarification is important because not all symptoms clearly manifest as a recognized disease at the beginning and certain conditions, such as Myalgic Encephalitis/Chronic Fatigue Syndrome (ME/CFS), may progressively lead the person to a highly debilitating state in which she or he may not be able to walk or even get up from bed. In these cases, when fully developed manifestations of the disease are observed, credibility of these patients' conditions may be obvious (Prior and Castillo 2015).

The study conducted by Peterson et al (1992) comparing the contributions of the medical history, the physical examination, and laboratory investigations to arrive at the diagnosis of the patient, concluded that the medical history is the most important instrument leading to the final diagnosis. This statistical finding also supports the enduring belief that most medical diagnoses derive from the medical history that the doctor co-constructs with the patient. Although the physical examination and the lab results led to fewer diagnoses, the study found that these methods were instrumental in excluding certain diagnostic possibilities and in increasing the physicians' confidence, resulting in the diagnosis. The case of contested illnesses, however, (which was not included in Peterson's et al study), presents many diagnostic challenges for healthcare professionals; for instance, lab test results may often be inconclusive (Aronowitz 1998; Edlow 2003). Although Peterson's et al (1992) study confirmed the importance of the patient's narrative in order to arrive at a diagnosis, the patient's narrative can also be a source of controversy and contestation, especially when objective medical evidence is not found.

Indeed, the literature in medical sociology and medicine indicates that the symptoms of individuals with contested illnesses are more likely to be treated as psychological (e.g., somatization, hysteria) or as morally problematic (i.e., as malingering or exaggerating) by medical practitioners, resulting in interactional tensions between healthcare practitioners and patients (e.g., Armentor 2017; Lian and Robson 2017; Swoboda 2005, 2006; Werner and Malterud 2003; Werner et al 2004; Ǻsbring and Närvänen 2002, 2003).

Whereas for physicians, on the one hand, the face-to-face encounters with patients with contested illnesses are interactionally challenging because they can jeopardize the doctor's biomedical expertise and authority (Freidson 1970; Swoboda 2008); on the other hand, for patients, the challenge lies in not being believed or in having their description of symptoms called into question, which tends to result in hurt feelings of stigmatization, delegitimization, and self-doubts (e.g., Dickson, Knussen, and Flowers 2007; Werner and Malterud 2003). In comparing the likelihood of delegitimization during consultation, research has shown that delegitimizing experiences are less commonly reported in those individuals who present with a strong physical etiology (Kouyanou et al 1998, cited in Dickson, Knussen and Flowers 2007). There is also a gender component associated with the treatment of contested illnesses. Women are more affected than men by contested conditions (e.g., Dusembery 2018; Wall 2005), and women's descriptions of symptoms are more likely than men to be interpreted as psychologically or morally based, rather than physically based (e.g., Frances 2013; Hoffman and Tarzian 2001; Malterud 2000; Wallen, Waitzkin, and Stoeckle 1979). Although men suffering from contested diseases are not exempt from experiencing stigmatization and disbelief (Dickson, Knussen and Flowers 2007; Deale and Wessely 2001), I adopt here a feminist position based on the long history of misunderstanding, neglect, and even misogyny in medicine, reported by women, which has devalued women's words as less credible than men's (e.g., Dusembery 2018; Cleghorn 2021; Shorter 1992, 1994; Veith 1965)

Excerpt 1 from Amy Berkowitz (2015), a fibromyalgia sufferer, clearly states the patient's plead to have her words taken as sufficient evidence of her condition:

Excerpt 1

> Fibromyalgia is largely defined by a lack of visible symptoms or identifying lab tests. The only diagnostic criteria are the frustratingly vague tender points. ‘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.’* (Berkowitz 40) (emphasis added)

Excerpt 2 from memoirist Polly Murray (1996), a post Lyme sufferer and a precursor in the research about Lyme disease, reports about her struggles to have her doctors believe that she was not fabricating her symptoms and that she believed she had an organic condition that was difficult to explain.

Excerpt 2

> I told them [the doctors] that I first sensed that my well-being was threatened… I was reacting to something, and that something was making me feel miserable…. They were unable to find a physical cause for my complaints. He [the doctor] then looked at me and said, *‘You know Mrs. Murray, sometimes people subconsciously want to be sick.’ I asked him what he was implying, and he went on to say that sometimes psychiatric problems manifested themselves with physical symptoms.* (Murray 33-35) (emphasis added)

Another excerpt from another post Lyme sufferer, Ally Hilfiger (2017), tells us about the struggles to have post Lyme recognized as an organic disease by high authority medical institutions.

Excerpt 3

> *Many in the medical community don’t think chronic Lyme disease even exists*. Even the CDC has trouble acknowledging it. Instead, the government health agency believes that people with Lyme symptoms that last more than six months after an initial antibiotic treatment have post-treatment Lyme disease syndrome. (Hilfiger 2017, 226) (emphasis added)

All these narrators tell us that because organic bases were not found in their cases (at least initially), then their symptoms were treated as “nerves” or as if they were psychosomatic, i.e., as narrators colloquially put it “all in your head,” that is, literally as "non-existent." In other words, the lack of visibility of signs of their diseases may lead some physicians to assess these patients as having imaginary conditions, as hypochondriac and even hysteric, i.e., as non-doctorable conditions (see chapter three).

In this dissertation, I analyze how these patients/memoirists rhetorically and discursively construct credibility about their conditions from a narrative viewpoint, given that narratives are told with a point (Labov and Waletzky 1967; Labov 1997, Labov 2013). In analyzing how they construct credibility about their conditions, we will see that they need to construct credibility about their own stories as well; their stories tend to be as disputed as their conditions. Contested illnesses are likely to become contested narratives. Thus, this dissertation contributes to the existing literature about this topic from social science and medicine by offering a novel methodology: discourse analysis may shed new light onto the social role of these memoirs. This study is mainly interdisciplinary, reflecting the interdisciplinary nature of the medical/health humanities field. I draw on history, feminist studies, sociology, anthropology, and sociolinguistics. Below, I introduce the main thesis and methodology.

2. Rationality and Credibility

One of the main interesting aspects about the term "contested illness" is its association with the problem of truth and reality versus imagination, delusion, irrationality, and deception. In our Western culture, rational knowledge is seen as an assertion of the correct, the logical, and the appropriate, and rational knowledge "is always a legitimating idea" (Wright 1992, quoted in Kroll-Smith and Floyd 2000, 85). From this rationalist perspective, contested illnesses challenge rationality and by default, reality, and truth. The observation of the strong social link between rationality and truth is asserted in Jean- Francois Lyotard's (1992) critique of modernity when he states that, "all that is real is rational, [while] all that is rational is real" (29). Then, as Kroll-Smith and Floyd (2000) note, to accept someone's account is to tacitly commit to the belief embedded in that account or, otherwise, to risk the charge of aligning with irrationality. Thus, it can be asserted that not only physicians are highly trained to seek rational explanations but also society in general places a great deal of value on the authority of rational knowledge to regulate nature and health.

As mentioned, contested illnesses create a central theme of dispute or contention between patients and their doctors. This tension may result in a sort of epistemic duel between authorities of knowledge, i.e., the doctor's medical knowledge and the patient's visceral knowledge (Belling 2012). The patient's expectation to have her contested condition deemed doctorable lies at the center of the conflict concerning the hierarchy of diseases, as observed by French medical philosopher Georges Canguilhem ([1978] 2015, 39) (see chapter three). Thus, not all diseases are deemed equal in the hierarchy of diseases in medicine. Similarly, not all patients' report of symptoms has the same epistemic status (Fricker 2007); social variables such as gender, race, and class play a role in their epistemic status.

Furthermore, as we will see, all patients need to justify their visits to their doctors by producing a doctorable condition (Halkowski 2006). The selected excerpts (1-3) quoted earlier, seem to indicate that contested illnesses tend to amplify the problem of credence and credibility for the patient's illness narrative, whose words may not be taken as sufficiently, epistemologically valid to corroborate disease.

3. Thesis: The Patient's/Narrator's Dilemma

According to conversational analyst Timothy Halkowski's (2006) chapter, "Realizing the Illness: Patients' Narratives of Symptom Discovery," when patients go to their doctors' offices, they all face a social dilemma; that is, how to present their conditions in a way that warrants the medical attention and intervention of the physician without making more of the experience than it may require. For this reason, the patient needs to rationally justify seeking medical assistance by making her case doctorable and credible without giving the impression that is seeking medical attention due to hypochondriasis. It has come to my attention that the patient's dilemma about how to make her or his symptoms doctorable shares similarities with the narrator's dilemma that sociolinguist William Labov (1997, 2008, 2013) has observed in his narrative theory, based on the study of oral narratives of personal experience. The narrator's dilemma is based on the concept of the *reportability paradox* (see chapter six). To address this issue, I will begin explaining the concept of narrative that I will use.

Labov and Waletzky (1967) defined narrative as "one verbal technique for recapitulating past experience, in particular a technique of constructing narrative units which match the temporal sequence of that experience" (13). Narrative is one means to transfer experience to another person, the events presented in the narrative are expected to match the original events as they occurred in the world. This conceptualization of narrative is informed by the assumption that the reported events are in a referential relationship with the events of the actual life experience (see chapter six). This conception of narrative reflects a realistic and positivistic epistemology, which is insufficient to explain narratives of contested illnesses because the reference to reality in the case of contested illnesses is ambiguous and uncertain. Nevertheless, momentarily, this conception of narrative is useful to me in this analysis given that my purpose is to show the narrative aspect that links the reportability paradox to narrative of contested illnesses.

One requirement to be successful in transferring experience to others is that narrators must be able to call the attention of the listeners/readers. Thus, narratives need a reportable event that is worthy of the attention of the listeners/readers. In Labov's (1997) theory, the conceptualization of the most reportable event, as the event that has the greatest effect on the needs and desires of the participants (including the narrator), indicates that the most reportable event is the result of the narrator's evaluative process in deciding what is worth telling. The narrator's problem, though, is that as higher the reportability of a story, given its eventfulness, surprising effect, or maximum impact on the narrator, the less likely the story will be believed by the listener/reader. Consequently, the higher the effort the narrator must devote to establish credibility. As Labov (1997) asserts: "The fundamental dynamics of narrative construction are built on the inverse relationship between reportability and credibility: the more reportable an event, the less credible" (8). For this reason, the narrator's dilemma (and a problem for the listener/reader as well) is how to resolve the reportability paradox in the telling of the narrative. Considering this narrative thesis, then I am particularly interested to see how the memoirists in these autopatographies or illness narratives address the reportability paradox and manage to construct credibility. One way to examine this aspect is by analyzing how patients/memoirists use discursive and narrative devices to construct credibility. I systematically focus on the analysis of the introductory section of the narratives (i.e., orientation, the complicating action or most reportable event, and evaluation) (see chapter six). The following questions guide this study:

Research Questions:

1. How may constructing doctorability constitute a narrative problem (or reportability problem) for patients with contested illnesses and their doctors?

2. What kind of evaluative, discourse strategies do patients/memoirists of contested illnesses use to claim credibility in writing about their illness experiences?

3. Do patients/memoirists of non-contested illnesses use evaluative stances and discourse strategies to construct credibility about their conditions? If that is the case then, what could be their communicative purposes—if their conditions are not contested?

4. Credence and Credibility in Doctors' and Patients' Encounters

Considering the proposed thesis above that equates the patient's dilemma with the narrator's dilemma, I would like to clarify that my approach to the problem of patients/narrators' credibility stands from a narratological viewpoint. In defining credibility, I draw on Labov (1997) who defines credibility in the following manner: "the credibility of a narrative is the extent to which listeners believe that the events described actually occurred in the form described by the narrator" (407). When I refer here to the problem of credibility, I mean the challenge that patients with contested illnesses face in receiving credence that their symptoms are doctorable. Credence is defined as "the mental acceptance of something as true or real" (Merriam-Webster 2021). However, credence may not be easy to disentangle from credibility. In assessing and making evaluations about the credence of a statement, speakers and listeners tend to depend on the reliability of the identity of the source of information and not as much on his or her reportiveness, observes Mushin (2001, 74). For instance, culturally, women in general tend to be given less credence than men (e.g., Dusembery 2018; Cleghorn 2021).

Since antiquity, as medical historian Iza Veith (1965) has observed, women tend to be seen as less reliable narrators of their bodily symptoms than men, as exaggerating or dramatizing their symptoms. A criticism of this perception is addressed in recently published books, such as *In the Kingdom of the Sick* by Edwards (2013), *Doing Harm* by Dusembery (2018) and in *Unwell Women* by Cleghorn (2021). Drawing on personal experience or on data analysis as well as on historical documents, these publications assert that women are more likely than men to have their illness narratives in their doctors' offices constructed as somatoform or as *hysteric* (conversion disorder) (Frances 2013). Following Fricker (2007), it can be asserted that women are more likely than men to suffer from "epistemic injustice;" that is, the state in which a speaker's credibility is diminished or erased due largely to prejudice on the part of the listener that is based on the identity of the speaker. This observation is also made by rhetorician Catheryn Molloy (2020) in her study on rhetorical ethos considering different types of data collection (ethnographic, archive, interviews).

In sum, so far, two aspects associated with credence/credibility overlap: on the one hand, given the unspecified characteristics of contested illnesses, patients are likely to be granted less credence for their illness stories; for instance, Quinn Schone (2019) observes that "the fibromyalgia patient reporting debilitating pain is not often afforded the same epistemic status as an individual with say, gallstone problems" (127). And, on the other hand, given the history that has culturally and socially shaped the perception of women as prone to imagination and as less reliable about their bodily symptoms (see also Harrington 2008; Shorter 1992, 1994), women are likely to be afforded less credibility than their men counterparts.

The following excerpt from *The New York Times* (2010) article "Voices of Fibromyalgia," illustrates one of the readers'/responders' skeptic reactions. The reader/responder, who happens to be a doctor, expresses his skepticism about patients' complaints who claim to suffer from fibromyalgia:

> Count me as one of the skeptics. Not necessarily whether fibromyalgia exists, just that that vast majority of sufferers actually have it. I won't use the word hypochondria because I think that is inadequate. I think that many of these people suffer from a somatoform or somatization disorder. Still a disorder in need of treatment, but not fibromyalgia.… So many people who report these symptoms also complain of other vague maladies and bring to doctors their own self-diagnoses ... [But] What are the odds, mathematically, that one person should suffer from so many obscure and medically unconfirmed maladies? Maladies that have symptoms that can only be accepted … based on *your word* [the patient's] that they exist? … Disorders that seem to show up in varied combinations among middle aged women, commonly with a history of childhood abuse, begs [that] question. (Dr. Hirschberg March 3, 2010, 5:04 pm) (emphasis added)

There are many aspects to point out about this reader's (a physician) skeptical comment. First, it can be observed that although this doctor accepts the existence of fibromyalgia as a disease entity, he believes it is over diagnosed. Although overdiagnosis could be a possibility, he attributes the etiology of these patients' physical complaints to "somatoform or somatization disorder." Somatization, explains neurologist, Suzanne O'Sullivan (2016), "refers to the tendency of a person to have physical symptoms in response to stress or emotions" (17). Whereas somatization is a common response to stress or emotional troubles that manifests physically (e.g., headache, tiredness, nausea), it may not always lead to the psychiatric diagnosis of “somatization disorder” as classified in the Diagnostic and Statistical Manual (DSM V). The latter is a chronic condition, which is subdivided in several other sub diagnoses. O’Sullivan states, “a somatic symptom disorder is a rare and devastating medical problem which represents one extreme of a spectrum of diagnoses” (18). Thus, to state that a person’s complaints are the expression of a somatization disorder implies the presupposition that the person’s fibromyalgia is psychogenic. However, this presupposition is problematic without having previously investigated whether there are underlying physical causes. Second, this responder/ doctor claims to be “skeptical” of the patient’s narrative as sufficient evidence for diagnosis, as he ironically states in the rhetorical question (“Maladies that… based on your word that they exist?”), aimed at the readers of the newspaper commentary section. However, it has to be observed that this doctor/responder already holds a negative bias against patients’ narratives that present with this type of complaint.

Another motive for his skepticism seems to be that as he reasons, mathematically it is not possible that a person could suffer from so many symptoms at once, evaluating the nature of the symptoms as “obscure.” It can be argued though, that whereas a diagnosis may be “obscure,” a person’s symptoms may not be well understood by the physician or may not be well explained by medicine yet. However, the patient is validating those symptoms by the act of verbalizing and communicating her or his illness experience. Thus, the use of the evaluative adjective “obscure” disqualifies the patient’s voice. Finally, this doctor/responder attributes a psychosomatic etiology based on childhood’s sexual trauma as the reason for these female patients’ symptoms. Whereas the attribution of sexual trauma as an explanation for the development of a contested illness, such as fibromyalgia, is a possible and valid explanation (see Berkowtiz's memoir in chapter seven), I suggest that this explanation is also often suggested as a quick, stereotypical explanation for women's contested conditions (see Norman's memoir in chapter seven). Moreover, because men are equally affected emotionally by childhood sexual traumas, the responder's omission to include men in the equation (i.e., men also suffer from fibromyalgia) implicitly puts the onus on the women themselves; that is, fibromyalgia is seen as an expression of maladaptive behavior (i.e., unable to overcome childhood traumas). This comment then reinforces the stereotype of contested illnesses as an inherently female, "hysteric" problem, rather than a problem that medicine has been unable to explain so far while patients may lack the sufficient linguistic and conventional resources to explain their symptoms.

Although it is possible, as this doctor/responder observes, that some cases presented as fibromyalgia might be indeed cases of somatization disorder, the responder's comment also illustrates the tendency toward the psychologization of contested conditions. Concerning this tendency, psychiatrist Allan Frances (2013) in his book *Saving Normal* raises a critique against the current DSM V category of "somatic symptom disorder" versus the previous DSM IV. He points out that the extension of the meaning in this umbrella term may have the negative effect of contributing to make "even fuzzier the already fuzzy boundary between medical and mental illness" (194) given that it provides a loose and easy-to-meet definition. He adds, "the result will be dramatically increased rates of mental disorder in all three patient groups: people whose diseases have clearly defined pathology; people whose diseases have less well understood causes (like fibromyalgia); and people whose physical symptoms are thus far unexplained but will later show a clear etiology" (194). Moreover, the burden of this umbrella category, he denounces, will fall mostly on women because they are more likely to be casually dismissed when presenting with physical symptoms (Frances 2013, 195).

In sum, this excerpt from *The New York Times* illustrates how credence and credibility are often intertwined in the context of illness narratives of contested diseases: the ambiguous and subjective reality of the patient's illness narrative, the listener's biases due to contributing social factors influencing his or her perception, such as gender, as well as race, social class, and age, among others. Whereas credence is associated with the epistemic status of the story itself (i.e., as being worthy of medical attention), credibility is associated with the identity of the patient as more or less worthy of epistemic status. Credence and credibility can overlap and frequently do so. Also, under certain social conditions and contexts, credence and credibility could be difficult to distinguish as illustrated earlier. To simplify, here I will mostly use the term credibility making the appropriate clarifications when necessary.[2]

Because in this study I will analyze memoirs, I can only examine how these narrators discursively construct credibility in their writing with the purpose to persuade their readers about the veracity of the ontological status of their symptoms and illness experiences with their healthcare providers. As memoirs are subjectively created in

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[2]. Studies in rhetoric tend to use the term "ethos" to refer to credibility. Molloy (2020) defines ethos as "credibility of the speaker, both in terms of reputation and in terms of real-time performance (earned and unearned)" (2). Although the implications of ethos intersect with my study, here I am concerned with a narrative approach to the problem of credibility; thus, I believe ethos is not the best term in this case.

reference to the authors/patients' extra textual experiences, the narrative discourse that the narrator uses shapes, and it is being shaped inevitably by those extra textual experiences resulting in a new reality. As an analyst, I consider what the memoirist says has happened to her or to him, as her or his narrative truth; this analysis, however, does not prevent me from making a critical assessment of the narrative discourse of the memoirs.

5. Memoirs and Credibility

Given that the focus of my analysis is the selected pathographies or memoirs, it becomes relevant to explain that a third aspect to the problem of credibility lies in the suspicion generated by the genre of memoir itself (Jurecic 2012; Sidonie and Watson 2010). Memoirs are not a fictional genre and yet they have some overlap with fictional works, observes Couser (2012, 7). Although readers of memoirs expect veracity, a positivistic approach to reading memoirs could always be suspicious about their stories' credence. We need to bear in mind that in telling their stories, authors of illness narratives (like historians) are always narrativizing their past, as Hayden White (1987) has argued; therefore, narratives are always a "figurative account" (48). The interpretation of those events by the author (and others) is always subjective and creative, and in that sense, fictional.

6. Memoirs and Truth

This study is not an ethnography; thus, it is not concerned with the facts or veracity of the authors' claims. I have not been a participant observer during these patients/authors’ encounters with their physicians; then, I do not intend to corroborate their lived experiences with their narrativized experiences in their pathographies. Nevertheless, I need to clarify my position as a researcher of these autopathographies or illness narratives.

I understand that illness narratives are subjective; therefore, they are not strictly about facts but rather about the author’s interpretations of those facts. The author’s interpretations of those facts are presented as the product of her or his narrative construction in which memory and desire, regret and frustration, intention, and purpose shape the final product. The author’s emotional lens and purpose cannot be removed from the way the story has been put together. I bear in mind Hawkins’ (1999, 14) advice on how to read these narratives. She observes that although pathographies tend to dramatize the events of illness, they need to be read as true stories (see chapter six). I will adopt here Hawkins’ position, which is common to the medical/health humanities. I begin analyzing these narratives with the assumption that narrators may fabricate to a certain extent. However, they do not necessarily need to lie; the realities they face are already out-of-the-ordinary. I proceed from what the narrators write and analyze how they construct their narratives/experiences. In my view, at the end, the story must hold onto its parts to be credible. In analyzing, we can examine how the narrator adjusts the story to her or his communicative interest.

In sum, in this study, I am concerned with the construction of patients’/narrators’ credence and credibility; I take these authors’ memoirs as their own narrative truths (Spence 1982), (i.e., as their core experiences). I agree to make an autobiographical pact with them. Notwithstanding, I bear in mind what Ochberg (1994) states about narratives as arguments: “a story is fundamentally an internal argument between what is said aloud and what is on the verge of being said” (141). In narrating, the narrator makes something of himself or herself in trying to maintain a positive self-image, the narrator makes an idealized image of himself or herself. As readers and listeners, we must be aware that some aspects of a story are highlighted and others downgraded, disavowed, or withdrawn in the narrator’s best interest.

7. Illness Narratives with a Purpose

According to Labov and Waletzky (1967) and Labov (1997, 2008, 2013), all narratives have a point. Here I argue that these autopathographies claim recognition for the validity and legitimacy of their “visceral authority”; that is, the specific intuition of the patient’s own body as known individually and subjectively only by the patient (Belling 2012, 37). Thus, one of the main communicative intentions of these memoirs, as I interpret them, is to legitimize their narrators’ illness narratives as rational, and to vindicate their experiences as real rather than imagined or “all in their heads.”

The fact that these memoirs, as published, have entered the public eye could be interpreted as an act of advocacy for the organic (i.e., anatomical, physiological, or cellular) bases of their conditions, which are not entirely deemed “diseases” yet. Ultimately, despite all efforts in establishing strict scientific criteria to determine when symptom clusters become disease categories, scientific criteria are not exempt or alien from the influence of social forces (Aronowitz 1998), including advocacy by means of memoirs (see chapter three). As it is discussed in chapters one and two, memoirs have emerged and proliferated by virtue of the effect of ideological and social changes, which were introduced, in part, by postmodernism and the Civil Right movements in the 1950s and 1960s in the United States. Then, memoirs can be a catalyst for social change. In the epilogue of Wall's (2005) memoir *Encounters with the Invisible*, she writes about the struggle of advocacy groups to gain recognition for the seriousness of chronic fatigue syndrome (CFS). She states,

> The appalling fact remains, though, that it has taken more than twenty years and a rebellious movement by patients and lay advocates, pushing against entrenched scientific thinking, to force a more serious look at this disease [CFS] … With the benefit of hindsight, we now know that as the CDC first confronted this illness in the mid-1980s, key decisions regarding the name, case definition, epidemiology and treatment were made. (Wall 247)

The influence of social movements to achieve medical and social recognition as well as better pharmaceutical treatment for sufferers was clearly seen in the impact that illness narratives (of all sorts) had on combating the HIV/AIDS virus in the mid-1980s. The publishing boom of illness narratives concomitantly emerged during this time, as both mutually reinforced each other (Jurecic 2012; Rak 2013), (see chapter two).

8. Design of the Study and Methods of Analysis

The twenty-two memoirs that comprise this study have been divided into primary and secondary sources; that is, between memoirs of contested illnesses and memoirs of non-contested illnesses. Eighteen autophatographies or memoirs about contested illnesses comprise the primary source of this study; they were published between 1994 and 2020 in the United States, Australia, and The United Kingdom. Four memoirs about non-contested illness comprise the secondary source. The memoirs were published between 1980 and 2015. The memoirs of the second source will be used for the methodological purpose of control; that is, to compare with the memoirs of contested illnesses to find similarities or differences in the way patients/narrators report about the experience of illnesses with their doctors. This study does not focus on how patients/narrators report their illness experiences to family members and friends, which can also be problematic.

The main selection criteria, for the primary source memoirs, was that the narratives were written about a contested illness. The memoirs in this category address a variety of conditions typically associated with the umbrella term of contested illnesses, such as chronic Lyme, fibromyalgia, multi chemical sensitivity, chronic fatigue syndrome, a neuroma in the pelvic area, endometriosis, autoimmune neurological conditions, and Morgellons. The narratives comprising the second source are three memoirs about cancer diagnosis: two were written by men and one by an African American woman. There is another memoir about a neurological condition (peripheral nerve injury) developed after an accident that injured one of Oliver Sacks' legs (see chapter six).

For the analysis of these memoirs, I draw on the concept of narrative theory following Labov and Walezky (1967) and Labov's (1972, 1997, 2013). The study of evaluation is a broad concept in discourse analysis, I complement Labov's textual approach to evaluation with the discursive concept of evaluation involving evidentiality (e.g., Aikhenvald 2005; Chafe and Nichols 1986; Hunston and Thompson 2000) and stancetaking (e.g., Englebretson 2007, Mushin 2001). Whereas on the one hand, Labov's concept of evaluation is useful to conduct a narrative analysis that focuses on the narrator's viewpoint, on the other, an approach to evaluation that considers evidentiality and stancetaking allows me to consider an intersubjective viewpoint between the memoirists, the protagonists in their lives, and their possible internalized readers (see chapter seven).

9. Overview of the Chapters

Chapter one reviews the sociocultural and narratological influences that have facilitated the emergence of illness narratives as an autobiographical genre in the twentieth century and contributed to its popularity today. Particular attention is dedicated to the importance of postmodernism to validate the voice of the lifeworld and therefore, to narratives, as legitimate voices against the grand narratives of science and biomedicine. In connection with postmodernism, chapter one examines the arguments of fiction and emplotment versus referentiality and reality, as these debates are central to autobiographical texts. Finally, the chapter proposes that the term "illness narratives" encompasses two main socio-cultural constructs that seem to have co-evolved. On the one hand, the construct of "narrative," as self-knowledge and, on the other, the differentiation between the concepts of "illness" and "disease." It is suggested that without the epistemological evolution of these constructs, the genre of illness narratives might not have flourished.

Chapter two traces the oral and written aspects of illness narratives, arguing that the term is polysemic despite its predominant association with autopathographies in the medical/health humanities field. Given that this dissertation focuses on written illness narratives, the literature on autopathography and memoirs is discussed.

Chapter two elaborates on the embeddedness of memoirs with the oral, extratextual world of the patient's experience. I argue that the term, "illness narratives," refers, on the one hand, to narrative co-constructions in face-to-face interactions between patients and healthcare professionals, caregivers, or family members, and on the other, to the genre of pathographies that I also call memoirs. The reason for acknowledging the oral aspect of illness narratives is that in writing their memoirs, these authors/patients not only claim the legitimate status of their contested diseases, but they also reclaim the reality and veracity of their illness narratives in conversations with their healthcare providers. Thus, a vestige of orality of their face-to-face encounters can be traced in these autopathographies or memoirs.

Chapter three reviews the philosophical differences between the biostatistics/biomedical and the constructivist/normative models in order to explain the limitations of the biostatistical model in accounting for the illness narratives of patients with contested diseases. The distinction between symptom and sign is discussed as the report of one or the other by the patient plays an important role in the diagnostic process. The report of symptoms versus the observation of signs is relevant in determining the implicit hierarchy of diseases in medicine. This hierarchy legitimates some conditions while it may diminish the ontological status of others. It is argued that illness narratives of patients with contested diseases tend to fail the test of credibility in doctors' offices given that their report of symptoms may not find a match with the medical/scientific repertoire of knowledge and nosology. Because these patients face more challenges to normalize their illness narratives, then it is argued that they face the reportability dilemma or reportability paradox, as observed in the narrative theory of Labov (1997).

Chapter four discusses in depth the distinctions between credence and credibility and overviews different perspectives to the problem of credibility in patients' illness narratives considering physicians’ cognitive biases and social biases with a focus on gender. The chapter offers a historical review of the evolution of explanations of hysteria from the reflex theory, and from the central nervous system paradigm to the psychological paradigm, as the basis for the historical deterioration of women’s credibility of their symptoms and illness narratives. Chapter four also examines the social and medical evolution of the construction of some contested diseases such as chronic fatigue syndrome from the so called “diseases of attribution” (Shorter 1992), as this evolution seemed to have paved the way to the attribution of agency to patients as imagining their conditions rather than seeing them as organically based. The chapter concludes with a reflection on the role of imagination as playing a role in scientific knowledge and self-knowledge.

Chapter five discusses credibility from a narratological viewpoint elaborating on William Labov’s concept of the reportability paradox and illustrating with several excerpts taken from illness narratives that belong to the corpus of this study and others from the media. The chapter shows that there is a continuum or degree to credibility in medicine and it illustrates the interconnections between fiction, literature, and factuality. The chapter’s main claim lies in the observation that metaphorical or figurative language is not simply rhetorical language but rather the patients’/narrators’ best attempts to describe and categorize their out-of-the-ordinary experiences. Thus, the chapter proposes to listen to these patients’ narratives and to read these narrators’ memoirs by suspending disbelief with the advice that we must be open to wonder and imagination; that is, to the possibility that what we deem fantastic may indeed permeate our realities, or even be our realities (Todorov 1973).

Chapter six introduces the memoirs that comprise the corpus of analysis (i.e., the illness narratives corresponding to the primary and secondary source) and it explains the criterion of selection. A brief background information about the narrators and narratives is provided. Chapter six also elaborates on the methods of analysis considering the orientation, complicating event, and evaluative section of each narrative. The concept of evaluation is explained, drawing on the one hand, on Labov's narrative approach and, on the other, on the concept of evaluation as evidentiality and stancetaking based on the literature of discourse and textual analysis (e.g., Chafe and Nichols 1986, Hunston and Thompson 2001). This chapter sets the basis for the discourse analysis of the narratives.

Chapter seven presents the close reading analysis of the seven selected memoirs from the primary source category (i.e., narratives of contested illnesses) drawing on the analytic tools of evaluation and stancetaking, as elaborated on chapter six. Narrative and rhetorical patterns used by the narrators to construct credibility are observed and summarized in three main narrative strategies (see also Appendix B): (1) constructing credibility by challenging reliability by drawing on discursive devices of ambiguity and contradictions; (2) constructing credibility by means of "reported evidentials" that assert the narrator's visceral knowledge, as complementary to the knowledge of medical science; and (3) constructing credibility by displaying innovative, figurative linguistic devices as ontologically valid, rather than merely rhetorically figurative. This strategy seems to be useful because it gives language to other sufferers. Elements of each narrative strategy are found in all these narratives although with different degrees of intensity, some strategies are more predominant in some narratives rather than others.

Chapter eight presents the close reading of the four memoirs comprised in the second source category (i.e., narratives of non-contested illnesses) and it draws on the analytic tools of evaluation and stancetaking as elaborated on chapter six. The analysis of these memoirs allowed me to derive some comparative observations; for instance, I could confirm that the narrators of this category did not need to construct credibility about their ontological reality of their conditions. However, they used discursive devices to make other sorts of claims: claims regarding their personal needs to have their suffering acknowledged by their physicians (e.g., Frank) and to have the freedom from choosing a post-mastectomy body-image without stigmatization (e.g., Lord). Methodologically, the analysis of the memoirs in this category allowed me to compare the narrative strategies used in both categories and derive further concluding observations about their uses of rhetorical devices. The final chapter is the conclusions in which I summarize the findings and discuss the contributions of this study in the context of other studies.

CHAPTER ONE

ILLNESS NARRATIVES as an AUTOBIOGRAPHICAL GENRE: SOCIOCULTURAL and NARRATOLOGICAL BACKGROUND

In this chapter, I trace the sociocultural influences that have facilitated the emergence of illness narratives in the twentieth century, as the popular genre that it is today. Although we may currently take the genre of illness narratives for granted, it has been interesting to me to see that its existence dates only from around fifty years ago (see Hawkins 1999). I have come to the realization that disentangling the origin of this genre is a complex task due to the variety of sociocultural factors. The present chapter is not a history of the genre, but the concepts elaborated here may help to provide a context for the understanding of narratives of contested illnesses that I shall address in this dissertation. Regarding the social context, it is important to bear in mind that as history shows, in the period of less than a century, advances in medicine made possible the extension of life expectancy (see Shorter 1985). Yet these advances paradoxically contributed to the rise of chronic illnesses along with social and ethical challenges associated with the care of the chronically sick, the disabled, and the elderly. Thus, it is not coincidental that fields such as bioethics, palliative care, and medical humanities concomitantly emerged in the 1970s (see Cole, Carlin, and Carson 2015) along with the illness narrative as a subgenre of autobiography (Hawkins 1999). The increasing sophistication of biotechnology has made it possible that some illnesses, once looked upon with suspicion and associated with hysterical dysfunctions (e.g., Lyme disease and multiple sclerosis), have now become formally recognized diseases (see Harrington 2008). Such recognition has given hope to some patients of other currently contested diseases, such as fibromyalgia and chronic fatigue syndrome, that one day science will find their biological bases and recognize them also, assuming that in all cases biological bases can indeed be discretely identified.

Another important concept to bear in mind is that the term "illness narrative" encompasses two major sociocultural constructs that seem to have co-evolved—on the one hand, the construct of "narrative" as beyond its structural and textual definition, and on the other hand, the social construct of "illness" as a different concept from disease (see Engel 1977; Kleinman 1988). I suggest that without the epistemological evolution of these constructs, the genre of illness narrative would not exist today, or it would probably be something different. Moreover, there is another notion that needed to evolve, that is the notion of "self" which led to the development of autobiographical texts (see Olney 1980). For reasons of organization, I will develop the relevance of the notion of self in connection to the autobiographical genre in the next chapter, when I address the oral and written aspects of illness narratives. In the next sections of this chapter, I will elaborate on the sociocultural influences that have contributed to the emergence of illness narratives; that is, postmodernism, the narrative turn in the humanities and the social sciences, the rebellion against Parsons' (1951) sick-role model, and the commodification of private stories.

1.1 The Narrative Turn and the Interconnection with Postmodernism

In his article "Trusting the Tale," Martin Kreiswirth (1992, 631) sets the year 1980 as the "annus mirabilis for narrative theory in North America." In that review of the literary/linguistic, psychoanalytic, phenomenologic/hermeneutic, and cognitive publications on narrative theory, Kreiswirth (1992, 631) asserts that “the study of narrative actually took center stage, and ushered in the beginning of what might be termed the narrativist decade of the 1980s.” Authors Cole, Carlin, and Carson (2015), in their book *Medical Humanities*, also set the 1980s as the time when the genre of illness narratives seen as *pathographies* (Hawkins 1999) really expanded. They notice that while memoirs of dying (e.g., *Stay of Execution* by Stewart Alsop) characteristic of the 1970s continued to predominate, “[they] were now augmented by accounts of living with maladies of mind and body, soul, and self” (126). There is agreement in the literature regarding the 1980s as a centered stage for narratives in general, and illness narratives, in particular. This overlapping is one factor, but not the only one at indicating that, most likely, illness narratives could have not developed as a genre without a new intellectual and public interest in narratives per se.

To begin, the development of illness narratives in the late twentieth century cannot be isolated from the influence of the narrative turn and postmodernism in the humanities and the social sciences (e.g., Frank 1995; Jurecic 2012). I shall elaborate, first, on the influence of the narrative turn from its inception, as most of its initial attention was paid toward the linguistic and structural aspects of literary texts; second, I shall elaborate on how this initial focus on form evolved into seeing narratives as a form of knowing and self-knowledge with the contributions of authors such as Paul Ricoeur and Jerome Bruner. The relevance of this historical review lies in gaining an understanding of the purpose and function of illness narratives as a genre.

The “narrative turn” is an umbrella term that focuses on the study of narratives in different disciplines such as the humanities (e.g., history, literature, philosophy), the social sciences (e.g., sociology, psychology, sociolinguistics, anthropology), medicine, and law. Czarniaska (2004, 2–3) notes that the impulse toward the study of and emphasis on narrative originated in the humanities with hermeneutic studies of religious texts. In the twentieth century, along with the influence of the teachings of Ferdinand de Saussure (1857–1913), new schools such as Russian Formalism (represented, for instance, by Vladimir Propp and Tzvetan Todorov) began to look at texts from a structural perspective. In a search for structural aspects of narrativity, Russian formalist Vladimir Propp (1968) focused his study on Russian folk stories, as he thought that the orality of these folk stories, transmitted from generation to generation without significant changes, would preserve the deep structures associated with the narrative structure. Later, sociolinguists such as William Labov and Joshua Waletzky (1967) in the United States also focused on oral narratives, especially on narratives of life experience. Their hypotheses were that deep narrative structures were better identified by looking at the unplanned and unconscious wisdom of everyday oral narratives rather than at the planned and crafted products of high literature:

> In our opinion, it will not be possible to make very much progress in the analysis and understanding of these complex narratives until the simplest and most fundamental narrative structures are analyzed in direct connection with their originating functions. We suggest that such fundamental structures are to be found in oral versions of personal experiences: not the products of expert storytellers that have been re-told many times, but the original productions of a representative sample of the population. (Labov and Waletzky 1967, 12)

I suggest that the influential approach of Labov and Waletzky (1967) should not be seen as a rejection of literature but instead as the belief that cultural products are interconnected, forming a continuum with all uses of natural language, as Butler (2002, 31) notes. However, the structural concern with texts could not be held within the boundaries of linguistics. The structuralist methods of analysis extended to the humanities and social sciences, such as anthropology and psychoanalysis, among other disciplines.

The interest in narrative as an enclosed textual structure evolved into new directions; for instance, critical attention focused on the reading act as a co-construction and interaction with the reader. From the traditions of hermeneutics and phenomenology, the French philosopher Paul Ricoeur (1913–2005) contributes to another conceptualization of narrative as he articulates the relationships among narrative, time, plot, memory, and identity. Ricoeur draws on Heidegger's (1962) phenomenology of time, especially on the concepts of *within-time-ness* (i.e., the existential experience of time in which certain events in life become more relevant, conscious, and significant than others for the individual) and *being in time* (i.e., the abstract, chronologic measuring of time in days and hours of which we are often unaware), to conceptualize the narrative as composed of two dialectical dimensions: the chronological or *episodic dimension* that corresponds to the story in which events unfold in chronologic time, and the configurational dimension (nonchronological) that corresponds to the plot. For Ricoeur (1980, 178), "the plot construes significant wholes out of scattered events." The plot is an individual creation that although it may draw on events from the real world, is based on memory and emotions. Thus, the plot, associated with-timeness reflects the individual experience of time in which for whatever reason certain events became more relevant and significant in one's recollection.

Under the light of Ricoeur's views, a narrative has been seen to be the result of the individual creation that makes sense of relevant events by means of putting together a plot while, at the same time, the individual construes his/her personal identity by means of narrative: *a narrative identity* (Ricoeur 1992). From Ricoeur's (1992) standpoint, the self is embodied through its own narrative and, through narrative, the self-inaugurates a new identity, i.e., recreates itself. In this regard, the narrative of personal experience is a quest for one's self and, simultaneously, the quest for one's self is a narrative endeavor. Whereas events are contingencies in a person's life, the role of emplotment is to weave together these contingencies into a meaningful story. Thus, the function of the plot is to somehow draw together discordant events into a concordant unity within a temporal span. Then, once the events have been emplotted, they are no longer contingencies. At this point, we can assert then that the plot is an *individual creativity*.

Another major intellectual influence that contributed to the shift in direction from the focus on text to the integration of the sociocultural context is the work of Russian author Mikhail Bakhtin (1895–1975). His notable ideas on heteroglossia, unfinizability, answerability, dialogism, and speech genres emphasized the plurality of views and voices in the novel—as a modern cultural expression— as well as the influence of context in meaning (see, e.g., Emerson and Holquist 1986). Bakhtin's ideas offered a different, nonstructural approach and, more importantly, a non-monologic view that transcended the formal work of structuralists enclosed in the structure of the text as its sole and isolated universe.[1]

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[1]. Structuralists had one major goal in their attempts to isolate universal, textual structures, which is to demonstrate that the study of language (and literature) could be isolated from other disciplines and studied in a scientific way. Although their attempts proved to be highly challenging, they did contribute to the development of linguistics as a discipline and to proposing systematic ways of reading literature that were not based merely on a psychological interpretation of the characters.

1.2 The Influence of Postmodernism and Narrative as a Mode of Knowledge

A prominent vision of narrative as a mode of knowledge can be found in the work of Jerome Bruner (1986, 1991) and Donald Polkinghorne (1988). Because Bruner's insight of narrative as a form of knowledge was inspired by the work of Jean Francois Lyotard (1984, 1992), as the pioneering theorist of postmodernism, I shall elaborate first on Lyotard's arguments.

French theorist Jean Francois Lyotard (1984) defined postmodernism as "incredulity toward metanarratives," (xxiii–xxiv) or toward grand narratives. Typically, postmodernist ideas and attitudes (see, e.g., Butler 2002; Harvey 1989) have been characterized as showing antagonism toward grand narratives while emphasizing self-reflection and pluralism of interpretations, distrust in monolithic formulations of truth, resistance against hierarchical and bureaucratic structures, and active vindication of countercultures that explore the realms of the individual. For the most part, postmodernists' ideas seem to inform the social work that illness narratives do in vindicating the legitimacy of the lifeworld; that is, the legitimacy of the individual/patient's experience against the grand narrative of science and biomedicine, as *the voice of medicine* (see Mishler 1984).

In his famous report titled *The Postmodern Condition*, written in 1979 and translated into English in 1984, Lyotard notes that science and the scientific method draw on reason and progress to legitimate their superior epistemological status over other disciplines (Sim 1996, 146). In that report, Lyotard reasons that narratives cannot be demonstrated, i.e., they are not false or true; thus, they do not have claims of veracity or truthfulness. Yet scientific claims about reality and the nature of the world are not so much about “proof” as rather an “adequation between theory and experimentation” (24). Lyotard (quoted in Sim 1996, 24) poses the following question, “What I say is true because I prove it is but, what proof is there that my proof is true?” It seems that Lyotard is concerned with the circularity and tautological aspects of proving truth. Lyotard attributes to Plato and his cave allegory the inaugural dependence of science on narrative.

The cave allegory legitimizes the authority of Plato’s philosophical theory of truth. Then, paraphrasing Lyotard, we could ask: How do we know that those men in the cave facing the walls are not seeing the truthful side of things but rather their own shadows? How do we know that true reality is outside the cave rather than inside? It seems, following Lyotard, that we depend on an external, authoritative narrative to confirm that that is the truth; consequently, it can be derived, following Lyotard, that we depend on narratives to access truths. Lyotard argues, then, that science cannot meet its own condition of proof without relying on the narrative about its own superior access to knowledge. Science is a narrative that tries to pretend that it is not a narrative because admitting this idea would severely damage its cultural status and authority in the process. Nevertheless, Lyotard’s questioning of the legitimacy of science should not be seen, I suggest, as a denial of the importance and the benefits of science to humankind but rather as a calling into question the totalizing power of grand narratives such as science, whose social influence has been in effect since the Enlightenment. Thus, in their emphasis on the lived experience of illness, illness narratives call into question the grand narrative of science and medicine in describing diseases from a biomedical perspective that is disconnected from the personal experience and human suffering of the sick person (see Cassell [1991] 2004; Frank 1995; Kleinman 1988).

As mentioned above, Jerome Bruner draws on the pioneering work of Lyotard in his report on knowledge. In the essay “Two Models of Thought” (1986), Bruner proposes that narrative is a mode of thought, an apprehension of reality, and a mode of communication fundamental to the human cognitive makeup. Bruner (1986) further elaborates on the difference between the logico-scientific form of knowledge and the narrative one. He observes that the logico-scientific mode is based on the need to confirm or reject hypotheses through their testing against empirical data. Thus, the logico-scientific form of knowledge (also called “paradigmatic,” Bruner 1986, 11) looks for objective and generalizable truths that facilitate predictions. However, the narrative mode of knowledge is not concerned with objective and general truths but with making sense of experiences from a subjective perspective. Verisimilitude is the internal logic of narrative, rather than truth. Thus, the narrative mode is concerned with the vicissitudes of the human experience rather than with identifying general patterns. In so doing, the emphasis of the narrative mode is on the unique way classic human dramas are emplotted. Similarly, readers may make different interpretations of the same narratives. For that reason, Bruner (1986, 25) notes that narratives operate by means of suggestive language that invites readers to make inferences and subjective interpretations, leaving the interpretation of the text open to multiple perspectives.

Following Bruner’s lead, Donald Polkinghorne (1988) also emphasizes that the function of narratives is not to demonstrate but to explain. The narrative explanation articulates temporality and causality into a story; “in the narrative schema for organizing information, an event is understood to have been explained when its role and significance in relation to a human project is identified," states Polkinghorne (1988, 21). Instead, in the logico-scientific mode of thinking, an explanation is understood to occur when "an event can be identified as an instance of an established law or pattern of relationship among categories" (Polkinghorne 1988, 21). For Polkinghorne, the concept of emplotment is fundamental in the narrative way of knowing. Emplotment is what transforms a list of events or a sequence of disconnected events into a unified story with a point and a theme.

The critical questioning of grand narratives contributed to two main postmodernist attitudes: skepticism and relativism, which had an impact on the conceptualization of narrative interpretation and narrative creation (see Jurecic 2012). Along with Lyotard's influential writings, authors in the fields of deconstruction (e.g., Jacques Derrida), poststructuralism (e.g., Roland Barthes), and social constructionism (e.g., Berger and Luckman) became associated with the typical skeptical and relativistic attitudes of postmodernism in Europe and the United States in the second half of the twentieth century.

In his introduction to postmodernism, cultural historian Christopher Butler (2002, 15) describes postmodernism as a pluralistic age in which the arguments of scientists and historians have no unique or reliable fit to the world, no certain correspondence with reality: "They are just another form of fiction" (15). Interestingly, the idea of scientific arguments as fiction, as noted by Butler (2002), is associated with the postmodernist concepts of emplotment (as a subjective configuration, a combination or collage of different standpoints in which truth is seen as relative) and intertextuality, as promoted by poststructuralist authors such as Jacques Derrida and Roland Barthes, among others. To explain the idea of scientific argument as fiction, as characteristic of postmodernism, I would like to refer to the work of Swiss linguist Ferdinand de Saussure and his foundational concept of language, from which Derrida and Barthes based their own theories on deconstruction and poststructuralism, respectively. These thinkers have had great influence in the unfolding of the narrative turn.

The concept of the arbitrariness of the linguistic sign between a signified and signifier was pioneered by Ferdinand de Saussure in 1911. According to Saussure (1959), the arbitrariness of the linguistic sign means that there is no natural connection between word and the world. In Saussure’s theory, language is the result of complex and historical social conventions: “[language] is both a social product of the faculty of speech and a collection of necessary conventions that have been adopted by a social body to permit individuals to exercise that faculty” (Saussure, 9). The linguistic sign is “unmotivated, i.e., arbitrary in that it actually has no natural connection with the signified” (Saussure, 69). Words are not making reference to things in the world but rather to abstract linguistic signs that conceptualize and represent their meanings. For instance, the word “tree” does not refer to a tree but to the abstract concept of what a tree has been agreed upon to mean in certain cultures. Thus, the meaning of the linguistic features does not lie in the world but in their systematic relations of similarity and opposition to other linguistic features. Saussure’s famous metaphor is *the chessboard,* with which he illustrates the workings of the linguistic terms in the structure of language: “la langue” is the chessboard. In the chessboard of “la langue,” for instance, the Spanish phoneme “p” is similar to “b” in their occlusive vocal aspect, but they differ in their sound/soundless features, respectively. As

Saussure (1959, 88) states, “the respective value of the pieces depends on their position on the chessboard just as the linguistic term derives its value from its opposition to all the other terms.”

Saussure’s theory was indeed the beginning of sociolinguistics as a social science, and although the *Course in General Linguistics* presents a mechanistic and positivistic view of language, it become the source of inspiration for structuralists, such as Roland Barthes, and for deconstructionists, such as Jacques Derrida, as mentioned above. On the other hand, Saussure’s structuralist theory served as a point of refutation by authors such as Mikhail Bakhtin and Paul Ricoeur, who also became highly influential in the conceptualization of narrative from the dialogic and phenomenological viewpoints. I shall elaborate on Derrida’s theory first and on Bakhtin’s and Ricoeur’s later.

Derrida’s ([1967] 1974) deconstructionism criticized the Western logocentric confidence in language as the mirror of nature. Derrida argues that this logocentric confidence is an illusion that places the basis of reference in reality and nature in itself rather than in the reference to other texts (or linguistic features in Saussure’s terms). For deconstructionists and structuralists, no text ever finally establishes anything about the world outside itself, but all texts are referring to each other rather to any external reality. In this view, intertextuality, as the dissemination of texts, replaces referentiality, and literal meaning does not unambiguously refer to reality but, instead, to other metaphorical and symbolical systems. Thus, the concept of meaning ends up being a subjective interpretation consisting of references to other texts, i.e., a creation or emplotment that could be interpreted as a form of “fiction.”

Like Derrida, historian Hayden White (1973) argued that there can be no discipline of history but only of historiography. Even drawing on the same facts, each historian may emplot the historical events (i.e., configuring or making relationships of causality) in different ways, seeing motives where others may see coincidences. In White's (1985) words, "historical narratives […] are verbal fictions, the contents of which are as much invented as found and the forms of which have more in common with their counterparts in literature than they have with those in the sciences" (quoted in Butler 2002, 33). The relationship between the invented or constructed and the found or the evidential is a matter of interpretative dispute: the historian like the novelist cannot escape the metaphoric system of language that he or she has inherited, as Butler (2002, 34) observes. Yet regarding postmodernist relativism, Butler (2002, 34) warns us about a slippery confusion: relativism does not mean that facts do not matter or that faction and fiction are the same. Postmodernists emphasize the awareness of the rhetorical effect of how facts are being emplotted and integrated in the story, i.e., an awareness of the relationships of causality and temporality that interpreters create among events. Thus, postmodernists call attention to the rhetorical aspects that inform events and to the fact that the same events can be described in different ways. In any description of events, historians/narrators are always leaving some aspects out; there are absences and gaps in the process that reflect their biases or just the things that command their attention, resulting in the way they emplot the stories. Postmodernists call for self-reflexivity and self-awareness about the theoretical assumptions we use to support and legitimate our narratives. Yet narratives can be said to be "more or less adequate to the interpreted evidence, and new evidence can still overturn narratives," asserts Butler (2002, 36). Like novelists, historians are not entirely free to make things up, as controversy over Holocaust deniers has shown (e.g., Lipstadt 1993). To summarize this section, it needs to be emphasized that the concept of emplotment which is at the center of the postmodernist debate, is a relevant theme in this dissertation thesis that examines aspects of truth, credibility, and unreliability in narratives of contested illnesses (see chapter 5).

1.3 The Influence of Postmodernism and Narrative as Self-Knowledge

The postmodern need for constant self-reflection by means of narrative as a means to find continuity in one's identity is emphasized by sociologist Anthony Giddens (1991) in his book *Modernity and Self-Identity*. Like Lyotard, Giddens discusses a skepticism about grand narratives. Within the context of late modernity and the sociocultural changes introduced by advances in technology, medicine, and communications in industrialized countries, where life expectancy has been extended, Giddens (1991) observes that people have been subjected to a multiplicity of perspectives and exposed to a multifaceted reality characterized by phenomena such as the dissolution of cultural traditions, the systematicity of doubt regarding any sort of knowledge, and the diversity of lifeworlds and lifestyles. Giddens points out that grand narratives drawn from traditional sources, such as religion and modern medicine, have been called into question or doubted, or they have lost the effectiveness of their rhetorical comforting effects. The postmodern condition, asserts Stuart Sim (1996, 31), is when universal theories (or grand narratives) of the past can no longer be relied upon to provide the necessary foundations for discourse. Giddens (1991) explains that in order to resist this sense of fragmentation and discontinuity that renders one's personal sense of identity provisional, self-reflexivity becomes paramount. Thus, narrative, as a form of self-reflection, contributes to maintaining a sense of identity and, if necessary, to reconstructing one's sense of identity continuity. He calls this process of self-preservation the ongoing *reflexive project on the self*, which "consists in the sustaining of coherent, yet continuously revised, auto-biographical narratives" (Giddens 1991, 5). In writing a self-referential narrative, authors need to contextualize and interpret their personal story within the historical and sociocultural contexts of their lives. In so doing, the narrative creates meaning, which in turn can be recreated given that the same historical circumstances can be reinterpreted by the subject in different ways, that is, through selective cognitive, psychological, and emotional processes similarly to the way metaphors and plots are created (see Lakoff and Johnson 1980, and Ricoeur 1984). In the next section, I will address the emergence of illness narratives as a genre that emerges as a reaction against the sick-role model.

1.4 The Rebellion against the Sick-Role Model

An important theoretical conceptualization in this study is the distinction made by medical historians, philosophers, anthropologists, and sociologists among the concepts of disease, illness, and sickness. The distinction among them is methodological and it is relevant to contextualize the genre of illness narratives.

There is consensus in the literature that while the concept of disease refers to the objective biomedical category, illness is subjective and experiential. For that reason, a person may feel ill without being diseased, or vice versa. Following Marshall Marinka (1975) (cited in Quinn Shone 2019, 24), diseases can be measured, quantified, somehow touched by apparatus and observation. There is a "statistical objectivity to [diseases], they present themselves as a deviation from biological norm" (Quinn Shone, 24). Instead, illness is "a feeling, something inward, only accessible by the patient, an underworld of experience.… [Illness] is inconsistent and variable" (Quinn Shone, 24). Sickness, though, is understood in terms of the societal sanctions and consequences that disease/illness may entail for the person, such as job or school absenteeism. Furthermore, the concept of sickness, as aligned with sociologist Talcott Parsons' (1951) sick-role model, seems to be reduced to a matter of societal negotiation between the physician, the patient, and his or her social context. The patient is responsible to get well by following the doctor's orders and showing that the state of being sick is a socially undesirable state. The medical voice may decide whether to grant a waiver for the person's social responsibilities. Parsons' (1951) book *The Social System* offers a social theory about how medicine as an institution inscribes the individual into the sick role in order to provide her with a temporal exoneration from the responsibilities of labor. Sickness, when legitimated by a doctor, becomes a justifiable reason for the individual's lapse in productivity. Entering the sick role, however, requires submission and compliance with doctors' diagnoses and treatments under the social penalty or sanction of being considered "deviant" if failure to adhere to the medical treatment is observed. Although entering the sick role is deemed as the legitimate way to deviate from social and productive responsibilities without suffering social stigmatization for it, the sick-role model describes a form of social control that threatens with stigmatization if the person does not accommodate to this role.

In *The Wounded Storyteller*, medical sociologist Arthur Frank (1995, 11–13) explains that in modern times, patients have consented to the sick-role model; that is, when medicine successfully prevented and treated mostly acute conditions or infections with sulfa drugs and antibiotics, or vaccination. However, with the advance of chronic diseases as a consequence of the improvement of health of populations and the extended life expectancy of thirty years on average (see Shorter 1985), patients began to resist the sick-role model. With chronic illnesses people not only live longer but they also have more time to reflect about their experiences living with chronic illness. In reaction, patients feel trapped by the intrusion of medicine into their lifestyles and by the medicalization of a range of behaviors that once were seen as part of life, i.e., normal.[2]

Frank (1995, 5) observes that whereas in the modern period, the medical voice prevailed as the main and only story of illness subjecting the patient to a "narrative surrender," postmodern times emphasize the patient's capacity for telling her own story. The patient's narrative acquires a legitimacy on its own. Patients want to have their own suffering recognized in their individual particularity. Patients no longer accept their narratives being reduced to nomothetic conditions, called diseases, by the voice of medicine: "They want to speak rather than being spoken for," asserts Frank (1995, 13). Thus, patients' emplotment of their illness narrative emerged fortified, self-validating, and challenging the authority of medicine even if it did not substitute it (see Shorter 1985, 1992).

In sum, Frank sees illness narratives as expressing patients' rebellion against the silencing of their stories or as being placed in a second-degree category. And he

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[2]. In his book *Saving Normal*, psychiatrist Allen Frances (2013) calls into question the new diagnoses documented in DSM-5, writing that "My forgetting names and faces would be covered by DSM-5 'minor neurocognitive disorder.'… My well-known hyperactivity and distractibility were clear signs of 'adult attention deficit disorder.'… An hour of amiable chatting with old [colleagues], and I had already acquired new DSM diagnoses. … Normal needs to be saved from the powerful forces trying to convince us that we are all sick" (Frances 2013, Preface, e-book).

compares the patient’s struggle to regain her own voice with the struggle of postcolonial subjects who want to be recognized as individuals in their own rights. The postcolonial theorist Gayatri Spivak notes that while the “master texts” need us in their construction, they do not, however, acknowledge that need (cited in Harasym 1990, 73). Similarly, Frank (1995, 11) asks, “what do the master texts of medicine need but not acknowledge?” as illustrated with irony by the character of Vivian Bearing in Margaret Edson’s (1999) play *Wit.*[3] The protest expressed by patients through illness narratives against the reifying language and actions of medicine does not emerge in a social vacuum. Rather, it is a reaction against the Parsonsian theory of the sick role. “Postmodern times are when the capacity for telling one’s own story is reclaimed,” asserts Frank (1995, 7). Patients want their subjective illness experiences (i.e., their illness narratives) to count as much as their diseases may ontologically count for their physicians.

1.5 Postmodernism and the Commodification of Private Matters

In the book *Condition of Postmodernity,* David Harvey (1989, 63) asserts, following Jameson (1984) and Mandel (1975), that postmodernism is “nothing more than the cultural logic of late capitalism.” These authors agree in seeing postmodernism as an era in which, since the early 1960s, the production of culture has become integrated into commodity production. In Harvey’s words,

> While some would argue that the counter-cultural movements of the 1960s created an environment of unfulfilled needs and repressed desires that postmodernist popular cultural production has merely set out to satisfy as best it can in commodity

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[3] [Dr.] Kelekian and [Dr. Posner] “are simply delighted. I think they foresee celebrity status for themselves upon the appearance of the journal article they will no doubt write about me. But I flatter myself. The article will not be about me, it will be about my …. peritoneal cavity, which, despite their best intentions, is now crawling with cancer” (Edson 1999, 53).

> form, others would suggest that capitalism, in order to sustain its markets, has been forced to produce desire and so titillate individualistic sensibilities as to create a new aesthetic over and against traditional forms of high culture. (Harvey, 1989, 63)

Another relevant aspect of this new sensitivity, in which illness narratives are an expression, is that marginalized forms of identity and behavior not only are claimed but they became public. As Arthur Frank (1993) observes, the emergence of the illness narratives requires the condition that "people must consider it appropriate for private experiences to be represented as public events" (40).

In addition to the AIDS narratives that emerged in the 1980s and 1990s, a good example of the commodification of private matters is the feminist work of Mary Kelly (cited in Butler 2002, 65), who documented her relationship with her baby son in her art exhibition titled *Post-Partum Document* (1973–1979). The exhibition included controversial photos and objects documenting daily chores associated with the care of a baby, such as dirty diapers. That exhibition highlighted the cultural shift (e.g., taboo aspects involving daily life) in which one's intimacy and vulnerability are not only reclaimed as a public topic, but also become available for social consumption. The publication of personal, intimate, and vulnerable aspects of the self, such as illness, also makes a political statement, a claim for acknowledgement that seeks validation and recognition in the public sphere: "the illness narrative presents who the ill person has become and stakes a public claim on this new identity," asserts Frank (1993, 42).

According to his article "The Rhetoric of Self-Change," Frank (1993) asserts that illness narratives as a new genre can be identified for the first time with the publication of Stewart Alsop's *Stay of Execution* in 1973. Frank's argument lies in the observation that Alsop (a well-known political journalist from *Newsweek* at the time) began to devote some of his *Newsweek* political columns to writing about his own experiences with leukemia, thus mixing politics with making his own illness public. For Frank, this is the beginning of a new way of writing about illness as a means of embracing taboo topics in a public way.

1.6 Illness Narratives and the Publishing Boom

If autobiographies as (self) life writing were initially seen as a private matter (I shall further elaborate on autobiographies in the next chapter), illness narratives became a matter of public consumption as explained above. This public consumption was stimulated by the cultural and publishing boom of illness narratives (see Jurecic 2012) and it could be explained, in part, by the shift in sensibility that came along with the ideological changes introduced by the postmodernism, the commodification of narratives as life writing (as discussed above) and the Civil Right movements in the 1950s and 1960s, as I shall explain.

Jurecic (2012) observes that the social influx of the Civic Rights movement in the United States overlapped with the claims of HIV/AIDS patients and their family members for better therapies and care. As an infection transmitted by contact with infected blood, the HIV/AIDS epidemic brought to the fore women's health claims, especially concerning reproductive rights, as well as the claims of LGTBQ minority groups for their rights to have their sexual preferences and identities officially acknowledged. Furthermore, the publishing boom of illness narratives would not have been possible without the paperback revolution of the 1939 that reduced the cost of books, and in the mid-1990s, the invention of the internet along with the presence in the market of electronic devices, facilitated access to all sorts of publications. The combination of the paperback revolution and the shift in sensibilities may explain the explosion of narratives around AIDS, which she compares with the lack of publications concerning the devastating flu pandemic of 1918 that killed fifty to a hundred million people (Jurecic 2012, 1). With the shaping influences of these socioeconomic factors, illness narratives became part of a new sensitivity of consumption (not fiction though, but rather autobiographical works) in which it became acceptable to indulge one's voyeuristic impulses into the dramatic and messy life circumstances of others.

1.7 Illness Narratives in the Era of Risk Society

Another important factor that has motivated the emergence and popularity of illness narratives, is "our increasing awareness of statistically calculated risk," asserts Jurecic (2012, 18). And then, she adds emphatically, "as health statistics have proliferated, so have illness memoirs" (18). To explain her argument, Jurecic draws on the influential, sociological studies of Ulrich Beck, *Risk Society*, and *Individualization,* co-written with Elizabeth Beck-Gernscheim. Beck's concept of risk society emerged in the 1980s and explains the loss of confidence in scientific and technological progress during late modernity that had been gained earlier, especially when in the industrialized world, medicine seemed to have under control the spread of infectious diseases. In late modernity, new pandemics like AIDS in the 1980s, SARS in the early 2000s, and most recently COVID-19 emerged as new pandemic threats to humanity causing numerous deaths and economic destruction.[4] These threats are new in the sense that are a hybrid of

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[4]. At the time of writing this dissertation we are experiencing the Novel Coronavirus pandemic or SARS 2-19, whose outbreak was identified in the United States in January 2020. Up to this date, there is no cure for the infections with HIV/AIDS or SARS 2-19.

nature (i.e., the effects of global warming), society, and culture. As a result, probabilistic assessments of the degree of certain risks have supplanted master narratives previously based on beliefs in fate, and also, they have cast doubt on the capacity of science and technology to prevent and control risk.

In this social context, “risk narratives” (Jurecic 2012, 19) may play the function to contain fear and uncertainty by enforcing normalicy—a theory proposed by Lennard Davis (1995); or they may be a way of contemplating and negotiating life risks—as Beck and Beck-Gernscheim (2002) propose. Beck and Beck-Gernscheim see in (auto)biography, the central genre of the risk society. As Giddens (1991) talks about the *ongoing project of the self*, Beck and Beck-Gernscheim see the self as having to manage and adapt to the constant assessment of risks and probabilities in the risk society. Beck and Beck-Gernscheim (2002) note that never, needed before, humanity faced the burden of this level of knowledge and detailed information and the degree of refined awareness of the consequences that seemingly insignificant decisions may bring.[5] The case of contested illnesses may challenge the notion of risk. Whereas risk involves uncertainty, it also involves probabilities; however, risk presupposes the existence of a danger or threat, thus if a disease is seen as a threat, then its danger is assessed or evaluated. Yet in the case of contested illness, risk is less clear to assess because contexts of exposure and risks factors are poorly understood. Also, given that contested illness have a dispute ontological status, risk factors tend to be neglected or under studied. As Davis (1995) sees in the genre of autobiography and in the novel the expression of a normalizing

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[5]. Some authors do not see risk as equivalent of disease; for instance, psychiatrist Allen Frances (2013) points out in the preface of his book *Saving Normal*, that risk is not the same as having a disease.

device, I suggest that this may be the case also in narratives of contested illnesses given that patients/narrators have to deal with the reportability paradox in which out-of-the-ordinary events need to be narrated as ordinary to gain credibility.

1.8 Conclusions

This chapter reviewed the sociocultural and narratological factors that gave rise to narratives as legitimate tools to know the world and oneself in their own idiosyncratic manner. Narrative emplotment emerges as an essential concept that allows us to understand that narratives and therefore, illness narratives, are representational constructions in which narrators organize the events by means of their subjective lenses and communicative priorities. The very same concept of illness (as a subjective narrative) is linked to the concept of emplotment as opposed to disease, as a nosological type of entity. By reviewing the sociocultural influences, this chapter showed that illness narratives are the sociocultural product of postmodernism in which the voice of lifeworld is asserted over the voice of medicine, despite patients/narrators' continuous claim for recognition from the voice of medicine. Other social factors, such as the grass root movements in the fight against the AIDS epidemic along with the civil right movement in the United States have also contributed to the development of illness narratives as an autobiographical genre because they reinforced the voice of lifeworld. It is fair to say that the genre of illness narratives would have not evolved as a publishing boom without the social desire and need to put (and commodify) private matters in the public view, as a way to claim medical attention and, paradoxically, as a way to resist the voice of medicine.[6] Moreover, if illness narratives are a way in which patient/narrators deal with probabilities and risk, as argued by Beck and Beck-Gernscheim (2002), in the case of contested illnesses the memoirists here will show how risk cannot be recognized, unless a condition is first legitimized. In the next chapter, I will focus on the literature review on illness narratives from the linguistic, narratological, and literary perspectives. I will also provide the autobiographical context that led to the emergence of the genre of pathographies and memoirs.

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[6]. The terms the voice of lifeworld and the voice of medicine are borrowed from Elliot Mishler's (1984) book, *The Discourse of Medicine*.

CHAPTER TWO

ILLNESS NARRATIVES as INTERACTIONAL ACHIEVEMENTS and AUTOBIOGRAPHICAL TEXTS

This chapter traces the evolution of illness narratives from the linguistic turn (Hydén and Mishler 1999; Whitehead 2014) to the narrative turn (Hawkins [1993] 1999; Hunter 1991) drawing on a review of the literature in linguistic and literary/narrative traditions. Although in this dissertation I will analyze memoirs, that is, written illness narratives or autopathographies as part of life writing, according to Smith's and Watson's (2010) categorization, I acknowledge the oral, interactive, and narrative aspects that these patients faced before becoming narrators of their autobiographies. In fact, as I shall elaborate, the term illness narratives may refer, on the one hand, to the oral productions that patients co-construct in consultation with their healthcare providers, and on the other, to the written memoirs. Before I elaborate on this point, two main aspects about the intricacies between orality and literacy involving illness narratives deserve our attention.

First, the creation of an autopathography by a person who has decided to write her or his illness experience is a transfigured product of that experience done retrospectively; it involves processes such as memory, introspection, emplotment, and representation, which in turn recreates that experience in the act of writing. However, before telling their stories about their contested illnesses in a written form, these memoirists were patients who told their illness narratives to their healthcare providers in face-to-face encounters with them. Encounters that, in many cases, were not satisfactory because their oral narratives were not acknowledged or believed. In turning to writing, these memoirists draw onto the authority of the published book (Ong 1982) to reclaim the credibility of their oral narratives, which were previously dismissed as non-doctorable. Thus, when Arthur Frank (1995) asserts that illness narratives are a means for patients to reclaim their voices, I suggest that that reclaim is not only of their own subjectivities against the sick-role model as he accurately observed, but also a reclaim of their literal voices in conversations with their healthcare providers. Whereas writing and publishing empower and amplify these patients' dimed voices, the print fixes their voices in space and the reprints help reproduce their voices in time.

Second, although as written texts autopathographies are autonomous, the writing can never be entirely disconnected from the reference to the extratextual oral world. In other words, the written text cannot be entirely disconnected from the person's oral and interactional experience of illness; otherwise, it would not be autobiographical. Walter Ong (1982) clearly explains the boundaries between orality and literacy. He states, "although texts are autonomous by contrast with oral expression [which depends on contexts], ultimately no text can stand by itself independent of the extratextual world. Every text builds on pretext" (162). Thus, autopathographies are self-referential to one's own life experience (see chapter five).

Here, I argue that the term illness narrative is polysemic. As I will explain, it has become almost synonymous with memoir by virtue of the influence of what some authors identify as the narrative turn, but I would rather identify as the literacy/literature turn. Here, given the autobiographical nature of autopathographies, I would like to call the attention to the embeddedness of memoirs with their oral and extratextual worlds, despite their autonomous character as written texts.

The term “illness narratives” refers to narrative co-constructions (e.g., Duranti 1986; Kleinman 1988; Schegloff 1997) in face-to-face interactions between patients and healthcare professionals, caregivers, or family members; and also, it refers to memoirs or pathographies (Hawkins [1993]1999) achieved by means of introspection, as narrative reconstruction (Frank 1993, 1995). The term “pathographies” appeared in Hawkins’ (1999) pioneering book *Reconstructing Illness* in which she used that term in the introduction to delimit the boundaries of illness narratives to “written narratives and only to narratives [written] by an ill person or by someone who is very close to that person” (xviii). Thus, the distinction of illness narratives as oral accounts or as conversational narratives that take place in doctors’ offices on the one hand, and as written memoirs on the other, is not frequently made in the medical/health humanities. However, this clarification is important not only because they correspond to different genres (i.e., to oral and written texts), but also to different forms of data collection and analytic methodologies. For the purpose of the analysis, I believe a distinction between these two denotations of the term illness narratives is necessary to establish in this dissertation. Although I will be analyzing written texts, that is, the patients as authors or memoirists’ illness narratives I need to base my analysis on what the authors report that happened to them in their interactions with their healthcare providers. Thus, I see their illness narratives as built, in part, on the pretext of their face-to-face encounters with their healthcare providers.

In this dissertation, the term “illness narratives” refers either to the patient’s oral account or to the author’s/patient’s memoir. However, when differentiation is needed, I will refer to the written illness narratives as pathographies or as memoirs.

2.1 Illness Narratives as Conversational, Explanatory Models

Prior to Hawkins' (1993) original study on pathographies, the term "illness narrative" was used by the psychiatrist and medical anthropologist Arthur Kleinman (1988), especially to address the case of chronic illness. Kleinman (1988) states,

> Patients order their experience of illness—what it means to them and to significant others—as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings. Over the long course of chronic disorder, these model *texts shape and even create experience*. The personal narrative does not merely reflect illness experience, but rather it *contributes to the experience of symptoms and suffering.* (49) (emphasis added)

Kleinman's statement contains several conceptual aspects that I would like to unpack.

First, he sees the patient's illness narrative as an oral account the patient shares with others (including her physician) and constructs in order to find meaning and convey her explanatory model of illness. Yet, as Kleinman observes, the patient's narrative is not a mere reflection of her illness experience; the linguistic and structural form of that narrative shapes and even creates the experience of illness. Kleinman's observation that the patient's narrative contributes to the experience of symptoms and suffering, foregrounds the reciprocal interconnection between language and experience; that is, how illness may inform our plots and, also, how the plots we create inform our experience of illness in either hopeful or pessimistic terms. Kleinman's position can be placed in context with that of discourse analysts who share consensus regarding the interconnections of language and the lifeworld. For instance, the discourse analyst Barbara Johnstone (2018, 35) asserts, “Discourse both reflects and creates human beings’ ‘worldviews.’” Similarly, the psychiatrist Howard Brody (2003) in his book *Stories of Sickness* notes, “The way we experience the world influences the language we use and the stories we tell, but just as important, the ways we use language and tell stories influence the way we experience the world” (24).

Another important aspect in Kleinman’s (1988) conceptualization of illness narratives is the role of the clinical encounter as a setting, and the role of interaction in shaping the unfolding of the patient’s narrative. On the one hand, Kleinman observes the importance of the personal countertransference of the physician and his or her professional interest in the way the physician interprets the patient’s illness narrative. On the other hand, Kleinman sees the patient’s illness narrative as a co-construction that results from the interaction between the patient and her doctor. As he notes,

> Even before the physician identifies an elusive illness into a precise disease, the very ways of auditing the illness account influence the giving of the account and its interpretation. Patients are usually aware of the demands of different settings … and how these [demands] help cast the story in a certain form …. The way they [physicians] nod their head, fidget, or look at the patient influences how the patient tells the illness story. (52)

Kleinman’s observation about the roles of the speech situation as well as the listener in shaping the trajectory of an account of illness, matches Hydén’s and Mishler’s (1999) observation about the importance of the interaction, as this is evocative of studies in linguistics and communication published around the time of Kleinman’s book, *Illness Narratives*. For instance, the linguistic anthropologist Alessandro Duranti writes in his article “The Audience as Coauthor” that the interlocutor can influence and shape the trajectory and outcome of the conversation. The form and content of verbal exchanges, like storytelling, are continuously reshaped by the co-participants through their ability to create certain alignments and suggest or impose certain interpretations (see Duranti 1986). In another study, the communication scholar Charles Goodwin (1986) also comments on how an unsympathetic or uncooperative audience can deeply affect the performance of any speech act. Goodwin also notes the importance of different types of listeners, such as those who either share (or do not) background information with their speakers. Sharing background information influences the "structure of attention" (Goodwin 1986, 285), which may vary depending on these factors. Consequently, tellers may treat recipients or listeners differently, depending on the degree of attention they may get back from them.

To the extent of my knowledge, Kleinman's (1988) emphasis on the interactive and co-constructive aspect of the patient's illness narrative in the clinic, is not traditionally observed in the literature about illness narratives in the medical/health humanities. One possible reason for this lack of attention to Kleinman's interactive emphasis is that his most observed contribution lies, rather, in his emphasis on the illness narrative as the patient's explanatory model. Kleinman's focus on illness narratives is in line with the idea of the patient's explanatory system as giving voice to her experience of illness, as well as on the patient's suffering, in contrast to the biological and physiological concerns from a biomedical perspective. As Hydén (1997, 51) points out, Kleinman's attention toward the patient's illness narrative helped shift the focus from the physician's viewpoint to the patient's viewpoint. In turn, Kleinman's notion of illness narrative emerges in the context of Engel's (1977) biopsychosocial model, as Kleinman (1988) himself refers to it:

> In the biomedical model the disease is an occluded coronary artery; in the biopsychosocial model it is a dynamic dialectic between cardiovascular processes (hypertension or coronary artery insufficiency), psychological states (panic or demoralization), and environmental situations (a midlife crisis, a failing marriage, the death of a parent from the same disorder). (6)

Engel (1977) claims that the adherence to biomedicine has reduced the definition of disease to somatic, biochemical, or neurophysiological processes considered to be independent of the social, psychological, and behavioral dimensions of illness. For that reason, in the biopsychosocial model, the patient's disease cannot be reduced to an anatomical pathology or physiological dysfunction; rather, all the patient's contexts, including her own explanatory model of illness (i.e., her illness narrative), need to be considered.

Within Engel's model, the physician's professional role is not only limited to cure but is also expected to facilitate the healing process of the individual. The biopsychosocial model creates the necessary basis for the significance of the patient's narrative, not only because of its clinical relevance but also because of the need to consider the patient's account. Thus, the patient's narrative reveals the interplay between disease and experience. Engel's (1977) proposal for a different medical model that includes all contexts of the patient's life as well as Kleinman's focus on the patient's suffering have contributed to a view of the patient's illness experience and her illness narrative as an object of study in its own right. In this regard, Hydén (1997) acutely observes, "This [contribution] makes it possible to study the patient's illness experience and illness world as a social reality apart from the conception and definition of illness as formulated by biomedicine" (52). In her ethnographic study entitled *The Body Multiple*, the philosopher Annmarie Mol (2002) traces how the illness narratives that patients articulated in their doctors' office became a possible object of study. Mol explains that the publication of Talcott Parsons' *The Social System* (1951), with its foundational theory of the sick role model, was a decisive moment in the human view of diseases because the social sciences manage to appropriate the body and its diseases from the exclusive domain of biology. Mol's (2002) recognition to Parsons' contribution is because he inaugurates the idea that "there is more to say about sick people than is told [just] by biomedicine" (12). Following Mol's observation about the important role that Parsons' sick role model plays, it can be pointed out now that illness narratives as an object of study either by social scientists or literary scholars, have become rather more complex texts than they appear to be, this is because they can be read through the lens of interdisciplinary studies involving the humanities and social sciences.

2.2 The Linguistic and Narrative Turns in the Study of Patients' Illness Narratives

In their "Language and Medicine" article, Hydén and Mishler (1999, 174) explain that the importance attributed to the patient's narrative was initially seen in instrumental ways; that is, the narrative was considered relevant only for the doctor's clinical work to treat the patient. The patient's narrative was thought of as the account the patient tells his or her doctor. It could be said that this instrumental view of the patient's narrative is in tune with the famous dictum attributed to physician Sir William Osler (1849-1919), "Listen to the patient, he is telling you the diagnosis" (as cited in Roter and Hall 2006, 12). At that time, the patient’s narrative per se was an instrumental and, therefore, a secondary concern, as Hydén (1997, 51) noted.

In the late 1970s, the “linguistic turn,” as Whitehead (2014, 109) uses it, gave rise to many publications on doctor–patient interactions that were concerned with the verbal characteristics and linguistic organization of the medical consultation, including the patient’s story. A well-known study of this period is the work of Byrne and Long (1976) which examines the different speech events involved in a clinical consultation. Hydén and Mishler (1999) characterized these initial studies as (a) “speaking to patients” (174). The aim of the studies in (a) was to examine how well physicians communicated with their patients to achieve their clinical tasks. A drawback of these studies, observed by Hydén and Mishler (1999, 175), was that they neglected to consider sociocultural contexts of illness and patterns of care, reproducing in that manner the biomedical model.

A second group of studies on doctor–patient interactions, which emerged in the 1970s and 1980s, drew on sociolinguistics and conversation analysis methodologies. This second group is called by Hydén and Mishler (1999, 175) (b) “speaking with patients.” The studies in (b) were possibly informed by seminal publications that were having an impact on linguistic studies at the time (e.g., studies by Gumperz and Hymes 1972, Goffman 1981, and several articles by Sacks [1992] 1995). These studies categorized as (b) “speaking with patients” originated within the frames of sociolinguistics and conversation analysis. The studies within the frame of sociolinguistics approached clinical encounters as speech events, susceptible to being shaped by the listener and the context of situation, as well as by sociocultural and socioeconomic variables (e.g., Fisher and Todd 1983, Mishler 1984). The studies within the frame of conversation analysis focused on the ordinary methods by means of which participants socially organize interactions, such as the sequential organization of the turn-taking between physicians and patients (e.g., Frankel 1990). A distinctive approach of these studies is that they traditionally bracket previous sociocultural assumptions.

The studies in the category (b) “speaking with patients” became critical of biomedicine, as observed by Hydén and Mishler (1999, 177). The critical stance that distinguished these studies from those in the previous category (a “talking to patients”) can be seen in their focus on the asymmetric power reflected in conversation between physicians and patients. Following Clark and Mishler (cited in Hydén and Mishler 1999, 178), an important contribution of these linguistic studies on asymmetry is their emphasis on how the professional and institutional power of the physician may shape the interaction with the patient in ways that can either hinder or facilitate patients’ narratives. Interestedly, the observation about the interactional and co-constructive aspect of these studies takes us back to Kleinman’s (1988) formulation of illness narratives as co-constructed, as described earlier.

The third category of studies described by Hydén and Mishler (1999, 181) is (c) “speaking about patients.” These studies (c) “speaking about patients” emerged simultaneously around the time of the so-called linguistic turn discussed earlier (i.e., studies in the categories a and b), but they were not focused on the interactional aspect of the doctor-and-patient encounter. Instead, their main authors (e.g., Montgomery Hunter 1991; Hawkins 1999) are scholars trained in literature studies. Kathryn Montgomery Hunter’s (1991) seminal book, *Doctors’ Stories* is one of these influential studies. Hunter argues that, in spite of medicine’s scientific basis, narrative is pervasive. The narrative structure of medicine can be seen from the narratological ways in which doctors construct their diagnoses to the way in which physicians make chronological sense of their patients' stories, to the different storytelling events (e.g., case presentations, case conferences, medical charts, and others) that organize the medical day, and beyond. As Hunter (1991) states,

> The patient's account of illness is the first account but not the only one. The physician's own discourse about illness takes the form of a story. The space between the patient's first words to the physician and the physician's closing recommendations to the patient is filled with medicine's narratives … Medical stories are a well-established way of sorting through and tackling problems of diagnosis and treatment. (Hunter 5)

Another major argument raised by Hunter is her view of the patient as a text. She states,

> The patients are the texts to be examined and studied and understood by the physician. Sometimes, they can be read like the text of a newspaper story or a piece of straightforwardly expository prose. In other instances, the "interesting" cases, patients' stories resemble novels or poems, those more complicated works that do not always readily yield an easy paraphrase at their meaning. (Hunter 1991, 8)

The view of patients' illness narratives, as elaborated by Hunter (1991) and also by other authors such as Charon (1989), Hawkins (1999) and Frank (1995) has clearly established an enduring link between medicine and narrative, not only as a literacy but also as a literary form, and consequently between the act of reading and the interpretation of patient's narratives as text. In recent years, with the creation of the narrative medicine field (see Charon 2006, Charon et al. 2017), Charon has taken further the comparison of the patient to a (literary) text by comparing the act of reading a narrative text with the act of listening to patients' narratives. As Charon (2017, 168) states, "these skills of the attentive reader are then transferrable to the skills of the attentive listener.” It can be speculated that the entrenched association of illness narratives with memoirs has been facilitated also by the concomitant explosion of autobiographical narratives, including illness narratives, which emerged in the mid-1980s along with the boom memoir (Rak 2013) in the United States and Britain (e.g., Jurecic 2012) (see chapter one).

The final category of studies classified by Hydén and Mishler (1999, 182), namely, (d) “speaking by patients” concerns the view of narratives as voicing the disrupted identity of the ill person (e.g., Bury 1982, Kleinman 1988, Frank 1995). As Hydén and Brockmeier (2008) eloquently put it, “it appears that people who are ill tend to weave the threads of their illnesses and their presumed origins and therapeutic trajectories together with their personal life stories and identity constructions” (4). In the studies involved in the (d) category (“speaking by patients”), narrative becomes intrinsically associated with identity to the extent that the identity concept is subordinated to the narrative concept, as asserted by Hydén (1991, 52). As Cassell (2004) observes, sickness is always individual and particular: “Each person’s illness is different from that of another even if they share the same pathophysiology or impairment of functioning. Different people assign different meanings to similar events and thus will act differently in response to their occurrence” (16). Thus, it is expected that their narrative experiences will be different.

As a reflection about the distinction between the linguistic and narrative turns used by Whitehead (2014), I would like to observe that these terms could be misleading. Written narratives are based on language and, therefore, susceptible to linguistic studies. In other words, the linguistic analysis is not excluded because the narratives are written.

For that reason, I propose a distinction between studies that focus on oral, co-constructed narratives on the one hand, and written illness narratives on the other hand. Thus, I see the line of studies that focus on the written illness narratives as part of an autobiographical, literacy/literature turn to be precise, rather than on the narrative turn; the latter term seems to have appropriated the term “narrative” and to have excluded the reach of linguistic analysis to the written texts.

Furthermore, because in this study I am concerned with memoirs of contested diseases, I proceed from the assumption that if the disease of these patients/authors were deemed contested, then their illness narratives were likely to be deemed discursively contested as well; inevitably enmeshing the patient/narrator’s narrative with her or his contested condition. Given that their illness narratives were delivered in the context of a system in which signs and symptoms must match or correlate with nosological categories, then if they cannot be matched, doctors might not be able to hear them from their biomedical perspectives. Patients’ struggles for legitimacy as well as their struggles to be heard and understood and their suffering (physical and emotional) acknowledged by their healthcare professionals is observed in the analysis of the selected memoirs by focusing on what these authors have reported (see chapters seven and eight). Although the struggles of patients to acquire legitimacy about their conditions have been studied by means of interviews using Grounded Theory, in the literature in the United States and Europe (e.g., Armentor 2017; Olaug and Robson 2017; Swoboda 2005, 2006; Werner and Malterud 2003; Werner, Isaken, and Malterud 2004; Ǻsbring and Närväen 2002), the present study contributes to the literature on this topic by focusing on memoirs and by using a discourse analysis and narrative analysis methodologies.

Because in all the memoirs included in this study, their authors have received a diagnosis for a contested condition despite their struggles, it is argued here that in writing their memoirs, these authors/patients try to revert the contested status not only of their diseases but also, simultaneously, of their own conversational narratives with their doctors. In turning to publishing, as printed texts, memoirs can be even more efficient tools to claim credibility and legitimacy; memoirs are more difficult to refute. Among several reasons for the refutation of memoirs, which I will elaborate on later, one of those is that the author is in absentia. As Ong (1982) observes, "texts are inherently contumacious" (79). They are final unless they are retrieved from the market by the publishers. Thus, with these memoirs, their authors retrospectively claim their visceral knowledge as expressed in their conversational narratives with their doctors. Their memoirs become a performative act of narrative self-reconstruction.

2.3 Illness Narratives, Autobiography, and Self-Knowledge

If we look at the phenomenon of illness narratives from a historical perspective, scholars such as Georges Gusdorf (1980) remind us that autobiography only emerged when cultural conditions facilitated the emergence of a consciousness of *the self*: "Autobiography becomes possible only under certain metaphysical preconditions. To begin with, at the cost of a cultural revolution, humanity must have emerged from the mythic framework of traditional teachings and must have entered into the perilous domain of history" (30). It is possible then that illness as a source of uncertainty and existential crisis would be associated with the need for reflection, explaining the relevance of writing as a practice of self-reflection. Moreover, writing, as a method of fixing ideas in space (Ong 1982, 84), also becomes a method of fixing identities despite being subject to interpretations and reinterpretations. As Gusdorf (1980) continues,

> The man who takes the trouble to tell of himself knows that the present differs from the past and that it will not be repeated in the future; he has become more aware of differences than of similarities; given the constant change, given the uncertainty of events … *he believes it is a useful and valuable thing to fix his own image so that he can be certain it will not disappear like all things in this world.* (30) (emphasis added).

If, following Gusdorf (1980), the rising consciousness of the self is seen as a precondition for the emergence of autobiography, and illness narratives as a genre draw on the cultural consciousness of the "self" which made it socially acceptable to write about one's life narrative, then another phenomenon needs to be explained; that is, the concept of the "sick person." From an autobiographical perspective, illness narratives draw on the emergence of the consciousness of the self but also, as we shall see, on the emergence of the concept of the "sick person." We currently may take concepts such as the "self" and being "sick" for granted; yet historically this has not been the case.

Illness is a challenge to the sense of self. According to the sociologists Herzlich and Pierret (1987, 54), the concept of the sick person emerged in society as the result of the association between work and the right to receive legitimate social protection when one has fallen ill and is prevented from working; such association involved a process of secularization. Illness, as a human experience, seems to have lost its connection with the transcendental as fate, and instead, it has acquired a social status that gives a person a certain role.[1] This process, however, indicates a double movement. On the one hand, a

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[1]. In this regard, Hawkins (1999, 49) observes that contemporaneous pathographies tend to emphasize a displacement of religion and the afterlife with constructs (and agents) of science and technology.

person's illness is seen as her own individual responsibility (instead of the act of fate or destiny), but, simultaneously, society is seen as having the responsibility to take charge of the sick person. Thus, personal responsibility becomes embedded in a new social category—the sick category—that legitimizes a temporary waiver from work and from the social responsibilities of production (see Parsons 1951). However, whereas the sick status may validate and legitimate time out from the responsibilities of work, uncompliant behavior with the doctors' recommendations for treatment (or rather doctors' orders) is seen as deviant behavior based on the assumption that the patient lacks the desire to regain health or may want to abuse her social status. Thus, the rise of the social right to a social safety net may turn, paradoxically, into a system of control and stigmatization.

> With the damaged individual the new value of the biological capital made its appearance; and although it was a social value, the individual was held responsible for its preservation. A different type of relationship emerged with this notion of responsibility, which pitted the sick person against society. Society's taking charge of illness, finally, marks the emergence and the recognition of a specific type, the sick person, toward whom society has duties and obligations. [Sickness] can henceforth be interpreted through its relationship with a social order [rather than a divine order or nature] which has become only that, without reference to a transcendent principle. (Herlich and Pierret 1987, 98)

In conclusion, illness narratives as an autobiographical genre may lie at the historical and epistemological intersection of the notions of self, sickness, illness/disease, and narrative. In the next section, I focus on the autobiographical discourse.

2.4 Autobiographical discourse

As mentioned in the previous section, illness narratives in the sense of pathographies are understood as a subgenre of autobiography. To provide the context of the autobiographical discourse, I follow the work of Smith and Watson (2010) on autobiography and self-life writing, among others.

A definition of autobiography that has become a classic comes from Phillipe Lejeune, the renowned French theorist. Lejeune states that an autobiography is “the retrospective narrative in prose that someone makes of his own existence when he puts the principal accent upon his life, especially upon the story of his own personality” (Lejeune 1971, as cited in Smith and Watson 2010, 1). While Lejeune offers a modern definition, autobiographies were not always seen as the purview of all individuals, and not all life stories were legitimized as autobiographies.

In its traditional sense, as influenced by the Enlightenment, the term “autobiography” became associated with the autonomous individual and the master narratives of the sovereign and rational self (Smith and Watson 2010, 3). While these narratives of the Enlightenment were claiming individuality, rationality, autonomy, and self-determination, they were also clustered, forming a literary canon that privileged the narratives of some authors but excluded the narratives of *the other* (e.g., narratives of slaves and women’s domestic lives).

According to Smith and Watson (2010, 3), some literary critics in life writing became concerned with the adequacy of the traditional genre of autobiography, which until that time had been seen as representing the highest life-writing achievement of individuality. Not only did literary critics consider it insufficient to describe the extensive historical range of experiences and the diverse genres and practices of life writing, but they also favored another term: autobiographical discourse (see Rak 2004, cited in Smith and Watson 2010, 3). This term, which became associated with the discursive formations of truth telling in the Western world, goes beyond a change of names.

Autobiographical discourse opened the autobiographical inscription to other subjects and identities as well as to other forms of representation (and, I would add, to other modes and channels of communication) that go beyond the printed version of the life story. Currently, we are seeing new forms such as autobiographical and performative acts, blogs, and artistic representations, among others. Thus, the term “autobiographical discourse” addresses issues of power and representation in order to negotiate definitions of normalicy, genre, and traditional frames of identity as well as forms of representation. As such, the term includes the narratives of those whose identities, experiences, and histories remain marginal, invalidated, and invisible. To talk about one’s illness was deemed, not that long ago, to the private rather than to the public sphere (see e.g., Frank 1995; Jurecic 2012). It could be said, then, that the genre of illness narratives owes, in part, not only its emergence but also its current legitimacy to the critical validation of *autobiographical discourses*, whose flexibility and democratization in incorporating all types of narratives and topics made of illness narratives the acceptable form of autobiographical discourse that it is today.

With the intention to account for the complexity of genres involved in autobiographical discourse and also to problematize Lejeune’s definition of autobiography offered earlier, Smith and Watson (2010, 4) presented a useful distinction between “life writing,” “life narrative,” and traditional Western biography. I draw upon these categories with the intention to frame the present study. Smith and Watson (2010) see *life writing* as referring to writing that takes a life as its subject, either one's own or another's. Life writing could be historical, novelistic, or autobiographical. Pathographies can be included in the category of life writing and they can be either self-referential (i.e., written by the person who experienced an illness, such as Audrey Lorde's *Cancer Journals*) or written by a third person, such as David Rieff's *Swimming in a Sea of Death*, a narrative about his mother's (the cultural critic Susan Sontag) illness and demise (cited in Jurecic 2012, 25). *Life narrative*, on the other hand, sees self-presentation that takes the producer's life as her subject, as adopting any form or channel of communication; in other words, it could be written, performative, filmic, digital media-based, and so forth.

In sum, the main difference between life writing and life narrative is that the former is articulated in writing while the latter is a narrative that may adopt any form or mode of communication for self-presentation. Thus, the illness narratives or pathographies that I shall analyze can be framed within the category of life writing and also as self-referential. I will elaborate further on the memoirs and methodology of analysis in chapter six. At the present, I can say that all the memoirs that are analyzed for this study are autobiographical, thus written by the authors themselves.

2.5 Biography and Self-Life Writing

Although biographies are a form of life writing as defined in the preceding section, they have specific characteristics that distinguish them from self-life writing.

Biographies are composed by scholars who document other people's lives from an external point of view on the subject, either during the life of the person or after the person's death. In writing biographies, scholars are concerned with providing objective evidence (e.g., historical documents, interviews, photos, family archives, and others) that can validate the authenticity of the person's biography (see Olney 1980). By contrast, in self-life writing, subjects write about their own life experiences from their own, subjective, point of view, even if writing about themselves in the second or third person. The narrative ends if the author's life ends; thus, it has to be written during the writer's life span or published posthumously, as in the case of Anatole Broyard's (1992) memoir *Intoxicated by My Illness*, which was published by his wife. Furthermore, in self-life writing, the events narrated are selected based on the author's subjective decisions; they are those events that the author feels compelled to tell for personal motivations and are not "a history observed by others" (Smith and Watson 2010, 6). The life writer, in contrast to the biographer, cannot tell us so much about the social, historical person but more about the self as experienced by that person. Stephen Spender (1980) used the comparison of the driver as the biographer "who can record the history, characters, and motivations of the driver … but only the life narrator knows the experience of traffic rushing toward [her] and composes an interpretation of that situation" (116). I find this comparison illuminating of, on the one hand, the objective and distant point of view of the biographer and, on the other, the experiential, subjective, and phenomenological viewpoint of the life narrator.

Regarding the veracity of the life story, the narrator of the self-life narrative is not as much concerned with offering objective evidence of her life events but rather with telling her story from her viewpoint, which is inevitably influenced by memory. Social sciences studies and cultural studies (especially *Testimony* studies) have shown us that memory is subjective and therefore selective, impregnated with acts of perception, imagination, and desires that make it fallible (see Felman and Laub 1992).

Memory resists full external verification, thus, life writing is asserted on "the subject's authority," as Smith and Watson (2010, 7) claim. On the other hand, while factual details may be rendered inaccurately, this does not necessarily mean the story is untruthful, as Miguel de Cervantes with irony reminds us in his masterpiece novel, *Don Quixote de la Mancha*.[2] At this point, suffice it to say that Frank (1995) and Hawkins (1993) see illness narratives as truthful, I shall address this aspect in chapter five when I discuss the problem of factuality and narrative truth. The problem of veracity, verisimilitude, and configuration of self-life narratives lies at the heart of my analysis of the selected illness narratives of contested diseases. For now, I would like to assert that self-life narratives cannot be fairly assessed by considering only the facticity or

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[2]. "In a village of La Mancha, the name of which I have no desire to call to mind, there lived not long since one of those gentlemen that keep a lance in the lance-rack, an old buckler, a lean hack, and a greyhound for coursing. An olla of rather more beef than mutton, a salad on most nights, scraps on Saturdays, lentils on Fridays, and a pigeon or so extra on Sundays, made away with three-quarters of his income. The rest of it went in a doublet of fine cloth and velvet breeches and shoes to match for holidays, while on weekdays he made a brave figure in his best homespun**.** He had in his house a housekeeper past forty, a niece under twenty, and a lad for the field and marketplace, who used to saddle the hack as well as handle the billhook. The age of this gentleman of ours was bordering on fifty; he was of a hardy habit, spare, gaunt featured, a very early riser and a great sportsman. They will have it his surname was Quixada or Quesada (for here there is some difference of opinion among the authors who write on the subject), although from reasonable conjectures it seems plain that he was called Quesada. *Though this concerns us but little, provided we keep strictly to the truth in every point of this story"* (Cervantes 1946, 3) (emphasis added).

contingencies of the events they describe. I think that such an approach would neglect their sociocultural, literary, and even political and rhetorical meaning.

2.6 Final Remarks

As a final remark to this chapter, I would like to make a few observations. People frequently talk about their illness experiences with their family members and friends, with health care providers and caregivers. Talk is pervasive, yet not all people can articulate their illness experiences as narratives: depression, trauma, neurological dysfunctions, brain injuries, and so forth may preclude that ability (see, e.g., Hydén and Brockmeier 2008). Not all individuals can write about their illness experiences and construct autobiographical novels. This is a task that requires not only a certain degree of literacy skill but also self-awareness and, overall, a capacity for emplotment. It could also be the case that not all people find writing, as a mode of communication to be the best mode of expressing themselves or to communicate their message. Others may find, for instance, that graphic novels are a more suitable medium for them or simply speaking to others, including their doctors.

In her article, “The Limits of Narrative,” Angela Woods (2011) challenges the claim that narrative articulation is essential to create a sense of self, as this has been one of the major claims formulated by the narrative turn. Woods points out that the universalization of narrative, as the only means to the construction of self, to provide authentic insight into someone’s subjectivity is not an ethical imperative for achieving true or full personhood for everybody. This position, she observes, neglects those who cannot employ narrative competence and those whose preferences are not narratively oriented.

2.7 Conclusions

This chapter problematized the meaning of the term illness narratives by reviewing the literature, on the one hand, on oral narratives as explanatory and interactional achievements between patients and healthcare professionals in face-to-face consultations and on the other, on written narratives associated with the literary genre of memoirs in general, and pathographies in particular. The relevance for this review is twofold: first, the medical/health humanities with its academic links with literature and narratology, has typically associated illness narratives as an autobiographical genre that belongs exclusively to the written register. Although in the medical humanities, the identification of illness narratives with the autobiographical genre was necessary in order to provide illness narratives with an academic status and identity as a genre, this act may inadvertently neglect the personal and medical implications that patients' oral narratives might have in consultation and the repercussions in the writing of memoirs, as I argued.

Second, in doing a literature review that considers oral as well as written texts, although I focus on analyzing pathographies, I wish to raise awareness about the fact that pathographies are constructed, to a certain extent, in reference to the extra textual world, or the oral world of their protagonists; texts need pretexts, as Ong (1982) observed. Finally, this chapter proposed that the memoirists of the selected contested illness narratives (see chapter six) have turned to writing because of the authoritative power, illusion of finality and irrefutability that writing and the printed word can give to personal experience. By means of writing and publishing, these memoirists reclaimed not only their subjective experiences as patients (i.e., their visceral knowledge) but also their own oral narratives in conversations with their healthcare professionals as rational, sensible, and credible.

CHAPTER 3

WHEN ILLNESS DOES NOT MATCH DISEASE CATEGORIES: SOME IMPLICATIONS for PATIENTS and PHYSICIANS

In this chapter I examine the concepts of disease, health, and illness in their interplay with the concepts of normalicy and pathology from the perspectives of the philosophy of medicine. These concepts are relevant to understand the point of view of the patients and the clinicians. In reviewing these concepts, I examine some possible implications for physicians and patients, especially those experiencing contested illnesses (see Hart 2014; Quinn Schone 2019) because this study is concerned with narratives addressing contested illnesses (i.e., those conditions that remain unaccounted for by biomedical models). I shall argue here that the case of contested illnesses amplifies the complexity of the concepts of disease and illness and exposes the delicate interplay between what is deemed a disease category and what is regarded as an illness.

As an overview, it is necessary to state that one of the main challenges in formulating a neat definition of *disease* is the fact that illness and disease do not always match; that is, they do not stand in a one-to-one relationship (see, e.g., Eisenberg 1977, 11-13). For instance, a person can be ill without having a disease, or a person can have a disease without being ill, at least in the early stages. There could be an inconsistency or a lack of correspondence between symptoms and a disease category, as I shall further elaborate in this chapter. In part, because of their ambiguous and ambivalent nature and also because of social norms, contested illnesses amplify and expose the inconsistency that can sometimes arise between disease and illness; that is, not all illnesses are deemed diseases. Furthermore, not all diseases are seen as equal pathologically, as observed by the French medical philosopher Georges Canguilhem ([1989] 2015, 39): “A vulgar hierarchy of disease still exists today, based on the extent to which symptoms can—or cannot—be readily localized, hence Parkinson’s disease is more of a disease than thoracic shingles, which is, in turn, more so than boils.” Canguilhem reflects that an explanation for this scale or degree of diseases lies in the element of visibility and measurement, which has given to ontological sickness its predominance and to the germ theory of disease (e.g., Louis Pasteur’s and Robert Koch’s discoveries in the mid-nineteenth century), in particular, part of its success over the miasma theory of the eighteenth and early nineteenth centuries.[1] To approach this topic, I shall begin by elucidating the concepts of health, normalicy, and the pathological by reviewing some historical perspectives on these concepts and by elaborating on the naturalist and normativist theories of disease in the philosophy of medicine.

3.1 Some Historical Considerations

Georges Canguilhem ([1989] 2015) observes that one conceptualization of health and disease comes from antiquity as revealed in the Hippocratic writings. This theory offers a dynamic rather than static conceptualization. In this theory, health means harmony, and the disturbance of this harmony is called disease (Canguilhem [1989] 2015,

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[1] .The miasma theory attributed the cause of many diseases to an infection from an “invisible, and possibly otherwise undetectable, emanation from rotting organic matter” (Hamlin 2009, 33).

40); and disease is seen as nature’s way of restoring harmony. “Disease is a generalized reaction designed to bring about a cure; the organism develops a disease in order to get well,” states Canguilhem ([1989] 2015, 40–41). Thus, this view of disease puts the emphasis on the natural capacity of the body to restore its balance and return to homeostasis without external, therapeutic intervention.

In the Renaissance, however, Swiss physician Paracelsus (1494–1541) pioneered the idea that diseases were entities, such as a parasite, in contrast to the Hippocratic dogma that viewed diseases as states of being (Engelhardt 1981, 33). Paracelsus’ view anticipated the current ontological conceptualization of disease as an entity that could vary and show specific changes and etiologies, forestalling the practice that specific therapies should be sought for specific diseases. Engelhardt (1981, 33) observes that the ontological concept of disease as developed by Paracelsus allowed the possibility of classifying therapies according to the specific causes of diseases. In turn, specific diseases led to specific local organ changes being sought, and therefore, to the beginning of modern pathology. Furthermore, the evolution of technologies such as the microscope, facilitated the development of histology, pathological anatomy, and anatomy physiology. In addition to William Harvey’s (1578–1657) discovery of the circulation of the blood in the seventeenth century, which showed the physiological workings of the heart as a muscular pump, in the eighteenth century, Italian physician Giovanni Battista Morgagni (1682–1771) pioneered the studies in anatomy pathology. Morgagni’s dissections and more than seven hundred autopsies, documented in his famous book *On the Sites and Causes of Disease* (see Cole, Carlin, and Carson 2015, 48), allowed physicians to identify and correlate symptoms of the living with their postmortem anatomical lesions. In addition, Morgagni’s studies allowed physicians to locate particular diseases associated with specific organs (Cole Carlin, and Carson 2015, 48), contributing to the development of nosology, namely by linking the lesions of certain organs to groups of stable symptoms while finding a substratum in anatomical analysis (Canguilhem [1989] 2015, 42). In sum, these scientific advances reinforced the view of disease as an ontological, visible, and real entity. The following quotation from Morgagni, cited in the *Medical Library and Historical Journal*, is illustrative of the weight medicine began to put on the observation and visibility of organic phenomena as evidence of reality: “Those who have dissected or inspected many (bodies) have at least learned to doubt, when others, who are ignorant of anatomy and do not take the trouble to attend to it, are in no doubt at all” (as cited in Adams 1903, 276). From Morgagni’s words, it can be inferred that doubt is valued as a legitimate and productive instrument but only if it is based on the examination of the ontological reality; without empirical examination, there is no doubt but only ignorance. In conclusion, these medical discoveries contributed to a slow but definitive shift in the way of thinking about diseases and therapeutics; that is, away from a holistic and more into an ontological view. For instance, Cole Carlin, and Carson asserted that “Disease came to be seen less as systemic imbalances in the body’s natural harmony and more as a set of distinctive signs and symptoms that could be analyzed, separated, and measured in isolation” (2015, 49). By the time of World War I, medical historian Edward Shorter (1985, 81) notes that the advances in tissue pathology and germ theory helped medicine to develop the technique of *differential diagnosis*; that is, matching signs and symptoms to a specific, underlying lesion (e.g., an abnormal change in the structure or function of an organ) that correlates with one disease entity. By facilitating the identification of the abnormality, the technique of differential diagnosis has contributed to refining the competence to establish a specific diagnosis as well as the treatment and prognosis of the disease.

Another phenomenon that accompanied the ontological conceptualization of disease is the displacement of the qualitative concept of the pathological (i.e., as presence or absence of disease) into a quantitative measure against a dichotomous scale (i.e., normal versus abnormal) (see Canguilhem [1989] 2015). Cole Carlin, and Carson (2015, 49) explain this process by asserting that by the 1850s, physicians had begun to measure health in terms of statistical norms rather than in terms of the patient's natural state of health; the empirically determined *normal* began to replace the philosophically grounded *natural* as the paradigm of order and health. The shift from natural to normal (as derived from "norm") has had a powerful effect to this day, not only in the theory but also in the practice of medicine: the concept of disease transpired to be most likely determined by what the physician validates to be a disease according to the statistical norm, rather than by what the patient tells the doctor regarding her symptoms and illness experience. As Canguilhem ([1989] 2015) states, "The end result of this evolutionary process is the formation of a theory of the relations between the normal and the pathological… The pathological departs from the normal not so much by a- or dys- as rather by hyper- or hypo-" (42). In the next section, I expand on the concepts of norm and normal.

3.2. On Norm and Normal

Two meanings are derived from the concept of norm: On the one hand, there is the idea of what ought to be (i.e., as a value or social norm); and, on the other, norm is "that which is met within the majority of cases of a determined kind, or that which constitutes either the average or standard of a measurable characteristic" (Canguilhem [1989] 2015, 125). In other words, norm is seen, on the one hand, as a statistical standard, and on the other, norm is seen as a sociocultural value of what it means to be healthy or unhealthy. These two meanings tend to overlap. I shall elaborate first the concept of norm as a statistical standard, which is the basis for the naturalist or biomedical model, and second, the concept of norm as a sociocultural value.

3.2.1 The Biostatistical/Naturalist Model of Norm and Normal

Davis and Bradley (2000, 7) explain that the meaning of "normal" in statistics is "average," in the sense of describing what is most representative of a class or group, which becomes the norm as a fixed standard. Consequently, a norm is the mathematical standard against which certain measurements are compared. In this view of the norm, norms such as those associated with, for instance, normal blood cholesterol levels represent the ideal rather than the average blood cholesterol levels found in the adult population. In his article "On the Distinction between Disease and Illness," Christopher Boorse raises the argument that health and disease should (and can) be defined from a strictly biological viewpoint. Drawing on C. Daly King's conceptualization of normal as "objectively, and properly to be defined as that which functions in accordance with its design" (see Boorse [1975] 2004, 81), Boorse assimilates the normal to the natural in the sense of the physiological function that each organ is expected to accomplish from a biological point of view, stating, "The state of an organism is theoretically healthy, i.e., free of disease, insofar as its mode of functioning conforms to the natural design of that kind of organism" ([1975] 2004, 81–82). Thus, in his view, disease is assumed to interfere with the proper or normal physiological function of the organs. However, given that organ dysfunction (or abnormality) could occur as a result of not only dysfunction in the internal systems of the body, but also as a result of external or environmental reasons (such as bacteria or viruses, as the germ theory has demonstrated), the question that arises is: What is the norm in the case of disease caused by germs? To provide an answer to this question, I draw on Quinn Shone (2019, 51) who explains that Boorse proposes the idea of disease as a standard deviation from the norm: "A disease is therefore present if there is a statistical abnormality, the result of which impairs some aspect of a person's physiological functioning and is untypical for that individual's reference class" (Quinn Shone 51). Thus, according to the biostatistical theory, the concept of *norm* derives from the statistical mean of the population in the interplay with the reference class. Hence, a certain physiological dysfunction is deemed pathological only if it interferes with the natural functioning of the organs and if it is far below the average norm considering the reference class of the individual. Then, disease is established depending on its place in the statistical continuum, and the label *pathology* depends on the statistical distance from the population mean (Coles, Carlin, and Carson 2015, 242). It can be anticipated that this statistical ideal of the norm that renders disease as a purely statistical deviation, seen as an independent, free-value concept, will not be adequate to match or explain all illnesses that people experience. In fact, this concept of disease, based on a statistical ideal, may leave out of the schema many of the illness experiences patients report, especially in their illness narratives. However, Boorse's influential biostatistical model has become representative of biomedicine as the Western ethnomedicine. The biostatistical model and the dominant view of the abnormal as a statistical measure has raised many critiques and concerns. I shall address the controversy, especially as articulated by the normativist philosophers, in the next section.

3.2.2 Controversial Aspects of the Quantitative Concept of Norm and the Normativist Position

Accepting the norm as the ideal measurement raises the question concerning the exact point when the abnormal begins and the normal ends. In other words: How far from the norm or center is abnormality considered to be? Statistically, normalcy is especially vexing in the case of mental illnesses, as highlighted by psychiatrist Allen Frances.

Following Frances (2013, 6), the bell curve cannot say what defines *normal* due to the abundance of social and cultural factors, including value judgments as well as considerations about the context in which tests are conducted. However, the bell curve as a tool allows us to learn by approximation by looking at the distribution and aggregate of all readings in the curve. The curve’s peak will tell us about the most frequent measures, from which we can infer the mathematical mean. Then, the successively less likely measures show at what point they trail down on both sides of the golden mean. The problem, though, lies with the measures that are placed at immediately opposite sides of whatever boundary or mean is established. The meaning of the far opposites to the mean are clear. However, the intermediate points at both sides of the mean, where clarity is most needed, present the greater ambiguity; thus, those are the points where arbitrary decisions most likely have to be made. Though a person with a severe psychotic disorder can be recognized as mentally sick by many, the most difficult judgment is to decide when everyday anxiety or sadness can be considered a mental disorder. Thus, although abnormality as a quantitative value is necessary for reaching a diagnosis, this value does not determine what disease is. Despite the impression of accuracy, the statistical concept of the norm is useful only in terms of providing mathematical references, but the patient's history and physical and mental status are necessary to complement the diagnosis; this is also the reason the patient's narrative is so important. The major problem for the patient could be when the mathematical concept of abnormality is used to either diagnose or, instead, discard a diagnosis based on the quantitative concept of abnormality while disregarding the patient's narrative altogether. This point is clearly illustrated by author, Ally Hilfiger, who suffered for many years from undiagnosed Lyme disease. In her memoir, *Bite Me,* Hilfiger describes an encounter with a physician in which they discuss the ambiguous results of her blood test, which may determine the presence or absence of Lyme infection:

> [The doctor] concluded from my blood work that I might have Lyme disease, but the tests were inconclusive. He told us that the blood levels were just borderline positive. 'It could be multiple sclerosis,' the doctor said which we'd heard before… 'But it is probably fibromyalgia,' the doctor continued… I knew something was not right, but I hung on to the diagnosis. (Hilfiger 2017, 62)

As the Hilfiger quote illustrates, the range measures of her blood test were mathematically inconclusive to determine that she indeed had Lyme disease (which she only learned about years later). However, the point of her story is that the mathematical measures of her blood test were taken by her doctor at face value instead of complementing these mathematical measures by also considering Hilfiger's illness narrative. Hilfiger was a teenager at the time and a female, and it is probable that her narrative was deemed not sufficiently objective or reliable to be believed and it was taken as the determinant of a diagnosis based solely on her personal experience. However, this is a problem that physicians may encounter on a regular basis: How to balance the quantitative measures with the qualitative undertones of the patient’s illness narrative? I shall return to the problem of credibility of the patient’s personal experience in chapters four and five. In the next section, I need to elaborate on the naturalist versus normativist conceptions of disease and health.

3.3 The Biostatistical/Naturalist and the Constructivist/Normativist Concepts of Norm, Health, and Disease

Despite its strong influence in biomedicine, Boorse’s ([1975] 2004) theory has been highly criticized, especially by those scholars espousing a constructivist/normativist position. As we saw earlier, and as explained by Canguilhem ([1989] 2015), the other side of the concept of norm is that of what ought to be. In his essay “Concepts of Health and Disease,” Engelhardt (1981, 33) argues that health is a normative concept in the sense that it is shaped by social values. Health is associated with what is desired; conversely, disease is associated with what is undesired. Thus, disease is associated with what needs to be changed or modified:

> The concept of disease acts not only to describe and explain, but also to enjoin to action. It indicates a state of affairs as undesirable and to be overcome. It is a normative concept; it says what ought not to be. As such, the concept incorporates criteria of evaluation, designating certain states of affairs as desirable and others as not so. It delineates and establishes social roles such as being sick or being a physician, and it interconnects these roles with a network of expectations structured by rights and duties. The concept is both aesthetic and ethical, suggesting what is beautiful and what is good. (Engelhardt 33)

According to Engelhardt (1981, 43) the concept of disease is both an evaluative and explanatory concept, and health as a more positive concept is rather a regulative idea to which society attaches beliefs and moral values with political agendas.[2] For instance, not that long ago, the first edition of the American Psychiatric Association's *Diagnostic and Statistical Manual (DSM)* published in 1950 (Cole, Carlin, and Carson 2015, 243) labeled homosexuality as a mental disease associated with moral decline although this diagnosis was not based on any evidence of anatomical or physiological pathology in people who self-defined as homosexually oriented.

Another example of the historical construction of disease is that the number of disease diagnoses has also changed throughout history. Frances (2013, 17) notes that in the initial census of mental patients in the mid-nineteenth century, only six mental disorders were listed, but now "there are close to two hundred" (Frances 17). The increase in types of mental disorders not only shows the advances in technology and science that made it possible to confirm new diagnoses but also evidences the sociocultural values and norms that influence the determination of diagnoses. Another phenomenon that has contributed to the influx of new disease categories has been the increase in the patients' willingness to seek care for reasons for which they would not have done so in the past (examples of this increase could be new categories such as chronic fatigue syndrome and Morgellons disease), whereby patients' advocate groups seek to obtain recognition by means of mobilizing the creation of new disease categories. In his book *Bedside Manners*, medical historian Shorter illustrates this point: The postmodern patient, Shorter (1985, 20) observes, has become since the 1980s far more sensitive to symptoms and more willing to seek medical care for her/his symptoms than ever before. Shorter reports greater numbers of acute illnesses per one hundred of

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[2]. See Johnattan Metzl's and Anna Kirkland's (2010) book, *Against Health,* for an elaborated illustration of this point.

population, a 158 percent increase in this period from before World War II (1985, 211–212).

The aforementioned (i.e., the case of homosexuality, and the increase in the number of disease categories) are illustrative of the socio historical factors shaping disease categories and diagnoses. In sum, the act of diagnosis involves not only a medical explanatory act of seeking treatment and prognosis but also a social and political evaluation: “Choosing to call a set of phenomena a disease involves a commitment to medical intervention, the assignment of the sick role, and the enlistment in action of health professionals” (Engelhardt 1981, 41). For this reason, in contrast to Boorse’s ([1975] 2004) model, described earlier, medical philosophers embracing a normativist perspective, such as Engelhardt, cannot see disease as an independent, free-value concept but rather as a socially and medically institutional process. Furthermore, Davis and Bradley (2000, 8) observe that the highly quantitative concept of the statistical average can simply be manipulated according to social norms. If levels of abnormality or normalicy (i.e., disease or health) are measured, then it needs to be considered that measurements are not devoid of moral and social values despite their apparent precision:

> Medicine has defined clinical norms for many laboratory findings by deriving mathematical values from the results of clinical tests and then deciding which of these values are included within a normal range. While normal values are determined in various ways—by averaging, by empirical decisions about what is healthy…—many have increasingly come to define what we consider to be “perfect” or “desirable” or “healthiest.” (Davis and Bradley 2000, 8) (emphasis in original)

I emphasize Davis and Bradley’s observation with the purpose of pointing out that what is defined as the healthiest measurement becomes tacitly normalized or institutionalized (i.e., in the sense of being adopted as an institution). Influenced by the work of Michel Foucault, medical philosopher Annemarie Mol (2003, 60) notes that medicine has become a crucial discipline in intermingling the biological with the social norm. The effect of this intermingling is that medical knowledge has become a mediator between the order of the body and the order of society: “It is within medical knowledge that the normal and the deviant person is differentiated” (Mol 60). Thus, given the concept of abnormality as deviation, disease is no longer thematized as a species inhabiting an organism (i.e., as it had been formulated by the germ theory) but, instead, “as a deviant state of that organism” (Mol 2003, 60). Mol’s observation sheds light on the interplay between biology and society and how people deemed sick may no longer be seen as only biologically sick but also as deviant from societal norms (for instance, the case of HIV/AIDS patients has been a clear example given the associated stigmatization). In this manner, health associated with desirability and disease associated with undesirability becomes entangled with social identities.

Medical historian Charles Rosenberg explains the process of institutionalization that informs the act of diagnosis in his book, *Our Present Complaint*:

> Disease entities are social realities . . . Just as disease can be created by ideological and cultural constraints in traditional societies—as anthropologists have reminded us—so contemporary medicine and bureaucracy have constructed disease entities as socially real actors through laboratory tests, pathology—defining thresholds, statistically derived risk factors and other artifacts of seemingly value-free biomedical scientific enterprise. (Rosenberg 2007, 250)

To conclude this section, I would like to point out that regardless of whether a clinician may adopt the naturalist or the normativist model, at the root of these models of disease lies the interplay between disease and illness; especially when the patient’s symptoms do not clearly match disease categories. A difference to be observed between the naturalist and normativist models lies in how these approaches orient differently toward patients' illness narratives. We can anticipate that a strictly naturalist/biomedical approach will not be well suited to offer empathic listening to patients with contested illness or, rather, to any patient whose diagnosis has an uncertain link with the organic. This observation has been made in reference to the problem of suffering by several authors such as Cassell (2004) and Kleinman (1988), to mention some of the most representative authors.

In the practice of medicine, a clear-cut separation between the biostatistical/naturalist and the normative models may not be desirable. Rather, both could be used in complementary ways. Though the very act of naming a condition 'a disease,' or calling a person 'sick,' has profound personal and social implications, it is important to acknowledge that quantitative statistical approaches have been and are useful for the purpose of diagnosis, prognosis, and treatment. However, medicine as an institution, health care professionals, and society in general may forget or become oblivious to the fact that the statistical measures used to determine what defines normal or abnormal are just that, namely methodological tools; they do not define health or disease per se. Thus, the problem is when the method of assessment or the logarithm become the main social and discursive meanings of normalcy and deviancy, and ultimately silence patients' and even physicians' voices. On the other hand, it is also the case that statistics can empower patients' inner realities. This is thanks to the value society places on the authority of rational knowledge to regulate nature and health. As such, this is a two-way situation. Meanwhile, quantitative measures of normal references can be equally empowering or disempowering depending on the context. In the next section, I elaborate on the discrepancy between illness and disease by addressing the problem of the lack of correspondence between symptoms and signs.

3.4 Signs of Disease and Symptoms of Illness

As mentioned earlier in the introduction, one of the challenges in reaching a universal definition of disease is the lack of systemic correspondence between symptoms of illness and signs of disease. Both clinicians and patients are aware that it is not always the case that a correspondence between the patients' symptoms and biological markers of disease can be established. Moreover, there is not always consistency between the patient's symptoms and a diagnosis for a disease category; that is, illness and disease do not always stand in a one-to-one relationship. There are cases of illnesses without disease, as observed by Leon Eisenberg (1977, 11); that is, illnesses without detectable organ pathology and diseases without illnesses, at least in the early stages of a condition. The latter can be explained by individual variabilities and capabilities of adaptation, which are in turn determined either by personality, culture, or social expectations. Sociocultural variabilities may have an impact on the way individuals symptomatically respond to disease. For instance, in his book *From Paralysis to Fatigue*, Shorter argues that over different historical periods, culture has strongly encouraged patients to unconsciously manifest psychogenic physical symptoms (i.e., those that arise in the mind and manifest physically) according to the sociocultural symptom pool, that is, "the culture's collective memory of how to behave when ill" (Shorter 1992, 2). Shorter's hypothesis about the symptom pool is based on the case of hysteria whose etiology and symptoms he reviewed as having changed over the centuries to its disappearance at the early twentieth century (Shorter 1992, 199). Here it is important to refresh the distinction between the concepts of disease and illness, which was initially observed by Eisenberg (1977) and disseminated by the work of Kleinman (1988). “Patients suffer ‘illnesses’; physicians diagnose and treat diseases,” asserts Eisenberg (1977, 11). “Illnesses are experiences of disvalued changes in states of being and in social function; diseases, in the scientific paradigm of modern medicine, are abnormalities in the structure and function of body organs and systems” (Eisenberg 1977, 11). Thus, while signs are considered the objective, anatomical, and molecular alteration of the organs that can be observed, symptoms are considered the patient’s experience of the alteration or dysfunction of those organs. Consequently, symptoms could be more difficult to evaluate or verify by an observer given that they remain at the level of the patient’s subjective experience (Aronowitz 2001, 3).[3]

Robert Aronowitz’s article entitled “When Do Symptoms Become a Disease?” traces the evolution of the meaning of the concepts of signs and symptoms from the nineteenth to the twentieth centuries. Aronowitz (2001, 804) observes that in modern medicine, the symptoms that affect the patient’s experience are no longer seen as equally valid or legitimate to support the diagnostic validation of a disease category. A shift has occurred in the way diagnosis is achieved.[4] The scientific and technical imperative that began to unfold in the nineteenth century, explains Aronowitz (2001, 803), originated a

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[3]. It is important to clarify that symptoms are not always necessarily pathological or abnormal. Symptoms can also indicate the body’s working to recuperate homeostasis (see Canguilhem [1989] 2015).

[4]. Despite this trend in medicine, it needs to be acknowledged that there have been several movements such as the patient’s centered-care movement in the 1970s, the medical/health humanities, and most recently the narrative medicine in the mid-2000s that have refocused the attention on the patient’s narrative (see e.g., Charon 2006; Engel, 1977; Frank 1995; Pellegrino 1979).

sociohistorical shift from the symptom-to-disease criteria to the current, deemed more objective and scientific, evidence-based sign-specific criteria. In this process, ill health became “increasingly defined more by signs than by symptoms” (Aronowitz 2001, 803). Simultaneously, symptoms have become less likely to constitute disease because they do not arise from “the alteration of the organs” but rather from the organs’ “less precise functions [physiology],” states Aronowitz (2001, 803).

Similarly, as previously observed by Canguilhem and mentioned in the introduction, Aronowitz (2001, 802-803) has also observed that not all symptoms are treated equally and not all diseases have been equally legitimized, namely by following the same scientific, evidence-based criteria. For instance, some cluster symptoms are treated as a legitimate disease (e.g., asthma) while other symptoms, despite their persistence, are no longer considered a disease (e.g., peptic ulcer)—if organic evidence or objective abnormality is not detected by visualizing a gastric or duodenal ulcer. In that case, a new disease category is created (e.g., non-ulcer dyspepsia).

Although the biological specificities of duodenal ulcer may not stand for all cases of contested illnesses, the phenomenon that takes place in the creation of new disease categories may be. Aronowitz (2001, 803) argues that in modern times, symptoms by themselves are less likely to constitute disease because they do not arise directly from the alteration of the organs. Similarly, Cassell (2004, 7-8) notes that the belief in medicine (in tune with the principle of etiological specificity) that all changes in the function of an organism are correlated to changes in its structure, has made of the search for a diagnosis essentially the search for altered structure. Consequently, when non-structural abnormalities are present or seen, the patient is told that “there is nothing wrong” (Cassell

8), that no disease is present. As a result, many patients lost their symptom-based and clinically based diagnoses and became "medical orphans," asserts Aronowitz (2001, 803). To support his argument, Aronowitz provides us with a historical review of the case of several diseases. I find his review highly illuminating and relevant for this chapter on the significance of the concepts of health and disease and their influence on the ways contested illnesses are seen, so I summarize it here.

Aronowitz reviews the case of some rheumatologic diagnoses (e.g., Still disease and the Reiter or reactive arthritis syndrome) to illustrate how these conditions owe their diagnostic status to the previous symptom–disease validation criteria. As Aronowitz (2001, 805) states, "I strongly doubt whether these diagnoses could be newly coined and promoted today. Experienced clinicians have less authority with which to get such work accepted and published…. What is new and exciting today, with few exceptions, are disease defined by new agents and (preferably molecular) mechanisms, not by purely clinical criteria."

Another interesting example provided by Aronowitz (2001, 804) is the case of "angina pectoris" because it illustrates the growing gap between anatomically diagnosed diseases and the so-called functional diagnoses. He observes that though in the early twentieth century, the etiology of angina pectoris was debated (i.e., whether it was correlated with coronary artery obstruction leading to myocardial ischemia or with a functional disorder not linked to one organic lesion), it was not ontologically downgraded as a less "real" disease if concrete signs of coronary obstruction were not found. In that case, the diagnosis was named functional angina pectoris, but he observes that "for the purpose of diagnosis, distinctions between mind and body, anatomic and functional, were less clearly demarcated" (Aronowitz 2001, 804). Finally, he presents the case of asthma to illustrate his point with a disease case whose diagnostic criteria has retained the symptom-based diagnosis. Aronowitz (2001, 806) notes that although the diagnosis of asthma has been strengthened since the nineteenth century, thanks to innovations in technology (e.g., using stethoscopes, lung volume, and other physiologic measurements) that allowed new insights into its pathophysiologic basis, asthma has remained a clinical diagnosis based mostly "on what the clinician sees and hears" (806). The reason for the retention of a clinically based diagnosis for asthma has been its practicality and convenience, given the idiosyncrasy of asthma. Because the etiology of asthma is wide ranging (i.e., attacks could be triggered by a spectrum of different emotional, environmental, and physiological triggers), he explains, and the symptoms of what is called an "asthma attack" could have different manifestations (i.e., not all wheezing may translate as asthma, and some asthma patients may not cough or may not have paroxysms of breathing difficulties), then the diagnosis of asthma is performed clinically. In other words, asthma has become an umbrella term that allows patients and clinicians to use a great diversity of approaches to a highly heterogenous patient population, explains Aronowitz (2001, 806). Consequently, the example of asthma shows the case of a condition that is deemed medically legitimate while medical practice continues to diagnose it using a symptom-based and clinically rooted approach, despite the availability of technical advances to find organic evidence.

In sum, Aronowitz's (2001) article shows that, as he states, "social influences have largely determined which symptom clusters have become diseases" (803). Ultimately, the difference between symptom-based conditions and sign-based diseases is compared by Aronowitz with the arbitrary distinction in sociolinguistics that pits dialects against languages. Although from a strictly linguistic viewpoint, dialects are languages, in the institution of medicine some symptom-based illnesses in comparison are not formally recognized as diseases as, in societies, dialects may not be formally recognized as the native language of those populations. The practical implication of this lack of recognition is for people not to have linguistic recognition and, consequently, institutional recognition (the cases of aboriginal languages remain as painful examples of the lack of social prestige and access to cultural power). For patients, this shift in the practice of diagnosis means that symptom-based illnesses (for which organic or physiological evidence cannot be detected or observed) will see their chances to gain access to quality treatment, drug experimentation, and research into their conditions diminished because their conditions have not yet been formally recognized as medically legitimate. Consequently, their conditions remain socially uncertain; they cannot enter the *sick role model* (see Parsons 1951) that grants them the right to be sick. As Rosenberg (2002, 257) eloquently articulates, “Disease categories provide both meaning and a tool for managing the elusive relationships that link the individual and the collective, for assimilating the incoherence and arbitrariness of human experience to the larger system of institutions, relationships, and meaning in which we all exist as social beings.” The case of contested illnesses is clearly applicable here. Given that they are characterized by a lack of known biological cause or abnormality, patients have to rely on their linguistic and narrative skills to communicate about their symptoms because there is no direct access to the experience of others. I shall further elaborate on the linguistic challenges on chapter five. Meanwhile, in the next section, I elaborate on the implications that this shift from symptoms-based conditions to signs-based diseases has had for patients by drawing on some excerpts from patients' narratives.

3.5 Some Implications Resulting from the Sign-based Diagnosis and the Case of Contested Illnesses

Several implications arise from the shift in medicine to sign-based or evidence-based diagnosis. In this section, I would like to provide some concrete examples that can illustrate these implications. First, as mentioned earlier, it is important to note that not all diseases can be diagnosed by biological markers, which is especially true of mental illness as observed by Frances (2013), who states, "The absence of biological tests is a huge disadvantage for psychiatry, it is like having to diagnose pneumonia without having any tests for the viruses or bacteria that cause the various types of lung infection" (12). However, it is also important to consider that even in those cases in which organic evidence is found, for instance, some people may be infected with the tubercle bacillus despite not having developed tuberculosis; or others may be carriers of the mycobacterium *Helicobacter pylori*, yet they have not developed a duodenal ulcer (Cassell 2013, 4). These examples seem to indicate that the presence (or absence) of biological markers may be necessary but not sufficient to trigger the onset of disease, which in turn indicates that determinants other than physical distress, such as psychological, cultural, and social, may also play a part in people's responses to symptoms (Cassell 2013, 4). In sum, these examples reveal that a strict biomedical approach is unable to explain these phenomena.[5] One of the effects of this

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[5] . See George Engel's (1977) well known article, "The Need for a New Medical Model" for a critique to the biomedical model.

epistemological but also practical problem is that the conditions or symptoms that cannot be explained by means of organic evidence tend to be explained by diagnostic hypotheses of psychological or emotional distress, which in turn reproduce the dualistic construct of body and mind distinction. Anthony Komaroff (1990), an expert in chronic fatigue syndrome, asserts,

> Before a pathophysiologic basis was established for systematic lupus erythematosus, Lyme disease, or multiple sclerosis, for example, patients with these illnesses who presented with fatigue, headaches, myalgias, arthralgias, blurred vision, numbness, tingling, and related symptoms were frequently given psychiatric diagnoses. Indeed, in our experience, the same error is still made today in some patients with these illnesses. (Komaroff 589)

Komaroff's argument can be illustrated by Polly Murray's autobiographical illness narrative, *The Widening Circle: A Lyme Disease Pioneer Tells Her Story*. Murray suffered from Lyme disease unknowingly for many years without a proper diagnosis. Her work as an advocate during the 1970s and 80s made possible the recognition of infection with Lyme as a legitimate disease. In the selected excerpt, Murray (1996) narrates how her doctor, at the time, pleaded with her to prevent her from continuing to seek treatment. He rather saw her case as a psychiatric illness: "Please, please accept the fact that everything has been done, and forget this fruitless search for a label. Nothing at all has shown up on tests, we can do no more. I personally think you are … obsessed with making a case for a disease that exists most likely only in your own mind" (58). However, while Komaroff's and Murray's points are important, it is also necessary to acknowledge that the opposite is also true; that is, psychiatrists may fail to recognize organic illness that can cause or exacerbate psychiatric symptoms.

Another implication resulting from medicine's emphasis on evidence-based diagnosis can be seen to affect the doctor–patient relationship. The physician who went through years of rigorous training to learn how to treat organic diseases may not be prepared for how to deal with those patients who do not fit into the sign-based criteria. My next example comes from Annmarie Mol's (2002) ethnography based on a hospital in the Netherlands, with patients suffering from atherosclerosis of the leg. Mol documents the following narrative from one of her participants, a vascular surgeon:

> Some of these stories [that] patients tell are so typical… But it's always important to do a physical examination as well. A patient's pain can have many causes. They may even have picked up the story they tell at some party, or from the television. So, I carefully feel their pulsations. Inspect their skin. And usually, I know from the interview what I will find. *But it does happen that a story sounds impressive while the legs are perfectly warm, and the foot arteries pulsate happily. I don't like that. I prefer to have a nice, coherent clinical picture*. (Mol 51) (emphasis added)

There are many interesting aspects to discuss in this excerpt, but for the moment, I would like to observe that in spite of doctors declaring that they are feeling uncomfortable with these stories, many patients' stories are indeed "impressive" to the extent of being seen as fantastic and difficult to believe. As Mol's vascular surgeon observed, the form of many patients' illness narratives shares a "fabulous" component, which may overlap with the characteristics we attribute to verisimilar and literary fiction. The aspect of patients' credibility due to the "fabulous" component of their narratives is a major problem for patients (and doctors), but this is especially so for those patients with contested illnesses, and it is one that I believe has not received much analytical attention. In his book *Contested Illness in Context*, Quinn Schone (2019) observes that contested illnesses remain unaccounted for by biomedical models. He states,

> They straddle both the physical and the mental but share a sense of dislocation; doctors are not trained to help [patients'] non-specific pain, partners are not naturally inclined to sympathize, and institutions are not willing to accept them as genuine. They are precisely those illnesses which disconnect from our expectations of disease, and in the gap created lay bare our previous assumptions

> about what a disease is or what is necessary for someone to be sick. (Quinn Schone 6)

Society places a particular premium on the authority of rational knowledge to regulate nature and health; knowing the nature of the body depends upon a detached observer who is trained to identify the intricacies of biological and physical signs and to confirm the evidence of the patient’s narrative, as Kroll-Smith and Floyd (2000, 85) observe. It happens, then, that not all patients’ stories pass the test of credibility in the doctor’s office—because they may not pass that test in other sorts of social interactions either, unless they follow a certain conversational structure.

In his paper “On Doing ‘Being Ordinary,’” conversationalist analyst Harvey Sacks (1984) argues that the entitlement to rational knowledge is treated differently in society than entitlement to personal experience. While knowledge may enter the repertoire of a community and thus, we may feel entitled to it, a person’s experience is carefully regulated (Sacks 1984, 428). A person’s story may not be trusted if the way the story is told does not match the preexisting repertoire of knowledge. Sacks asserts, “There is an attitude, the attitude of working at being usual, which is perhaps central to the way our world is organized” (1984, 429). There are conversational and discursive strategies to “doing ordinary;” that is, to normalizing events that are extraordinary. The patient’s narrative must show that her visit to the doctor’s office is justified and that she displays herself as a reasonable and accountable teller. However, if the patient’s narrative does not match this expected knowledge (i.e., if the symptoms do not match the disease criteria), then the story needs to be normalized, that is, made to fit the repertoire of knowledge already existing or to justify its deviance therefrom. However, sometimes this is not possible because reality may exceed the repertoire of knowledge of the community. (I will further elaborate on this topic in chapter five.)

The following excerpt from Amy Berkowitz's (2015) book *Tender Points* illustrates her need to be believed despite not showing organic signs. She writes, "Fibromyalgia is largely defined by a lack of visible symptoms or identifying lab tests. The only diagnostic criteria are the frustratingly vague tender points. '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*'" (Berkowitz 2015, 40) (emphasis added). The assertion of her experience of pain and the repetition of that assertion may not, however, fulfill her desire to be believed—as Sacks (1984) observes, a person's experience is carefully regulated. This is probably why Berkowitz, like many other patients who became authors, as we shall see, had to write a memoir to legitimize her "extraordinary" stories. I will return to this point later. However, if we go deeper into this problem of credibility, the patient's narrative style may not be the only issue.

Patients asking to be believed—as well as physicians wanting to believe their patients— are against a social construct, that is, nosology, which, while it is represented and embodied in the physician, she or he is only its most visible face. In dealing with the patient's extraordinary and incredible story (as Mol's doctor stated earlier), the physician must assess the words of the patient against the current nosology. This is eloquently articulated by Rosenberg (2007): "On the one hand, the physician status is enhanced by serving as an access provider to the knowledge and techniques organized around disease categories. Yet at the same time, the physician is necessarily constrained by the very circumstantiality of that generalized knowledge, by the increasing tightness of diagnostic and treatment guidelines" (253).

The patient's request to be believed, as illustrated in Berkowitz's (2015) narrative, may turn into an implied request for the physician to defy the institutional constraints of her or his profession. Berkowitz's request could be rephrased in the following manner: *Please disregard the nosology to which you must professionally adhere. Use your imagination to fit my symptoms into a suis generis diagnosis. Create one if necessary. But, please, believe my story to make it real.*

Such a request would be essentially an oxymoron, if we consider that diagnostic criteria are institutional categorizations as observed by Rosenberg (2007). Furthermore, it would present an institutional challenge to the physician who has to adhere to the current nosology—unless new diagnostic criteria are created.[6] And new diagnostic criteria have, indeed, been created over the years, but this seems to be a conflictive and negotiated process that involves the interplay of science and social mobilization as the authors cited here have observed (e.g., Aronowitz 2001; Murray 1996; Frances 2013; Shorter 1985, 1992). Thus, contested illnesses seem to bring to the fore the conversational, interactional and institutional dilemma already observed by sociolinguistic studies (e.g., Drew and Heritage 1992; Mishler et al. 1981; Mishler, 1984), that binds physicians to the institution

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[6]. An illustrative example of the action of breaking with strict biomedical procedures can be found in Victoria Sweet's book *God's Hotel*. Sweet narrates how as a physician in the Laguna Honda Hospital in San Francisco, she decided to imagine how Hildegard, a twelfth-century Benedictine nun, musician, mystic, and healer from Germany, would have addressed and treated her patients back then and to extrapolate Hildegard's methods to her own. Sweet (2012, 180) states, "I understand Hildegard's [framework] enough to put myself inside it and even use it sometimes, as a way of thinking about a patient, a disease, or a medication, as a way of thinking outside my box." Sweet steps into Hildegard's healing methods to seek inspiration into a new way of looking at patients' illnesses.

of medicine and patients to their subjective experiences. Yet the plea of the patient over contested illnesses may not go away easily. Pain and anger can be powerful tools, despite their debilitating effects.

In conclusion, not all symptoms can be easily translated into a disease category that matches the current nosology. The etiology of some conditions is still scientifically unknown, thus, patients who experience symptoms associated with contested illnesses have fewer chances to have their conditions recognized and receive the care they need within the biomedical model. To receive treatment, the patient's symptoms need to exist within the institutional and ontological space that diagnosis provides. That said, the normative model shows that in the clinical encounter between doctor and patient, the distinction between symptom-based and sign-based diseases is rather a matter of institutional legitimatization. Physicians as well as patients are constrained by nosology and diagnostic criteria. However, despite the intensification of scientific criteria to regulate diagnostic categories, the creative power of patients to make their voices heard cannot be underestimated, as the influx of illness narratives and the evolution of this genre has shown us in chapters one and two.

CHAPTER 4

A GENDER PERSPECTIVE to the PROBLEM of CREDIBILITY in PATIENTS' NARRATIVES of CONTESTED ILLNESSES

In this chapter I begin by offering an overview of the problem of credibility in patients' illness narratives considering the perspectives of physicians' cognitive biases as well as social biases, including gender as a social factor. The history of hysteria is reviewed as relevant to understand the biased association between women's narratives and their lack of credibility throughout the history of medicine, in its evolution from the central nervous system paradigm to the psychological paradigm. The emergence of contested illnesses, such as chronic fatigue syndrome, as the modern manifestation of hysteria, is explained through the cultural thesis of influential medical historians, such as Edward Shorter and Ilza Veith. I conclude the chapter following Arnowitz's (1998) thesis, elaborating on the importance of naming new functional conditions as highly consequential to help patients gain access to medical care; naming can give patients language and legitimacy. I add to the discussion the need to be open to imagination and validate the role of imagination as a source of scientific knowledge and self-knowledge.

4.1 Illness Narratives and Credibility

The problem of credibility of patients' narratives (either oral narratives offered by patients in their doctors' offices or in the patients' written memoirs) has become a relevant social phenomenon in our post-modernist culture. On the one hand, the problem of credibility has risen in part due to the increase in chronic conditions, which are now affecting nearly 50 percent of the population. By the year 2025, it is estimated that chronic illness will affect 164 million Americans (Edwards 2013, 11). On the other hand, contested illnesses are more elusive to diagnose, and the symptoms (e.g., myalgia, fatigue, general malaise) associated with these conditions are either highly subjective or they mirror other diseases, which make them ambiguous and difficult to categorize. Patients' concerns about their credibility in interactions with doctors have been expressed in different textual genres, either directly or indirectly, over the last decades. For instance, the genre of illness narratives, which I elaborated on chapters one and two, could be considered a form of denunciation of the lack of credibility—about which patients complain.

Illness narrative is an umbrella term that can include a range of publications such as memoirs, blogs, and Facebook groups, which have proliferated in recent years (e.g., Jurecic 2012; Rak 2013). Additionally, there have been popular and journalistic publications (e.g., Dusembery 2018), and academic and professional publications that address credibility from different perspectives and disciplines, such as rhetoric (Molloy 2020), medicine (e.g., Groopman 2007; Orfi 2020), sociology (e.g., Belling 2012), and the medical/health humanities (e.g., Garden 2010; Montgomery 2006; Shapiro 2011). Moreover, numerous studies in sociology, anthropology, and medicine have documented disparities in access to health care between men and women (e.g., Hoffman and Tarzian 2001) and among race, ethnicity, and gender (e.g., Farmer, Connors, and Simmons 1996; Sabin et al. 2009; Smedley et al. 2003). Although these studies do not address credibility per se, they are relevant to understand the disparities in the epistemic status of different populations.

Women are more likely to experience contested illnesses than men, and women are more susceptible than men to autoimmune diseases, which are part of the group of contested illnesses; for instance, eighty five percent of fibromyalgia and multiple sclerosis patients are women, and eighty percent of chronic fatigue syndrome patients are women (see Ramsey 2020, 21). Also, women are more likely to have their illness narratives constructed as *hysteric* or *hypochondriac* than men, and, for that reason, they are more likely to receive less pain medication than men (e.g., Dusembery 2018; Edwards 2013). Overall, a pattern emerges in these publications where patients, especially female patients, claim that they were treated as chronic complainers, or as if their conditions were "all in their head" (Edwards 2013). This pattern is illustrated in Hillary Mantel's (2013) memoir about endometriosis, *Giving up the Ghost*, where she wrote, "The more I said that I had a physical illness, the more they said I had a mental illness," and "the more I questioned the nature, the reality of the mental illness, the more I was found to be in denial, deluded" (quoted in Norman 2018, 187). I will analyze illness narratives or memoirs in chapters seven and eight; however, first, in this chapter, I outline the historical context of the credibility problem from a gender perspective and its origins to the present. This outline is expected to serve as a cultural background that will shed light onto these narrators' testimonies.

4.2 Credence and Credibility

Before discussing different gender perspectives to the problem of credibility, I would like to clarify the distinction between the nouns, “credence” and “credibility.” Credibility is defined as the quality of power to inspire belief; credence is defined as the mental acceptance of something as true or real (*Merriam-Webster* 2021). Thus, whereas credence is the acceptance of a belief or claim as true, especially on the basis of evidence, credibility is the quality of being believable or trustworthy. I find that this distinction is important: the denial of credence on a claim may not always translate into the denial of a person’s credibility as a distrusted, discredited, or spoiled identity. The problem of credibility could be partially explained by the divisions of race, ethnicity, and gender. Thus, social biases may be related to the perception of the patient’s credibility and the degree of agency and responsibility attributed to certain social groups. Also, lack of credibility could be associated with the perception of a patient as being malingering (i.e., in the case of absence of organic disease), hypochondriac, or hysteric (i.e., in the case of having a psychosomatic illness), as if somatization were not a real condition capable of causing serious health damage to those patients (O’Sullivan 2016).

The credibility regarding patients’ narratives of contested illnesses, especially in their doctor’s offices, seems to have enlivened the nineteenth century tensions between organicist theories of diagnosis and psychogenic theories, as I will further elaborate. However, it can also be said that those tensions were never put to rest. Up until today, despite the increasing number of studies in psychosomatic medicine, including alternative medicine such as mindfulness meditation, as the psychiatrist and medical humanist

Howard Brody (2016) asserts, “there is a continued debasement of therapies that involve the mind” (278). In other words, these therapies and approaches are still seen with suspicion by biomedical professionals and may be stigmatized.

One perspective to understand the problem of credibility can be seen in the literature about the cognitive and social biases that shape doctors’ perceptions. Recent publications by renowned medical authors, such as Gerome Groopman (2007) and Danielle Orfi (2020), focused on cognitive aspects involving the conscious and unconscious biases that frequently lead to diagnostic errors associated with the way doctors think. From their professional perspectives, these authors frame the problem of medical errors in terms of their concerns about misdiagnosis and malpractice.[1] In his book, *How Doctors Think*, Gerome Groopman reported that patients who are thought to have a psychological disorder “get short shifts from internist and surgeons and gynecologists” (39). This could be explained by the perception of being hypochondriac, hysteric, or having emotional conflicts. As a result, these types of patients’ physical maladies are often never diagnosed, or the diagnoses are delayed because the doctor’s negative feelings cloud their thinking (Groopman 2007, 39). To avoid these sorts of errors, Groopman advised physicians, saying, “When a patient tells me, ‘I still don’t feel good. I’m still having symptoms,’ I have learned to refrain from replying, ‘Nothing is wrong with you’” (264). The conclusion that what is wrong is psychologically based, he said, “should be reached only after a serious and prolonged search for a physical cause for the patient’s complaint” (264). In contrast, when patients do present with psychogenic symptoms, giving credence to the patient’s reality and experience of suffering is still

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[1]. According to Orfi (2020), medical errors constitute the third leading cause of death in the United States, higher than heart disease and cancer.

essential to offer them appropriate care. Neurologist Susanne O'Sullivan (2016) stated, "One of the greatest challenges for most doctors is the struggle to believe in the truly subconscious nature of their patients' psychosomatic symptoms. [But] if I cannot believe that, then I am calling every patient I see a liar, whether I say it aloud or not… To believe in the subconscious nature of the symptoms is difficult but absolutely necessary for both patient and doctor" (129). One thing is evident, though; credibility of the patient's narrative is essential to creating a partnership with the patient and building a therapeutic alliance.

An interesting aspect of the problem of patient narrative credibility is that it does not always reveal itself as explicit distrust against the patient. Notwithstanding, I suggest that socially biased errors (i.e., those motivated by race, gender, or others) could be associated with a lack of credibility of the patient's narrative. Although indirectly, socially biases or errors may reveal lack of attunement with the patient, or lack of interactional alignment between patient and doctor. In other words, socially biased errors may reveal the inability to listen to what the patient has to say and take her word for it, instead of projecting stereotypical assumptions onto her narrative. I suggest that the failure to listen to the patient may subtly involve, concomitantly, the failure to believe what the patient says. This point is illustrated in Abby Norman's (2018) memoir, *Ask Me about My Uterus*. Norman has suffered from menorrhagia since she was a teenager, as well as from pelvic and genital pain disorders. At age nineteen, she was diagnosed with endometriosis as a result of the discovery of a cyst in one of her fallopian tubes. Despite several medical procedures and numerous alternative medicine treatments, Norman continued to have chronic pain that prevented her, among other things, from establishing long-lasting social and romantic relationships. Whereas, on the one hand, she was successful in persuading one of her doctors to do a laparoscopy, after her own investigations led her to realize that endometriosis might have affected her appendix, on the other hand, her gynecologist resisted removing her fallopian tube, given concerns that such a procedure would jeopardize Norman's reproductive ability. Norman claimed that she explained to the doctors before the procedures that she was willing to lose an ovary if that could preserve her from pain and disruption. However, she reported that her doctors were more concerned about Norman's fertility than about her decision to eliminate pain from her life. That resistance could be explained by the culturally and socially shaped unconscious biases that see the role of women as primarily that of bearing children. As Norman writes,

> I tried to explain this to Dr. Paulson, to Dr. Wagstaff, to Jane [her therapist] to anyone who would have listened, really. And inevitably, I would wince with a little half-smile and offer a half-hearted, 'Maybe I'd like to have a baby when I'm older …' in order to placate them because expressing a preference toward childlessness is apparently quite the faux pas… The things that actually did concern me—the pain, the nausea, the complete loss of everything that I loved and that made me happy…—didn't seem to carry the kind of weight that concerns about my fertility did. (Norman, 196)

This type of unconscious biases interferes in the communication between doctor and patient.

Leaving the problem of credibility aside for a moment, there is, however, an important fact that needs to be mentioned: all patients, regardless of their social status, need to make their cases doctorable (i.e., credible, that there is a legitimate health reason for seeking medical care) (see Halkowski 2006). Conversational analyst Halkowski (2006) observed that patients face a moral dilemma—not to waste doctors' time and resources—and also a social dilemma—to preserve their self-image and reputation (112). Consequently, patients need to be believed by their doctors to achieve their goals (i.e., restoring their health). It seems that the test of credibility is the burden of the patient. It is a social fact that some patients, such as women, have more obstacles to make their cases doctorable than others, and they will find this task more difficult to achieve than others (see Malterud 2000; Wallen, Waitzkin, and Stoeckle 1979). Then, given that patients need to make their cases relevant to gain access to health care, I see the credibility of the patient as a discursive and interactional problem that could have medical repercussions for both parties. In the present study, however, I can only examine the patients' retrospective, written evaluations and reactions to their experiences of not having been believed—that is, as the memories of these experiences are narrated in their memoirs or illness narratives. In addition, I wish to note here, that I discuss the problem of credibility only in connection with the diagnostic process, but there could be other speech events in which credibility is doubted, such as in the case of prescription of medication and patients' adherence to those prescriptions.

From a communicative perspective, I see credibility as an essential tool for the strengthening of social interactions (even though it is obvious that people can lie), and as a fundamental element that forms part of what philosopher of language Paul Grice (1975) has named the cooperative principle.[2] If cooperation does not take prevalence, then communication would be a nihilistic enterprise. Another important author that

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[2]. Grice (1975) saw communication as constructed upon cooperation. The cooperative principle comprises four maxims: the maxim of quantity (make your contribution as informative as required), quality (do not say what you believe to be false), relation (make your contribution relevant), and manner (be perspicuous). Even when speakers flout these maxims, people still use conversational mechanisms to repair these maxims' violations and to make sense of utterances, based on the assumption of cooperation (see Mey 2001).

illuminated the problem of credibility is sociologist, Ervin Goffman (1959), who in his book, *The Presentation of Self in Life,* wrote about the need of social actors to perform credibility as an essential component of gaining acceptance in social interactions:

> When an individual plays a part [in a social interaction] he implicitly requests his observers to take seriously the impression that is fostered before them. They are asked to believe that the character they see actually possesses the attributes he appears to possess, that the task he performs will have the consequences that are implicitly claimed for it, and that, in general, matters are what they appear to be. (Chapter one, Kindle edition)

Given this theoretical context, it is easy to anticipate that patients with contested diseases are highly vulnerable to the problem of credibility. Symptoms are not always what they appear to be, impressions of a person's degree of sickness may be misleading (the person may be sicker than it looks or the reverse), and illness experiences are often difficult to articulate when pain is present. Finding inspiration in Goffman's (1959) dramaturgical theory, I would like to propose that credibility is a social capital. As social capital, credibility is essential for the successful management of impressions during social interactions. Moreover, credibility is essential for patients with a contested illness to gain credence about their narrative. Health-care professionals would then ultimately determine whether the condition is doctorable (i.e., worthy of attention and care).

In the case of contested illnesses, the major dilemma of the patient is to make the case for a doctorable condition by displaying an illness account that is deemed reasonable and to avoid being seen as hypochondriac, hysteric, or malingering. As discussed earlier in chapter three, there is a hierarchy of diseases (Canguilheim 1978). In this hierarchy, contested illnesses are placed at the bottom. The organic hierarchy that ranks diseases as "real" instead of imaginary and thus deserving primordial medical attention, is associated with an epistemic status that ranges from certainty to uncertainty. For instance, “the fibromyalgia patient reporting debilitating pain, is not often afforded the same epistemic status as an individual with gallstone problems,” asserts Quinn Schone (2019, 127). For patients with contested illnesses, being accused of malingering is a particular concern because they are aware of the subjective nature of their complaints: “Having a purely symptomatic illness can generate the uncomfortable feeling that those around you and those professionally responsible for your wellbeing have ceased to trust the way that you present yourself” (Quinn Schone 2019, 33).

As social capital, credibility can be achieved at one single encounter or be built over time by maintaining consistency. However, once a characterization such as hypochondriasis or anxiety is made for a patient, then, by virtue of this information being perpetuated in the electronic medical record, that characterization may become a permanent label that stigmatizes the patient (Swinglehurst, Roberts, and Greenhalgh 2011). Thus, it can be said that patients with contested illnesses may experience the burden of proof, but not receive the benefit of the doubt. For instance, returning to the case of fibromyalgia, Quinn Schone (2019) noted that a significant number of doctors and a lower, but still relevant, number of specialists doubt the credibility of the disease, and they may believe outright that those who claim to suffer from it are malingering (33). Only a doctorable condition can gain legitimacy. If it is not seen as legitimate, then their conditions might be deemed as invalid, which is stereotypically associated with a not real condition. Experiencing self-doubt after a medical professional can cast doubts onto the reality of a condition and is a common phenomenon that many patients have documented in their illness narratives or memoirs. This point is illustrated by Kat Duff (1993) in her memoir about chronic fatigue syndrome, *The Alchemy of Illness:*

> So developed the thinking that nothing is real unless it can be physically proven—a notion that has caused considerable anguish for many people with CFIS and other undiagnosed illnesses whose doctors refuse to believe they are actually sick because researchers have not yet found the tests that can objectively confirm it. When I was getting sick, feeling tired and achy all over, *I kept wondering: Is this real, or is it just my imagination? as if my experience were not real*. (51) (emphasis added)

Moreover, Ally Hilfiger (2017), in her memoir about Lyme disease, *Bite Me*, wrote, "Your family, your friends, and even your doctors tell you it's all in your head, or that it's something else that's easily treatable… So, you start to fool yourself. Maybe they're right, you say" (107).

Another aspect of the problem of credibility lies in the attribution of agency. When conditions are clearly based on pathophysiological abnormalities or physiological malfunctioning, the patient is less likely to be held responsible. However, when the condition is contested and suspected to be psychogenetic (which is generally socially deemed as non-real), then the patient is more likely to be held responsible for creating or imagining the condition. This moral aspect involved in agency or responsibility for the disease is one of the reasons patients tend to reject a psychogenic etiology: if it is in the head, there is the false assumption that it can be controlled and changed with willpower. When conditions are indeed of psychogenic origin, there are still many medical professionals who believe that patients are faking the condition, observes neurologist, Suzanne O'Sullivan (2016). In a bitter statement, reflecting the anger that these kinds of medical beliefs and biases trigger in patients, Paula Kamen (2005) in her memoir *All in My Head* wrote about suffering from chronic migraines, paraphrasing Susan Sontag's classic book, *Illness as Metaphors*, “A problem becomes most vulnerable to metaphor when its origins and treatment are ‘unknown.’ Unable to cure the patient? Then blame the patient. The less doctors know about a problem, the more psychological, spiritual, and moral meaning it takes on” (90).

4.3 Gender Perspectives to Credibility

As mentioned earlier, female patients are most likely to report they have not been believed or that their conditions were assumed to be of psychogenic origin. In the book, *In the Kingdom of the Sick*, Laurie Edwards (2013) summarizes this perception about women’s unreliability:

> As patient narrative, research, and history will illustrate, gender remains an incredibly important variable in the chronic illness experience. Partly, this is because more females than males manifest chronic and autoimmune conditions. However, throughout history, deeply ingrained ideas about women as unreliable narrators of their pain and symptoms, as weaker than men, and as histrionic or otherwise emotional have had a profound impact on their ability to receive accurate diagnoses and appropriate care. (20)

Similarly, in *Doing Harm*, journalist and health advocate, Maya Dusembery (2018) presents a well-researched account of the disparities in access to quality health care of women suffering from chronic illnesses, especially autoimmune diseases. She identified two main causes to the disregard or neglect of women’s health care: the problem of knowledge and the trust gap. Dusembery asserts that there is a knowledge gap between what doctors know about men and what they know about women. She claims that the average doctor does not know as much about women’s bodies and the health problems that afflict them, as they do in comparison with men (11). In her research, Dusembery also explains that this knowledge gap is, in part, the result of women being underrepresented in clinical research and the fact that medical education does not focus on training physicians to pay attention to gender variables—or specifically on women's differing hormonal states and cycles (11). The second cause is the trust gap, "women's accounts of their symptoms are too often not believed" (11) or they are "brushed off as the result of depression, anxiety, or the all-purpose favorite: stress" (4). As with Edwards (2013) above, Dusembery attributes the trust gap to the lasting influence that *hysteria* has had historically and culturally in shaping the perception of women's health problems.

In the next section, I will review the history of hysteria in connection with the issue of credibility, which aligns with Dusembery's (2018) and Edwards' (2013) position. However, before concluding this section, I wish to observe the irony in the fact that the attribution of psychological factors comes to the rescue when organic abnormalities cannot be found; this is because medicine has become more evidence-based oriented over the past decades. As physician, Eric Cassell (2013) asserts, "Belief in the molecular and genetic determinants of disease has so firmly captured medicine that acceptance of any other causes seems to have fallen by the wayside" (4). To this day, the Cartesian mind-body dualism still has an impact on our way of approaching health. Yet organic diseases can affect us psychologically and emotionally, and the reverse is not only possible but probable (see O'Sullivan 2016). Furthermore, whereas some patients may be cured with placebos, others need heavy drugs. The lack of evidence of disease does not mean the lack of evidence of illness, but a denial of an illness to a patient could have a nocebo effect—that is, it might become a contributing factor in reinforcing the patient's symptoms or preventing a cure altogether, as the patient's need to demonstrate that her condition is doctorable. The fact that an illness may not be deemed ontologically real for medicine only tells us that the physician has not been able to imagine its phenomenological existence yet.[3] I next draw again on Norman's (2018) memoir to provide an example of this point.

Norman wrote about her own research into her condition: endometriosis. Thanks to her research, she was able to identify the origin of her intolerable pain as coming from her appendix, as she hypothesized that she had endometrial tissue implanted in her appendix (see Medline 2021). However, her physician doubted her hypothesis, responding, "You're either brilliant or the most well-educated hypochondriac I've ever met" (180). Ultimately, she persuaded her physician to do the laparoscopy, at risk that, if she were mistaken, she would have to withdraw from his medical care. Norman's self-diagnosis was confirmed by the pathological analysis. Norman wrote, "There wasn't a lot of research on it [endometrial tissue adhered to the appendix], and the majority of doctors didn't believe it was even possible" (184). Using Norman's example, I argue that the doctor's failure to believe Norman's hypothesis (and her narrative) was a failure of imagination of the possibility that endometrial tissue could grow in her appendix, despite the medical literature validating the fact that growths could be found even in the lungs (see Medline 2021). I speculate that patients' narratives are not given credence, especially when the conditions are rare or present a low probability of existence. I will return to the failure of imagination later, but before that, in the next section, I elaborate on the historical origins of hysteria and the possible repercussions in the present.

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[3]. It is my hope that the wondering effect that the so called COVID-19 "long haulers" is triggering among physicians may help those other patients with contested illnesses, such as post-Lyme, to be believed.

4.4. Historical Review

4.4.1 Hysteria and Credibility

The term hysteria is etymologically associated with women's bodies and health conditions. Hysteria derives from the Greek word "hystera," which means "uterus" (Veith 1965, 1). Despite the fact hysteria was also observed and described in men by some authors (e.g., by Jean-Martin Charcot), it has been historically, predominantly associated with women and their reproductive system. The Greeks considered hysteria to be an organic disease caused by what they call a "wandering uterus." Although, in the eighteenth century, it was known that organs were fixed in place, it was still believed that, through the power of the four humors, the uterus had the ability to bring other organs into sympathy with it (O'Sullivan 2016, 76). The theory of the physical movement changed its physical attribution to an emotive one—that is, the energetic power of sympathy as a source of metaphorical interaction among the organs.

In the nineteenth century, it was discovered that muscle fibers were excitable and contracted in response to electric stimulus. This contraction was understood as a reflex, which was believed to be mediated by nerves in the spine (O'Sullivan 2016, 76). Adherents of the "reflex theory" asserted that the spine could communicate its distress to the rest of the body, independently of human will. Spinal irritation became an explanation for hysteria (see O'Sullivan 2016, 76). The effect of the spinal irritation as a medical interpretation probably enhanced the perception of women as automata regulated by their uteri and more passive than men (Shorter 1992, 40). However, Shorter (1992, 201) observed that, later in the nineteenth century, the reflex theory was challenged by two new paradigms. One paradigm involved the presence of invisible but real diseases in the brain and the spine that could cause dysfunction in the individual psyche, which became known as the central nervous system paradigm.[4] By the end of the nineteenth century, the central nervous system paradigm would explain conditions such as neurasthenia and psychoses, as manifestations of dysfunctions in the brain. The other paradigm was the psychological one, which involved assigning mental or emotional causes to physical diseases, a process known as somatization. The most relevant point about these two paradigms is that, with the development of the psychological paradigm, the idea that mental or emotional etiologies could not represent an organic threat to the body also grew. The psychological paradigm of the nineteenth century seems to be the product of the evolution of ideas that started with suggestion, mesmerism, and hypnosis and led to psychoanalysis. I will review the evolution of these paradigms because the history is relevant to understanding the split between the medical, organic views of hysteria and the psychological ones as "all in the head." The split between these paradigms had an impact not only in medicine and psychiatry but also on the perception of women, their health, and treatment by doctors.

In the mid-nineteenth century, James Braid (1795–1860), a Scottish physician, helped develop hypnotism, which he distinguished from animal magnetism or mesmerism.[5] Braid claimed that the therapeutic effect caused by mesmerism was not the effect of "animal magnetism" but rather the effect of "fixation of the mind and eye" by

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[4]. A representative of this paradigm was the German physician Wilhelm Griesinger, who reduced all mental symptoms to organic dysfunctions that originated in the nervous system, overlapping neurology with psychiatry (Shorter 1992, 208).

[5]. Franz Anton Mesmer (1734–1815) was a German physician who, following Newton's theory of gravity, theorized about the possibility of channeling natural energy or magnetic fluid, emanating from all beings, that he called animal magnetism. This natural energy could be channeled for healing practices. However, in 1784, a Royal Commission in France determined that, although his cures were real, there was no evidence of magnetic fluid. Rather, the effect of the treatment derived from the participants' imagination (Harrington 2008, 42).

means of concentration on a single monotonous idea while staring at some designated object (Harrington 2008, 54). Hypnosis caught the attention of the renowned French neurologist, Jean-Martin Charcot (1825–1893). However, whereas Braid used hypnosis as a therapeutic treatment for all people, Charcot instead saw it mostly as a diagnostic tool for hysteria. By 1882, in a lecture before the French Academy of Sciences, Charcot defined hypnotism as an “artificially induced modification of the nervous system” (quoted in Harrington 2008, 54). This definition had a dramatic effect on bringing hysteria to the organic field of neurology, ratifying the central nervous system paradigm rather than the psychological paradigm. Hypnosis allowed researchers to manipulate the nervous system of hysteric patients in a controlled fashion—that is, as a tool capable of revealing certain laws of physiology under pathological conditions (Harrington 2008, 54). Under hypnosis, Charcot observed that hysteric patients responded to a pattern of neuromotor and neurosensory automatic responses that he described as the hysteric stigmata—in other words, as hemianesthesia, constricted visual fields, and headaches alternated with convulsive fits, called *la grande hystérie* (Harrington 2008, 54; Shorter 1992, 177). Veith (1965, 235) asserted that, despite Charcot’s neurological theory of hysteria, and despite the fact he found no organic abnormality at postmortem in his patients, he recognized the role of emotions, suggestions, and psychological trauma in affecting hysteric patients as being susceptible to hypnosis. Although Charcot saw the symptoms of his hysteric patients as mimicking organic diseases (e.g., epilepsy), he still considered women with hysteria as being sick rather than being simply malingers or pretenders seeking attention. Veith reports, “For [Charcot], even the person who pretended an emotional illness was not entirely a pure malinger but was suffering from a neurotic state" (238). For him, hysteria presupposed a hidden organicity as an inherited neurological illness—not a psychiatric one. Charcot insisted on the sensory side of the nervous system in somatization (Shorter 1992, 166). However, not long before his death, new scientific theories would jeopardize Charcot's view of hysteria as an organic condition, and hysteric women would become more likely to be perceived as deceivers rather than truly sick and suffering, triggering repugnancy in doctors rather than compassion.

The psychological paradigm grew further by the mid-1880s, when Hippolyte Bernheim (1840–1919), a French physician, challenged Charcot's neurogenic theory, with his theory of suggestion. In 1887, in his publication *Suggestion in the Hypnotic State and in the State of Waking* (Harrington 2008, 58), Bernheim argued that hypnosis did not reveal how the nervous system worked under the spell of hysteria, but, rather, it was informed by a mental stimulus rather than an organic one. According to Bernheim, patients feel and behave in a way consistent with the doctor's implanted idea and without reflecting on its sense of plausibility. Then, as hypnosis was able to trigger pseudo neurological symptoms, it could, simultaneously, make them disappear; a technique that Charcot, however, had never used with a curing purpose. I suggest that Bernheim's theory of suggestion contributed, probably unintentionally, to a view of hysteria as not deserving medical attention because it was seen as induced by hypnosis and therefore, "all in the head." That view was probably rooted in the perception that hysteria was the product of automatic responses under the spell of hypnosis (i.e., as a mental effect).

Another contributing factor to the dismissal of hysteria by medicine, concomitant with the growth of the psychological paradigm, is that, after Charcot's death in 1893, one of his most loyal students, Joseph Babinski recognized before the Neurology Society of Paris that they had been mistaken about the neurological manifestations of hysteria. Babinski concluded that because hysteria was a response to an induced stimulus triggered by suggestion (following Bernheim's arguments), then medicine needed to pay no more attention to it (see Harrington 2008, 60).

In her book *The Cure Within,* historian Anne Harrington (2008, 59) observed the following parallelism: as the argument of imagination was used in the eighteenth century by the French Royal Commission to demolish the credibility of Mesmer's animal magnetism (despite recognizing the positive effect of his treatment), the psychological argument of suggestion in hypnotism was used with a similar intention (i.e., to undermine the credibility of the physicalist etiology in medicine). The underlying thought was that patients were cured—not because of healers' actions—but because of the influence of their own imagination and suggestion; thus, there was no medical intervention to which to give credit. Consequently, hysteria was put aside as a non-doctorable condition, and instead, motivated by suggestion and imagination, thus no longer the concern of medicine.

Harrington (2008) noted that the medical reaction of the time was to displace suggestion (although it had started as a medical practice) to the competence of psychology, instead of investigating the reasons for its curing effects. As hysteria lost its doctorable status, as previously supported by the organicity theory, the chasm that began to take hold upon Charcot's death would only become broader. This shift would also have implications, as we will see in the next section, to the perception of women suffering from hysteria as malingers.

Another contributor to the growth of the psychological paradigm was French philosopher and psychologist Pierre Janet (1859–1947), who developed a thesis about the unconscious for his doctorate in psychology at the University of Paris (Encyclopedia Britannica 2020). Through his research, Janet brought hysteria further to the realm of the mind as he worked toward his MD thesis at the Salpệtrière, invited by Charcot. In *The Mental State of Hystericals,* published in 1892, Janet observed that hysteric patients were under the influence of an obsession of emotional origin, or "idee fixe" that developed below the level of consciousness (see O'Sullivan 2016). Again, it seems that, unintentionally, Janet's theory contributed even further to the psychologization of hysteria, making it an "all in the head" diagnosis.

In Vienna, Joseph Breuer and Sigmund Freud also published in 1893 a theory of the unconscious in their work, *On the Physical Mechanism of Hysterical Phenomena*. Freud theorized that, in the case of hysteria or hysteric episodes, the patient re-experiences or reenacts the original psychic trauma that remains repressed in the unconscious mind. In his famous publication, *Studies on Hysteria* (1895) co-authored with Josef Breuer, Freud argued that psychological conflict was "converted" into physical symptoms, which gave rise to theories of somatization and conversion disorder. Hysteria arose when traumatic memories of a sexual nature were repressed in the unconscious and then expressed as symptoms in the body. Later, he elaborated that the nature of the psychic trauma leading to a neurosis was of a sexual nature, whether it was a current sexual conflict or the effect of earlier sexual experiences. In synthesis, Freud's theory was based on three pillars: the idea of repression, the unconscious, and infantile sexuality (Veith 1965, 270). Although Freud's sexual theory was rejected in academic circles, he continued working on this theory and would eventually arrive at a surprising realization that would change the course of psychoanalysis, along with the perception of women. His primary theory of infantile seduction, based on sexual trauma in childhood, was transformed into the Oedipus complex, or the expression of unconscious Oedipal desires. As he revealed in his *Autobiographical Study* (1927), Freud stated, "I must mention an error into which I fell for a while and which might well have had fatal consequences for the whole of my work." (42). The "error" he referred was to have believed that his female patients' stories of seduction in childhood from adults (mostly from their fathers or uncles) were true—that is, that they really happened. Furthermore, in his essay "Femininity," Freud asserted,

> In the period in which the main interest was directed to discovering infantile sexual traumas, almost all my women patients told me that they had been seduced by their father. I was driven to recognize that these reports were untrue and so came to understand that hysterical symptoms are derived from fantasies and not from real occurrences. It was only later that I was able to recognize in this fantasy of being seduced by the father the expression of the typical Oedipus complex in women (quoted in Ahbel-Rappe 2006, 184).

In his autobiography, Freud did not explain how he arrived at the conclusion that the stories were not veridical, but he blamed himself for his "credulity" (43), almost as he would have felt deceived or misled by his female patients. After a period of reflection reconsidering his theory of seduction, Freud (1927) claimed that the scenes of seduction that women had told him about their childhoods were rather fantasies, expressing Oedipal desires. "When I had pulled myself together, I was able to draw the right conclusions from my discovery: namely, that the neurotic symptoms were not related directly to actual events but to fantasies embodying wishes, and that as far as the neurosis was concerned psychical reality was of more importance than materiality" (44). As I will develop in the next section, Freud's revision of his theory would also have dramatic implications for the perception of women's health and the credibility of their words.

4.4.2. The Psychologization of Hysteria

There is debate in the psychoanalytic literature regarding Freud's revision of his theory. Whereas some authors consider the shift of his seduction theory into Oedipal fantasies as a continuation, other authors consider it as an abandonment of reality. Regardless of one's personal position about this debate, Freud's revision of his theory would have a long-lasting effect on the perception of women and on their health. Psychoanalyst Karin Ahbel-Rappe (2006) provided an interesting explanation, arguing that Freud viewed the unconscious as not differentiating between factual trauma and imaginary trauma. He asserted, "We might say that [Freud] became indifferent to the question of the reality of [real] seduction, adopting himself the indifference he attributed to the unconscious" (178). In my view, Freud's (2013), at least, apparent indifference or neglectfulness can be observed in *A Case of Hysteria, Dora.* When Freud's patient, Dora, tells him about a scene in which a friend of her father suddenly kissed her, taking her by surprise, there was no acknowledgement of Dora's reporting of disgust. Instead, Freud's attention was focused on analyzing Dora's unconscious desires and motives disregarding Dora's expressions of disgust. Given Freud's position on female fantasy, the feminist movement in the 1980s in the United States accused Freud's theories of betraying the women who were confiding in him about their ugly sexual experiences of abuse, which people did not want to hear back in nineteenth century Vienna (see Harrington 2008, 75).

In contrast, Freud's influential theory of the Oedipus complex can be seen as contributing to reinforce pre-existing prejudices about women as unreliable narrators, as this was already a trend in the history of medicine. Freud was not the only one, but perhaps one of the most influential intellectual figures that sedimented the cast of doubt about the credence of women's illness narratives as hysteria (i.e., as fabulating).

As mentioned earlier, a perception of unreliability was already in progress before the nineteenth century, which had been initiated, although probably indirectly, by those who emphasized the healing power of suggestion and mesmerism (e.g., by Paracelsus in the sixteenth century and by Mesmer in the eighteenth century), and hypnosis (e.g., by Bernheim and Janet). Moreover, as the role of suggestion became interrelated with hysteria, it also overlapped with the perception of women as being more easily suggestible, and therefore less trustworthy and reliable than men. Medical historian Iza Veith (1965, 211) quoted, as an example of the contemptuous attitudes against women, the influential pronouncements of psychiatrist Jules Falret (1824–1902) at the Salpệtrière Hospital, who saw hysteric patients as "veritable actresses" who do not know of "greater pleasure than to deceive … [and] exaggerate their convulsive movements" as examples of moral and psychogenic insanity.

The negative connotations and associations between hysteria and women can be traced to the present time, in which patients express not being believed. In her book *Doing Harm*, feminist writer Maya Dusembery (2018) states, "One of the biggest myths about hysteria is that it disappeared in the first part of the twentieth century" (70). She observes that, nowadays, even though hysteria is not considered per se as a disease category (although conversion disorder is its closer version), the psychological and social connotations associated with hysterical women have remained in our male-dominated culture. For instance, Moira Donegan (2020), a feminist writer, asserted in her essay titled, "How Bertha Pappenheim Cured Herself," "[Freud's] conclusions mirror the now-typical misogynist response used by those who disbelieve women's accounts of sexual violence: she's lying, and even if she isn't, she wanted it anyway" (10).[6] Another important observation is that women not only seem to have lost credibility but they have been at risk for losing their voices; psychiatry and medicine will speak for them. Again, drawing from Dora's case, although she claimed to Freud that she was disgusted by her suitor's physical advances, Freud interpreted that she was unconsciously in love with him.

There is a paradoxical aspect to the psychologization of hysteria—that is, that the psychological paradigm developed at a significant time in the nineteenth century when the central nervous system theory was developing, and medicine was starting to define disease as that abnormality that could be seen and verified with the technologies of the time. Apparently, the countereffect of these advances in medicine is that those symptoms that could not be explained were then attributed to the "unconscious mind," particularly in the case of women (see Dusembery 2018, 70), as a case of diagnosis by exclusion. In contrast, it needs to be pointed out that, although the effects of psychologization weighed heavily on women, male soldiers during the Great War (WWI) who suffered from "shell shock" were also accused of faking their symptoms, just as their female counterparts were seen with suspicions of faking their convulsions (see Harrington 2008, 81). Thus, the perception of malingering was not exclusive to women, but it can be asserted that it affected them greatly. This phenomenon of doubting the patient's narrative seems to be at

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[6]. The name, Bertha Pappenheim, refers to the real name of Anne O, a patient whose case was highly influential for Freud's development of his theories on transference and the Oedipus complex.

the core of Cartesian dualism, leading to the rational, materialist, and reductionist approach of current medicine (Marchant 2016, xi) and to the influence of the split between organicist and psychologist theories in the nineteenth century.

Nowadays, however, technological advances have developed to the point where certain conditions can be demonstrated to be psychogenic, despite initial distrust or doubt from patients. O'Sullivan (2016) observes that modern technologies such as magnetic resonance imaging (MRI) and computerized tomography (CT) scans can show differences in the imaging of a person with organic paralysis (as caused, for instance, by a spine injury), pretended paralysis (as portrayed by an actor in a play), and psychogenic paralysis (as in the case of conversion disorder). She explained that, whereas less activation can be observed in the motor area of the brain, a different part of the frontal lobe activates. The MRI can demonstrate that the brain is not functioning as it should in those with psychogenic paralysis; consequently, asserted O'Sullivan, an MRI can tell us that "psychogenic paralysis is not feigned" (80). In other words, psychogenic paralysis can cause atrophy of the muscles by a learned (or rather self-taught) inability to move, despite the absence of anatomical or physiological pathology. As a testimony of her own prior reluctance and the acknowledgment of the disservice that she might have caused to her patients by saying, "there is nothing wrong" (12) when an organic etiology was not found, O'Sullivan wrote, "I have found myself astounded by the degree of disability that can arise as the result of psychogenic illnesses" (13). Furthermore, O'Sullivan explained that she realized that these psychogenic disabilities could have a purpose, "when words are not available our bodies sometimes speak for us, and we have to listen" (13). Notwithstanding, she acknowledges that patients do not want to be labeled with psychosomatic illnesses. As mentioned, psychosomatic disorders are typically diagnosed by exclusion (i.e., by lack of evidence of organic dysfunction). Thus, it can be difficult for patients to accept that they suffer from a conversion disorder, or a medically unexplained (pseudo) neurological symptom (O'Sullivan 2016, 55). Often, patients insist on the organicity of their symptoms instead of confronting the hidden messages of their psychic lives. However, with this argument, we may fall again into the same dilemma that was brought forth by what Freud called in his autobiography his "credulity error"—that is, the dilemma of whether to give credence to the patient as a conscious agent, whether to consider her capable of discerning between her fantasies and her reality, or whether to systematically doubt the patient as unable to make such distinctions because she may be deceived by her unconscious.

In his book, *From Paralysis to Fatigue*, medical historian Shorter (1992, 3) proposed the theory that each culture and historical period has an unconscious, but predominant belief of what symptoms may be legitimate expressions of a certain disease; patients, he asserts, do not want to select illegitimate symptoms because they do not wish to be stigmatized; thus, they select their symptoms from a symptom pool (see chapter three). Notwithstanding, if this was the case, then so many patients would not be currently complaining of the lack of legitimacy their symptoms seem to have. Nevertheless, I follow Shorter's (1992) argument because it sheds light onto two interrelated aspects: on the one hand, the fading of hysteria as a disease category in the early twentieth century, and, on the other hand, the continuation of hysteria transmuted under a new form, as a psychosomatic disease or rather a contested disease. Shorter includes under psychosomatic diseases several contested diseases such as chronic fatigue syndrome and anorexia nervosa. He defines these diseases as diseases of organic attribution, as I will elaborate further. For his thesis, Shorter used the theory of the cultural symptom pool to explain the shifting symptoms of hysteria from paralysis (as reflecting the reflex paradigm) to fatigue (as reflecting the central nervous paradigm). In that manner, he shows how the mechanisms of attribution to an organic etiology, which had been conferred to hysteria in the mid-nineteenth century, seem to have been adapted and transmuted in the mid-twentieth century into the form of new psychosomatic diseases. His argument about the psychosomatic nature of chronic fatigue syndrome is controversial. However, I will further elaborate on it because it is relevant to illustrating the problem of credibility. To conclude this section, I suggest that although the psychological paradigm was helpful in developing treatments for neurosis and understanding the mechanisms of the human mind, it certainly did not help to have increased the credence regarding women's narratives and women's credibility.

4.4.3 From Paralysis to Fatigue as Cultural Symptoms

As a medical historian, Shorter (1992) is interested in the intersection of culture and individual expressions of disease. He argues that, in psychosomatic illnesses, the body responds to stress or unhappiness according to the unconscious, which is in turned informed by culture. Where what is thought to be as legitimate disease symptoms are ascribed to the organic realm for which patients cannot be blamed, those other symptoms, instead, deemed by culture as illegitimate, are thought to be undeserving; thus, individuals endure great pressure on the unconscious mind to produce only legitimate illnesses (Shorter 1992, x). This theory of cultural pressure helped Shorter explain how, inasmuch, as the culture changes its mind about what constitutes legitimate disease symptoms, the manifestation of psychosomatic symptoms also changes. Apparently, patients borrow symptom patterns from what Shorter (1992) calls a “symptom pool” (270), to which patients are drawn by virtue of their social exposure. Shorter (1992) believes that patients learn from the press about the doctors’ new paradigms of disease manifestation, or directly from the physicians’ discussions in front of the patients, and then they respond accordingly, mirroring their physicians’ expectations (270).

Then, as doctors’ notions of what constitutes genuine organicity change over time due to the result of new scientific and technological advances, patients with psychosomatic illnesses tend to mimic and reproduce those symptoms, according to doctors’ expectations. This relationship between doctors and patients is reciprocal and “as the ideas of either party about what constitutes legitimate organic [symptoms of] disease change, the other member of the duo will respond” (Shorter 1992, xi). Thus, according to him, it is the interaction between doctors and patients that determines how psychosomatic symptoms change over the years.[7] For instance, given the predominance of the reflex theory in the first decades of the nineteenth century, Shorter (1992) argues that the motor manifestations of hysteria (e.g., paralysis of the limbs, eyelids, vocal cords, as well as paroxystic expressions, also called hysteric fits among patients) were influenced by the expectations associated with the reflex theory (Shorter 1992, 95–96).

In contrast, as mentioned earlier, the central nervous system paradigm stressed the presence of invisible but real diseases in the brain that cause an abnormal expression of

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[7]. In contrast, although patients’ notions of disease tend to follow doctors’ ideas, the literature suggests that this obedience began to fracture at the end of the twentieth century. Chapter one reviews some of the sociocultural factors (e.g., a popular reaction against Parsons’ theory of the patient role model) that in the 1980s contributed to a shift from modernism to post-modernism—that is, from acceptance of the authority role of the physician to rebellion against the institution of medicine.

the individual psychic functions.[8] The central nervous system paradigm would evolve by the end of the nineteenth century through the description of new conditions, under the umbrella term of “nervous illness” or “nerves,” such as neurasthenia which were thought to be the manifestations of brain dysfunctions. Consequently, according to Shorter (1992), patients at the end of the nineteenth century and in the first quarter of the twentieth century abandoned the classic hysteria symptoms of the reflex theory (e.g., paralysis) and, instead, adopted sensory symptoms, such as generalized pain and fatigue, reflecting the medical expectations of the central nervous system paradigm.

Similarly to Shorter’s (1992) argument, in her history of hysteria, Veith (1965, 273) writes that, in the mid-twentieth century, behavior that included “kicking about” and “waving the arms and legs” was met with suspicion, distaste, and lack of sympathy; if it was tolerated, it was, at best, only among screaming mobs of teenage girls in response to their current idols; thus, the typical hysteric symptoms, as were popularly known, have become an unrewarding behavior. Veith (1965) concludes that the lack of reward, probably motivated the disappearance of traditional hysteria in the nineteenth century.

Although the central nervous system paradigm offered a legitimate organic and medically accepted explanation for the female patients, this paradigm was challenged by the psychology paradigm, as discussed earlier with the theories of Pierre Janet and Sigmund Freud. This evolution, however, seemed not to have had a positive effect on the perception of women and their health. Although the psychology paradigm gained predominance over the central nervous system, it needs to be clarified that this

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[8]. A representative of this paradigm was the German physician Wilhelm Griesinger, who reduced all mental symptoms to organic dysfunctions in the nervous system, amalgaming neurology with psychiatry.

predominance was only in terms of explaining diseases such as hysteria (i.e., as a psychiatric illness or as somatization of a psychiatric illness). Probably, as an unintended effect of the psychological paradigm, hysteria was assumed to have only a mental etiology, and, therefore, its impact on the body and organs was relegated to the realm of the patient's imagination and suggestion. In contrast, the physiological basis of the central nervous system that explained mental illnesses as brain dysfunctions, would continue to gain traction over the twentieth century. However, an etiological and gender division had been already activated.

4.4.4 From Hysteria to Chronic Fatigue Syndrome

By the end of the nineteenth century, Shorter (1992, 281) documents that extreme fatigue became the new symptomatic manifestations of hysteria or "great exhaustion," coinciding with the expectations of the central-nervous system paradigm, which tended to attribute a physiological brain dysfunction as the cause of nervous illnesses. In the United States, Shorter (281) reports that chronic fatigue was observed among the middle classes as early as the 1870s, and it figured prominently in the symptom pool, acquiring epidemic proportions in the 1960s. In sum, Shorter argues that fatigue became a symptom that patients chose as an expression of their distress (i.e., a somatization) because it was available in the symptom pool—and thus legitimate. Along with chronic fatigue, symptoms including generalized malaise, weakness, and mental changes such as decreased memory, became part of chronic fatigue syndrome, which, in turn, would become a medical diagnosis in the 1980s. To explain the origin of chronic fatigue syndrome, I need to draw on Shorter's (1992) concept of illnesses of attribution.

In his historical review, Shorter (1992, 305) considered that illnesses of attribution involved two phases: First, there was the appropriation of an organic disease, the cause of which was difficult to detect and substantiate. This organic disease, which was deemed genuine by medicine, was used as a template by patients to support or legitimize their contested conditions. Second, there was a period of broadcasting and diffusion (e.g., by the media) in which people learned about others with similar symptoms and, by means of the support they found in the group, embraced the template as a medical explanation of their ill health. In the case of chronic fatigue syndrome, Shorter traced the organic templates to several diseases. One of these diseases was brucellosis (a bacterial infection transmitted from farm animals to humans) and then the so-called “chronic brucellosis” as an explanation for those patients who claimed to continue experiencing the symptoms (e.g., malaise, muscular pain, fatigue, depression) after the infection had abated, or as a sequela of the previous acute infection. The dilemma for physicians was to distinguish between those who had had a brucellosis infection and those who were having the symptoms without evidence of the infection (i.e., they were somatizing in Shorter’s theory). Then, chronic brucellosis became available as a disease attribution for those “who may never have been infected, yet nonetheless had symptoms" (Shorter 1992, 306).

Another disease that contributed as a template to chronic fatigue syndrome was polio. The polio epidemic of the 1950s led to an interesting case in the Los Angeles County General Hospital, where numerous health-care professionals got sick, but with an atypical case of poliomyelitis. It was called atypical because they had symptoms, such as muscle weakness and fatigue, that incapacitated them, but they did not display the typical signs of polio, such as changes in the cerebrospinal fluid or the classic localized paralysis. At first, these patients, who were health-care professionals, were treated as hypochondriacs. However, after numerous complaints, and lawsuits involving disability, this epidemic of atypical poliomyelitis received widespread attention in the news. Then, patients in other parts of the country who were experiencing similar symptoms claimed to also have this condition. Last, but not least, another template for chronic fatigue syndrome was mononucleosis. One of the contributing factors whereby mononucleosis became a template was the uncertainty associated with the symptoms. The Epstein-Barr virus was discovered in 1964 (Shorter 1992, 309), and it was later correlated to mononucleosis. However, whereas most of the population bears the Epstein-Barr virus, not everybody develops mononucleosis. Thus, again, this created diagnostic uncertainty.

According to Shorter (1992), the antecedent of brucellosis, and then polio and mononucleosis “provided the presumption of organicity for self-labeled sufferers of chronic fatigue in the United States and Canada” (310). With the purpose of naming the condition that was affecting those people who either did not have mononucleosis or rather showed prolonged symptoms after acute infection, the name changed from chronic Epstein-Barr virus to chronic fatigue syndrome (CFS), a term coined in 1988 by the Centers for Disease Control and Prevention. Although, currently, CFS is the term most popular, patients and advocates complained that it was not sufficiently evocative of the possible organic bases for the condition (although not yet discovered), so CFS was renamed chronic fatigue immune dysfunction syndrome (CFIDS) to emphasize its organicity. The uncertainty of diagnosis gave rise to tensions between patients, including advocacy groups, claiming the organicity basis of the disease, and their doctors, who were left to evaluate the conditions as either organically based or as somatization, per their own medical decisions.

Resuming the symbolic parallelism between hysteria and CFS, as hysteria was seen as a psychosomatic illness (i.e., mimicking organic symptoms), then CFS, as an illness of attribution, was similarly seen as borrowing symptoms from the templates of organic diseases. Although Shorter was careful to emphasize the reality of the suffering that these patients experience, he explained CFS as a psychosomatic illness, which in this case meant a somatization or as "all in the head."

As mentioned earlier, in the twentieth century, the psychology paradigm took dominance over the central nervous system, at least to explain psychosomatic conditions. However, the paradox was that the triumph of the psychological paradigm did not make the population, necessarily, more acceptable of psychogenetic disorders (see Harrington 2008). It seems that the reaction was rather the opposite. A similar response can be found in the present. A consistent pattern observed in illness narratives associated with contested illnesses is the patients' refusal to be treated as having a psychogenic condition, as well as their demands and struggles to find an organic cause for their ailments. This refusal is sometimes reported with a reflective disposition and the intention to educate physicians about patients' experiences, as in Murray's (1996) memoir:

> The purpose of my book is to tell the story of a disease from the viewpoint of the patient, and to emphasize that what patients tell their doctors can be important in the diagnostic procedure… The patient is armed with a different type of knowledge—that of experiencing the disease, of living within the disease. When these two perspectives are brought into balance, good medical caretaking ensues. (xi)

Other times, that refusal is expressed with anger and defiance, as in Kamen's (2005) memoir:

> Chronic pain mainly affects women, both in overall numbers and in accounting for those primarily affected by most types of pain disorders, including chronic migraine and head pain… Instead of responding adequately, many doctors, therapists, and cultural critics dismiss it, using the catchall psychosomatic diagnosis of ‘hysteria,’ and overstating the influences of any contributing mental, emotional, and political factors. Many academics, even feminists, who are in the business of talking about how our culture ‘creates’ certain illnesses (such as chronic fatigue syndrome, a common target), but not about how strongly that same culture often denies them. This is a legacy that continues in full force a hundred years after Freud, denying major scientific discoveries of the past several decades, such as information gained through advanced types of brain imaging. (xv)

As with others, the refusal is expressed with irony and sarcasm, drawing on famous, literature characters, such as Sherlock Holmes, to mock the medical professional’s inability to find out the correct diagnosis, as in Ramey’s 2020 memoir:

> ‘Now, Ms. Doe,’ he says cheerfully. ‘What can I do for you?’ The interaction begins very seriously, a furious scribbling of notes, a furrowing of the brow, a lot of nodding. The usual diseases are ruled out and Jane confirms she has been tested, twice, for everything under the sun… Sherlock Holmes scribbled furiously, hot on the trail, bent on solving her mystery—he now leans back in his swivel chair, tip of his pen in the corner of his mouth, checking his watch. His look is saturated with understanding, for he has solved the case. What we have here is not a rare, tropical disease, Watson. What we have here is an unhappy woman, badly in need of an antidepressant. (10)

These three memoirs are representative of the range of emotional reactions and rhetorical devices used by memoirists to respond to the psychologization of their conditions by medical professionals. They respond didactically with the intention to educate physicians, defiantly against medical power, and sarcastically mocking medical knowledge about their conditions.

4.4.5 The Social Creation of New Medical Conditions

In his book, *Making Sense of Illness,* rheumatologist Robert A. Aronowitz (1998) offered a patient-oriented perspective regarding the creation of new medical conditions whose organicity is not clearly established. Although I have addressed the social aspects involved in the creation of diagnostic conditions in chapter three, it is useful here to refresh the idea that new terminologies, such as chronic fatigue syndrome or post-chronic Lyme disease, emerge out of the necessity to categorize and designate new biological, social, and cultural realities.[9] Aronowitz thus adopted a sociolinguistic perspective regarding the creation of new terms, which can be observed in the following statement:

> My working assumption is that a new consensus about illness is usually reached as a result of negotiations among the different parties with a stake in the outcome. Insights from the clinic and laboratory create options for a new disease category or a different meaning of an existing name, but do not ultimately determine the outcome of a largely social process of negotiation. (3)

As he put it, disease categories and names are not solely the result of medical or biological processes but also the product of social conventions, reached by means of negotiations between different social agents, such as patients, advocacy groups, medical organizations, pharmaceuticals, and others. In this view, medicine is not impervious to social pressures but rather part of it. Aronowitz's (1998) explanation emphasizes the agency of patients, irrespective of whether their conditions are psychosomatic. Furthermore, the naming of new functional conditions is highly consequential because, as he asserted, "it represents a negotiated solution to the problem of idiosyncratic suffering not readily explainable by specific pathology" (16). In other words, new concepts as new

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[9]. It is worth noting that although the conditions I have mentioned so far here are deemed contested, they, however, have been assigned a name or medical term that allows them to have social and medical recognition, even though their identities as contested are spoiled. Sarah Ramey's memoir shades light onto the experience of those patients whose symptoms cannot be categorized at all. Then, in a graduation scale the designation goes from "contested" to "mysterious." This grading scale indicates that mysterious illness enjoys even less of an ontological status than contested illness.

categories and terms help patients gain access to medical care; patients with unspecified conditions and their family members need categories with which to make their idiosyncratic suffering socially acceptable and, thus, treatable. If so, even when the conditions may not be entirely cured, then at least conditions could begin to be addressed and sanctioned. The social pressure can be explained and justified as a result of the reductionist models of disease etiology that are not open to the possibility of idiosyncratic suffering.

In search of a practical solution, and in favor of the patient's predicament, Aronowitz proposed a compromise between the different parties. Given that medical knowledge is provisional, the somatic bases of some conditions, such as chronic fatigue syndrome, could be held provisionally until new technological developments prove the organic basis of these conditions. This provisional negotiation would help patients gain access to a legitimate medical establishment that would treat their condition. However, a social negotiation among doctors, medicine as an institution, and patients, as Aronowitz proposed, does not fit into the strict norms of biomedicine, which require operating under the illusion of absolute results rather than provisional ones. As described, this biomedical position has been a source of frustration for many physicians: "Throughout my medical training I have been frustrated by the simpleminded and stigmatized way that physicians—myself included—treated patients with 'functional' disease, as well as the confusing scientific and lay debates over their legitimacy" (Aronowitz 1998, 15).

As a reflection, Aronowitz's position seems to align with philosopher of science, Karl Popper (1902–1994) (quoted in White 2010). For Popper, scientific knowledge must first be proven to have been false in order to be considered scientific. In other words, Popper believed that scientific knowledge is deemed provisional until new observations may reveal the theories to be false; “it is the willingness to suppress the desire for absolute certitude that protects Western Culture, from totalitarianism” (quoted in White 2010, 106). In conclusion, Aronowitz’s position shows the social advantage to treating contested diseases as organically based to help patients gain legitimacy while new scientific discoveries can confirm their organicity. This is a practical and clinical position whose concern lies in the patient’s need rather than in the nosology of the disease as an abstract category. In contrast, a different solution, although a difficult one, could lie in erasing the biases against psychosomatic illnesses as unreal and the bias against imagination as an inferior cognitive skill.

4.5 The Claim for the Value of Imagination

Beyond biomedical, historical, or social explanations of patients’ legitimacy of symptoms, there is another aspect that I would like to address concerning the failure to accept certain symptoms as valid representations of disease categories. I suggest that this is a failure of the medical imagination to give at least provisionally, legitimate status to certain dimensions of reality, despite their apparent fictionality. In addition, the historical contempt against imaginary symptoms recorded earlier in this chapter, and its association with the feminine gender seems to indicate, in my view, medicine’s lack of self-awareness about its own imaginative, figurative, and metaphorical process to explain certain conditions. For instance, the theory of the wandering uterus of the antiquity and the reflex theory of the eighteenth century were not accurate explanations but rather approximations to achieve a scientific explanation—that is, we can deem them provisional; they were cognitive and linguistic models (i.e., narratives), useful to categorizing *the impossible* logic experience or out-of-the-ordinary experience of some patients and their symptoms. Thus, I point out that the imaginary symptoms and fantasies that had been, for centuries, attributed to hysteric patients or, currently, to patients with contested illnesses, could be seen rather as a social resistance or protest, against imagination as a valuable way of thinking and knowing. If one considers the factuality of psychosomatic aspects in contested illnesses, then the question that begs to be asked is: *Why the epistemological and metaphorical methods, informed by imagination, have been accepted for medicine for centuries, but denied to patients (female patients in particular) to make sense of their own bodily symptoms and ill health?* It seems that labels such as “contested,” “somatization,” “malingering,” and “hypochondriac” deny the phenomenology of the patient’s capacity to explain their unfolding realities.

Imagination could be used to alternate with, rather than exclude, the rational, logical way of thinking and knowing. In other words, the wandering uterus and the reflex theory were historical narratives at the time that have been used, as narratives do in general, to explain “deviations from the ordinary in a comprehensible form” (Bruner 1990, 47). I would add that these narrative explanations may work provisionally, even though some elements of the narrative do not entirely match or are not coherent with reality. I ascribe to the position that, in denying the products of the mind, such as myth, symbol, and imagery as real forms of knowledge and self-knowledge, science limits itself—and patients—by refusing to admit those aspects of the mind that are not commensurate with its own vision of reality (White 2010, 9). If science could understand and better explain the workings of imagination, then medicine would be closer to offering concrete evidence to patients that imagination is not distinctive from reality but embedded in it. In the next chapter, I will address the interconnections between the problem of the patient’s narrative credibility, imagination, and narrative, as a genre.

CHAPTER 5

NARRATIVE REPORTABILITY and CREDIBILITY: THE INTERCONNECTIONS BETWEEN REALITY, LITERATURE, and FICTION

In this chapter, I would like to propose a narratological perspective to the problem of credibility of the patients' narratives about contested illnesses. I will focus on the narrative tensions between the concepts of reportability and credibility created by what Labov (1997, 2013) called, the reportability paradox. As an introduction, the reportability paradox says that the more reportable the story, the less credible it will be. I will argue here that although a continuum in the degree of reportability and credibility can be observed among autopathographies, the reportability of some narratives about contested illnesses seem to amplify the reportability paradox that all narratives have to contend with, creating a more challenging credibility dilemma for the patient/narrator and for the listener/reader alike. I will illustrate my arguments with excerpts extracted from autopathographies of contested illnesses selected for this study (see chapter six) as well as from excerpts extracted from the media, which although do not form part of the corpus of analysis they are useful for the purpose of contrast.

Pathographies or autopathographies, as memoirs, as discussed in chapter two, are always suspicious of veracity. Here I adopt Hawkins' position toward autopathographies. In her pioneered work on pathographies, Ann Hunsaker Hawkins (1999) observes that illness narratives or pathographies return the voice of the patient to the world of medicine where that voice is rarely heard: “what the voice of the patient tells us can be shocking, enlightening, or surprising” (12); that is, the reader may call into question the veracity of those accounts. Hawkins (1999) argues, that although pathographies tend to dramatize the events of illness, they need to be read as true stories, yet they cannot be taken as accurate records of experience: “they are too highly charged, as the ambivalence and prosaic quality of everyday living is resolved into sharp contrasts and clear-cut issues” (14).[1]

I will start by arguing that narratives of contested illnesses are shaped to tell their stories not only by the constraints of medicine but also by narratological constraints; that is, they are constrained by the reportability paradox, which I will further explain. Listeners/readers’ worldviews are shaped by cultural expectations that inform ways to organize and shape experience (Bruner 1990). This argument does not minimize the patients/narrators’ competence in narrativizing their experiences but raises awareness about the discursive and narrative challenges these patients/narrators may face in their narrative attempts. As Jerome Bruner (1990, 39) observes in his book, *Acts of Meaning*, people have beliefs about how the world is organized in certain ways: when things are as

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[1]. In addressing the aspect of reportability and credibility, I base most of my interpretations (with exception of one case) on the written illness narratives or autopathographies that I have considered for this dissertation (see chapter six). This study is not an ethnography; I have not witnessed the medical encounters of these patients/narrators with their caregivers. Thus, I base my examination on what the patients wrote about their illness experiences. The narratives are my primary source to analyze the way they articulate what they have experienced. In approaching these autopathographies, I take these authors’ narratives as representations, as Hawkins (1999, 14) advises us, that is, as “stories,” but also, I consider them valuable social critiques of their medical experiences while raising problems of representation associated with life writing and illness experiences. Furthermore, in approaching these autopathographies as a reader and a researcher, I made an autobiographical pact, by means of which, borrowing from Lejeune (1989, 22), my aim is not simply finding verisimilitude but resemblance to the truth in their narratives. Then, in this chapter, I offer a speculative explanation to the problem of credibility about these patients/narrators’ illness narratives.

they should be, then, narratives … are unnecessary. However, when constituent beliefs have been violated, narratives help us reconstruct our histories. Notwithstanding, as Bruner also notes, "'truth is stranger than fiction'" (40 emphasis in text). Thus, I propose that given the unfamiliarity or uncanniness that narratives of contested illness may convey, patients/narrators or contested illness could have a difficult task in persuading their listeners/readers (including their physicians) of the veracity of their stories, as we shall see.

Another important clarification is that issues of reportability and credibility seem to be sensitive to contexts and genres (i.e., oral and written), which could influence how narrators' accounts may be interpreted. This means that what may not be credible for a patient to say in a face-to-face encounter with her physician, may be, however, accepted as credible in a memoir. Conversational analyst Harvey Sacks (1984) explains that given that we do not have access to other subject experiences, accounts of personal experience are highly regulated by society. Therefore, there is a strong pressure in face-to-face encounters that shapes reportability and credibility. For Sacks (1984) and we will see later also for Labov as well (1997), credibility is associated with rationality, consistency, logic, and, moreover, objectivity that detaches from emotionality. Sacks observes that to be perceived as rational, speakers are constrained to report experiences of extraordinary events by means of "the ordinary cast of mind" (Sacks 1984, 424). As a result, the expectation about verbal behavior is that speakers may need to normalize extraordinary events as "ordinary." However, the regulatory constraints that apply in face-to-face encounters may be relaxed in written texts, such as autopathographies and memoirs. Whereas readers expect to learn about the author's truthful story, they do not expect a replica of all facts but rather the author's interpretation of her life (see Lejeune 1989, Pascal 1960).

As I will analyze some texts here, I make the distinction between accounts that may have taken place in face-to-face encounters and accounts that have been written, as in illness narratives. However, I am mainly drawing on written texts to infer what patients, now turned narrators, report about the challenges they faced in being believed while they were interacting in face-to-face encounters. I argue that there is a trace of orality in these patients/authors' memoirs. My focus in the present analysis is not on what really happened in those medical encounters, instead I ask: *What discursive or narrative aspects could be implicated in these patients' dilemma of credibility that made them susceptible of not being believed?* Now, let us consider the following excerpts as examples of the dilemma of credibility, and their degrees of reportability in connection to credibility.

Excerpt 1 (Gail Anderson):

> I thought that there were worms in my eyes. I have felt that something was eating me—the top of the tissue. And I could see me in my left eye that there was something going on. And up inside the inner of my upper eyelashes, I had white spots, all in there, they looked like little, tiny eggs. (NPR/Health January 24, 2008)

Excerpt 2 (Lubix Pascoe):

> I have a parasite inside me. I hear its sounds as it traverses my terrain and its gurgle as it comes up my esophagus. I feel pain as it passes, quickly, through my aorta. Sometimes, it spasms and quivers, much like you would imagine a parasite to do, in my legs. (Pascoe 2019, 6)

Excerpt 3 (Diana Crumpler):

> My headaches remain constant, varying only in intensity. Walking was no longer an automatic function. I had to will my right leg to move, and often feel as my leg and

body differed over what was going where I would try to pick up something, but my fingers would not close around it; or I would over-reach, as if some invisible refractory element had ruined my perception of distance. Then came pains which stabbed through my chest, up my throat and jaw, and down my arm—so jolting that breath and life would seem to hang suspended. More predictions. More tests. More verdicts of stress and nerves. Well, if that was so, they were not going to beat me.… determined to overcome the damning consequences of 'just nerves.' I could not see a possible alternative to this explanation, as the doctors had proven time and again that there was no physical problem. (Crumpler 1994, 28)

Excerpt 4 (Polly Murray):

In the two years after Wendy was born, I would get sudden headaches, so excruciatingly painful that I would want to close my eyes and sleep. The bouts of sore throats and laryngitis continued. I had periodic shooting pains in my legs, hips, and knees. At times my knee felt as if it were popping out of joint. Sometimes the pain would be in my buttocks, radiating down the backs of my legs. One day when I … couldn't straighten up without intense pain. When I consulted my doctor, he diagnosed slight scoliosis and thought I had transient nerve root irritation. (Murray 1996, 31)

Excerpt 5 (Abby Norman):

When I was seventeen, one morning I noticed that I was having a hard time getting my feet to firmly hit the stairs. I grabbed the banister and laughed it off, thinking I must either not be quite awake or had slept weird and irritated a nerve in my leg. I brushed it off and carried on with my day assuming it would resolve. But the next morning, the same thing happened. Then I started having difficulty using the stairs at school in between classes. Most unnerving, a short time later I began to have trouble feeling my foot on the pedals when I drove. Pretty soon I was hobbling around …. (Norman 2018, 28)

Excerpt 6 (Dorothy Wall):

I can do this, I thought.… One hour later I put the book down. My head was spinning. The words stopped taking shape, my vision cut by a white swath of confusion. I felt inside a fog bank, clarity, and sharp outlines somewhere beyond, out of reach. I couldn't absorb another sentence. [My book] landed upside down; my head landed on my pillow. I had been able to function for an hour. I lay flat on my back the rest of the day. I don't have any idea how I managed that summer…. But I do recall the day in September when I woke and thought, with the relief that comes with a gush of spring air, I think I'm well. The next day I was hit again, as if by some invisible, inhabiting force. I was ill as I'd been two months earlier, with the exact same symptoms. (Wall 2005, xx-xxi)

These excerpts illustrate cases of Morgellons (excerpts 1 and 2), multi chemical sensitivity (MCS) (excerpt 3), post Lyme disease (excerpt 4), endometriosis (excerpt 5), and chronic fatigue syndrome (CFS) (excerpt 6). All these cases have been deemed as contested conditions. I could have selected more examples, but I believe these are representative of most patients' accounts with contested illnesses. I will argue here that one way to approach the credibility dilemma of these patients' narratives is by looking at the very features that characterize narrative as a genre per se, especially the reportability paradox. Before I discuss these examples regarding reportability and the degree of credibility, I would like to establish how the medical encounter unfolds as a narrative.

5.1 The Narrative Structure of the Medical Encounter

One of the first scholars to argue that the medical encounter between patients and doctors unfolds as a narrative was Kathryn Montgomery Hunter (1991) in her groundbreaking book, *Doctors' Stories: The Narrative Structure of Medical Knowledge*. Montgomery Hunter discusses the pervasiveness of narratives (e.g., diagnosis, cases study, rounds) that mediate the healthcare system as well as the pervasiveness of the narrative structure in informing not only the medical encounter but also medicine as an institution: "Narrative is the ultimate device of casuistry in medicine which enables practitioners who share its diagnostic and therapeutic worldview to fit general principles to the single case and to achieve a degree of generalization that is both practicable and open to change" (47). Montgomery Hunter also discusses the narrative process that takes place between patient and doctor in the medical encounter; a process that requires listening/reading, interpreting, and translating the patient's text into the institutional frame of a medical diagnosis.

> Patients' stories within medicine are more or less pared-down autobiographical accounts that chronicle the events of illness and sketch out a commonsense etiology […] Physicians take such a story, interrogate and expand it, all the while transmuting into medical information. Sooner or later, they will return it to the patient as a diagnosis, an interpretative retelling that points toward the story's ending. In this way, much of the central business of caring for patients is transacted by means of narrative. (Hunter 1991, 5)

Here, as I try to provide a narrative perspective to the problem of credence to the patients' illness narratives, especially in the case of contested illnesses, I would like to highlight the communicative and linguistic challenges that patients may face in trying to articulate their bodily sensations and experiences (see Scarry 1985). These challenges may be summarized in the reportability paradox, as the patient's credibility dilemma.

On the one hand, a patient's account may not be perceived to be medically problematic if her narrative and signs do not match a conventional nosology. The patient's account needs to be doctorable in order to be believed. When the patient's account is not perceived to be medically problematic, and, I would add, especially if it is not deemed credible as in the case of contested illnesses, then her account is not translatable into a medical narrative, observes Montgomery Hunter (1991, 127). As discussed in chapter three, disease is discussed as a pathoanatomical, pathophysiological and microbiological facts. And as philosopher Kay Toombs (1993) points out, "[M]any biomedical practitioners tend to assume that such 'objective facts' alone constitute the reality of illness. That is, it is concluded that patients' complaints that do not correlate with demonstrated pathoanatomical and pathophysiological findings are not bona fide illnesses" (39). This seems to be the case in all the excerpts above. Also as discussed in chapter three, as observed by Aronowitz (2001), patients' symptoms such as fatigue, limb pain, and general malaise, have become less likely to constitute disease because they do not arise from "the alteration of the organs" (i.e., anatomy) but rather from the organs' "less precise functions [physiology]" (803). The shift in medicine from symptoms to signs has meant that symptom-based illnesses for which organic or physiological evidence cannot be detected or observed will have "a difficult time meeting any proposed normative criteria for a bona fide specific disease" (Aronowitz 2001, 804). In sum, these patients' accounts face the reportability paradox: although they are highly reportable given their mysterious symptoms, their accounts are less credible because they do not match or correlate with a legitimized disease category or convention.

5.2 The Complicating Action or the Most Reportable Event

If we approach narratives as a text-type rather than as a mode of knowing (i.e., as epistemology and method), then the story is the object of study and the events are seen as the stuff of which the story is made (De Fina and Georgakopoulou 2012, 1-2). One of the features of a narrative is that it not only (re)presents a series of temporally and causally related events, but it also introduces some form of complication or disruption, experienced by the characters, that they need to overcome; then, rising the action from exposition to climax (Labov and Waletzky 1967; Prince 2003). Furthermore, narratives are told with a point (see Labov and Waletzky 1967) and they need to call the attention of the reader/listener, who may also get emotionally involved in the story.

Montgomery Hunter (1991, 75) notes how aberration stories become relevant for physicians, whereas, instead, classic textbook cases such as appendicitis, pneumonia, or a broken bone provoke no anecdotes, they are seen as uneventful textbook cases that have passed from illness to recovery. She also notes, though, that when illnesses are too puzzling to fit the conventional nosology, the reactions can be various; for instance, the stories may be forgotten at first as too idiosyncratic and anomalous; the stories may be told and retold until a certain number of physicians would recognize it, or as in the case of AIDS (and since 2020, COVID-19), the story will become such a devastating new social reality that by then, it may overwhelm the medical system demanding absolute attention. Yet many patients with CFS, fibromyalgia, endometriosis, chronic or post Lyme disease, multichemical sensitivities, and other conditions feel that they are protagonists in hidden and silent epidemics that are not properly recognized: "This disastrous illness [CFS] was a silent epidemic, kept invisible by lack of official acknowledgement and concern. Victims suffered with little recognition or support," asserts Wall (2005, xviii), a sufferer of CFS.

In her memoir, *The Lady's Handbook for her Mysterious Illness* about her own chronic illness, Sarah Ramey (2020, 23) enumerates the main characteristics that in her view render contested illnesses "mysterious." She identified: *invisibility*, that is, these conditions do not receive sufficient attention despite they are widespread; *lack of funding* and *the research gap*, that is, these conditions do not receive sufficient funding for research and consequently, there is a research gap to keep up with proper diagnosis and treatment; *vagueness*, that is, symptoms are nonspecific and they may overlap or mirror other conditions, thus patients frequently receive several inadequate diagnoses before being properly treated; *gender biases*, women are more likely to be affected by these conditions but less likely to be believed; *shame*, patients are frequently shamed when biological evidence is not detected, which leads to poor and inadequate treatment options. These characteristics summarized by Ramey (2020), undoubtedly foster the credibility dilemma and the vacuum of care that these patients frequently experience as they report. However, these characteristics do not tell us about the credibility dilemma as part of narrative discourse per se. To elaborate on this idea, I first explain the conception of narrative and reportability paradox that I will use. To start, I draw on Labov's and Waletzky's (1967) and Labov's (1997) definition of narrative.

5.3. Narrative and the Reportability Paradox

Labov and Waletzky (1967) defined narrative as "one verbal technique for recapitulating past experience, in particular a technique of constructing narrative units which match the temporal sequence of that experience" (13). Narrative is one means to transfer experience to another person and the events presented in the narrative are expected to match the original events as they occurred in the world. This conceptualization of narrative is informed by the assumption that the reported events are in referential relationship with the events of the actual life experience. And it reflects a realistic, positivist epistemology, which, as we will see, is insufficient to explain illness narratives of contested illnesses. Nevertheless, this conception of narrative is useful to me in this analysis with the purpose to show the narrative aspect that links the reportability paradox to narrative of contested illnesses.

One requirement to be successful in transferring experience to others is that narrators must be able to call the attention of the listeners/readers. Thus, narratives need a reportable event or complicating event that is worthy of the attention of the listeners/readers. In addition to the complicating event, another important feature of narrative is the narrator's own evaluation of her experience. The evaluation reveals the narrator's positioning or attitudinal orientation toward the story. Labov (1997) refined the argument of evaluation by elaborating on the concept of reportability; that is, the observation that the narrator intentionally selects the most reportable event to fulfill her own needs and desires. The idea of reportability confirmed Labov's and Waletzky's (1967) initial argument that all stories are told with a point. Otherwise, the listener/reader may wonder: what is the purpose in telling the story?

The most reportable event is the result of a subjective assessment, that is, the narrator's decision about how to begin telling her story. One traditional way to define it is to say that the most reportable event is the complicating action that changes the character's destiny from fortune to misfortune. Prince (2003) states that a reportable event can be perceived as the worthiest of being told (shown to be) extraordinary, wonderful, or bizarre as opposed to ordinary, commonplace, humdrum (see Prince 2003, 145). According to Labov (1997), the most reportable event is defined as "the event that is less common than any other in the narrative and has the greatest effect upon the needs and desires of the participants in the narrative" (407). Thus, by reportability, Labov (1997) understands "the telling of at least one event that has a great effect on the needs and desires of the participants in the narrative" (406). Whereas in the traditional conceptualization, the complicating event is deemed as a consensus of what an extraordinary, wonderful, or bizarre event could be (as opposed to ordinary and commonplace), in Labov's theory, the most reportable event is the result of the narrator's evaluative process in deciding what is worth telling. Both concepts, as defined by Prince and Labov, can be used in complementary ways. I follow Labov's conceptualization because of its focus on the narrator's agency in selecting the most reportable event in constructing the narrative. Thus, in Labov's theory the most reportable event seems to be a strategic, narratological choice, made by the narrator as it will become clearer (see also chapter six).

Whether we refer to it as the complicating action or as the most reportable event, we can observe that in terms of credibility, the effect seems to be the same: as higher the reportability of a story because of its eventfulness, surprising effect, or maximum impact on the narrator, the less likely the story will be believed. Consequently, the higher the effort the narrator must devote to establishing credibility. "The fundamental dynamics of narrative construction are built on the inverse relationship between reportability and credibility: the more reportable an event, the less credible," asserts Labov (1997, 8). A task of the narrator (and a problem also for the listener/reader) is to resolve the reportability paradox in the telling of the narrative. All narrators need to deal with the tension between reportability and credibility. I am particularly interested to see how the memoirists in this study deal with this tension, in order to construct credibility. Although I will further elaborate on this point in the next chapter, in this chapter I explore first what makes these narratives highly reportable, though less credible.

One way to deal with the tension between reportability and credibility, and be believed, is by being objective. Labov (1997) argued that objectivity, detached from emotivity, is one of the most efficient strategies a narrator uses to build her credibility. He argued that narratives based on object observation and description, seem to have a stronger impact than narratives that report events in a more subjective way: "reports of objective events are more credible than reports of subjective events," stated Labov (1997, 412). However, objectivity is oxymoron to the patients' accounts and auto-pathographies or narratives of illness. It can be anticipated that from Labov's (1997, 2013) perspective then, that in considering his theory of narrative, narrators of illnesses deemed contested will have a challenge in performing their narrative tasks. This challenge will take place in face-to-face encounters and, perhaps, also in writing, as we shall see. In the next section, I examine the reportability paradox in excerpts (1-6), which illustrate that there are degrees of reportability and credibility.

5.3.1 The Most Reportable Event

The idea of the onset of illness as a biographical disruption has been paradigmatic in sociology of medicine (e.g., Bury 1982; Frank 1995). The conceptualization of illness as biographical disruption reflects the denial and resistance of our Western culture to see illness and disability, not as an expected event in the cycle of life but, rather, as a temporary interruption in an otherwise, seemingly normal temporal line. Given this conceptualization of illness as an interruption, the event of illness becomes a reportable event; (i.e., "noteworthy and potentially narratable," observes scholar Thomas G. Couser 1997, 9). Thus, in many personal narratives of illness the onset of illness—as diagnosed by a physician— is a biographical disruption that can be linked to the most reportable event in the narrative. However, I have also observed that in many of the selected narratives of contested illnesses, the patients' feelings of being ill emerged surreptitiously, in subtle and mundane ways, almost as part of ordinary events, in other ways, as seemingly non-reportable. For instance, getting a rash after sitting in the sun one afternoon in the spring (e.g., Murray 1996), getting a urinary infection after going for a swim in a lake (e.g., Ramey), getting a headache while inserting one's contact lenses (Kamen 2005), feeling of malaise after moving to a farm in Australia (Crumpler 1994), and so on.

Notwithstanding, what transforms these surreptitious events into reportable events is the disproportionately degree or intensity with which these events will affect their sufferers. In turning to report their seemingly uneventful stories, they will find themselves lacking rationale or linguistic resources to explain how something apparently so insignificant could have had such a disproportionate effect on them. Thus, their stories may fall prey to credibility. In sum, the most reportable event is in part subjectively constructed. These patients/narrators knew though, that they were ill despite having not received a proper diagnosis at that time, as their illness is reflected in their physical limitations and even disabilities.[2]

Although for patients of contested illness, the onset of illness as diagnosed by a physician could certainly be a biographical disruption, what seems to be even more surprising and unexpected is the elusiveness of their symptoms, the lack of referentiality to the world and its intangibility, which seems to render their accounts unsubstantiate to their listeners in general and to their physicians in particular. It seems as if the linguistic

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[2]. This point is clearly illustrated by Kay Toombs (1999), when she reports about a time, as a MS sufferer, in which she experienced unusual muscular pain, in addition to her muscle weakness as usually linked to her condition. Her doctor prescribed a muscular biopsy, which indicated that a "primary myopathic process [was] going on" (40). However, the biopsy did not give them an explanation for the cause of it or guidance for treatment. Thus, in her discouragement, both because of her increased disability and the lack of answers from the biopsy, she called into question the utility of the procedure to her physician, to which he replied: "Oh, but we have [gain]! Now we KNOW something is wrong" (40). Toombs states, "For me, as a patient, to know what something was 'wrong' was to be acutely aware of my bodily dysfunction and discomfort…. For the physician, to know that something was 'wrong' was to have 'objective' evidence in the form of an abnormal pathology report with respect to the muscle tissue removed from my thigh." (40).

and rational resources available to them to describe, explain, and narrate their illness experiences would be insufficient to transfer that experience to others—not because patients/narrators are “poor historians” (see Coulehan 1984), but because they are narrating seemingly extraordinary bodily experiences within ordinary daily life contexts, which are difficult to relate to others who have not shared those experiences. In the next sections, I will further elaborate on the different degrees of reportability and credibility by discussing excerpts (1-6).

5.3.2 The Patients/Narrators’ Accounts of the Most Reportable Events

Gail Anderson (excerpt 1) gave her illness experience account in National Public Radio (aired in January 2008). Lubix Pascoe’s account corresponds to the first lines of her memoir. Both express their experiences living with Morgellons disease.[3] It seems that the most reportable events in Anderson’s and Pascoe’s account is their perception of experiencing unfamiliar and strange bodily sensations (e.g., crawling and stinging), along with the belief of hosting a parasite. Anderson believes that “larvae” inhabit her eyes and eyelashes, Pascoe believes a parasite inhabits her internal organs (esophagus, aorta). There are interesting differences though between these accounts, which I will discuss promptly.

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[3]. Morgellons is a dermatological condition characterized by the presence of multicolored filaments that lie under, are embedded in, or project from the skin. There is evidence that is linked to Lyme disease as a skin reaction to the infection caused by the spirochete, the causative agent of Lyme disease. Because individuals afflicted with Morgellons may have crawling or stinging sensations and sometimes believe they have an insect or parasite infestation, most medical practitioners consider it as a purely delusional disorder. For that reason, Morgellons illness overlaps with Delusional Parasitosis, which is a rare, but well-known condition in which individuals believe to have been infested by parasites or worms, although they have not (see Middleveen, Fesler, and Strickler 2018).

Excerpt 3 is part of Diana Crumpler's (1994) illness narrative, *Toxic Environment* published in Australia, about her experience with multi chemical sensitivity. In Crumpler's account it seems that the most reportable event is not that she had a constant headache but rather her sense that her body did not respond to her intentions, as if she experienced some sort of kinetic delay between her conscious intention to move and her body movement; a self-reflexive process that objectifies her body. This kinetic delay is also accompanied by seemingly unconnected symptoms such as stabbing and moving pain through her chest up to her jaw.

Excerpt 4 is part of Polly Murray's (1996) illness narrative, *The Widening Circle,* about living with chronic Lyme disease. In her account, the most reportable event seems to be her sensory experience of erratic, sudden, and transient pain in different parts of her body accompanied by headaches and sore throats that appeared and disappeared.

Except 5 is part of Abby Norman's (2018) illness narrative, *Ask Me About my Uterus,* about her experience of living with endometriosis as a young woman, with no family ties for help and emotional support. The most reportable event in this account seems to be also her sensory experience ("I noticed") of losing control of her body as well as the inability to sense her foot on the car pedal, which she describes as numbness. And except 6 is from Dorothy Wall's (2005) illness narrative *Encounters with the Invisible* about chronic fatigue syndrome. In Wall's account we can point out two reportable events that act in combination. First, the sensory experience of dizziness, the perception of losing her vision, concentration ability, and her mental lucidity, which she describes as a "fog bank" (Wall xx). This sensory experience takes place at a punctual moment in time. The recollection of her sensory experience is meaningful as the event associated with that punctual moment is significant in the context of her life history: She was reading a book in preparation for her Masters' Degree thesis defense. However, there is a major event, which overlaps with her sensory experience (e.g., dizziness, fatigue, lack of concentration, malaise), that is, the sense that her body has betrayed her: "The next day I was hit again, as if by some invisible, inhabiting force. I was as ill as I'd been two months earlier, with the exact same symptoms" (Wall xxi).

A general observation about these six accounts is the vagueness of their symptom descriptions in the sense that are difficult to represent in one's mind if the listener has not had that same experience, the elusive detection (or rather non-detection) of morphological and biochemical markers of pathology. Also, it can be observed the overlapping of symptoms described and similar malaises, despite the authors self-reported suffering from different conditions. In terms of aspects of reportability and credibility, I need to disentangle it in steps.

5.4 Analysis of the Excerpts: Degrees of Credibility and Reportability

5.4.1 Anderson's and Pascoe's Accounts

I will start examining Gail Anderson's and Lubix Pascoe's accounts (excerpts 1 and 2), and I will point out a difference between them. As discussed earlier, reportability and credibility are inversely intertwined. However, we can observe some differences in the degree of credibility. Labov (1997) noted that what is reportable, changes according to situations and cultures. Indeed, what is worthy of being reported may be determined by culture. For instance, whereas the presence (or perception) of having worms in one's eyes is indeed a defamiliarizing story in our culture, it may not surprise, in the same manner, a person living in sub-Sahara Africa who is familiar with, or has been exposed to, the devastating disease of Onchocerciaris or River Blindness caused by a parasitic worm, the Onchocerca volvulus (see World Health Organization). Thus, the familiarity with that reality may preclude people from that culture to quickly judge Anderson's and Pascoe's statements as simply imaginative or as delusional (i.e., "delusional parasitosis"). Nevertheless, it is fair to acknowledge that if Pascoe's account were an oral account delivered in the doctor's office it is likely that it would have been diagnosed as delusional not because of her mentioning of the parasite, but rather because of her description about her extraordinary capacity to sense how the parasite "passes, quickly, through [her] aorta" (Pascoe 2019, 6).

Although having parasites could be a more or less ordinary experience in certain parts of the globe, the presence of worms in the eye is less common; thus, we infer that depending on the situational or cultural contexts, stories can become more or less reportable (and also credible). Nevertheless, given the uncanniness and unfamiliarity of the events reported by Anderson and Pascoe, their stories may be heard/ read as a piece of science fiction or magic realism. The challenge for the listener/ reader is that we may not be entirely comfortable suspending disbelief, if a parasite is not found, as we would do, instead, in the case of a fictional narrative. Thus, although Anderson and Pascoe stories are highly reportable, they are less credible if we compare them with a story that can be verified. An example of this, is the story of Abby Beckley, as reported by the Associated Press (February 12, 2018). It reads:

Excerpt 7 (Associated Press):

> NEW YORK — An Oregon woman who had worms coming out of her eye is being called the first known human case of a parasitic infection spread by flies. Fourteen tiny worms were removed from the left eye of the 26-year-old woman in August 2016. Scientists reported the case Monday. The woman, Abby Beckley, was diagnosed in August 2016 with *Thelazia gulosa*. That's a type of eye worm seen in cattle in the northern United States and southern Canada, but never before in humans. (Associated Press 2018)

The story of Abby Beckley in this news report is highly reportable because of its eventfulness and the unfamiliar effect on the narrator and listener. Despite its unfamiliarity, and unlike Anderson's and Pascoe's accounts, Beckley's account of worms in her eyes is confirmed by the doctor who reportedly pulled out fourteen tiny worms and by the CDC who supports the story with a legitimate diagnosis, *Thelazia gulosa*. Although the case is extremely rare, this was the first time *Thelazia gulosa* was observed in humans, we can say the diagnosis is supported by what we know about the biological reality of nature as a possible world. Our interactions with the environment and with other animals make it possible, and probable, to assert that although rare, the infection with parasites which typically inhabit animals can find in humans an aberrant host. Then, whereas Anderson's and Pascoe's stories are highly reportable, Abby Beckley's story is not only reportable but also entirely credible, according to the criterion of evidentiality: it has been verified.

In Labov's terms, we can say that in Beckley's case we can match the reported events of experience with reality. Gail Anderson's and Lubix Pascoe's stories are, however, apparently more dubious. Given that Pascoe claims to have a parasite, her statement could be falsified if a parasite is not found. Anderson's case is slightly different though, her statement is not entirely assertive. Anderson mitigates her assertion telling us that she "thought" there were worms in her eyes. As a verb of opinion in this case, "I thought" constitutes a mental clause. Mental clauses, unlike material clauses, are concerned with our experience of the world of our consciousness (Halliday and Matthiessen 2004, 211). The use of this verb mitigates the assertion about the truth condition of the statement as a belief or perception (instead of reference to a material entity), thus leaving a margin of uncertainty about the identity of the entity that causes her to have that belief.

In sum, we could say that unlike Pascoe's account, Anderson's account expresses a subjective epistemic commitment that mitigates her assertion of evidentiality to the real word. Yet, there is another aspect that cannot be mitigated by the use of the verb "I thought" and it is important to clarify. Whereas Anderson may be uncertain about the ontological existence and the entity that causes her to have that belief, she still asserts to experience crawling sensation throughout her body. In other words, Anderson may not be certain about the entity, but she is certain of her bodily experiences. As listeners/readers we are not in a position to prove or disprove the nature of her bodily sensations. Anderson's story may not be credible for some listeners. However, her story is the only thing we have in order to understand her experience or to have access to it. Then, the questions that arise are the following: *what is Anderson's (or any of these other narrators') point, in telling her story in this manner? And why would she tell the story in that manner knowingly that it seems incredible?* Essentially, these are the questions that I explore in this chapter. Assuming that these patients' accounts are not the accounts of malingers, then *why tell us about their stories in this manner, at risk of not being believed?* At the end, we only have the patient/narrator's discourse. Their discourse will always be their own representation, thus inaccessible to us. In this sense, it is interesting to observe that as these accounts are unverifiable and unfalsifiable, they may share some borders with literature.

If we consider these stories as literature, then, the reader might decide to suspend disbelief and consider the assumption that what we are reading is possible, in some possible world (see Coleridge cited in Smith and Watson 2010, 10). However, we read memoirs or autopathographies as autobiographical texts. So, Pascoe's assertion of extreme sensory capacity creates disconcert despite the reader's understanding that as autobiographical text, the memoir is not "the effect of the real, but the image of the real," as Lejeune (1989, 22) says. Whereas the suspension of disbelief may allow us to accept fiction as a possible or as an alternative world, we still expect the autobiographical text, which conveys the narrative's truth (Spence 1982) of the author, to be verisimilar. Yet, Pascoe challenges this assumption. Notwithstanding, a satisfactory explanation to the dilemma of credibility that Pascoe presents could be found in Lauren Slater's (2000) memoir *Lying: A Metaphorical Memoir*, which reflects about the fuzziness and fluidity between factual and factitious stories. I resort to Slater's memoir or rather pseudo-memoir to explain Pascoe's memoir, for reasons that hopefully will become clear later.

Slater (2000), supposedly a sufferer of epilepsy, intentionally blurs the boundaries between reality and fiction as an unreliable narrator, who is constantly asking her readers to believe her story and then, to disbelieve her story in order to infer her narrative truth. For instance, she tells us about an occasion when she was a teenager in which she attended, along with her mother, the funeral of a neighbor. Slater describes how (as the reader infers that she had a seizure) she collapsed and fell into the empty grave where the coffin had yet to be lowered (58). Her chapter concludes after a long description of how the terrified witnesses helped her to climb back out of the hole; but, in the next page she surprises her reader by adding a postscript that denies the veracity of the events previously reported. Her postscript is a provocative confession that calls into question the reliability of her memoir, in particular, and the reliability of memoirs, in general, as an autobiographical genre. It reads:

> Not quite. This is a work of nonfiction. Everything in it is supposed to be true… Therefore, I confess. To the establishment. I didn't really fall into the grave. I was just using a metaphor to try to explain my mental state. The real truth is I went to the funeral, the hearse had engine trouble, the coffin was late, I looked into the grave, and I thought about falling in. I imagined myself falling. (Slater 60) (emphasis in text)

Slater's postscript serves as a clarification that helps us understand that the event reported was not a fabrication despite its fictionality. The event reported (i.e., falling into the grave) gives a linguistic shape to her internal and emotional reality at that particular moment of attending the funeral. Furthermore, the act of imagining falling into the grave enacts her internal and emotional reality, although factually she did not fall into the grave. Her imaginative act performs the belief that she did fall, as the reader experiences a sense of surprise and uncanniness that may reproduce in the reader the sense of Slater's own subjective experience. As readers, we gasped with surprise and horror, stepping into the representation/fiction of the memoir as if we were witnessing her fall, although we imagined it, in the same manner Slater imagined herself falling into the hole. For us as readers, our emotions are real, as for Slater her imagination of the event was real, although objectively nobody fell, and we did not witness such reality. Then, we can understand that as Slater, objectively, did not fall into the grave, Pascoe could not probably sense the parasite traversing through her organs. Nevertheless, both are linguistically enacting their sensory experiences in their readers by eliciting surprise and even disgust.

It can be speculated that as a strategy for self-understanding and to cope with the unfamiliar sensations (e.g., spasms, quivering, twitching, others) of her body, Pascoe (as well as Slater) uses language metaphorically rather than literally and with a performative intention; that is, to produce an effect. Then, not only Slater's image of falling into the grave gives shape to her subjective mental state at that moment but, also, her story is told with a point: it has a performative effect on the reader (e.g., disgust, surprise, others) that may occasion the reader to momentarily experience a similar emotion, and perhaps, to identify and solidarize with the narrator. But, unlike Slater, Pascoe does not alert us of the figurative aspect of her assertion; that is, that she can sense the parasite traversing through her organs. Thus, her assertion creates an unfamiliar and uncanny effect in the reader, which is elicited by virtue of her statement as an embodied reality. In that manner, Pascoe challenges her reader to remain open to the possibility of the fantastic, to infer that that is her way to conceptualize and materialize her experience. "Metaphors may create realities for us," assert Lakoff and Johnson (1980/2003, 156). The fact that Pascoe uses figurative language to describe a sensory experience does not necessarily mean, though, that her experience was delusional. I suggest that the use of figurative language is not merely a poetic expression with an illustrative purpose, but rather a way to conceptualize her reality and, perhaps, her only way to explain her experience to others: "Metaphors as linguistic expressions are possible precisely because there are metaphors in a person's conceptual system" (Lakoff and Johnson 1980/2003, 6).

Pascoe may not make strict reference to reality; and yet, she conceptualizes her illness (i.e., Morgellons) as a living being inhabitant her body, traversing throughout her body: an invisible entity is materialized by means of a personification, which is as much experienced as it is verbalized. The common view that figurative language is merely feigned language, as Lakoff and Johnson (1980/2003, 6) point out, comes out of a concern with referentiality and objectivity seen as a truth conditional. In the case of Pascoe's and Slater's illness narrative, I argue following Lakoff and Johnson that figurative language is truthful to the authors' conceptualizations and representations of their conditions, despite their conceptualizations may not be generalizable and transferable to others. For this reason, these memoirs challenge language as a social referent.

Although illness narratives as auto-pathographies are not, in general, verifiable, as expected by a positivist conceptualization of reality, they still express an epistemic commitment (Lyons 1995, 254) to the authors' narrative truths. Pascoe is using figurative language to articulate and materialize an invisible, almost incommunicable reality for herself (and her readers). If we interpret her narrative "literally," then I believe we are doing a disservice to her creative capacity to articulate her experience. However, a metaphorical reading will consider the following questions: why did she need to describe her symptoms in that manner? In other words, what does her figurative language tell medicine about her illness experience? Although to my knowledge, people in general do not have the capacity to sense a parasite moving through their internal organs (as part of our world experience), Pascoe might provide medicine with figurative, descriptive, and diagnostic clues about that experience, and I suggest here to listen to it rather than discarding it automatically as delusional.

5.4.2 Crumpler's, Murray's, Norman's, and Wall's Accounts

Unlike the fantastic sense of estrangement that Anderson's and Pascoe's narratives may convey to us, I will argue that Crumpler's, Murray's, Norman's, and Wall's accounts also challenge our sense of credibility, but in slightly different ways. First, we may be more familiar with the symptoms they report in comparison to Andersen's and Pascoe's accounts. People in general can identify with these accounts (excerpts 3-6) because of having experienced, at least once in their lives, headaches, sore throats, laryngitis, shooting pains, extreme fatigue, numbness, and general malaise. In that sense, it could be said that the references to these common symptoms are ordinary, and therefore, do not seem to constitute reportable events. However, I suggest that the seemingly uncanniness of their reported experiences lies in the apparent randomness or erratic ways in which those symptoms are experienced, as well as in the apparent disconnection between them. These characteristics render these events reportable, though.

Their apparent disconnection emerges in their narratives as if their report of symptoms were lacking logic, cohesion, and coherence, that is, a plot. For instance, headaches are reported along with losing control of motor skills as in walking (e.g., Crumpler, excerpt 3) or along with shooting pains in legs, hips, and knees (e.g., Murray, excerpt 4). Numbness in one leg is reported along with loss of equilibrium in climbing stairs that last more than a few minutes (e.g., Norman, excerpt 5). And sudden dizziness is reported along with incapacitating exhaustion (e.g., Wall, excerpt 6). Thus, the reportability in these narratives lies not as much on the reference to common symptoms (e.g., headache, sore throat, laryngitis) but, rather, on the linguistic collocation of those symptoms in the account, forming syndromes that seem to challenge conventional diagnoses.

5.5 General Observations about the Excerpts

All these accounts may elicit a hesitance in the listener/reader to believe the accounts. The hesitance could be based on the one hand, on the uncommon and extraordinary quality of the events (i.e., as in worms in the eyes) as we saw in Anderson's and Pascoe's. For instance, in Pascoe's case, the complicating event is the presence of an invasive entity. Unless objectively detected, these types of accounts may be linked with the genre of fantastic literature, thus, these accounts could be seen as less credible. However, on the other hand, the hesitancy could be based on how the symptoms have been packaged as forming seemingly unfamiliar conditions; that is, the hesitance could be based on how erratic and unfamiliar conglomeration of symptoms have been emploted. In excerpts 3-6, conventional complaints (e.g., headache or sore throat), do not seem to match, at least, immediately, with other symptoms such as difficulty walking, loss of balance, stabbing pain, limb numbness, and so on. Thus, whereas these symptoms are highly reportable by the patient because of their out-of-the-ordinary quality, for the very same reason, they could be less credible.

In sum, Anderson's and Pascoe's accounts do not seem to make reference to the external world, despite Pascoe's asserts she has a parasite. Rather, they are making reference to their subjective, internal, bodily experiences. Consequently, their accounts are unfalsifiable. The use, however, of a referential entity such as a parasite makes the account uncanny because we cannot entirely discard it as ficticious. Whereas all these accounts are characterized by fitting into the reportability paradox, the very same quality of their subjective, non-material, and attributive experience amplifies the problem of credibility.

Philosopher of medicine, Kay Toombs (1992) noted that in the clinical encounter, in order to cooperate with the physician, the patient must explicitly attend to her body as object in the "giving of an 'objective report of body sensations, in self-administering treatments and reporting back on all changes in the external appearance and internal sensations of the body" (74). However, as we could imagine, the sort of elusive bodily experiences as described by narrators in excerpts (1-6) is not possible to articulate in objective terms. That is a problem, especially in the case of contested illnesses. Elaine Scarry (1985) asserted in her book *The Body in Pain*, that in order to transform physical pain into an objectified state, "a great deal … is a stake in the attempt to invent linguistic structures that will reach and accommodate this area of experience normally so inaccessible to language" (5). Although these excerpts do not address the topic of excessive pain, I believe a parallel can be established.

In conclusion, these accounts are highly reportable not only because they present a "bizarre" complicating event (Prince 2003, 31), which has the greatest effect on the needs and desires of the participants (Labov 1997), but also because the nature of their stories is unfalsifiable; thus, they border with the fantastic. Furthermore, it can also be argued that even if physiological or anatomical evidence were found in these patients that would confirm their diagnoses, we still could not deny the way they feel or experience their illnesses as they articulate it. The way they articulate their illness experiences is not a reconstruction in an archeological or historical sense, but, instead, their own construction; thus, it becomes reality (Spence 1982, 175). For that reason, we could say that the nature of some of these stories borders with the nature of literature, as Todorov (1973) asserted, “literature sentences are no more false than they are true” (3).

Notwithstanding, the ethical problem we face is that patients’ accounts of illness are not literature in the sense of fiction. People’s experiences of body alienation, incapacity, and pain are existentially debilitating. Medical philosopher, Toombs (1993), who is also a sufferer of multiple sclerosis, clearly articulated the phenomenological experience of being ill:

> In illness the body intrudes itself into lived experience…. The objectification of the body not only as physical encumbrance but, more particularly, as a malfunctioning physiological organism further contributes to the sense of bodily alienation which characterizes illness. And this renders explicit the experience of the body as ‘uncanny.’ Bodily dysfunctions disclose the latent implication of embodiment and reveal what it means to be embodied. (Toombs, 71-72) (emphasis in original).

Consequently, one way to approach these accounts, especially when the patient cannot give an objective account of bodily sensations, is to suspend disbelief and take the patient’s account as face value. In getting to recognize their new bodies under their unfamiliar symptoms and experiences, patients may need time for self-examination and self-understanding of their bodies, and to develop language to articulate their experiences in conventional ways—if that is at all possible. Again, this is not to say in any way that patients cannot articulate their symptoms; however, this is a recognition of the linguistic challenges that patients may face in having to articulate, in doctorable ways, uncanny and unfamiliar bodily sensations.

5.6. Summarizing the Credibility Dilemma

As discussed in previous chapters, a common characteristic attributed to patients' accounts of contested illnesses is that these patients' narratives reflect an "all in your head" conditions, that is, they suffer from psychogenetic conditions, hypochondriasis, or hysteria (e.g., Dusembery 2018; Edwards 2013; Quinn Schone 2019). Their accounts are stereotypically seen not as part of the actual world but rather, as a product of their imagination: "It is commonly believed that when a physical basis for pain cannot be demonstrated—no lesion sufficient to explain the pain can be found, or the pain does not conform to expectations—then the pain is emotional (psychogenetic) in origin," observes Cassell (2013, 208), calling into question this belief. In trying to shed light into this problem, in this chapter I have examined the language and emplotment of some narratives from the perspective of the reportability paradox.

According to the examination of excerpts 1-6, the credibility dilemma or hesitancy in believing these accounts may be explained by the oscillation between, on the one hand, the belief about the presence of certain symptoms that have a conventional reference to people's experiences in the actual world (e.g., headaches, limb numbness, and sore throat) and, on the other, the disbelief in the emplotment of those symptoms, as that emplotment seems to challenge conventional diagnoses. I have speculated that the disbelief might originate in the fact that these patients' accounts may emplot conventional symptoms, but with unconventional syndromes that represent unfamiliar schemas or categories. By unconventional schemas or categories, I refer to the seemingly incoherent report of symptoms for which the clinician may not find, at least at first, a logic, coherent, and cohesive explanation, as if these patients' accounts lacked a conventional, identifiable plot (i.e., a conventional diagnosis). For instance, parasites are accepted as part of the actual world, but the extraordinary sensory experience of hearing the sound of a parasite “as it traverses my terrain,” as Pascoe (2019) says, is not. Sore throats and headaches are typically associated with the experience of the actual world; however, the emplotment of these symptoms in concomitance with shooting pains in legs, hips, and knees could make the account more disconcerting and suspicious when not finding biological evidence of that account.

The suspicion about the credibility of these patients’ accounts is not only due to the fact that these accounts may not easily translate into possible disease diagnoses, but rather because the accounts may sound uncanny, at least at first hearing. For clinicians, diagnosing and treating these patients will require not only a high medical expertise but also a high narratological expertise in how to approach and listen to the emplotment of patients’ accounts. The physician, along with the patient, are responsible to find an internal cohesion and coherence for this seemingly unrelated assembly of symptoms to construct a diagnosis. Yet, this difficult task that requires not only medical expertise but also imagination and narrative skills, has become even more difficult with the prevalent reductionist view of the specific etiology that has dominated medicine.

The principle of etiological specificity of diseases implies that every disease entity is produced by a particular cause, that different diseases cannot come from the same cause, nor can different causes produce the same disease. We now conceive of each of the pathological processes as a single, gradually developing phenomenon resulting from the action of a specific etiological agent, though with variations depending on individual circumstances or external conditions (Lewandowsky quoted in Cassell 2004, 7). Whereas this way of thinking as promoted by the principle of etiological specificity has contributed to the progress of medicine, it also, paradoxically, could deter physicians from a necessary creative imagination to approach new and extraordinary conditions, especially if they have not yet been statistically proven (see Cassell 2004). However, extraordinary conditions can happen in medical encounters. The experience of seeing extraordinary cases has been acknowledged by the CDC, first investigator of Morgellons, Dr. Michelle Pearson. When asked by the NPR reporter about the unusualness of the condition described by patients with Morgellons like Anderson and Pascoe, Pearson responded: “I admit, it's a little bit unusual, but in medicine, we see a lot of unusual things…” (emphasis added) (NPR 2008).

At the writing of this chapter, I cannot resist making the point that we have indeed been witnessing a lot of unusual things recently. Since January 2020, we have been living in a pandemic under the threat of SARS Convid-19 infection. As journalist Kim Stanley Robison wrote a year ago in *The New Yorke*r on the occasion of witnessing and experiencing extraordinary realities and highly reportable events: “The virus is rewriting our imaginations. What felt impossible has become thinkable…. [S]cience fiction is the realism of our time” (May 1, 2020).

5.7 Final Remarks

As we saw in chapter four and discussed also in this chapter, women treated for contested illnesses claim that they have been systematically perceived or rather, constructed, as malingers, delusional, and deceptive. In other words, as fabricators of symptoms that only were in their imagination, or as part of their repressed desires. This attitude toward disbelief could be explained in part by Jerome Bruner's (1990) observation about Western scientific and rationalist attitude to reality that denies other approaches as valid:

> Since the rejection of introspection as a core method of psychology, we have been taught to treat such 'said' accounts as untrustworthy, even in some odd philosophical way as untrue. Our preoccupation with verificationist criteria of meaning … has made us devotees of prediction as the criterion of 'good' science, including 'good psychology.' Therefore, we judge what people say about themselves and their worlds or about others and their [worlds] almost exclusively in terms of whether it predicts or provides a verifiable description of what they *do*, *did*, or *will do*. If it fails to do so, then with a Humean ferocity, we treat what was said as 'naught but error and illusion.'" (16) (emphasis in text)

I discussed in this chapter that many of the patients' accounts who experience contested illnesses are characterized by the reportability paradox. That is, they are highly reportable in terms of the seemingly unfamiliar events and experiences they bring to the fore. However, for the very same reason, paradoxically, they are less credible because they are not objective, their accounts cannot make reference to the world, but rather to the internal, subjective, world of the narrators. Thus, I suggested that the reference of these accounts to internal realities that cannot be verified, amplifies the credibility dilemma of these patients/narrators. In other words, these accounts are not only suspicious because they report unfamiliar events but also because their accounts are unverifiable. Unfamiliar events like the case of *Thelaziasis gulosa* become credible though when they can be verified. Also, although these cases might be shocking at first, they are accepted later as they offer a parallelism with the animal world; it is a documented reality that infections previously seen in animals can adapt and affect humans, as in the case of zoonic diseases (e.g., such as COVID). However, we need to consider that it is possible that the story of Abby Beckley (excerpt 7) could have been taken as delusional and uncanny if had not been published by the Associated Press with a legitimate veterinarian diagnosis, which transferred to a human being. In this case, its reportability lies in its eventfulness, given that it was the first time such condition was diagnosed in humans; its credibility lies in the objectivity and verification of facts as well as the reputation of the news organization. The problem is that not all conditions are verifiable, and the meaning of verification has been conflated with truth; in order words, not all things that cannot be verified are untrue.

I also considered another aspect in explaining these patients/narrators' dilemma of credibility: patients with contested illnesses are constrained by the narrative structure of the reportability paradox as well as they may be linguistically constrained by the very same vagueness, lack of referentiality, and lack of conventionality of their experiences that make their accounts suspicious. Therefore, they are linguistically challenged without necessarily being "poor historians." Consequently, patients/narrators may need to appeal to the use of figurative language as well as to form unconventional syntagmatic associations. The problem is that as language is a social convention, as Ferdinand de Saussure (1959) observed in the early twentieth century, it is possible that the use of new language and syntax to describe unfamiliar conditions, such as those described here by these patients/authors, has not yet been conventionalized.

Aronowitz (2001) observed the linguistic parallelism between symptom-based conditions and dialects, and sign-based diseases and languages. He states, "social influences have largely determined which symptom clusters have become diseases" (803), as social influences also largely determine what dialects will conform to a standard language. Similarly, as the term "contested" indicates, these conditions such as CFS, chronic Lyme, endometriosis and others are yet not entirely accepted by the entire medical community as conventional diagnoses. They need "standardization" as sufferers and advocates are making social pressure to change diagnostic conventions (see Aronowitz 1998).

I also argued that contested illnesses challenge not only clinicians' interpretative and narrative skills but also patients' linguistic skills to sound as ordinary as possible, and to convey their experiences according to "the ordinary cast of mind" that Sacks (1984, 424) described. Finally, if we adopt Labov's conceptualization of narrative, as a means of transferring experience, then listeners/readers will be always challenged by the fact that these narratives elude objectivity, and verification is not possible. Then, I suggest that a solution is to read them as literature by suspending disbelief; however, to listen to them as the patients' figurative realities. As a writer and creator of magic realism, Gabriel García Márquez (1982) noted, reality is more fictitious than literature: "There is no line in my novels that is not based on reality" (50) (my translation).

I conclude by proposing that these patients' accounts are representing and enacting their own internal realities. Although these accounts may seem factitious, they are still conveying their narrative truths; they are articulating their inner experiences to the best of their linguistic capabilities. Thus, the best way to approach these "contested accounts" is by suspending disbelief as if we were reading fiction, but with the awareness of wonder that we are listening or reading the best linguistic and descriptive approximation to their illnesses. In the next chapters, I will explain the design and methodology of this study (chapter six) and examine how patients/narrators rhetorically deal with the tension between reportability and credibility (chapters seven and eight). I will examine how they build credibility by means of their narratives

CHAPTER 6

THE CORPUS of MEMOIRS and METHODS of ANALYSIS

In the previous chapter I explored the question, *how constructing doctorability and credibility may constitute a narrative problem for patients with contested illnesses and their doctors?* With this question in mind, I drew on Labov's (1997, 2013) narrative concepts of reportability and credibility. I addressed the question by presenting excerpts from selected memoirs. In this chapter, I introduce the corpus of illness narratives that comprise this study and I elaborate on the criterion of selection. I also explain the concept of *evaluation* following on the one hand, Labov's narrative approach and, on the other, evaluation as evidentiality and stancetaking drawing on the literature of discourse and textual analysis (e.g., Chafe and Nichols 1986, Hunston and Thompson 2001). This chapter sets the basis for the discourse analysis of the narratives, and it raises the question: *What kind of evaluative, discourse strategies do patients/memoirists use to claim credibility in writing about their illness experiences?*

6.1 Origin of the Idea and the Corpus of Memoirs

The idea for my thesis originated in an interview I once conducted to a friend of mine, who in the mid-1980s showed symptoms associated with Lyme disease. Her condition, however, remained undiagnosed for years because her doctor saw her symptoms as psychosomatic rather than organically based. Although she showed her doctor a skin rash in one of her legs suspecting that her symptoms were associated with that rash, she was prescribed a psychiatric evaluation. Only later, she would learn that her rash was called *erythema migrans* and that that rash was the first sign of having been bitten by the blacklegged tick, which in her case was infected with the bacterium responsible for Lyme disease. Because she remained untreated, my friend developed chronic Lyme disease and suffered a myriad of symptoms over the years. She was finally diagnosed thanks to her chiropractor doctor, whom she consulted due to her joint aches. He prescribed her a blood test that confirmed she had advanced Lyme disease. However, the long-term effects of Lyme disease and the side-effects of the treatment to cure her brought her serious health complications over the years, which worsened her overall health.

It later happened that as I began to read a few illness narratives or memoirs about chronic Lyme, I observed that a similar story to my friend's emerged: patients reported how, despite suffering on and off from symptoms (such as fever, headache, extreme fatigue, muscle and joint aches, swollen lymph nodes and general malaise), and in some cases for months or years, had difficulties in making their symptoms doctorable to their physicians and they felt disempowered by the lack of credence that was given to their words and stories of illness. The difference with my friend was that many of these patients turned their stories into written memoirs. However, not all patients have the ability to narrativize.

In observing the pattern of these patients/narrators in making their conditions doctorable, I decided to extend my reading to other memoirs about other contested conditions, such as fibromyalgia and endometriosis, to see whether patients reported similar complaints. In reading these narratives it became clearer to me that contested illnesses seem to amplify the problem of credibility that these patients face in trying to make their conditions doctorable to their physicians, as Halkowski (2006) observed that that is the patient's dilemma (see chapter five). Consequently, I decided to focus on this topic as this present dissertation shows.

6.2 The Corpus: Memoirs of Contested Illnesses and Criterion of Selection

The twenty-two memoirs that comprise this study have been divided into a primary and secondary source; that is, between memoirs of contested illnesses and memoirs of non-contested illnesses.

Primary Source. Eighteen autophatographies or memoirs about contested illnesses, published between 1994 and 2020 in the United States, Australia, and The United Kingdom, constitute the primary source. The main criterion for the selection of the primary source memoirs was that the narratives were written about a contested illness, as the memoirists self-identified as having a contested condition. With exception of one memoir, all the rest are written by female memoirists. The memoirs in this category address the following conditions: chronic Lyme (*Bite Me* by Hilfiger 2017 and *The Widening Circle* by Murray 1996), fibromyalgia (*Tender Points* by Berkowitz 2015), multi chemical sensitivity (*Chemical Crisis* by Crumpler 1994), chronic fatigue syndrome (*The Alchemy of Illness* by Duff 1993; *The Night-Side* by Skloot 1996; *Encounters with the Invisible* by Wall 2005, and *Fatigue* by Acker 2019), a neuroma in the pelvic area (T*he Lady's Handbook for her Mysterious Illness* by Ramey 2020), chronic headaches (*All in My Head* by Kamen 2005), endometriosis (*Ask me about my Uterus by* Norman 2018), autoimmune neurological conditions, e.g., anti-NMDAR Encephalitis (*Brian on Fire* by Cahalan 2012), and Morgellons (T*he Beast Lies Within: A Secret Diary of a Morgellons Sufferer by* Pascoe 2019). Typically, all these conditions are associated with the umbrella term of contested illnesses (see chapters three and four).

Secondary Source. Four narratives about non-contested illnesses comprise the secondary source. This secondary source will be used for the methodological purpose of control, that is, to look for similarities or differences in the way patients/narrators write about their experience of illnesses with their doctors. The narratives comprising this secondary source are three memoirs about cancer diagnosis, two written by men (*At the Will of the Body* by Frank 1991; *A Lucky Life Interrupted* by Brokaw 2015) and one by an African American woman (*The Cancer Journal*s by Lorde 1997). Finally, there is a memoir about a neurological condition (*A Leg to Stand On* by Sacks 1984), developed after a hiking accident on a mountain.

6.3 Method of Collection of the Memoirs and Criterion of Selection

6.3.1 About the Memoirs

I became aware of these narratives by different means. I heard of them in the media, for instance, *The New York Times*, *PBS* and *NPR* shows, or I learned about them as they were cited in scholarly publications about illness narratives. Others were referred to me by experts in my social circle. Thus, in a sense, it can be said that this has been a sort of snowball sampling in which one source led to another. Nevertheless, a total of twenty-two publications constitutes a small number if considering that illness memoirs have become a burgeoning genre. A Google search showed 6,470.000 titles under the term illness narratives and 1,310,000 results under memoirs of contested illnesses. However, the engine results are not entirely reliable because they do not limit just to memoirs; they also include scholarly articles and books. The problem in trying to find a more accurate number of publications is that what is deemed “contested” is debatable, that is, what is referred as “contested” may include, or overlap with diseases that are seen as diagnoses of exclusions, such as “irritable bowel syndrome,” or as mysterious illnesses, that is, diseases for which medicine has no biological explanation, such as Morgellons disease. Another current term for contested is “undiagnosable” illnesses. However, I find the term “undiagnosable” a little vague and imprecise. Most of the patients who have written about their conditions ended up with a diagnostic label, such as fibromyalgia or chronic fatigue syndrome, that has categorized their illness experiences in particular ways, I believe. In sum, these memoirs have been included because their own authors claim, either directly or indirectly, that they have suffered a form of contested illness. It is fair to say that more memoirs, or other memoirs, of contested illnesses could have been included in this primary source. Thus, these memoirs are only a sample that contribute to an exploration of the problem of credibility from a narratological point of view.

Most of these narratives are in print, with exception of Pascoe’s (2019) and Acker’s (2019) memoirs, which have been published online as e-books in Kindle format. Pascoe’s is a self-publication and Acker’s was published by Amazon Publishing. The publishing companies of these memoirs correspond to different editorial houses, and they may differ in reputation and prestige, but they are all part of popular culture as they reflect the postmodernist interest in consuming memoirs (see Couser 2012 and Rak 2013). The decision to include mostly printed memoirs, instead of blogs or social media narratives, is because they may guarantee a high quality and because the print may give them an authorial voice by fixing their narratives in space and time. It can be presumed that by being published by a publishing company they have at least undergone a minimum process of peer reviewing and editing that was conducive to the publication decision. Although prestigious publishing companies do not always offer guarantee that memoirs are based on the authors' truth life stories (for instance, the case of the book, *A Little Million Pieces* by James Frey 2003 published by Anchor Books, a division of Random House, is a controversial example), the fact that they have been exposed to the public can serve to provide a form of consensual or public attestation to their degrees of veracity. In other words, public debate, and even withdrawal of publication contract, is likely to emerge if fabrications are suspected or detected in the memoirs, as has been the case in Frey's book.[1]

It is important to notice that all the narratives in the primary source are written by women, with exception of Floyd Skloot's (1996) *The Night Side*, as the only male memoirist. Also, they are not written by professional writers, with few exceptions; for instance, Kamen (2005) is a journalist and has written several books, Wall (2005) holds

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[1]. *A Little Million Pieces* by James Frey (2003) was originally published as a memoir about the author's struggles with drug addiction and recovery. However, several media organizations denounced its lack of facticity by pointing several fabrications. These organizations unleashed a public and ethical debate. The book was later published as semi-fictional rather than autobiographic, along with the publisher's decision to refund those readers who felt defrauded by Frey's story (see Couser 2012; Porter Abbot 2002).

an MFA in writing, and Skloot (1996) is an American poet and writer with several publications and awards. Nevertheless, with exception of these authors, these memoirs can be called, “nobody memoirs” (Couser 2012, 3), that is, written mostly by anonymous individuals, who gained some recognition with their publications.

The memoirs comprising the secondary source were selected with the purpose to examine how patients with a non-contested condition report about the experiences with their doctors. But also, a difference with the memoirs comprising the primary source is that these memoirs are written by “somebodies” (to use Couser’s 2012 terminology), that is, individuals who are well known by virtue of their scholarly work. For instance, Arthur Frank is a medical sociologist. He may not be well known in public arenas, but he is very well known as an academic in the field of medical and health humanities and sociology. Writer and social activist, Audre Lorde (1934-1992) was a feminist poet and civil right activist advocating for women’s rights and LGTB people. Tom Brokaw is a well-known, retired American journalist with numerous awards and public recognitions; he anchored NBC Nightly News for decades. Oliver Sacks (1933-2015) was a British neurologist who lived and practiced medicine in the United States, wrote best-selling books that were collections of case studies of people from his own practice, including his own medical case, *peripheral nerve injury*. Some of his books were turned into films with popular acclaim, such as *Awakenings* (1990).

6.3.2 Criterion of Selection of the Memoirs

These narratives were included because they address contested as well as non-contested conditions. The quality of their writing or literary craft was not a criterion of selection. In fact, these memoirs vary in writing quality. Some even present editorial errors, such as Hilfiger’s (2017) in which at moments, the bacterium as the vector responsible for Lyme disease is mistakenly called a virus. Nevertheless, my interest does not lie in the literary excellence of the narratives, but in the way these patients manage to construct credibility about the ontological existence of their conditions by means of their narratives.

For the purpose of the analysis, the different narrative skills that these memoirs display are considered equally significant. I approach them in the same manner as we understand that not all native speakers of a language have the same linguistic command of the standard varieties; yet their productions could be sophisticated and revelatory. Nevertheless, it could be argued that the narratives of the secondary source, which were written by scholars and a journalist, may show a higher narrative quality than some of those narratives in the primary source written by non-professional writers. However, I do not position myself as a literary critic who judges their craft. The interest of this study lies in the discursive and rhetorical strategies used by these narrators who suffered contested and non-contested illnesses.

6.3.3 Classification of the Memoirs

To organize the analysis of the memoirs corresponding to my primary source, the memoirs of contested illnesses, I classified the memoirs in categories (see Appendix A, tables 1 and 2) according to the authors’ self-identified diagnoses. Per this criterion, most of the memoirs about contested illnesses that comprise the data collection of this dissertation correspond to category (1) Myalgia Encephalitis/Chronic Fatigue Syndrome (ME/CFS). The rest of the memoirs are grouped under the categories of (2) Lyme disease, and (3) Chronic Pain memoirs. The latter is an umbrella term in which I include memoirs from different conditions such as fibromyalgia, chronic headaches, neuroma, and endometriosis. Although the category of chronic pain comprises different diseases with different etiologies, I decided to group them together given that chronic, debilitating pain, and progressive incapacitation is the main complaint that characterizes these authors' memoirs. The last category is (4) Miscellaneous, which comprises one memoir related to multichemical sensitivity, one about autoimmune disease, and one about Morgellons disease whose etiology is unknown. I would like to emphasize that the classification of these memoirs is merely operational, and it does not follow a medical criterium.[2] Thus, the reason for establishing these categories is to follow the authors' self-assigned or self-identified illnesses as they were diagnosed by their respective physicians. Despite their different diagnoses, most of these patients/narrators reported experiencing similar symptoms (e.g., extreme fatigue, muscular and joint pain, headaches, general malaise, low fevers, losing cognitive functions, neurological symptoms, psychological and emotional distress, among others).[3]

6.4 Method of Analysis of the Memoirs

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[2]. It is worth mentioning that conditions such as ME/CFS and fibromyalgia have been seen by some medical scientists as triggered by Lyme disease (see Edlow 2003, 209). This theory was meant to explain the persistence of symptoms remaining over the years that some patients experience, despite having been treated with antibiotics to counteract the bacterium responsible for Lyme disease. This condition is known as post Lyme disease. However, there is no consensus in the medical community that Lyme will trigger ME/CFS and fibromyalgia (see e.g., Edlow 2003).

[3]. It is possible though, for different diseases to share a similar semiology. For instance, muscular pain and low fever could signal a variety of diseases. This is one of the medical challenges to properly diagnose contested illnesses (e.g., Aronowitz 1998)

To analyze the memoirs corresponding to the primary and secondary source (see Appendix A, tables 1 and 2), I conduct a close reading analysis of selected memoirs in chapter seven and eight. Because some disease categories, either in the primary or secondary source, comprise more than one memoir, in the next chapter, I will present a full analysis, as a manner of illustration, of two selected narratives corresponding to each disease category. Although the rest of the narratives have been examined, I cannot develop a full written analysis of all the narratives in the chapter for space reasons.

The close reading focuses on the abstract, orientation sections and evaluation, and I elaborate on these concepts in the next section. To identify the abstract and orientation sections in the memoirs, I follow Labov and Waletzky (1967), Labov (1972). Also, I examine evaluative devices used by the memoirists to either describe and characterize their conditions or to characterize how their physicians talked to the memoirists about their illness symptoms. To analyze the evaluative devices, I draw on Labov's (1972) evaluative devices as well as on evidentiality and stancetaking, as elaborated in discourse analysis. I elaborate on evidentiality and stancetaking in the next section. Before addressing these concepts, I need to explain the reasons for focusing the analysis on the abstract, orientation, complicating event or most reportable event, and evaluation sections.

The sections of the abstract, orientation, and evaluation would correspond approximately to the preface, introduction, and first chapter of each memoir. However, this criterium does not mean that I may not refer to other chapters, if needed. I focus on these sections primarily because they provide the listener/reader with information about the most reportable event, the time, place, characters, and the assignment of praise or blame from the narrator’s perspective, according to Labov’s (1972, 1997) theory (see also Introduction). In the memoirs’ orientation section, I also identify the most reportable event and then analyze the evaluative devices used by the narrators to construct credibility about the most reportable event, or to reclaim their conditions as doctorable. Although I focus on the abstract and orientation sections, I do not limit myself to analyze evaluative devices in the “orientation” section; that is, in the preface or introductory chapters of the memoirs. When relevant for the purpose of credibility and doctorability, I extend my analysis to other chapters or sections given that as Labov (1972) observed, evaluation is interspersed across the narrative.

6.4.1 Evaluation: Evidentiality and Stance

Because in this study I am concerned with the way patients/narrators wrote about their experiences to gain credibility about their symptoms and their stories of illness, I draw on the one hand on Labov’s (1972) identification of evaluative devices. This is because to analyze how narrators self-assess and self-evaluate their own illness experiences, it is necessary to understand how they construct credibility. However, Labov’s concept of evaluation is constrained to the analysis of the narrative and the narrator’s point of view. For Labov, credibility is seen as a narrative problem; that is, whether the story told by the narrator holds consistency and coherence to its parts. However, as discussed in chapter four, credibility is also influenced by the identity of the speaker. Women’s illness narratives could be tainted by gender prejudices associated with hysteria. Despite its major influence in narrative analysis, one of the critiques to the Labovian model is that evaluation does not solely derive from the narrator itself, rather evaluation is negotiated between the speaker and the listener (or between the narrator and its possible audience). Thus, the way a story's recipient may respond to a narrator (or to an internalized story's recipient) can affect the narrator's way of telling the story (see Cortazzi and Jin 1999) (see also chapter two). For that reason, I complement Labov's concept of evaluation with the concept of evaluation seen as *evidentiality* and *stance* (e.g., DuBois 2007), which goes beyond the structure of the narrative as told by the narrator and, instead, it considers intersubjectivity between the narrator and its audience.

In sum, evaluation is a broad concept in discourse analysis. The discursive concept of evaluation involves *evidentiality* (e.g., Aikhenvald 2005; Chafe and Nichols 1986; Hunston and Thompson 2000) and *stancetaking* (e.g., Englebretson 2007, Mushin 2001) although both may overlap. Thus, whereas Labov's concept of evaluation is useful to conduct a narrative analysis that focuses on the narrator's viewpoint and on the narrative as a text, an approach to evaluation that considers evidentiality and stancetaking is useful to conduct a discourse analysis that focuses on strategies and linguistic devices involving aspects of intersubjectivity (in this case between narrators, their internalized addressees, and their potential readers). Then, this approach to evaluation will allow me to expand the analysis by considering the influence of the addressees or internalized addressees in the writing of the memoirs; in other words, it will allow me to consider the influence of intersubjectivity.

In arguing here that one of the reasons for memoirists to write their illness narratives is to legitimate their illness experiences, then I suggest that they write not only with a targeted audience in mind who may be interested in their life stories, but also with the intention to reclaim credibility from a real or internalized audience (i.e., the healthcare professionals); for instance, an internalized skeptical audience who initially doubted their conditions to be organically based. In the next sections, I elaborate in depth on Labov's concept of evaluation, and I review the literature on evidentiality and stancetaking as the two sides of evaluation.

6.4.2 Labov's concept of evaluation

Narratives are told with a point (see Labov and Waletzky 1967). Narrators need to orient in their narratives to the relevance of telling the story; otherwise, the audience may wonder "so what?" and the narrator may risk losing his or her speakership position. Thus, a concern of the narrator, like a concern of the patient earlier mentioned in Halkowsky's (2006) article, is to rationally justify her purpose in telling the story. With this purpose, the narrator needs to evaluate her own narrative. Before addressing the concept of evaluation per se, I need, however, to present new concepts and review previously discussed concepts.

The way in which a story begins has an impact on the narrator's success in telling the story and captivating the attention of the audience. In telling the story, the narrator must decide what constitutes the most reportable event; that is, the event that is "less common than any other in the narrative and has the greatest effect upon the needs and desires of the participants in the narrative" (Labov 1997, 406). The most reportable event can be found as a summary, typically at the beginning of the narrative, that is in the abstract section, although not all narratives need to have an abstract.

The abstract is a description of the most reportable event, i.e., what the narrative is about, but without providing the sequence of events that led to the most reportable event (Labov 2013, 27). For that reason, the telling of the most reportable event in the abstract does not constitute a narrative yet. The abstract is followed by the orientation section (see also Labov and Waletzky 1967).

In *the orientation*, the narrator provides the audience with information about the time and place of the events as well as introduce the actors and their behaviors. Moreover, Labov (1997) observes that the orientation section is likely to reveal the narrator's viewpoint or evaluation about the events. The narrator's viewpoint or evaluation may involve the assignment of praise or blame about the actors in the narrative by means of polarizing or integrating devices. Although Labov (1997) notes that in oral narratives, the narrator usually conveys her or his viewpoint or evaluation without awareness, I shall argue that in a written memoir these memoirs are written with a strategic purpose in mind: the purpose to construct credibility about their illnesses and simultaneously advocate for the organic based of these conditions.

Labov (1972) defined *evaluation* as "the means used by the narrator to indicate the point of the narrative, its raison d' être: why [the narrative] was told, and what the narrator is getting at" (366). In the evaluation, the listener/reader can grasp how the narrator's life experience, articulated in the narrative, has been integrated and assimilated into the narrator's biography. In the case of the illness narrative, in the evaluation the listener/reader can grasp how the illness experience has been integrated into the person's past story and into her new projection of the future (see Frank 1995).

Whereas initially in Labov and Waletzky (1967), the evaluation of a narrative event was identified with a particular section in the narrative structure (i.e., the evaluation section) located between the complicating event (or the most reportable event) and the resolution, Labov (1972) revised this concept. He then observed that although evaluative devices tend to concentrate in the evaluation section; that is, in proximity to the most reportable event, these devices can be distributed throughout the narrative (Labov 1972, 369). The view of evaluation as a semantic rather than structural concept that can be distributed throughout the narrative is central to Labov’s theory of narrative, and its theoretical importance has been widely acknowledged in the literature.

One reason for the view of evaluation as semantically rather than structurally organized is that evaluation is seen as disclosing the purpose why a narrator feels a story is worth telling, or why the events of the story are reportable. The narrator needs to show that the narrative is worth telling, and this depends on the selection of the most reportable event (i.e., “where should I begin?”) to answer the question “so what?” (i.e., why the event, deemed as the most reportable, is worth telling?) Then, the evaluation offers the reflection of the narrator about the events and her perspective on the events.

Another reason for the semantic approach to narrative by Labov (1972) is based on the observation that in reporting their own experiences, adults have a metalinguistic ability: “The most highly evaluated form of language is that which translates our personal experience into dramatic form,” i.e., narrative, asserts Labov (1972, 396).

Labov (1972, 1997, 2013) observed several evaluative categories. Each category comprises different discursive strategies, such as the use of hypothetical events, negatives, modals, and future tense, as a means to compare what happened with what did not in fact occur.

Labov (1972) distinguishes between external evaluation and embedded or internal evaluation. Through *external evaluation* devices, the narrator suspends the telling of the sequence of events to step out of the story world and comment explicitly on aspects of the story. The story world and the narrator's assessment of it can be distinguished in external evaluation. However, *internal evaluation* comprises evaluative strategies that form part of the narrative discourse as if they were part of the story world. In internal evaluation, the narrator embeds his or her evaluation while narrating the story, i.e., as if these evaluative strategies were part of the story world. For instance, while narrating the story, the narrator may present her thoughts or emotions as if they were concomitant to the occurrence of the events in that moment, i.e., as embedded within the story world. Also, the narrator may report an *internal dialogue* or may report her thoughts as she happened to have them at the time the events were taking place. In sum, we can say that in the embedded or internal evaluation, the narrative discourse (i.e., the telling or presenting of a story) infiltrates the story world and vice versa. Because Labov's study is based on oral narratives, he did not find that embedded or internal evaluation was a typical device of oral narratives. However, given that in this study I will analyze evaluative devices of written memoirs, we can expect that internal evaluation will be prevalent. Some of the evaluative devices observed by Labov are comparators and intensifiers, which I also frequently observed in the memoirs. Below I elaborate on these devices.

Comparators. "Comparators provide a way of evaluating events by placing them against the background of other events which might have happened, but which did not. They compare the events which did occur with those which did not" (Labov 1972, 381). Labov identifies functioning as comparators, not only comparative adjectives, as the comparators par excellence, but also verbs in the future and imperfect tense, negatives, questions embedded in the action, and modal verbs.

***Intensifiers*.** Intensifiers are other types of identified features by Labov (1972) that serve to emphasize a specific event among a chain of events; they include *modifiers* (e.g., adjectives and adverbs), *quantifiers, wh-exclamations* (e.g., why! where!), and *lexical repetitions* among others. All these devices will become clear in the next chapters when I present the discourse analysis of the memoirs.

6.5 Evaluation: Evidentiality and Stance in Text

Evaluation in language is a wide-ranging concept in linguistic literature. Evaluation is not only found in narrative texts, as a genre, as presented in Labov (1972, 1997, 2008, 2013) and Labov and Waltezky (1967). Rather, evaluation is found in discourse as an intersubjective phenomenon. Evaluation reveals the speaker's or writer's subjectivity; for this reason, it is connected to the concept of evidentiality and stance in language. I shall start by addressing evidentiality to explain how it is connected to the concept of stance and, therefore, to evaluation.

For some authors, such as Aikhenvald (2005, 4) evidentiality is strictly a linguistic category by means of which the speaker or writer indicates the source of information about her statement. Although some languages have specific morphological markers for evidentiality (e.g., Quechua), most Indo-European languages, such as English, do not. Nevertheless, speakers and writers convey their source of information by means of semantic extensions, that is, by means of lexico-grammatical, textual, and pragmatic structures that function as evaluative devices, observes Aikhenvald (2005).

Evidentiality conveys how the source of information of the speaker's utterance has been obtained by the speaker or writer. The reported or expressed information could have originated ***first-hand***, either as an internal sensory experience (e.g., introspection) or as an external perception (e.g., visual, or aural experience); that is, it could have been inferred by means of observation or reasoning. Also, it could have been obtained ***second-hand*** by means of being reported by others or hearsay. Or, finally, the information could have been derived from ***speculation***.

According to Chafe (1986), evidentiality can be understood in a narrow or in a broad sense. In a narrow sense, evidentiality is the speaker's/writer's indication of the source of information of her or his utterances; that is, from where the information is taken. And, in a broad sense, evidentiality is the speaker's/writer's stance; that is, her attitude toward her knowledge of reality. Looking at evidentiality from a broad perspective, speakers and writers not only convey the source of information, but they can also reflect the degree of certainty, possibility, or probability about their source of information (i.e., epistemic modality) (see e.g., Chafe and Nichols 1986). For this reason, evidentiality and stancetaking are interrelated concepts and they tend to overlap in the linguistic literature; for instance, another way of taking a stance could be by means of indicating the source of information. Mushin (2001) observes that "the lack of consistency in defining evidential meanings arises from the lack of a clear boundary between specification of source of information and specification of speaker attitude towards the information and its source" (15). In sum, evidentiality and stancetaking can both be considered forms of evaluation. Hunston's and Thompson's (2001) definition of evaluation seems to condense both concepts also. They state that "evaluation is the broad cover term for the expression of the speaker's or writer's attitude or stance toward viewpoint or feelings about the entities or propositions that he or she is talking about.

That attitude may relate to certainty or obligation or desirability or any number of other sets of values" (5).

As speakers/writers can convey their attitudes, emotions, and points of view or stances (e.g., agreeing or disagreeing), they can also convey their degree of affiliation or commitments to what they say or hear. According to DuBois (2007), speakers can convey this range of information all at once. In every instance, speakers and writers can express their evaluations or stances by linguistic, semantic, and pragmatic means while simultaneously encoding multiple levels of information all at once. To condense the range of categories associated with evidentiality (e.g., source of information, epistemic modality, deontic modality) and with stance (e.g., attitude, opinion, emotions, others), DuBois (2007, 167) observes that evidentiality is to be understood as a triune act or as tri-act. In taking a stance or making an evaluation, the stancetaker realizes three actions simultaneously: she evaluates an object, positions a subject (usually the self) with respect to that object, and aligns herself with other subjects (either present or absent).

Implicit in this triune act is the view that stancetaking is a dialogic activity, in which speakers and writers are making not only propositional statements but also evaluative comments by either engaging directly or indirectly with prior resonant stances. For DuBois (2007), stancetaking is an intersubjective or dialogic process. As he asserts, "much of the dialogic quality of stance comes from the way a present stance may resonate with a prior stance …. [R]resonance across stances shapes the socio-cognitive alignment between speakers, and this helps intersubjectivity" (167).

DuBois' (2007) concept of stancetaking seems to share similarities with Bakhtin's (1981, 1986) concepts of dialogism and addressivity. Bakhtin's (1981) concept of dialogism observes that there is a constant interaction between speakers' meanings, all of which have the potential of conditioning each other. Related to dialogism is the concept of addressivity (Bakhtin 1986). In responding to the utterances of others, speakers/writers anticipate others' responses and in so doing, speakers/writers' utterances are being influenced by the intersubjective perception of others' expectations. Thus, in giving their answers, speakers/writers are qualifying others' utterances by means of their own answers, in an unfinished chain (Bakhtin 1981, 426).

For Bakhtin (1981), a stance is always made in response to others. For that reason, "evaluation never takes place in a void, to assign value implies to assess and rank [what others have said before]" (428). A stance evaluates an object regarding or considering others' views while simultaneously revealing the speaker's attitude toward that object. Thus, evidentiality and stancetaking are ways to acknowledge the role of subjectivity but also the role of intersubjectivity in language use. Despite the common points between stancetaking and Bakhtin's dialogism, the advantages in doing an evaluation or stancetaking analysis is that it provides us with a full array of linguistic devices to analyze these memoirs, as writers evaluate their own stories as well as others' statements.

6.6 Evaluation, Reliability, and Credibility

The presence of evidentialities in the discourse or text does not guarantee credibility, though. As Aikhenvald (2005) bluntly says, "linguistic evidentiality has nothing to do with providing proof or indicating what is true or indicating one's own belief" (4). For this reason, there could be a pragmatic mismatch between the text and the speaker’s communicative intention. According to Chafe (1986), the way the acquisition of different types of knowledge is achieved (e.g., belief, induction, hearsay, or deduction) invariably leads to an assessment of the speaker’s reliability. For instance, although the use of a direct evidential may represent the speaker as more involved, and the use of a *reportive evidential* may represent the speaker as taking more distance from the event, these parameters may be independent of whether the speaker believes in the validity of the information she is conveying. The same can be said about the speaker’s commitment to the reported information. The speaker may or may not commit to the information reported, but still interlocutors will be influenced to believe or attribute more reliability to the speaker with authoritative power. Consequently, how stories are told and received by listeners is not totally independent of the perception of the speaker’s authority and reliability as a social entity, regardless of the speaker’s use of certain evidentials to convey credibility.

Mushin (2001) explains that the person who has been assumed to have authority is perceived as taking responsibility for the validity of the information, whether her statement is truthful or not. As Mushin (2001) states, “Assumption of authority, whether it is self or socially imposed, will inevitably affect not only the evidential categories that are used, but also how they are used to implicate different degrees of commitment” (22). One strategy to gain credibility that may be used by a person who has less authority could be to cite someone who has more authority in the matter with the purpose to demonstrate their strong belief in the information and persuade others of the reliability of their statements. In this case, the device called *reportive evidentiality* could be used as a strategy to vouch for information. This device has been frequently observed in the analysis of the memoirs, as I will present on chapters seven and eight. In conclusion, not always, linguistic evaluative devices systematically translate into a direct correspondence between the speaker's utterances and what the listener believes, nor with what the speaker says and the actual course of events.

As previously mentioned, speakers may be influenced by the social pressure of their speech situations and the listeners or audience. On the one hand, speakers may convey their information in certain ways to try to avoid social conflicts or mitigate the effect of certain statements. Thus, there could be a mismatch between the pragmatic or the communicative intention of the evidential marker and the epistemological stance of the speaker toward the propositional information. "Speakers are motivated to adopt a particular epistemological stance (i.e., assessment) partially on the basis of their source of information, but also on the basis of their rhetorical intentions on how they want their own utterances to be understood and treated in the moment of the interaction" (Mushin 2001, 58). However, on the other hand, evidential devices can be used by the speakers to assert and reclaim their own beliefs and personal truths, regardless of the truth condition of the events. And, in this study, I take this approach.

Despite these methodological considerations between what is uttered or written and what is intended by the narrator, here I look at how evaluative devices are used by the narrators to reclaim their own selves and reclaim the ontological status of their conditions. I am not interested in the factual truth of these memoirs, but rather on their narrative truth (Spence 1982). Thus, I adopt Frank's (1995) and Hawkins' (1999, 14) advice on how to read these narratives, that is, not only taking their stories as truthful but also taking their writing process as truthful. As Hawkins observes, “to emphasize the ‘story’ [term] in pathography is in no way to denigrate their truth-value” (14).

In conclusion, the clearest distinction between Labov’s narrative approach to evaluation and the discourse and textual analysis approach may be dependent on the views of credibility and believability. If the narrator is not believed, then the narrator will lose not only her speakership position and the attention of the audience, but also her status as a narrator. As mentioned earlier, for Labov, credibility is a matter for the narrator in creating a consistent story. For Labov (2013, 23), credibility neither depends on the listener’s confidence in the honesty and good moral character of the narrator nor on the narrator’s social identity, but on the likelihood of the chain of the events that led to the most reportable event as well as to the rational links of causality between the events. Thus, in Labov’s model, credibility does not depend on the identity of the narrator. This approach is relevant for this study because as I study memoirs, I am unaware of the identity of the authors. However, as discussed earlier in chapter four, we know that women, historically, tend to be seen with suspicion regarding the legitimacy and authenticity of their authorial voice, and they are seen, in general, as less capable for holding responsibility for the veracity of their stories or as rather, they are seen as more prone to fabulation (see e.g., Cleghorn 2021). For this reason, I consider necessary to complement Labov’s approach with perspectives on evidentiality and stancetaking that take into account the influence of the interlocutor. In complementing these approaches, I consider not only how narrators evaluate their own stories to orient their readers to the point, but also how narrators may construct credibility in response to their internalized addressees’ scientific skepticism or gender prejudice. The next chapter presents the close reading analysis of the illness narratives comprising the primary source (i.e., illness narratives about contested diseases), by drawing on the concepts of evaluation, as elaborated in this chapter.

CHAPTER 7

EVALUATIVE DEVICES in NARRATIVES of CONTESTED ILLNESSES

This chapter presents the discourse analysis of the selected narratives corresponding to the category of contested illness memoirs (see Appendix, table 1), as explained in chapter six. The theoretical background concerning the discursive devices involving evaluation and stancetaking were elaborated in the previous chapter. Here, I will focus on the close-reading analysis of the discursive devices that narrators may use to construct credibility as they are found in the orientation section of their memoirs, the complicating event, and in the evaluation section (i.e., the prologue, introduction, and first chapters). I argue, drawing on Labov (2008), that narrators need to show reliability and credibility in their narrating to be able to gain the attention of their listeners/readers. For this reason, all narratives are told with a point. If, in chapter five of this dissertation-thesis, the research question was *How constructing doctorability and credibility may constitute a narrative problem for patients with contested illnesses and their doctors?* (see Introduction), in this chapter, the research question asks: *What kind of evaluative, discourse strategies do patients/memoirists use to claim credibility about their conditions, in writing about their illness experiences?* Thus, here I focus on how patients/writers of these memoirs, empowered by their written word, use language in their narratives to rhetorically construct credibility about their illness experiences. As an observed commonality to most of these memoirs of contested illnesses, they share a similar experience: at a certain point in the course of their illnesses, the memoirists' main complaints and symptoms were treated as psychosomatic, or as related to stress and, even hysteria; therefore, as non-doctorable conditions.

7.1 Analysis

The discourse analysis by means of close reading focuses on selected memoirs corresponding to each group within the primary source category; that is, the memoirs of contested illnesses. Chapter eight will analyze the memoirs corresponding to the secondary source category; that is, the memoirs of non-contested illness (see Appendix A, table 2). As introduced in chapter six, the memoirs comprising the primary source are grouped as (1) Myalgia Encephalitis/Chronic Fatigue Syndrome (ME/CFS) memoirs, (2) Lyme disease memoirs, (3) Chronic Pain memoirs, and (4) Miscellaneous. The latter group comprises memoirs from different conditions such as multichemical sensitivity (MCS), autoimmune disease, and Morgellons disease. For the analysis, I have selected, at random, two memoirs corresponding to groups (1), (2), and (3), and one memoir corresponding to group (4). The analysis compares the memoirs in the intra-group and across the groups.

The analysis proceeds, systematically, by identifying the initiating or most reportable event in the orientation section of each memoir and the evaluation section. It is important to note that depending on the narrative organization of the plot, the most reportable event can be found in other chapters rather than in the first chapters (which we call here orientation), including at the very end of a memoir. Nevertheless, if the orientation does not present the most reportable event of a memoir, it always, at least, presents the initiating event. The initiating event is a variation of the reportable event; the only difference is that it precedes or anticipates the chain of events that would lead to the most reportable event until a resolution has been achieved (see Labov 1997). Thus, like the most reportable event, the initiating event may reveal the narrator's stance or evaluation regarding the onset of illness.

In addition, I analyze the evaluation section of the narratives, which is typically placed after the most reportable event. To refresh the idea of evaluation as elaborated on chapter six, Labov (1972) defined *evaluation* as "the means used by the narrator to indicate the point of the narrative, its raison d' être: why [the narrative] was told, and what the narrator is getting at" (366). Thus, narrators usually evaluate the reportability of their stories in the orientation section by means of discursive devices; however, evaluative devices can be found throughout the whole narrative. Here, I will analyze selected excerpts that evaluate the initial or most relevant events as a way to justify their credibility. Finally, in the last section of this paper, I will summarize the discursive patterns that have emerged from my analysis; that is, the discursive patterns that the narrators of these memoirs display in constructing credibility (see also Appendix B for clarity).

7.1.1 ME/CFS Memoirs

ME/CFS memoirs tend to start by identifying the onset of their illness as an out-of-the-ordinary degree of fatigue that is disconcerting.[1] The effect of this fatigue is disproportionate with respect to the level of energy sufferers usually require to do their daily activities in comparison with their past performances or in comparison with the level of energy a non-sick person would normally require. Thus, it can be said that extreme, debilitating fatigue for which they have no comparable measure because they never experienced it before, constitutes the most reportable event shared by the narrators of ME/CFS memoirs. However, the debilitating fatigue that typically marks the onset of their illness can manifest differently, depending on the narratives.

7.1.1.i *Encounters with the Invisible* by *Dorothy Wall (2005)*

Excerpt 1

> The day I was drawn into this social and medical drama was an innocuous one, as life- changing moments often are, their explosive significance revealed only in retrospect. *My pivotal moment* came amid a swirl of green paint on a June day in 1980. I had awakened that morning feeling sluggish, fluish. It was a fine early summer day, and *I was flush with ambition, having just completed my M.A. coursework in creative writing* and quit my bookstore job…. I relished the day as one of homey chores and accomplishments, a day leaning toward a bright future. *I had only to take my M.A. orals and was set to plunge into the itinerant college teaching circuit in the fall, a rather* optimistic ambition that involved commuting all around the Bay Area…I was as sure that I could make a go of it as I was that I could paint that desk…
>
> *Sinking with fatigue*, I sloshed a too bright green—what had I been thinking? across the desk. With each glistening brushstroke I sank further, my head strangely fibrous, my body a wooden bulk I struggled to animate. Sunlight off the paint was blinding, the fumes peculiarly refracted, as I could smell each distinct molecule. I kept working until the last green stroke melted into a

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[1]. It seems that the complexity of the stories and suffering of these patients is correlated to the extent of time they spent without being diagnosed or properly diagnosed. For some, such periods lasted five months (e.g., Skloot), but for others, years (e.g., Acker 2019 and Wall 2005).

> plasticized sheen, then went in to lie down. An exhaustion thick as sod settled in my head and limbs. (Wall xix-xx) (emphasis added)

This excerpt can be considered part of the narrative orientation. In the orientation, as typically observed by Labov (1997), the narrator provides information about the time (i.e., the year 1980) and place (i.e., Bay Area, California) where the action takes place and it also positions the assignments of praise or blame (i.e., in this case blame to her illness). By reading Wall's excerpt, we learn that something in her life has departed from the normal parameters of health. In the author's note section, readers are informed that Wall is experiencing the onset of symptoms associated with ME/CFS disease. The decision to reveal the diagnosis in that section, rather than disclosing it in the first chapter, is rhetorically relevant. Whereas, on the one hand, the reader is given privileged information about her condition in the author's note, on the other hand, the reader is placed as a witness of Wall's uncertain journey in chapter one. Thus, the narrator's point of view from which the author reports her "pivotal moment" (xix) is contemporaneous to Wall, the protagonist. This means that the reader learns about the evolution of her symptoms and reactions simultaneously as the protagonist does.

The intensity of the perceptual and sensorial experiences (e.g., feeling sluggish, fluish) that Wall had at that pivotal moment, can be considered disproportionate with respect to the necessary amount of energy or effort a healthy person may normally require in painting a small desk. The contrast between the physical task (i.e., painting a small desk) and the energy required by the protagonist to perform it, indicates that this is a highly reportable event; it indicates an event that goes against normal expectations in a young, healthy person; for that reason, it is an out-of-the ordinary event, and it is altogether difficult to believe or at least to understand her level of fatigue. Here, the reader (or listener) may be placed in an ambivalent position. On the one hand, it can be said that Wall's assertion of sensorial experience cannot be denied given that it is subjective. However, on the other hand, for the same reason, Wall's subjective evidence of extreme fatigue cannot be measured by an external source, or in a visible way. Wall's experience is opaque to us and therefore, it cannot be easily confirmed by medicine: there are no x-rays or CT scans that can measure the exact meaning of "sinking with fatigue" (xix). Wall is only equipped with language as her evidence of persuasion.

The symptoms that Wall (the protagonist) experienced at the time in which the action of painting is taking place, are described by means of figurative language. By means of this visual metaphor, Wall compares herself implicitly with a boat, as a non-agent, exposed to the elements as she is exposed to her fatigue. The use of the present participle "sinking" is indexing an ongoing action as a frightful and alien process. Both the metaphor and the grammatical form act as intensifiers that serve to enhance the reader's own experiential reading; they aim to construct credibility by inviting the reader to visualize her experience as ongoing, thus as veridical. Other symptoms are described by means of synesthetic images that combine tactile (e.g., "fibrous"), interoceptive perceptions (e.g., her body as "wooden bulk") with olfactive and visual experiences (e.g., the fumes as refractory). In this manner, a meticulous description of her internal perceptions is asserted as her experiential knowledge or visceral knowledge (Belling 2012), and as the patient's *first-hand* or *direct experience* (Aikhenvald 2005).

Whereas the use of figurative language may seem as merely illustrative, metaphors create realities, as I argued in chapter five following Lakoff and Johnson ([1980] 2003, 156). Therefore, the way Wall describes her internal, sensory experience has a personal, conceptual meaning for her. In other words, it may have an ontological weight rather than a representative and abstract one, even though others may interpret the use of figurative language as a simple rhetorical device to illustrate her perceptions.

Another interpretation about the use of figurative language is that the use of metaphors could be the protagonist's way to normalize bodily experiences that may seem alien and bizarre to others, including herself. Although figurative language may seem innocuous, as seen merely rhetorical and it may be disregarded as illusory or non-real, credibility is constructed in this manner, paradoxically, by means of seemingly fantastic and hallucinatory descriptions (see chapter five) because using metaphoric language seems to be one socially sanctioned way to communicate out-of-the ordinary experiences. Figurative or metaphoric language is embedded in conceptual systems grounded in the body experience and in our cultural experiences, as argued by Lakoff and Johnson (1980/2003); thus, figurative language is a way to create new conceptual systems and new realities. In this case, Wall's figurative language to talk about her illness experience with ME/CFS is a way of constructing new conventional ways of feeling sick with ME/CFS.

The narrator's evaluation of her pivotal event as one of "explosive significance" (xix-xx) is embedded within the storyline of painting a small desk: "My pivotal moment came amid a swirl of green paint on a June day in 1980" (xix). When the evaluation is embedded within the story line, it is called *internal evaluation* (Labov 1972). It is a way for the narrator to state her sentiment as something occurring to her at the time of the events (simultaneously) rather than addressing it to the reader/listener outside of the narrative (Labov 1972, 372).

The embeddedness of the evaluation (as part of the narrative discourse) within the story world (painting the furniture) creates a rhetorical and dramatic effect at the service of constructing credibility. Further analysis shows that the author's realization of that "pivotal moment" in her life is not conveyed by means of cognitive or affective verbs as it would be expected but, instead, the action is nominalized.[2] Thus, it is not the agent (in this case the protagonist) who "realizes" or "thinks" or "feels" about that moment as "pivotal," but instead, it is "the pivotal moment" that occupies the agent position and, consequently, it is infused with power over the object (i.e., the protagonist). The nominalized action seems to reflect the *mirative stance* as one lacking agency. In her book *Evidentiality*, Aikhenvald (2005) refers to "mirative" as a linguistic, evaluative device that covers the speakers' "unprepared mind" (195). The term "unprepared mind" (see DeLancey 1997 quoted in Aikhenvald 2005, 195) refers to the speaker's reaction to unexpected information or to new information along with its concomitant surprise. English does not have specific morphemes to indicate mirative devices, but speakers or writers can convey the sense of the unprepared mind by means of discursive strategies. I suggest that Wall's "pivotal moment" (xix-xx) which the narrator identifies as the onset of her illness, reflects Wall's (the protagonist) unprepared mind. We can speculate that one reason for this unpreparedness of mind is the participant's failure to understand the real significance and implications of that knowledge at that time (i.e., her level of fatigue). That type of knowledge may be disregarded as nonsensical or as a bodily oddity at that time, and, initially, it may pass inadvertently away from attention only to be acknowledged later by the force of its constant presence.

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[2]. A nominalization is a type of grammatical metaphor which represents processes as entities (Fairclough 2003, 220).

Overall, mirative devices suggest that the event is beyond one's control or command. The knowledge for Wall, as the sufferer, that that event (i.e., her sense of extreme fatigue at the time of painting that small desk) had an explosive significance reveals itself only as a "deferred realization" (Aikhenvald 2005, 202); that is, as the result of her diagnosis, which will take place several years later in the story. Once again, the author's source of knowledge is her *visceral knowledge* (Belling 2012), but this type of knowledge cannot be confirmed as real and credible by others unless it is reported as a *deferred realization*. Yet, its historicity gives validation to the reporting. Thus, only if presented as a deferred realization, then Wall's experience is reportable and credible (Labov 2008) because the reader has confirmation that the experience happened to be a true alteration of normalicy.

Another important observation I would like to make about the connection between the unprepared mind and the deferred realization is that, ultimately, the confirmation of her extreme fatigue is possible because Wall received the social sanction of the *voice of medicine* (Mishler 1984) that confirmed the diagnosis as ME/CFS.[3] As a narrative device, though, credibility is constructed by contrasting the protagonist's limited knowledge about the significance of her critical fatigue at that time, with the knowledge she gained as a deferred realization. From the readership perspective, at that early point in the narrative, the narrator still requires from the reader to take the author's

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[3]. The voice of medicine is a term used by Elliot Mishler (1984) in his foundational book *The Discourse of Medicine*. The *voice of medicine* is distinguished from the *voice of lifeworld* "representing, respectively, the technical-scientific assumptions of medicine and the natural attitude of everyday life" (14). These two types of "voices" underline different frameworks of meaning and contexts of interpretation; thus, the voice of medicine aligns with the constructs of biomedicine, as an ethnomedicine, and the voice of lifeworld with the everyday, common-sense knowledge of the patient.

words in good faith under the expectation that the significance of that punctual event will be disclosed later in the memoir, and it will be confirmed by a medical authority. So, the narrator creates anticipation by holding in suspense the logical explanation for her symptoms while the reader expects that a reasonable explanation will be provided eventually.

In further examining the internal evaluation in Wall's excerpt, another device is the use of the *frustrative stance* (Aikhenvald 2005, 392). The frustrative stance is a type of modality that simply indicates that the action was done in vain. Or I would add that the expected course of actions has been unfulfilled. If we imagine the actions of the story being placed on a temporal axe, then the protagonist's "pivotal moment" is placed by the narrator at the center, in the middle of her past and future. Considering the events that took place prior to the identification of her pivotal moment (e.g., she completed her MA coursework, *relished* the day as one of homey chores), these events are expressed by the simple past, and they show us a reliable window into Wall's life. However, on the temporal axe, we can identify narrative actions that convey potentiality, as her wishes and life expectations about the future, which have been probably unfulfilled ("I had only to take my M.A. orals and was set to plunge into the itinerant college teaching …").

Whereas the events that correspond to the story world did materialize (as expressed in the past tense), the evaluative comments that take a self-reflective stance convey doubt. Thus, the narrator shows a dramatic contrast between the potentiality of a bright future and what life turned out to be for Wall. The narrator's assessment comparing her certainty to be able to accomplish her life wishes ("I was as sure that I could make a go of it as I was that I could paint that desk") will turn out, in retrospect, to be rhetorically ironic: her illness proved that her self-assessment was wrong. The modal verb “could” is, ironically, expressing a *frustrative stance* (Aikhenvald 2005, 329): as we learn in the memoir she was not physically able to teach due to her condition.

Furthermore, if we adopt Bakthin’s (1981, 1986) concept of *dialogism* and *answerability* as elaborated in the previous chapter, in which all participants’ utterances are said in response to someone’s else utterances (present or internalized), then I suggest that the frustrative stance responds to an internalized skeptical reader. This skeptical reader may question the veracity of her report. However, the frustrative stance serves to appeal to the reader’s rationality: *Why would a person with so many aspirations about the future, want to cancel her plans if her reason had not been due to a real and debilitating disease?*

In sum, the close reading analysis of this brief excerpt shows the narrator’s use of several complex strategies to construct credibility. Comparators and intensifiers as represented by means of lexical and figurative language as well as grammatical devices; for instance, the alternation of verb tenses to convey the narrator’s different point of views or knowledges (depending on the time) as intertwined with the narrator’s self-reflections. These stances were mainly, initially, of shock and surprise characteristic of the unprepared mind. The unprepared mind gives account of the out-of-the-ordinary sense of fatigue that overpowered the protagonist in comparison to the level of energy required for the task. The first-hand, sensorial stance is emphasized by means of the figurative language but also by means of a sophisticated contrast between two epistemic stances (i.e., uncertainty as the lack of knowledge that the protagonist experienced at the time of the onset of her symptoms, and certainty as the knowledge that she gained retrospectively). Also, we observed that the frustrative stance serves to compare the protagonist's expectations about her future (at a vulnerable time in which she is about to complete her MA degree) and her current debilitating physical circumstances, which will be understood only retrospectively by virtue of the knowledge provided by her medical diagnosis of CFS. The next excerpt is from Floyd Skloot (1996), *The Night-Side*, also a ME/CFS sufferer. As we will see, the narrator in Skloot's memoir displays other discursive devices to construct credibility.

7.1.1.ii The Night-Side, Skloot (1996)

Excerpt 2

> I got sick on December 7, 1988, my personal "Day of Infamy." As Thanksgiving approached, I was 41 and *fitter than ever, running seven or eight miles a day at 5:30 AM. A serious competitive racer*, I *was winning ribbons* in my age group nearly every weekend in 5Ks, 8Ks, and 10Ks. Throughout summer and early fall, *I'd trained intensively* and broken personal records at every distance from one mile to the marathon. *I'd just completed a second novel and third chapter book of poems.* My new writing was appearing in magazines like Harper's, the New Criterion, Shenandoah, and Prairie Schooner. I was awarded a poetry fellowship by the Oregon Institute of Literary Arts and received a prize for my fiction … At work, where I was a *Senior Public Policy Analyst for a diversified energy corporation, I'd gotten a bonus and raise for my performance during the last legislative session and had been given new responsibilities.* It was common for me to be on the phone dealing simultaneously with questions on proposed legislation in Oregon, Washington, California, Montana, Idaho, *and* Wyoming*; people were waiting for my advice before acting.*
>
> On December 7, I was in Washington D.C. at an energy policy seminar. I woke up to run at 6:00 A.M. … but something was wrong. *The room reeked, as thought I could smell the odors of everyone who'd ever stayed there, and I was too exhausted to fold back the sheets. I felt dizzy and disoriented, ... Jet lag, I thought, this can't stop* me. So, I forced myself out of bed, had to concentrate in order to tie my shoes … I couldn't stay awake during the seminar. I had no desire for dinner … Back at the hotel, though deeply tired, I couldn't sleep …
>
> *Sudden onset, consistent with viral infection, is a classic symptom of CFS. The baffling speed with which my power was stripped—and never returned—remains shocking for more than seven years… It took till January 20 before I finally could not get out of bed at all. My body was shot, my mind was shot, and*

> *my head was so disconnected from my body that I still thought a couple of nights sleep would do. My family convinced me that this was more than flu to the fifth power. It took five months to get diagnosed with CFS.* (Skloot 8-9) (emphasis added)

This excerpt from Skloot (1996) corresponds to the orientation section and it presents the most reportable event: the day he calls “Day of Infamy.” As typical in the orientation section, the reader is oriented to the place where the story takes place (i.e., Washington D.C.) and the time where the event(s) took place (i.e., December 7) and the protagonist’s information (Skloot’s job, activities, and interests).

Skloot finds himself suddenly unable to physically perform according to the expectations of his normal routine (e.g., rising early, running, working, and having a social life). The elaborated enumeration of all his physical (e.g., his racing competitions) and intellectual achievements (e.g., his awards in poetry and writing) respectively is used rhetorically to contrast with his current shocking fatigue, which prevents him, on the one hand, to do the most seemingly physically unsignificant tasks (e.g., “too exhausted to fold back the sheets”) and, on the other, from remaining alert and attentive. The orientation also presents the assignment of blame and praise.

In this memoir, the narrator blames the infamous day (“my personal Day of Infamy”) (7), as it transformed him from a highly functional, reliable, and active individual, into a passive one, no longer reliable to complete his tasks, and who is not even aware of his own decline; for instance, his family has to alert him of his deteriorating physical state. Skloot’s understanding of his shocking symptoms that day will be gained retrospectively: Skloot was diagnosed five months later after that “day of infamy” (7) that marked his onset of illness, in the hotel in Washington, DC, on

December 7. In Wall’s memoir, we saw that the narrator also used a deferred realization to legitimize a biographical context. However, another strategy can be observed in Skloot, that is, *ventriloquizing*.

When the narrator asserts, “Sudden onset, consistent with viral infection, is a classic symptom of CFS” (8), we observe that legitimization of his symptoms is achieved rhetorically by shifting from the first-person position (e.g., “I got sick …,” “I forced myself out of bed…,” “I couldn’t stay awake during the seminar,” “I had no desire for dinner …”) in which the reader learns of his experience as a first-hand sensory information, to a third person position (“sudden onset … is a classic symptom”). This rhetorical shift ventriloquizes a (pseudo) medical voice that conveys his diagnosis. *Ventriloquizing* (a term attributed to Bakhtin’s (1981) translators, according to Tannen (2010) could refer to a person adopting the voice of another, or to a person who speaks through another. Also, according to Bakhtin (1981) as related to his concept of *dialogism* discussed earlier, ventriloquizing could be the expression of an internalized interlocutor’s message, or internalized belief. Tannen (2010, 402) adds another important concept; that is, that the ventriloquized utterance is a form of constructed dialogue that involves a change in the framing of discourse. In other words, ventriloquizing another’s voice cannot take place without causing a change of frame or a change in the speaker’s positioning and therefore, a change in the meaning of the utterance. One of the implications of ventriloquism, for instance, is the creation of the illusion of a discursive distance from the subjective perspective of the narrator. In Skloot’s memoir, the narrator ventriloquizes the voice of medicine in his own personal narrative as making an internal evaluation (“Sudden onset, consistent with viral infection, is a classic symptom of CFS,” 9). By means of ventriloquizing, the narrator informs his reader of his condition while, simultaneously, Skloot, the protagonist, distances himself from his audience as the subject of that diagnosis. As such, the narrator rationalizes and legitimizes Skloot's symptoms as medically and biologically validated by the voice of medicine. Also, Skloot, the protagonist, distances himself from that experience of illness by objectifying it and representing it in another's voice. By adopting a medical voice, Skloot's narrator is also shifting frames of interpretation by assuming another footing (or stance), as Goffman (1981, 128) has observed. In Skloot's memoir, the narrator's alignment with the voice of medicine foregrounds his experience as an objective medical experience rather than a subjective one, or even as an experience of imagined or hysterical sickness, as has been the case with Wall (2005).

Another example in which the narrator shows objective distancing is in the following excerpt in which Skloot evaluates ME/CFS: "[…] *I have an illness* for which there is *no cure or treatment*, an illness *so misunderstood* that it had been *virtually ignored* by most medical practitioner and researchers, …" (19) (emphasis added). Not only the narrator's use of intensifiers such as "*so* misunderstood," or "*virtually* ignored" can be validated by external evidence in documented research about the history of ME/CFS in the United States (see e.g., Johnson 1996, Shorter 1985) but also, it worthy to note that the narrator does not personalize his experience. In other words, he does not state that he has been misunderstood or his condition ignored, but rather his experience of being misunderstood and (virtually) ignored are objectified as *having* an illness ("I have an illness")—not as *being* his illness, as an existential statement. Linguist Suzanne Fleischman (2003) observes that the genitive construction "I have" "casts the pathology as an external object in one's possession" (491). In this case, Skloot's ventriloquizing strategy is the opposite from Wall's, who ventriloquizes the voice of medicine to criticize some medical practitioners from her experience, in the following excerpt:

Excerpt 3

> Increasingly you could find physicians who were politely tolerant. But there were still plenty of doctors who would … get that tense look on their face when you told them you had CFS: *'We know of no organic basis for this illness'.* Chronic fatigue syndrome was an *irritant*. It's so *blatantly unmedicalized, so subjective*, another one of those so called 'functional illnesses,' like irritable bowel syndrome, that have always *plagued* medical practitioners, presenting symptoms with no known cause. (Wall 9) (emphasis added)

In this excerpt, the narrator's selection of intensifiers, such as "irritant," "blatantly unmedicalized," "so subjective," "plagued medical practitioners" carry a higher emotional involvement that seem to reproduce Wall's own position, based on her personal experience with her doctors. In other words, the ventriloquized voice expresses what she interpreted her doctors to have said about CFS or believed CFS to be, rather than a general, objective assessment about the characteristics of the CFS in the United States.

In summary, I would like to point out that Skloot's most representative discursive strategy is the use of ventriloquism to legitimize his symptoms as conforming to an objective medical diagnosis (i.e., ME/CFS). This strategy also indicates an alignment with the medical voice, which seems to reflect a less attitudinal conflict than in Wall's case. Although there was a level of conflict as Skloot expresses in this statement, "About the only thing the medical practitioners seemed not to be doing was listening to me" (10), Skloot takes a stance in which he tends to align with the voice of medicine. I suggest here a few speculative explanations for the narrator's attitudinal disposition. First, Skloot was diagnosed relatively quick (i.e., in five months): “It took five months to get diagnosed with CFS. From January to May 1989, my former wife and I went to a half dozen doctors in search of an explanation for deteriorating health” (9). Although this statement expresses the narrator’s complaint about the waiting he had to endure, we can fairly say that in comparison with Wall’s experience (and other memoirists in this study) who spent years searching for medical answers, his waiting period can be relativized, even though the delay of five months was undoubtedly burdensome. Second, whereas Skloot had to endure “skeptical doctors” (9), I have not observed in his memoir any reference to his doctors treating his condition as “hysterical” or caused by “nerves.” Thus, this is another important difference that might have contributed to the narrator to align with the voice of medicine without major conflicts.

7.1.2 Lyme Disease Memoirs

If the most reportable event among ME/CFS memoirs is the out-of-the-ordinary and disconcerting level of fatigue as analyzed above, the most reportable event in Lyme disease memoirs cannot be reduced to the experience of one singular symptom. Lyme disease patients report a myriad of symptoms, including fatigue, and sometimes these symptoms may overlap with ME/CFS symptoms. Years of searching for medical explanations as well as enduring the treatment of their illness narratives as non-doctorable, characterize the journey of these patients. As Lyme disease mirrors other diseases, this adds to the level of complexity in diagnosing it. In analyzing the orientation sections from *The Widening Circle* by Polly Murray (1996) and *Bite Me* by Ally Hilfiger (2017), we will see that narrators draw on different sorts of strategies to construct credibility about their most reportable events.

7.1.2.i The Widening Circle (Murray 1996)

Polly Murray's narrative begins with the recollection of a punctual event in the past, the morning of "November 16, 1983" (4) when she drove from Lyme, Connecticut, where she was living, to Yale University Medical School in New Haven, to attend the First International Symposium on Lyme Disease.

Excerpt 4

> Early in the morning of November 16, 1986, I left my rural home … and made the sixty-minute drive to New Haven.… I knew every turn and dip in the road … I remembered how I had felt like a trespasser there as I timidly walked through the rotunda and down the stately hall, studying, as much as I dared, the impressive old portraits of eminent doctors and the display cases of antique medical instruments and journals. I had gone there in search of answers.… I had hoped to find some overlooked clue, some disease description that would mirror the symptoms I had—the mysterious rashes, the terrible fatigue, aches, swelling, and fevers. I was so tired in those days, so tired of asking, "What is the matter with me?" only to be told again and again that my symptoms fit no known disease. (Murray 1996, 3-4)

The recollection of this trip (chapter 1) constitutes the orientation of Murray's narrative. From a temporal viewpoint, the narrator begins the narrative cataphorically; that is, directing the attention forward to the end of her story and to the end of her illness struggles (including her struggles with the medical system that treated her symptoms as psychosomatic), instead of beginning with the onset of her illness symptoms. This is a stylistic difference from the other memoirs. Following Genette (1980, 40), we can say that the narrator tells us in advance, an event that will take place several years later in the story (i.e., prolepsis).

Murray's narrative decision has a rhetorical effect. The anticipated temporal reference to that trip serves as an evaluative contrast between her past of uncertainty while searching for an explanation to her handicapping symptoms, and her present experience of success, discovery, social recognition, and self-assertion. If the health condition that affected her for most than a decade was back then (i.e., before this conference event in 1986) unknown and unnamed, now—in the present of the narrative—she drives back to Yale School of Medicine to attend a medical symposium about a recognized disease entity: Lyme disease. If she had gone to the Yale School of Medicine before "in search of answers" to her question "What is the matter with me?" (4), now she hints to her readers that she has finally found an answer.

As observed by Labov (1997, 2013), contrastive temporality and negative devices serve to evaluate. The contrast between the narrator's use of past perfect e.g., "I had felt," "I had gone," "I had hoped" (Murray 3) and the preterit or past simple e.g., "I left my rural home," "I looked in my rearview mirror, as though to make sure those hard times were indeed behind me" (Murray 3) serves to evaluate not only two chronological periods of her life but also two emotional aspects of Murray's predicament in her story. The contrast is marked by the conditional perfect (i.e., if she had not fought for credibility and endured in her pursuit) and her successful present circumstances in having been invited at that historical symposium.

A second major validation to Murray's story, which constitutes the most reportable event, comes from the rhetorical question Murray received at the symposium by Dr. Malawista upon her arrival. "[I] turned around, pleased to see Dr. Stephen Malawista coming toward me. He was then professor of medicine and chief of rheumatology at Yale. I stood up to greet him. He shook my hand, welcoming me, and quietly said, "'*See what you started?'* … I felt overwhelmed" (Murray 4) (emphasis added). Malawista's question can be interpretated as a praise that offers a validation as a "quotative evidential" (Aikhenvald 2005, 392) or it is used as a reported evidential (Mushin 2001) to vouch for the fact of Murray's attendance to that conference but also as confirmation of her role as a patient who advocated for having her illness recognized as a disease. Thus, the credibility of Murray's story is validated by her first-hand experience as well as by the direct speech or quotative evidential of an expert in the field, who was a witness of Murray's attendance to the event (i.e., the International Symposium on Lyme Disease at Yale). For this reason, this is an objective event. According to Labov (1997), "narratives that report experience objectively are more efficient [in creating credibility] than those that report subjectively" (412). Next, I analyze the excerpt in detail.

The expression "I turned around" indicates the transition of temporal frames from one mental and emotional scene associated with her past struggles into a new time and scene, associated with her victorious present. Then the "turn around" expression indexes to the restoration of fortune, that is, from a past in which she felt doubted and morally injured given her doctors' belief that her "mysterious symptoms" were psychogenetic rather than biologically based, to a present of vindication asserted by Dr. Malawista's praise, that her suffering all those years was related to an insidious infection, which became known as Lyme disease. Thus, whereas the doctor's praise "See what you started?" has at that time an encoded meaning for Murray, the reader will only be able to understand the emotional significance that those words had for her after reading the whole memoir. It needs to be added that Malawista's praise is not only a vindication for the organic basis of Murray's disease but also a recognition for her persistence in having prompted the medical community at Yale to study the etiology of those symptoms.[4] For this reason, Murray became a crucial actor in the discovery of Lyme infection, despite not being herself a physician but a patient with no medical training.

Several contrastive elements are observed that reaffirm Murray's accomplishments, for instance: the contrast between "rural home" versus a prestigious school, the feeling of being a trespasser whereas now she is being "welcomed" into the symposium, and the contrast between being a busy mother with four children ("three of my four children were born in New Haven," Murray 3), who, nevertheless, took the time to become a Lyme activist for her community. For these reasons, following Labov (1997), I identify the doctor's praise to Mrs. Murray, "See what you started?" as the most reportable event (i.e., the event that has had the greatest effect in Murray's life story), consequently, the less common event (typically scientists and physicians rather than patients help discover new diseases).

In deciding to place, cataphorically, the event at the symposium as the most reportable event, the narrator sets the tone of her narrative: a story of personal vindication despite the odds and moral struggles she had to endure to be believed. From these initial pages, moving forward into the chronological unfolding of the story, the reader may wonder in anticipation: *What was Murray's involvement in the story of the discovery of Lyme disease that makes her the recipient of praise by one of the medical authorities in the field?* But before being able to answer that question, though, the reader has already been influenced to believe Murray's version of the story given the cataphoric, temporal

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[4]. Currently, it is acknowledged that Lyme disease is endemic to the Northeast of the United States where it has acquired epidemic proportions (see e.g., Johathan Edlow 2003)

order of the narrative, which foregrounds her successful present against her frustrating past of having been disbelieved or disregarded so many times.

The relevance of the most reportable event “See what you started?” can be better understood by comparing it with another chapter. Murray’s story could have started chronologically as in chapter three, where she states, “In the spring of 1956, when everything in my life seemed to be in bloom—I was pregnant with my first child; Gil and I were fixing up our tiny house; I was even taking sailing lessons—I began having an array of inexplicable health symptoms” (Murray 12). However, if the narrative had started in chronological order, it would have been more difficult to establish the credibility of the narrator from the beginning and persuade the reader of her reliability. For instance, the characterization of “inexplicable” as a modifier of the noun phrase “inexplicable health symptoms” would have only indicated the uncertainty of that statement and it would have emphasized the subjective basis of her experience instead of the objective, historical fact of the symposium. Then, by starting her narrative with a reference to the most recent past (e.g., the symposium), the once “inexplicable” symptoms are no longer a mystery. The reader already knows, now, that her affliction was caused by Lyme disease as a real entity.

In sum, the temporal emplotment of the narrative serves as a vindication of the power of her voice as a patient, and it places the narrator’s stance in alignment with the voice of medicine as equally important and as complementary; that is, as an essential allied that medicine must remember not to neglect again. Several discursive strategies have been observed in Murray’s narrative to build credibility: a metaphorical and contrasting effect between a past of uncertainty, loss of face, and moral injury, and a present of recognition and validation; the cataphoric emplotment, and the quotative evidential of a medical authority, who confirms the reality and veracity of Murray's role in the historical discovery of Lyme disease. Last, but not least, we observed the "mirative effect" of the unprepared mind, or surprising effect (Aikenvald (2005). Like Murray, the reader is not prepared to witness that Murray was going to be praised and honored by a distinguished doctor in the field. Because the reader learns about the sequence of the events at the same time the narrator/protagonist also learns about them (i.e., *simultaneous narrating* in Genette 1980, 217), credibility is more effectively achieved because it creates the illusion that the reader is witnessing the events in real time.

In conclusion, the use of these discursive strategies that I identified in Murray's narrative, aimed at achieving objectivity to gain credibility. As mentioned earlier (and, also explained in chapter six), the achievement of objectivity is according to Labov's (1997) a major requirement for the story to be credible. As he states, "Because it is generally agreed that the narrator's observation can be affected by their internal states, reports of objective events are more credible than reports of subjective events" (Labov 1997, 412). Whereas Murray, as a narrator, chose narrative devices that emphasized the objectivity of her story to gain credibility, not all memoirists in this study followed this path. As we will see next, Hilfiger's narrative does not seem to conform to Labov's observations about objectivity.

7.1.2.ii Bite Me (Hilfiger 2017)

Hilfiger's narrative begins like Murray's with the report of a punctual event, but her style will be different. The narrator reports about Hilfiger's mother remembering (and telling her daughter) about the time she found a tick on her daughter's "tummy" (xv), which suggests that Hilfiger was a child at the time that punctual event took place. The orientation section, where, according to Labov's theory, the reader should get information about time, place, and protagonists, starts in *Bite Me* with a negative first sentence, "I don't remember when I was bit. It might have been in the summer of 1991 or '92" (xv). Because at this point in the narrative (the very beginning), the reader does not know when the narrator/protagonist was born, it is unclear whether Hilfiger was a toddler or a young girl. This is a delayed knowledge that contributes to vagueness in the description of details despite its relevance. Only later in the narrative the reader will learn, in chapter one, that she was born in 1985, which indicates she was six or seven years old at the time of that event; that is, when a tick was found in her abdomen by her mother. But again, the imprecision remains. The narrator does not facilitate the information about her age in an explicit manner; instead, the reader must infer it. Another element of vagueness and epistemic uncertainty is that the tick anecdote provided by her mother is an incomplete story. Although Hilfiger's mother was able to tell her about the approximate years (1991 or 1992) in which the finding of the tick occurred, she was unable to tell her where the event took place because she did not remember it: "My mother does remember [the approximate dates], but she's not sure where it happened. It could've been on Nantucket, or in Bridgehampton, New York, or even in our yard in Greenwich, Connecticut, she thinks" (xv). In addition to the uncertainty of time, the narrator emphasizes the uncertainty about the place where the event happened despite several places being mentioned as options. The source of the information is Hilfiger's mother recollection, as a secondary source. However, while on the one hand, the mother's *reportative evidential* (Mushin 2001) vouches for the credibility of the event and legitimizes the story by drawing on an authority-figure, on the other, the recollection is imprecise and vague, generating doubt. As the narrator illustrates in the following excerpt:

Excerpt 5

> The tests came back 'inconclusive' but leaned more toward the negative side of the spectrum … (xv). *It's fitting somehow, though, that neither my mom nor I remember where the bite occurred and that doctors missed the correct diagnosis.* Lyme disease is as sneaky as it is nasty: About half of the people infected by Lyme are like me: They can't tell you when they were bitten. (Hilfiger xv) (emphasis added)

The reader may wonder what the reference of "fitting" is. The phrase, "it's fitting somehow" is ambivalent. In this excerpt, on the one hand, the narrator describes the uncertainty that Lyme patients, like herself, regularly face. They might have received negative tests, when in fact, they were infected. In this sense, "fitting" refers to the common experience of many Lyme patients whose symptoms were misdiagnosed, or their diagnoses delayed and, consequently, they experienced serious ill effects. In this manner, Hilfiger's narrator validates her experience as a comparable experience to many other Lyme patients. On the other hand, the meaning of "fitting" is used ironically: actually, there is no "fitting" given that no match was found between her blood test and the infection with the B. burgdorferi bacterium responsible for Lyme disease. The narrator generalizes that event in the epidemiological context that lab tests for Lyme are mostly fallible (at least at the time her test occurred), "Studies now find that some 50 percent of commonly used Lyme testing misses positive Lyme cases" (xv). However, although there is a margin of error in Lyme testing, it needs to be considered that not all ticks necessarily carry the B. burgdorferi bacterium (see Edlow 2003). Along with Hilfiger, we will never know for certain whether the lab test result she refers to in her childhood was correct or incorrect. However, the narrator's interpretation that she was misdiagnosed is sufficient to persuade us of its narrative truth as I shall explain. Because the orientation in *Bite Me* (a daring title that exhorts the reader and challenges metaphorically the tick to a fierce opponent) includes the most reportable event (i.e., the finding of the tick), the location of this complicating event in the orientation section suggests that the author contracted the Lyme infection at this time in her story, that is, in 1991 or 1992. However, as explained earlier, the narrator's assumption is not evidential; this tick might not have been the origin that triggered the chain of the events. It lacks material objectivity. Nonetheless, this is the moment that the narrator subjectively identifies as the punctual moment that marked the beginning of her illness journey. Thus, as readers, we take her narrative as "a commitment to a belief in the possibility," rather than as "a commitment to evidence" as Spence (1982, 275) reminds us. (xvi). Notwithstanding, the imprecision in the narrative construction diverges from the definition of credibility provided by Labov (1997), which is the belief that the events happened as the narrator describes them. Here, the narrator reports her interpretative inference as a fact, but it is not an evidential fact (for instance, her test could have been correct at that moment, and still she could have contracted the infection after that event); as readers, we take her narrative as the author's narrative truth, though. Spence (1982) explains that narrative truth can be defined as the criterion we use (as readers) to decide when a certain experience has been captured to our satisfaction; it depends on continuity and closure, and to its aesthetic finality. "Once a given construction has acquired narrative truth," he states, "it becomes just as real as any other kind of truth" (31).

Thus, in Hilfiger's narrative, credibility is constructed subjectively by establishing relationships of causality (e.g., tick, therefore infection) that are dubious, and, yet rhetorically effective. Objectivity does not seem to be a goal in this narrative, but plain subjectivity is asserted. She implores the reader, "Believe me. I know." Hilfiger's story about the time of her infection and the tested tick cannot be proved, but it cannot be disproved either. Therefore, there is always the benefit of the doubt. As Spence (1982) observes, we are less interested in the truth of the particulars than in a story that offers us an explanation that makes sense to nonsensical events.

In Hilfiger's memoir, reliability is challenged as a social value. Part of the author's positioning in adopting this challenging attitude could be found in the description of Lyme as a "thief" that not only steals one's ability to live a normal life but also one that "swipes your memories just as soon as you turn your back" (xvii). Therefore, the narrator's message could be to show that reliability is not a logical expectation when assessing and diagnosing contested conditions; reliability is not even a logical expectation when reading these memoirs.

In sum, the forgetfulness, the ambiguity, and imprecision of details that render the narrative of the events as unreliable, may be difficult to believe for a person who did not suffer from Lyme disease; however, it may be credible to a person who did experience Lyme or can identify with those sufferers. In fact, many readers may identify with Hilfiger's imprecision and inaccuracy. But, although factual details may be rendered inaccurate and unreliable, this does not necessarily mean the story is not credible or that it is not essential to her narrative truth as defined by Spence (1982). Thus, the discursive strategies used in Hilfiger's narrative indicate that vagueness and uncertainty, as associated with subjectivity, can also be used as a strategy to accomplish credibility, although not so in the sense defined by Labov (1997). The narrator challenges the need for reliability by being, precisely, unreliable, that is, by making a critical statement about the unreliability of medical science in detecting Lyme disease.[5] In this sense, Hilfiger's memoir seems to be more postmodern in comparison to the other memoirs.

In conclusion, from this analysis, one may derive that Murray and Hilfiger draw on different discursive resources and strategies to construct credibility. Although Murray's narrative adheres to Labov's observations of objectivity, it can be said that these strategies are more expected in a narrative whose communicative intention is mainly to educate physicians to listen to their patients' knowledge. The audience Murray must persuade might be convinced that she possesses valuable knowledge as a patient, if she uses the same resources of objectivity with which physicians are trained. On the contrary, Hilfiger's narrative is based on referential and linguistic vagueness as enacting and reproducing the effect of Lyme-associated symptoms. In so doing, Hilfiger's memoir seems to point out the futility in expecting patients' reliability as a denial of Lyme effects on patients. Thus, although both memoirs are about the experience of suffering from Lyme disease, they respond to different social expectations.

From the analysis of these narratives, one may assert that, in the end, the styles are influenced by the intended audiences. Yet, and according to Labov's (1997, 2013) thesis, because the more reportable an event the less credible it is, it might be the case

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[5]. Regarding the vagueness that medical science confronts in diagnosing diseases such as Lyme disease, the perspective of physician and epidemiologist Johnathan Edlow (2003) is illustrative and illuminating. Also see the film *Under Our Skin* by director Andy A. Wilson (2008).

that until a seemingly extraordinary event enters the socio-cultural background of common knowledge (as Lyme infection finally acquired a nosological category in 1975; thanks, in part, to patients like Murray), credibility will still be questioned, especially if the threat and risk of death is not imminent to the patient, regardless of her suffering and disability. Notwithstanding, narrators of contested illnesses, like Hilfiger's narrator, may continue to challenge, with the purpose to denounce, an order of things based on conceptualizations of objectivity and evidentiality by drawing on unreliable descriptions and vague spatiotemporal references.

7.1.3 Chronic Pain Memories

The memoirs in this category do not share a common medical condition. This category comprises a memoir about fibromyalgia, endometriosis, chronic headaches, and a neuroma on the left side of her vagina.[6] In their narratives, the onset of the experience of pain that is marked as a reportable event varies from the ways it announces or manifests itself. The initial event that triggers the chronic pain may be seen by the memoirists as uneventful, innocuous, and inconsequential. However, the complicating event starts when the normal expectation that the pain will resolve (either naturally or by medical intervention) is not fulfilled. For instance, one morning, Kamen (2005) puts her contact lenses as usual, but that day her eye feels on fire followed by a headache that gradually increases over time or reappears in intervals, thus, transforming the ordinary,

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[6]. "A neuroma is a benign tumor of fibrous tissues that grows directly on a nerve. It is caused by some kind of trauma to the nerve itself; it can be very painful and left untreated. Neuromas can progress into an uncommon but severely debilitating syndrome." (Ramey 2020, 385).

almost universal human experience of a headache into an out-of-the-ordinary event. Another onset of chronic pain may manifest as the sudden recollection of a repressed trauma, as in Berkowitz's (2015) case; or the triggering event may violently erupt while performing a daily routine with an acute and paralyzing episode of pain that requires a visit to the ER. In the memoirs in this category, it is interesting to observe that whereas the experience of pain may be the most reportable event, the narrator's evaluative stance constructs pain as the consequence of other factors rather than a cause of their condition.

7.1.3.i Tender Points (Berkowitz 2015)

Berkowitz's (2015) illness narrative about fibromyalgia and vulvodynia is written in non-chronological order. There seems to be no storyline. Each page presents a temporal disconnected new entry as a book of poetic prose: "I have fragments. I remember it was cold. I remember more or less what the doctor said.… But I don't have the complete narrative. And so, the black holes in my memory become part of the story. I mean, they are the story" (69). Behind that apparent disconnection, however, there is a plot. The reader can infer the narrator's relations of causality; that is, the narrator's evaluation as her explanatory model (Kleinman 1985) for her present illness: "My Body is Haunted by a Certain Trauma …" (69) (sic). Thus, sexual abuse is suggested as an evaluative cause of the most reportable event: chronic pain.

Excerpt 6

> My body is washing dishes and it's in pain. My body is on hold with California Blue Cross Blue Shield and it's in pain. My body is dancing and it's in pain. My body is…taking a shower and it's in pain. … My body is politely saying no and it's in pain. My body is reading a book and it's in pain. My body is writing this and it's in pain. My body is walking to meet you and it's in pain. (*Berkowitz* 128)

The source of evidence for the narrator's credibility of her symptoms is her subjective, interoceptive experience; that is, her direct perceptual experience. Because, unlike electricity, experiences of pain are untransferable; to gain credibility the narrator must convey that experience of pain through language. Several rhetorical devices are observed to be combined for effecting this goal. First, a series of actions, such as "reading," "writing," and "walking" are enumerated and ordered from the mental realm to the physical one, as conveying progression and a sense of transition. Second, the effect of the enumeration is amplified by the repetition (or epanalepsis) of the same words, at the beginning and end of each sentence ("my body is … and it's pain"). This evokes an iteration that becomes physical and sensorial in the reader's ear. The iteration evokes a complaint or a lament that gets closer and closer to the reader, in the very same act of reading the passage. This effect creates the illusion of breaking the barrier between the story world and the reader's world to persuade the reader of the existence of her pain while transforming the reader into her witness. The narrator's rhetorical strategy to transmit her sense of pain becomes more relevant when we bear in mind that although in pain, Berkowitz's life might not be at risk. Thus, the challenge to be believed is even higher. As David Morris (1991) observes in his book *The Culture of Pain*, "chronic pain is invisible in large part … because it is commonplace and nonfatal" (66).

Although as mentioned, in *Tender Points* there does not seem to be a storyline; there is an evaluation section associated with the most relevant event. I identify the following excerpt as the evaluation:

Excerpt 7

> The story of my pain is not an easy story to tell. And I'm not talking about the emotional difficulty of telling it; I mean the plot itself is confusing. Trauma is

> nonlinear. There are flashbacks and flash-forwards. And my story is a story about forgetting. Forgetting is one of the main protagonists; in fact, he may be the hero. Forgetting swoops down on a rope to rescue me right after my rape. He holds me with his free arm as we swing back to safety, saying, 'You can't handle this right now, but you'll remember when you're 23, and you'll have better psychological defenses then, and a good therapist.'… If Forgetting is the hero of the story (which is assigned a masculine gender), the reader wonders who Memory is. And what happens to Memory in the end? (45).

One interpretation of the narrator's evaluation is that the relevance in writing about her illness experience may be found in the narrator's dialogue with Forgetting, written with capital letters as if it were the first name of an animated protagonist (i.e., prosopopoeia). In this dialogue, the narrator acknowledges that writing about trauma, as her own explanation for her fibromyalgia, is not easy, precisely because trauma defies narrative coherence and language. As the narrator asserts in another entry, "I have fragments, I remember it was cold. I remember more or less what the doctor said. I remember the waiting room had a TV. But I don't have the complete narrative. And so, the black holes in my memory become part of the story. I mean, they are the story" (69). Thus, while forgetting the main culprit of her traumatic experience may provisionally help her to get rid of the past, the body cannot be fooled into forgetting; the body does not have a narrative, but it remembers the traumatic past. The narrator's dilemma is the lack of linguistic resources to articulate it, as Elaine Scarry (1985) has argued in her well-known book *The Body in Pain*. Paradoxically then, the memory needs to be reshaped by narrative, i.e., by a narrative structure that gives shape to the traumatic experience by representing it by means of writing (see Charon et al 2017).

Given that in Labov's (1972, 1997) theory, the evaluation reveals the point of the story, and why the story is being told, the point of Berkowtiz's memoir is to show that, paradoxically, remembering a traumatic experience is a narrative problem: trauma cannot be easily put into a linear, narrative storyline. Yet, remembering can only be realized by the act of narrating; that is, by the act of constructing a narrative that may not be a truthful reproduction of what happened, but her interpretation or rather her creation. I return here to Spence (1982) who explained this phenomenon in an eloquent way, "Once we conceive of interpretations as artistic creations that have the potential of producing an aesthetic response, we are, …, less interested in the truth of the parts" (276). To construct credibility then, Berkowitz's narrator must reproduce the vacillations, memory gaps, changing reports, flashing images and uncertainty of trauma by means of effective rhetorical devices.[7]

Indeed, in Berkowitz's memoir we find, for instance, *contradictions* about her age across the memoir, "I'm 21 years old and I feel like I'm 50. … I am only 22 and I feel like I am like 60… I feel like I'm in my 80s, but I'm only 46" (43). We also observe the adoption of *antagonistic voices* against the ontological reality of fibromyalgia. "I have to deal with these nutcases at work and I flat out call them fakers to their face. They need to get up off their lard-asses and get a job. They're just whiney people who love to be 'sick.' (41). The "I" subject in this line voices Berkowitz's sarcastic response to comments she might have heard or received in a working place environment. She is the referent of the "whiney people" who missed job days because they "love to be sick" (41). Her

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[7]. Although it can be argued that imprecision and vagueness are discursive characteristics shared by memoirs or autobiographical writing, I claim that they are intentionally crafted as part of Berkowitz's rhetorical style.

ventriloquism is then a stance of denunciation and resistance against those who are uneducated about fibromyalgia.

Another rhetorical device frequently used by the narrator of *Tender Points* is *repetition of words and variations* of the core same sentences. For instance, we find a repetitive variation of the rhetorical question, “Why were we alone in the exam room?” in different entries in the book (see pages 51, 53, and 106). The question refers to Berkowitz’s traumatic memory of being sexually abused by a doctor in his office. The pronoun “we” refers to herself and her doctor in the room. The variation of the same rhetorical question slowly clarifies the hidden logic of memory: “Why were we alone in the exam room? That’s the question that trips everything up. The hole in the story (the story is a hole).” (51). “Why were we alone in the exam room? That’s the question that trips everything up. The hole in the story/That makes people doubt me/Or does it just make me doubt” (53). “I ask myself why we were alone in the exam room /I ask myself why we were alone in the exam room?” (106). The use of repetition could have several meanings: Is the question repeated because the abuse happened more than once? Or is the question repeated as it is repeated in her mind as an invasive thought for which she cannot find a logical answer or explanation. Ultimately, the repetition has a mortifying tone and ambiguity has a physical and material or corporeal effect.

Whereas the source of information is Berkowitz’s own first-hand experience, the frustrative stance stems from her own recognition that events happened in a way that challenges normal expectations or routines. For instance, typically a nurse or a parent is present when a young girl is in the doctor’s office. The repetition emphasizes the interruption of the out-of-the-ordinary event into the normalized ordinariness of how things should be. Although chronic pain is the most reportable event, the narrator's stances and evaluations reveal that the most troubling aspect is our human incapacity to accept the reality of the unexpected events as a normal probability. Consequently, if this is difficult to accept for the protagonist/narrator, then the same applies to others: "the hole in the story that makes people doubt me/Or does it just make me doubt" (53). The repetition pragmatically informs the frustrative stance. Nevertheless, and despite this doubt, I suggest that the narrator in Berkowitz's memoir constructs credibility by showing us how her story cannot move forward. The holes are emotional and narratological ones, but she embraces them by reproducing them rhetorically.

7.1.3.ii Ask Me about My Uterus. (Norman 2018)

Norman's (2018) illness narrative is about endometriosis but also about the experience of chronic pain, and ultimately is a story about her own resilience. The initiating event can be identified in the prologue. Norman experienced an episode of excruciating pain when she was nineteen years old. At that time, she was an undergraduate student attending the college of her dreams in New York City. After two visits to the ER with no specific diagnosis, in her second visit, a physician tells her that he suspects she might have an ovarian cyst. This diagnostic hypothesis is later confirmed by a gynecological surgeon in Maine, upon her return to her home state after withdrawing from college. In Maine, the surgeon who drained the cyst "larger than … the fimbria of [her] left fallopian tube" (39) also observed endometriosis on the wall behind Norman's uterus. However, some months later after her surgery, she starts experiencing new symptoms:

Excerpt 8

> For one thing, the pain was extremely specific. The vague stomach and chest pain that come from panic and anxiety *were nothing like* the persisting, pulsing ache that seemed to have taken up residence between my midriff, hip bone, and lower back. The dizziness and nausea that came from nerves *was nothing like* the sudden, breathtaking nausea that overtook me after just a few bits of food … And the exhaustion *was like nothing I had ever experienced in my life.* I also became unusually prone to spilling things or knocking things over or running into walls. (Norman 125) (emphasis added)

According to Radley and Billig (1996), quoted in Figueras Bates (2018, 98), the description of symptoms is an effort of legitimization or a *rhetorical warrant* that serves to confirm the narrator's *direct evidential*; that is, "an evidential which covers speakers' own sensory experience" (Aikhenvald 2005, 392).[8] In this description about her new symptoms, the comparative expression "[this/these symptoms] were nothing like," marks a contrast between, on the one hand, the symptoms associated with anxiety and nerves and, on the other, these most recent physical symptoms whose etiology is still unknown to her at that moment in her story. The second term of the comparison is specifically described, for instance, "persisting, pulsing ache" and "sudden, breathtaking nausea" in comparison with the symptoms that Norman associated with emotional or psychological etiology. As observed, these rhetorical warrants emphasize not only the ontology of her symptoms but also, I suggest, following Bakthin's (1981) concept of *answerability*, they anticipate and respond to biomedicine's skeptical view that would merely explain these types of symptoms as psychogenetic or as form of hysteria.[9] Later, Norman reports her

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[8]. Any social order requires legitimation—a widespread acknowledgement of the legitimacy of explanations and justifications for how things are and how things are done. Much of the work of legitimation is textual …. Textual analysis can identify and research different strategies of legitimation—by reference to authority or utility, through narrative and so forth (see Fairclough 2003).

[9]. Bakhtin (1986) has observed in his concept of *answerability* that all statements are a response that anticipate the speech of others. Any speaker is himself a respondent to a greater or

physician’s explanation to her symptoms, “You were probably molested as a child, and this is just your body’s way of trying to handle it” (127) using a direct quotation as evidential.

The contextual background reporting the disbelief she experienced, serves to highlight the most reportable event: Norman will research her own symptoms despite not having any medical training and will prove her doctor to be mistaken. In fact, Norman discovers that her persistent, new symptoms (despite her previous surgery), are associated with her endometriosis as possible chronic appendicitis. And again, when Norman presents her research hypothesis to her doctor, he doubts her, “You’re either brilliant or the most well-educated hypochondriac I’ve ever met, he said, shaking his head lightly” (184). However, this time, she persuaded him to do a laparoscopy, to which he agreed under the warning that she would be discharged from his clinic if her hypothesis was not confirmed. Norman did have endometriosis tissue attached to her appendix; thus, her hypothesis was correct and, this time, her doctor acknowledged, “You were right” (184) as a *quotative* evidential (Aikhenvald 2005). Notwithstanding, as if reporting her doctor’s words would not be sufficient evidence, she clarifies: “It wasn’t just that it was my appendix, though. It would need to be confirmed with pathology” (184). Then, a third party, that is, the anatomy pathology analyst, confirmed the doctor’s clinical observation during surgery.

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lesser degree. He is not, after all, the first speaker, the one who disturbs the eternal silence of the universe. The speaker presupposes not only the existence of the language system he is using, but also the existence of preceding utterances—his own and others’—with which his given utterance enters into one kind of relation or another (builds on them, polemizes with them, or simply presumes that they are already known to the lister). Any utterance is a link in a very complexly organized chain of other utterances.

From the prologue, Norman's narrative argues that her pain was treated as hysterical and that even herself, at a certain point, considered the possibility that she suffered from conversion disorder. Another predominant discursive device in Norman's narrative that functions as a legitimator to construct credibility is the use of *intertextuality* in which, stories of other women (e.g., autobiographical, historical, and also mythological) serve to substantiate her own story with endometriosis as treated as a hysteric symptom, and as part of a cultural pattern toward women's health issues.[10] I follow Tannen's (2007) definition of intertextuality as involving the "notions of relationality, interconnectedness and interdependence in discourse" (8) and also Fairclough's (2003), "how texts draw upon, incorporate, recontextualize and dialogue with other texts" (17). To counter-argue against cultural constructions of hysteria in women who had been misdiagnosed, Norman reviews the story of renowned cultural figures who represent intellectual authority to legitimize her own account. One example of these memoirs is the publicized case of the late Gilda Radner (1946-1989), self-reported in her memoir *It's Always Something* (1989). Radner was a famous American comedian who died of stage IV ovarian cancer after experiencing a myriad of symptoms for almost a year that were treated as stress or nerves; symptoms like those experienced by Norman although the etiology of her symptoms was different. Another example is the case of Karen Armstrong. Armstrong is a British author of several books about religion and a recipient of several awards. For years, she suffered from undiagnosed epilepsy and

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[10]. The term intertextuality is usually assigned to Bakhtin. However, the term was devised by literary and cultural critic Julia Kristeva in her introduction of Bakhtin's works to Western readers (Tannen 2007, 11).

was prescribed psychoanalysis. In her memoir, *The Spiral Staircase* (2005), Armstrong reports how her symptoms were treated as psychosomatic, although an encephalogram was not prescribed to exclude epilepsy until much later.

In addition to referring to these memoirs, the narrator in Norman's memoir insists on struggling against the stigma of hysteria by reviewing Sigmund Freud's famous cases studies such as Anna O and Dora as well as on the myth of Cassandra, who was cursed to foresee the future without being believed. Because of the extensive use of illustrative cases about and against hysteria, I suggest that, in this memoir, intertextuality is used as a form of *overcorrection* or *hypercorrection*.[11] In other words, the overuse of cases is a frustrative stance against, on the one hand, the *testimonial injustice* (see Fricker 2007) experienced by women when they describe or report vague health symptoms to their doctors, and on the other, against the socio-cultural belief system that promotes testimonial injustice.

In sum, although Berkowitz's and Norman's memoirs deal with symptoms of chronic pain, their discursive and narratological approaches are very different. In Berkowitz's memoir, the most reportable event is her pain. Her trauma in childhood serves as an evaluative stance that explains the etiology of her illness. In Norman's memoir, however, the most reportable event is her correct self-diagnosis over her doctor's disbelief and distrust. However, in Norman's memoir the narrator self-

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[11]. I borrow this term from linguistics in which a form is overused beyond the norm or standard to produce a style that could be described, although ironically, "as more correct," but rather reveals the speakers' self-consciousness or insecurity about the actual norm (see Holmes 2001, 241).

downgrades her own story to a self-effacing evaluative comment, “I had never wanted to be right, only to be well” (184). This comment is a stance that implicitly anticipates (and responds to) a potential cultural criticism: *how could a young woman, with no medical expertise, challenge the authority of her male doctor?* It seems that a conventional way to report this information—and be credible—is by downplaying one’s own educated guess, at risk, otherwise, of sounding pretentious and, therefore, unreliable. Furthermore, it is interesting to point out that whereas Berkowitz’s memoir uses her sexual trauma as an explanation or illness narrative (i.e., her sexual trauma), Norman rejects that explanation from her physician as a non-scientific, biased, medical explanation toward women’s health issues: To her doctor’s comment “You were probably molested as a child, and this is just your body’s way of trying to handle it”(127), Norman replied: “I raised an eyebrow in contempt—surely the seat of my emotional discontent would not sequester itself to a single organ [the uterus]. And even if it had, perhaps this was not the time or the place to bring it up. Certainly not quite so casually.” (127-128). In the next section, I analyze *Chemical Crisis* by Diana Crumpler from the Miscellaneous category.

7.1.4. Miscellaneous

7.1.4.i Chemical Crisis: One woman’s story, humanities' future? (Crumpler 1994)

Chemical Crisis narrates Diana Crumpler’s struggles dealing with enigmatic symptoms through the 1970s and 1980s, that plagued her and her young family (her two children and husband) during years, while living in different rural areas in Australia and taking care of a farm. Crumpler’s young children struggled with allergies, hyperactivity, learning disabilities, among other symptoms, and she herself, also suffered from a myriad of symptoms, as I will illustrate.

Whereas most of the memoirs I have analyzed here present a clear initiating event or most reportable event, it has been difficult to identify an initiating event in Crumpler's narrative. The reason, I speculate, is that although it can be argued that the most reportable event is the experience of disconcerting symptoms, these symptoms, however, are not reported as a punctual action in the past in which the narrator suddenly realizes that something is seriously wrong with her health. Instead, the symptoms are reported as a progressive realization that seem to have taken time to acknowledge as an illness:

Excerpt 9

> Weird sensations *came and went.* Food would suddenly *taste vile.* Pain would stab up my legs as *if steel rods were being hammered up my bones.* My throat was forever sore, my lymph glands tender and swollen. Tingling, burning, and numbness developed in my hands and feet, and my *skin crawled* as if invaded by a million ants. Strangest of all was a *crazy feeling*, like *ice melting and trickling* deep into my brain. I went shopping in winter in shorts and a T-shirt and shivered on a summer's day … 'Mum needs a new thermostat,' the boys joked. Later we were to realize how prophetic that comment was. (Crumpler 25) (emphasis added)

In the excerpt we can observe a sense of progression or perfective aspect that indicates that Crumpler became aware that she was ill in a progressive manner. For instance, some conjugated verbs in the simple past (e.g., "sensations came and went") convey, thanks to the coordinating conjunction, a sense of iteration and an imperfective aspect of progression. Other actions such as, the legs felt as if "steel rods were *being hammered* up my bones" (i.e., the use of the past progressive indicates the verbal aspect of an ongoing action) as well as the gerund forms in "ice *melting* and *trickling* deep into my brain." These actions indicate duration and progression; for that reason, they are not typical of a sudden realization of a drastic change of state from health to sickness.

As analyzed earlier in Wall's description of her fatigue, Crumpler's source of knowledge is her own subjective, interoceptive experience as a "direct evidential" (Aikhenvald 2005). And, like Wall's description, the narrator in Crumpler's memoir uses figurative language to account for experiences related to her sense of tact (e.g., "skin crawled") and taste (e.g., food would "taste vile") to convey the ontological reality of her pain. However, as mentioned earlier, these sensations and symptoms are not presented by the narrator as her sudden realization of the onset of an illness as in the case of other memoirists (e.g., Wall, Skloot). It seems that Crumpler's awareness of being sick comes later with time when she was forced to quit her job as a librarian. The deferred realization about her need for a "new thermostat" (25) would prove to be correct as she was diagnosed some years later with "environmental illness" (46) by an allergist doctor, whose diagnosis, at the time, was not seen as a conventional to mainstream medicine. Crumpler would later learn that the family farm was set on pesticide-contaminated land, and her symptoms and her children's symptoms were all related to "environmental illness" (46) or multichemical sensitivity (MCS), as it is commonly known. As she noticed in her daily activities, she was developing a chemical sensitivity to a variety of products, but later this sensitivity evolved into a "chemical intolerance" (53) to all sorts of chemicals such as plastics, cloth fibers, and food.

Crumpler's struggles, however, were not only related to dealing with the symptoms of her illness. She confronted resistance at different fronts; for instance, within her community and with neighbors, who did not believe that the fumes of industrial waste affected her. When Crumpler's husband offered a neighbor to throw his industrial waste for him in their own bin if that would prevent him from burning the plastic, the man replied, "Affected by plastic!" I've never heard the likes of that one. She's … crazy" (47). Also, like the previous memoirs, Crumpler's doctors did not find any physical ailment and diagnosed her condition as caused by "nerves" (28, 34) or "stress" (173). However, Crumpler neither personalizes her doctors' resistance nor makes it a gender biased issue such as we saw in the previous memoirs written in the United States. Instead, Crumpler transforms it into a general statement that advocates for the need of medical science to pay attention to individual cases like hers and to learn to recognize when it is the time to diagnose inductively rather than deductively.

Excerpt 10

> Orthodox diseases generally conform to accepted rules. *Doctors are secure in the knowledge that they know these rules and may simply refuse to accept that a common condition of special sensitivity can be represented by such diverse, individual symptoms.* While the concept of environmental illness is so deceptively simple that most doctors refuse to consider it, the practicalities are so complex that most cannot accept it. *If every sensitive person developed hyperactivity as a reaction to apples … life would be simpler for most doctors and their patients. Unfortunately, it does not happen like this.* Just as we all have different fingerprints and a different genetic imprint, so do we react differently to environmental incitants. (46) (emphasis added)

In this excerpt, the narrator makes a statement that implicitly compares the preference of doctors for acknowledging symptoms that are associated with an already nosologically established condition, and their reluctance to treat patients who present vague symptoms, like those associated with MCS, that are not easy to match with a particular disease. In addition, the narrator's statement points out to the challenge that diagnosing conditions such as MCS present for physicians. Although this statement is voiced in a less personal manner and by establishing some emotional distance, we can observe the narrator's sympathetic stance in alignment with the medical community. The narrator acknowledges the problem, "If every sensitive person developed hyperactivity as a reaction to apples …"; that is, that conditions such as MCS could be triggered (or not) in various ways among different people, and different people may react to the same chemical exposure by presenting different symptoms. Consequently, it seems that in this excerpt Crumpler shows sympathy to the fact that contested conditions such as MCS seem to challenge medical standards on how to define certain diseases, and to physicians who may struggle when these medical standards become uncertain. Furthermore, the use of the disjunction "unfortunately" in the sentence, "Unfortunately, it does not happen like this" (46), aligns the narrator with the medical community, although critically.[12] Because a disjunction is a "conjunction with an attitude" (Thompson and Zhon 2001, 124), the disjunction "unfortunately" also reminds the medical community that they need to pay more attention to individual cases and listen to the patient's narrative. The type of sympathetic although critical message that Crumpler conveys by illustrating this problem with her own narrative, has been analyzed theoretically by authors such as rheumatologist, Aaron Aronowitz, in an essayistic way. Aronowitz (1998) asserts that in the current practice of medicine, clinical approaches based on listening to the patient's narrative are "underdeveloped and undervalued" in favor of "objective data" (4), despite being the best ways in which physicians may learn what is best for their patient. Thus, as we will see, Crumpler's critical statement has the purpose to advocate for patients'

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[12]. According to Geoff Thompson and Jianglin Zhou (2001), "disjunctions are adverbials such as *unfortunately* and *obviously* which are traditionally seen as expressing the writer's comment on the content or style of the sentence in which they appear." (123) (emphasis in text)

narratives as a way to change the medical ways in which new illnesses and conditions are being recognized and accepted as disease categories.

On the one hand, it can be asserted that Crumpler's excerpt comments on the *testimonial injustice* that patients with MCS, like her, may experience given that their symptoms do not easily fit into identifiable, disease categories. However, on the other hand, Crumpler's critique (and for that reason, one of the main purposes of her memoir) is to claim for the recognition and acceptance of illnesses, such as MCS, that have not been recognized as legitimated diseases. As discussed in chapter three of this dissertation, medical institutions may propose disease categories. However, what sort of afflictions are considered doctorable and what type of suffering remains nameless and silenced is part of a social process that is the "result of [social] negotiations among the different parties with a stake in the outcome," asserts Aronowitz (1998, 3). I argue here that illness narratives form part of this social process that seeks for the vindication of certain illness experiences to be acknowledged and accepted as *doctorable conditions*.

To show the reliability of her argumentation, we observe that the narrator draws on *intertextuality* by providing numerous examples from the history of science. By means of intertextuality, Crumpler compares her personal case of environmental illness, treated as nonsensical, with examples from the history of medicine, which were dismissed and resisted at first, but have shown for centuries to ample benefit humanity. We can consider these historical cases as a form of *reported evidence* that give her credibility. The use of intertextuality is similar to the way Norman drew on the example of famous authors' memoirs to counter argue against her condition as being characteristic of hysteria, as it was evidenced by those memoirist cases. Crumpler reviews, for instance, the case of

British biologist and physician Edward Jenner (1749-1823), who promoted vaccination against smallpox in England, based on his direct observations that people who had contracted cowpox were somehow protected against smallpox. Although Jenner's practice of vaccination was initially resisted and mocked, it has become a standard practice of modern medicine to vaccinate populations to acquire immunity and protection against infectious diseases and viruses.[13] Another scientific text that Crumpler mentions to build support for her cause, is Rachel Carson's best seller *Silent Spring,* published in 1962 about the contamination of the environment with chemical pollutants. Whereas Carson encountered high resistance and critique from chemical corporations, her research also raised environmental awareness about the danger of chemical toxics. In considering these examples, Crumpler adopts a stance in alignment with medical science, despite having suffered disappointments with several physicians who treated her condition as psychosomatic, or as a synonym of imagined symptoms.

Finally, I would like to provide a last excerpt from Crumpler that in my view best illustrates her message about biomedicine's need to pay attention to patients' individual narratives to contribute to a more humane practice of medicine.

Excerpt 11

> As for myself, while I have restored my self-respect, my sense of ego has virtually disappeared; no longer as a result of humiliation and derision, but as a

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[13]. Our present history under the Covid-19 pandemic shows us that resistance against vaccination persists today. Although vaccination is embraced by the medical and scientific community, it is not universally embraced by all sectors of the population despite the evidence of its effectiveness to reduce risk of death.

> part of the oneness that I have come to feel for all that is. *What happens to me personally is immaterial in the greater scheme of things. What has happened to me, in medical terms, however, is very important.* (311) (emphasis added)

In this excerpt Crumpler teaches her readers that the point is not her individual story for the sake of her individual destiny but rather, the point is that her individual case is illustrative of an affliction that can affect humanity and what medicine can learn from her experience. Thus, her individual experience might seem insignificant but, it is that individuality what can warn humanity of the devastating effects of multichemical sensitivity. In this manner, in Crumpler's memoir credibility is paradoxically achieved by humbly forsaking her personal story (i.e., attention on the self as the protagonist in her memoir), to become one case study representative of the effects of environmental illness on humanity. Considering her individual case as a source of knowledge means the need of considering all contested illness cases as potential new diseases that require medical attention. Like Murray's memoir discussed earlier, Crumpler's has a didactive intention: her suffering will be of value to others, especially to medicine in order to change its reaction and attitude toward what is unknown.

7.2 General Observations

Seven selected memoirs have been closely read, applying narrative analysis drawing on Labov (1972, 1997, 2008, 2013) and evaluation and stance analysis (Aikhenvald 2005; Mushin 2001). The analysis focused on the orientation section of each memoir where, either the initiating event or the most relevant event was identified, followed by the analysis of the evaluation of the most reportable event. As previously discussed, (see chapter five), all the narratives draw on diverse discursive and narrative devices to construct credibility and reliability. I summarize here some rhetorical and narrative devices observed in these memoirs.

All memoirs orient to construct credibility, although narrators may do so in different ways. Memoirists hold two principal reasons for constructing credibility. First, as narratives they must resolve the tension between reportability and credibility, that is, they must resolve the reportability paradox, as discussed in chapter five. To hold the attention of their readers/listeners, memoirists must orient to rational and reliable explanations for their out-of-the-ordinary experiences. As Labov (1972) has famously said, all narratives are told with a point. Second, as sufferers of contested illnesses, narrators are challenged to show the doctorability of their claims about their illness to enter the sick-role and gain access to treatment (see chapters three, four and six). These two reasons intertwined in the narratives. Considering the close reading analysis of these seven memoirs, I observe here that to gain credibility, narrators display their source of knowledge about their illness experiences in two major ways by drawing on: *first-hand source* and on *second-hand source* of knowledge.

7.2.1 First-Hand Source Knowledge is based on the narrators' interoceptive perceptions about their bodily experiences with illness and their subjective claims about their illness experiences, including their subjective experiences about their encounters with their doctors. Rhetorical and narrative devices such as figurative language, intensifiers, repetitions, and comparators are associated with first-hand knowledge and they can be observed in the narrating of the most reportable event, in the evaluation sections or in connection with both, given that they are not always strictly divided.

In the analysis of the first-hand source of knowledge, I distinguish between those narrators' evaluations about their illness experience and those evaluations about the most reportable event or the complicating event. This distinction is important because not all narrators have identified the most reportable event as the onset of their illness:

- 7.2.1.(a) Evaluation of illness experiences, such as description of symptoms by means of figurative language, intensifiers, repetitions, and comparators.
- 7.2.1.(b) Evaluation of the initiating or most reportable event: the narrator's evaluation and stance about their own experience of illness and their doctors' reactions by means of the visceral stance or direct evidential, the mirative stance, frustrative stance, and the use of conditional and hypothetical verb tenses as well as imperfective aspect. Below, I summarize the findings for each sub-category. (See also Appendix B).

7.2.1.(a) *Evaluation of illness experiences*: The description of symptoms has been presented as a *rhetorical warrant* (see Figueras Bates 2018) that affirms and legitimizes the ontological existence of their illnesses, as we saw in the memoirs of Wall, Skloot, Norman, and Crumpler in particular. In the description of symptoms, some narrators, such as Wall, draw on *figurative language* by means of metaphors and synesthesia which contributed to convey a sense of materiality and corporality, thus credibility. I also argued that, on the one hand, figurative language may serve to normalize out-of-the-ordinary experiences. Figurative language tends to be perceived as illustrative and non-real; thus, it may be seen as less threatening. However, figurative language is embedded in conceptual systems that are based on our bodily experiences and cultures;

consequently, capable of creating new linguistic conventions (see Lakoff and Johnson 1980) that, in turn, may give voice to the experience of being sick. Figurative language serves not only to understand the experience of being sick with a contested condition, but it also creates knowledge; figurative language has an epistemic value, as observed by neuroscientists Samuel Moulton and Stephen Kosslyn cited in Starr (2015, 249).

Another rhetoric device observed in the description of symptoms is the use of *intensifiers.* Intensifiers are lexical expressions, such as adjectives or adverbs that function to enhance or heighten the narrator's stance or point of view. But we need to bear in mind that intensifiers work in any direction, either favoring a negative or positive pole. Thus, narrators can use intensifiers to either neutralize a stance, such as in Skloot's memoir in his description of CFS (see excerpt 2) in which he adopts the voice of medicine; or narrators can use intensifiers to animate the patient's visceral or experiential stance, which serves to establish an implicit critique toward biomedicine, as in Wall's (see excerpt 3). Repetition can be a pragmatic form of repetition.

Repetition is another rhetorical device observed in the reporting of the initiating or most reportable event. According to Labov (1972), repetition can be rhetorically used as intensifiers as well. The most illustrative example of repetition is observed in Berkowitz's memoir (see excerpt 6). As discussed, repetition also creates a physical and sensorial experience in the reader's ear that reproduces the narrator's frustrative stance in coming to terms with the circumstances that led to her traumatic experience, which she identified as eliciting her fibromyalgia.

As explained in chapter six, comparators compare the events which did occur with those which did not" (Labov 1972, 381). Labov identifies functioning as comparators not only comparative adjectives, as the comparators par excellence, but also verbs in the future and imperfect tense, negatives, questions embedded in the action, and modal verbs. Among these excerpts, the best example of a comparator of temporality in the narrative can be seen in Wall's excerpt 1, contrasting her present moment at the time of writing her memoir with the deferred realization that her expectations about her future did not materialize, implicitly because of her illness. The comparison creates a dramatic contrast between what was expected and what transpired in the narrator's life, as beyond her control.

7.2.1.(b) *Evaluation of the initiating or most reportable event:* As elaborated on chapters six, evaluative stances reflect the source of knowledge about the narrator's statements (Aikhenvald 2005) but also, and often, simultaneously, they reflect the narrator's attitudes, personal feelings, as well as degree of commitment or involvement (i.e., degrees of certainty or doubt) toward the entities or propositions that they are talking or writing about (see Hunston and Thompson 2001). The evaluative stances observed in the orientation sections of these memoirs are the *mirative stance*, the *frustrative stance*, and the *visceral knowledge* stance.

The mirative stance is related to the "unprepared mind" (see DeLancey 1997 quoted in Aikhenvald 2005, 195) and refers to the speaker's reaction to unexpected information or to new information along with its concomitant surprise. I would say that the mirative stance is almost synonymous with the experience of a contested illness, in which we cannot find a logical explanation or a relationship of causality to our previous bodily states. Illness as seen as an interruption (Bury 1982) is embedded in our unprepared mind. We saw examples of the mirative stance in the narratives of Wall (excerpt 1), Skloot (excerpt 2), and Murray (excerpt 4). Also, traumatic events are informed by the mirative stance and frustrative stance alike when it is difficult to accept a rational explanation for the events that happened, as it is shown in Berkowitz's memoir (excerpt 7).

The frustrative stance, as mentioned, is a type of modality that simply indicates that the action was done in vain or that the expected course of actions has been unfulfilled. In these memoirs, the frustrative stance was expressed by a *deferred realization*, such as in Wall's narrative (excerpt 1) when only retrospectively she realized that her expectations for having an active, physical engagement with the world have been in vain. Also, the frustrative stance was expressed in Berkowitz's memoir in pragmatic terms by means of the repetitive reference to the traumatic event as an expression of the inability to understand it. Thus, the frustrative stance and the mirative stance could act concomitantly. Finally, the frustrative stance was expressed by means of references to other memoirs (i.e., by means of *intertextuality*), in which the accumulation of memoirs or case studies can be interpreted as an amplified, frustrative reaction against the testimonial injustice (see Fricker 2007) experienced by women in trying to have their symptoms believed or taken as organically motivated. This strategy was observed in all memoirs, but especially in Norman's and Crumpler's. I will return to the connections between intertextuality and the frustrative stance when I address the devices associated with the second-hand source.

Finally, the visceral stance or visceral knowledge is a term that I borrowed from Belling (2012), and it indicates the patient's *first-hand* or *direct experience* (Aikhenvald 2005). The visceral knowledge is manifested in narrators' reports of their illness experiences as expression of their subjective knowledge, as analyzed above. An illustrative example of visceral knowledge can be seen in Hilfiger's memoir when she asks her readers, "Believe me. I know" (xvi), as she presents her subjective knowledge as experiential and narrative evidence about the problems associated with Lyme disease and its diagnosis. However, as discussed in chapter five, in our Western culture introspective knowledge or in this case, visceral knowledge, has been undervalued and seen with suspicion under the preoccupation for verification and evidence, as observed by Bruner (1990). Given that the first-hand source of knowledge is culturally devalued, we can observe that narrators have drawn on second-source knowledge devices to gain an external, and "objective" source of evidence that would triangulate and legitimize their experiences. In the next section, I summarize those devices as second-hand source of knowledge.

7.2.2 Second-Hand Source of Knowledge

Devices associated with the second-hand source of knowledge point out to an external source of information, i.e., to an objective form of observation. I observed that this external source could be animated or non-animated (see Appendix B).

The animated second-hand source of knowledge could take the form of a witness or a professional expert whose words are directly or indirectly reported (e.g., as in the case of Murray's memoir in excerpt 4), or they are ventriloquized by the narrator with a legitimizing or critical intention. In that case, the narrator incorporates the voice of another agent to respond and resist to that voice (e.g., as in the case of Berkowitz's memoir in excerpt 7) or rather to align with it. The latter can be seen in the case of Skloot's memoir in excerpt 2 in which the narrator defines his condition in medical terms as a way of objectifying it for credibility, or in the cases of Murray (excerpt 4) and Crumpler (excerpt 10), in which they see the value of their experiential knowledge as complementary to the scientists' and physicians' knowledge.

The non-animated second-hand source of knowledge could be an historical event (as in Murray's memoir) or external sources. Also, narrators tend to legitimize their reporting about their illness experiences and stances by means of *intertextuality*, for instance, by referring to other publications, including other memoirs, case studies, and even scientific books. I observed this pattern in all memoirs, but as shown in Norman's excerpt 8 and in Crumpler's excerpt 9, this strategy was overused. In referring to other publications, narrators implicitly compare their illness experiences with those other narrators or characters to either validate their stances or to offer counterexamples.

7.2.3 Narrative Emplotment

Other discursive forms of validation are grounded in narrative emplotment, that is, the temporal organization of the narrative or the order in which the events are narrated. Emplotment is relevant to narrative credibility because of the narrator's decision about in what order to tell us the unfolding of events. In other words, what information the reader learns first or second is relevant to influence the reader and construct credibility. For instance, the narrator in Murray's memoir (excerpt 4) organized the narrative cataphorically. Murray's memoir starts at the end of her medical journey when she had achieved recognition, rather than at the beginning of her struggles when she lacked the language to articulate her experience and the medical system did not have a name for her condition. By beginning her narrative cataphorically (i.e., from the end of her medical journey to the present), the narrator in Murray's memoir legitimized her story as a form of vindication (i.e., she did not have a psychosomatic illness but Lyme infection). In a similar manner, but rather done anaphorically as a form of deferred realization, Wall's memoir (excerpt 1) resorted to the temporal strategy of using conditional and hypothetical verb modes to indicate a *deferred realization* about her predicament. The deferred realization is validating because of its historicity. Whereas it gives proof that her disproportionate exhaustion in doing a trivial domestic task happened as the narrator says it did, it also serves to rationalize and explain that the reason for that out-of-the-ordinary experience was her illness, i.e., her CFS.

7.3 Final Remarks

Whereas several memoirists drew on their self-awareness regarding the onset of symptoms to mark the most reportable events (e.g., Wall, Skloot, Norman), not all memoirists, though, followed this narrative strategy. In Berkowitz's memoir, for instance, illness is presented and interpreted as the consequence of her traumatic event as being sexually assaulted by her doctor; the sexual assault rather than fibromyalgia was the most reportable event. And in Hilfiger's, the most reportable event is not her self-awareness of her illness symptoms either, but the problem of narrative reconstruction of the precise moment in her past in which she was bitten by the infected tick (or ticks) that led to her path with chronic Lyme disease. These narrative strategies might be motivated by different communicative purposes as we shall see.

The narrator's decision to either match the most reportable event with her or his awareness of illness symptoms or with other themes, seems to inform the rhetorical destination of the memoir. In the cases of Hilfiger's and Berkowitz's memoirs, it is as if illness were not the memoirists' main narrative concern, thus they were not oriented as the most reportable events. Rather the ontological elusiveness of their illness experiences, the linguistic and bodily indistinctness, and its unfathomability occupied the place of the most reportable event. For that reason, it is safe to assert that their discursive styles are intentionally marked by contradictions, repetitions, redundancy, and descriptive vagueness that deliberately embrace the subjective, first-hand experience as intentionally challenging the objective paradigm of reliability and credibility. Furthermore, it is as these young memoirists would resist the logic of objectivity and would clearly assert that their conditions cannot be narrated in a reliable manner by virtue of the malleability and mutability of their conditions. Their styles inform the malleability and vagueness of their contested conditions.

Although the selection of these memoirs in the primary source comprises only one memoir written by a male writer, it needs to be pointed out that Skloot makes no mention of having been treated as hypochondriac or hysteric as did his female counterparts. He does report though, about his doctors being "skeptical[s]" (9), which presupposes that they were skeptical of his report of symptoms or perhaps, they were skeptical about the biological basis of his condition. However, Skloot does not clarify this point because it seems that credibility is not the major narrative issue of concern for him. There seems to be a difference in the linguistic degree of intensity between the emotional connotation of adjectives such as "skeptical" and "hysterical." Thus, considering the analysis of stancetaking and addressivity as discussed earlier, given the more neutral tone of Skloot's lexical choices, his narrative perspective is less personalized, and it seems in closer alignment with the voice of medicine. This marks a slight gender difference in this sample that allows me to speculate that as a male narrator, he might have been less threatened by social aspects of credibility; consequently, his lexical choices did not need to be rhetorically defensive or emotionally reactive. However, we cannot generalize this explanation.

Skloot's stance taking is in clear contrast with other memoirists. As discussed earlier, Crumpler also used a less personalized tone and I analyzed her sympathetic position toward the medical community in dealing with conditions such MCS. However, Crumpler critiques medicine in her memoir by taking into consideration the individual, subjective, personal cases like hers, as a source of information from which to induce new knowledge. Thus, although she uses a less personal voice (like Skloot), Crumpler does not align with the voice of medicine.

Another contrast can be seen between Skloot's memoir and Murray's. The narrator in Murray's memoir centers the most relevant event in her doctor's acknowledgement of her agency in having successfully called the attention of the medical community to study the epidemic dimensions of Lyme disease. For memoirists such as Murray, having been acknowledged and having received credibility by her doctors after long, painful years of doubt and self-doubt defending her visceral knowledge, is the main point of her memoir rather than just telling us about her suffering with Lyme.

In brief, the rhetorical and discursive devices described, have a discursive and pragmatic effect; that is, they accomplish social actions in the best interest of the narrators. Narrators used the devices described here accomplishing different social actions intended to construct credibility. For instance, (1) they challenged narrative reliability (e.g., Hilfiger and Berkowitz) as an absurd expectation that is in contradiction to their illness experiences; (2) they asserted their visceral knowledge (e.g., Murray, Crumpler, and to some extent Norman) in rational ways by deploying their research, documentation, their introspection and observation; (3) they asserted their symptoms and experiences by *constructing a new linguistic dimension* into the experience of illness, which may give language to other sufferers (e.g., Wall, and to some extent Skloot); (4) and last, but not least, they managed to transform out-of-the-ordinary experiences into narratives, negotiating the tension between reportability and credibility. In the next chapter, I analyze the memoirs that belong to the second source; that is, the memoirs of non-contested illnesses to compare the narratives pertaining to both category sources.

CHAPTER 8

EVALUATIVE DEVICES in NARRATIVES of NON-CONTESTED ILLNESSES

In the previous chapter, I did a close-reading analysis of the discursive devices that narrators used to construct credibility in the orientation and evaluation sections of the memoirs comprising the primary source, i.e., narratives of contested illnesses (see Appendix A, Table 1). In this chapter I will proceed in the same manner, but I will analyze narratives of non-contested illnesses (see Appendix A, Table 2). The narratives comprising this secondary source of non-contested illnesses are three memoirs about cancer diagnosis, one written by an African American woman (*The Cancer Journal*, Lorde 1980), and two written by men (*At the Will of the Body*, Frank 1991; and *A Lucky Life Interrupted*, Brokaw 2015). There is another memoir about a neurological condition called peripheral nerve injury, developed after a hiking accident on a mountain, written by neurologist Oliver Sacks, *A Leg to Stand On* (Sacks 1984).

To refresh the concepts, in this dissertation I have considered contested diseases as those characterized by insufficient or lack of known biological cause or abnormality that present unspecified pathophysiological or anatomical characteristics, resulting in a disputed disease status as lacking medical legitimacy (Hart 2014). Also, it has been established (see Introduction chapter) that contested diseases are typically symptom-based illnesses rather than sign-based (Aronowitz 2001); therefore, the symptoms associated with these conditions are highly subjective and unverifiable. For that reason, patients' illness stories are difficult to corroborate. As the memoirs selected in this chapter comprise a memoir about breast cancer, multiple myeloma, heart attack and cancer, and peripheral nerve injury, I consider them according to the definition as non-contested illnesses, given that they present objective anatomical and physiological characteristics which are sign-based and therefore, available for medical corroboration. Because the diseases of the narrators/memoirists in this secondary source are more likely to be seen as doctorable, it is assumed here that narrators will not need to appeal to discursive devices to claim credibility or doctorability for the ontological reality of their illnesses. Nevertheless, I analyze the memoirs to be able to confirm whether narrators in this category rhetorically orient to make their illnesses ontologically credible, and then I will compare observations. I will proceed systematically, as I did in the previous chapter, by identifying the initiating or most reportable event in the orientation section and the evaluation section of each memoir (i.e., the preface and introduction chapters) (see chapter six). Like in the case of the memoirs of contested illnesses, I wish to know whether narrators may still use evaluative and discourse stances to construct credibility about their conditions. If these discourse stances are found, then I will ask, what could be the communicative purpose in emphasizing the ontological reality of their conditions—if their illnesses are not contested?

8.1 Analysis

8.1.1 Cancer and Heart Attack Narratives

8.1.1.i *The Cancer Journals* (Lorde 1980)

In her *Cancer Journals* (1980), Audrey Lorde (1934-1992), a Black, lesbian poet, as she used to define herself, tells us about her struggles with breast cancer, her mastectomy, and her fears of cancer recurrence and death. Furthermore, she tells us about her decision to not wear a prosthesis despite the social and medical pressures to conform to certain standards of being a patient and to fit into certain identities. These standards can be identified as two types: first, the standard of how to be a good post-mastectomy patient according to medical expectations, and second, the standard of feminine beauty according to social and cultural expectations. Before I elaborate on these standards, I would like to give a general description about Lorde's memoir. Lorde's goal in *Cancer Journals* is to give voice to women and empower women. She states,

> Breast cancer and mastectomy are not unique experiences, but ones shared by thousands of American women. Each of these women has a particular voice to be raised in what must become a female outcry against all preventable cancers, as well as against the secret fears that allow those cancers to flourish. *May these words serve as encouragement for other women to speak and to act out of our experiences with cancer …, for silence has never brought us anything of worth.* (Lorde 8) (emphasis added)

Lorde focuses on empowering women by giving voice to women. For this purpose, she addresses a series of topics that are of women's concern (e.g., the medical enforcement of breast prosthesis, the presence of carcinogenic in food, and others) with the purpose to raise her argument about the silencing of women's voices. Lorde's writing cannot be separated from her advocacy and activism for feminine gender and LGTQ rights. Although published in 1980, Lorde's words still resonate today.

Because the first chapters are more expository and journalistic, I would say that the most reportable event (i.e., the event that has the greatest effect on the needs and desires of the participants, including the narrator) in Lorde's memoir can be identified in chapter three, "Breast cancer: Power vs. Prosthesis" (see excerpt 1). This is a chapter in which we learn about a particular event in connection with the problem of wearing breast prostheses. Lorde reports a troubling encounter with a nurse during a follow-up visit to her oncologic surgeon, after her mastectomy. In that visit, Lorde was not wearing a prosthesis, which was deemed a censurable behavior by the nurse:

Excerpt 1

> Ten days after having my breast removed, I went to my doctor's office to have the stitches taken out. This was my first journey out since coming home from the hospital, and I was truly looking forward to it…. *When I walked into the doctor's office, I was really rather pleased with myself, all things considered, pleased with the way I felt, with my own flair, with my own style.* The doctors' nurse, a charmingly bright woman of about my own age who had always given me a feeling of quiet no-non-sense support on my other visits, called into the examining room. On the way, she asked me how I was feeling**.** *'Pretty good,' I said, half-expecting her to make some comment about how good I looked. 'You're not wearing a prosthesis,' she said, a little anxiously, and not at all like a question. 'No,' I said, thrown off my guard for a minute. "It really doesn't feel right,"* referring to the lambswool puff given to me by the Reach For Recovery volunteer in the hospital**.** Usually supportive and understanding, the nurse now looked at me *urgently and disapprovingly* as she told me that even if it didn't look exactly right it was *'better than nothing,' and that as soon as my stiches were out, I could be fitted with a 'real form.' 'You will feel so much better with it on,' she said. 'And besides, we really like you to wear something, at least when you come in. Otherwise, it's bad for the morale of the office.' I could hardly believe my ears! I was too outraged to speak then, but this was to be only the first such assault on my right to define and to claim my own body*. (Lorde 59-60) (emphasis added)

The narrator's evaluative strategy proceeds skillfully by describing Lorde's physical image and emotions on the day of her doctor's visit. Although this description is not included in the selected quote above, we learn that before going to her doctor's appointment, Lorde took special precautions to ask a friend to wash her hair (a significant detail if we consider that she was unable to raise her arm due to her recent surgery), she dressed up for the occasion with an African "tunic and new leather boots" (60), and was even wearing jewelry (e.g., "a single floating bird dangling from my right ear in the name of grand asymmetry") (60). All these details about her attire affirm her sense of recovery and being in good spirits despite her recent mastectomy. She states, "When I walked into the doctor's office, I was really rather pleased with myself, all things considered, pleased with the way I felt, with my own flair, with my own style" (60). The function of this detailed self-description is to contrast it with the nurse's striking lack of acknowledgement of Lorde's good physical image and the considerable effort she had made to look well for her doctor's appointment.

Lorde's account of her encounter with the nurse is, for evidential purposes, constructed by means of direct speech (i.e., verbatim quotation) and reported speech. We can observe that there is no reply from the nurse to Lorde's statement "Pretty good." Or rather, the reply does not acknowledge Lorde's statement but directly points out to Lorde's absent prosthesis. Thus, the nurse does not engage in small talk, which might have served to smooth the interaction and assess the general wellbeing of a post-mastectomy patient. The absence of small talk and the overlap in the response also indicates the nurse's level of anxiety in her comment to Lorde, "You're not wearing a prosthesis" (60). As Lorde indicates, the rising intonation did not mean it was a question, but rather an exclamation involving a negative evaluative assessment as if Lorde had committed a medical transgression instead of an act of free will by means of which she expressed a personal preference. Thus, the nurse's comment can be interpreted as an indirect complaint to Lorde.

In starting the narrative by describing her physical and emotional state, the narrator creates a rhetorical contrast between the time before her mastectomy and afterwards, which plays an evaluative function as observed by Labov (1997). The narrator compares the nurse's behavior, previously perceived by Lorde as "supportive and understanding" with the nurse's now disapproving reaction that shows a non-supportive behavior. Thus, we see that although Lorde does not claim doctorability for her condition (i.e., the type of evidence that she had cancer is materialized in her visible lack of one breast, as first-hand evidence), she still needs to claim her right to be the type of patient she wants to be and to have the type of body she wants to show. As Lorde will demonstrate with her line of argumentation, these two rights are interconnected. In reading Lorde's narrative, we can infer the first argument: as patients, women are constrained by the voice of medicine to be submissive; and the second argument: women are silenced by patriarchal expectations of beauty that demand women to have a symmetric type of body. I will begin by analyzing the first argument.

Although free of the suspicion of not having a doctorable condition, like patients/narrators reported in the previous chapter, Lorde is now seen under the suspicion of what type of patient she is or will be for this nurse and medical office. If we draw on Talcott Parsons' theory of the sick role as referred in chapter one and three, Lorde's disease is a legitimate one; thus, she is not deemed responsible for her cancer. However, according to Parsons' (1951) theory, she is deemed responsible for her recovery; and therefore, she is expected to comply with doctors' prescriptions and treatments. Given that wearing a prosthesis is seen by the nurse as psychologically and morally necessary, Lorde's resistance is considered against her own recovery and the recovery of others in the office: "Otherwise, it's bad for the morale of the office" (60) as the nurse says to Lorde.

The nurse's idea that Lorde "will feel so much better with [the prosthesis] on" (60) seems to be based on an implicit psychological interpretation that wearing a prosthesis will help the patient feel compensated for her lack of a breast. Yet this is an interpretation with which Lorde disagrees and sees as a deception, as I will elaborate on later. To make sense of the moral attributes attached to wearing a prosthesis as the nurse put it, I draw on sociologist Ervin Goffman in his theory of face and stigma (Goffman 1952, 1967).[1]

The absence of a breast could be considered an undesirable state for most women in society, and thus, in Ervin Goffman's view, a visible sign for a stigmatized identity. According to Goffman (1967), society tends to control the presentation of the self by regulating norms for self-protection of one's face and for protection of others' face. Social norms of interaction indicate that not only the person is expected to save face by controlling and monitoring her own body (e.g., body image, body movements, body fluids, and others), but also the person is expected to save others' face by avoiding behaviors or body image that could be embarrassing to others. Having a "discrediting" body mark, such as a mastectomy, would require, in Goffman's theory of stigma, not only the need for the individual to pass as "normal" (i.e., by wearing a prosthesis) but also it would require the person to have to "pass" (i.e., to hide her identity as a post-mastectomy patient) to protect others from the specter of cancer, disfiguration, or

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[1]. Face is an explanatory concept in human interaction originally introduced by Goffman (1967). Face is the public image that the speaker presents to the rest of the world. Brown and Levinson (1987, 61) have added the idea that face is the public-self-image that every member wants to claim for himself or herself. In its usual interpretation as adopted by Brown and Levinson (1978 and 1987), face has two aspects: a positive one and a negative one. In the positive face, a person's status as an autonomous, independent, free agent is affirmed; the person desires to gain the approval of others. In the negative face, the stress is on a person's immunity from outside interference and undue external pressure. The person desires not to be unimpeded by others in one's actions. (see Mey 2001)

deformation. Goffman states, “A woman who has had a mastectomy … [is] forced to present [herself] falsely in almost all situations, having to conceal [her] unconventional secret because of everyone’s having to conceal the conventional ones” (75). Goffman’s quote can be interpreted in this manner: the need for concealment of one’s discrediting attribute seems to be part of the social accord to protect all people’s faces. Thus, whereas Lorde is not deemed responsible for having had cancer under Parsons’ theory, she is still made responsible by the nurse for her recovery. Given that wearing a prosthesis is deemed part of the patient’s recovery by the medical establishment, then, Lorde is made responsible for her appearance. Her resistance to wear a prosthesis is thus seen as morally blemishing. In Goffman’s terms, not only Lorde seems to resist to “pass” as a post-mastectomy patient, but by the nurse’s evaluative comment, Lorde resists to protect others (including the nurse) from the specter of cancer.

In sum, under Parsons’ theory, Lorde would be transgressing the behavior of submission and compliance that is required from the patient by medicine to guarantee her recovery. For that reason, we can interpret that she is seen as socially “deviant” as a patient by the nurse. On the other hand, from a biomedical perspective, it can be argued that wearing a prosthesis is a questionable standard of care for breast cancer. In other words, wearing a prosthesis is not an essential/biological or pharmaceutical treatment for a patient to recover from breast cancer or to enter the “remission society” (Frank 1995), as it would be the case if a patient would object to chemotherapy or radiation. Therefore, although Lorde does not need to claim her condition as doctorable, she needs to reclaim her “self.” This sort of claiming is what Frank (1995) calls “reclaiming the self” (64) given that “the ill person’s voice has been taken away” (64) by the voice of medicine (Mishler 1984). Lorde needs to claim the type of post cancer patient she wants to be.

Considering the second argument that women are silenced by patriarchal expectations of beauty as symmetry, then Lorde has several reasons for resisting to wear a prosthesis. Her resistance involves personal reasons that as she will demonstrate, are also political. Lorde’s stance about prosthesis is stated in previous chapters in the memoir, but the most reportable event in the encounter with the nurse is presented in chapter three. For instance, in the “Introduction,” Lorde calls prosthesis “a travesty” (7) and a “cosmetic sham” (14) for reasons that she elaborates. Because Lorde sees the interplay of the personal, the political and the social, she observes that failures in public health policies affect individuals. Women’s individual voices are not heard, she claims, because their conditions are taken in isolation, they are seen as individual manifestations of the cancer rather than seeing cancer as socially occasioned by the failure of public health protections to regulate carcinogenic products for public consumption. Thus, Lorde reasons that when women wear prosthesis, they may be implicitly complicit in covering and silencing the social factors that contribute to their breast cancers in the first place. She states, “I believe that socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other. … [W]hat would happen if an army of one-breasted women descended upon Congress and demanded that the use of carcinogenic, fat-stored hormones in beef-feed be outlawed?” (15). Thus, the problem cannot be fixed by women wearing prostheses but by fixing the public health system to prevent it or reduce the incidence of breast cancer among the population.

To the nurse's objection that Lorde was not wearing a prosthesis, Lorde responded, "It really doesn't feel right." Lorde's response is interpreted by the nurse in the context of her own mindset; that is, that Lorde resists wearing a "lambswool puff" as a provisional prosthesis because she still does not have the "real form." But Lorde's meaning is quite different. For her, what does not "feel right" is to cover up the irrevocable fact that she lost her right breast due to cancer with a prosthesis. Because Lorde's voice is interrupted and her language is used to say something she did not intend, then she has to claim her voice as her true self and belief. Contrary to the nurse's belief, she will not "feel so much better with it" (60). For Lorde, wearing a prosthesis would be denying the fact that she is a cancer survivor. Whereas her absence of breast is a mark of a proud identity for Lorde, which she bears with honor, her lack of a breast is reduced to a shameful and stigmatizing identity by the nurse's comment in Lorde's interpretation. Thus, Lorde confronts the task of reclaiming her own body as she wants it to be rather than as others want it to be.

Moreover, by asking Lorde to wear a prosthesis with the justification that that, at least, would help keep the morale of others, the nurse is asking Lorde to do "emotion work" (see Hochschild 1983) that will satisfy others.[2] In Hochschild's (1983) use of this concept, emotion work is characteristic of workers in service jobs, such as flight

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[2]. Hochschild (1993/2012, 29) defines emotional labor or emotion work as the management of one's feeling to create a publicly observable facial and bodily display that is sold for a wage and therefore has exchange value. The problem, Hochschild observes, drawing on Marxist theory, is that in doing this emotion work, workers may feel alienated and involved in a self-estrange process, which is common in advanced capitalist systems. In this dissertation, I extend this concept to social interactions in which participants may still feel socially alienated although non-exchange value is involved.

attendants and nurses. The worker's management of her emotions to create an expected publicly facial and bodily display is seen as a commodity that the customer purchases as part of the service; however, this emotion work is at the expense of the worker's alienation or self-estrangement. In this sense, the nurse's request to Lorde to wear a prosthesis to satisfy other people's desires (including those of the nurse and the physician's office) rather than Lorde's desires, can be seen as an inversion of the social roles, in which the nurse (the offeror of service) feels entitled to request the patient (the receiver of those services) to do the job for her. In that sense, the nurse's request for this emotion work is a form of silencing her patient's right to define and claim her own body, at the emotional cost of the patient, in Lorde's case. Thus, with this request comes the risk of self-alienation or self-estrangement to one's own body or self, that Hochschild observed.

From Lorde's critical perspective, women should not be expected to hide the fact that her body will ever be the same. Instead, post-mastectomy women who do not wish to cover their lack of breast should be acknowledged for the emotional courage they have to gather in accepting their new bodies and realities. It is not as if Lorde would not miss or care about her absent breast; rather, Lorde makes another point as we see in excerpt two:

Excerpt 2

> For me my *scars are an honorable reminder* that I may be a casualty in the cosmic war against radiation, animal fat, air pollution, … but the fight is still going on, and I am still a part of it. I refuse to have my scars hidden or trivialized behind a lambswool or silicone gel. I refuse to be reduced in my own eyes or in the eyes of others *from warrior to mere victim,* simply because it might render me a fraction more acceptable or less dangerous to the still complacent, those who believe if you cover up a problem it ceases to exist. I refuse to hide my body simply because it might *make a woman-phobic world more comfortable.* (Lorde 61-62) (emphasis added)

According to this excerpt, Lorde claims that it should be the responsibility of the nurse to acknowledge the fact that Lorde had survived her surgery and it is trying to come to terms with her new body appearance and reality. In terms of social justice, Lorde argues that it is not her job to hide her body "imperfections," but the nurse's job to accept Lorde's new body instead, as marked by a new physical identity as the result of her mastectomy due to cancer. Thus, the responsibility is not Lorde's but her nurse as a health professional. Lorde states, "I refuse to hide my body simply because it might make a woman-phobic world more comfortable" (61). By not acknowledging Lorde's efforts, the nurse seems to display her own phobic reaction to cancer when Lorde is the patient who truly experienced cancer and, therefore, needs compassion. In sum, the nurse's rebuke indicates that there are social, medical, and cultural expectations about how to be a patient and how to be ill as Kleinman (1988) observed. Kleinman (1988) defines "illness problems" (4) as the principal difficulties that come along as the result of the disease. Although Lorde's cancer resulted in a mastectomy of her right breast, the claiming she is doing is not triggered by cancer itself but by social and cultural expectations; that is, the politics of appearance in breast cancer culture and heteronormativity that seem to have influenced medicine as an institution and this nurse as a member of that institution. Complying with these expectations by adopting prostheses or reconstruction would be, in Lorde's view, a way of complacency with the very same capitalist system that promoted the development of cancer through contaminants of the air, water, and food, and/or failed to prevent it. "Prosthesis offers the empty comfort of 'Nobody will know the difference.' But it is that very difference which

I wish to affirm, because I have lived it, and survived it, and wish to share that strength with other women" (62), as she vehemently says.

In claiming a new body and the type of self she wants to be, Lorde draws on the metaphor of the female "warrior" invoking the Greek myth of the Amazon (27) women who cut or cauterized their right breast to have a better control of the bow and arrow. Thus, Lorde advocates for women's rights to choose their physical appearances against the constraints of patriarchal expectations of beauty (see DeShazer 2013). Lorde asserts, "And every woman there could have used a reminder that having one breast did not mean her life was over, nor that she was less a woman, nor that she was condemned to the use of a placebo [prosthesis] in order to feel good about herself and the way she looked" (61). Lorde evaluates beauty as an internal state of self-acceptance instead of an external state, measured by others. She rejects the visual value associated with prosthesis because of the deceptive visual evidential it provides. Accepting a criterion of beauty based on a mere visual appearance would be falling into the tramps of objectification and depersonalization that see women only as mere sexual objects. As she states,

Excerpt 3

> Attitudes toward the necessity for prostheses after breast surgery are merely a reflection of those attitudes within our society toward women in general as objectified and depersonalized sexual conveniences. *Women have been programmed to view our bodies only in terms of how they look and feel to others, rather than how they feel to ourselves, and how we wish to use them.* (Lorde 65-66) (emphasis added)

In conclusion, considering the research question above, I can say that although Lorde did not have to claim doctorability for her disease, she did draw on evaluative stances, such as figurative language, verbatim quotation, and rhetorical contrast to reclaim the type of patient she wanted to be and the type of feminine body she wanted to show. Allusions to her “scars,” the scar of her mastectomy is visual evidence that she is a survivor. Hiding her scar by covering it, would be as if she were to deny her identity as a “warrior,” who is proud of surviving the battle of cancer. As a warrior, she fought against concrete chemical toxins and pollutants that typically jeopardize women’s health as well as symbolic toxins that jeopardize women’s sense of gender identity. The scar, as a visual evidential that cancer happened, is embraced by Lorde if the act of wearing a prosthesis comes from women’s internal decisions (i.e., when women are aware of the political implications behind prostheses); but rejected when wearing a prosthesis is imposed onto women to do emotion work to benefit patriarchal interests against their own self-interest and self-care. In these cases, prostheses are evaluated in the narrative with intensifiers such as “pathetic,” (e.g., “a pathetic puff of lambswool”) (61), which could be interpreted as a metonymic reference to those who hold patriarchal biases. Thus, although patients like Lorde may not need to claim entering in the sick role model as having their illnesses recognized as diseases, they still need to claim their identities as free to choose their own body images. In the next section, I analyze Arthur Frank’s memoir. So far, I have cited Frank as a medical sociologist and theorist several times in this dissertation, but now I analyze his own illness narrative.

8.1.1.ii *At the Will of the Body* (Frank 1991)

Arthur Frank, a medical sociologist, and a founder father of the medical humanities, writes not only from a theoretical perspective but also from his experience as a patient. In his memoir, *At the Will of the Body*, Frank (1991) tells us about his experience with heart attack, at the age of 39, and about his diagnosis with testicular cancer, fifteen months later. Although a memoir, Frank’s book is mostly a philosophical and a sociological reflection about the experience of being a patient and the role of medicine in treating patients. Thus, this memoir’s style alternates narrative with exposition. Although Frank (1991) states that he does not write from a place of expertise, “I present myself only as a fellow sufferer, trying to make sense of my own illness,” (5) it is clear that his theoretical knowledge informs his insights about the sociological and philosophical reasons affecting his experience of being a patient.

Given the diagnosis of heart attack and cancer, Frank’s conditions were non-contested. Although he did not have to claim for the doctorability of his diseases, Frank had to claim for what he calls “recognition” (11) of his subjective experience of illness. After surviving his heart attack (a ventricular tachycardia event), Frank reports on his conversation with his doctor:

Excerpt 4

> We talked about my heart as if we were consulting about some computer that was producing errors in the output. ‘It’ had a problem. Our talk was classier than most of the conversations I have with the mechanic who fixes my car, but only because my doctor and I were *being vague*. He was not as specific as my mechanic usually is. I knew more about hearts than I knew about cars, but *this engine was inside me, so I was even more reluctant to hear about the scope of the damage*. What was wrong with that conversation, for me as an ill person, was precisely what made my physician’s performance so professional. (Frank 10) (emphasis added)

The problem of recognition that Frank refers to is, on the one hand, the problem of dissociating the person’s disease from his illness experience. It is the objectification of the disease, in this case the construction of his heart as an entity or an impersonal “it” that is separated from Frank, the person, who experiences the heart attack and is living with the personal, familiar, and social implications of his disease. The comparison of his heart with an engine—and by implication, the body with a machine—is an old metaphor that has long been observed in the medical humanities. This metaphor is attributed to René Descartes' (1596-1650) body-mind dualism since his famous dictum *cogito, ergo sum,* Latin for "I think, therefore I exist." But as Frank clarifies, "*this* engine was inside me, so I was even more reluctant to hear about the scope of the damage" (10) (emphasis added). The reference of the demonstrative adjective "this" indexes to Frank's own body in opposition to an outside engine. Thus, the demonstrative adjective personalizes the "engine" as Frank's and by implication, as a non-engine but, rather, as his organ. Frank's verbal strategy consists in resisting the demand of dissociation placed upon him concerning biomedical distinctions between disease and illness.

Excerpt 5

> Hearing this talk, I knew full well that I was being offered a deal. If my response was equally cool and professional, I would have at least a junior place on the management team. I knew that as a patient's choices go, it wasn't a bad deal, so I took it. I was even vaguely complimented….
>
> *I did not yet know the cost of taking that deal.* Experiences are to be lived, not managed…. *No one should be asked to detach his mind from his body and then talk about this body as a thing, out there.* (Frank 10) (emphasis added)

As we saw earlier with Lorde, Frank was required to do emotion work; for instance, to talk with his physician about the probabilities of dying as if they were not talking about his own probabilities of dying but as someone else's, or as his heart attack had not happened to his own heart but to an external engine. As Frank explains, "The demand being made of me was to treat the breakdown as if fear and frustration were not part of it, to act as if my life, the whole life, had not changed" (11). Like Lorde, then, the demand of this emotion work involved self-estrangement and alienation. Frank accepted this demand as part of the Parsonsian bargaining by which a patient is offered “cure” in exchange for compliance; in this case, compliance to self-objectify and self-detachment from his own disease. Although Frank was rehabilitated from his heart attack and was able to return to become a productive member of society in Parsonsian terms, he hints at the moral and personal cost of accepting that deal: “I did not yet know the cost of taking that deal” (10). The reader is left to imagine the cost as per the subtle tone of regret that his words cast, as a form of “deferred realization” (Aikhenvald 2005, 202).

Given this analysis, the type of recognition that Frank claims to his physician is the recognition of how his heart attack had affected him as a person, a recognition of the problems of illness (Kleinman 1988) that came along with the diagnosis. As he states,

Excerpt 6

> I needed some recognition of what was happening to me. That day I became someone who had come very close to dying, and I might very soon come that close again. To become such a person is to change. *After I heard that I had had a heart attack, how I lived in my body changed, and my doctor should have found a way to let me know he recognized that.* (Frank 11) (emphasis added)

The verb ‘should’ expresses a deontic modality of obligation. Thus, it calls into question the doctor’s behavior. Yet it goes deeper than a simple disappointment with his physician. Frank is calling into question the professional and interactive expectation that doctors must remain aloof and emotionally detached. We can infer that Frank disapproves the “detached concern” pedagogy typical of the modern professional, in favor of the “engaged concern,” proposed in current postmodern times.

In describing Labov's (1997) narrative theory in chapter six, it was explained that the orientation section is likely to reveal the narrator's viewpoint or evaluation. And this evaluation may involve the assignment of praise or blame about the actors in the narrative by means of polarizing or integrating devices. In Frank's narrative, the use of the modal verb "should" (excerpt 6) acts as an assignment of blame and a polarizing device between Frank's experience as a patient and his physician's behavior. However, this assignment of blame is quickly counteracted and to a certain extent, neutralized, by Frank's intellectual analysis. As he states,

Excerpt 7

> The point is not that my physician was incompetent. On the contrary, *he did exactly what professionals are trained to do. And I acted as patients are trained to act.* What is important for ill persons to understand is that *there are limits to professional competence. Physicians too often do not express to the patient that they recognize her experiences of fear, frustration, and personal change.* Their talk is about diseases, about the parts that have broken down, not about the whole, which is living that breakdown. *But physicians' self-imposed limitations dictate the reciprocal roles patients are expected to play in responding to physicians.* (Frank 11-12) (emphasis added)

Probably because *At the Will of the Body* is a memoir rather than a theoretical essay, Frank does not elaborate on the theoretical explanations for the "limits to professional competence" as involving a self-imposed limitation on what to say to patients. Although here it is not the place to lay out a sociolinguistic explanation about those self-imposed limits to ways of speaking in verbal interactions, I would like to mention that Frank's observation has been addressed and supported by studies in sociolinguistics and conversation analysis.[3] Physicians and patients alike, interacting in institutional settings, are constrained in their verbal encounters because of the interactional (Goffman 1983) and institutional orders (Sarangi and Roberts 1999) that inform participants' norms of interaction.[4]

According to the communicative activity type theory proposed by Levinson (1992, 69), participants in institutional interactions are constrained to certain ways of speaking as well as to certain allowable contributions, which are informed by their memberships.[5] Only those ways of speaking that match the communicative setting are part of the activity type. As a sociologist, in excerpt eight, Frank (1991) clearly illustrates the ways of speaking to which physicians are constrained, but he does so as he experienced it himself as a patient:

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[3] These norms are learned by participants by means of what Harold Garfinkel (1963, 1967) called *membership.* In Garfinkel's term, to be a member means the mastery of the language and social norms associated with certain groups or institutions. Similarly, Sarangi and Roberts (1999) point out that all institutions are made up of shared habitual practices (i.e., interaction orders) that participants can understand by reference to their own history and tradition (i.e., by the fact of being members of the same institutions). Drawing on these authors' social explanations about how social interactions are shaped, it is not surprising that physicians, as Frank observed, would, normally, verbally behave restrictively in self-imposed ways that are limiting to their expressions of concern toward their patients.

[4] Since the end of the nineteenth century at the birth of germ theory, physicians trained in the biomedical theory of disease have been socialized into focusing on the disease as an entity while undermining patients' illness narratives as subjective experiences. As discussed in chapter three, a biomedical approach to care focuses on curing by treating the disease. In this approach, the person is seen as a host of the disease (Fox 1997). From this viewpoint, the clinical meaning of care is directed at symptom management (Frey et al. 2013), neglecting to see disease (and care) as a constitutive part of the patient's life-story, history, culture, beliefs, and social relations (Mino and Lert 2005).

[5] "I take the notion of an activity type to refer to a fuzzy category whose focal members are goal-defined, socially constituted, bounded, events with *constraints* on participants, setting, and so on, but above all on the kinds of *allowable contributions*. Paradigm examples would be teaching, a job interview, a jural interrogation." (Levinson 1992, 69) (italics in original)

Excerpt 8

> To be professional is to be cool and management oriented. Professional talk goes this way: A problem seems to have come up, more serious that we thought, but we can still manage it. Here's our plan; any questions? Hearing this talk, I knew full well that I was being offered a deal if my response was equally cool and professional, I would have at least a junior place on the management team. I knew that as a patient's choices go, it wasn't a bad deal, so I took it. I was even vaguely complimented. I did not yet know the cost of taking that deal. (Frank 10)

As Frank suggests, this managerial way of talking is faulty in terms of providing the kind of acknowledgement and recognition to the patient's experience that Frank's craved. Speakers are constantly negotiating the limits between these social constraints and their allowable contributions according to the learned norms matching the communicative setting. Although there are social, self-regulating ways of conversation and interaction, as communicative activity type theory notes, there is no law that would prevent physicians from expressing their compassionate recognition to their patients' emotional journeys into illness. And this seems to be the core of Frank's claim. Nevertheless, social constraints about professional expectations between patients and doctors in North America have a powerful and intimidating effect, given that protecting "face" is highly valued in Anglo-American culture (see Brown and Levinson 1987, Goffman 1952).

The counterproductive aspect to these ways of speaking is that patients subconsciously learn from their physicians' behaviors, those expected ways of behavior that limit them from asking and verbalizing their own needs. As Frank states, "… [P]hysicians' self-imposed limitations dictate the reciprocal roles patients are expected to play in responding to physicians" (12). In his role as a patient, Frank did not verbalize his need directly to his physician. The previous statement seems to be Frank's own acknowledgement that, although as a sociologist he is aware and conscious of the social expectations of the sick role, he fell, nevertheless, into submission to accept the "deal." There seems to be a tone of regret for his own naiveté in Frank's voice, "I did not yet know the cost of taking that deal" (10).

It can be said that Frank had to write his memoir for him to find a way to express to his doctor his own need to be acknowledged. Thus, it can be inferred that these learned social behaviors between doctors and patients seem to enter a vicious circle of self-constraint and self-limitation, resulting in possible dissociation and detachment from more compassionate and spontaneous expressions of care for others and oneself. When Frank states, "No one should have to stay cool and professional while being told his or her body is breaking down, though medical patients always have to do just that. The demand being made of me was to treat the breakdown as if fear and frustration were not part of it, to act as if my life the whole life, had not changed," (11) we can recognize not only the narrator's complaint about a poor approach to care that he observes it has been standardized and normalized, but also his own emotion work in accepting and playing his role accordingly to that expectation.

To conclude, Frank does not use evaluative devices to reclaim the doctorability of his condition. On the contrary, the doctorability of his condition seems to be self-evident given the interactional demands to which he felt he had to accommodate to; that is, he had to accommodate to the expectation of dissociating his subjective and his existential fear of dying, as if it were not about his heart. "I acted exactly as patients are trained to act," (11) he acknowledges. And later he adds, "I was naive about physicians and illness and accepted these limitations. It thus took me much longer to recognize the power of illness to change my life and the way I think about myself. The beginning of understanding was to recognize the difference between disease and illness.” (12). Frank’s evaluative stance as “naïve” and slow at understanding the social dynamic in which he was forced to play, is not only highly introspective but also almost confessional, and self-deprecating rather than defiant. From this experience, a claiming of the self also emerges, but now the tone is didactic by adopting an impersonal voice of generalization in explaining why, sometimes, patients may betray their own emotional interests:

Excerpt 9

> When a person becomes a patient and learns to talk disease talk, her body is spoken of as a place that is elsewhere, a ‘site’ where the disease is happening. In speaking this way, the patient identifies with the physician, for whom the patient’s body is elsewhere. Since the ill person can see that it is far safer and more comfortable to be the physician, this confusion of identity is understandable, but it remains mistaken. The cost of this confusion to the ill person is forgetting that she exists as part of ‘it.’ (Frank 12-13)

Like Lorde, Frank also claims the self, but by means of self-reflection and regret by adopting for moments a didactive voice as it would be representative of the patienthood experience. In his claim of the self, Frank does not attribute responsibility to his doctor. Instead, he self-examines the cost to do emotion work on behalf of his physician’s implicit demand, without realizing at that time, how self-alienating accepting that deal would result for him.

8.1.1.iii *A Lucky Life Interrupted: A Memoir of Hope* (Brokaw 2015)

American, NBC network television retired journalist and author Thomas Brokaw wrote a memoir about his experience with multiple myeloma (MM).[6] At the time of his cancer diagnosis, he had recently turned 73 years old. As we will see in the analysis, his age is an evaluative detail that the narrator brings to the attention of the reader. During his illness Brokaw wrote a diary which was turned into his memoir *A Lucky Life Interrupted* (2015). At the time Brokaw finishes writing his memoir, his cancer was in remission; but there is no cure available yet to MM.

The most reportable event can be easily identified in the preface of his book (i.e., what I consider the orientation) as the time when he learned about his cancer diagnosis. Brokaw had been experiencing persistent lower-back pain, which he attributed to his intense physical activity. He was a frequent traveler domestically and internationally and a lover of outside sport activities. Bicycling and fishing were his passions. He had had two falls in one of his fishing excursions that intensified his pain. In a previous consultation with a New York orthopedist, an X-ray showed no major anomalies besides an expected thinning of a lower-level disc associated with aging. However, on a trip to Rochester, Minnesota, while as he tells his readers, he was attending a board of public-trustee meeting of the Mayo Clinic of which he was a member, he decided to make a consultation there. Whereas the second orthopedist he saw in Rochester agreed with the initial evaluation of his first orthopedist, Brokaw's primary care physician recommended a blood check to explore further the reasons for his persistent pain. By comparing the

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[6] Multiple myeloma is a "cancer that forms in a type of white blood cells called a plasma cell" Multiple myeloma - Symptoms and causes - Mayo Clinic

results of the blood tests, the hematologist at the Mayo Clinic working with his primary care physician, concluded that Brokaw had a malignancy.

Excerpt 10.a

> Making no attempt to prepare me for what was coming, he plunged ahead, saying it appeared I had multiple myeloma, a cancer of plasma cells in the bone marrow…. 'It is treatable but not curable—yet.' We are making progress. Fifty percent of the progress has been made in the last five years, and I want to review your record overnight to make sure we've got this right. (Brokaw 16).

Excerpt 10.b

> I attributed [the pain] to long plane rides and an active lifestyle. If it didn't get better, I planned to see a renowned orthopedist when I returned to New York, a sports medicine doc who, over the years, had treated me for similar ailments after a summer of rock climbing, backpacking, trekking, long-distance running, and bushwhacking to remote mountain lakes….
>
> Probably require some therapy, I thought, never considering it could be anything more than an overexercised back. *The conceit of a long, lucky life is that bad things happen to others…. Not for the first time, I was wrong, but in early summer I had no idea what was to come. I was determined to work through the steady, nagging pain and spend July and August on the trout waters of Montana.* (Brokaw 4-5) (emphasis added).

Given the doctor's statement, Brokaw does not need to construct credibility for the doctorability of his condition or to persuade his doctors of his pain. Rather, quite early into the diagnostic process, he is directly told the reason: lower-back pain is a symptom associated with that type of cancer (Mayo Clinic). In Brokaw's memoir, the narrator evaluates the most reportable event as an unexpected and surprising unfolding of reality as we have seen in other narratives, but the context of the news is characterized as a busy life, full of social engagements and activities, with leisure trips and intellectual projects that keep him active and young in spirit despite his age. The retrospective evaluation about the time of receiving the news of his cancer focuses, however, on his good luck. Attributing his lower-back pain to overexertion due to his active life, Brokaw's timely diagnosis is constructed as the result of his good luck thanks to the efficiency of others who cared for him (rather than to those who did their jobs responsibly). However, it can be said that without this effective and quick move on the part of his doctors, his lack of self-awareness about the risks that were involved in his lower-back pain would have had, probably, a catastrophic outcome. Thus, privilege in having access to the best health care cannot be just reduced to an evaluation of good luck.

Comparing Brokaw's diagnosis with the cases of Murray, Hilfiger, Norman, Ramey, and others in the previous chapters, he did not have, like other memoirists, for instance, to insist for studies to his doctors or that his back pain was real. The expression of his pain was taken by his words, and he was immediately studied with blood tests and imaging techniques. In establishing a contrast between a hypothetical situation that did not materialize (dying from his MM) and the reality (remission), the rhetorical effect is the construction of a lucky identity as highlighted in the title of the memoir *A Lucky Life Interrupted*, but it sounds more like the result of a privileged existence with access to excellent healthcare and a strong social support network.

The theme of being cared for by others, as part of a lucky identity, is also observed in the preface. After receiving his diagnosis, Brokaw decides to skip a social dinner event and instead goes to his hotel to start working on his next project (a script about JFK for NBC he was planning), when a friend, noticing his absence at the dinner, called him. “A fellow trustee and friend so close we might as well be brothers called to ask, ‘Where are you? Is something up?’ Ron Olson, the lawyer for Warren Buffett and various major corporate interests, intuitively knew that my absence from the trustee’s dinner meant something was amiss. I said, ‘Meet downstairs for a martini’” (28). His friend’s call serves as a witness that something is “amiss” with Brokaw who as a regular and committed attendant would have not missed, otherwise, the event, if it had not been for a serious and justifiable reason—as the reader is led to infer. Moreover, the narrator’s description of his friend’s profession and social prestige, mentioned by name (as associated with one of the richest men in the world), is used not only to validate Brokaw’s predicament but also, again, his good luck in being cared for by good and influential friends. This description serves several purposes, it reinforces the image of a lucky person who is surrounded by good friends who were available even when their assistance and attention were unsolicited, and also it reinforces his powerful and privileged position by association with an influential friend. In this manner, Brokaw constructs credibility and reliability as a narrator because he counts not only with his own social status as a journalist to validate his story, but also with the reported evidential (Aikhenvald 2005) of others who can vouch for his story as true and can verify it as lucky story.

“Before my diagnosis, I was sympathetic to friends with cancer, but I really had no idea what they were going through. Now I try to help others, and also try to absorb all I can about the various forms of cancer, new treatments, and the care of patients” (xii). The validity of his offering for help (and advice) to his readers is justified then because it originated in someone who not only has lived through the experience of MM but also enjoys a privileged social position—as this would guarantee credibility. As observed by Mushin (2001), one strategy to gain credibility is by citing or mentioning other authors or people who are believed to hold authority, as a secondary source of information.

In conclusion, Brokaw does not need to construct credibility about his condition. His doctors facilitated that information for him in a timely manner. However, we observe that as a narrator, to justify the purpose of his memoir and to legitimize his role as a memoirist who endured the vicissitudes of MM treatment, he not only draws on his experience with MM but also on his narrative authority. The image of being lucky as being cared for by others, despite his own obliviousness and lack of self-awareness could be an enticing device for certain readers because this discursive construction taps into ideas of masculinity and invulnerability, despite suffering from a terminal disease.

8.2 A Peripheral Nerve Injury Narrative

8.2 *A Leg to Stand On* (Sacks 1984)

Neurologist Oliver Sacks' memoir *A Leg to Stand On* starts by telling us the story of his hiking accident in a mountain in Norway in 1974 after coming face to face with a bull hidden behind a boulder. In his panic, thinking that the bull was after him, he started running and fell with his leg "twisted grotesquely beneath [him]" (21), and consequently, no longer able to support his body on that leg. As he diagnoses himself, he describes his injury in this way: "[T]he entire quadriceps has been torn from the patella. But though it has torn loose, it has not retracted—it is wholly toneless, which might suggest nerve injury as well. The patella has lost its major attachment, and can be flipped around—so!—like a ball-bearing. It is readily dislocated—there is nothing to hold it" (22). Unable to walk, he has to push himself down the mountain with his arms, using an umbrella as a splinter to support his injured leg. Suddenly aware of his loneliness and mortality (if not found before nighttime he estimated he could perish of hypothermia), he is luckily rescued by two reindeer hunters at dusk.

The leg accident in the mountain can be considered the initiating event in Sacks' narrative. However, the most reportable event is Sacks' peripheral nerve injury, which can be identified in chapter two "Becoming a patient."[7] His peripheral nerve injury resulted from the accident in which the nerves of his injured leg were severed, and the leg lost the nerve supplied (i.e., denervation), resulting in muscle atrophy, inability to contract the muscles, and loss of the sense of proprioception as well as a strange sense of alienation from his leg.[8] Sacks, himself, as a neurologist, self-diagnoses his condition despite his initial self-doubts, after several frustrating experiences with his healthcare providers.

Once in the hospital in London and after the surgeon (Dr. Swan) reattached the tendons of his quadriceps to his knee, Sacks suddenly realizes that he was unable to tense the quadriceps of his injured leg.

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[7] According to NIH, "The peripheral nervous system consists of the nerves that branch out from the brain and spinal cord. These nerves form the communication network between the central nervous system (CNS) and the body parts. The peripheral nervous system is further subdivided into the somatic nervous system and the autonomic nervous system. The somatic nervous system consists of nerves that go to the skin and muscles and is involved in conscious activities. The autonomic nervous system consists of nerves that connect the CNS to the visceral organs such as the heart, stomach, and intestines. It mediates unconscious activities." (Peripheral nervous system)

[8] Unlike injuries of the central nervous system, in the case of peripheral nerve injuries the brain has some capabilities to rewire. Neurogeneration is possible depending on the extent of the injury. (https://dbpedia.org/page/Neuroregeneration)

Excerpt 11

> Smiling with anticipation, I tensed the quad—and, inexplicably, nothing happened, *nothing at all*. At any rate I didn't feel anything…. I tried again—a strong pull this time—watching the quadriceps closely at the top of the cast. Again nothing—no visible motion whatever, not the least trace of any contraction. The muscle lay motionless and inert, unmoved by my will. Tremblingly I put down my hand to feel it. It was tremendously wasted, for the cast … Some atrophy, at least, was only to be expected, on the basis of disuse. What I did not expect, and what struck me as exceedingly strange, and disquieting was to find the muscle completely limp… in a way one would never find with disuse alone. Indeed, it scarcely felt like muscle at all—more like some soft inanimate jelly or cheese. It had none of the springiness, the tone, of normal muscle; and it wasn't just 'flabby' it was—completely atonic. I had a qualm of absolute horror and shuddered; and then the emotion was immediately repressed or suppressed. (Sacks 54) (emphasis in text)

The mirative stance (Aikhenvald 2005) in excerpt 11 shows Sacks' unprepared mind for his sudden realization of a totally unexpected event (i.e., the denervation). Several symptoms indicated that something was very wrong with his leg or with himself (as he speculated): his inability to flex the quadriceps, the complete motionless of his leg that did not respond to his will to move, and the severe atrophy and waste of the muscle that went beyond the reasonable explanation of disuse. At first, Sacks tries to dismiss this strange manifestation of reality only to be able to understand it later, as his awareness begins to awaken in his dreams.

In one of his dreams, Sacks reports talking to himself saying, "'There's something the matter—quite dreadfully the matter. The muscle's been denervated, somehow … It's not just the tendon—the nerve-supply's gone!' I strained and strained, but it was no use at all. The leg lay motionless, and inert, as if dead" (56). The most terrifying aspect of his condition manifests in his sense of physical disconnection between his injured leg and his sense of self, as if his brain would not recognize his leg as part of his body image. The full awareness and acceptance of his condition will manifest as a slow and anxious process in which he struggles to reconcile his own experience of reality with the medical expectation of a normal, healing process, after the tendons of his leg were surgically reattached.

Excerpt 12

> I could say that I had lost the leg as an "internal object," as a symbolic and affective "imago." It seemed, indeed, that I needed both sets of terms, for the inner loss involved was both "photographic" and "existential." Thus, on the one hand, there was a severe perceptual deficit, so that I had lost all feeling of the leg. On the other, there was a "sympathetic" deficit, so that I had lost much of my feeling for the leg. Both were implied in the terms I used—the sense of my personal, living, beloved reality having been replaced by a lifeless, inorganic, alien dissolution of reality. (Sacks 75)

Two main problems are reported in this excerpt: the loss of the neurological imago or representation of his limb as constituting part of his body image (i.e., photographic loss), and the loss of his sensory experience of his leg in its "sympathetic" deficit; in other words, in the capacity to feel and move his leg (i.e., existential loss). Without being unable to feel his leg (in addition to being unable to see it due to the cast), Sack experiences a form of "anosognosia" (79), a lack of awareness or a form of cortical blindness in which not only the leg but also the space occupied by it disappeared from his cognitive recognition, as we learn from reading about it in one on his dreams. However, Sacks does not disclose any of these thoughts about his inner experience to his healthcare providers. These thoughts are part of his inner monologue.

I would like to provide some examples of his reluctance to reveal his own self-diagnosis. This reluctance may be significant because it tells us about his concern about not being understood or believed, and therefore, his need to save face (Brown and

Levinson 1987) to protect his reputation. For instance, in the interaction with his physiotherapist, Sacks explains his wasted muscles in his injured leg due to inactivity, even though he suspects at the time that it was due to the denervation (see excerpt 11). Moreover, to save face he positions himself as responsible for his supposed “failure” to flex his quadriceps, as he states, “‘I don’t seem to be very good at this,’ I said in a small voice” (61), as if it were a matter of failed will power. As it happened earlier with his physiotherapist, later Sacks will experience another, even more defamiliarizing event. One morning, one of the nurses finds Sacks’ injured leg hanging outside the bed and almost touching the floor, but he has no conscious awareness of the position of his leg in space, at the time. When Sacks realizes that the alarmed nurse was not joking, he makes no effort though, to explain to her that poor proprioception could be caused by peripheral nerve injury. Rather, Sacks reasons that explaining this to his nurse would be even more defamiliarizing for her; thus, the explanation might do more harm to his reputation than the possible explanation:

Excerpt 13

> I imagined her thinking, behind her smooth Javanese brow, ‘and now *he’s acting weird!’ She would have been far more disturbed* … had she had any conception of what I was thinking, experiencing, feeling. ‘*Weird’ she would have found much too feeble a word. Indeed, she would have found no word in her language, my language, any language, to convey the inconceivable character of what I was experiencing.* (Sacks 72) (emphasis added)

Sacks’ imaginative act of what nurse Sulu had thought if he would have explained his diagnostic hypothesis to her, is expressed by ventriloquizing her words along with the use of the conditional tense. But this paragraph is more revealing about Sacks’ need to save face and not be perceived as imaging it, than about nurse Sulu’s. It shows that Sacks is confronted with the reportability paradox (Labov 1997) as discussed in chapter five. He is experiencing an extraordinary phenomenon, but it is constrained to tell it to others by the "ordinary cast of mind" (Sacks, H. 1984) that would require him to tell an extraordinary story as if it would be a rational and ordinary event. We need to consider that this is a sort of problematic information to disclose to someone with whom one is not entirely confident, that she or he will understand. To lose the sense of one's leg position in space is indeed an extraordinary event and before it may be qualified as a neurological pathology, it is more likely that it will be qualified as a "weird" manifestation of reality, as a weird behavior, or the person may be even qualified as weird given our natural resistance and apprehension to what seems illogical and out of the ordinary.

Although Sacks is cautious not to reveal his thoughts to his nurse and his physiotherapist as if they could not understand his complex case, he has great expectations instead to discuss his own diagnosis with his surgeon. In the case of his surgeon, Sacks assumes that Dr. Swam will be willing to hear and discuss his diagnostic hypothesis with him. He even thinks that Dr. Swam has seen that neurological phenomenon in other patients in the past, and consequently he would be receptive to hear his hypothesis. However, none of these assumptions will happen to be the case, and Sacks' expectations will be deflated as we see in excerpt 14:

Excerpt 14

> 'Well, Sacks,' he said. 'How does the leg seem today?'
> 'It seems fine, Sir,' I replied, 'surgically speaking.'
> 'What do you mean—surgically speaking?' he said.
> 'Well, umm'…
> 'It's … it's … I don't seem to be able to contract the quadriceps … and, er… the muscle doesn't seem to have any tone. And … and … I have difficulty locating the position of the leg….' (Sacks 104)

> ‘Nonsense, Sacks,’ he said sharply and decisively. ‘There’s nothing the matter. Nothing at all. Nothing to be worried about. Nothing at all!’ ‘But…’ He held up his hand, like a policeman halting traffic. ‘You’re completely mistaken,’ he said with finality. ‘There’s nothing wrong with the leg. You understand that, don’t you?’” With a brusque and, it seemed to me, irritable movement, he made for the door, his Juniors parting deferentially before him…. I was stunned. All the agonized, agonizing uncertainties and fears, all the torment I had suffered since I discovered my condition, all the hopes and expectations I had pinned on this meeting—and now this! I thought: what sort of doctor, what sort of person is this? He didn’t even listen to me… (Sacks 105)

Excerpt 14 clearly illustrates how Sacks is disregarded when he describes his symptoms. Dr. Swam directly tells him that he is “completely mistaken” about his inner perception. Though Sacks is not treated as hysteric or told “it’s all in your head” (as we saw in the case of several narratives in chapter seven), the inferential meaning is that he has difficulties in “understanding” that there is nothing wrong with his leg because he is hypochondriac. Belling (2012) explains that hypochondriasis describes a person’s pervasive and recurrent fear that a serious disease is present or about to emerge; this fear is based on the patient’s interpretation of subjective bodily sensations as symptoms of imaginary disease, in the terms of modern Western medicine. However, despite medical reassurance that no disease is present, the patient persists in believing that medicine can and should eventually discover the disease (Belling 2012, 14). In Sacks’ case though, the surgeon does not seem to examine Sacks’ leg to verify that he cannot contract the quadriceps or that the muscles are wasted and have no tone, as Sacks complained. Thus, the surgeon’s disclaimer that “there’s nothing the matter” lacks empirical validation.

In conclusion, Sacks does not need to construct credibility regarding his injured leg as the evidence is clear (i.e., his muscles and tendons were torn for which he needed surgery), but he finds himself in the predicament to self-diagnose an underlying condition (i.e., peripheral nerve injury), which surprisingly manifests after the surgery when he is expected to regain control of his muscles. As a neurologist, Sacks is in a difficult predicament to communicate his diagnosis to others under the constraints of his role as a patient, but also, he is in a privileged one. When his surgeon resists to listen to his observations, Sacks is not entirely disempowered by his doctor's response, as other patients were, as we saw in chapter seven. He still has his own knowledge and experience as a neurologist himself and has access to other resources. For instance, Sacks will initiate an epistolary correspondence with the renowned Russian neurologist, A.R. Luria (1902-1977), who will help him to validate his out-of-the-ordinary body-ego experiences as caused by his peripheral nerve injury.

According to the criteria for contested diseases, explained earlier in this chapter, peripheral nerve injury is not considered a typical contested disease. However, we can say that Sacks' subjective experience of anosognosia and sense of alienation from his own leg was contested, despite he presented obvious signs (e.g., muscle waste and inability to contract the muscles) that could have led to a plausible diagnostic hypothesis to explain his proprioception and alienation from his leg. Nevertheless, even though his surgeon resisted listening to Sacks' complaints, as a narrator, Sacks still needs to make his story credible to his readers and resolve the problem of the reportability paradox, as explained in chapter six. Thus, in order to construct credibility about the way his surgeon treated him, the narrator draws on the use of direct speech as a reported evidential using the direct words of the surgeon to render objectivity to his story. But, like Frank, who took responsibility for doing emotion work for his doctor, Sacks takes responsibility by self-assessing his language choice in conversation with his surgeon, to justify his doctor's rebuke.

Excerpt 15

> And then I thought—*I am being terribly unfair. I was provocative, unwittingly, when I said ‘surgically speaking.’* Further, we were both on the spot, because of the formality, the officialdom, of Grand Rounds. Both of us, in a sense, were forced to play roles—he the role of the All-knowing Specialist, I the role of the Know-nothing Patient. (105) (emphasis added).

In this reflection, Sacks as a member and insider to the medical community realizes that his attempt to talk to his surgeon as his peer was frustrated because of the constraints of the speech situation and activity type (Levinson 1992) in which both were involved, that is, the Grand Rounds. The social and normative expectation of that activity type constraints the ways of speaking of the participants: any negative evaluation about the operated leg in front of the surgeon and his students could be interpreted, not as a request for help as Sacks probably meant it, but rather as a threat to the positive face of the surgeon and his reputation. Sacks realizes that socially, he miscalculated his role in the speech situation in which both find themselves. Thus, although he is a physician himself, he is not considered a colleague by Dr. Swam at that moment; he is seen as a patient. Indirectly, then, Sacks, justifies the rebuke he experienced from Dr. Swam: “You’re completely mistaken” (104). Certainly, other interpretations are possible, but it is interesting to observe that Frank as well as Sacks, both draw on explanations informed by theories in interactional sociolinguistics, to give account of their problematic encounters with their healthcare professionals. With their explanations Frank and Sacks are pedagogical, but they are also self-deprecating. The effectiveness of their rhetorical strategies in building credibility may lie in the display of self-reflection that shows the complexity of the interactions between healthcare professionals and patients, and in the need to consider the viewpoint of the other.

8.3 General Observations

The analysis of the most reportable event in these narratives shows that these narrators did not construct credibility regarding their conditions. Lorde's breast cancer, Frank's heart attack, and Brokaw's multiple myeloma offer objective, biological evidence that grant doctorability to their illness stories. However, Sacks' narrative presents a challenge. Although his condition of peripheral nerve injury due to his denervation of the injured leg in the accident is not strictly a contested disease, we can say that Sacks' experience including his sensorial experience of disconnection from his leg, faced him with the communicative challenge of the reportability paradox. Thus, we can consider that his peripheral nerve injury becomes a contested condition due to the subjectivity of his body-image experiences and the challenges to credibility.

Sacks' narrative is interesting because it allows me to suggest that narrators dealing with a contested illnesses are not just dealing with the insufficiency or lack of known biological cause or abnormality given the unspecified pathophysiological or anatomical characteristics of the disease. Rather, the narrators of contested illnesses are confronted with the challenge of the reportability paradox; that is, the challenge to communicate as ordinary and normal, experiences, feelings, sensations, symptoms that are deemed out-of-the-ordinary.

Another observation that derives from the analysis of these non-contested narratives is that although authors did not have to claim credibility about their conditions or claim credibility about their illness stories with their healthcare professionals, they were still compelled by narrative norms as described by Labov (1997, 2013), to construct narrative reportability and credibility. In narrating their memoirs, narrators still need to make a point; therefore, they need to render their narratives credible to their readers despite not having a contested illness.

As we saw in the analysis, Lorde did not have to claim doctorability for her disease, but she did draw on evaluative stances about her mastectomy to reclaim the type of patient she wanted to be and to reclaim the type of feminine body she wanted to express in society. For this purpose, she used the reported evidential in quoting the words of her nurse; also, she used intensifiers and metaphors alluding to the Amazon myth in the cultural background, as well as first-hand evidence as the visible mark of her absent breast as a way of embracing a new identity. All these devices had a point: to lead and empower other women into reclaiming their own “selves” by becoming aware of the hidden workings of a system that has failed to protect them from the toxins that triggered their breast cancers in the first place. Like Lorde, but also with important differences, Frank does not need to claim for the doctorability of his condition. However, he claims to be acknowledged as the person who is undergoing the illness, instead of being asked to think of his own body (e.g., his heart) as if it were an external object to himself.

Whereas Lorde politically criticizes the emotion work that was requested from her, assigning the blame to her nurse’s expression, Frank, in a more self-compassionate tone, assigns responsibility to himself for his action as he self-assesses his own participation in doing emotion work. He also regrets the naivete that led him to self-alienation. The narrative point of Frank’s memoir seems to be to educate and advise the reader into the dangers of being complacent in one’s self-alienation in order to enter the sick role. Frank does not use reported evidential, but he uses popular metaphoric language, comparing his body with a car and his heart with an engine to illustrate his alienation from his own body.

In his memoir, Brokaw does not present any of the social concerns that Lorde presents with political indignation and Frank presents with analytic and didactic self-reflection. Rather, Brokaw constructs reportability and credibility by creating the image of a lucky man and a lucky identity, although luck might not have been necessarily a determinant factor. This image contrasts with his acknowledged lack of self-awareness of his age and own body messages (as if he were a young person unpreoccupied with mortality), which he is able to counteract thanks to the support of his efficient and prestigious social network (e.g., his renowned doctors, friends, and family). The support of his social network bestows him with social worth and value by virtue of their care. This image seems to socially justify the telling of his memoir by endowing him with an authority that transcends the authority given by his illness experience.

Finally, Sacks' narrative shows us that unlike the memoirs of other authors suffering from contested diseases, as analyzed in chapter seven, he was in the condition to diagnose himself. On the one hand, his position as a neurologist, gave him the chance to assess the social risk in revealing his sensorial experience to his nurse and physiotherapist, and therefore opt out of that risk by remaining quiet and saving face. Other patients, who are not physicians themselves, though, may not be able to opt out of that risk. On the other hand, we can say that Sacks was very much alone, like his fellow sufferers, in the sense of the challenge to communicate an extraordinary experience with others as if it were an ordinary event and protect himself from casting doubts about his rationality. Also, like many authors analyzed in chapter seven, Sacks was alone in confronting the fact of not being believed that something was amiss with his body.

As a narrator, Sacks still needs to construct credibility in his memoir to persuade his audience that his perceived "strange" condition was indeed real, a rather pathological condition. He struggled not only to understand what the problem with his leg was but also, he faced as a narrator the problem of the reportability paradox; thus, he struggled to communicate his experience with others and to be believed. For this purpose, the narrator uses direct speech as well as the report of dreams, as first-source evidential. His dreams are a source of knowledge because thanks to his unconscious mind, his diagnosis reveals to him. Also, he uses introspection and self-reflection to assess the social risks of disclosing his diagnostic hypothesis to others, and to reflect about the way he talked to his surgeon. In sum, the reader can appreciate the inner struggles that Sacks went through as he had to suppress his suspicion and knowledge. In his memoir, he does not construct himself as a victim of the circumstances, but he empowers himself by means of his self-reflection, as Frank does. Sacks' memoir, as about a non-contested disease but leading him to experience extraordinary sensations that were not well reported in the medical literature in the 1970s, helps us understand that patients/narrators of contested illnesses face more than the problem of disputed biological evidence. Narrators of contested illnesses face the challenge to report extraordinary, inner and subjective experiences that are unverifiable, as if they were ordinary occurrences of reality, under the social expectation of rationality and the ordinary cast of mind. This observation suggests that in dealing with a contested illness, patients/narrators simultaneously have to deal with the reportability paradox. They can appeal to language, but not for verification. Thus, the suspension of disbelief may be seen as a solution to the problem on how to listen to these patients and whether to take their narratives as truthful.

CHAPTER 9

CONCLUSIONS

To summarize, this dissertation asked three main questions: (1) How constructing doctorability may constitute a narrative/reportability problem for patients with contested illnesses and their doctors? (2) What kind of evaluative, discourse strategies do patients/memoirists of contested illnesses use to claim credibility in writing about their illness experiences? And (3) Do patients/memoirists of non-contested illnesses use evaluative stances and discourse strategies to construct credibility about their conditions? The study comprised twenty-two memoirs involving the narratives of authors with contested illnesses (eighteen) and the narratives of authors with non-contested illnesses (four) (see chapter six, and Appendix A).

To answer these questions, I used discourse analysis as articulated by the stancetaking and evaluative theories in textual analysis (Aikhenvald 2005; Chafe 1996; Hunston and Thompson 2000; Mushin 2001). For my conceptualization of narrative, I followed the narrative theory of Labov and Walentzky (1967) and Labov (1997, 2013) and according to their narrative theory, I consistently analyzed the orientation, complicating event or most reportable event, and evaluation sections corresponding to the preface, introduction, and initial chapters of all the memoirs. [1] I did not look at the resolution or coda, though. I looked at the ways the narrators reported the most reportable event and how the narrators evaluated those events. Typically, the most reportable event

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[1]. Here, I use the terms most reportable event or complicating events interchangeably. Although the concepts are similar, the change in terminology corresponds to the evolution of Labov and Waleztky (1967) and Labov (1997, 2008, 2013) theories about oral narratives of personal experience.

coincided with the reporting of their onset of illness. However, it needs to be reminded that this was not the case in all memoirs. For instance, Murray's memoir, as analyzed in chapter seven, placed as the most reportable event not the onset of her symptoms but, rather, her attendance at the first academic conference on Lyme disease, organized at Yale University (i.e., she started her memoir cataphorically). Thus, this narrative decision is revelatory of a particular evaluation, stance or moral positioning that the author wants to convey about herself as a patient; let us say as someone "proud" of her years of advocacy and struggles as a patient for recognition, which finally came to fruition.[2] For other narrators such as Berkowitz (2015), the most reportable event was the sexual assault she experienced, which she saw as the origin of her illness. Given that her memoir is shaped by the experience of trauma, her style attempts to reproduce that trauma now reenacted in her fibromyalgia.

Then, the reason for focusing on these sections instead of on the resolution or coda of the narratives is that in the orientation and complicating events, the narrators not only reported but also evaluated their experiences regarding the onset of illness, giving us a glimpse into how they assessed their experiences, and how their healthcare providers assessed them. As clarified in chapter six, I only focused on the narrators' accounts concerning their healthcare providers rather than their accounts about family members or acquaintances, given that issues of credibility are particularly relevant regarding the tension between the visceral knowledge of the patient and the medical knowledge of the

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[2]. The fact that the most reportable event tends to coincide with the onset of illness, but not necessarily, led me to distinguish in the analysis between the linguistic description of illness per se and the evaluation of the most reportable event (see chapter seven, and Appendix B). Both, however, are intermingled.

healthcare provider. Nonetheless, the experience of disbelief at the hands of skeptical family members, friends, or acquaintances would deserve a study on its own merits (see e.g., Armentor 2017).

Because this dissertation was set to study how patients/narrators constructed credibility in their memoirs, the best sections to study credibility, to my judgement, were the orientation, the complicating event or most reportable event, and the evaluation of those events by the narrator. As already observed in the case of Murray's memoir, there are always rhetorical decisions that narrators make in telling their stories the way they do. Readers may ask, for instance, why is this story told in the way it is? What are the discursive effects? Among all possible complicating events, why is a particular event placed as the most reportable event? And what place or chronological order does that event occupy in the whole story?

There are advantages and disadvantages about focusing only on these sections. Given the large number of memoirs and the intense work of close reading each memoir, an advantage has been identifying these sections in each memoir and then comparing these sections among the memoirs in order to draw discursive patterns in a systematic way (see chapter six and Appendix B). The disadvantage, though, is that this study did not analyze the resolution or coda sections of the memoirs. Such study could ask other types of questions to explore; for instance, how did these authopathographies narratively resolve the complicating actions they presented? How did they come to terms with their illnesses? Or, how did narrators make sense of their experiences, especially if cure was not achieved? And others.

As mentioned, discourse and narrative analysis were the methods of analysis; however, the technique was close reading. Close reading is a fine-grained analysis, detailed oriented on language devices and its rhetorical effects in the construction of the narratives (see chapter six). This is an intense and time-consuming analysis that requires not only several readings of the same text but also close attention to the sentences, paragraphs, and chapters. The benefit of close reading is that not only themes and categories can be extracted but also discourse patterns of language use, which reveal an appreciation of the way the narrator emplots the story. Also, in doing close reading, discourse patterns are taking in relationship to their surrounding linguistic environments and discursive contexts, and this allows us for a more refined look at language use and textual construction. This is important in my study because I focused on how narrators constructed credibility especially from discursive and narrative viewpoints.

Given the use of these methods and technique, the first important conclusion is that this dissertation confirms the observation done by previous studies (e.g., Armentor 2017; Dickson, Knussen, and Flowers 2007; Lian and Robson 2017; Molloy 2020; Swoboda 2005, 2006; Quinn Schone 2019; Werner and Malterud 2003; Werner et al 2004; Ǻsbring and Närvänen 2002, 2003) concerning the challenges to credibility that patients with contested illnesses typically face. All these studies drew on Grounded Theory for their methodology rather than discourse analysis, and they based their analyses on interviews, archives, or ethnographic observations, but they did not focus on memoirs. Also, the lens of these studies was psychological, sociological, rhetorical, and medical. Thus, the present study adds to the literature on credibility concerning patients with contested illness while offering a novel method of analysis from a medical/health humanities perspective.

The medical/health humanities perspective means that this is an interdisciplinary study in which I considered historical and medical perspectives about medicine, health, and illness, sociological and cultural perspectives tracing back to postmodernism and the evolution of the illness narratives as a literary genre, to provide the context of the autopathographies studied here, as well as literary and narratological perspectives. Moreover, this study embraces a humanistic perspective of the problem these patients face. Thus, here I advocate for the cause of these patients/memoirists to be listened to and be cared for. The study showed that contested illnesses raise an appeal to care, open mindedness in scientific research and in the clinic, as well as the importance of personal attitudes toward the possibility of the fantastic and mysterious as it can intersect our reality. Whereas science might not yet be able to explain these conditions entirely, the medical/health humanities can make sense of them in analyzing their authors' voices. Also, a medical/health humanities approach has allowed me to show that these patients' conditions raise concerns about ontology, agency, legitimacy, the role of institutions such as medicine, and the need for a humble negotiation of knowledges; that is, the negotiation of the acceptance that scientific knowledge draws its expertise, in part, from nature and everyday life observations (de Certau 1984), including from the narratives of the patients' visceral knowledge. My position is that both need to be complemented in respectful ways with appreciation of the other's source of knowledge.

A second important conclusion is that this study has shown that patients with contested conditions face the likelihood of having attributed to them a contested narrative. In this study, at least, contested illnesses happen to be synonymous with contested narratives. Although this is not a generalizable observation that could be extended to all narratives of contested illnesses, as I will show later, I can confidently assert that this is a highly likely association. To arrive at this observation, I paralleled the concept of the patient's dilemma (Halkowski 2006) with the narrator's "reportability paradox," as observed by Labov (1997, 2013) (see chapter six). In other words, to gain the listener's or reader's credibility and attention, narrators must tell their personal stories within certain discursive and narrative constraints, probably dictated by socio-cultural expectations about the limits of what is considered normal, real, or possible. The tacit question is, what kind of personal stories can be accepted as such? What kind of questions can we afford to believe? And what kind of stories are discarded as non-credible?

As examined in several chapters of the dissertation (Introduction, chapters five, six, seven, and eight), all narrators face the challenge of the reportability paradox (Labov 1997, 2008, 2013). However, I argued that patients/narrators with contested illnesses are particularly challenged by the demands of the reportability paradox by virtue of the vague, subjective and out-of-the ordinary nature of their realities that seem to push further the conventional and cultural boundaries of what we can afford to accept as rational and possible.

To demonstrate my argument, I analyzed several excerpts from the selected memoirs in the primary source (memoirs of contested illnesses) (see chapter five, Appendix A) and I used external narratives to the sample, such as Slater's (2000) memoir *Lying: A Metaphorical Memoir*, to discuss the problems of representation regarding narrative reportability, credibility, and its interplay with the boundaries of autopathographies, as life-writing literature and its limits with fiction. One of the relevant aspects presented in chapter five is that I did not presuppose that these contested illnesses would automatically lead to a contested narrative. Instead, by virtue of the analysis, I reached the following observations:

(I) The credibility dilemma or hesitancy in believing patients' accounts of contested illnesses may be explained by the oscillation between, on the one hand, the credibility about the presence of certain symptoms that have a conventional reference to people's experiences in the actual world (e.g., headaches, limb numbness, and sore throat) and, on the other, the lack of credibility based on the narrator's emplotment of those symptoms, as that emplotment seems to challenge conventional diagnosis. In brief, it is speculated that the disbelief or incredulity may originate in the fact that these patients' accounts tend to emplot conventional symptoms along with unconventional syndromes that represent unfamiliar schemas or categories. For instance, parasites are accepted as part of the actual world, but the extraordinary sensory experience of hearing a parasite "as it traverses my terrain," as Pascoe (2019) asserts, is not. The question here though is: Is this sort of articulation the product of Pascoe's "delusional" imagination? Or rather, her unconventional, figurative way to articulate an out-of-the-ordinary experience and illustrate the degree of intensity of her sensations? Moreover, sore throats and headaches are typically associated with the experience of the actual world; however, the emplotment of these symptoms in concomitance with shooting pains in legs, hips, and knees could make the account more disconcerting and suspicious when finding biological evidence of that account is not possible.

(II) As mentioned earlier, patients with contested illnesses are constrained by the narrative structure imposed by the reportability paradox. Thus, they may be linguistically constrained by the very same vagueness, lack of referentiality, and lack of conventionality of their experiences that make their accounts suspicious and rationally dubious. Therefore, these patients are linguistically and narratively challenged without necessarily being themselves poor historians (Coulehan 2003). Consequently, the use of figurative language may be a need for these patients as well as the need to form unconventional syntagmatic associations. The problem is that as language is a social convention (Saussure 1959), these patients' use of figurative language and unconventional syntagmatic associations may be misinterpreted. The listener may be ill prepared for those kinds of descriptions.

(III) Contested illnesses challenge not only clinicians' interpretative and narrative skills but also patients' linguistic skills to sound as ordinary as possible, and to convey their experiences according to "the ordinary cast of mind," as Sacks (1984, 424) described. For clinicians, then, diagnosing and treating these patients will require not only a high medical expertise but also a high narratological expertise in how to approach and listen to the emplotment of patients' accounts. Narrative medicine (Charon 2006; Charon, DasGupta, Herman et al 2017) has emphasized the need for this kind of narrative approach to practice medicine and this study confirms the benefits of such an approach, as well.

(IV) Finally, I proposed that in order to approach patients with contested illness, it may help to listen to their narratives (or read their narratives), by practicing the suspension of disbelief. This practice may be necessary to facilitate a therapeutic relationship and the building of mutual trust, essential to the medical encounter. It needs to be considered that patients' use of figurative language may not be an artificial, eccentric device but rather, their best, most illustrative linguistic means to express unconventional realities to their listeners and readers. Thus, the practice of suspending disbelief, at least in the first instance, may help reduce anxieties and acknowledge that we all in society expect the delivery of personal narratives within truthful and rational boundaries, but sometimes evidence may take time to discover. Thus, in the efforts to answer the first research question, chapter five argued that medical science and clinical practice can learn a great deal from literature and its openness to deal with the uncanny.

Like previous studies (e.g., Dusembery 2018; Edwards 2013; Molloy 2020, Quinn Schone 2019; Wall 2005) discussed in several chapters, this dissertation also confirms the current tendency to psychologize the case of patients, especially female patients, with contested illnesses, as the expression "all in your head" summarizes it. The tendency to psychologize the etiology of contested illnesses seems to be a symptom of the way our culture deals with an uncomfortable reality that is poorly understood and poorly known, that challenges the institutional authority of medicine and clinicians' authority in particular (e.g., Swoboda 2008; Lian and Robson 2017). Although somatoform disorders exist as O'Sullivan (2016) clearly illustrates this problem in her book (see chapter three and four), I suggest that the problem with contested illnesses seems to be rather, the lack of validation of their illness experiences that these patients report. The tendency to psychologization is explained, in part, by psychiatrist Allan Frances' (2013) critique of the most recent version of the Diagnostic and Statistical Manual (V) as contributing to favor the hyperinflation of psychiatric disorders in the population. One of the consequences of this hyperinflation is the misdiagnosis of physical conditions that could pass as psychiatric symptoms (see Introduction and chapter three). The analysis of the memoirs corresponding to the primary source (i.e., the narratives of contested illnesses) in chapter seven, showed the narrators' indignation about their healthcare providers' insinuations, replies, or suspicions that they were imagining or somaticizing their afflictions. This was especially the case in the memoirs written by Berkowitz (2015), Hilfiger (2017), Norman, and Kamen (2005), but it was a constant theme observed, with different degrees of emotional intention, in all the narratives, even in Oliver Sack's memoir *A Leg to Stand On*, despite he did not suffer from a conventionally defined contested illness. I will return later to this point. Thus, although in this study I did not set to explore the reasons for the psychologization of patients' physical symptoms, I would be omissive if I were not state their discontent, sense of abandonment, and suffering these patients reported when their ailments were doubted as "all in their heads,"— an euphemistic new term for hysteria as developed in chapter four.

Furthermore, comments of suspicion about the psychological etiology of patients' symptoms that resulted in a contested illness, undoubtedly convey an evaluation about the personality of the patient as somehow irrational, unreliable, and lacking control of herself or himself as clearly illustrated in *The New York Times* reader's comment about fibromyalgia (see Introduction). Because, as discussed in chapter four, there is plenty of historical evidence (e.g., Cleghorn 2021; Harrington 2008; Shorter 1992, 1994;Veith 1965) indicating that all these negative attributes are gender specific, and have been more frequently attributed to women than men, this suspicion not only reproduces and reenacts old stereotypes of women as prone to fantasy, delusion, and hysteria but it may also reinforce the medical bias that contested illnesses may have a psychosomatic etiology, thus curtailing the chances for research on these conditions, as it happened with hysteria in the nineteenth century. The success of the central nervous system paradigm in that century influenced the idea that emotional and mental disorders were no longer the purview of medicine (see chapter four). Thus, as Dusembery (2018) observed, even though hysteria is nowadays not considered per se a disease category (although conversion disorder is its closer version), the popular belief that hysteria disappeared in the first part of the twentieth century is just a myth (Dusembery 70). The psychological and social connotations associated with hysterical women have remained present in our male-dominated culture. However, it needs to be observed that in this study, men were not entirely exempted from the bias of psychologization, such as in the cases of Skloot's (1996) and Sacks' (1984) who were hinted to be hypochondriac. Yet this perception was not as emotionally and linguistically charged as in the case of the female memoirs in this study.

To resume, whereas on the one hand, the psychologization of contested illnesses may lie in the very subjectivity of the symptoms experienced by patients with contested illnesses; on the other, the same subjectivity that makes the communication of vague symptoms difficult, gives, paradoxically, to these patients, the right to assert their visceral knowledge, as the impossibility for the other to refute their symptoms with absolute certainty. Thus, what may disempower these patients on the one side, it may empower them on the other. Finally, and as a side observation, I would like to state that a psychological attribution to contested conditions whose biological etiology is still poorly understood, seems to carry in this culture a heavier emotional burden for patients than, for instance, saying that it is stress related. Whereas the expression "it's all in your head" alludes to a level of agency or intentionality on the part of the patient as a fabricator of somatic delusions, the expression "it is stress related" may lessen the level of agency attribution. The causative agent refers to something impersonal, such as everyday life struggles; thus, stress is vague and indeterminate. Moreover, as an evaluative comment, "it is stress related" seems to convey a conventional but implicit acknowledgement on the part of the healthcare provider that she or he lacks a medical explanation for the patient's condition. At the same time, this expression may result in a more compassionate management of personal impressions in the interaction with the patient. My suggestion here is rather speculative though, and it would require a further line of investigation.

Regarding research question (2) concerning the types of evaluative and discourse strategies patients/memoirists used to claim credibility, two levels of analysis need to be disentangled: one is the narrative level regarding the fact that narratives are told with a point, and the other, is the pragmatic effect and social purpose with which the narratives were written. The purpose was drawn from the analysis of the narrative construction. A sensible observation is that all narratives showed a discursive orientation to create credibility, even those in the secondary source (i.e., non-contested illnesses). This was explained by Labov's theory that all narrators need to deal with the reportability paradox, and all narratives are told with a point as explained in chapter six. However, there are some exceptions to consider. First, although most memoirs corresponding to the primary source (i.e., memoirs of contested illnesses) oriented to claim credibility about the ontological status of their conditions, not all of them claimed credibility to their doctors; this was observed, for instance, in Duff's memoir, as I shall elaborate. Second, although all memoirs corresponding to the secondary source (i.e., memoirs of non-contested illnesses) made claims, their claims were not oriented to the ontological status of their conditions with exception of Sack's memoir, as I shall elaborate when I address research question three.

Kate Duff's (1993) memoir, *The Alchemy of Illness,* is clearly written to give voice to validate her personal narrative and the experience of patients with ME/CFS like her. However, the assignment of blame for that lack of validation was not oriented to her doctor but rather to an abstract entity. In her case, the assignment of blame was aimed at our Western, cultural division between mind and body which, in her view, prevents the proper understanding of patients with contested conditions. Duff attributed the onset of her ME/CFS to a childhood sexual trauma; thus, she saw her illness as psychosomatic. In this sense, Duff's approach is unique given that as previously discussed, most patients/authors resisted a psychologization of their symptoms. Perhaps, Duff's own counseling training could serve as an explanation to her approach. Another distinction in Duff's memoir is that unlike other authors, she praised her doctor for validating her emotions as well as bodily sensations:

> I remember the day I mentioned to my doctor, as an aside, that I had been depressed for months; she stopped, stared at me for a moment, and exclaimed, 'Why didn't you tell me?' Apparently, severe depression can be a symptom of allergic response, chemical sensitivity, or an imbalance of neurotransmitters, all of which are common occurrences with CFIDS [ME/CFS] and can be treated. '*Please,' my doctor continued, 'tell me all your symptoms, not just the physical ones, but the mental and emotional ones too…. I have learned with the help of my doctor to take the seemingly imaginary symptoms—the depression, fears, nightmares, body memoires, confusion, and disorientation—as seriously as the apparently physical ones.* (Duff 31) (emphasis added).

Furthermore, Duff's personal explanatory system of health is singular in this study because of her attempt to integrate the mental/emotional/spiritual with the physical, as no other memoirists offered this approach. Also, Duff constructs her illness experience as a bonus to her own psychological maturation and personhood. She claims that thanks to her illness she was able to make sense of her trauma and heal. In this sense, Duff's memoir is representative of the kind of illness narrative described by Frank (1995, 2007) and Hawkins (1993); one that finds in illness a bonus:

> I have also learned, with the help of my dreams, that this illness is facilitating my recovery from childhood sexual abuse by taking me to deeper layers of my body memory, activating a cellular consciousness that remembers not only what has happened, but to heal…. The longer I am sick the more I realize that illness is to health what dreams are to waking life—the reminder of what is forgotten, the bigger picture working toward resolution. (Duff 32-33)

In sum, memoirs like Duff, although singular in this study, allows me to suggest that claiming credibility about the ontological status of a contested condition does not always have to be in conflict between the personal, intuitive, and visceral knowledge of the patient on the one hand, and the conventional, institutionalized knowledge of science and medicine, on the other. Rather, both can coexist and complement each other, as Duff puts it.

As mentioned, these memoirs in the primary source are written with a social purpose: to reclaim the reality and truthfulness of their illness experiences. It was argued that with their memoirs, patients/authors responded retroactively to the fact of having had their illness experiences discredited in their doctors' offices. Thus, traces of their oral experiences can be retrieved within their memoirs in the use of direct or reported speech. However, as narrators of a written text, they had to construct credibility according to the narrative constraint of the reportability paradox, as explained. Thus, these memoirs are, on the one hand, an act of discursive vindication for the lack of credibility and the epistemological neglect they experienced, as almost voicing a complaint, and, on the other, they are an act of engagement with the present in which claiming credibility for their conditions is a form of personal activism and a way of self-empowering. By constructing credibility, memoirists can also build community and galvanize the public attitudes toward their diseases; they can give voice to their fellow sufferers and help them by sharing their personal stories, educate and warn the public about these diseases and their risks, and/or they can pursue all these purposes at once. In sum, these patients' memoirs are not socially naïve. As the lessons of the successful movement around HIV/AIDS activism in the 1980s and 1990s remain alive in the collective memory, these patients know that their individual voices would be lost if they do not appeal to social mobilization by adopting strategic discourses, such as memorializing their personal experiences.

To construct credibility about their most reportable event, which in most cases coincided with the onset of illness, these patients/narrators used diverse narratives devices (e.g., verb tenses, figurative language, intensifiers, comparators, narrative emplotment, others) and evaluative devices (see chapter seven, and Appendix B). Both narrative and evaluative devices are, in essence, discursive devices; however, whereas narrative devices refer to the analysis of the text, evaluative devices reveal evidence about the speaker/narrator's source of knowledge, along with her or his stance; that is, the speaker/narrator's emotional, judgmental, attitudinal position with respect to her or his experience as well as to other subjects. Thus, whereas narrative devices are based on the structure of the narrative as a text and on the narrator's narratological decisions, stancetaking is intersubjective. The combination of these two frameworks enriched the discourse analysis of the memoirs. It is also important to clarify that the narrative and evaluative devices overlap and intersect each other, even though I separated them for clarity.

Two main evidential sources of the speaker/narrator's knowledge were accounted in the analysis of these memoirs: First-hand source of knowledge (i.e., subjective, internal knowledge about one's own sensations and symptoms) and second-hand source of knowledge (i.e., objective, external knowledge) (see chapters seven and Appendix B). I would highlight here a few strategies that personally called my attention in both sources of knowledge.

First-hand Source of Knowledge

Intensifiers

Among the narrative strategies used by the memoirists, the use of intensifiers to evaluate the onset of illness is a good example. Memoirists referred to the onset of illness by means of intensifiers that foreground that event as a biographical marker. For instance, as the "pivotal moment" (Wall 2005, xix) or the moment of "explosive significance" (Wall, xix), or as the "day of infamy" (Skloot 1996, 8). These types of intensifiers indicate that these events were indeed remarkable and can be punctually identified as the most reportable events in these sufferers' narratives. Thus, most patients remember these events as biographical markers in their life stories.[3] However, other memoirists described the onset of symptoms as bothersome, but innocuous manifestations or symptoms that

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[3]. The documentary *Forgotten Plagues* about ME/CFS by directors Ryan Prior and Nicole Castillo (2015) clearly illustrates this point.

seemed inconsequential at the time. For that reason, the imprecision and seemingly inconsequential quality of these events made them appear as uneventful. Only a retrospective reflection will reveal the significance of their real nature. Crumpler's (1994) memoir about the onset of multichemical sensitivity offers an example of these seemingly uneventful symptoms, "Tingling, burning, and numbness developed in my hands and feet, and my *skin crawled* as if invaded by a million ants. Strangest of all was a *crazy feeling*, like *ice melting and trickling* deep into my brain" (25) (emphasis added). What marks the description of these symptoms as uncanny and colors them with intensity and action, is the retrospectively acquired knowledge that these symptoms were rather harbingers of troubling times in the life of that person. Another related point to this quote is the author's description of her symptoms by means of figurative language and metaphors. Without the context of the retrospective knowledge, a listener including a healthcare professional, is likely to misunderstand this type of language given its lack of conventionality. As explained earlier, the patient is using reference to everyday objects and actions but emploting them in an unconventional way.[4] While these emplotments are acceptable in literature as they are acceptable to the readers of these memoirs, they are, however, likely to be rejected in real life interactions, as in doctors' offices: these emplotments challenge the ordinary cast of mind. In these cases, my recommendation is provisional suspension of disbelief and judgement until more information could be acquired. Curiosity and open mindedness are essential for listening to bodies' oddities.

Use of Comparators

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[4]. The film *This is Going to Hurt* by director Lucy Forbes (2022) illustrates a scene in which a pregnant patient presents at the ER with seemingly innocuous symptoms. What made it seem innocuous was her unconventional way to articulate them, as a sensation in her tongue and teeth. She was dismissed as hypochondriac when indeed she had eclampsia.

Another distinctive strategy that seems to structure and organize the narratives is the use of comparators in which the narrator begins the story by describing and enumerating a list of positive, personal attributes such as, his or her personal achievements around sports, work, or studies, a description of healthy habits, active, and social lifestyle, and others. All these positive attributes tend to portray the author's vibrant personality, as a well-adjusted individual, who is socially committed and, moreover, a productive member of society. However, immediately after this robust description of positive attributes is introduced, a contrasting difference depicting a deteriorating state is shown. The effect of this contrast is powerful and may have several meanings. It elicits the mirative stance of surprise at the evident contrast, given the drastic change in the person's attitude, behavior, and demeanor. Also, it seems to convey a moral stance; that is, the memoirist's tacit way of saying that her illness is beyond her agency. The contrast is the evidence that the memoirist's illness was not due to dubious or reprehensible moral attributes but, on the contrary, to an illness that is beyond her personal control; thus, defending herself from a spoiled identity.

Second-hand Source of Knowledge

Quotative evidential and reported evidential

When we quote the words of others, we are indexing, among other meanings, the source of our knowledge. In the memoirs, it could be observed the use of direct or reported speech. Typically, quoting another persons' words positions a speaker/narrator as having a more reliable source of knowledge rather than reporting, as in the case of indirect discourse (Mushin 2001). Memoirists tend to use quotative discourse

(Aikhenvald 2005; Mushin 2001) to validate their arguments as well as their moral positionings, as in the emotional quote in Murray's (1996) memoir: "see what you started?" (4). This remark came from one of Murray's team doctors who saw her at Yale University. The rhetorical question was a compliment in reference to Murray's tenacity in insisting to the medical community around Lyme, Connecticut, that the illness she was experiencing had a biological rather than a psychogenic etiology. Her persistence mobilized the scientific community, whose efforts resulted in the organization of the first conference about Lyme disease. As Murray did, memoirists commonly used quotations to draw onto the authority of relevant figures to gain legitimacy. However, they also used quotes to invalidate their critics or to point out procedural or scientific deficiencies, as in Hilfiger's quote of the CDC websites (see chapter seven). Whereas the effect of quoting may be validating and legitimating, this effect is achieved by either aligning with a sympathizer or misaligning against a critic. In other words, the rhetorical effect does not lie in the linguistic device per se but, rather, on its use and communicative intention (Tannen [1993] 2003). In the case of the reported voices, legitimization is achieved by foregrounding one's voice over the reported person's voice, while having, though, the authoritative influence of that person as a backup. Reported evidential is a vicarious, discursive way to gain authority.

Animated and non-animated references

Another strategy observed in all memoirs corresponding to the second-hand source of knowledge is the reference to either animated, or non-animated external sources of evidence that can count as verification of the memoirists' assertions and experiences. As animated references, memoirists referred to the cases, as examples, of media figures or intellectual figures, whose stories serve them to reinforce credibility about their own cases. All memoirists used this strategy although with different degrees of frequency. One example is the memoir by Norman (2018), a sufferer of endometriosis, who referred to the late comedian Gilda Radner to illustrate the case of women whose symptoms had been psychologized as hysteric, with devastating consequences for their health.

Non-animated sources of evidence included references to historical and scientific events as mentioned earlier in Murray's case, but most notable, reference to scientific publications, newspaper articles, and literature in general. I called this strategy *intertextuality*, based on non-animated references to external, discursive sources of evidence, following the literary tradition. Intertextuality was used systematically by the memoirists to validate and legitimate their personal stances about their experiences. The use of this strategy was also identified by Molloy's (2020) study. She used the term "recuperative ethos," instead. Molloy stated, "Participants also attempt to establish ethos with reference to book and scholarly knowledge in two ways: through allusions to important texts and through descriptions of educational achievements" (127). In the present study, though, references to animated and non-animated external sources of evidence which may account for legitimization, are described in linguistic terms; for this reason, they are broader, including quotative and reportative evidentials. It is important to point out that memoirists' references to external sources of evidence were biased, in general, toward their own positions and arguments (e.g., essentially, that their conditions were biologically based rather than psychosomatic). Seldom these authors closely made or analyzed intertextual references that contradicted their positions. When done so, it was done in a more complaining tone rather than an analytic, or pedagogical one. I would say that exceptions to this style were the memoirs of Crumpler and Murray, among the memoirs of the primary source, and Frank, among the memoirs of the secondary source. With their pedagogical styles, these memoirs intended to educate the medical community about their illness experiences.

Ventriloquizing

This strategy refers to a person adopting the voice of another, or to an internalized interlocutor's message which conveys a change of frame or a change in the speaker's positioning when used (Tannen 2010). Ventriloquizing was observed in most memoirs, but with different speakers' positionings (i.e., adopting a neutral tone or a combative one). For instance, ventriloquizing was a form of constructing credibility by speaking from the position of the voice of medicine (Mishler 1984), as in Skloot's excerpt, "Sudden onset, consistent with viral infection, is a classic symptom of CFS" (9) (see chapter seven). The effect of ventriloquism in this case is to legitimize one's statement by drawing on the authority of medicine. However, while Skloot's narrator may have managed to validate his statement, Skloot, the protagonist, distanced himself from the experience of illness by objectifying it in another voice. Thus, the narrator may have gained credibility, but the protagonist seemed to have lost emotional involvement in his own cause; that is, the claim of being ill with ME/CFS rather than having ME/CFS as a real disease (Fleishman 2003).

Although stereotypically representative of the gender distinctions associated with verbal behavior, as critically observed in the linguistic literature (see e.g., Eckert 1998; Eckert and McConnel-Ginet 1998; Tannen 1994), Skloot's style seems to fit the stereotype of objectivity and emotional distance associated with male's verbal behavior.[5] An explanation, though, for the preference of the use of this style could be the belief that adopting a neutral and scientific perspective would help him legitimize his claim about being diseased.

Similarly, the memoirs of Hilfiger (2017) and Berkowitz (2015) seem to fit the stereotype of women's verbal behavior as characterized by indirectness and imprecision (Lakoff 1975; Holmes 1986). The interesting point is that in these memoirs, linguistic vagueness in the descriptions of symptoms as well as the use of contradictions seem to be highly strategic. In other words, the use of these devices seems to be a deliberate way to embrace a subjective, visceral knowledge stance; the first-hand source of interoceptive evidence used with the purpose to challenge the scientific, objective paradigm for reliability and validity (see chapter seven). I suggest that these narrators artistically and discursively challenged the logic of objectivity as reliability that was pressured upon their narratives in their encounters with their doctors. Their "unreliable" styles reconstruct the evidence against objectivity, emphasizing the elusiveness and irrationality of their conditions.

Finally, research question (3) was addressed in chapter eight. The analysis of the second source of memoirs (i.e., non-contested narratives) was used as a comparison. The analysis indicated that with exception of Sacks' memoir, most narrators did not have to

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[5]. These stereotypes assign male's verbal style as being objective and women's verbal style as being indirect and subjective. A linguistic debate about language and gender developed within sociolinguistic studies since Robin Lakoff's (1975) initial publication on this subject. Tannen (1994) enumerated the convictions of the interactional sociolinguistic approach showing that linguistic features associated with male or female verbal behavior cannot be reduced to essentialist associations with sex or gender. Rather, verbal behaviors are mainly the result of the interplay of several factors, including context, communicative intentions and purposes, and social roles among other factors.

claim credibility to their healthcare professionals, about the ontological status of their conditions. However, they made claims to their healthcare providers of other sorts, for instance, concerning the acknowledgement of their suffering and fear, or claims about the rights to choose their body images and sexual identities against medical conventions or expectations. These claims confirmed that as narratives, autopathographies are told with a story point as well as with a social purpose by means of collectivizing personal experiences (a postmodernist characteristic as elaborated on chapter one). The fact that most memoirs corresponding to the secondary source (i.e., memoirs of non-contested illnesses) did not claim credibility, then indirectly confirms that autopathographies about contested illnesses share a common claim: they claim for the ontological status of their conditions as well as for the credibility of their stories, given that their stories challenged the boundaries of the credibility paradox. Thus, I would like to suggest that these types of autopathographies may constitute a special subgenre which adds to Frank's (1995) categorization or typography of illness narratives (i.e., the restitution, chaos, and quest narratives). The term for this new category, I propose, would be *ontological narratives*. I expect this name would restore these narratives to a higher epistemic status. Ontological narratives need, in essence, two characteristics to be considered as such: a narrator who is experiencing a typically deemed contested illness, which is marked by a degree of epidemic proportion in the community, and the person's narrative struggles for gaining credibility about the ontological status of her condition as disease rather than an illness.

Regarding Sacks' memoir corresponding to the second source, this memoir proved to be important for this study precisely because it constitutes the exception. After a hiking accident in the 1970s, late neurologist and writer Oliver Sacks experienced a series of phantasmagorical symptoms (e.g., he was no longer able to recognize his injured leg as part of his body or to be aware of the position of his leg in his body image) as the consequence of what he would self-diagnosed as peripheral nerve injury. At the time, his condition was not well understood, or there was not high awareness of this condition under the radar of neurology at the time. Thus, like the memoirists in the primary source, Sacks also struggled to articulate and communicate his symptoms to his caregivers given the expectations of the reportability paradox (see chapter eight). Telling a story to his caregivers, involving his feeling that his leg no longer belonged to him would have sounded irrational and unacceptable to an audience used to expecting rational explanations. Like his fellow sufferers in the first primary source category, Sacks used terms to describe his symptoms that were vague and indirect, saying that the leg did not feel "right" or that the leg felt like "a wooden leg" (see chapter eight). In other words, metaphors and indirectness that once verbalized to a listener unaccustomed to these sorts of experiences and without the appropriate frame of mind to interpret them, were most likely to be misunderstood and conventionally constructed as "all in the head."

Sacks' story is exemplary. As readers, medical/health humanities practitioners, and healthcare providers, we can imagine that if someone like Sacks—a neurologist and storyteller—faced linguistic as well as interactional challenges (see chapter eight) to communicate his symptoms as well as suspicions of being hypochondriac, experiencing incredulity on the part of his healthcare providers, then the same can easily happen to other sufferers less competent or less privileged than Sacks. I argue here that in addition to social factors (e.g., race, ethnicity, gender, age, and others) as well as to particular social circumstances (e.g., social roles), which can have an unquestionable impact on the degree of people’s credibility in interactions, what also makes patients with contested illnesses so vulnerable to suspicions of unreliability is the very same narrative nature of their stories. As we saw in the analysis (chapters five through eight), these narratives challenged the ordinary cast of mind, posing to the narrator an even higher challenge to circumvent the reportability paradox.

In my view, this narrative aspect has been less considered in the literature in comparison to the study of the impact of social factors on reliability and credibility. Although all these factors are equally important to address the impact that suspicions on reliability may have on the patient’s wellbeing, I specially advocate for the understanding and acceptance that out-of-the-ordinary narratives may also have an impact on credibility, for which there seems to be, however, less awareness. These stories test the ordinary cast of mind and challenge the narrators to linguistically and artistically manage the narrative limits imposed by the reportability paradox. I also propose here that a way to deal with narratives of contested illnesses is by suspending disbelief and taking these narratives as the narrators’ best attempts to articulate and transfer to others their uncanny nature.

Language is an essential way of communication; however, the creation of new linguistic conventions to refer, designate, articulate, and signify new realities may take time to develop and it involves the participation of several social actors to produce and legitimize discursive change that will be accepted as normalized. In the meantime, while medical knowledge about the etiology of these conditions is currently uncertain and treatments are still tentative despite scientific progress, linguistic, and narrative uncertainty about these conditions can be expected but also, linguistic creativity and resistance. I suggest that ontological narratives as studied here, may contribute to a social, discursive change about contested conditions. “Change involves forms of transgression, crossing boundaries, such as putting together existing conventions in new combinations, or drawing upon conventions in situations which usually preclude them,” asserts discourse analyst Norman Fairclough (1992, 96). Furthermore, in the memoirs studied here, I would argue that narrators may be already doing what Fairclough describes as discursive change:

> Change leaves traces in texts in the form of the co-occurrence of contradictory or inconsistent elements—mixtures of formal and informal styles, technical and non-technical vocabularies, markers of authority and familiarity, more typically written and more typically spoken syntactic forms, and so forth. In so far as a particular tendency of discursive change ‘catches on’ and becomes solidified into an emergent new convention, what at first are perceived by interpreters as stylistically contradictory texts come to lose their patchwork effect and be ‘seamless’. Such a process of naturalization is essential to establishing new hegemonies in the sphere of discourse (Fairclough 1992, 97) (emphasis in text).

It is also my belief that this linguistic, cultural, and narrative change will be reinforced or at least, be helped by the currently recognized, although yet poorly understood case of “long Covid” illness, which affects sufferers for months with a myriad of symptoms and health complications after acute infection with the virus has passed.

As patients with long Covid are being identified and recognized by medicine as a condition of biological etiology, there is hope that by analogy patients in the chronic disease and disability communities as discussed here will enjoy more credibility, and that more financial support will be invested by the NIH in studying these conditions. In the words of Dr. Lekshmi Santhosh, a pulmonologist and director of the newly created center for long Covid patients, the “Long Covid and Post ICU Clinic” at UCSF Medical Center said, in an interview with journalist Ezra Klein.

> I hope [that] we are listening now more than ever, as we should have been all along, to our patient advocates in the chronic disease community, in the disability advocacy community, and the rare diseases community. And I hope, as you said, that we are getting lessons learned that spill over, biological insights that spill over from long Covid to other conditions. The link towards MS and virus was a huge scientific discovery as well…. *[W]e have to believe patients, we have to take it seriously, we cannot label these symptoms as, quote, "all in your head."* We cannot label them as psychosomatic or not real…. And having that humility in the medical and research community that perhaps this is something that we just don't understand yet. And we've seen that time and time again, right? If you look at the old reports of women being labeled with hysteria, and you can draw that line to where we are today and say, now we have this opportunity to listen to our patients, to study the biological underpinnings of these illnesses, and to, hopefully, change our society for the better to being a more inclusive space in general to help all people, right? And so I think that's another key concept that these communities have taught us, is that when you have protections for all people, everyone benefits. (*The New York Times*, June 21, 2022) (emphasis added)

Finally, autopathographies, as memoirs, are literary life writing texts that share many narrative techniques with the novel, to the point that the two are sometimes indistinguishable based on internal evidence alone, asserts Couser (2012, 6-7). Couser (2012) observes that this should not be surprising considering that the modern novel emerged as imitations of life writing (7). Given this observation, I suggest here that for patients/memoirists of contested illnesses in particular, the genre of memoirs is it itself validating and legitimizing: where else can a person give account of out-of-the-ordinary experiences and enjoy some credibility, if it is not by means of a literary genre that allows the hybrid interconnection between the real and the seemingly fantastic? Literature seems to be the place where the fantastic is accepted as real. Memoirs of contested illnesses or rather, ontological narratives as I proposed, constitute, in my view, the "threshold genre" (Couser 2012, 9) per excellence, not only because of some previously silent populations have been given voice for the first time as Couser claimed, but also because these memoirs challenge expectations of normalcy and confront us with uncertainty.

APPENDICES

Appendix A

Table 1. Primary Source Memoirs of Contested Illnesses

Disease Categories	**Memoirs**
ME/CFS	• *The Alchemy of Illness* (Duff 1993) • *The Night Side* (Skloot 1996) • *Encounters with the Invisible* (Wall 2005) • *Fatigue* (Acker 2019)
Lyme disease	• *The Widening Circle* (Murray 1996) • *Bite Me* (Hilfiger 2017)
Chronic pain	• *All in My Head* (Kamen 2005) (chronic headaches) • *Tender Points* (Berkowitz 2015) (fibromyalgia) • *Ask Me about My Uterus* (Norman 2018) (endometriosis) • *The Lady's Handbook for her Mysterious Illness* (neuroma) (Ramey 2020)
Miscellaneous	• *Chemical Crisis* (Crumpler 1994) (environmental chemical sensitivity) • *Brain on Fire* (Cahalan 2012) (autoimmune disease) • *The Beast Lies Within* (Pascoe 2019) (Morgellons)

Table 2. Secondary Source
Memoirs of Non-contested Illness

Disease Categories	**Memoirs**
Cancer	• *At the Will of the Body* (Frank 1991) • *The Cancer Journal* (Lorde 1997) • *A Lucky Life Interrupted* (Brokaw 2015)
Neurological Condition	• *A Leg to Stand On* (Sacks 1984)

Appendix B. Narrative and Evaluative Devices

Narratological/Rhetorical devices		**Intersubjective/ Evaluative devices**	**Discursive/ pragmatic effects**
Linguistic descriptions of illness experiences or the most reportable events 7.2.1 (a):	***First-Hand Source of Knowledge:***	Linguistic evaluations of the most reportable events 7.2.1 (b):	**Constructing credibility**:
Use of: • Figurative language: (e.g., personification and metaphors) • Intensifiers • Repetitions • Comparators		Use of: • the visceral stance or direct evidential • mirative stance • frustrative stance, • tense and aspect: use of conditional and hypothetical verb tenses as well as imperfective aspect	• Challenging reliability. • Asserting visceral knowledge. • Articulating out-of-the-ordinary experiences. • Others
	Second-Hand Source of Knowledge:	Linguistic evaluations of the most reportable events 7.2.1 (b):	
	Animated	Non-animated:	
	• Reference to a witness or a professional expert whose words are directly or indirectly reported, or are ventriloquized by the narrator	• Reference to historical events • Intertextuality (other memoirs, scientific publications, newspaper’s articles, public cases, others)	Same as above
Narrative Emplotment	• Use of chronologic, cataphoric or anaphoric temporal	• Assignment of praise or blame	Same as above

	organization of the events in the narrative		

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