WHY ME? REFLEXIVE PRACTICES IN ILLNESS MEMOIRS

by

HWA-YEN HUANG

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ABSTRACT OF THE DISSERTATION

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By HWA-YEN HUANG

Dissertation Director:

Judith Gerson

My dissertation analyzes memoirs of chronic illness as cultural sites of
reflexive identity construction. Specifically, drawing upon 40 critically acclaimed
illness memoirs published between 1980 and 2017, I explore how authors of illness
memoirs make sense of their experiences and identities by reflecting upon what
Everett Hughes (1945) calls the contradiction of status that they commonly face.
Authors tend to embody both the non-normative status of being ill and the
normative status of privileged individuals, i.e., mostly white, highly educated,
successful, professionals, e.g., professors, doctors, actors, authors, activists, etc.
Sociologist Arthur Frank (1995: 119-120)—himself a memoir writer—rightly
emphasizes that authors themselves tend to be highly aware of, and often exploit
this contradiction of status. Yet, while aware of the privileged status of memoir
authors, scholars—including Frank—have yet to explore the momentous cultural
implications of authors' effort to make sense of their dual status.

Through the reflexive work of making sense of the contradiction of the status
of being both privileged and ill, authors of illness memoirs become sensitized to two
opposite, culturally powerful, and still under-studied assumptions about the

relationship between social privilege and illness: "privileged people are immune to illness" and "no one is immune". I argue that authors tend to be critically reflexive towards both assumptions, which they recognize as one sided or double edged. In order to explore how authors critically reflect upon these two assumptions, I develop two concepts of reflexive practice that respectively deal with a particular assumption: the practice of estrangement that critiques the assumptive association between privilege and immunity, and the practice of normalization that critiques the assumption that no one is immune.

The assumption that "privileged people are (more) immune to chronic illness" often serves to essentialize social inequality through medicalized language: equating privilege with the normative biological status of health, and vice versa. The "privileged people are immune from illness" assumption is not simply a myth that reinforces difference in privilege, however, but is actually supported by two competing discourses of public health. What I call the responsibility theory of health accounts for the association of privilege with health alluding to privileged people's supposed tendency to adhere to the value of responsibility towards one's own health. The resource theory of health, in contrast, seeks to explain the association by emphasizing privileged people's access to a greater pool of resources, such as money, power, prestige, knowledge, and social connections.

The alternative to the presumptive association between privilege and immunity is the assumption that no one is immune. This assumption is supported by what I call illness identity discourse. Basically, illness identity discourse argues that biology autonomously divides people into two categories, regardless of their social

privilege: healthy and ill people. In this view, healthy people are insiders simply

because of their biological luck of not yet becoming ill, while ill people are outsiders

from the normal world simply because of their illness. In view of this dualism

between insider and outsider, I call the process of becoming ill, estrangement.

Moreover, illness identity discourse tends to emphasize that, given our inability to

control the onset and the development of chronic illness, and the illegitimate social

stigma of the ill, the difference between healthy and ill people is regarded as the

most fundamental dividing line in society. Or, being ill is the worst.

Even more interestingly, while authors generally find the assumption that no

one is immune useful in making sense of their becoming ill "in spite of" of their

privileged status, they also come to critique the assumption for making it hard for

them to normalize their illness. By this I mean the process of coming to both

recognize that healthy and ill people as not wholly distinct, and to recognize that

illness per se may actually not be the worst kind of suffering. The assumption that

no one is immune to illness can render normalization difficult by overemphasizing

the role of biology in the determination of embodied well-being. It may thus easily

lead to the wholesale denial of differences in privilege in the shaping of embodied

well-being, which is what the responsibility and resource theories of health

emphasize. This recognition tends to lead to the reflexive effort to create a middle

ground between the contradictory assumptions and the discourses that support

them.

In view of the double-edged character of both assumptions, I construct two

heuristic conceptions of reflexive practice to explore how authors critically reflect

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upon a particular assumption about health and illness in their effort to make sense of their own contradiction of status. First, the reflexive practice of estrangement mediates the author's shift from the insider status of being healthy and privileged to the outsider status of being ill yet privileged. In this shift, authors come to invalidate the commonsense association of privilege with illness, while adopting the counter-assumption that no one is immune from illness. In adopting this counter-assumption, authors give up the commonsense view of society as stratified along differences such as race, class, gender, sexuality, etc. Instead, they come to regard society as fundamentally divided by the uncontrollable power of biology, which allows some to remain healthy while making others ill in a random manner. Illness is seen as the worst because it is both uncontrollable and leads the person to be stigmatized even though she is morally blameless for her illness.

Second, the reflexive practice of normalization mediates the authors' effort to both blur the boundary between healthy and ill people and to limit their sense of worstness of being ill. In doing so, they critique the one-sided adoption of the assumption that no one is immune, which is supported by illness identity discourse. Rather than adopting the counter-assumption that privileged people are immune to illness, however, the practice of normalization seeks to reassert the role of personal and collective agency underlying the responsibility and resource theories of health in a limited manner. In doing so, authors give up illness identity discourse's dualistic view of well-being as fundamentally defined by biology. They thus come to adopt a complex and dynamic view of society where biology, personal agency, and collective agency collaboratively shape the embodied and symbolic well-being of individuals.

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Chapter One

Between Assumptions: "No One Is Immune from Chronic Illness" and

"Privileged People are More Immune"

Introduction

My dissertation looks at two reflexive practices—estrangement and

normalization—through which authors of memoirs of adult-onset chronic illnesses

juggle two assumptions about health and illness: "no one is immune from chronic

illness" and "privileged people are (more) immune." Authors of popular chronic

illness memoirs are often people who face what Hughes (1945) calls the "dilemmas

and contradictions of status," as they are both socially normative privileged people

and nonnormative members of the world of the ill. In coming to terms with their

illness experiences, they reflect upon the two competing assumptions in order to

authenticate both a sense of crisis from illness onset and a very different motivation

to normalize their illness, i.e., to regard illness as both normal and not necessarily

the worst thing.

Published first-person accounts of chronic illness, especially memoirs of

chronic illness (sometimes referred to pathographies or autopathographies), have

experienced an unprecedented boom in post-war America, particularly since the

1980s (Hunsaker ([1993] 1999, Couser 1997). These memoirs have special

significance in the cultural imagination at least in part due to the contrast between

the privileged social status of the authors and the privations of their illness

experiences, and also because of the institutional legitimation of the memoirs they

write. To begin, published memoir authors are often socially privileged individuals such as university professors, journalists, doctors, activists, artists, athletes, and politicians; further, most of them are white. Sociologist Arthur Frank, himself the author of an influential memoir on heart attack and testicular cancer, notes that illness memoirs are often written by "people of public status" or "famous people" (1995, 120). In addition, the serious attention focused on these works across the domains of popular media, patient self-support groups, and academia, in departments ranging from the humanities and social sciences to medical schools, have established both the genre and a significant number of works as canonical. Memoirs such as Paul Kalanithi's *When Breath Becomes Air* (2016), currently ranked number one on the *New York Times* list of best-selling health books (https://www.nytimes.com/books/best-sellers/2018/03/11/science/), have attained the status of modern classics through book reviews and reading lists offered by illness support groups, booksellers, publishing companies, literature review agencies, and last but not least, academic books on illness memoirs (see Hunsaker, 1992; Frank, 1995; Couser, 1997; Jurecic, 2012).

Despite the general tendency of published illness memoir authors to be people of privileged status, sociologists have yet to explore how such authors make sense of the apparent contradiction between the common assumption that associates social status with immunity from (chronic) illness, i.e., the idea that privileged people are immune from illness, and underprivileged people are not, and the undeniable fact that they are ill "in spite of" their socially privileged statuses. Rather, the sociological exploration of first-person accounts of illness in general, and

illness memoirs in particular, tends to focus on how authors reflexively challenge a non-status-relevant assumption of illness immunity: "I am immune from chronic illness," or what Bury (1982, 169) succinctly summarizes as the assumption that "the worlds of pain and suffering, possibly even of death … [are only] … distant possibilities or the plight of others." This non-status-relevant sense of immunity is attributed to the modernist belief in the ability of science and technology to subdue biological contingency in the hopes of maximizing predictability in our personal and social lives (Frank, 1995, 20, 41-43). That is, the underlying sense that even if one were to fall ill, illness will not become a chronic condition, because it should be able to be thoroughly controlled by medical intervention. Practically speaking, this belief that all illness can be fully treated through biomedical intervention justifies healthy people's tendency to regard people who do not get cured as having deviant motivations to remain ill, as exemplified by the Parsonian theory of the sick role (Parsons [1951] 2012, 306-8).

However, reviewing a significant number of critically acclaimed illness memoirs will show a very different, highly status-relevant, understanding of immunity that emerges through illness memoir authors' experience of chronic illness. After falling ill, these authors emphatically criticize a previously taken-for-granted assumption that privileged people like themselves are more immune to chronic illness than socially underprivileged people—an assumption reminiscent of the fundamental social paradox epitomized by Orwell's *Animal Farm*'s ([1945] 2009, 112) maxim, "All animals are equal, but some animals are more equal than others." Even though we seem to know that all humans are vulnerable to disruptive chronic

illnesses given the limited preventive and curative powers of biomedicine, yet privileged people are nevertheless considered, or see themselves, as more immune from chronic illness than underprivileged people. The awareness that highly educated and worldly people like themselves can fall victim to such assumption is driven home by authors' shock that they actually become ill in spite of their two supposedly illness-preventing markers of privilege: responsible living, and access to a large pool of resources including money, power, prestige, knowledge, and social connections. It will be shown in the following empirical chapters that it often seems that the authors had believed in responsible living and resources as having quasi-magical powers that would shield them from chronic illness, due to two public health discourses that I respectively call the responsibility theory of health and the resource theory of health.

The presumptive association between social privilege and immunity should not be regarded as only a self-serving myth that privileged healthy people tell themselves. Rather, it is widely shared as part of the cultural toolkit (Swidler 1986) of citizens of late-modern societies such as the United States. The cultural force of the association of privilege with health can be easily seen: our knowledge of an individual's socio-economic status serves as a mental shortcut, making her probable health state or health outcome intelligible. This is why we are often "bewildered" upon learning that successful and healthy-looking people of high socio-economic status—doctors, professors, artists, journalists, politicians, athletes, etc.—have been diagnosed with or living with—sometimes secretly—disruptive chronic illnesses. A recent case is the public shock in response to the "untimely" death of the famous

journalist, screenwriter, and director Nora Ephron in 2012 from pneumonia caused by acute myeloid leukemia, a condition she had kept secret for several years from the public and most of her colleagues and friends.

My issue with the cultural association of privilege and health goes beyond the potential errors that we make when unthinkingly using a person's social status to predict her immunity from (presently) unimmunizable chronic illness. The differences in health profiles associated with the difference in privilege may also serve to essentialize social inequality through medicalized language (Epstein, 2007). This assumption serves to validate the socially normative status of privileged people by associating it with the seemingly objective index of their biological state of health. Further, the equation of social privilege with excellent health is not the only way that biological well-being becomes an instrument for essentializing social hierarchies and differences. For example, even though a significant percentage of people living with HIV are heterosexual women or IV-drug users, HIV/AIDS nevertheless continues to be associated primarily with men who have sex with men.

Yet, we should not regard the association of privilege with immunity from sickness as unscientific or a myth. Medical scientists also hold such beliefs, and they reinforce the same assumptions through the production of scientific theories. In her award-winning book on the gendered associations of different types of headaches, for example, Joanna Kempner (2014) offers a powerful case of how representations associating cluster headaches with hypermasculine men reinscribe stereotypes of successful masculinity. Even though cluster headaches are diagnosed in both women and men, sufferers of cluster headaches are commonly depicted as

cisgender, financially successful men who, driven by the extreme pain of their headaches, isolate themselves in their homes, striving unsuccessfully to conquer their pain while protecting the peaceful sleep of their implied dependents, i.e., female partners and children (Kempner, 2014, 137-140). Given this medicalized representation of heterosexual masculinity, when confronted with the contradictory evidence of women sufferers of cluster headaches, medical experts tend to ignore the asymmetry in their initial assumption about who suffers from cluster headaches. Instead, they rationalize their initial association of masculinity with cluster headaches by assuming that the woman who suffers from cluster headaches must be in some way lacking in femininity (Kempner 2014, 142-3). On the surface, the association between a certain form of head pain with a particular gender studied by Kempner is not exactly the same as the association between immunity to illness (or permanent health) with a more generic understanding of privileged status, as studied in this dissertation. Yet, I would argue that these two different forms of association are two manifestations of the similar cultural dynamic of naturalizing the difference in social status with the difference of biological state.

In contrast to public health discourses that seek to explain the assumptive association between privilege and immunity, there is a countervailing discourse of illness identity, one that underscores the assumption "no one is immune." This discourse emerged in modernity through first-person accounts of privileged tuberculosis sufferers such as Franz Kafka, but has become popularized in late modernity's condition of the epidemiological transition, where chronic conditions have taken over communicative and acute diseases as the main sources of morbidity

and mortality (Omran 1971). The discourse of illness identity argues that ill people share common experiences and interests diametrically different from healthy people. Ill people, especially those who face adult-onset chronic illness, share the experience of being thrown into life crises by uncontrollable forces of biology. They also share the common experience of being misunderstood, silenced, and marginalized by healthy people for illnesses for which they should not be blamed. Illness identity discourse argues for the common interest of ill people to create alliances between the ill that cuts across social differences and even differences in illness type in order to collectively challenge the dominance of healthy people.

In spite of illness memoir authors' being both socially privileged yet ill, my dissertation argues that, in practice, authors do not take an either-or stance towards the competing assumptions "no one is immune from chronic illness" and "the privileged are immune," or the cultural discourses of illness identity and public health that respectively support them. Rather, authors tend to emphasize upsides and downsides to both assumptions in terms of making sense of their contradictory statuses and their personal relationships with their illnesses. As stated, authors of illness memoirs are often both socially privileged individuals who are ill. Hence, even though they may share with other ill people similar experiences and interests, their experiences with less privileged ill people are also likely to differ. At the same time, even though authors may benefit from using illness identity discourse to authenticate their life crises, their equally strong motivation to normalize their illnesses may be obstructed by illness identity discourse.

In the following sections, I first briefly discuss the two public health discourses that provide scientific accounts for the assumption "privileged people are immune to chronic illness": the responsibility theory of health and the resource theory of health. In doing so, I show how these accounts surreptitiously reinforce the essentialist association of social privilege with immunity from illness through an overly optimistic view of biomedicine and public health measures. I then turn to the countervailing discourse of illness identity, which espouses the assumption "no one is immune from illness." Then, I discuss the drawbacks of taking illness identity discourse too seriously, and point to the ways in which a limited reemphasis of personal and collective agency as embodied in public health discourse may be helpful to the ill person. Subsequently, I introduce two reflexive practices as heuristic guides to my empirical analyses in the following chapters. Finally, after a brief discussion of my data sampling and analytic methods, I offer an outline of the four empirical chapters of this dissertation.

Two Scientific Explanations for Why Socially Privileged People Are (More) Immune from Illness: The Responsibility and Resource Theories of Health

In daily life, we tend to explain our implicit association between health and privilege (especially high socio-economic status) with two attributes of socially privileged people living in the contemporary United States: a culture that values personal responsibility, and access to a large pool of resources. First, privileged people are viewed as more immune from chronic illness because they, unlike their underprivileged counterparts, believe in and practice the value of personal

responsibility towards their own health and thus are more attentive to exercise,

nutrition, and a range of health-promoting practices. Second, the resource-based

account argues that it is not so much personal responsibility that makes privileged

people more free from illness, but rather the fact that they have easier access to

valuable resources such as money, power, prestige, knowledge, and social

connections, compared to their underprivileged counterparts.

While the responsibility and resource theories of health appear to be mere

commonsense explanations, they are actually embodied in two main currents of

contemporary public health discourse. Moreover, an intense debate exists regarding

the comparative validity of the two approaches. This debate is not only due to

disciplinary boundaries but also the political perspectives undergirding each

approach. Psychological accounts tend to view personal responsibility as a main

independent variable, while sociological analyses generally focus on the distribution

of resources such as money, power, prestige, knowledge, and social connections. In

addition, the resource approach finds favor among liberals and progressives, while

the personal responsibility explanation is often central to neoliberals or

conservatives. Despite these differences, however, the approaches have more in

common than their supporters tend to see; this is especially true historically and

conceptually. Historically, as Foucault ([1978] 1990, 139) argues, the inculcation of

the value of personal responsibility and the more equitable distribution of resources

are really two sides of the coin that is the modern public health regime.

Conceptually, as a means to address or explain health disparities, both approaches

share an overly optimistic view of modern medicine and public health that is drastically challenged by disruptive chronic illnesses.

The responsibility theory of health argues that socially privileged people have earned the privilege to remain healthy because of their commitment to the value of personal responsibility with regard to one's own health. Although commitment to the value of personal responsibility to health is internalized, we can and do measure a person's commitment to health through visual indexes such as the person's mode of consumption and her bodily appearance, the latter often regarded as informed by the former. In the late modern era, the mode of consumption that is seen as health-promoting is often referred to as self-care, or what Crawford (1980) dismissively calls the "healthist" mode of consumption. The healthist mode of consumption purports to make the body feel and appear healthy, i.e., slim, athletic, and appearing younger than one's actual age (Lupton, 1994). In an era of overconsumption, the non-productivist emphasis of the healthist lifestyle may be read as a mark to differentiate socially privileged people from their underprivileged counterparts, whose ideal mode of consumption instead purports to make the body "strong" and hence productive (Featherstone, 1987, 832).

Self-care contains both positive and negative actions. Positively, self-care involves exercising, eating certain foods (often more expensive and less tasty due in part to lower levels of sugar and fat), learning to recognize and understand one's emotions, etc. Negatively, self-care requires the person to refrain from engaging in habitual or pleasurable risk behaviors such as smoking, overeating, having multiple sexual partners without using protective measures, privileging emotional impulses

over reason, and so on. As the individual element of the modern public health regime, self-care is regarded as preventive not only because it can minimize an array of health risks but also because of its presumed beneficial psychosomatic effects. In addition to its efficacy in keeping the person free from illness, the health benefits of self-care may be equated with the way it makes the body appear and feel healthy in a normative sense.

In contrast to the responsibility theory of health, the resource theory of health argues that socially privileged people, especially those of high socio-economic status, are more immune to illness not so much because of their responsibility per se, but because they have access to valuable resources such as money, power, prestige, knowledge, and social connections. For one, socially privileged people consume in a healthy way not simply because they are committed to the value of personal responsibility, but also, and perhaps more importantly, because they can afford to do so. A healthy lifestyle is costly: healthy foods tend to be more expensive than unhealthy foods; physical and/or emotional fitness programs require leisure time and financial assets; workout gear, equipment, gym memberships, trainers and therapists are costly; healthy foods and fitness programs tend to be located in prosperous neighborhoods (MacKendrick 2018). Besides allowing privileged people to consume in a healthy way, material resources can also insulate the person from health risks, as public health researchers have shown: "a person with many resources can afford to live in a high SES neighborhood where neighbors are also of high status and where, collectively, enormous clout is exerted to ensure that crime, noise, violence, pollution, traffic, and vermin are minimized

and that the best health-care facilities, parks, playgrounds, and food stores are located nearby" (Phelan et al. 2010, s30). Such resources may even limit the illness-producing effect of stress. Even though both privileged and underprivileged people are exposed to stress, because the former enjoy higher control over their personal situations due to superior resources, the stress faced by privileged people, although real, tends to be less illness-inducing (Marmot, 2015).

In contrast to the responsibility theory of health, the resource theory of health argues against the assumption that underprivileged people are more prone to illness because of their lack of responsibility. However, the resource-based account does not totally discount the possible medical effects of personal responsibility. Rather, the resource-based account regards the assumption that socially underprivileged people are more prone to illness due to a lack of *responsibility* to be an instance of the individualistic fallacy of "blaming the victim" (Ryan, [1971] 1976). It insists that underprivileged people's apparent lack of commitment to self-care is largely due to their lack of *resources.* For example, public health researchers argue that "homeless and extremely poor women … [are forced to] … turn to prostitution as a survival strategy … [and thus] … may not have the options or resources that would enable them to refuse to engage in risky sexual behaviors, no matter how well informed they may be about the risks they face" (Link and Phelan, 1995, 85). A second example is the social fact that, even knowing that contaminated environments pose health risks, and perhaps already registering the health effects from living in contaminated environments, underprivileged people often have no other choice than to live in such environments. This is shown in Swistun and

Auyero's (2009) study of the inhabitants of Flammable, a shantytown in Buenos

Aires, which is highly contaminated due to being the site of a chemical plant. Even

though the inhabitants know that the polluted air and water emitted by the plant is

making them sick, they nevertheless stay there even while fearing for the worst

because Flammable is the only place where they can afford to live, find jobs and

social connections, and receive social services through clientelistic relationships

with Peronista activists.

Despite differences, the responsibility and resource theories of health share a

sanguine view of human or social control of biology. In the personal responsibility

account, humans are assumed to be more likely than not to remain free of illness

through responsible living; those who become ill could have prevented it by

exercising personal responsibility for their health. And, implicitly accepting the

health-promoting and illness-preventing effects of cultural practices of self-care, the

resource-based account argues that illness can be promoted via another cultural

invention: the redistribution of resources, which may allow everyone to access and

engage in illness preventing and curing services. In other words, both approaches

imply that humans can, eventually, fully control our inherent biological vulnerability

through human invention.

This shared optimism regarding the cultural control of biological illness is

severely challenged by disruptive chronic illnesses such as cancer, Parkinson's

disease, amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's disease),

multiple sclerosis, intractable and severe migraine, etc. By definition, disruptive

chronic illnesses are illnesses that cannot be avoided or even treated through the

present state of medicine, let alone auxiliary cultural supports of health such as practices of self-care or more equitably distributed resources. In this regard, socially privileged people are no less vulnerable to severe chronic illness than their underprivileged counterparts. In fact, a consensus among sociologists of chronic illness is that the optimism that cultural measures, whether personal responsibility or socially managed resources can cure or prevent such illnesses, is rooted in early to mid 20th century, when the combination of medicine and public health outreach were indeed effective (for example, see Kleinman, 1988; Charmaz, 1991; Frank, 1995; Becker, 1999). Along with acute diseases such as influenza and asthma, devastating epidemic diseases that had formerly wiped out whole populations became preventable and/or treatable. In the present context of epidemiological transition, however, the association of privilege with immunity to illness could well be seen as anachronistic, as rates of non-communicable chronic diseases have risen dramatically across social categories.

In the context of disruptive chronic illness, the discourse of the inevitability of illness seems to be more plausible due to the assertion that no one, no matter how high his or her income or how healthy they appear to be, is immune from disruptive chronic illness. This conviction grounds the argument for an identity of the ill person that transcends social divides as well as illness types. At the same time, it argues for the autonomous though not wholly separate existence of a world of the ill, whose membership is solely based on being ill with disruptive chronic conditions, in contrast to the world of the healthy. In the next section, I first discuss the origin and meaning of the discourse of universal illness identity. Then, from the

perspective of the ill person, I discuss the advantages and disadvantages of that discourse in relation to the essentialist association between privilege and health.

Illness Identity Discourse: No One Is Immune from Disruptive Chronic Illness

According to Herzlich and Pierret's highly influential historical study *Illness and Self in Society* ([1984] 1987), the notion of the identity of the ill person first emerged among middle-class sufferers of tuberculosis in 19th and early 20th century Europe: "in the nineteenth century, and particularly with the advent of tuberculosis, the figure of the sick person crystallized existentially and socially, assuming its modern form" (Herzlich and Pierret [1984] 1987, 29). Illness identity differs from the Parsonian sick role in that in the former account, illness is permanent and shapes all areas of life, while in the latter, illness is assumed to be both spatially and temporally delimited. The sick role is temporary because of its curability through intervention in biomedical space. While Herzlich and Pierret do not explicitly explain what they mean by the "existential" and "social" emergence of "the figure of the sick person," it may be deduced that by "existentially," they mean the common experience of people of different statuses who face disruptive chronic conditions that radically alter their bodies, daily lives, and self-understandings (see esp. Bury, 1982 and Charmaz, 1983), and by "socially," the autonomous yet not wholly separate existence of a "world of ill people" from the "world of the healthy." Even though individual members of the world of the ill can and do shuttle between the two worlds as they interact with "normal" institutions and healthy people in the form of their family, friends, co-workers, acquaintances, total strangers, and medical

practitioners; the world of the ill is nevertheless bounded apart, spatially and culturally, from the world of the healthy. This spatial and cultural boundedness is evident in the form of illness support groups both within and outside of medical facilities.

In the spirit of French historians of medicine such as Canguilhelm and Foucault, Herzlich and Pierret argue that, for illness identity to be even thinkable let alone practicable, there need to be two different historical preconditions. First, illness identity would not be possible without a culturally shared awareness of a fundamental similarity of an existential condition among all ill people that cuts across different individual expressions of biological vulnerability. This is only made possible by the emergence of modern medicine. As medicine came to relativize the previously held differentiation between the nature of tuberculosis in the middle and upper classes and the tuberculosis of the working class, the sense of a common biological or biochemical existential basis began to take form. Previously, the tuberculosis of the middle and upper classes had been regarded as a side effect of their leisurely and cultured lives, and the tuberculosis among the working class had been attributed to a lack of education, unsanitary living conditions, or even a biologically degenerate character. Progress in medical science broke through the façade of social differences and discovered the same bacterial infection underpinning these hitherto individually and socially differentiated manifestations of illness. By enabling the shift of focus from individualized symptoms to shared biochemical processes in the body, modern medicine "provided the basis for the appearance of a homogeneous status that could arise from all kinds of failures of the

body" (Herzlich and Pierret [1984] 1987, 30). Thus, even though scholars like Rosenberg (2002) and Clarke et al. (2003) are highly suspicious of modern medicine's tendency to overlook individual manifestations of suffering by favoring underlying disease entities and genetic risks, this tendency is actually the basis of a sense of unity among ill people that cuts across otherwise salient differences in social status and illness profile.

The second precondition for the world of the ill refers to the particular features of the lives of middle-class tuberculosis patients. For the world of the ill to be thinkable, we first need a level of medical development that would allow the ill person to stay alive long enough to experience the world through such a lens. Thus, whereas tuberculosis had wiped out populations in the past, 19th-century medical science and technology made it possible for the ill person who could afford the best care to survive without being cured. Further, the world of the ill requires a social space of its own, separate from the world of the healthy, in order for it to develop a specific culture of its own. In the case of middle-class people living with tuberculosis in the 19th century, this meant the sanatorium (Herzlich and Pierret, [1984] 1987, p. 31). The culture of the sanatorium acted as an intermediary between the world of the sick and the world of the healthy by allowing the ill person to freely mingle with the world of the healthy—receiving visits and, on occasion, taking leaves—even while experiencing the mutual support and discipline provided by fellow ill persons (Herzlich and Pierret, [1984] 1987, 30).

Based on their historical discussion of the origin of illness identity and the world of the ill, Herzlich and Pierret point out the tendency for illness identity to

become a master status among the ill. The notion of the master status is based upon the social practice of foregrounding a particular status, especially nonnormative status such as illness and criminality, while backgrounding other statuses in making sense of a person's identity. Thus, the person's behaviors and experiences become primarily understood as manifestations of the foregrounded status, which is socially defined as her essence (Hughes 1945, Becker [1963] 1997). This process of illness becoming a master status can happen in both positive and negative ways. First person accounts by writer-patients such as Franz Kafka, Marie Bashkirtseff, and Katherine Mansfield show that illness identity can be useful as a source of empowerment and destigmatization, and yet can also become monopolistic, supplanting the ill person's other identities. Illness identity as a positive identity is an offshoot of the Romantic notion of illness as a source of creativity, where the ill person as artist comes to look at the ordinary world of the healthy from an outsider perspective informed by her time away from it via the sanatorium (Herzlich and Pierret, [1984] 1987, 31). However, there is also a negative variant of illness identity. This can happen when the ill person over-identifies with the lifestyle of the sanatorium and feels unable to rejoin the world of the healthy even when physically able to do so. Alternatively, the ill person may find her life inundated by the physical symptoms of the disease and the thought of unending pain and ultimately death to the extent that nothing else seems to matter (Herzlich and Pierret, [1984] 1987, 33-35).

Even though the recognition of illness as constituting identity may have originated in the 19th century, the sense of an illness identity that cuts across

differences in illness type and social status has become a cultural staple in the post-war United States. This all-encompassing notion of illness identity is encapsulated by writer and cancer survivor Susan Sontag's *Illness as Metaphor and AIDS and Its Metaphors* ([1978] 2001). In the opening paragraph, Sontag makes explicit her sense that no one is immune to any illness of any kind:

> Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag, [1978] 2001, 3)

In her highly metaphorical depictions of health and of illness, the latter of which she claims to detest, Sontag underscores the notion that all kinds of illness share the existential character of being *normal* albeit highly disruptive parts of human existence. No matter their positions in society and their biographical peculiarities, those who live in the kingdom of the well—those who are healthy—represent the daylight side of life. Sontag further drives the home the point that no one is immune by proposing that the easier, less onerous lives of healthy are only temporary, as "sooner or later each one of us," irrespective of how responsible we are or appear to be regarding our health and how much power we exert in social life, will become "at least for a spell" full-time members of the "kingdom of the ill."

In the next paragraph, Sontag further seeks to dispel the commonsense tendency to associate illness, or certain types of illness, with certain social types, arguing instead for a unitary illness identity:

> I want to describe, not what it is really like to emigrate to the kingdom of the ill and live there, but the punitive or sentimental fantasies concocted about the situation: not real geography, but stereotypes of national character. (Sontag, [1978] 2001, 3)

Sontag's notions of "punitive or sentimental fantasies" and "stereotypes of national

character" are similar to what I call the commonsense association of illness with

people with low privilege. These stereotypes of national character are found in the

three paradigmatic cases of tuberculosis, cancer, and HIV in her study of metaphors

of illness. In the case of tuberculosis in 19th century Western Europe, as seen above,

even though it was understood that not only members of the middle (and upper)

class, but also the working-class people could and did get tuberculosis, tuberculosis

among the middle-class was commonly understood as an embodied mark of cultural

sophistication, and tuberculosis among working-class people as both evidence and

consequence of their lack of culture and biological degeneracy. Despite the

supposed cultural advancement in post-war America, such stereotypes have not

disappeared but rather have found new ground, as in the examples of cancer and

HIV. Even though we know that many apparently healthy and content people may

have undiagnosed cancers, or may be living relatively comfortably with cancer,

cancer nevertheless is often associated with people who are unable to express their

feelings in healthy ways (Sontag [1978] 2001, 50-1). Similarly, even though there is

considerable evidence that a significant portion of people infected with HIV or living

with AIDS are heterosexual men and women, with disproportionate representation

from people of color and people who contracted the virus from IV drug use (and

who, often, have then transmitted the infection through heterosexual sex),

HIV/AIDS is still associated with gay men, who were the disease's first victims.

Illness Identity Discourse Troubles

For people who suddenly or unexpectedly find themselves ill, especially privileged people who assume themselves to be more immune to illness because of their resources and healthy lifestyle, the assumption that "no one is immune from illness" embodied in illness identity discourse seems eminently more reasonable than the commonsense association of privilege with immunity to illness. After all, the privileged became ill in spite of their putative higher sense of responsibility and their resources. More importantly, as with other forms of identity discourse, illness identity discourses empowers the ill person. However, like all identity discourses, illness identity discourse is not without its problems, both as a particular kind of political discourse and as a guiding discourse for the lives of ill individuals. As a particular kind of identity discourse, illness identity discourse tends to both overemphasize the difference between members of the ill world and the healthy, as well as underemphasize the difference among members within the two groups (see Seidman 1997, 34-5). As a guiding discourse for the lives of ill individuals, illness identity discourse thwarts the ill person's motivation to normalize her illness (Goffman, 1963), i.e., to acknowledge both the normality of illness and that illness is not necessarily the worst of all kinds of suffering in the world. In other words, the limits of illness identity discourse point to the reemphasis on social differences and personal differences, which are underscored by the resources and responsibility theories of health.

The discourse of illness identity socially and epistemically empowers the ill person of any social status by assuring them that they are not at fault for their

illness. Socially, it helps the ill person, no matter her level of privilege, realize that she is not isolated by her illness but is a member of the world of the ill, while at the same time she is able to recognize that the world of the healthy does not have a monopoly over what is right or normal. In epistemic terms, moreover, illness identity discourse justifies what Hill Collins (1986) terms an "outsider-within" perspective. In Hill Collins's analysis (1991), the outsider-within perspective integral to Black feminist thought is experienced by African American women who are intimate with the daily family lives of whites but also feel or recognize that whites will never accept them as belonging to the former's world. Similarly, we may imagine the outsider-within perspective of the world of the healthy as situating the world of the ill as intimate with yet also separate from the world of the healthy. In this case, we can expect the ill person to come to regard healthy people's taken-for-granted understandings of and practices surrounding illness as "anthropologically strange" (Garfinkel, [1967] 2017, 9) because of her intimate yet also alienated relationship with the world of the healthy as experienced through encounters with putatively healthy family, friends, coworkers, medical practitioners, etc.

The disadvantages of illness identity discourse are similar to yet also different from identity discourses in general. The problem shared by illness identity discourse and other identity discourses lies in the tendency to block awareness of how social differences may robustly differentiate the experiences of individual members of their identity-differentiated world, who are assumed to share fundamentally similar plights in spite of social differences as well as types of illnesses. In particular, status differences among the members of the world of the ill

may produce significant differences in the ill person's sense of control. For one thing, the fact that illness memoir authors tend to hold professional jobs that offer good insurance creates a much higher degree of control when it comes to access to healthcare, thus differentiating the illness experiences of privileged and underprivileged people living in the United States, even though privilege does not immunize one from severe illness. The power of privilege to shape the sense of control of the ill person is also obvious when we look at early articulations of illness identity discourse by, for example, Kafka (Herzlich and Pierret [1984] 1987) and Sontag ([1978] 2001). If they had not had the knowledge, skills, and economic means to allow them to retreat from daily life and focus on writing while sick, illness identity discourse and the independent world of the ill might never have been articulated as such.

Furthermore, illness identity discourse shares with other identity discourses the potential to understate or devalue other kinds of suffering. Commentators on both the right and the left have criticized this tendency to overlook other kinds of suffering in order to focus on the particular kind of suffering that unites "us" as a cornerstone of contemporary identity politics (for an example of a critique from the right, see Hunter, [1991] 1992; from the left, see Butler, [2015] 2018). On a positive note, as in the case of illness identity discourse, claims of identity based upon a particular kind of suffering may indeed empower people who endure a form of suffering and raise public awareness. On a negative note, however, identity claims based on a particular kind of suffering may become overly inward looking if not invidious, as claimants may require fellow members of the identity group, along

with the public, to regard their particular kind of suffering as "the worst" (for a sociological perspective on the definition of a particular kind of suffering as the worst, see Cerulo, 2006; Clarke, 2006). In accentuating the centrality of suffering to illness, illness identity discourse may block awareness of the existence of and calls to attend to other forms of suffering in the world caused by, for example, collective violence, sexual violence, natural disasters, job loss, bereavement, and so on. As with illness, these types of suffering may often cross social divides but are often more likely to happen to, and fall especially hard on, minorities in social divides.

Besides a shared tendency to minimize internal social differences and other forms of suffering, illness identity discourse poses another problem for the ill person's making sense of her relationship with illness. That is, while illness identity discourse may help the ill person authenticate her sense of life crisis due to illness onset, it nevertheless poses a specific problem for the ill person in order to normalize her illness. I take the term normalization from Goffman's 1963 *Stigma*, albeit with some expansion to the definition. Goffman uses the term to refer to the practice of creating a psychological distance between the self and illness by learning to regard illness not as outside of normality, but as just as normal as health: "treating the stigma as a neutral matter to be looked at in a direct, off-hand way" (Goffman [1963] 1986, 31). Broadening Goffman's definition, I understand normalization as touching upon both the symbolic and experiential aspects of illness. In my definition, normalization does not simply mean to regard being ill as an aspect of normality, but for the ill person to seek to limit her sense of the "worstness" of her illness, shifting from seeing her illness (or illness as a category)

as "the worst" to seeing it as "one among the many possible worsts" to even "not really the worst" (for a discussion of worstness as a cultural construction, see Clarke, 2006: 12-16).

How, then, can illness identity discourse both help the ill person need to have her sense of crisis recognized and nevertheless make it hard for the socially privileged ill person to normalize her illness? On the one hand, illness discourse helps the privileged yet ill person recognize the reality of her overwhelming sense of crisis of having her body, her daily routines, her assumptions, her social life, and her self being permanently and often abruptly challenged by the onset of illness (see esp. Bury 1982, Charmaz 1983). At the same time that it recognizes the ill person's sense of crisis, which healthy people tend not to appreciate, illness identity discourse further enables the privileged yet ill person to know she is not alone in having to face the life crisis caused by illness. Everybody, no matter how responsible they appear to be for their health and no matter how many resources they have access to, will sooner or later face crises because of illness.

On the other hand, illness identity discourse can make it difficult for the privileged yet ill person to transcend her sense of illness as the worst. First, by erasing social differences among the ill, the privileged yet ill person may fail to notice and appreciate her advantages compared to those of socially underprivileged people with the same diagnosis. Secondly, by positing that no one is immune from chronic disruptive illness, the discourse makes it hard for her to temper her understandable sense of (her) illness as the worst. The overemphasis on the

uncontrollability of illness may obstruct the ill person's recognition of the extent to which individual and collective agency can help limit the worstness of illness.

To sum up, both the assumptions that "no one is immune from illness" and the assumption that "privileged people are immune," as well as the cultural discourses that support them, are double-edged. Illness identity discourse helps authors recognize that they are really not immune from illness in spite of their privilege. Yet it is limited by its tendency to downplay the role of personal and collective agency emphasized by the responsibility and resource theories of health in shaping our biological vulnerability. Further, both assumptions and cultural discourses have advantages and disadvantages in addressing the personal needs of ill people. The assumption that no one is immune helps authenticate the ill person's sense of crisis and helps her see that she is not alone in the suffering, yet detracts her from recognizing how personal and social agency may ameliorate embodied suffering.

In light of this double-edged character, my dissertation examines critically acclaimed illness memoirs to explore how authors engage in reflexive practices regarding the assumption that their own lived experiences contradict, "privileged people are immune to illness." I explore how these privileged yet ill authors reflect upon the possible risks of the assumption that "no one is immune from illness," that is, the tendency to overlook how privilege matters to illness experience and thus downplay other forms of suffering. In the next section, I discuss the recent sociological framing of disruptive chronic illness as both a crisis and an opportunity in the sense of enabling the radical rethinking of one's premises about health and

illness. Then, building on Schutz' theory of reflexivity as catalyzed by experiences of shock or boundary crossing; I construct two types of reflexive practice, estrangement and normalization, as heuristic guides to my empirical analysis.

Chronic Illness as Catalyst of Reflexive Practices

My study of illness memoir authors' reflexive practices is inspired by the recent sociological reframing of disruptive chronic illness as constituting both "crisis" and "opportunity." The notion of chronic illness as a crisis situation first emerged in Bury's foundational 1982 article "Chronic Illness as Biographical Disruption" in *Sociology of Health and Illness*. Bury's framing of chronic illness as a kind of crisis or disruption is rooted in his critique of the Parsonian ([1951] 2015: 452) understanding of illness as a temporary deviance from normality. To the new generation of sociologists of health and illness such as Bury, the Parsonian theory of the sick role assumes illnesses that are acute yet also fully medically treatable. Parsons proposes that as long the person is able to afford medical care and can reignite a sense of responsibility towards the body and society, the alterations to the body and daily life caused by the illness will be temporary and readily overcome. This view of illness as temporary deviance does not fit the case of chronic illness, where the present state of medicine is able to only partially treat the person, often leaving her with some degree of diminished capacity and/or unmanageable pain. The Parsonian conception of illness as temporary aberration thus erases the experiential crisis faced by the chronically ill person. In instances of chronic illness, the person experiences irreversible and often overwhelming changes to her

previously taken-for-granted body and daily experiences, as well as the assumptions that orient the person with regards to her body and daily routines (Bury 1982, 169). Reinforcing Bury's effort to reframe chronic illness as a crisis situation, in a second foundational article published a year later in the same journal, Kathy Charmaz (1983) further clarifies the subjective meaning of crisis or disruption as a "loss of self" instigated by the ill person's shock upon experiencing the restricted life, social isolation, stigmatization, and sense of becoming a burden stemming from the illness.

Alongside the framing of chronic illness as a kind of crisis situation, sociologists of health and illness have further framed chronic illness as a kind of opportunity for reflective transformation, which Frank (1995, 1) elucidates as an ambivalent opportunity that forces the ill person to "learn to think differently" in order to adapt her thinking to the new situation. In foregrounding the ill person's capacity to engage in transformative thinking, recently sociologists further challenge Parsons's understanding of the ill person's agency solely in terms of actively wishing to get better and following medical orders. In short, sociologists have been interested in how reflexive thinking is possible in the midst of illness. The very possibility for reflexivity arises through the often painful experience of being forced to reckon with both the existence and the non-obviousness of one's background assumptions—which Bury (1982, 169) variously calls "forms of knowledge," "taken-for-granted assumptions and behaviors," "commonsense boundaries," or "explanatory systems normally used by people"—through their being disconfirmed by radical changes in practical circumstances.

Of all possible assumptions that can be disrupted by illness, sociologists have taken a special interest in the assumption of biographical continuity, which is put into question by a "sudden" radically and permanently altered situation rendered through the onset and/or diagnosis of disruptive chronic illness. With an eye to the ill person's new awareness of the non-obviousness of the assumption of biographical continuity, sociologists have looked at how the ill draw upon illness experience to render strange the modern assumption of the linear continuity of time from the outsider-within perspective of "the world of the ill" (see esp. Frank, 1995). They have also studied how the ill person may seek to normalize her illness by searching within her experiences and cultural traditions for ways to create a middle ground between absolute biographical continuity and discontinuity (for fine examples of this line of research, see Charmaz, 1991; Frank, 1995; Ezzy, 2000).

Building on recent work on chronic illness as both crisis and opportunity, my dissertation explores how ill people, especially privileged authors of critically acclaimed memoirs of illness, engage in reflexive practices regarding the two understudied yet culturally influential assumptions: "privileged people are immune from illness" and "no one is immune from illness." I use the "reflexive practices" rather than "reflect upon" to avoid positing the act of reflecting upon an assumption as something purely in the head. While the act of reflection requires a functional brain and mental effort, it is nevertheless generally mediated by reflexive *practices*.

What kind of work is done by reflexive practices? Simply put, reflexive practices are social practices that render assumptions and cultural discourses that support those assumptions "anthropologically strange" (Garfinkel [1967] 2017: 9).

Specifically, as Schutz ([1983] 1989) so cogently puts it, reflexive practices involve the "crossing of the boundaries" of experiences underlying a particular assumption. The crossing of the boundaries is made possible by the reflective person's foregrounding of experiences that "transcend" the boundaries of the assumption under challenge (see Schutz [1983] 1989: 105). The crossing may be less effortful, as in the case of the ill person suddenly finding her body and her daily routines suffused by previously "inexperienceable" experiences of suffering (for the term experienceability, see Schutz [1983] 1989: 107). As Drew Leder (1990) argues, most of our bodily parts and processes are inexperienceable when we are still healthy. These bodily processes enter our field of experience with a vengeance in the form of previously unimaginable pain or disorder when we become ill. The reflexive crossing of boundaries may also be more effortful, as in the case of the ill person who seeks to normalize her illness by searching for experiences that help her transcend her sense of illness as the worst.

While particular forms of reflexive practice may vary in the effort needed to produce the sense of shock, all reflexive practices require selective effort on the part of the reflective subject to reflect upon the assumptions put into question by the shock. This is because the person tends not to choose all experiences that transcend a particular boundary. Rather, she selects certain kinds of experiences that she finds most capable of transcending the boundary set by the assumption. Moreover, the reflective subject also needs to provide implicit or explicit reasons for why the assumption does not match reality.

Reflexive practices thus contrast with practices that are commonly studied by ethnomethodologists, especially those under the rubric of "doing gender" and, more generally, "doing difference" (Kessler and McKenna 1978, West and Zimmerman 1987, West and Fenstermaker 1995). For ethnomethodologists, these practices assume reflexivity in the sense of being able to actively make sense of the relationship between assumptions and experiential evidence. Yet, unlike the reflexive practices to be studied in this dissertation, the practices requiring reflexivity in ethnomethodological research do the reverse kind of work: sustaining the experiential boundary underlying an assumption in the face of "disconfirming" experience. For example, in Garfinkel's ([1967] 2017) study of a transgender woman named Agnes, he shows how Agnes, who is born with a penis, regards the penis as extrinsic to her identity as a woman and seeks to downplay her maleness by explicitly accentuating her femininity. In a similar vein, parents and physicians of intersexed children have long been tempted to regard the child as essentially either male or female, rather than complexifying assumptions about biological sex (for an influential account on the limit of the two-sex model, see Fausto-Sterling 1993; also see Kessler and McKenna 1978). Surgical removal of "non-essential" parts often follows from the determination of the child's essential sex based on the two-sex model.

Two Practices of Reflexivity: Estrangement and Normalization

Two kinds of reflexive practices, estrangement and normalization, shape my empirical study of reflexive practices among illness memoir authors. My

conceptualization of these two types of reflexive practices serves as heuristic devices to sensitize sociologists to the phenomenon of interest and the relationship between the phenomenon of interest and its contexts (for the notion of theory as increasing empirical sensitivity rather than positing trans-historical laws, see Blumer, 1954). Estrangement and normalization are basically two ways in which authors account for drastic changes to their lives and, in the process, perhaps gain "a greater sense of control and understanding of their environment" and "a greater sense of hope and will for the future" while increasing the ability "to cope with emotionally charged and stressful events," "produce some degree of closure," and "establish order in daily relational experiences" (Orbuch, 1997, 459). Despite the similarity of their purpose, these two reflexive practices differ in terms of the assumptions to be critically reflected upon and the new assumptions that better suit the altered situation. Further, given the particular experiences of socially privileged ill people, the reflexive practice of estrangement logically comes first, preceding the reflexive practice of normalization.

Estrangement refers to illness memoir authors' reflexive practice to mediate the estrangement from the normative world of the healthy towards becoming a member of the nonnormative world of the ill. The reflexive practice of estrangement does not merely disrupt the assumption that privileged people are more immune to illness, but also brings the ill person closer to the assumption that no one is immune from illness. As the assumptions are embodied in discourses, the practice of estrangement thus tends to involve the criticism of public health discourses such as the responsibility and resource theories of health, which provide explanations for

the presumptive association between privilege and health. At the same time, the practice of estrangement involves the adoption of illness identity discourse, which strongly endorses the no one is immune assumption.

In the following chapters, I demonstrate the practice of estrangement as catalyzed by two kinds of shocking experiences, which alert authors to their crossing the experiential boundary underlying the assumptive association of privileged with immunity. First, the practice of estrangement is rooted in their experience of suddenly shifting from the world of the healthy to the world of the ill. Beyond the fact that no one really expects to become chronically ill, this sense of unexpectedness is due to the apparent contradiction between becoming ill and being socially privileged. Second, estrangement is rooted in the unexpected shift from good to ill health and, in consequence, a similar shift in the ill person's relationships with healthy people. Despite the fact that they are still living in the healthy world, and may be still interacting with the "same" healthy people they knew before the illness, the privileged ill person nevertheless finds a qualitative shift in how they are now treated by healthy people. This is often because healthy people tend not to understand what ill people are going through, are uncomfortable with or even hostile to ill people's desire to be listened to and cared for, and fear for their own health in the face of evidence of illness.

The reflexive work of normalization mediates the authors' effort to normalize their illness. Socially speaking, this is a shift from regarding the healthy world as wholly distinct from the ill world, towards seeing the two as both parts of the same social world. Normalization refers to authors' coming to render strange

the assumption that no one is immune from illness. As discussed above, the assumption that no one is immune from illness, and the attendant discourse of illness identity, can help the ill person authenticate her sense of crisis and to obstruct her need to normalize the illness. Specifically, normalization would involve a greater sensitivity towards the role of personal and collective agency in shaping one's biological vulnerability. However, rather than a simple return to the responsibility and resource theories of health, the practice of normalization creates a new, hybrid assumption that balances out the excesses of both assumptions. Discursively, this also means producing a new, hybrid social theory that seeks to balance out the excesses of both illness identity discourse and the two public health discourses.

In the empirical chapters, I explore how the practice of normalization is catalyzed by two patterns of crossing the experiential boundary underlying the assumption that no one is immune from chronic illness. First, it involves finding evidence of mental agency among both healthy and ill individuals to prove the limited power of the mind to transcend biology. Second, the practice of normalization involves recognizing the ways in which differences in resources between the privileged and the underprivileged have great repercussions for the wellbeing of both the healthy and the ill. This recognition points to the ways in which collective agency can mitigate suffering.

Data and Methods

In order to explore the reflexive practices of estrangement and normalization of illness memoir authors, I draw upon 40 critically acclaimed illness memoirs published between 1980 and 2017. I choose the year 1980 as my starting point because it is usually considered a watershed moment for the historically unprecedented "illness memoir boom" (Couser, 1997). Specifically, my sample includes one particularly influential memoir published in 1980: Audre Lorde's critically acclaimed and widely read *The Cancer Journals*. Furthermore, using 1980 as a starting point allows me to explore the influence of illness identity discourse, as embodied in Sontag's 1978 *Illness as Metaphor,* on subsequent reflections on illness represented in memoirs written by privileged ill people.

The critical acclaim of the memoirs in my sample is measured primarily by their being chosen by illness support websites, general literature websites such as *Goodreads* and *Flavorwire*, and, previous academic studies as worthy of reading. My basis for selection is memoirs that have been mentioned at least twice in these different venues. For illness support websites, I referenced resources from health magazines and online publications, including "16 Must-Read Memoirs about Health Written by Women" by *Self* (https://www.self.com/gallery/must-read-health-memoirs), "11 Books that Shine Light on Cancer" by *Healthline* (https://www.healthline.com/health/cancer/inspiring-books-about-cancer#1), and "60 Must-Read Chronic Pain Books for Those Living with Pain" by *Paindoctor* (https://paindoctor.com/chronic-pain-books/). In terms of general literature websites, I explored booklists by *Goodreads*, including "Best Memoirs of Illness"

(https://www.goodreads.com/list/show/92562.Best_Memoirs_of_Illness), "Popular

Chronic Illness Books" (https://www.goodreads.com/shelf/show/chronic-illness),

and "First-hand Accounts of Living with Chronic Illness"

(https://www.goodreads.com/list/show/30740.Firsthand_Accounts_of_Living_with

_Chronic_Invisible_Illness_es_), as well as "Sick Lit: 10 Essential Memoirs" by

Flavorwire (http://flavorwire.com/101444/sick-lit-10-essential-illness-memoirs),

"14 Memoirs about Illness and Medicine" by *Reading It Forward*

(https://www.readitforward.com/bookshelf/14-memoirs-about-illness-and-

medicine/), and "Memoirs of Coping with Chronic, Rare, or Invisible Diseases,

Including Mental Health Problems" by *Writers and Editors*

(http://www.writersandeditors.com/blog.htm?post=800711). Lastly, I referenced

the memoirs discussed in four major academic works on the subject: Hunsaker's

Reconstructing Illness ([1993] 1999), Frank's *The Wounded Storyteller* (1995),

Couser's *Recovering Bodies* (1997), and Jurecic's *Illness as Narrative* (2012).

      A common feature of such critically acclaimed works is that they are

generally written by people with significant cultural capital, often college professors

in the humanities (primarily English and gender studies), medical doctors with a

background in the humanities (e.g., Kalanithi), medical researchers, journalists,

artists, activists, etc. As Hunsaker ([1993] 1999) notes, these critically acclaimed

authors also tend to be secular, socially conscious, and aligned with a progressive

outlook in social politics. In contrast, less critically acclaimed, but still popular,

authors of the illness memoir genre tend to be less embedded in the secular

humanist fold and tend not to be working in professions that require significant

cultural capital. Authors of critically acclaimed memoirs like to distinguish themselves from popular yet non-critically-acclaimed memoirs that endorse a positive view of illness: a paradigmatic example is Kris Carr's *Crazy Sexy Cancer Tips* (2007). Echoing Ehrenreich's (2009) critique of the increasing influence of positive psychology in illness support group culture, critically acclaimed authors tend to regard the perpetuation of such memoirs' rosy views of illness as both romanticizing illness and contributing to a sense of blaming or shaming the ill person if they are not similarly optimistic. In fact, a mark of the critically acclaimed memoirs in my discussion is that their emphasis on the ways in which illness "sucks" or is "really depressing" (Kempner, personal communication, 2016).

In my sample, I exclude co-authored memoirs, as well as memoirs by authors whose illnesses do not constitute a crisis in their bodies and daily lives. I exclude co-authored memoirs not simply to limit the size of my sample—as my definition of cultural authoritativeness can include both sole- and co-authored memoirs—or to control for the degree to which co-authored memoirs are shaped by professional writers who may be more experienced in constructing narratives that will find a market. Of course, this does not mean single-authored memoirs may not be written by ghostwriters or unacknowledged second writers. Rather, my decision to exclude co-authored memoirs is based on my interest in studying reflexive practices. Arguably self-written memoirs call for greater reflexivity on the part of the author, not simply because she has to reflect upon and identify the overarching theme of her life at the time of the writing, but also because my understanding of the writing process is that it intensifies the writer's dialogue with her experiences and

assumptions about herself in a way that is different from when, say, the memoir

subject is interviewed by a professional writer and the resulting book is marketed

with both credited as co-authors. Thus, I exclude popular memoirs such as Lance

Armstrong's 2000 *It's Not About the Bike: My Journey Back to Life*, co-written with

Sally Jenkins, an award-winning sports writer for *The Washington Post*.

     I further exclude memoirs whose authors do not consider or discuss how

their illness constitutes a fundamental sense of break in their bodies and lives. Thus,

I exclude memoirs written by authors who have been ill since birth and those by

authors who became ill in the past but whose illness has stabilized to the extent of

being no longer disruptive to their assumptions and patterns of life. I therefore

reluctantly exclude Irving K. Zola's classic memoir *Missing Pieces: A Chronicle of

Living with a Disability* (1982). Zola became ill with polio when he was 16, which led

him to walk with a cane. However, the memoir is not about his sense of crisis at the

onset of his illness, nor is it mainly about his sense of the contradiction between his

illness and being a privileged person—and ultimately a famous sociologist of

medicine and disability. Instead, it is mainly about how his visit to Het Dorp, a Dutch

village set up for disabled people not in need of immediate medical assistance,

forced him to rethink his disability. I do, however, include Christina Crosby's *A Body

Undone: Living On After Great Pain* (2016). Ostensibly, Crosby's memoir is similar to

Zola's, as both authors identify as disabled. However, Crosby's memoir is about how

her life was turned upside down after an accident that broke her spine. Moreover,

while Zola's condition appears to be stable and painless, Crosby's condition includes

both impairment and illness in the form of chronic pain.

In the spirit of Simmelian analysis of cultural patterns that transcend individual variations of context (Zerubavel, 2007), I make it a point to maximize the variability of the life circumstances of authors included in this study. While seeking to maximize the variety of illnesses under discussion, I rule out cases where the disease is congenital or where the disease leads to a stable state of impairment in order to explore the interpretive work elicited by illness disruption. With this proviso, following Couser (1997), I divide my sample into four general kinds of disease that are culturally salient in contemporary America: cancer, pain, neurological disorders, and immunological disorders. Within the category of cancer, I have included ovarian cancer, uterine cancer, prostate cancer, testicular cancer, blood cancer, tumors on the spine, and prophylactic mastectomy. Migraine, neck pain, and pain resulting from past injuries or illnesses make up my category of pain. The category of neurological disorder includes different forms of stroke and pain, while that of immunological disorders comprises cases of HIV, multiple sclerosis, and undiagnosed immunological disorders. I also include the statistically lesser cases of chronic heart disease and chronic fatigue syndrome.

In terms of the social characteristics of the authors, given that women writers predominate as memoir authors (Hunsaker, [1993] 1999), I have consciously tried to add more men to my sample. In addition, knowing that the stories of white, middle-class professionals are over-represented among published chronic illness memoirs in the U.S., I have tried to include as far as possible works by non-white men and women. Also, because critically acclaimed memoirs tend to be

written from secular perspectives (Hunsaker, [1993] 1999), I have added memoirs written by authors who are explicitly religious.

Data are analyzed based upon a combination of grounded theory methodology and abductive analysis (Charmaz 1990, Tavory and Timmermans, 2014). In Charmaz's classic account of how grounded theory helps researchers "discover chronic illness," she argues for a social constructionist approach to study social psychological processes that cut across experiences of diverse chronic illnesses. At the same time, based on the grounded methodology's critique of linear understandings of research, Charmaz (1990, 1161) argues for the researcher to accept the dialectical relationship between deduction and induction: (1) developing and refining the research and data collection questions; (2) interrogating the conceptual meanings of terms; (3) asking more conceptual questions on a generic level; and (4) making further discoveries and clarifying concepts through writing and rewriting. Recently, Tavory and Timmermans have further sought to elucidate the still somewhat murky relationship between deduction and induction in grounded theory research by pointing to the term abduction as a mental process that includes and transcends both deduction and induction. Drawing inspiration from the pragmatist philosopher Pearce, they argue that "theory construction is an ongoing pragmatic process of 'puzzling out' and problem solving that draws on existing ways of understanding what the phenomenon is 'a case of'" (Timmermans and Tavory, 2012, 167).

In light of grounded theory's traditional emphasis on being open to the dialectical relationship between data and theory, and the emphasis in abductive

theory on being open to the reframing of the data, my research has gone through

three major phases of understanding what the data is "a case of." All three phases

were based on the dialectical process of reading, theorizing, and data analyzing. I

began research with a vague question about what kinds of socially relevant

reflective work might be found among authors of chronic illness memoirs. The

second phase led to the specification of two kinds of reflective work: estrangement

and normalization. In this phase, the assumptions attacked by these two reflexive

practices were two dimensions of the commonsense tendency to regard illness as

outside of normality. In the third and final phase, I came to reframe reflexive

practices as constituting and deconstructing illness identity via questioning

assumptions. At the same time, the assumptions were further sharpened to be

mainly about immunity from illness. As a result, the dissertation examines two types

of such assumptions, respectively embodied in particular forms of cultural

discourse: the responsibility theory of health, the resource theory of health, and

illness identity discourse.

Chapters Overview

      The empirical chapters are divided into two main parts, each comprised of

two chapters. In the first part, I discuss how authors engage in the first form of

practices of estrangement (Chapter Two) and normalization (Chapter Three), which

juggle the personal responsibility theory of health with illness identity discourse.

The second part investigates how authors engage in the second form of practices of

estrangement (Chapter Four) and normalization (Chapter Five), which juggle the resource theory of health with illness identity discourse.

In Chapter Two, I explore how authors engage in the first form of estrangement: shifting from the responsibility theory of health to illness identity discourse. I find authors tend to draw upon two types of experiences of shock that are especially common in the early phases of illness trajectories. First, the authors draw upon their experiences of shock upon becoming ill surprisingly when they claim to feel at their healthiest or to all appearances had a healthy life. Even authors who should "know better"—doctors and those who are relatively older—fall prey to this quasi-magical association between healthy living and immunity from illness. Second, they emphasize shocking experiences of becoming targets of victim blaming and responsibilization. Victim blaming involves authors being blamed for their illnesses—for having been secretly irresponsible about their health—by healthy privileged people including their friends, family, coworkers, and doctors. Responsibilization refers to healthy people's demand for ill people to act responsibly, i.e., being able to mask negative emotions and to act autonomously, rather than "acting sick." The authors interpret these experiences as strategies on the part of socially privileged healthy people to restore a sense of confidence in the healthy lifestyle despite the contradictory evidence of privileged yet ill people.

In Chapter Three, I examine how authors engage in the first form of the reflexive practice of normalization: to create a new balance between illness identity discourse and the personal responsibility theory of health. Given that they became ill in spite of making healthy choices, they do not deny the mind's inability to fully

control the body's health. Nevertheless, these authors come to emphasize that ill people and healthy people can develop alternative mental practices to enhance the wellbeing of the ill, such as finding the humor in their lives and cultivating the aesthetic appreciation of the everyday. Moreover, somewhat surprisingly, they emphasize that many ill people still have a lot to learn about empathy towards other ill people while also emphasizing the possibility for healthy people to nurture empathy towards the ill.

In Chapter Four, I explore how authors practice the second form of estrangement: shifting from the resource theory of health to illness identity discourse. By pointing to the shock of suddenly finding themselves ill often at the point when they felt most successful and powerful in their private and public careers, they challenge the commonsense association of resources such as money, power, prestige, knowledge, and social ties with immunity to illness. Moreover, they render strange the practical ways healthy people affirm the association of material and social resources with health in light of the "contradictory" evidence of resourceful ill people. Rather than being accepted as resourceful yet ill people, these authors tend to feel that they are seen as merely ill by their healthy counterparts. The fact that they are also socially privileged becomes secondary to their being ill, with the effect that they are often simply ignored and excluded by the world of the healthy.

In Chapter Five, I explore how the illness memoir authors in this study do the second form of normalization: to balance illness identity discourse with the resource theory of health. To begin, they remind themselves that, even though they

are in great pain and sorrow, they are nevertheless very fortunate for not having to worry about how to pay for medical care since their jobs, unlike those of socially underprivileged ill people, provide quality health insurance. Further, they remind themselves that bodily distress and life disruption are not unique to ill people, but are experienced when categorically based violence, such as war, genocide, and domestic violence, is perpetrated by privileged people against the socially underprivileged. They conclude that suffering categorical violence is as bad if not worse than illness since becoming ill is a morally neutral event, whereas categorical violence is premised on the idea that the biologically healthy bodies of social others are nevertheless pathological and hence deserve extreme violence.

Part One:

Between the Responsibility Theory of Health and

Illness Identity Discourse

Chapter Two

Estrangement I:

From The Responsibility Theory of Health to Illness Identity Discourse

Introduction

This chapter explores how, through their "contradictory" experiences of becoming ill "in spite of" their responsible living, illness memoirs authors come to shift from the commonsense assumptive association of social privilege with immunity to the assumption that no one is immune. In other words, I will look at how the authors critique the commonsense responsibility theory of health from the perspective of illness identity discourse. The responsibility theory of health argues that that the reason why socially privileged people tend to be less prone to illness than their underprivileged counterparts is that the former tend to be responsible towards their own health while the latter tend not to. The underlying conception of the human being is therefore Cartesian, in the sense that the mind—understood here as responsibility—is considered to be not only independent from, but also dominant over, the biological body. In contrast, illness identity discourse argues that no one, no matter how responsible towards one's own health, can be immune from the uncontrollable biological shift from health to illness.

Now, responsibility and irresponsibility are not directly visible because they are "internal" mental attitudes and processes. In practice, we tend to read a person's level of responsibility towards her health through her adherence to what Crawford (1980) dismissively refers to as the healthist lifestyle, which is often regarded as

predominant among middle-class professionals. According to Featherstone (1987),

the predominance of the healthist lifestyle can actually serve as boundary marker

separating the middle and upper classes and the working class, who tend to prefer a

lifestyle that enhances "strength" rather than "health." Beyond discerning a person's

responsibility as expressed by her daily health regimen, a person's responsibility is

also understood by her attitude after the onset of illness. The ill person is expected

to take charge during illness: being positive and proactive, as she had been

previously, rather than constantly "acting sick," exhibiting behaviors understood as

overly emotional and dependent. The demand on the ill person to be responsible

has been codified as scientific knowledge through so-called positive psychology,

which regards the ill person's understandable negativity as leading to an

emotionally or even therapeutically problematic state of learned helplessness (for a

critique of the increasing influence of positive psychology in illness self-support

culture, see Ehrenreich 2009).

　　　　This chapter is organized into two major sections. The first explores the ways

in which authors constitute illness identity that cuts through privilege-based

differences in lifestyle through the "shocking" realization that they could actually

become severely and irreversibly ill "in spite of" their previous seemingly successful

efforts to nurture their health. In particular, I look at two groups of authors who

should not have been shocked at becoming ill: medical practitioners and those in

late middle age. I supplement the discussion by describing reactions from a small

number of authors who were shocked by their illnesses even though, according to

the standard of healthism, they had not lived responsibly.

In the second portion, I explore the ways in which authors render strange the responsibility theory of health through their shocking experiences of being excluded by healthy people simply because they are ill. The two main ways in which healthy people do the exclusion are blaming the victim and responsibilization. By blaming the victim I mean the healthy person's attribution of the ill person's illness to her alleged irresponsibility. Responsibilization refers to the healthy person's demand that the ill person refrains from acting sick, i.e., being overly emotional and dependent in response to their illnesses. Instead, the ill person is expected to act responsibly, i.e., cheerful yet dispassionate, exercising willpower in vowing to fight the illness rather than succumb to its effects. Finally, I discuss how the authors' work of estrangement from the responsibility theory of health gives a particular form to the dualistic understanding of society inherent in the illness identity discourse.

Becoming Ill In Spite of Responsible Living

One common theme in illness memoirs is the authors' shock at becoming ill in spite of their practice of the healthist lifestyle. They detail their dismay and astonishment with descriptions of the drastic contrasts between their somatic and social lives before and after the onset of illness, as well as the writers' sense of the speed and violence of those changes to their bodies and daily lives. At the same time, however, authors also question precisely the very shock upon becoming ill despite having tried to take sensible actions to protect and enhance their health. After all, they "know" that no one is immune to illness. Their professional training, including,

in many cases, medical training, and worldly experience should have disabused

them of the fantasy of permanent health. The shock thus forces the painful

realization that educated and worldly people like them nevertheless adopt the

irrational belief that privileged people are above chronic illness simply because they

adhere to the healthist lifestyle. To illustrate this general sense of consternation, I

turn to memoirs written by authors who "should have known better": medical

practitioners diagnosed in their mid-30s and prominent figures whose medical

crises occurred in their early 60s.

The Case of Young Doctors

Medical practitioners should know better than expect their healthy lifestyle

to immunize them from illness because they are actually trained to anticipate worst-

case scenarios in matters of illness. According to Cerulo (2006: 164), medical

practitioners are exceptions to the rule in a highly optimistic American cultural

context, whose members tend to anticipate good outcomes rather than dwell on

disastrous possibilities. As a professional community, medical practitioners are

trained to not only anticipate the worst but also to actively seek signs and evidence

of the worst. The sad truth, however, as illness memoirs written by doctors

generally admit, is that, while medical practitioners tend to anticipate the worst case

scenarios for their patients, they tend to regard themselves as immune to illness,

whether or not the illnesses that they get fall within their specialty. The doctor's

sense of immunity from illness tends to be enhanced when she adheres to the

healthy lifestyle. To illustrate how doctor-authors render strange their prior

assumption of responsibility (indexed by their adherence to the healthy lifestyle) as
fully immunizing them from illness, I draw upon Jill Bolte Taylor's *A Stroke of
Insight: A Brain Scientist's Personal Journey* (2006) and Paul Kalanithi's *When Breath
Becomes Air* (2016).

In both memoirs, authors emphasize their sense of responsibility not simply
towards their own health, but also to their jobs and their patients. Bolte Taylor
emphasizes that her choice of profession as a medical researcher and activist was
rooted not in the profession's promise of financial stability and/or prestige, but
entirely based upon her commitment to understanding and treating brain disorders.
She attributes this early commitment to her experience growing up with a brother
who acted significantly differently than others and who was later diagnosed as
schizophrenic. This experience allowed her to be sympathetic toward the plight of
people living with mental illness and their caretakers and initiated her abiding
interest in the connection between the mind and the brain (Bolte Taylor 2009, 6).
After she finished her Ph.D. in life science, she became a successful researcher on the
neurological basis of mental illness and an advocate for the rights of the mentally ill.
As part of this advocacy, she campaigned for the donation of postmortem brain
tissue to aid research on mental illness. In 1996, when she was 37, Bolte Taylor
suffered a massive stroke. After her remission, or what she felt to be a full recovery
from the stroke, she became an inspirational speaker.

In retrospect, Bolte Taylor recognizes the irony of having felt that, despite
her commitment to brain medicine, her expertise as a neurological researcher, and
her family history of brain disorder, it was unthinkable for her to experience a brain

disorder (Bolte Taylor 2009: 11). She explicitly attributes this unthinkability to her relatively young age and her professional success. As she notes, she learned "in one fell swoop [that] the rosiness of [her] life and promising future could suddenly disappear (Bolte Taylor 2009: 11). Implicitly, however, Bolte Taylor concedes she mistook her healthy lifestyle as crucial to her sense of physical invulnerability. This can be seen in her initial attempt to lessen her strange symptoms on the fateful morning of the stroke, feeling bewildered and agitated with a throbbing pain behind her eyes, which she might have regarded as symptoms of stroke had others reported them. In her own case, however, she simply assumed that these were somewhat irregular yet not life-threatening discomforts. Despite even more ominous symptoms involving apparently transcendent experiences and loss of balance after exercise, she remained "ignorant of the degree of danger [her] body was in" (Bolte Taylor, 2009, 39). Not even considering the possibility that she might have had a stroke, she reasoned that using her exercise machine to "get [her] blood flowing" might help relieve her discomfort (38). Rather than calling 911immediately, Bolte Taylor's medical judgment was entirely overcome by the quasi-magical equation of doing healthful activities such as riding a bicycle with immunity to disease. Ironically, however, the very riding of the bicycle to get her blood flowing may have actually ended up killing her by pumping more blood into her brain. As the symptoms of the stroke increased, her abilities to create and follow a plan, dial a phone, and speak intelligibly were diminished. Nevertheless, she was ultimately able to summon help and be treated.

While Bolte Taylor's inability to quickly identify and respond to the symptoms of stroke may have been due to her training as a neuroanatomist rather than clinician, Kalanithi's *When Breath Becomes Air* (2016) makes evident that the committed and experienced medical practitioner may be blind to the possibility of having an illness similar to those suffered by his own patients because of his relatively young age, adherence to healthy lifestyle, and professional success. Like Bolte Taylor, Kalanithi emphasizes that he did not go into medicine for the money or the prestige. He knew medicine was the path of least resistance for a second-generation immigrant like himself, born to middle-class Indian American parents who were both medical practitioners. Yet, he did not find the career attractive, as he was angry with his doctor father's frequent absences from home. His interest in the brain only began in college, when he read a book suggested by his girlfriend. His passion for neurological disease was further catalyzed by his anger towards society's negative view of people with brain damage. His anger first emerged when he learned of parents of children hospitalized after brain damage caused by drowning often abandoned them. His outrage at society's dismissal of people with brain disorders became stronger when his college mentor suggested that brain-damaged children would be better off dead. In medical school, he took pride in his commitment to medicine and the brain and was critical of fellow medical students who applied for so-called lifestyle medical specialties such as dermatology and cosmetic surgery. In contrast, he chose neurosurgery, which demanded the highest academic achievement and was regarded as the most challenging of all specialties.

Neurosurgery was also relevant to him philosophically because he saw the brain as

the "crucible of identity."

In 2013, his seventh and final year of residency in neurosurgery at the

Medical Center at Stanford University, Kalanithi was diagnosed with late stage lung

cancer. In his memoir, Kalanithi is critical of his previous felt sense of immunity

from illness, in spite of his commitment to the human side of medicine and his

extensive medical experience. He began seeking medical attention after noticing

symptoms such as weight loss and back pain:

> Dressed in a thin blue gown on a cold examining table, I described the symptoms. . . . "Of course," I said, "if this were a boards exam question—thirty-five-year-old with unexplained weight loss and new-onset back pain—the obvious answer would be cancer. But maybe it's just that I'm working too hard. I don't know. I'd like to get an MRI to be sure."
>
> The X-rays looked fine. We chalked the symptoms up to hard work and an aging body, scheduled a follow-up appointment, and I went back to finish my last case of the day. The weight loss slowed, and the back pain became tolerable [with ibuprofen]. . . . My journey from medical student to professor of neurosurgery was almost complete: after ten years of relentless training, I was determined to persevere for the next fifteen months, until residency ended. I had earned the respect of my seniors, won prestigious national awards, and was fielding offers from many major universities. (Kalanithi 2016, 4-6)

Despite their professional awareness of the diagnostic significance of his symptoms,

both Kalanithi and his doctor saw fit to instead ascribe these symptoms generic

causes such as "hard work" and "aging." Why did Kalanithi and his doctor so readily

dismiss the possibility of lung cancer, even though he displayed its textbook

symptoms? Although he does not specify whether he lived a full-blown healthy

lifestyle, Kalanithi links his sense of immunity to lung cancer to the fact that he "had

never smoked" in his life. After his death, his wife made a point of informing her

Twitter audience that—contrary to their veiled and overt accusations to the contrary—"you don't have to smoke to have lung cancer." His sense of immunity was further strengthened when his body appeared to bounce back and he had his choice of placements at prestigious medical centers.

Kalanithi was only persuaded that there was something very wrong with his body when the symptoms not only recurred and worsened:

> A few weeks later, I began having bouts of severe chest pain. … Some nights, I'd waked on soaked sheets, dripping sweat. My weight began dropping again, more rapidly now, from 175 to 145 pounds. I developed a persistent cough. Little doubt remained. (Kalanithi 2016, 7)

Amazingly, even though Kalanithi felt that "little doubt remained," he continued to postpone getting medical attention, instead flying to New York to visit friends from college. He was finally persuaded to see a doctor when excruciating back pain forced him to lie on a bench in Grand Central Terminal. Ironically, the diagnosis of cancer did bring out some "good" in his personal life: He was able to make up with his estranged wife after the diagnosis. His wife became pregnant when he was in treatment.

In Bolte's and Kalanithi's memoirs, we do not simply find that adherence to a healthy lifestyle (and professional success, more on this in Chapter Four) can lead the medical expert to regard herself as immune to illness. Rather, it seems that all it takes for the privileged person to regard herself as immune is just adopting particular items available from the whole healthy lifestyle package, such as having a treadmill and perhaps using it once in a while or even when one feels discomfort, as well as refraining from smoking. If asked, medical practitioners may well find the quasi-magical belief in the preventive power imputed to the healthist lifestyle and

responsible as wholly unfounded. Yet, as long as they still have their health, they regard their healthy lifestyle, even if imperfectly adhered to, as overriding specific risk factors such as family history as well as the general risk all humans face.

The Case of Older Authors

The quasi-magical association of the healthy lifestyle and permanent health expressed by Bolte Taylor and Kalanithi may be due to their being in their mid-30s at the time of their health crises. Common understandings of stroke and cancer relegate their occurrence to more advanced ages. However, the same quasi-magical association of healthy lifestyle with permanent health is expressed in memoirs by similarly highly educated and worldly authors, despite their advantage of additional decades of knowledge and observation, as well as the knowledge that many health issues are linked with advancing age. Here, Michael Korda's *Man to Man* (1996) and Susan Gubar's *Memoir of a Debulked Woman* (2012) illustrate how their sense of immunity following their adherence to the healthist lifestyle was challenged.

An English-born immigrant to the United States, Michael Korda became the editor-in-chief of the publishing company Simon & Schuster and a best-selling writer. His memoir begins with a diagnosis of prostate cancer at age 61, which he describes as "unexpected" (5). He then confides the non-obviousness of his sense of shock at the diagnosis, as he had long dealt with issues, including a series of scary symptoms, related to his enlarged prostate, which is medically associated with high risk of cancer: "the fatigue, the urinary problems, the simple, deep-down feeling that *something* was wrong" (Korda 1996, 41, emphasis in original). Nevertheless, Korda

felt immune to prostate cancer because he made the effort to switch to a healthy

lifestyle a few years before the diagnosis:

> Until a few minutes ago, . . . I had assumed myself to be a reasonably healthy
> man—with some pride, I should add, for I had given up smoking six years
> earlier, I ate and drank moderately, and I ran, worked out at the gym, or swam
> every day. Now I had cancer. (Korda 1961, 41)

While proud of being able to stop smoking, moderate his intake of food and alcohol,

and exercise daily, Korda also emphasizes that he did not accept the entire healthy

lifestyle package. Specifically, he felt uneasy with the healthist dictate to listen to

one's own body:

> I had always made fun of those well-meaning friends, recent converts to health
> food, or yoga, or some other fad, who were always warning, "You should listen
> to your body."
> My concern had always been more along the lines of getting my body to listen
> to *me*, a natural preoccupation for a man in his sixties, when all sorts of
> functions that used to take place at will begin to present difficulties. Yet I could
> now see, quite clearly, that my body *had* indeed been trying to catch my
> attention, to warn me that something was dreadfully, dangerously wrong, and I
> had stoutly refused to listen. (Korda 1996, 41, emphasis original)

Korda's resistance to listening to his body—despite feeling that something was

fundamentally wrong—is not simply due to a sense of needing to deny the prospect

of the worst. It is also connected to his imputation of femininity to such demand to

listen to one's body, which contradicts his masculine image of his independent,

omnipotent self.

While Korda attributes his sense of immunity to cancer to his adherence to a

masculinist version of the healthy lifestyle, Susan Gubar's *Memoir of a Debulked*

Woman (2012) illustrates that being a woman or having a feminist does not

necessarily increase a person's likelihood of anticipating impending illness. A

feminist writer and prominent professor of English and gender studies, Gubar was

diagnosed with late-stage ovarian cancer at age 64 in 2008 and underwent the

painful surgical process known as debulking. In contrast to Korda, Gubar recalls her

attitude toward her healthy lifestyle as significantly less sanguine: "Regardless of

my efforts to live a responsible and responsive life, it never entered my mind that I

might be exempt from the common lot" (Gubar 2012, 6). This sense of reality is

partly explained by her understanding of what it means to age: "to grow

increasingly decrepit" (Gubar 2012, 7). Gubar further attributes her sense of

vulnerability to her upbringing as the only child of survivors of the Holocaust.

Growing up, she heard stories of family members killed in concentration camps and

saw the toll of those traumatic memories on her family life and on the psyches of her

parents. Her father committed suicide while she was still young. Her mother, with

whom she has had a troubled relationship, is unhappily residing in a nursing home

as Gubar writes (Gubar 2012, 7).

Despite her realistic view of biology and human reality, Gubar nevertheless

comes to realize that, like Korda, she had imagined herself to be immune to illness.

This sense of immunity is revealed through Gubar's "shock" at her diagnosis:

> I felt that my body had been betrayed or had betrayed me, but I could not
> comprehend why or when or exactly how a malevolent presence had
> trespassed into the core of my being. (Gubar 2012, 13)

To be sure, Gubar's sense of immunity is more complex than the aforementioned

cases. For one, the cancer was entirely asymptomatic. Her sense of being ill only

surfaced after undergoing the radical surgical treatment *debulking*, which she

accentuates by adapting the word as an adjective permanently marking herself in

the title of the memoir. Nevertheless, the above quote illustrates her previous quasi-

magical sense of being in control of her body, which should not be able to "betray" her. That sense of being in control of her body is linked to her sense of effort in living a "responsible and responsive" life.

Reviewing these four memoirs, a clear pattern emerges through the authors' accounts of their shock at becoming ill "in spite of" their efforts to live a healthy life. Having achieved professional success, they each feel that they are in control of their lives. While each author's version of the healthy lifestyle suited their tastes and identities, varying in levels of exercise, food and alcohol intake, mind-body practices such as yoga or meditation, they all felt that they had "earned" the status of permanent health. The sad truth, however, is that health can never be fully earned because a lot of it has to do with uncontrollable and oftentimes unknowable processes of biology.

Belief of Self-Immunity among "Irresponsible" Privileged People

A somewhat surprising finding among the memoirs reviewed for this dissertation is that a very small minority of authors who deliberately live unhealthily—at least to the standard of contemporary healthism—also imagined themselves as immune to illness. I illustrate this with Jean-Dominique Bauby's *The Diving Bell and the Butterfly: A Memoir of Life in Death* (2008) and Thomas Larson's *The Sanctuary of Illness: A Memoir of Heart Disease* (2014).

Before Jean-Dominique Bauby was struck by a massive stroke followed by full paralysis, he was a French actor, author, and editor of the French fashion magazine *Elle*. His memoir begins with him waking up in an emergency room after a

massive, potentially fatal stroke. He describes the onset of the stroke as feeling so

out of this world that he could only compare it to an LSD trip. Even though he was

saved from what formerly would have been certain death, he survived in a condition

commonly known as locked-in syndrome: "Paralyzed from head to toe, the patient,

his mind intact, is imprisoned inside his own body, unable to speak or move. In my

case, blinking my left eyelid is my only means of communication" (Bauby 2008, 4).

With the remaining ability to blink his left eyelid, Bauby was able to write a

coherent and moving memoir by signaling each letter and word to a note-taker.

Despite this demonstration of psychological strength in the face of adversity, he was

nevertheless overwhelmed by the complete contrast between life before and after

the stroke. Life before illness is what it means to be living, as he was free to do

things that he enjoyed without the assistance of others, including eating sumptuous

meals and taking long baths, being with his wife and children, spending time with

friends and glamorous people, and so on. In contrast, the locked-in state felt like a

pseudo-life. He uses two metaphors to describe his experience of pseudo-life after

full paralysis: feeling as if a giant invisible diving bell is holding his body captive

(Bauby 2008, 3) and being given a life sentence. The latter imagery of a life sentence

emerged when he was told that he would have to be carted around in a wheelchair

for the rest of his life. Even though the occupational therapist said with a smile, "You

can handle the wheelchair," to him the purposefully lighthearted "remark had a ring

of a life sentence" (Bauby 2008, 9).

In light of his new double recognition of the existence of locked-in-syndrome

and that he happens to be an example of such condition, Bauby reflects on his prior

sense of immunity towards illness, especially consequential yet relatively commonplace illnesses such as stroke. In contrast to most other authors who regard themselves as being fooled by their healthy lifestyles, Bauby realizes that he had actually been quite irresponsible with respect to his health. An index of his irresponsibility is his prior complete lack of interest about neurological disorders:

> Up until then, I had never even heard of the brain stem. I've since learned that it is an essential component of our internal computer, the inseparable link between the brain and the spinal cord. I was brutally introduced to this vital piece of anatomy when a cerebrovascular accident took my brain stem out of action. (Bauby, 2008, 3-4)

The moral of this reflection is clear. Even though the knowledge of neurological disorders per se will not immunize us from them, we could at least make the effort to search for such knowledge and be better acquainted with it. Armed with knowledge about neurological disorders, we could at least make some changes in our daily habits in order to diminish the risks of stroke.

The irony in Bauby's case, however, is that even if he had prior knowledge about neurological disorders; he still might have failed to make the necessary changes in his lifestyle, especially with regards to diet. A significant part of his self-identity prior to the onset of locked-in syndrome is his sense of being a gourmand and bon vivant. Here, he contrasts his dietary habits prior to and after the stroke:

> But no call for alarm: I haven't starved. By means of a tube threaded into my stomach, two or three bags of brownish fluid provide my daily caloric needs. For pleasure, I have to turn to the vivid memories of tastes and smells. Once, I was a master of recycling leftovers. Now I cultivate the art of simmering memories. . . . If I do the cooking, it is always a success. (Bauby 2008, 36)

To Bauby, one of the major punishments of locked-in syndrome is the change in dietary routines. Before the stroke, he relished eating and cooking foods rich in

"taste and smells" without too much concern for caloric intake and perhaps ingredients such as sugar and fat. Now, he is eating calorie-measured "brownish fluid" fed through a tube. For him, his past eating habit appears to be merely a source of pleasure and thus does not seem to have consequences for his health.

While Bauby does not seem to be aware of—or perhaps is in denial of—the possible link between his past dietary habits and his stroke, Thomas Larson tells us that, even when he was well aware of how his lifestyle—including his dietary choices—may be implicated in his heart attack and chronic heart condition, he still regarded himself as immune to illness. Larson's memoir begins with his suffering a life-threatening heart attack while teaching a college-level writing class. According to his doctor, he was temporarily dead during the emergency surgery. He survived the ordeal with three stents implanted and the prognosis of a further major attack in his future. The shock of illness turns out to be not so shocking after all; as he shares a family history of obesity and heart conditions, which ultimately killed his brother. Even though Larson knew he was in danger of cardiac arrest and also knew full well the connection between his sedentariness and his habit of indulging in non-healthy food, he still did not find the situation serious enough to begin adhering to the healthist lifestyle. Only after his initial attack, a few more health scares, and the repeated urgings of his partner did he ultimately subscribe to the healthy lifestyle and change his behaviors.

Why would otherwise highly educated and highly worldly people like Bauby and Larson believe themselves to be immune to common yet highly consequential

chronic illnesses even though they do not make the effort to live in the healthist

way? According to Larson, this is because we are biologically wired for carelessness:

> In evolutionary terms, the passing of fear and pain prescribes our
> heedlessness. . . . Experience teaches us we're often incapable of learning much
> from experience, though we fancy that what just happened is a great teacher.
> (Larson 2014, 18)

For others, Bauby's and Larson's sense of entitlement to immunity to illness without

having to exert any effort or sacrifice their non-healthy lifestyles may be simply due

to a masculinist sense of entitlement. Without challenging these explanations, I

would further add that, deep down, they may be aware of the limit of the power for

the healthist lifestyle to immunize one from illness. After all, we often hear of

exceptional cases where people enjoyed long, healthy lives while making what

believers of healthism regard as the least healthy choices. Thus, to ask them to

compromise their comfortable habits for an unknown future seems excessive and

unwarranted.

Blaming the Victim: The Ill Person Became Ill Because of Her Alleged Irresponsibility

Besides detailed and painful accounts of their shock at the onset of disruptive

chronic conditions, illness memoir authors also tend to offer disturbing accounts of

their experiences of interacting with healthy people in their new statuses as ill

people, whether those they had known prior to the onset of illness or those who

they only met after illness onset. While individual authors differ in their sense of the

severity of their experiences as ill people interacting with the healthy and in their

sense of the degree of discomfort they experience in different situations, they

nevertheless identify two main ways in which healthy people treat the ill: blaming

the victim and responsibilization. By blaming the victim I mean the healthy person's

tendency to explain the person's illness as due to their alleged irresponsibility

towards their own health. The term blaming the victim used here is transposed from

the sociological critique of using the language of meritocracy to explain the "failure"

of minorities (see Ryan [1971] 1976). The difference is that, rather than using the

language of responsibility to deflect attention to social structure, as in Ryan's

account, here the language of responsibility is used to turn attention away from the

uncontrollable power of biology.

By responsibilization I mean the healthy person's demand that the ill person

refrains from acting irresponsibly and thus to act responsibly, at least in the

company of healthy people. The term of responsibilization is transposed from the

recent critique of the neoliberal tendency to demand individuals to act responsibly

as if they had real control over multinational corporations and the increased de-

socialized state (see Butler 2015). In transposing this term onto the domain of

chronic illness, I use responsibilization as a demand for people to act responsibly as

if she really had mental—especially emotional— control over her biologically sick

body.

The memoir authors, each of whom has experiential knowledge that no one

can be fully responsible for his or her illness, understand both responses as acts of

aggression that say more about the healthy than about the ill. In particular, they see

these as attempts to protect the healthy person's sense of invulnerability when

confronted by the "contradictory" evidence of privileged ill people who are

generally assumed to be highly responsible people. The well person solves the cognitive dissonance not by altering their assumptive association between responsible living and immunity to include the possibility that one can be responsible and still get irreversibly and severely. Rather, the well person takes the path of least of resistance by blaming the privileged person's illness on a failure to be appropriately responsible.

In this section, I illustrate the ways authors come to relativize healthy people's acts of blaming the victim. I first draw upon Kathlyn Conway's memoir of breast cancer *Ordinary Life: A Memoir of Illness* (1996) to explore how socially privileged yet ill people render strange the acts of blaming the victim in daily life. I next explore two patterns of blaming the victim in medical settings through Kat Duff's *The Alchemy of Illness* (1993) and Lynne Greenberg's *A Body Broken: A Memoir* (2009).

According to Kathlyn Conway, healthy people blame the ill for a selfish reason: to reassure themselves that if they live responsibly, they will be immune from illness. After many years in remission from Hodgkin's lymphoma, which had been diagnosed and treated while she was pursuing a Ph.D. in English literature at Harvard at age 26, Conway was diagnosed with breast cancer at 42. While the memoir does not discuss the extent to which she may have taken care of her health after the Hodgkin's disease was in remission, she, like other authors, was shocked by the diagnosis of breast cancer. This shock bespeaks her sense of immunity to cancer even as she was in remission. The unexpected diagnosis of breast cancer

disrupted her professional life as a therapist and her personal life as a wife and

mother of two young children.

The dominant theme in Conway's memoir is that ill people are morally

blameless victims of the vicissitudes of biology (for the labeling of sufferers as

morally blameless victims, see Best 1990, Loseke 1992, Davis 2005), which create

uncontrollable crises in their bodily and personal lives. Thus, they should neither be

held (fully) responsible for becoming ill nor be judged for irresponsible reactions to

their illness such as being overly emotional and dependent. The way her friends and

relatives treated her follows a general pattern. Initially, there appears to be

wholehearted support of the ill person. After friends and family learn the bad news,

Conway remembers "[a]t first I feel only an outpouring of love and affection. Each

day I return to a long tape of messages on my answering machine" (Conway 1993,

57). However, the sense of being loved and supported soon dissipated: "As time

goes on, people's reactions became more complicated" (Conway 1993, 57).

Specifically, Conway notes the increase in questions about the causes of her disease.

While on the surface these questions appear to come from genuine concern, she

perceives them as efforts to blame her, the ill person, for unfortunate events that no

one can control:

> Once they absorb the news, they begin to protect themselves from their own
> feelings of vulnerability. Sometimes this means that by eating carrots or
> exercising they will be spared. They ask questions that leave me feeling
> blamed. Is there breast cancer in my family? Do I eat red meat, or meat treated
> with antibiotics, or any meat at all? Does my diet contain fat? Do I exercise?
> Have I been under a lot of stress? I begin to feel set apart, isolated and viewed
> as responsible for this cancer. (Conway 1993, 57-58)

To Conway, it is bad enough that so-called family and friends do not support her efforts to cope with her physical and emotional pain; worse, people in her private circles actively impute irresponsibility in order to explain why she became ill and to reassure themselves that they could continue to imagine themselves immune from similar illnesses due to their own responsible choices.

Despite feeling "judged and angry that people are considering their own psychic needs over my feelings," (Conway 1993, 58) Conway seems understanding enough to suggest that such fear may actually lurk in the subconsciousness of the healthy others, whose conscious feelings are otherwise. "Most people would be horrified at the suggestion that they are blaming me" (Conway 1993,58). Yet, she nevertheless comes to feel alienated from family and friends. Her sense of being an outsider leads her to refer to her family and friends as *they*. This linguistic choice signals her sense of estrangement from the world of the healthy, whose difference from the ill supplants differences in social distance in relation to the ill person. At the same time, the use of the term suggests Conway's sense of integration into the world of the ill, who despite their differences in social status and illness type, are collectively misunderstood and mistreated by the healthy.

While medical practitioners may pride themselves as more able than lay people to impartially interact with the ill, memoir authors often document doctors' acts of imputing irresponsibility to them in order to explain their illnesses. The doctors' practice of sustaining the initial association of the health of privileged people with responsibility seems most common in cases of contested illness and medical conditions with unclear etiologies. By contested illness I refer to illnesses—

for example, fibromyalgia and chronic fatigue syndrome—whose ontological status is still under debate in the medical community. Recognition of the illness as such is often achieved only after political organizing on the part of sufferers (see for example the discussion of fibromyalgia in Barker 2005). In the face of patients who consistently complain of symptoms that do not seem to have an objective basis, or who simply do not respond to treatment, doctors often conclude that either the person is faking it (possibly due to mental illness, as with Munchausen syndrome), or has a psychosomatic disorder: is experiencing physical symptoms caused by stress or subconsciously wants to be ill, perhaps in order to shirk duties (for the pathologization of sufferers of contested illness, see Barker 2005; Dumit 2006; Jutel 2010). Here, Kat Duff's *The Alchemy of Illness* (1993) and Lynne Greenberg's *The Body Broken* (2009) provide two different patterns of the attribution of irresponsibility to the ill person by medical personnel.

Duff, a Jungian psychotherapist, became ill with chronic fatigue and immune dysfunction syndrome, or CFIDS, at age 36. Her case illustrates how medical professionals cast blame on patients whose symptoms are subjectively real yet lack a definitive biological basis. Duff's illness emerges within the context of coping with the traumatic memory of sexual molestation when she was baby, which she perceives as linked to her CFIDS. For Duff, the symptoms and pain of CFIDS are all too real, best described as "a bad flu that never goes away" and as highly disruptive: "[c]onstant fevers, muscle aches, exhaustion, and memory lapses unraveled [her] life and sense of [herself] in a matter of months" (Duff 1993, xi). Despite the reality of her illness, the ontological character of CFIDS was contested.

> Anyone who has lived with an illness that eludes medical identification can attest that friends, family, and physicians are often quick to recommend psychiatrists and dismiss complaints as hypochondria—until a diagnosis is finally made. That is why so many sick people are relieved, even elated, to receive a diagnosis, even though the news is rarely. (Duff 1993, 30)

Duff's quote evinces her anger at failing to have her illness recognized as real and at being unable to persuade others that her illness is not due to an alleged lack of sense of responsibility to get better. Despite the dominant tendency to regard CFID as fake or purely psychological, because the medical community is split in its opinion about the reality and treatability of CFID, she was able to find support. While Duff does not explicitly say as much, she implies that the reasons for the medical dismissal of CFID are in part gendered, citing the finding of Stephen Strauss, the first researcher of CFIDS at the National Institutes of Health, that CFID is not a real disease but merely a "psychoneurotic condition" (Duff 1993, 29). This tendency to dismiss CFID as due to a neurotic condition or personality type echoes the significant percentage of migraine experts who explain the prevalence of migraine among women as due to their supposed over-sensitivity (see Kempner 2014). Duff's sense of the gendered character of medical professionals' general dismissal of CFID is further confirmed upon finding a female doctor who not only affirmed the biological reality of her illness but also shared her psychoanalytic theory that the illness was rooted in her memory of incest trauma and subsequent physiological reactions to that trauma.

While Duff's experience of moral blaming is based on an illness with an uncertain biological basis, Lynne Greenberg's case illustrates the possibility that a person can have an objective basis for the disease but still be regarded as mentally ill simply because of the intractability of the illness, in this case, chronic pain.

Greenberg's memoir begins with a serious, potentially fatal neck fracture that she experienced in high school. Although the injury ended her dream of becoming a dancer, otherwise she seems to have had a complete recovery and she thinks little about the injury for the next 20-odd years. At that point, a professor of English literature, married with two young children, enjoying a vibrant community of friends and having just taken up cycling six months earlier, she began to notice excruciating pain in her neck and head while doing research at the British Library. Initially dismissing the pain as caused by work strain, she was forced to seek medical attention by the end of the vacation, as the pain would make it impossible for her to return to teaching duties. Medical examinations revealed that her spinal injury had never healed. Individual doctors differed in their explanations, and none of their treatment regimens were successful. After consulting all kinds of specialists and trying different treatment modalities, Greenberg did not register any significant relief from the pain. Unsurprisingly, doctors began to focus on her stress level and mental fitness at the time when the pain started (Greenberg 2009, 17). After a series of questionings along this line, even Greenberg began to question her mental fitness, wondering whether the emotional pain from underlying dissatisfactions with life in general to difficulties adjusting to life in London caused the physical pain, rather than her initial assumption that the long-dormant physical pain of her incompletely healed fracture had led to her mental pain. Although tortured by such unresolvable issues, she felt unable to challenge her doctors' diagnoses (Greenberg 2009, 51).

To sum up, the authors, who represent themselves as responsible individuals in their professional, interpersonal, and physical lives, tend to feel that they should

not be held (fully) responsible for their illnesses. Instead, their lack of a cure or substantial relief from their symptoms indicates a failure of modern medicine. Often, family, friends, doctors fail to share this perspective; instead, they allege that the illness was caused by the ill person's irresponsible actions. From the perspective that they are not responsible for their illness, authors come to see the blaming as an attempt by healthy people to distance themselves from the ill and to reinforce the belief that they can maintain their immunity to illness if they only continue to live responsibly. Moreover, for doctors, the blaming of the ill person may simply serve to save face in light of their inability to diagnose and treat such problem patients effectively.

Given that the illnesses discussed in the present section are all commonly associated with women, whether, as in breast cancer, anatomical norms mean that the majority of diagnoses will occur in female bodies, or, as in CFID, are more often reported by women and that the authors writing about such conditions are women, a gendered character in the imputation of irresponsibility onto the ill begins to emerge. This initial finding opens up questions such as whether and how men's imputed irresponsibility is assigned as the basis for their illnesses, as well as how moral blame varies through the intersection of other lines of difference and types of illness.

The Practice of Responsibilization: Demanding the Ill Person to Act

Responsibly

In addition to the experience of being blamed for one's illness, authors also

often discuss another source of distress in their experiences of interacting with

healthy people: the experience of being demanded—explicitly or implicitly—by

healthy people to actively act responsibly and refrain from acting "irresponsibly" at

least in the company of healthy people. The so-called irresponsibility on the part of

the socially privileged yet ill person is manifested in her "acting sick," i.e., acting as if

wholly overwhelmed by one's illness, and in a way that strikes the healthy person as

overly emotional, dependent, and/or self-centered. Just as the healthy person's

responsibility lies in her effort to resist urges to overeat or to remain sedentary, the

ill person' responsibility lies in overcoming her natural tendency to show that she is

sick. For the memoirists in this study, the healthy person's demand for the ill person

to act responsibly says more about the healthy person than the ill person, in

particular by revealing the formers' unease at the sight of the irresponsibly acting ill

person. In order to explore how authors render strange healthy people's acts of

responsibilization of the ill in daily and in medical settings, I draw upon Nancy

Mairs's memoir of multiple sclerosis and paraplegia, *Waist-High in the World: A Life*

among the Non-Disabled (1996) and Arthur Frank's *At the Will of the Body* (1991).

Nancy Mairs's memoir begins with her diagnosis of multiple sclerosis at age

28, when she was an aspiring feminist poet about to begin her MFA degree and later

a Ph.D. in English at the University of Arizona. Even though Mairs does not explicitly

say whether she adhered to a healthist lifestyle, she nevertheless assumed that she

would never get multiple sclerosis, which led her to dismiss the possible

significance of symptoms such as increased limping when they appeared. Changes in

her body significantly disrupted her life. Her husband had an affair during her

health crisis, although the couple reconciled afterward. She continues to feel guilt

towards her children by not fully being able to care for them when they were young.

Mairs identifies as disabled rather than ill, and as a disability activist on

behalf of people such as herself. One main target of her activism is able-bodied

people's habitual explicit or implicit demand that disabled people to act as

responsible individuals, that is to appear to rise above and minimize the sometimes

overwhelming bodily, emotional, and social difficulties disabled people experience.

Such difficulties are normally seen by the able-bodied as causing the disabled

person to act irresponsibly, e.g., being overly emotional, focusing too much on

themselves, expressing the need for others to sympathize for them, etc. How do the

able-bodied impose responsibility on the person? Simply put, the able-bodied

demand that the disabled be grateful that their difficult situations offer spiritual

growth opportunities able-bodied are denied. Thus, disabled people should be

happy rather than always feeling dejected and bring able-bodied people down.

Mairs rejects this demand at the beginning of her memoir, announcing that she has

not written a feel-good, inspirational book about her journey from able-bodied

academic to wheelchair-using activist:

> I am not now, nor have I ever been, a member of the inspirational class. I suppose you might call this instead a "feel-real" book, and reality has never been high on any popular list. I ask you to read this book, then, not to be uplifted, but to be lowered and steadied into what may be unfamiliar, but is not inhospitable, space. (Mairs, 1996, 18)

For Mairs, the notion that becoming disabled is a blessing in disguise is harmful to both the disabled *and* the able-bodied. It is harmful to the disabled by denying them the possibility to mourn. As Ehrenreich (2009) similarly argues in her trenchant critique of the increasing influence of so-called positive psychology in the world of ill people, disabled people are required to appreciate their difficulties as blessings. As a consequence of the unvigilant adoption of positive psychology among the disabled and the ill, a deeper layer of harm is inflicted on a disabled person who cannot find anything good coming out of the challenges posed by her physical condition.

But perhaps the notion that being disabled is a blessing in disguise is even more harmful to the able-bodied because it renders them even more unable to come to terms with their existential fear that they themselves might become disabled:

> Most nondisabled people, except perhaps the very old, have gotten the message that it isn't politically correct to look me up and down and burst out, "Oh, you poor thing! I feel so sorry for you!" Instead, their response tends to take the form of unmerited admiration. "You are so brave!" they gush, generally when I have nothing more awesome than to roll up to the dairy case and select a carton of vanilla yogurt. "I could never do what you do!" Of course they could . . . do exactly what I do, maybe do it better, but the very thought of ever being like me so horrifies them that they can't permit themselves to put themselves on my wheels even for an instant. Admiration, masking a queasy pity and fear, serves as a distancing mechanism . . . Better to deny the perfectly ordinary qualities most cripples possess, thus ascribing to them an other, safely remote reality, than to risk identification of their own lives with a life that dismays and perhaps even disgusts them. (Mairs 1996, 32)

In defining the situation of the disabled as an extraordinary blessing that the able-bodied cannot access, the able-bodied person reinforces the cultural commonsense notion that disability and its companion, illness, are not normal parts of society and life. In contrast to the cultural tendency to regard illness/disability as outside of the

normal world, Mairs argues that the world of the disabled and the world of the able-bodied are really just one world. This is not simply because there is a high likelihood that people will experience one form or another of physical disability as we age. It is also because both the disabled and the abled face many different kinds of impairments and handicaps in their lives, even though the impairment of the disabled tends to be more visible. For example, an able-bodied person may feel impaired by her broken family, career disappointments, dearth of friends, etc., while the disabled person may have the loving family, career success, and a vibrant community that the former lacks. Notwithstanding, a key similarity between the worlds of the able-bodied and disabled lies in the fact that, in spite of all our visible and invisible impairments, the able-bodied and the disabled tend to make the best of their situations. This awareness of similarity that everyone, no matter their ability, wishes to make the best of their situations is driven home in her discussion while swimming with a fellow member of her support group:

> "What do you suppose [ablebodied] people will think when they see us?" asked Amy.
> "'Oh the poor things [normal people]!" I laughed. "They have no idea we're capable of having fun!" (Mairs 1996, 16)

Turning from Mairs's discussion of the ways able-bodied (and in other instances, healthy) friends and family demand that the ill person acts responsibly in daily settings, the sociologist Arthur Frank draws upon his experiences as a heart and testicular cancer patient to render strange the ways in which healthy medical professionals demand the ill person to act responsibly in caregiving and clinical settings. This may seem counter-intuitive, given medical practitioners' pride in

being more rational than non-medical lay people in treating the ill. However, as

Frank shows in his memoir, the healthy medical practitioner is often just as averse

to the ill person's overwhelmed responses to the overwhelming changes wrought by

disruptive chronic conditions.

Before discussing how Frank's memoir renders strange medical

practitioners' effort to responsibilize the ill person, it seems apposite to digress a

little and look at Frank's candid reflection. Despite his training as a sociologist of

chronic illness, he nevertheless fell victim to the quasi-magical equation of healthy

lifestyle and permanent health. Frank suffered a heart attack at age 39, the day

before a big race for competitive recreational runners for which he had been

training and had run the previous ten years. Even though he fainted because of what

he later learned was a heart attack, at the time he did not think much about the

incident: "The day I had a heart attack I could not imagine that my body was

breaking down" (Frank 1991, 8). Assuming that the fainting spell was due to nothing

more than over-exertion, he went home and then to a party that evening. He was

thus shocked when his doctor later told him that the fainting spell was caused by a

ventricular tachycardia, which could easily have been fatal. The sense of vigilance

inspired by this news quickly wore off, however, as he returned to normal life and

even recorded a personal best in the triathlon. Only his subsequent diagnosis of

testicular cancer fifteen months after the heart attack was enough to alter his

fantastical view of the healthy lifestyle. Hearing the diagnosis reminds him of a long-

forgotten yet now personally relevant bit of epidemiological knowledge. As a

sociology graduates student in the 1970s, Frank attended a seminar with a social

epidemiologist who emphasized that testicular cancer was most common among those who fit the cultural ideal of healthiness, i.e., young, white, middle and upper-class males, in particular, young university professors (Frank 1991, 23). Frank was then forced to recognize that his assumptions about his healthiness and immunity from devastating illness were premised on wishful thinking.

Besides using his experience of being shocked by his illnesses to illuminate healthy people's tendency to imagine that taking responsibility for one's health will immunize one from illness, Frank was further shocked to find that medical practitioners tend to use the rhetoric of responsibility to force the ill person to mask any vulnerabilities related to being ill. Specifically, he found that doctors often demand the ill person to act professionally, i.e., as a "junior colleague" in treating their own medical situation, thus blocking the ill person's need to be heard and cared for. Frank first noticed this widespread pattern after his heart attack:

> [H]e called me Dr. Frank, I called him Dr. -------. We talked about our heart as if we were consulting about some computer that was producing errors in the output. "It" had a problem. (Frank 1991, 10)

The first cue for him to act as a responsible and autonomous individual rather than an emotionally overwhelmed patient was the reference to him not as Arthur or Mr. Frank, but as Dr. Frank. Granted, the doctor may have wanted to express his sense of mutual respect to Frank, or feared offending him by not using his professional title. However, medical doctors seldom refer to those who hold Ph.D.'s as "Dr."; rather, in this case, referring to the patient as a doctor reminds him not to act like an emotionally overwhelmed and dependent patient. By asking Frank to wear the doctor hat, the physician implies that Frank will have to discuss his own body in a

detached way: his body was a machine rather than the corporeal site of his self. Yet, even when Frank was asked to be professional about his body, he understood that he was not fully equal with the doctor; he was only assigned "a junior place on the management team" (Frank 1991, 10).

To sum up, this section finds that the healthy person's act of demanding the ill person to act responsibly fully complements the healthy person's act of blaming the ill person for the latter's alleged irresponsibility. The two acts are in harmony with each other at both the conceptual and practical levels. Conceptually, both acts of aggression share the assumption that the biological body can be overcome by the mind, framed narrowly as responsibility. They only differ in what they deduce from the same assumption. In blaming the ill person, the healthy person ignores the possibility that responsibility has limited power to prevent illness, and instead argues that the person who becomes ill must have acted irresponsibly. Based on the same assumption that mental agency manifested through responsibility to overcome the biological, the responsibilization of the ill person argues for the possibility of, if not the necessity to, force the ill person to use willpower to ignore the overwhelming effects of her illness. At the practical level, blaming the victim and responsibilization serve two purposes. First, they each help the healthy person mask her fear regarding her own vulnerability, which is called forth by the presence of the ill person. Second, the two acts of aggression reinforce both the superiority of the socially privileged over their underprivileged counterparts and the superiority of healthy over ill people.

Conclusion

In this chapter, I explore the two main ways in which illness memoirs engage in the reflexive practice of estrangement from the commonsense responsibility theory of health, which often serves as one common account for the cultural association of social privilege with health. On the one hand, authors draw upon their experiences of shock at the fact that they became ill "in spite of" their longstanding acts of responsibility aimed at maintaining their health. The shock reveals healthy people's quasi-magical equation of responsibility with permanent health. On the other hand, the memoir authors draw upon their experiences of shock at being excluded by healthy people simply because of their illnesses. Healthy people are shown to exclude the ill—who may well be their family, friends, and clients—in two primary ways: blaming the victim and responsibilization. Due their conviction that they should not be held responsible for their illness, the authors come to regard such acts of exclusion as petty attempts to sustain the responsibility theory of health in the face of the contradictory evidence presented by their own experiences with illness.

By challenging the validity of the responsibility theory of health, the work of estrangement challenges the conceptual root of the responsibility theory of health: the Cartesian belief in the dominance of the mental over the biological. Since the quasi-magical belief in the preventive power of responsibility/healthism makes sense only given the background belief that the mental work of responsibility can overcome the vicissitudes of biology. In this light, healthy people's acts of imputing irresponsibility to the ill person (regardless of whether or she strives to make

healthy choices) and demanding responsibility from the ill person can be regarded as rituals to sustain the initial belief in mind over matter—that the mind is dominant over the body. The act of blaming the victim emphasizes that irresponsibility produces illness. The act of responsibilization emphasizes that the ill person can still use her mind to overcome emotional responses rooted in physical causes.

In contrast to healthy people's ill-founded belief in the dominance of the mental over the biological, these illness memoir authors draw upon their experiences to argue that ill people tend to have the correct understanding of the relationship between the mental and the biological: the biological body is dominant over the mind. That the biological supervenes the mind is demonstrated by the fact that a lot of privileged and responsible people become ill, while many irresponsible people remain healthy throughout their lives. Even more, the fact that healthy people use acts of exclusion to downplay evidence of the biological body supplanting the mind suggests that even the healthy know that truth is not on their side.

This dualistic representation of the world of the healthy and the world of the ill gives meaning to the basic understanding of the social world articulated by illness identity discourse. That is, the fundamental dividing line is not between privileged people and underprivileged people, who are marked by their different approaches to their own health. Rather, the truly fundamental dividing line is between people whose biological bodies allow them to remain healthy and people whose bodies unfortunately give away earlier.

The recognition that the biological body can supervene the mind further serves to challenge a core assumption of meritocracy, which underlies the professionalism that authors tend to subscribe to. According to meritocracy, individuals should be able to achieve any symbols of respectability if they set their minds on achieving such symbols (Merton 1938: 673-674). In this vision of society, ascribed status is regarded as secondary to achieved status. From the "shock" of authors when they find that they could actually lose health in spite of their sacrifice and effort to live a healthy life, we see here the problematic assumption that biological health is taken to be a mere symbol of prestige, just as luxury cars or expensive clothes. The obvious problem, here, is that, as a kind of symbol of prestige, health is a lot more unstable than luxury cars and expensive clothes.

More importantly, by regarding health as a kind of status symbol, the person forgets that health is really the unstable condition for our mental lives and our actions, rather than the consequence of mental action and effort. As Leder (1990) argues, the main problem of Cartesian mind-body dualism is not so much its pronounced rationalism, as postmodernist thinkers allege. Rather, the Cartesian mind-body dualism forgets that the very experience of having a mind that is relatively independent of, and in control of, the body is really the experiential manifestation of a healthy biological body. The mind only gets to work in the way stipulated by Cartesianism when the body and the brain function normally. At the same time, the body appears as a stable and transparent tool to the mind simply because the healthy body tends to render most parts and processes of the body inexperienceable. Not only are most parts and processes imperceptible to us, but

also that we have no control over most parts and processes of our bodies. According to Leder (1990), the real truth our exceedingly limited control over our bodies becomes clear when we become sick, as our bodies come to feel as self-moving torturers and our minds become overwhelmed by the pain and negative emotions.

While illness identity discourse has clear advantages over the commonsense view that the social world is separated into people who are responsible and healthy and people who are irresponsible and ill, the new dualistic representation presents its own conceptual and practical problems. At the conceptual level, it regards the world of the healthy and the world of the ill as two bounded and internally homogeneous groups. All healthy people share the "incorrect" belief that responsibility overcomes the biological and thus all engage in acts to exclude ill people. All ill people share the "right" belief that the biological supervenes on the mental and all are victims of the healthy. In short, there is neither room for similarity between members of the two worlds nor any possibility for intra-group variation. At the same time, there is room for variation in time. At the practical level, the dualistic representation of the world of the healthy and the world of the ill poses problems for the ill person's need to normalize her illness. At the very least, the notion that the biological dominates the mental makes it impossible for the ill person to create the necessary psychological distance from her biology and her situation. The next chapter explores how illness memoir authors seek to transcend these conceptual and practical limitations of illness identity.

Chapter Three

Normalization I:

Balancing Illness Identity Discourse with The Responsibility Theory of Health

Introduction

In this chapter, I explore the first way in which illness memoir authors do the reflexive practice of normalization: balancing illness identity discourse with the responsibility theory of health. As argued in Chapter One, normalization refers to the ill person's reflexive practice of coming to accept that, in spite of the crisis caused by illness, being ill per se is not being outside of normality and, more importantly, not necessarily the worst kind of suffering. In order to do so, the practice of normalization renders strange the one-sided emphasis of the biological body over the mind underlying illness identity discourse, which supports the "no one is immune from chronic illness" assumption. Yet, normalization does not shift from illness identity discourse to its opposite, i.e., the responsibility theory of health. This is because the two forms of discourse are actually mirror images of each other, such that, while illness identity discourse overemphasizes the biological body over the mind, the responsibility theory of health overemphasizes the mind over the body. In contrast to both one-sided alternatives, the first way of doing normalization seeks to produce a hybrid discourse that reconfigures the relationship between the biological body and the mind by balancing the illness identity discourse and the responsibility theory of health.

As seen in the previous chapter, memoir authors came to challenge the Cartesian assumption behind the responsibility theory of health: the mind is not only distinct from the biological body but is also able to exert independent control over one's body and one's life. The invalidation of the responsibility theory of health is most forcefully argued through their experiences of becoming seriously and irreversibly ill "in spite of" their responsible living, which is commonly associated with people of privileged status. However, in shifting from the responsibility theory of health to illness identity discourse, authors come to a reversed, and equally one-sided, ontological priority: biology supervenes the mind, such that no matter how responsible one fancies oneself to be, one can neither control the occurrence of illness nor one's subjective responses to illness. The sense that one cannot control how one feels and thinks in the midst of illness is driven home by authors' emphasis on their overwhelming and unaccustomed sense of dependence and emotionality in the midst of illness, which contradicts their sense, as socially privileged individuals who have enjoyed personal and professional success, of being not only in control but arguably in command of their destinies.

While illness identity discourse is superior to the responsibility theory of health in its argument for the limited power of responsibility to immunize one from chronic illness, it is also problematic because of its one-sided anti-Cartesianism: the body determines the mind. The one-sided emphasis of the body over mind obstructs authors' need to normalize their illnesses in two ways: it leads to both a strict separation of the healthy from the ill and the sense of worstness of illness as being totally helpless in the face of the whims of the biological body. On the one hand, by

using their physical differences as a touchstone of identity, illness identity discourse regards healthy people and ill people as fundamentally different in terms of their mental properties. Healthy people are able to use their minds to control their bodies and their lives. In contrast, ill people are homogeneously overwhelmed by the sorry states of their bodies. On the other hand, the view that the body determines the mind obscures the possible ways in which ill people can deploy their mental agency to make their lives more livable in spite of the crisis of illness. Specifically, it may limit the ill person's recognition to the possible ways in which healthy and ill individuals can shift their understandings of illness through alternative forms of mental practice.

In this chapter, I explore two kinds of unexpected experiences that illness memoir authors emphasize as ways of enabling them to recognize the possible ways in which the mind can exert limited yet significant independence from the biological body. First, I explore the authors' surprise of learning that they were able to develop their minds in alternative ways in order to limit their sense of worstness of their illnesses. There is often a recognition that these alternative mental capacities could not or would not have been developed if they were to remain healthy. Specifically, I explore two modes of alternative mental development: biographical contextualization of illness and aesthetic perception. Second, I explore the authors' unexpected experiences of interacting with healthy and ill individuals. Referring to unexpectedly good interactions with healthy individuals, authors recount their pleasure upon observing that healthy individuals who had previously been unempathetic could learn to be empathetic towards the ill. Referring to

unexpectedly negative interactions with "fellow" ill individuals, moreover, the authors learn that many ill individuals fall short in empathizing with and caring for other ill people.

Biographical Contextualization: Comparing Illness with Past Critical Situations

In illness identity discourse, the ill person is seen as wholly passive in relation to her illness' critical challenge to their bodies, daily habits, and previously taken-for-granted assumptions. The positive effect of this emphasis on the ill person's passivity with regards to her illness is that it illuminates the wrongness of healthy people's demands for the ill person to act responsibly—cheerfully and professionally—and downplay their "irresponsible"—overly emotional and dependent—responses to illness disruption. The negative effect of this emphasis on the ill person's passivity, however, is that it may obscure the alternative mental practices that the ill person may develop, which may enable her to limit her initial sense of criticality or worstness of their illnesses. In other words, illness identity discourse's assumption of the body as dominating the mind makes it hard for the ill person to come to understand her illness as only "partial" rather than "whole" crises.

In my sample, I find authors do not directly limit the criticality of their illnesses by imposing the counter view of illness espoused by positive psychology: illness is not a curse, but rather a blessing in disguise. As I have emphasized in the last chapter, authors generally find the expectation that they should regard their illnesses in a positive light wholly unacceptable, as they tend to see it as a ruse for

healthy people to responsibilize the ill (see Ehrenreich 2009). How, then, do authors come to limit the criticality or worstness of their illnesses? One way to do so is to shift from an over-blown understanding of illness as total biographical crisis to a partial biographical crisis by contextualizing their illnesses into their biographical contexts. This work of biographical contextualization of illness is performed through the reflexive comparison of their illnesses with real-life negative events that happened in the past but have been forgotten. Specifically, I find two major patterns of biographically contextualizing one's illness: to compare one's illness with past critical situations and to compare one's illness with relatively mundane negative situations in healthy people's lives. To illustrate the first pattern, I draw upon Robert Murphy's *The Body Silent: The Different World of the Disabled* (1987) and Cherie Kephart's *A Few Minor Adjustments: A Memoir of Healing* (2017).

Robert Murphy comes to limit his sense of crisis caused by his spinal tumor and ensuing quadriplegia by contextualizing his illness within a life that was once almost destroyed by his past alcoholism. Murphy's memoir begins with the diagnosis of a benign yet damaging spinal tumor in 1974 when he was 50. A son of Irish American working-class immigrants, Murphy was at the time of his diagnosis a respected anthropologist just finishing a challenging term as chair of the anthropology department at Columbia University. Disabusing the reader about the significance of his role as chair, he emphasizes his misery in the face of budget cuts and student protests. In contrast to such difficulties, he regards his future as entirely positive, with plans to complete two books while his wife is in Maine with their children for summer vacation. In the midst of his optimism, however, Murphy began

to recognize recurring symptoms including muscle spasms in his anus as well as tingling sensations in his left foot and loss of balance. Like other authors who did not live healthily but still considered themselves immune to illness, he simply dismissed the symptoms as a minor consequence of his heavy smoking (Murphy 1987, 17-18). After the "shocking" diagnosis of the spinal tumor, he was subjected to surgery and chemotherapy, neither of which halted the progressive paralysis. He came to depend upon the wheelchair for mobility and increasingly needed assistance with his daily routines. The resulting sense of alienation from his body and his social life, along with the prognosis that he would not live past age 56, led him to seriously ponder suicide for some time.

Despite feeling "badly damaged" by his illness (Murphy 1987, 66), Murphy was nevertheless able to limit his sense of illness crisis when he came to remember a long-lost memory of "another time when [he] had been forced into a similar condition" (Murphy 1987, 67), in this case, by his alcoholism, which left him feeling no less badly damaged. Despite his aversion to his father's alcoholism, Murphy nevertheless began drinking heavily as a way to cope with the stress and boredom of military life during the Second World War. The drinking worsened after the war, even as he enrolled in college and became an academic. From his initial work at the University of California in Berkeley and then at Columbia University, Murphy lived the double life of an apparently sober academic who attended class on time and published regularly and an actual alcoholic who regularly, but secretly, got drunk. This strategy of dissemblance began to fail by the mid-60s, as he became increasingly unable to juggle "the middle-class alcoholic's art of maintaining a

'plateau' of intoxication in public" and "getting too drunk at the wrong times and places" (Murphy 1987, 70). Feeling that alcohol was "destroying both my marriage and my career," such that he was "drifting downward and inward into the limbo in which my father had dwelled" (Murphy ibid.), in retrospect Murphy believes that his sudden decision to quit cold turkey enabled him to avert the complete disruption of his life toward which he had been heading. The memory of almost life-destroying alcoholism that initially seemed totally beyond his control, but later resolved through pure mental effort reminds Murphy of the importance of not allowing oneself to be mentally stuck in present woes as well as the importance of personal resolve to change one's situation.

In contrast to the personal agency celebrated in Murphy's work of biographical contextualization of his illness, in her 2017 memoir *A Few Minor Adjustments: A Memoir of Healing*, Kephart emphasizes the similarity between the total passivity that she faces as an ill person and her traumatic experiences of being powerless to prevent being raped. The passivity in Kephart's illness experience is not simply due to the illness, but also because she experienced symptoms for some five years without a conclusive diagnosis and treatment plan. Kephart is a writer and artist known for her philosophy of holistic healing; her award-winning memoir was reviewed in *Publishers Weekly*. Her memoir begins with her experiences in rural Zambia as a Peace Corps volunteer, after which she moved to California, where she found new work and was in a new heterosexual relationship. Unlike many of the other authors, she had had other health issues prior to the flare-up of the symptoms of unrelenting and unbearable neck pain combined with dizziness, when she was

around 33. Unable to work and often even to live independently, both holistic and biomedical practitioners seemed to offer only unclear or contradictory diagnoses and fruitless treatments. Similarly to other patients with illnesses that are hard to diagnose, she had to deal with accusations of malingering and mental illness from loved ones and medical professionals alike. Her sense of despair almost caused her to commit suicide by hanging. Finally, after five years of suffering, her illness was pinned down as a combination of Lyme disease and Epstein-Barr syndrome. A partially successful treatment plan was then initiated.

While Kephart's memoir follows the conventional pattern of beginning with her total shock at the onset of illness, her narrative suddenly shifts in the middle to focus on her traumatic experiences of rape by unknown men. One night after spending time at a bar with an ex-boyfriend, she was assaulted and raped by an unknown man as she made her way home. After being found unconscious outside of the bar, she was sent to the city's detox center, where she was again sexually assaulted, this time by a male staff member. Although Kephart was later able to identify the rapist at the detox center, who was promptly arrested and sentenced, her first assailant was never caught. She dealt with the rape trauma secretly because of her sense of shame and was only able to open up years later, after prompting from a trusted therapist.

Like many other authors who organize their memoir by first describing a contented life destroyed by their illness, and then discussing parallel past experiences of critical situations, neither Murphy nor Kephart offer an explicit explanation for why, after they introduce their presumably central experience of

life-disrupting illness, they would discuss in such detail another critical event that is apparently unrelated to the illness memoir. I argue that this pattern serves to remind the author (and the reader) that, while one's attention can be easily monopolized by illness crisis, one should nevertheless bear in mind that other events in one's past life could be easily the worst thing in their lives if not for their subsequent illness. In fact, these past events of suffering—acute alcoholism and rape—could have themselves been the focus of their memoirs. I suggest that this pattern of remembering one's past (or other people's) critical events serves to help authors recognize that illness is really one of the many kinds of really negative events that can happen, has yet to happen, or had already happened in our lives. My argument seems supported by an explicit effort on Kephart's part to even limit her sense of crisis from her experiences of rape by comparing them with "worse" experiences of women who were raped and then murdered. To her, even though "we all are victims at some point in our lives," she felt "lucky" that "[a]ll those men wanted from me was sexual gratification" and thus allowed her to survive the attacks (Kephart 20017, 114).

Biographical Contextualization: Comparing Illness with Mundane Expressions of Bad Faith

A second and minor pattern of limiting one's sense of illness through the work of biographical contextualization is to compare one's illness with mundane problems of living, especially what existentialists call bad faith or lack of authenticity. In my sample, this pattern is exemplified by Nina Riggs's *The Bright*

Hour: A Memoir of Living and Dying (2017). A writer and descendant of Ralph Waldo Emerson, Riggs was diagnosed with and treated for breast cancer at age 38 in 2015. However, the cancer metastasized later that same year and progressed quickly, no longer responding to treatment. She succumbed to cancer in less than two years, a few months before her memoir was published.

In the outset, Riggs asserts her intention to limit her overwhelming sense of crisis caused by her terminal illness by comparing it with what appear to be wholly mundane problems of living: "[t]here are so many things worse than death," including, for example, "old grudges, a lack of self-awareness, severe constipation, a lack of sense of humor, the grimace of your husband's face as he empties your surgical drain into the measuring cup" (Riggs 2017, 1). For Riggs, the sense that these mundane events and situations—including some aspects of caring for the ill person—are worse than death is not necessarily that they create worse bodily and emotional pains than the suffering of terminal illness. Rather, she seems to regard such events and situations as representative of the existentialist concept of bad faith, in this case living inauthentically by focusing on mundane concerns rather than attending to what truly matters: one's finitude and the value of connecting with one another. For example, remembering old grudges do not simply lead to unhappiness; it also renders each party unable to see themselves from the other's standpoint. For Riggs, lacking a sense of humor implies both the inability to confront the dark side of life and the inability to see the dark side as a normal, if tragic, facet of life. In contrast, due to her high sense of self-awareness in the midst of cancer, she

indicates that her life could be said to be better than the healthy yet unconscious or

inauthentic lives of others.

Why is Riggs so intent on comparing her terminal cancer with daily

situations of lack of self-awareness or bad faith? A dialogue with her husband offers

a clue:

> Speaking of the dark: It's past midnight, and we're lying in bed. "I just can't wait for things to get back to normal," says John [her husband] from his side of the moon.
> I'm not sure how to respond. I hadn't realized how attached I have become to the idea that, even in all of this, we are moving ahead somehow, and that dealing with all this is something of value.
> "I can't handle you saying that," I say . . . "Thinking that way kind of invalidates my whole life right now. I have to love these days in the same way I love another. There might not be a 'normal' from here on out." (Riggs 2017, 73)

This quote demonstrates why Riggs struggles so hard for self-awareness in the

midst of terminal cancer. That is, she wants to remain authentic to her essential

finitude by forcing herself to recognize that the cancer is terminal and that the end

of her life is coming. Thus, contrary to her husband's wish, she would rather want to

make clear to herself and her husband that the present life lived in the midst of

terminal illness is indeed the new normal. Even though there would be obvious

comfort in imagining the cancer to be a mere bump in the road, she feels that doing

so would be an abdication of human agency in the face of changing circumstances.

Thus, to pretend that one is not dying while one knows otherwise may be worse

than the daily expressions of bad faith practiced by those with no sense of their

impending mortality. Although such daily instances of bad faith are based upon

refusing the fact of the finitude of life; most people who do so are unconscious of

their limited time to be alive, reckoning it in decades rather than a few years,

months, or days. In contrast, when one's finitude is fully in view, overt denials or covert refusals to acknowledge as much register as a complete abdication of one's authenticity.

To sum up, the last two sections examine two patterns of limiting one's sense of the criticality or worstness of illness through the reflexive work of biographical contextualization. In the cases of Robert Murphy and of Cheri Kephart, the overwhelming sense of being thrown into a state of crisis by illness is limited by contextualizing their illnesses into biographical contexts that have already been challenged by no less critical events from the past. In Riggs's case, the overwhelming sense of being in a crisis because of terminal illness is limited by comparing one's authenticity in the face of illness with inauthentic, mundane expressions of bad faith. An interesting similarity between the three cases is what they say about the fundamental fragility of masculinity in American society. First, masculinity in the form of rape and alcoholism points to the difficulty for masculine to just let things be. Instead, masculinity has to be performed through aggression, either against the self or against others, in particular women. Second, masculinity seems to be essentially a way to escape our human fragility as finite beings. This is brought home by her husband's understandable plea to Riggs to allow them to see her cancer as a mere bump in the road.

Aesthetic Perception: Seeing the Ordinary as Extraordinary, or the Case of Tree Tripping

The second form of mental development that limits the authors' sense of the criticality of their illnesses is aesthetic perception. Specifically, the emergent

aesthetic perception is seen as spurred by the disorientation created by disruptive illness. For illness identity discourse, illness means the loss of the validity of ordinary perceptions because of radical changes to the body and daily life. This loss leads in turn to a fundamental sense of disorientation. For authors who are motivated to normalize their illness, however, this sense of disorientation is not all bad. Under certain conditions, the disorientation can become the pre-condition for the reorganization of perception, leading to what may be called aesthetic perception. In my sample, I find two general patterns through which authors come to develop an aesthetic appreciation of the everyday precisely because of illness disruption. I call the first pattern the rendering of the ordinary extraordinary, which often manifests in ecstatic experiences including visions of trees. The second pattern may be called the rendering of the serious non-serious, in particular, the development of a sense of humor regarding one's disruptive illness.

In the present section, I explore the first aesthetic pattern of rendering the ordinary extraordinary, in particular through the ecstatic experience of envisioning trees. Drawing upon Arthur Frank's *At the Will of the Body: Reflections on Illness* (1991) and Eve Ensler's *In the Body of the World: A Memoir of Cancer and Connection* (2016), I respectively illustrate two sub-patterns of such visions: from incoherence to coherence as well as from instrumentality to trans-instrumentality.

Frank uses the tree as a way to restore a sense of coherence in the midst of the overwhelming sense of incoherence caused by his illness. In the last chapter, we saw that Frank's life was rendered incoherent both by his shock upon becoming severely ill despite his hyper-healthy living, as well as his shock that medical

practitioners would enlist him as a junior colleague rather than treat him as a

vulnerable patient. I turn now to how the sleep disruption caused by his disease

further exacerbated his sense of incoherence. Secondary tumors caused severe back

pains that often kept him awake at night. The resulting sleep deprivation heightens

his sense of incoherence; along with the fact that he had to face his pain alone while

the world, including his wife, is asleep.

Unexpectedly, it is precisely during his most incoherent time of insomnia

caused by cancer pain that Frank rediscovered coherence through an ecstatic vision

involving a tree:

> Although I never discovered a formula for dealing with pain, I did manage to
> break through its incoherence one night before it abated. Making my way
> upstairs, I was stopped on the landing by the sight—the vision really—of a
> window. Outside the window I saw a tree, and the streetlight just beyond was
> casting the tree's reflection on the frosted glass. Here suddenly was beauty,
> found in the middle of a night that seemed to be only darkness and pain. Where
> we see the face of beauty, we are in our proper place, and all becomes
> coherent. (Frank 1991, 33)

Frank does not make explicit whether the imaginary window and the tree and

streetlight seen from the window are based on his daily environment, a memory, or

simply a generic representation of an urban night scene. In any case, the vision of

the tree seen through a window was so captivating that he was inspired to write a

haiku:

> The streetlight behind the branches
> Project patterns
> On a misted window
> Do not wipe the glass
> Lest other awake. (Frank 1991, 34)

Although Frank does not describe how the ecstatic vision of the tree gave him a

renewed sense of coherence, I propose two connected explanations. First, his vision

of looking out a window onto a neighborhood with a tree and streetlights seems to do the work of reminding him that, in spite of the wholly individualized character of his pain, the pain does not merely reside in his body. Rather, the body in pain is embedded in a broader and organized context composed of interconnected things like trees, houses, people, streetlights, and so on. Frank thus seems to have learned the importance to avoid looking at the world solely through the prism of one's own pain, but rather to look at one's pain from the objective perspective of the world. Second, his ecstatic vision of the tree renewed in him a need to communicate with the broader social world rather than wallow in his own bodily pain. The sharing of the profound experience memorialized through his verse allows him to temporarily connect with the world of expressive linguistic communication. He is thus enabled to transcend his previous sense of being lost in an experiential world that healthy people simply cannot understand through the verbalization of his ecstatic experience of the tree: "Pain that is inexpressible isolates us; to be mute is to be cast out from others" (Frank 1991, 34).

While Frank uses the tree to reconnect himself to the world, Eve Ensler uses the tree to remind her that the instrumental orientation in daily life is only one way of perceiving the complex world. Ensler's memoir begins with her late-stage uterine cancer diagnosis and treatment at around age 56 in 2009. An internationally acclaimed feminist artist and activist, most famous for writing and supporting the performance of *The Vagina Monologues* around the world, at the time of her diagnosis Ensler was doing activist work at a women's shelter and health center for

survivors of sexual violence committed during the Congo civil war. Her diagnosis

and treatment took place in the United States.

Ensler's aesthetic appreciation of trees emerged during her stay in the

hospital, where she found it a great pastime to look at a tree from her hospital bed:

> Unless the tree would be wood, would be house, would be table, what value
> was there to tree? So to actually lie in my hospital bed and see the tree, this
> was the awakening. Each morning I opened my eyes. I could not wait to focus
> on the tree. I would let the tree take me. Each day it was different, based on the
> light or wind or rain. The tree was a tonic and a cure, a guru and a teaching.
> (Ensler 2013, 102)

In this quote, Ensler clearly distinguishes between the commonsense instrumental

and the aesthetic attitude towards the very same tree. In the instrumental attitude,

the tree is not considered as having value in and of itself but is instead seen as

material for the making of useful final products such as houses and tables. In

contrast, the aesthetic attitude focuses on the tree itself or more precisely on the

ways in which the same tree appears to the perceiving subject to appear differently

in shifting contexts, altered by externals such as "the light or wind or rain." Ensler's

renewed appreciation of the tree in its phenomenal fullness helps her cope with the

sense of victimhood she associates with growing up in the most instrumentally

rational of societies, the United States but which also relates to her observations and

interactions with women in the Republic of the Congo. The instrumentalization of

women's bodies is clear not simply in the systematic act of raping women living

with enemy combatants during the Congo Civil War, but also in the case of incest, of

which Ensler is a victim:

> I was raised in America. [A]ll value lies in the future, in the dream, in
> production. There is no present tense. There is no value in what is, only in

what might be made or exploited from what already exists. Of course the same was true for me. I had no inherent value. (Ensler 2013, 101)

In presenting herself as material for instrumental manipulation, Ensler is not simply speaking of the capitalistic reduction of humans to their monetary or productive value. At the same time, she is also speaking of the reduction of women's bodies to mere objects good only for, and for the extent to which, they satisfy men's sexual pleasures.

Aesthetic Perception: Seeing the Serious as Non-Serious, or the Case of Illness Humor

Besides developing the capacity to see the ordinary as extraordinary precisely because of illness-caused disorientation, Gilda Radner argues that her cancer actually led her to develop a sense of humor towards cancer itself:

> Cancer is probably the most unfunny thing in the world, but I'm a comedienne, and even cancer couldn't stop me from seeing humor in what I went through. So I'm sharing with you what I call a seriously funny book, one that confirms my father's favorite expression about life, "It's always something." (Radner 2009, xvi).

By rendering funny the "most unfunny thing," i.e., cancer, Radner argues for the possibility of rendering the serious non-serious. The seriousness of Radner's ovarian cancer is palpable in the memoir. It disrupted her movie career—she was already an established comedian *Saturday Night Live*—and her marriage with actor Gene Wilder. Even though the cancer briefly entered remission, it recurred and became terminal.

How, then, exactly, does Radner render cancer non-serious? It is encapsulated in her father's favorite saying, "It's Always Something," which she also

appropriates as the title of her memoir. The notion that "it's always something"

enables her to analogize illness with other more mundane nuisances or problems in

unexpected ways. I hereby illustrate two examples of Radner's humorous

analogization of cancer with minor problems in daily life. The first example is found

in a videotape that Radner and her husband made for her to watch during

chemotherapy. The tape shows Radner playing tennis as she had been accustomed

to do every week with her husband and friends. After the footage of her playing

tennis, Radner approaches the camera to offer a testimonial-like speech: "Through

the miracle of chemotherapy, I am able to play tennis as badly now as I did before I

had cancer." Then she names the drugs being used to treat her and adds, "Look what

they have done to my game" (Radner 2009, 136). According to Radner, the video

made the oncology doctors and nurses roar with laughter. Without having seen the

video, and not entirely understanding the humorous points made in the video, I can

only offer a few guesses as to why she and her medical team found the video funny.

First, Radner seems to find humor in the analogy between cancer and healthy

upper-middle-class people's first-world problem of losing face by not playing tennis

well enough. Second, she seems to find it funny to reframe chemotherapy as a

treatment for both cancer and for being bad at tennis.

　　　　Radner recounts a second humorous take on cancer from a support group

session at The Wellness Community, a nonprofit organization that provides

education and support for people living with cancer and those who care for them. It

was founded in Santa Monica (which is where Radner participated) in 1982. After

Radner's death, Gilda's Club was founded in New York in 1992 under the direction

of Radner's therapist, who was the one that initially suggested Radner join The Wellness Community in 1987. The two organizations merged to become the Cancer Support Community in 2009. According to Radner, the support of members of The Wellness Community helped her not only regain her sense of humor but also balance her sense of loss and pain with the humor. At one group session, a participant reflected on human vulnerability, "Look, nobody knows when somebody is going to die. You could get hit by a car." Building on the woman's effort to normalize cancer as only one of many likely causes of death, Radner yelled back, "Yeah, and it'll probably be me driving" (Radner 2009, 157). The joke seems to be that, besides being a cause of death as normal as cancer, car accidents can actually be caused by reckless driving on the part of people living with cancer. She thus cleverly reminds others that, since being ill does not make it impossible for the person to become a killer, hence being ill does not make it impossible for the person to live and even find joy in life.

The recognition that "it's always something" does not only help Radner cope with illness, however. In the early parts of the memoir, she uses humor to cope with setbacks in her professional career: "Show business is like riding a bicycle—when you fall off, the best thing to do is get up, brush yourself off and get back on again" (Radner 2009, 43). In this quote, Radner lessens the pain and humiliation of the inevitable setbacks common in show business, particularly as she had already achieved fame, by comparing them to the mundane processes of children learning to ride bicycles, which also comes with setbacks and potential embarrassment that must be withstood in order to gain success.

To sum up, Frank's, Ensler's, and Radner's development of aesthetic perception in the midst of illness all share the sense that there is something essentially limiting in the ordinary perception of the environment, which often carries into the context of illness. For Frank, ordinary perception is isolation from the environment; for Ensler, the ordinary perception only sees aspects of things that serve instrumental purposes; and for Radner, ordinary perception tends to overemphasize the seriousness of certain things at the expense of finding connections between those things and the rest of the world. By being forced out ordinary perception because of their illnesses, they come to recognize the possibility of breaking free from the limit of ordinary perception and recognize aspects and relations in daily life that were previously inattended or disattended by the healthy person absorbed in daily routines.

Further, I suggest that these processes of developing aesthetic perception are both different from and similar to Bourdieu's influential class-based theory of aesthetic perception. According to Bourdieu ([1979] 1987), the aesthetic mode of perception is understood as a part of the social reproduction strategy of upper- and middle-class people. Even though so-called disinterestedness of aesthetic perception among socially privileged people is rooted in the fact that they do not have to worry so much about the material world because of their superior resources, the privileged nevertheless tend to claim that their aesthetic perception is explained because they are dispositionally more refined their underprivileged counterparts. In contrast, the aforementioned three cases seem to argue that aesthetic development does not need to be based on socioeconomic differences.

Rather, through the fact that illness throws the ill person out of her ordinary concerns in daily life, the ill person may thus then learn to reorganize her perception into an aesthetic mode.

The irony in the development of aesthetic perception in the three cases discussed, however, is that differences in the mental capacities nurtured in a privileged lifestyle still seems to matter a lot in the midst of illness. For one, Ensler's anti-capitalist and feminist aesthetic was already developed prior to her illness. Radner's humorous analogies of real difficulties with seemingly mundane difficulties appear to be her main shtick as a comedian and also predate her diagnosis. In Frank's case, even though he is a professional sociologist, his phenomenologically oriented aesthetic and his ability to write haikus are also part of his education. In other words, even though the disorientation effect of illness is an independent factor in their expression of aesthetic perception in the midst of illness, there also seems to be evidence of the transposition of cultural capital across the boundary between the world of the healthy and the ill. In this way, Bourdieu may actually be partially vindicated.

Healthy Individuals Can Learn to Empathize with the Ill

In illness identity discourse, the healthy person is regarded as naturally un-empathetic towards the ill and the ill as naturally empathetic towards each other. That the healthy are assumed to be unanimously unempathetic towards the ill is firstly because they do not know what it is like to have one's body and daily life disrupted by illness. Second, healthy people's lack of empathy stems from their

unease with encountering ill people, especially socially privileged ill people who appear to live responsible lives. In contrast, the ill are expected to be in solidarity with one another because they share the experience of becoming ill and living with that condition. Moreover, they share the experience of victim blaming and responsibilization inflicted upon them by the ill. This dualistic understanding of the healthy and the ill may ring very true, especially at the beginning of one's illness trajectory. Yet, as the illness trajectory lengthens, authors often come to recognize a more complicated picture. To their pleasant surprise, some healthy individuals learn to become more empathetic towards the illness. At the same time, to their utter disappointment, some ill people seem to be highly unempathetic towards other ill people.

In this section, I illustrate the possibility that healthy people can learn to become more empathetic towards the ill through Robert Murphy's *The Body Silent* (1987). I then explore how the development of empathy is an ongoing effort, rather than a done deal, with Sarah Manguso's *The Two Kinds of Decay* (2009).

Like almost all of the memoir authors, Murphy has many negative observations about the medical profession's tendency to distance and blame the ill. In fact, he explicitly draws upon Goffman's influential notion of the total institution to elucidate his sense of becoming what he calls a "prisoner of the hospital" (Murphy 1987, 18). Besides his anger about the impersonal management of medical settings, Murphy is also critical of the expectation of medical staff that the ill will smile and respond positively to jokes when they are with practitioners (Murphy 1987, 20). Further, he distinctly remembers feeling blamed for his own disappointing health

outcomes. In one instance, he felt blamed by the surgeon when the outcome of his

surgery was not successful (Murphy 1987, 46). During his subsequent rehabilitation

the physical therapists repeatedly emphasized that progress is pegged to the active

participation of the ill person, thus, Murphy felt, tacitly blaming him (Murphy 1987,

51).

Although he is very conscious of the ways through which medical

practitioners distance themselves from the ill, Murphy also concedes that some

healthy medical practitioners and staff actually can learn to become more

empathetic. He finds this to be especially true during his stay in the Neurological

Institute of New York:

> The Neurological Institute is a part of the Columbia Presbyterian Medical
> Center and a teaching hospital of the Columbia College of Physicians and
> Surgeons. It is somewhat different from most hospitals I have visited. With
> only 100 beds, it is smaller; with long-term patients, there is less turnover. I
> suspect, too, that the longer stays mean there are fewer visitors. In any event,
> the Institute is quieter than other parts of the hospital complex, and its small
> size makes for more relaxed rules. The nurses and aides also become better
> acquainted with the patients, so relations are less impersonal. I was never
> asked, "How are *we* today?" (Murphy 1987, 22)

Murphy's satisfaction with his interactions with the practitioners and staff at the

Neurological Institute is exemplified by his never being addressed in the first person

plural, implying that his experiences and feelings were taken seriously as his own.

Further, he draws upon his expertise in political anthropology to provide a

structural, rather than a psychological or cultural, account of why the staff at the

Neurological Institute could move beyond the healthy person's tendency to blame

the victim or responsibilize the ill person. Two conditions increase the likelihood

that the staff and practitioners will come to know their patients in a more diffuse

and intimate way, allowing them to overcome their initial sense of difference from their patients. The first condition is the degenerative character of neurological diseases, which lengthens the stay of most patients. By staying longer, the patient gets have more contact with the practitioner, thus enabling the latter to regard the former as a more complex human being rather than just a patient. The second condition is the smaller space matching the lower number of patients, which drastically reduces the hustle and bustle of visits, and hence facilitates more leisurely, less emotionally charged interactions between practitioners and ill people.

It should be emphasized, however, that there cannot be an endpoint to the medical practitioner's process of learning to be empathetic towards the ill. This is because different patients have different needs and experiences. Further, their needs and experiences can shift over time. This processual understanding of empathy development in medical practitioners is made clear in a dialogue between Sarah Manguso and her primary care doctor in *The Two Kinds of Decay* (2009). An award-winning poet, Manguso recounts her experience of a very rare immunological disease called chronic idiopathic demyelinating polyradiculoneuropathy (CIDP), which is a rare form of the already rare Guillain-Barr syndrome. The symptoms emerged during her junior year in college and lasted for four years. She was initially struck with what seemed to be a bad cold that refused to go away. During spring break, resting at her parents' home with the cold still making her uncomfortable, she found herself unable to breathe, her hands tingling, her extremities and torso numb. At the hospital, she was told that, if her diaphragm weakened a little more, she would have to be intubated. After an arduous

process of eliminating possible causes, she was first put on a periodic regimen of

having her plasma completely removed and replaced. Later, she was put on

prednisone, which has a host of side effects, including rendering her clinically

depressed. Manguso entered remission four years after the onset of symptoms, her

memoir emerged seven years after that. Here, she recounts an unfortunate attempt

at empathy:

> [M]y primary care doctor visited me and said I'd already endured something
> much worse than most people have to endure in an entire regular-length life.
> His voice shook. He was forcing tears either forward or back.
> Before the diagnosis, I would have loved hearing him say that.
> The doctor was older than my parents, and he must have had plenty of
> younger patients, but he didn't understand yet that suffering, however much
> and whatever type, shrinks or swells to fit the size and shape of a life.
> (Manguso 2009, 83-4)

In this quote, we find the ironic gap of understanding between an apparently truly

caring primary care doctor and Manguso's shifting needs after the diagnosis. Prior

to the diagnosis, when she was incapacitated, not knowing whether her illness could

even be correctly diagnosed, she did feel that her life was gone. After the diagnosis,

however, Manguso seemed to entertain some hope for the illness's remission and

thus the possibility of resuming her life. Given this new situation, what she needed

was not the simple validation of her sense of disruption, but rather the validation of

her need to live and the assurance that she might even prosper in spite of her illness.

  In a sense, it could be argued that Manguso may have been asking too much

of her primary physician. However, she also makes the forceful point that even

though the doctor may have had a lot of clinical experience with young patients and

worked hard to develop his empathy, he also mistakenly assumes that the same

empathetic act would be effective for everyone. Without allowing the possibility that

patients may develop different expectations of the future in different phases in their

illness trajectories, doctors' attempts to empathize may thus serve to fix their

patients in a state of helplessness rather than helping them move forward with their

lives.

Variation of Solidarity among the Ill

In illness identity discourse, solidarity among the ill is normally taken for

granted. This is due first to the belief that all ill people share the same experiences of

disruption, which is further believed to be wholly unintelligible to healthy people.

Second, it is based on the belief that all ill people share the same experiences of

exclusion from well people and must, therefore, find common cause with one

another as different from the well. However, through shocking experiences of

exclusion among "fellow" ill individuals, many authors become disabused of the

romantic vision of a taken for granted illness solidarity. Instead, they recognize the

need for ill individuals to develop empathy with other ill individuals. Vignettes from

Kathlyn Conway's *Ordinary Life: A Memoir of Illness* (1997), Bauby's *The Diving Bell

and the Butterfly* (1997), and Christina Crosby's *A Body Undone: Living On after

Great Pain* (2017) exemplify how physical and attitudinal differences among the ill

threaten the presumption of natural solidarity among the ill.

Conway candidly explains how even herself, i.e., a psychoanalyst whose very

job is to be empathetic towards other people's suffering, may be unable to

empathize with fellow ill people simply because of her awareness of physical

differences between them. For at least some time after her diagnosis and treatment,

Conway avoided cancer support groups:

> Statistics indicate that people who join cancer support groups increase their chances of surviving for five years. Yet, I'm afraid to join a group. If it included people whose diagnoses are worse than mine, I would feel undeserving of their concern and guilty about my more promising situation. On the other hand, with people whose prognoses are better than mine, people with smaller tumors who are not having chemo, I would feel envious and frightened about myself. But mainly I am afraid to hear breast cancer stories, especially those providing me with new ideas about what could go wrong. I want only a mirror image of myself, an identical twin whose prognosis is neither better nor worse than mine. (Conway 1997, 153)

Conway relates that, even though she knows that going to support groups is

supposed to give her a better chance at living and a better quality of life, she prefers

not to be exposed to the potentially disturbing experiences and views of other

patients whose experiences are not like hers despite their shared disease. While

support groups are meant to emphasize the unity of ill people despite social and

physical differences, she nevertheless felt it impossible to refrain from invidiously

comparing her condition with that of others. Like the narcissistic comparisons of

body types among healthy people, negative emotions of guilt and envy can also arise

among ill people.

Physical difference among the ill may further lead to outright exclusion, as

Jean-Dominique Bauby depicts in a painful scene in *The Diving Bell and the Butterfly*

(2008). In the scene, Bauby is wheeled into the recreational/rehabilitation area in

the hospital, where he is a long-term resident patient. Expecting a sense of

community with those he imagined were comrades, he unfortunately experienced

the reverse:

> Below people laugh, joke, call out. I would like to be part of all this hilarity, but as soon as I direct my one eye toward them, the young man, the grandmother, and the homeless man turn away, feeling the sudden need to study the ceiling smoke detector. The "tourists" must be very worried about fire. (Bauby 2008, 34)

Added to his previous shock at becoming a fully paralyzed person living in the midst of healthy people is the shock that his paralytic state made it impossible even for supposedly fellow ill people—even the presumptively curious young man, empathetic grandmother, or down-on-his-luck homeless man—to make eye contact with him. Through "fellow" ill individuals' overt gesture of exclusion, i.e., staring at the ceiling instead of acknowledging him, Bauby learned painfully of a great gulf among two types of paralytics he comes to distinguish as the tourists and those trapped in the fire. *Tourists* refer to physically impaired people who are not fully paralyzed and thus come to the hospital for visits and physiotherapy sessions. In contrast, people like Bauby (there were at least two others in Bauby's hospital with locked-in syndrome) are not *tourists* but are *trapped in the fire*. To Bauby, there was no essential difference between his level of impairment and that of the tourists. To the tourists, however, the difference was both real and disturbing. Apparently, just as Bauby's appearance would remind the healthy of their vulnerability, his appearance also reminds the "fellow" ill people of their vulnerability.

Besides physical differences, the putative solidarity among the ill can further be threatened by attitudinal differences among them. Specifically, just as healthy people may demand that ill people act responsibly and hence not be overly emotional and dependent, some ill people may demand the same of other "fellow" ill people. This is illustrated by Christina Crosby's sharing of her ambivalence towards

the social model of disability in her memoir, *A Body Undone: Living On after Great Pain* (2017). Crosby's memoir discusses her experiences of spinal injury, which immediately paralyzed her and further created unrelenting pain in her body, caused by a bicycle accident at age 50 in 2003. At the time, she was a respected feminist scholar and the head of the English literature department at Wesleyan University. Despite her brother's paralysis due to multiple sclerosis, Crosby had never imagined that quadriplegia could happen to her. Nor does she seem aware of the inherent risks of cycling, regarding it merely as emblematic of a healthy and active lifestyle, even though her spine injury was caused by a bicycle accident.

Crosby shares her ambivalence towards the social model of disability in the introductory chapter of the memoir. On a positive note, she is thankful for the struggles of activists to reshape the social understanding of disability by conceptually distinguishing impairment and disability, arguing that disability is a social and hence changeable condition mediated by "building codes and education policy, subway elevators that don't work and school buses that don't arrive, and all the marginalization, exploitation, demeaning acts, and active exclusion that deny full access and equally to 'the disabled'" (Crosby 2017, 6-7). On a negative note, however, Crosby also feels critical of the social model's tendency to downplay the inherent physical vulnerability of humans and the actual effects of impairment on the lives of the disabled/ill person, as in the following quote:

> To focus on intractable pain, then, or grief at the loss of able-bodiedness, as I do here, may be thought to play into a pathologizing narrative that would return disability to "misshapen" bodies and "abnormal" minds. When I presented some of this work to a study group, one guy in a wheelchair more or less told me to "man up" and get on with my life—after all, that's what he had done decades ago, before ADA, even (7).

In this quote, Crosby shares her experience of being silenced by a fellow disabled person for not being able to get over her chronic pain and sense of loss. To her, the act of silence does not merely demonstrate the social model's definition of a good disabled person as a person who can mentally overcome impairment, but also a masculinist bias to use the mind to "man up" in order to conquer her pain and emotions about her physical vulnerability. In making this critical observation, Crosby thus echoes recent internal criticism in disability studies, which argue for taking seriously the actual effects of impairment in the daily living and senses of self of the disabled person (Hughes and Patterson 1997; Sherry 2016).

Conclusion

This chapter explores how illness memoirs authors do the work of normalization by balancing illness identity discourse and the responsibility theory of health. Illness identity discourse posits itself as challenging the responsibility theory of the healthy persons' assumption that socially privileged people are more immune from illness because of their greater sense of responsibility towards their own health. In contrast, illness identity discourse argues that responsibility is limited in its power to control the vicissitudes of biological processes. Despite underscoring the relative independence of the biological over the mental, however, illness identity discourse errs in its one-sided belief that the mental is subservient to the biological. Thus, even though illness identity discourse helps neutralize the moral blame that healthy people tend to impose upon the ill, it also poses dire problems for the ill person's motivation to normalize her illness. To begin, by

overemphasizing the autonomy of the biological body over the mind, illness identity

discourse overemphasizes the difference between the worlds of the healthy and the

ill, making it impossible to see the two worlds as parts of the same world. Further,

illness identity tends to foreground one particular kind of biological vulnerability

from which no one is immune, i.e., illness, while forcing to the background many

other kinds of vulnerability from which no one is immune, e.g., rape and alcoholism,

although as I have shown above, the victimhood to these kinds of vulnerability is

often gendered.

In order to restore a proper balance between mind and body, illness memoir

authors do the work of normalization by emphasizing two kinds of surprising

experiences that challenge the overemphasis in illness identity discourse of the

biological over the mental. First, the authors point to two surprising experiences of

mental change in their own illness trajectories. By pointing to surprising

experiences of limiting their sense of the worstness or criticality of their illnesses,

authors come to recognize that they do not have to become mentally locked onto

their illnesses, as illness identity discourse tends to emphasize. Rather, they can

create a sense of psychological distance from the illness by comparing their illnesses

with other disruptive events in their lives. Moreover, as in the example of Nina

Riggs, the power of mental creativity can actually define down the disruptiveness of

illness by enabling her to compare her experience of terminal cancer with mundane

expressions of bad faith. Second, by pointing to surprising developments in one's

capacity for aesthetic perception, authors come to recognize that the disorientation

caused by illness is not all bad, as illness identity discourse tends to emphasize.

Under certain circumstances, the disorientation can actually become the pre-condition for authors to either regard the ordinary as extraordinary or to regard the serious as non-serious.

Secondly, authors use surprising experiences of interacting with the healthy and the ill to challenge the illness identity notion that all healthy people are equally unempathetic towards the ill and that the ill naturally find solidarity with one another. Rather than simply assuming that differences in biological health and illness naturally determine a person's attitude towards the healthy and the ill, the authors point to the role of active learning with regards to empathy. Thus, rather than agree with illness identity discourse that all healthy people are equally unempathetic towards the ill, some authors point to pleasantly surprising experiences of finding that healthy people can actually learn to overcome their fear or aversion towards the ill. At the same time, through experiences of being excluded by fellow ill people, authors come to recognize that being ill does not inevitably render the ill person able to see beyond physical and attitudinal differences among the ill.

Based on these empirical findings, I suggest that, in their work of normalizing illness, authors come to build a particular kind of hybrid ontology that incorporates the best of both illness identity discourse and the responsibility theory of health, while avoiding their obvious defects. Through their experiences of becoming ill in spite of their responsible living, they naturally take for granted the relative autonomy of the biological with regards to the mind. Even though they are fully aware of how the biological can shape the mind, especially in the form of making the

ill irresponsible and for causing the healthy to be unempathetic towards the ill, they

do not succumb to the allure of regarding the biological as wholly determining of the

mind. Yet, in their effort to restore the relative autonomy of mind over body, authors

also do not reinstate the responsibility theory of health. Nor do they dismiss

wholesale the role of responsibility. Rather, they come to regard responsibility as

only one of the many manifestations of the mind. Besides the capacity to restrain

one's bodily weaknesses and desires, authors point to the existence of different

forms of mental agency—biographical contextualization of illness, aesthetic

perception, and empathy. More than just pointing to the existence of different

mental capacities, authors further argue that the development of these capacities

requires conscious commitment on the part of the healthy and ill individual to rise

above their biological bodies.

In this re-emphasis on the person's effortful application of mental agency in a

way that is relatively independent of the biological body, we see a limited

reassertion of both modern meritocracy and the underlying Cartesian ontology of

the individual. In particular, authors argue that ill people can learn to create

psychological distance from their illness, in spite of the obvious pull that illness

crisis exerts on the ill person. At the same time, authors argue that healthy people

can learn to create psychological distance from their embodied sense of distance

from the ill. This re-emphasis of mind over body in shaping the quality of life of ill

people seems to echo Robert Zussman's award-winning work (1992) on ICU

doctors' decision on whom to save. In an explicit effort to add nuance to the one-

sided sociological view that doctors make life-and-decisions decisions based on the

social worthiness of the ill person, Zussman argues that ICU doctors primarily make decisions based upon their sense of the quality of life of patients after being saved through often heroic means. Like the memoir authors, doctors regard the patient worth saving is one who, even though she may be physically incapacitated, but can at least have the mental capacity and willingness to participate in social life in a meaningful way: "[having] a certain clarity, mental clarity, that would allow you to communicate with your family and friends" (Zussman 1992: 129). My findings further show that, besides mental clarity, a livable life seems to further require the development of alternative mental capacities and communication skills.

Despite the renewed emphasis on mind, albeit in alternative forms such as biographical contextualization, aesthetic perception, and empathy; the memoirs point repeatedly to the fact that these authors' activity does not simply happen within the mind. As discussed in the first chapter, mental processes are mediated by knowledge practices, and knowledge practices are embedded in institutional and organizational spaces that are organized not simply according to particular functional dictates but also social differences such as race, gender, sexuality, etc. Thus, in exploring the development of aesthetic perception, I highlighted the mediation of certain forms of cultural capital, such as poetry, critical theories of society, aesthetics, and so on, which are often transmitted through socialization processes within middle and upper-class families and in institutions of higher education. Furthermore, the fact that these authors regard tree tripping as not religious but only aesthetic in character exemplifies the secularity of their middle-class professional worlds.

Besides class, gender also figures importantly in the learning process. A case in hand is Crosby's experience of being silenced by a male disability activist for what to him was too much focus on vulnerability. According to her, the "fellow" support group member's criticism essentially boils down to the notion that instead of talking about her pain and sense of loss after the spinal cord injury, she should just "man up" and get on with her life. For Crosby, the fellow disability activist was not merely asking her to follow the individualistic model of personhood so that she could overcome her sense of pain and loss through mustering courage and will. The very demand for her to man up is felt to be offensive not only because of her being a biological female, but also because of it seeks to over-simplify her identity as "femme butch," which I will discuss more in the next chapter.

All in all, the introduction of class, gender, and sexuality into the discussion of health and illness highlight the importance of resources such as money, power, prestige, knowledge, and social connections in matters of health and illness. In the next two chapters, I will therefore explore illness memoir authors' work of reflection upon the resource theory of health as another popular way of account for the "privileged people are immune from illness" assumption and its relationship with the illness identity assumption that "no one is immune."

Part Two:

Between the Resource Theory of Health and

Illness Identity Discourse

Chapter Four

Estrangement II:

From the Resource Theory of Health to Illness Identity Discourse

Introduction

In this chapter, I explore how authors of illness memoirs in my sample

engage in the second form of the practice estrangement: shifting from the resource

theory of health to illness identity discourse. The resource theory of health uses

status-based differences in resources to account for the commonsense association

between socially privileged people and immunity to illness. In challenging the

validity of the resource theory of health, authors come to validate illness identity

discourse's fundamental assumption that no one is immune from illness, which in

the present case translates into the commonsense notions that illness does not

discriminate as well as that illness is the great leveler of social differences.

The resource theory of health argues that privileged people are able to be

healthier or even to be immune from chronic illness primarily because they have

easier access to valuable resources such as money, power, prestige, knowledge, and

social connections (for a major statement in the epidemiological literature, see Link

and Phelan 1995). For example, privileged people eat in a healthy way not simply

because they are committed to the value of personal responsibility, but also, and

perhaps more importantly, they can afford to do so. A healthy life is costly: healthy

foods, especially organic and minimally processed vegetables and meat, are often

more expensive than non-healthy food; physical and/or emotional fitness programs

require leisure time; workout clothing and gear, and expensive gym memberships. Moreover, access to healthy food and fitness programs is often limited to areas with a high cost of living and other less obvious class/race segregating mechanisms. Besides enabling the privileged to make healthy consumption choices, their material resources can further insulate them from health risks: "a person with many resources can afford to live in a high SES neighborhood where neighbors are also of high status and where, collectively, enormous clout is exerted to ensure that crime, noise, violence, pollution, traffic, and vermin are minimized and that the best health-care facilities, parks, playgrounds, and food stores are located nearby" (Phelan et al. 2010, s30). Such resources may even override the illness-producing effects of stress. As Marmot (2015) argues, even though both the privileged and underprivileged are exposed to stress, but because of privileged people's access to a greater pool of resources, their stress is limited by their higher control of their situations. Hence, the kind of stress that the privileged experience tends to be less illness-inducing than that of their underprivileged counterparts.

The resource theory of health does not merely do the political work of essentializing status inequality through explaining status-based differences in health outcome. It further does the ontological work of arguing that society is not only independent from the biological, but more importantly, determining of biology. The resource theory of health affirms the belief that biological vulnerability can be almost fully controlled by resources such as money, power, prestige, knowledge, and social connections, the existence and efficacy of which arise through the conventional agreement between autonomous yet also social beings. Further, it

argues for the need for collective action to reshape the distribution of resources, such that the illness-immunizing power of resources can be more equitably distributed in the population.

How, then, do authors come to challenge the resource theory of health, and its underlying ontological presumption that society determines biology, given their seemingly contradictory statuses as both socially privileged people who enjoy access to resources while at the same time being ill people with disruptive chronic conditions? I argue that they tend to emphasize two kinds of surprising experiences that alert them to the non-obviousness of the resource theory of health. First, they point to experiences of becoming ill "in spite of" enjoying access to a large pool of resources. Specifically, they point to both the experiences of becoming ill when they felt most successful, as well as experiences of recognizing chronic illness as a leveler of social privilege.

Second, authors emphasize the surprising experiences of interacting with healthy people in light of the "contradiction" between their nonnormative statuses as ill people and their normative status as socially privileged people. They find that healthy people tend to solve the "contradiction" by attending mainly to their status as ill, while disregarding or remaining silent about their other social statuses and their large pool of resources. Nevertheless, the memoirists show that the transformation of one's illness into the master status may not be experienced as wholly negative. In fact, some authors find being defined primarily as ill as quite empowering, as they experience the lessening of social distance between them and underprivileged counterparts because of their illnesses.

Becoming Ill When One Has Achieved the Most

The first type of unexpected experience that challenges the validity of the resource theory of health is authors' accounts of becoming severely and irreversibly ill when they were at their most successful, professionally and, oftentimes, personally. This sense of professional achievement is associated not only from holding down respectable and well-paying professional jobs, but rather encompasses the assurance that one is good at and enjoys one's job, and even more importantly, is widely respected and regarded as having significant influence in one's professional field. Besides noting pride in her professional achievements, the person may additionally feel successful in her private life: both loved by and able to grow in personal relationships with romantic partners, children, friends, etc. According to the resource theory of health, this sense of achievement accompanied by resources such as money, power, prestige, knowledge, and connections, should be highly effective in preventing and treating illness. Ironically, the attainment of great success in their professional/personal lives is often accompanied by the memoir authors' first awareness of symptoms of illness with disruptive chronic conditions.

In the memoirs in my sample, authors speak of two types of situations in which they find themselves becoming ill in spite of their achievement in both their professional and personal lives. First, there are those who came from relatively privileged backgrounds but emphasize the effort they have put into reproducing or maintaining their privilege in a personally meaningful way. Second, there are those who come from underprivileged backgrounds and feel proud of their successes in

becoming upwardly mobile and doing well in their new social milieu. I will use Robert Horn's *How Will They Know If I'm Dead? Transcending Disability and Terminal Illness* (1997) to exemplify the first pattern and Audre Lorde's *The Cancer Journals* (1980) to exemplify the second.

Prior to the onset of Amyotrophic Lateral Sclerosis (ALS), commonly known as Lou Gehrig's disease, at around age 45 (in 1988), Robert Horn's life trajectory exemplified that of the person who, despite being born into a highly privileged background, celebrates the importance of personal effort in achieving his professional stature and personal happiness in his adult life. At the time of the diagnosis of ALS, Horn was an internationally recognized professor of political science specializing in the Soviet Union. He also led what he felt was a successful personal life; he emphasizes being happily married with children, having a rich spiritual life in his faith community, and successfully coaching girls' soccer teams. To be sure, Horn is one of the few authors whose privilege is expressed across all socially salient structural lines: while most of the authors in the study are "ethnically white," (for a classic sociological exploration of the historical broadening of who counts as white, see Williams 1990), he was a self-identified WASP heterosexual male from a professional middle-class background, which he summarizes as "growing up normal" yet "abnormal in the abundance of blessings and joys" he experienced (Horn 1997, 3). Horn's sense of growing up "normal" evinces his recognition of the distinct advantages afforded by his initial circumstances. However, his sense of growing up "abnormal" evinces his recognition of the difference between his "abnormal" privileged family—living in the midst of an

abundance of blessing and joys—and other "normal" privileged families—which

apparently lacked blessings and joys. To Horn, this difference in blessing and joys

between his and other privileged families is due to his parents' explicit effort put

into organizing family life, which Marxists tend to dismiss as mere mechanical social

reproduction:

> My mother was a housewife who did a lot of volunteer work but always made
> sure she was there when I got home from school. My father was a physician, a
> professor of pathology at the medical school of the University of Pennsylvania.
> I had a very happy and secure childhood, marred only by chronic, periodically
> acute, asthma. My brother, Tom, and sister, Ethel, both younger, and I were
> neither indulged nor deprived. (Horn 1997, 3)

The effort that Horn's parents put into reproducing their privileged status in their

children is palpable. At the least, his parents sought to make themselves good

examples to their children. As a doctor and professor at an elite institution of higher

education, his father was an exemplary model of masculine success and probity,

while his mother fulfilled her middle-class duties as a housewife and community

member. Besides showing their children the importance of steady professional work

and community participation, his parents also sought to instill in their children the

middle-class value of moderation, as manifested in their neither indulging nor

depriving their children. Having absorbed his parents' emphasis on effort even

when one is born with so much privilege, Horn is proud of his role in the apparently

effortless reproduction of his parents' middle-class WASP life as an adult:

> Granted, I was not wealthy financially or in material terms, but I considered
> myself rich in areas of far greater importance: family, religion, and
> employment. Judy and I had a loving and fulfilling marriage and our children . .
> . were doing well in all respects and continued to be a source of joy to us. We
> were active members of a dynamic Methodist church that more than met our
> spiritual needs, deepened our faith, and was filled with wonderful people.
> Finally, we both had jobs we enjoyed, college teaching in my case and directing

> pre-school in Judy's, and that we felt made a contribution to the community. Professionally, my research was going very well. (Horn 1997, 20)

As this quote demonstrates, Horn's adult life was not a soulless reproduction of his initial condition. More important to him was his sense of doing work that contributed to the community and his personal life as a heterosexual husband and father. Thus, while his life might appear to be similar to that of other college professors and married heterosexual men, he emphasizes the strong moral, ethical, spiritual and emotional aspects of his life despite, he says, not having achieved significant financial or material wealth.

Ironically, in spite of his awareness that his social fate could easily go sour, Horn did not think about the possibility that his biological body could also go deadly wrong in spite of all his effort and achievement. Neither did he consider how his life might fall apart in a drastic way as he began to lose his previously taken-for-granted bodily functions.

> It is still amazing to me how rapidly one can plummet from the heights of the mountaintop to the depths of the valley. Or at least how fast I could. And did. It was virtually instantaneous. One moment life was glorious and the next appeared to be over. I knew what Lou Gehrig's disease meant: progressive loss of muscle control leading to death with a few, short, agonizing years. I was never going to be normal again. And, very soon I was going to die. (Horn 1997, 21)

Understandably, Horn describes the diagnosis of ALS as a sudden, drastic fall. Right before the illness, he felt "on top of the world" and that "life couldn't have been much better" (Horn 1997, 20). When he was diagnosed with ALS, however, he felt that he had "plummet[ed] from the heights of the mountaintop to the depths of the valley" (21). Although drastic, at first the fall seemed to occur in slow motion. He was able to maintain his coaching efforts for some time and retired from his

professorship only when he could no longer breathe on his own. For more than five

years, Horn depended on a ventilator to breathe, was fed through a tube, signaled

meaning with an eyebrow, and used his foot to type on a keyboard. He finally

succumbed to ALS two years after the publication of the memoir.

In comparison to Horn, Lorde (1980) presents a pattern of rising from

relatively underprivileged initial circumstances into great achievement and then,

like Horn, became ill when she felt most successful in both her professional and

personal lives. While Horn identified as a WASP heterosexual male from a solidly

middle-class background, Lorde identified as a Black lesbian feminist, the daughter

of middle-class Caribbean immigrant parents who maintained a real estate business

in New York. While not necessarily being in economic want, Lorde feels great

success for being able to rise above the WASP heterosexual male-dominated social

order, becoming a successful activist, poet, and educator speaking on behalf of racial

and sexual minorities like herself. At the time of her diagnosis of breast cancer at

age 44, she appeared to be in a fulfilling romantic relationship with another woman,

as she discusses in her memoir. The fact she became ill in the midst of her

professional and personal success came as a total shock. Her new awareness of the

finitude of her life led her to recognize that her life as a successful activist and lover

can lose all meaning due to death by cancer:

> In becoming forcibly and essentially aware of my mortality, and of what I
> wished and wanted for my life, however short it might be, priorities and
> omissions became strongly etched in a merciless light, and what I most
> regretted were my silences. Of what had I *ever* been afraid? To question or to
> speak as I believed could have meant pain, or death. But we all hurt in so
> many different ways, all the time, and pain will either change, or end. Death,
> on the other hand, is the final silence. And that might be coming quickly, now,
> without regard for whether I had ever spoken what needed to be said, or had

only betrayed myself in small silences, while I planned someday to speak, or waited for someone else's words. (Lorde 1997, 18)

In this quote, Lorde acknowledges the ways patriarchal, heterosexist, White American society controls and silences those whose bodies or behaviors in any way challenge the hegemonic. As an African American woman and a Black lesbian, Lorde recognizes that she had internalized the real threat of psychic and physical pain, including death, that accompanies those identities with the result of too-often silencing her own voice and thus becoming complicit with existing hierarchies of privilege. Lorde learned through her experiences in activism and education that these injustices could still be controlled by a collective transformation of mind. The social silencing of minorities can be diminished through collective control, especially after the increased safeguarding of minority rights instituted after the Civil Rights movements (Skrentny 2002). In contrast, the biologically structured line between health and illness is in a strict sense uncontrollable. Furthermore, in contrast to the reversible social silence of minorities, the silencing of cancer is final, as one can no longer speak when one is dead.

Through Horn's and Lorde's experiences of becoming ill when they felt most successful both professionally and personally, I find two interesting conclusions regarding the resource theory of health. First, like the authors in Chapter Two who were shocked at becoming ill in spite of their responsible living, the shock experienced by Horn and Lorde indicates that they, too, had regarded their professional and personal success as a shield against illness. Now, it is not for sure to what extent the sense that one was at the top of one's professional and personal achievement when one became ill is a product of retrospective romanticization.

After all, it is easy to overemphasize the value of something that one had taken for granted but then lost from unanticipated changes in one's life. What is for sure, however, is that authors implicitly connect the resource theory of health with meritocracy. They felt that, as long as they put effort, they will not only become rich, powerful, and esteemed, but would also be entitled to permanent health. Again, at the bottom of this quasi-magical view of resources as a shield to illness is the assumption of health as solely the consequence of effort. However, to thus view health is to make the mistake of overlooking the equally important fact that health is not really just an achievement, but also a highly contingent pre-condition for effort and achievement. Hence the shock at the reality of the "fall" and the prospect of the "final silence," which evince the person's overwhelming recognition that one's achievement has not been wholly up to oneself, but has also been hinged upon the essentially unstable foundation of biological health.

Chronic Illness as the Great Social Leveler: The Case of Highly Privileged Authors

People accustomed to enjoying the benefits of great privilege are not just surprised by becoming chronically ill "in spite of" commanding superior resources. Oftentimes, they are surprised to find that the disruptive chronic conditions can render social distinctions relatively meaningless. This illustrates the limited power of resources to prevent and treat chronic illnesses. No matter the extent of one's material, psychic, and interpersonal resources, some disruptive chronic illnesses are impossible to prevent and challenging, even impossible, to treat, given the present

state of medical development. Because both the privileged and the underprivileged are unable to prevent and fully treat disruptive chronic illnesses, these illnesses can thus act as a special instrument of social leveling, creating surprising connections or at least similarities between people of differing statuses.

In my sample, I find two main patterns of responses to this recognition that status-based differentials of resources can mean very little in the prevention and treatment of disruptive chronic conditions. First, many privileged authors register their shock of recognizing that they are just as powerless as their underprivileged counterparts regarding chronic health conditions. Second, some relatively underprivileged authors—particularly African American professionals—are pleasantly surprised at the way disruptive chronic conditions can promote social justice by demonstrating that such illnesses cut across racial lines. To illustrate the first pattern, I draw upon Joel Havemann's *A Life Shaken: My Encounter with Parkinson's Disease* (2004) and Richard Cohen's *Blindsided: Lifting a Life Above Illness: A Reluctant Memoir* (2005). These two memoirs respectively delimit the efficacy of power and of money in preventing and treating serious chronic conditions. I will explore the second pattern in the next section.

Havemann's memoir emphasizes the limited effect of power in preventing and treating degenerative chronic conditions such as Parkinson's disease. He was diagnosed with Parkinson's disease in 1990, when he was 47. The son of a journalist, Havemann entered his father's profession after graduating with a mathematics degree from Harvard. At the time of his diagnosis, he was an editor at the Washington bureau of the *Los Angeles Times*. Like many of the authors in this

study, Havemann regrets not catching his early symptoms earlier. Ironically, he only

came to recognize the severity of his condition at a moment meant to impress a

prospective employee. During an interview at an expensive restaurant, he was

unable to keep his spoon from shaking, causing expensive raspberries to fall onto

the table. In the months that followed, his shaking became increasingly visible to the

extent that his seven-year-old son commented on it. Initially, Havemann was able to

control the symptoms and retard the progress of the disease through medication,

but after five or six years, the medication lost its effectiveness, and the physical

impairment progressed relentlessly. When the memoir was published in 2004,

Havemann had already been living with Parkinson's disease for 12 years.

Havemann's recognition of the limited efficacy of power in preventing and

treating illness emerges in a reflective comparison between his situation and those

of American presidents like Reagan and Truman, noting that both presidents had

experienced health challenges; Reagan, famously, due to Alzheimer's and Truman

after a fall in 1964:

> None of us, no matter how powerful in our prime, is immune. As I write this
> chapter, Alzheimer's disease has reduced Ronald Regan to a shell. Harry
> Truman, shortly after my memorable encounter with him in Kansas City, must
> have suffered a similar fate. (Havemann 2004: 67)

Havemann compares his progressive loss of control of his body with the mental

deterioration of Reagan and Truman. The intention of this comparison is clear. As

American heads of state, Reagan and Truman were each routinely referred to as "the

most powerful man in the world," commanding the "fire and fury" that is the

American Army and having a dominant say in global and domestic affairs. Yet, in

spite of all their power, which can be easily translated into other valuable sources,

neither of them was able to avoid and treat their illnesses. On a different scale, Havemann had also risen to a position of power, albeit as a captain of consciousness rather than the head of the American military-industrial complex. Yet, like Reagan and Truman, he was also powerless against severe chronic illnesses. Thus, at the biological level at least, these powerful white men are really just as powerless in the face of chronic illness as underprivileged people who have very little power.

Rather than power itself, Richard Cohen's memoir emphasizes the limited utility of money to prevent or even treat chronic conditions such as multiple sclerosis. A son of a doctor who also had multiple sclerosis (MS), Cohen was diagnosed at age 25, when he had just begun his career as a journalist. Although he had not reached the plateau of professional success at the time of the diagnosis, he writes that the illness occurred when he felt highly motivated in his career, covering events such as the Watergate scandal, the Vietnam War, and the Middle East conflict. Initially dismissing his symptoms, he only acknowledged the gravity of his situation when he was unable to hold a coffee cup in his hand while editing a documentary on disability activism. When his memoir was published, the progress of was evident: his balance was unsteady, causing him to fall when walking outside; he was legally blind; and he had limited bladder control. As the MS progressed, he further suffered two bouts of cancer.

Cohen's realization that money matters little in the prevention and treatment of chronic conditions such as MS stems from a conversation with his physician father, whose mother, like himself and his son, also had MS. Cohen's diagnosis came as no surprise to his father, who had informally diagnosed Cohen with MS earlier.

Nonetheless, despite being a physician, having firsthand experience with multiple

sclerosis, and having correctly predicted his son's disease, Cohen's father sought to

distance himself from his son's illness:

> I called my father and broke the news to him. "Welcome to the club," he said. "I
> will pay out-of-pocket expenses you have," my dad stammered, probably
> reaching out to me in guilt. "Dad, all your wealth won't buy *me* health," I
> answered, playing off a Beatles tune. (Cohen 2005, 19)

Hoping for some compassion and wisdom from his father as a doctor and survivor of

MS, Cohen instead felt silenced and dismissed by his father. He seems to have

understood why his father might feel guilty for transmitting multiple sclerosis, with

its physical and symbolic disruptions, to his son. (Although not an inherited disease,

some 200 genes have been associated with MS, so there is an inherent genetic risk

factor to MS.) Nevertheless, Cohen felt betrayed by the fact that his father would fall

back on money as an easy way to cover his sense of guilt, despite his own personal

knowledge that his son's condition cannot be cured by the best medical treatment

money can buy. Perhaps, as a young journalist who found great purpose in exposing

the abuses of the American government during the Vietnam War and the Watergate

eras, Cohen further saw some resemblance between his father's effort to assuage his

guilt with money and the corrupt governments and corporations around the world

seeking to buy the silence of their victims. Further, as a young person who came of

age during the 1960s, he may have read his father's effort to use money to allay his

sense of guilt as a manifestation of the capitalist myth that everything has a price,

hence his reference to a well-known song by the rock heroes of the countercultural

movement, the Beatles.

In Havemann's and Cohen's cases, we see two white heterosexual white male journalists who became disillusioned with the resource-based theory of health. In Havemann's case, he came to recognize the limitations of political power to prevent one from getting sick and getting treated from chronic diseases. Even though American presidents enjoy the best protection from bodily harm from the American military and secret service, and enjoy the best connections in all domains of social life, in this case being medicine and science; the fact that the diseases in question are biomedically unpreventable and untreatable puts a hard cap on the effect of power. In Cohen's case, he learns that even though money is very important in getting access to healthcare, it is a whole different thing when the best healthcare one can buy will not be able to fully treat or even diminish the consequences of one's chronic disease.

Chronic Illness as the Great Social Leveler: The Case of Relatively Underprivileged Authors

Havemann's and Cohen's accounts exemplify the shock at personally experiencing the limit of power and money to prevent and treat disruptive chronic conditions. However, for authors who occupy underprivileged categories in socially salient structural lines such as race, the realization that resources are of small significance in preventing and treating chronic conditions may actually lead to the pleasant surprise of seeing chronic illness as a promoter of social justice. This more "optimistic" response is evident in the memoirs of two African American authors,

Arline Dean's *Multiple Sclerosis: The Unseen Enemy* (1995) and Mark McEwen's

Change in the Weather: Life after Stroke (2008).

Dean's 1995 memoir discusses her experiences of multiple sclerosis and her

association of stress with its symptoms. Although she first experienced symptoms of

chest numbness in the 1970s, they subsided after two weeks, and at the time,

neither she nor her doctors suspected multiple sclerosis. The second, more serious

attack emerged until the 1980s, when she experienced "numbness . . . from the waist

down affecting both legs and . . . a great deal of pain" (7). Dean attributes the

resurgence of the symptoms to stress related to her divorce at the time, when her

husband suddenly told her that he had had an affair with her best friend and that he

was moving to her house. The memoir is not clear as to whether she was

subsequently able to return to her work as a flight attendant. Even though Dean

reports a greater sense of control over her physical condition than at her worst

moments in the 1980s, her sense of loss is still evident:

> Since MS is unpredictable, there are times when I feel absolutely wonderful
> and other times when I can't read anything without the aid of my glasses. . .
> Walking becomes, at times, a difficult task. Every now and then, my mouth will
> jerk slightly when I'm trying to talk. Fortunately, I have not had an acute attack
> for nearly seven years, so these little inconveniences are tolerable. (Dean 1995,
> 3)

The notion of multiple sclerosis as a promoter of social justice is one of the

many ways in which Dean comes to limit her sense of crisis in the face of her illness.

Besides comparing her condition with other survivors of MS living with worse

conditions (Dean 1995, 13) and alluding to negative situations in her own life such

as divorce, Dean also relates that MS is "good" for being able to level age, gender,

and most importantly, racial differences:

> I am African-American and in my early 50s. Multiple sclerosis can attack at any age but mostly in young adults, and it knows no gender. The only good thing about MS is that with all the prejudicial experiences we encounter, MS is not prejudice[d]. Any race is vulnerable. (Dean 1995, 13)

Dean's use of the adjective good to refer to the fact that both white Americans and African Americans are susceptible to multiple sclerosis may sound a little disconcerting, especially given her avowed identity as a Christian. However, it may be argued that, for Dean at least, the description of MS as good is analogous to the description of God as good. That is, while American society is divided by prejudices of race, age, and gender and is therefore not good, God and MS are both good because they are impartial and fair. We need not critique Dean for regarding racial inequality as mainly due to prejudice rather than institutional forms of racism (see Bonilla-Silva 2003), however. What is more important for the present purpose is the cultural function of her focus on the supposed impartiality of God and MS. I would suggest that Dean's recognition of suffering as the ultimate equalizer can function as a Weberian theodicy of the socially oppressed.

Mark McEwen's sense of illness as a promoter of racial justice emanates from the perspective of an African American male. In 2005, he was a popular daytime TV personality in Orlando, Florida and suffered a massive stroke in mid-air returning from Maryland to Orlando, he. When the plane landed, McEwen was feeling ill but did not know what was going on with him. After asking for help, he was put in a wheelchair by an airport staff member who then left the seriously ill man at the curb of the airport. A passing stranger helped him call 911 and he was admitted to the hospital. After a month-long hospital stay, he was in a rehabilitation facility for a year. Because the right side of his body, especially his right hand, was incapacitated

by the massive stroke, he had to relearn daily routines using his left hand. At the

time of the writing of memoir, in spite of continuing issues with his right hand, his

condition had generally improved.

Like Arline Dean, McEwen emphasizes the importance of limiting the sense of

crisis caused by illness by contextualizing one's illness within the broader social

context. Despite his sense of loss, McEwen was nevertheless also able to remind

himself that he was not the only person suffering from stroke, which was made clear

to him during his long stay in the hospital and rehab. Moreover, he came to regard

stroke as part of the human condition that can happen to anyone:

> I'm sharing my story here because I want stroke survivors to know that they
> are not alone. That stroke can affect anyone. *That stroke doesn't discriminate.*
> We'd all do well to keep open to the experiences of those around us, especially
> when it comes to stroke. There is no path to a full recovery, just as there is no
> shortcut. I knew this in theory, going into my ordeal, but it took reaching
> through to the other side to know it full well. (McEwen 2008, 200, my
> emphasis)

On the face of it, this piece of self-reflection appears to be just a reiteration of illness

identity discourse's assumption that "no one is immune from illness." Nevertheless,

it does not seem farfetched to say that McEwen's emphasis that stroke "does not

discriminate" may connote that stroke cuts crosses racial lines. As a middle-class

African American man growing up in post-World War II America and working in the

White-dominated news industry in a southern state, it seems unlikely that he was

unaware of the various modes of overt and covert, interpersonal and institutional

discrimination faced by African American men. African American people, in

particular, African American men, are often portrayed as "other" to civility and

legality as defined in white heteronormative contexts white (Alexander 2010). This

definition of African Americans as "other" both informs and is reinforced by the systematic denial of resources such as education, housing, health services, and desirable work, as well as the over-representation of African American men in the penal system, which further reinforces negative stereotypes and accelerates the disruption of African American families and communities. Yet, in spite of all the discrimination and marginalization of African American men in American society, African American men are nevertheless equal with their more privileged counterparts, especially white men, when it comes to chronic diseases. With or without resources, chronic diseases hit and challenge the person because there is simply no proven way to prevent and treat them.

Illness as Master Status: The Negative Cases

In addition to the surprising experience that one can actually become ill "in spite of" one's superior resources, authors also render non-obvious the resource theory of health through their interactions with healthy people as socially privileged yet also ill people. In the face of the authors' supposedly contradictory statuses of being both privileged and being ill, healthy people rarely question their initial association between privilege and immunity to illness. Rather, healthy people tend to resolve the "contradiction" by simply attending to the authors' status as ill people, while minimizing or ignoring their status as socially privileged people with abundant resources. Through healthy people's effort to resolve what Hughes (1945) calls the "dilemmas and contradictions of status" between being privileged and being ill, illness then becomes the "master status" of the memoir authors (Becker

1963). This new master status takes precedence in determining the authors'
identity, muting their many other statuses, but most notably their socioeconomic
status as highly educated professionals.

In my data, I find two patterns of surprising experiences in which authors
find their illness becoming the focus of healthy people's attention at the expense of
their many other statuses. First, there is the shock at finding oneself being "reduced"
to the fact of one's illness, which often leads to a sense of degradation. Second,
finding that one's illness enables connections between people of otherwise very
different—especially "lower"—social statuses can actually be a pleasant surprise to
some authors.

In this section, I explore the negative experience of feeling "reduced" to the
status of being ill. I will use David Biro's *One Hundred Days: My Unexpected Journey
from Doctor to Patient* (2000) and Christina Crosby's *A Body, Undone: Living On after
Great Pain* (2016). I will explore the pleasantly surprising experience of bridging
social differences through illness in the next section

David Biro's example illustrates the shocking discovery on the part of the ill
person who is also a medical doctor. That is, even his medical colleagues appear to
forget about his privileged status as a fellow doctor and also a white man, focusing
solely on his being a sick person. Biro was diagnosed with a rare and life-
threatening blood disease (abbreviated as PNH) at age 31. At the time, he was about
to finish his residency in dermatology and join his father's private dermatology
practice. His father is a Jewish survivor of the Holocaust who was sent from his
home in Austria to a German concentration camp, and then luckily found a way to

get to the United States (Biro 2000, 73). Like the medical practitioners and researchers discussed in Chapter Two, despite his ample medical training and knowledge of friends and colleagues who suffered and died from severe illnesses, Biro assumed that he would be immune to illness. Retrospectively, he attributes his foolish sense of immunity to his dedication to a healthy lifestyle: "[n]o other medical problems; no prior surgeries or hospitalizations; no family history of cancer or other diseases. I gave up smoking last year. I exercise daily. I am the spitting image of Health. I am Salus, for Christ's sake, the fucking God of Health" (Biro 2000, 12). Again, it is not for sure whether he really felt that healthy or that immune to illness right before the onset of illness, but he does drive home his retrospective criticism of the cultural association of privilege embodied in the healthist lifestyle and immunity. After the diagnosis, he checked in at Memorial Sloan-Kettering Cancer Institute, where he underwent a painful bone marrow transplant. The procedure required a highly debilitating radiation and chemical treatment to temporarily block his body's immunological defenses against foreign bone marrow, which was extracted from his younger sister.

In Memorial Sloan-Kettering, Biro was initially able to enjoy the social perks of being a colleague of medical practitioners. Having met a doctor at Sloan-Kettering during his residency, Biro was able to get a more spacious room with a window, which he felt was of paramount importance to his well-being in light of his claustrophobic disposition. (Even though his medical training should have made it clear to him that he would not suffocate during an MRI, which requires temporary enclosure in a somewhat coffin-like structure, he nevertheless had a panic attack

during his MRI study.) Despite receiving such benefits, however, Biro was forced to

reckon with the fragility of his doctor status when he was found to be a "zebra," i.e.,

a patient exhibiting medically ambiguous symptoms. To medical researchers and

clinicians, a zebra is valuable as a research object and clinical problem. Thus, Biro's

new status as an ill person supplanted his status as a doctor when he became the

object of grand rounds in the hospital, displayed to doctors and students who

proceeded to discuss his physical symptoms in the third person, while he was

presented to them in a wheelchair. He was highly ambivalent about the experience:

> A person who has already been stripped of citizenship in the normal, healthy
> world, is made to bare himself and his infirmity, to parade it in front of a group
> of strangers, to play the role of the freak, and, in many cases, get nothing out of
> it. Of course, there is always the glimmer of hope that someone in the audience
> will have a brainstorm, a flash of medical insight. But the majority of neurology
> patients have conditions like multiple sclerosis and Lou Gehrig's disease,
> which we currently can't do much about. We wheel them around, talk about
> the case for hours, gawk, then watch them languish and die. (Biro 2000, 33)

For Biro, it is one thing to recognize the medical and pedagogical function of the

institutional practice of displaying and discussing patients. Yet, it is wholly another

when such practice can easily function as what Garfinkel (1956) called a "status

degradation ceremony." In Biro's view, the work of status degradation in his case is

eminently successful, as he felt treated as a mere abnormal biological specimen

without acknowledging his particular social attributes and personal experiences.

Understandably, in light of his colleagues' training to focus on his biology at the

expense of his status as a doctor, he feels entirely bare and degraded.

It should be noted that Biro did find some redemptive meaning to his

humiliating experience as a zebra, using it as an opportunity to reflect upon his past

callousness towards a zebra patient of his own. Even though the patient was

suffering from a painful skin disease that caused him to look very different from others, Biro focused on the research opportunities offered by the zebra patient rather than the person suffering from the condition. In addition to displaying his patient to his colleagues without really thinking about what such experience did to the patient's self-esteem or even to his treatment process, Biro published an article about the patient in a prestigious journal without ever thinking of him as anything more than a challenging medical case.

While Biro was shocked by his loss of the normative status of doctor because of his illness, Christina Crosby was shocked by the loss of her accustomed gender identity because of her new status as paraplegic. As discussed in Chapter Three, Crosby's memoir begins with a bicycle accident while she was trying to relieve the stress of chairing the gender studies department at Wesleyan University. The accident was nearly fatal, and injured her spinal cord, rendering her paraplegic with intractable pain experienced as electric currents were coursing through her body.

Crosby's shock is due to the sense of having her gender identity destabilized as a result of her physical impairment. Before the accident, she had formerly taken pride in her status as a "femme butch," that is, in her words, both seeming "butchy" and having "big, gorgeous breasts" (Crosby 2016, 60) that together mark her as a particular kind of woman. Yet, after the accident, the nerve damage and the need for a protective harness to keep her in her wheelchair have transformed her, in others' eyes, into a "stone butch" or a man. In her life prior to the accident, Crosby had questioned society's binary understandings of gender and sexuality long before her accident while also questioning the binary of femme and butch within the lesbian

community. To Crosby, that binary reproduces normative gender divisions, which

she contests, even while identifying as a loyal member of the community. Even

though she sees herself primarily as a butch, Crosby is uncomfortable with the

tendency of stone butches to overemphasize their masculinity, in particular, their

domineering mode of sexual interaction with femmes and practice of binding their

breasts. In contrast to stone butches, she felt proud of identifying as a butch who

was not averse to her own femininity, wearing clothes that revealed her cleavage

and expressing her sense of vulnerability during sex. The shock of being having her

physical appearance understood by strangers as that of a man emerged as she

became dependent on a wheelchair for movement:

> I no longer have a gender. Rather, I have a wheelchair. I'm entirely absorbed
> into its gestalt. I'm now misrecognized as a man more often than ever, almost
> every time I go out. I'm not surprised. I know that 82% of spinal cord injuries
> are suffered by young men, and middle-aged butchy women must be
> statistically negligible in that accounting. Besides, when I'm outside wheeling
> my chair, I'm belted in [by a strap which secures her back against the chair]. . . .
> This I regarded as a great irony and a perverse injury, because I've never
> wanted to bind my breasts, unlike some butchy women. To the contrary, I used
> to wear my shirts unbuttoned at the top . . . and my zippers pulled down almost
> to the cleavage. . . . I love my breasts, and loved to show them off, but there's no
> way you'd know that seeing me now. (Crosby 2016, 60)

Crosby's painful experience of misgendering because of illness reaches a

climax when she found that her paralysis renders her metaphorically close to her

worst nightmare: the stone butch due to her loss of the sensation when sexually

touched by her partner. To Crosby, stone butches evince an asymmetric sense of

sexuality, such that they feel entitled to both touch the femme sexually and not be

touched sexually in return (Crosby 2016, 127). In contrast, she has long prided

herself in her enjoyment of being touched sexually by femmes. Crosby was thus

dismayed when her partner, in an effort to explain to the doctor how their sexual relationship has changed, compared Crosby's loss of sexual response to the apparent somatic insensitivity of a stone butch. In hearing this analogy, Crosby protested to her partner and her doctor that "I've never been stone, *ever*! I've always wanted to touch a*nd* be touched" and also that she "*would love to be fucking differently with Janet, if I could*" (Crosby 2016, 128; author's emphasis).

Illness as Master Status: The Positive Cases

In this final section, I examine how the status of being ill supplanting the usual dominance of privileged status can be experienced by the author as a pleasant surprise due to the author's sense that her illness lessens the social difference between her and others, especially those who are socially different or even socially marginalized. I will illustrate two different patterns of how this occurs with Fran Peavey's *A Shallow Pool of Time: An HIV+ Woman Grapples with the AIDS Epidemic* (1989) and Paul Stoller's *Stranger in the Village of the Sick: A Memoir of Cancer, Sorcery, and Healing* (2004).

In contrast to Crosby's pain at being misgendered due to her disability, Peavey saw her experience of degendering in light of her HIV as empowering. Peavey is a comedian known during the 1980s as San Francisco's "Atomic Comic," a social activist, and writer. The first page of her memoir reveals her former sense of gender immunity from HIV, as she thought that it was only a disease of gay men who practice risky sex. "[O]ne gets it from bathhouses where gay men do things that I cannot imagine" (Peavey 1989, 1). She was thus shocked to find that her HIV

infection was instead caused by a blood transfusion. However, precisely because her

experientially based recognition that HIV can be dissociated from male

homosexuality, she came to see her illness as enabling the deep sense of solidarity

with gay men living with HIV as summarized by Susan Sontag:

> Indeed, to get AIDS is precisely to be revealed, in the majority of cases so far, as a member of a certain "risk group," a community of pariahs. The illness flushes out an identity that might have remained hidden from neighbors, jobmates, family, and friends. It also confirms an identity and among the risk groups in the United States most severely affected in the beginning, homosexual men, has been a creator of community as well as an experience that isolates the ill and exposes them to harassment and persecution. (Sontag 1990, 113)

More than just arguing that illness can cut across the gender line, Peavey

points to an episode in her illness support group to argue that the ill, irrespective of

their gender and sexuality, can share a moral ground as ill people that is more

authentic than the shallow moral ground of healthy people:

> Last night's support group was very moving, and I learned so much. One told a story which all of us could identify with. While cutting something at a restaurant he works at, he had nicked himself and had begun bleeding on the food and on his work area. He freaked out inside, threw the food away, and went to get some bleach to clean the area. Some of his work mates asked him what he was doing with bleach . . . Of course he was not able to be open with them about why he was so careful. All day he was very conscious of the bandaid, checking it frequently to see that it was in place (Peavey 1998, 82).

In this quote, the fellow member in the HIV support group appears to be a working-

class man who makes a living by cutting ingredients at a restaurant. Whether the

man contracted the illness through a blood transfusion as Peavey did or through

heterosexual or same-sex sexual acts, Peavey emphasizes her sense of learning to

transcend the differences in gender (and possibly class) between them not simply

through the fact that they both embody a stigmatizing illness. More importantly,

through the man's example, she came to see the possibility that their illness can

actually be a source of an authentic morality. To Peavey, in cleaning the workplace

and making sure he did not bleed anymore, the man did not simply focus on getting

rid of evidence of his HIV-positive status in a society that stigmatizes the illness,

which could cost him his job. Rather, the man cared more about his responsibility

for protecting his coworkers and customers from possible infections:

> This opened up a long discussion about how we could feel good about
> ourselves when something so potentially bad is inside of us. . . . I know that I
> trust that man a great deal more than I did before hearing of the incident. I
> know how careful he is as a custodian of this virus, and how deeply he wants
> not to harm anyone. . . . This should help each of us feel better about ourselves
> (Peavey 1989, 82).

While Peavey's finds the status of illness transcending differences between

fellow support group members, Paul Stoller's memoir illustrates how his status as a

cancer patient can minimize the status difference between him and his healthy

college-level students. A white heterosexual male professor of anthropology

specializing in sorcery among the Songhay people in Niger, Stoller was diagnosed

with lymphoma at age 54, three years before the publication of his memoir. Like

most other authors who have enjoyed relative health and professional satisfaction,

Stoller felt immune to deep illness prior to the diagnosis. What sets Stoller's account

of his sense of immunity apart, however, is its connection to his peculiar

experiences of Songhay sorcery, i.e., having survived two highly incapacitating,

nearly fatal sorcery attacks. His experiences with sorcery began during his study of

the Songhay, when he became the final disciple of a famous Songhay sorcerer. As is

common in the highly competitive and morally neutral world of Songhay sorcerers,

he had been challenged twice by competing sorcerers. Ironically, the fact that he

emerged from the attacks relatively unscathed made him feel immune to illnesses,

including cancer. At the time of publication, his cancer went into remission after treatment.

Despite his sense of loss and helplessness as a lymphoma patient, Stoller was pleasantly surprised at how his status as an ill person enabled his college students to look past his privileged status, and identify with him at a more human level. The pleasantly surprising attitude of his students towards his cancer emerged after he decided to come out to them about his cancer and his chemo at the beginning of a class. He then proceeds to ask the students two questions: "When I'm completely bald, I'd like to get an earring. Which ear should I get pierced? And should the earring be silver or gold?" To his great pleasure, the students smiled at his questions. One female student even raised her hand and answered: "Get the gold and put it on the left ear" (Stoller 2004, 154). The sense of human-level identification hit home when students approached him after class:

> "It's good you told us, Dr. Stoller," one student said. "We think professors are so different. This makes you seem more like us."
> Several students voiced similar sentiments, all of which made my spirit soar. (Stoller 2004, 155)

Apparently, his students previously regarded Stoller in particular and professors in general as essentially different from themselves. It is not clear whether the students' sense of professors' difference was mainly due to their statuses in terms of race, class, gender, or even age, or to their sense of professors' greater pool of resources. Perhaps students find him to be different from most people due to his experiences as a practitioner of Songhay sorcery, which he shared with the public in the form of an autobiographical publication (Stoller and Olkes 1989).

Whatever the reason for the sense of social distance between themselves and Stoller, however, students came to overlook that distance in view of his status as a cancer patient. I suggest two possible reasons for the students to feel a sense of kinship with a professor with cancer. First, students may have recognized that, beneath all markers of status difference between them, his illness renders visible the fact that the professor is at bottom a vulnerable being made of flesh and bones just as they are. Second, the students might have identified a parallel between the professor's newly subordinate, vulnerable status as a cancer patient and their subordinate status as young people in addition to the economic vulnerability many of them must have experienced, depending upon their families for economic support. In addition, their empathy would be awakened by the fact that the subordinate status of the professor's existence as a cancer patient in many ways would be worse than the temporary state of being a student since the professor was confronting certain pain and possible death.

To sum up the last two sections, besides the surprising experience of becoming chronically ill in spite of their large pool of resources, the authors also come to question the resource theory of health by looking at how the contradiction between their status as socially privileged people and the status of being ill is managed in daily life. Basically, rather than accepting that social privileged statuses can be concurrent with the status of being ill, authors experience both the foregrounding of their relatively low status as ill people, and having their other statuses, especially their high socioeconomic status, set aside or even ignored.

This method of resolving the "contradiction of status" is not unique to chronically ill people. In his classic 1945 article, Hughes notes similar status dynamics in the increasingly mobile occupational world of the modern United States. Previously, professional jobs were associated with white men. "Contradictions of status" emerged when the increasingly mobile American society enabled African American individuals and/or women to attain the status of professionals. In order to manage the contradictory coexistence of professional status and nonnormative racial and/or gender statuses, the easy way out is to prioritize the race and/or gender of "contradictory" individuals and account for them only secondarily as professionals. Despite the similar practice of foregrounding nonnormative status (illness) and decentering the normative statuses (profession, financial status, race, etc.) of the ill person, my data show that the variation in responses to illness consistently reveals it as a master status. While Hughes appears to regard the foregrounding of nonnormative racial and/or gender status at the expense of professional status as wholly negative, some authors actually regard the experience of being regarded primarily through their status as ill first as wholly empowering.

Conclusion

In this chapter, I have explored the ways in which illness memoirs constitute an illness identity that cuts across status-based difference in resources by rendering as anthropologically strange the resource theory of health. To recap, the resource theory of health argues that the reason why socially privileged people tend to be

more immune from illness is due to their larger pool of resources such as money, power, prestige, knowledge, and connections. By themselves, such resources neither prevent nor cure illness. Rather, these resources enable the privileged to live in health-promoting environments, practice often-costly behaviors associated with healthist lifestyles, and obtain the best possible medical care when they do get sick.

My analysis shows that authors often come to recognize the relative irrelevance of resource in the domain of chronic illness through two major kinds of surprising experiences. On the one hand, they come to question the resource theory of health through the "contradictory" fact that they became chronically ill "in spite of" their large pool of resources. This contradictory experience enables the authors to recognize two underlying assumptions of the resource theory of health. First, they come to recognize their having taken for granted the quasi-magical view of resources as a shield against chronic illness. In other words, just as they tend to regard the effort at living healthfully as immunizing them from chronic illness, authors still make the mistake of regarding their health as a perk of their effort to achieve in a meritocratic society. Yet, this view of health as a kind of status symbol forgets that health is also special kind of resource that one needs in order to be able to compete in and enjoy the rewards in the meritocratic game.

Second, in focusing on the ways in which resources prevent and treat illness, the resource theory of health fails to distinguish illnesses that are medically preventable or treatable and illnesses that are not—especially disruptive chronic illnesses. From hindsight, authors discover that the resource theory of health mainly applies to the former types of illnesses, i.e., those that can be prevented and treated

as long as one can afford to take the necessary measures. In contrast, given the present limit in medicine's power to prevent and control chronic illnesses, there is an essential limit to the extent that resources can help us prevent and/or treat some chronic illnesses. This leads to the awareness that biology is the ultimate leveler of social differences. At least in the domain of chronic illness, biology thus supervenes both collective—in the form of peaceful or violent redistribution of resources—and personal agency—in the form of upward mobility—to level social differences.

On the other hand, besides the surprising experience of becoming ill in spite of one's large pool of resources, authors' surprising interactions with the healthy world as people who are both socially privileged and ill also undermine the validity of the resource theory of health. Authors generally find to their surprise that, rather than acknowledging the possibility that people can actually be both socially privileged and ill, the healthy world tends to sustain the resource theory of health by attending to authors' status as ill people, while discounting or even ignoring their other social statuses and their resources. To many authors, the foregrounding of their status as ill people and backgrounding of their other statuses is experienced as degrading. Thus, in light of the master status of being ill, Biro finds himself stripped of his doctorhood, while Crosby finds her hard-earned complex gendered identity simplified into maleness and stone-butchiness. Yet, some authors find that the focusing on their illness as the primary signifier enables them to create alliances that look past differences in status and resources. The looking past of social differences can emerge through the awareness of an authentic moral intuition shared by the ill, as in the case of Peavey. Or, it could emerge through the awareness

of the shared vulnerability between privileged yet ill individuals and underprivileged yet healthy individuals, as in the case of Stoller.

In their experientially based challenge to the resource theory of health, authors thus come to recognize the theory's overly optimistic reliance on biomedicine's and public medicine's power to control all illness, including acute and chronic illness. For the resource theory of illness, the distribution of health and illness within a population is mainly the result of the difference in resources, which is further seen as caused by differences in privilege. The resource theory of health thus argues that, as long as resources are distributed equitably within the population, the disparity in health outcomes in the population will tend to vanish. Yet, this tends to overlook the fact that many disruptive chronic conditions are neither medically preventable nor treatable. Thus, even if everyone could afford the best preventive and treatment technologies, chronic illness will still exist. In a true sense, the resource theory of health still retains the same over-optimism in the health-promoting function of resources as its illustrious predecessors Engels and Marx. According to Gerhardt, even though Engels and Marx were right in their connection between the prevalence of ill health and premature death among the working-class and their poor working and living conditions, they mainly saw "ill health and premature death (albeit suffered by individuals) were indicators of the capitalist society sui generis" (Gerhardt 1989: xv). Without recognition the relative autonomy of biology in general as well as individual differences in biology, they merely assumed that with social revolution, ill health and premature death will vanish in the world of working-class people.

In this critique of the resource theory's overly optimistic attitude towards biomedicine and public medicine, authors thus come to redraw the map of the social world. In the commonsense view held by healthy people, society is divided along socially salient lines such as a race, class, gender, sexuality, profession, etc. The divisions determine the distribution of well-being—including health—through the status-based distribution of resources. In contrast, through their experiences of becoming chronically ill in spite of their large pool of resources, authors seem to point towards a model of society that is fundamentally divided by the arbitrary forces of biology which enable some people to remain free from chronic illness while rendering others chronically ill, regardless of the resources available to individual members.

This view of society as fundamentally divided by the uncontrollable power of biology is double-edged. Positively speaking, it does argue for the relative autonomy of the biological differentiation between people who live with and those who do not live with chronic illnesses. The negative of this view of society is that it tends to overlook the ways in which well-being is complexly distributed in the social world in light of the intersection between biology and sociology. At the same time, it tends to overly downplay the ways in which collective action in the form of redistribution of resources may enhance well-being. In the next chapter, I will explore how authors come to regard the danger posed to their motivation to normalize their illnesses by this reversal of priority between the social and the biological.

Chapter Five

Normalization II:

Balancing Illness Identity Discourse with The Resource Theory of Health

Introduction

In this final empirical chapter, I explore how authors engage in the second form of the reflexive practice of normalization: balancing illness identity discourse with the resource theory of health. Through the work of normalization, authors challenge illness identity discourse's view that society is fundamentally divided by blind biological forces that randomly divide people into those who are healthy (or not yet ill) and those who are ill, without regard to individual differences in status and resource. Yet, rather than simply returning wholesale to the resource theory of health, authors come to construct a new picture of society that recognizes the complex ways in which status-based differences in resources intersect with biological processes in creating robust variations of well-being among both the healthy and the ill.

In the last chapter, given their experiences of becoming chronically ill "in spite of" their large pool of resources, socially privileged yet also ill authors come to recognize that the difference in resource between the privileged and the underprivileged may not matter as much in terms of preventing and treating disruptive chronic illness. Specifically, they come to recognize that the resource theory of health really applies to the acute and communicative illnesses that modern medicine—access to its services is heavily dependent upon one's resources—excels

at preventing and treating. In the domain of chronic illness, however, even if one were able to afford the best preventive and treatment measures, one can still not avoid and fully treat illnesses. Thus, status-based differences in resource may matter significantly less than sheer biological luck. This recognition of the limited power of resource to prevent and treat chronic illness leads to the sense of chronic illness as non-discriminatory and hence able to act as the ultimate social leveler.

The memoir authors' challenge to the resource theory of health has direct consequences to ontology and sociology. At the level of ontology, the resource theory of health assumes that society—understood in terms of the status-based distribution of resources—is not merely independent of, but also and more importantly, determinant of biology. In contrast, through their critique of the resource theory of resources as applying mainly to acute illnesses that are medically preventable and treatable, authors come to argue not simply for the limited power of the social in controlling the biological, but more strongly, for the determination of the biological over the social. This is driven home first by their realization that, while it may appear that resources determine health, the very ability to accrue and employ resources is based upon the contingent health of the body. Second, the determination of the biological over the social is shown through the fact that our social identities are often invisibly pegged on a healthy body, to the extent that a permanent loss of health may erase our prior social identities, substituting in their place the undifferentiated status of the ill person.

The shift in ontological vision tends to be accompanied by a radical shift in our picture of society. In the commonsense worldview of healthy people, society is

divided along socially salient lines such as a class, socio-economic status, race,

ethnicity, gender, sexuality, religion, nationality, etc. The social divisions are seen as

determining the distribution of well-being—including health—through the

categorically differentiated distribution of resources. In contrast, through their

experiences of becoming chronically ill in spite of their large pool of resources, these

authors point towards a model of society that is fundamentally divided in terms of

arbitrary forces of biology, enabling some people to remain free from chronic illness

while rendering others chronically ill, regardless of the pool of resources

individually available to them. In my sample of memoirs, no one depicts this shift of

sociology more tellingly than Miriam Engelberg in her influential comic memoir of

metastatic and terminal breast cancer, *Cancer Made Me a Shallower Person: A*

Memoir in Comics (2006, 14; Figure 1). Engelberg first cites author John

Hockenberry's analysis of "the world" as fundamentally divided into three groups:

the winners, the majority in the middle, and the losers. Here, the main dividing

factor appears to be both social and individual, such that individuals are born into a

society structured in this way, but they can still work their way up or down. After

Engelberg's cancer diagnosis, however, she sees the world as dualistic: those

without cancer (winners) and those with cancer (losers). With no regard to their

respective resources, she imagines that those who are healthy feel great ("yee

haw!"), while everyone with cancer is equally bodily and socially pained ("damn!").

LUCK
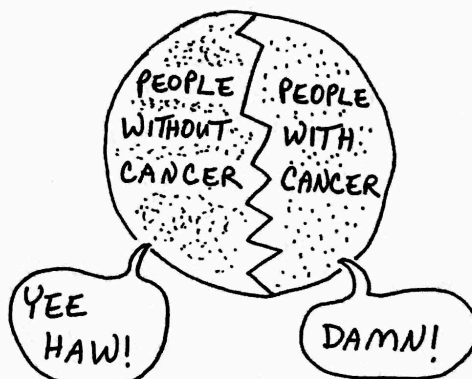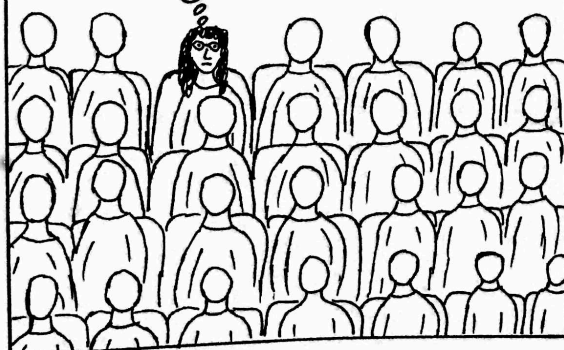
The problem with authors' experientially based critique of the resource theory of health is not simply the one-sided ontology and sociology. It is, more importantly, problematic for authors' need to normalize their illnesses, i.e., to recognize both that ill people are really not that different from healthy people, and that being ill per se is not necessarily the worst thing that can happen. The view of society as fundamentally divided by blind biological force first makes the sense of illness as normal untenable because illness is pictured as wholly outside of human or societal control. Besides making illness seem different from things that are amenable to some degree of social control, this view of society is fatalistic, as it may lead to the conclusion that collective action is of little utility in bettering the biological lives of individuals. Moreover, the sense that society is fundamentally divided into people who are blissful regardless of their social status and resources simply because of their being healthy, and vice versa, can often make it hard for the ill person to transcend the understandable yet faulty notion that illness is the only or the worst kind of suffering.

Based on authors' motivation to normalize their illness, I explore two kinds of unexpected experiences that the illness memoir authors emphasize as enabling them to recognize the relative autonomy of the social—understood as the social distribution of resources—over the biological. First, I explore their eventual realization that ill individuals have varying experiences, such that the socially privileged ill person's experience of illness is often considerably less bad than that of underprivileged ill people. This is especially true with regard to access to healthcare, as well as the powerful symbolic status of illnesses associated with

people of nonnormative social status, such as men who have sex with other men. Second, I explore their realization that otherwise biologically healthy individuals can be made to suffer from bodily and life crises simply because of their low social status and low resources. This is especially the case in racialized and gendered violence. They thus recognize that, contrary to their initial understanding of their illness as the worst, there may actually be worse forms of embodied suffering than merely being ill.

Resource-based Difference in Access to Healthcare

In the last chapter, illness memoir authors become estranged from the resource theory of health through their realization of the limitation of resources in preventing and treating chronic conditions. In other words, having a large or a little pool of resources has very little effect in rendering a person free from the highly disruptive effects of chronic illness. Besides their shared experiences of incurable bodily pain that can pose fundamental challenges to daily life and self-conception, the ill further share negative experiences in medical spaces, including impersonal discipline and side-effects from treatment. However, as they live and reflect upon their own and other people's experiences of illness, these authors also come to recognize that, even though resources may matter little in terms of the bodily suffering of the ill person, they still matter a great deal in the ill person's sense of control in the midst of illness. The resource-based differences in the ill person's sense of control can be clearly seen in terms of the access to healthcare and the

symbolic status of certain types of illness. In this section, I will focus on how status-based differences in resource robustly differentiate ill people's access to healthcare.

The memoirs present two major patterns through which authors recognize that one's large pool of resources significantly facilitates one's access to healthcare as opposed to the access afforded to "fellow" sufferers with fewer resources. The most commonly noted pattern emphasizes the perks of having a professional job. The second pattern emphasizes differences in terms of knowledge about access to healthcare. I draw upon Reynolds Price's *A Whole New Life: An Illness and a Healing* (1994) to illustrate the first, and Augusta Gale's *Older than My Mother: A Nurse's Life and Triumph Over Breast Cancer* (1996) to illustrate the second pattern.

Reynolds Price's reflection on his illness experience exemplifies the significant perks of having a professional job in the United States. In light of its exceptional, among advanced societies, lack of socialized medicine, access to healthcare is normally tied to employment (for a historical perspective of recent sociopolitical struggles over socialized medicine in the United States, see Starr [2011] 2013). Good health insurance is a routine, taken-for-granted benefit of corporate or professional jobs. The occupationally underprivileged, e.g., the underemployed, self-employed, and workers in small businesses, must purchase individual health policies, which are limited in its coverage and frequently impose burdensome restrictions, especially with regard to pre-existing conditions. Thus, even though authors spare no words in their criticism of their experiences of depersonalization and bodily torture at the hands of medical practitioners, they also tend to ironically concede their privilege of being able to access the highest quality

and attentive "punishment" due to their professional status and their employers'

benefits packages. This is especially the case among tenured professors at elite

universities such as Reynolds Price.

A novelist, playwright, and professor of English at Duke University, Price was

diagnosed with spinal cancer at age 51. The shock at the diagnosis was followed by a

major and risky operation to remove the tumor, radiation, medication that caused

serious side effects, untreatable and intense pain, and progressive paralysis.

Alongside his frustration at all these health setbacks, Price is uncharacteristic in his

critique of the impersonal treatment by medical staff:

> I understand the lamentably drastic limits of their training (the continued
> assumption that they'll work on machines, not sentient creatures); I'm aware
> of their burden in large hospitals or private offices, their frequent long hours
> and the potential psychical [*sic*] drains of their contact with anxious, pained or
> depressed human beings. . . But surely it's more than incumbent on the doctor
> to know the nature of the toll he or she has exacted from a fellow creature—
> someone in pain or fear—in forcing that move from the safety of home to the
> faceless threat of hospital hallways. . . . Those are merely the skills of human
> sympathy, the skills for letting another creature know that his or her concern
> is honored and valued and that, whether a cure is likely or not, all possible
> efforts will be expended to achieve that aim or to ease incurable agony
> towards its welcome end. (Price 1994, 144-6)

Through a rhetoric that is surprisingly similar to that of sociologist Arthur Frank's,

Price argues that the main problem with modern medicine is not its technical

aspect, even though it is still far from perfect, as evidenced in medical mistakes and,

most obviously, the inability to prevent and cure serious yet highly common chronic

conditions. Nor is the main problem organizational, which burns out practitioners

through its scheduling and high pressure. Rather, Price regards the fundamental

problem with the practice of modern medicine to be the apparent lack of sympathy

towards the ill on the part of its practitioners, often making the ill person feel that

she is not a person or even a paying customer, but just a problem to be dealt with in the most efficient way possible.

Yet, despite all his complaint about the medical practitioners' impersonal treatment of their patients, Price is nevertheless wise enough to recognize the irony that, all brusqueness and treatment issues aside, he enjoys a triple advantage compared to ill people of lesser social privilege:

> Since I was in one of the world's major hospitals—one in which I'd be treated by my university colleagues and where virtually all my expenses would be paid by the generous insurance policy provided by an unusually benign employer—I never considered second opinions. (Price 1994, 16)

The first advantage that Price has over the less socially privileged is that, as a professor of English at Duke, he feels at least a formal equality between himself and his attending medical staff as colleagues working in the same institution of higher education. The second advantage comes from his health insurance, available through his employment as a professor at Duke, which frees him from exorbitant expenses or even co-pays for the extensive inpatient and outpatient care his condition necessitates. Third, while not explicitly stated, the stability of his employment status as a tenured professor, which enabled him to keep his job even though absent for prolonged periods of time, was a significant and relatively rare advantage.

While Price summarizes the reactions of illness memoirists who recognize the good fortune of the access to healthcare provided through their employers, Augusta Gale points to the role of another major resource in shaping healthcare access: knowledge. Moreover, while she argues that the difference in knowledge is inflected by socio-economic status, she also emphasizes racial difference. Gale was

diagnosed with breast cancer at age 47, when she had just moved to New England to

advance her career in nursing. Like other authors, she was shocked by the

impersonality of some practitioners, e.g., a doctor who called her to tell her about

the diagnosis rather than telling her face-to-face (Gale 1996, 16-7). Like other

African American authors in this study, Gale's observations tend to be a more

racially conscious than those of most white authors. Specifically, she is uneasy about

the racial disparity in access to healthcare, which has prompted her to embrace

health advocacy:

> Much of my advocacy is directed at African Americans because we are so often overlooked, abused, used, and misused. But I am wise enough to know that we cannot—or at least should not—always blame others for our problems. About fifteen years prior to my breast cancer diagnosis I was doing public education, speaking as a volunteer for the American Cancer Society. Little did I know at that time just how valuable such information would be for me one day. I spoke at various churches. I tried to do an outreach for [sic] African Americans, but I stopped because black people would rarely come back to church on Thursday night for a health discussion. It always distressed me that when I would go to white areas, the places would be packed. (Gale 1996, 63)

Interestingly, Gale ascribes the unequal access to knowledge about healthcare

between whites and African Americans to a difference in what appears to a racially

inflected difference in interest about knowledge about cancer. This seems to point to

a sense that there is a lack of a personal sense of responsibility towards one's own

health among African Americans, at least churchgoers. While the use of cultural

difference to explain racial disparity to access healthcare may sound a little like the

proverbial blaming the victim (see Ryan 1971), Gale does not seem blind to the

overt and institutional ways African Americans are excluded in American society, as

she emphasizes that "we [African Americans] are so often overlooked, used, abused,

and misused." What she does emphasize, however, is that, in light the systematic

exclusion of African Americans, African Americans need to take more initiative in order to obtain services in a white-dominated society. This emphasis on personal initiative is driven home in her experience of getting access to healthcare. When Memorial Sloan-Kettering Cancer Institute declined her insurance and would not admit her to the hospital, she called then-first-lady Nancy Reagan's office for assistance (Gale 1996, 17). After the insurance company found that it had neglected to file the appropriate paperwork when she moved to another state for work, she was promptly admitted to Sloan-Kettering for treatment.

Yet, in spite of Gale's emphasis on the role of personal responsibility for one's health to help African Americans gain access to healthcare, she seems to overlook that, given African Americans are still systematically excluded from corporate and professional jobs in the United States, good-enough insurance is still often out of reach of many African American individuals. Thus, even though she demonstrates how reaching out to Nancy Reagan helped resolve her insurance issues, she overlooks the fact that her insurance policy is pegged to the contingent fact that she happens to be working at a hospital and is one that Sloan-Kettering is in principle able to accept. Perhaps, she is even arguing for the importance of the meritocratic ideal that one must earn one's health insurance by finding a good-enough job, no matter how unfair the playing field is set up for African Americans.

More Other than Other: The Worse Stigma of Illnesses that Violate Gender

Expectations

Besides differential access to healthcare, authors also show that ill people

differ in their control of the symbolic meaning of their master status as ill people.

This awareness serves to significantly complicate the emphasis inherent in illness

identity discourse that all ill people share the fate of being excluded by a healthist

society: because stigmatizing the ill is preferable to acknowledging that everyone

may someday become irreversibly and severely ill. Healthist society's tendency to

regard all ill people as other is driven home by examples in the previous chapter of

many authors' sense of denigration at finding their identities reduced to the status

of being ill. Being ill tends to become a master status because having a sick body

contradicts a crucial attribute of the modern understanding of the normal human

being: that people are and will remain healthy. Nevertheless, while authors agree

that being ill imposes an estrangement from healthist society, some illnesses render

the person more other than other. This is especially the case when the type of illness

is associated with nonnormative gender status and/or behavior. To illustrate this

recognition that some illnesses and/or those who experience those illnesses are

more other than other, I draw upon Harold Brodkey's *This Wild Darkness: The Story*

of My Death (1996) and Audre Lorde's *The Cancer Journals* (1997).

Brodkey's 1996 memoir accentuates his sense of the worse stigma of men

who contract HIV through sexual interactions with men. The book was published

the year that he died, three years after he came out in public about his illness. He

attributes his illness to his youthful "adventures in homosexuality" that took place

mostly in the late 1960s and the 1970s (Brodkey 1996, 2). At the time of his HIV

diagnosis and treatment, Brodkey had been married to writer Ellen Brodkey for well

over a decade. He claimed to be symptomless for the first twenty years after he

contracted HIV. When symptoms did emerge, Brodkey, like memoirists with a range

of chronic illnesses, sought to downplay the significance of his symptoms, regarding

them as merely caused by "literary exhaustion [he is famous for working on his first

novel for 32 years, which he finally published in 1991], and age, and bad-flu

bronchitis." He did not think that the symptoms could be caused by pneumocystis

pneumonia, a common infection among people living with HIV (Brodkey 1996, 6).

Because of his contracting of the virus by having sex with other men,

Brodkey was highly ambivalent about what the illness said about his masculinity.

This leads to both a sense of shame and an apparent need to overemphasize one's

masculinity. On the one hand, he felt "embarrassed to be ill and to be ill in this way"

(Brodkey 1996, 13). This embarrassment is connected to his sense that he got the

disease from sexual behaviors that contradict the hegemonic heterosexual ideal of

masculinity. As Kimmel (1997) argues, masculinity in American society means the

avoidance at all costs of homosexual behavior and desire, or at least to deny them in

spite of evidence to the contrary. The cultural power of the notion of HIV as a

punishment for gay promiscuity is such that, even though he has been in a stable

heterosexual marriage, Brodkey is simply unable to see his illness as a purely

biological matter:

> The separation from society, the political marginalization and the financial
> thefts, the attacks to see what can be stolen from you, and the indignity—
> including social indignity—of AIDS suggest a partial, sometimes fluorescent
> and linoleumed version of the death camps. (Brodkey 1996, 43)

Human right activists concerned about state violence embodied in death camps may

well cringe at Brodkey's comparison of the social situation of Americans being

hospitalized and/or treated for AIDS (hence the reference to fluorescent lights and

linoleum) with the situation of inmates of death camps. A more charitable

interpretation of this comparison seems to be that Brodkey means to emphasize the

worse sense of social ostracism experienced by men, presumed to be gay, living with

HIV than the social alienation common to people with normative social statuses

living with chronic conditions.

On the other hand, alongside his sense of shame at contracting HIV via sex

with other men, Brodkey also appears to engage in over-dramatizing his

masculinity, as indicated by his many emphatic assertions that he was not afraid of

death:

> Death is a bore. But life isn't very interesting either. I must say I expected death
> to glimmer with meaning, but it doesn't. It's just there. I don't feel particularly
> alone or condemned or unfairly treated, but I do think about suicide a lot
> because it is so boring to be ill . . . I must say I despise living if it can't be done
> on my terms. (Brodkey 1996, 152)

In this quote, Brodkey first challenges the commonsense view of illness and death as

a blessing in disguise, in the sense of providing access to transcendent meanings to

life. Secondly, he seems to adopt the stance of a Spartan warrior who looks down

upon non-warriors' common fear of death and desire to live at all costs. Brodkey's

effort to emphasize his transcendence from the commonsense fear of death strongly

indicates a desire to "do gender" (see West and Zimmerman 1987): to provide a

culturally normative account for his essential masculinity in spite of past

homosexuality and existing HIV-positive situation.

In contrast to Brodkey's shame about his illness' connotation of compromised masculinity, Audre Lorde focuses on the way in which her physical impairment after treatment for breast cancer threatens the gender normative understanding of the female body. The last chapter notes the ways in which Lorde came to recognize that her achievements as an activist, writer, and professor championing the Black, feminist, lesbian cause would lose all meaning if she were to die because of her breast cancer. Yet, things appeared to have gotten worse after she survived the mastectomy. Relieved that she did not actually die from the surgery, Lorde was shocked when "a charmingly bright and steady woman of about my own age who had always given me a feeling of quiet no-non-sense support on my other visits" (Lorde 1997, 27) suggested that Lorde wear a breast prosthesis. For Lorde, this suggestion was offensive not simply because it assumed that social expectations regarding her physical appearance took precedence over her pain and need to mourn her physical loss. It was further offensive because she was merely assumed to in a heterosexual relationship and therefore had an inherent need to appear physically attractive to her supposedly male partner, who is further assumed to be a man who is primarily interested in breasts rather than other parts of the female body. In fact, she appeared to be in a stable lesbian relationship at the moment. Her anger reached an apogee when a nurse told her that her wearing a prosthesis was not actually good for her self-esteem but also for the "morale of the [medical] office" (Lorde 1997, 60). To which she responded retrospectively in her memoir:

> Yet when Moishe Dayan, the prime minister of Israel, stands up in front of parliament or on TV with an eyepatch over his empty eyesocket, nobody tells him to go get a glass eye, or that he is bad for the morale of the office. The world sees him as a warrior with an honorable wound. . . . And if you have

> trouble dealing with Moishe Dayan's empty eye socket, everyone recognizes that it is your problem to solve, not his.
> Well, women with breast cancer are warriors, also. I have been to war, and still am. . . . For me, my scars are an honorable reminder that I may be a casualty in the cosmic war against radiation, animal fat, air pollution, McDonald's hamburgers and Red Dye No. 2, but the fight is still going on, and I am still a part of it. . . . I refuse to hide my body simply because it might make a woman-phobic world more comfortable. (Lorde 1997, 61)

In comparing her mastectomy with the loss of Dayan's eye, Lorde critiques the gendered interpretation of bodily loss. With regards to Dayan, the loss of his eye is interpreted as a symbol of his masculine strength, i.e., an "honorable wound" that comes from his brave participation in a war. In contrast, Lorde's breast wounds are regarded as a threatening lack of feminine beauty, in part because in the post-WWII United States, women's breasts were a primary cultural touchstone for both female identity and desirability. To Lorde, this gendered interpretation of bodily loss further masks the silent yet no less real war that we engage in the face of environmental degradation.

Harold Brodkey and Audre Lorde challenge the tendency of illness identity discourse to emphasize the similarity of all ill people's experiences of symbolic exclusion, irrespective of their social status and illness types. This is because by having a sick body, the ill collectively threaten the modern expectation for people to remain healthy for as long as possible. Beyond this generic view of the ill person as biologically other, Brodkey and Lorde argue that illnesses associated with nonnormative sexual behavior or gendered body types render sufferers doubly estranged: more other than other. They thus echo gender and sexuality scholars who emphasize that, even though we are all mere biological bodies, it is also nevertheless true that our bodies are often seen as sexed first and ill second. Given

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our gendered lenses of the social world, our bodies are often automatically

categorized as either female or male. The cultural force of the dualistically sexed

body is so strong that it is still really hard to accept that there may be more than five

ways in which "male" and "female" sexual organs and functions can be combined

(Fausto-Sterling 1995). The two-sex model of the body further makes it hard to

recognize the staggering sameness at the level of biology between bodies defined as

male and female (Friedman 2013). The cultural power of the dualistically sexed

body is further manifested in parents' and doctors' decision to surgically assign one

of the two sexes to intersex babies. In light of the fundamental vision of bodies as

either female and male, when certain types of illness challenge gendered and

sexualized behavioral or appearance norms, the illnesses are then rarely seen as

purely biological, but as challenging the apparently fundamental two-sex order.

More Other than Other: The Otherness of Medical Practitioners Who Are Non-White and/or Female

To supplement my exploration of the cultural definition of certain types of

illness as more other than other, I now explore the ways in which the social statuses

of otherwise healthy people can also be regarded as more other than other.

Specifically, I explore the recognition by a few authors that the sense of otherness

experienced by otherwise healthy medical practitioners of nonnormative social

statuses—in particular, non-white and female—may be more other than the sense

of otherness of an ill person of normative social statuses. I will use Robert Murphy's

The Body Silent: The Different World of the Disabled (1990) and Laura Liberman's *I*

Signed as the Doctor: Memoir of a Cancer Doctor Surviving Cancer (2009) to explore

this pattern in question.

As shown in Chapter Three, Robert Murphy's memoir begins with his initial

shock that his statuses as a white male professor at Columbia University were

disregarded when he became a patient at the hospital affiliated with Columbia's

medical school. Despite his overwhelming sense of becoming merely a patient

wholly at the mercy of medical practitioners, he nevertheless came to have two

discoveries about the situation of medical practitioners. First, Robert Murphy came

to recognize that medical practitioners could learn to be more empathetic towards

ill people. Second, and more relevant to present purposes, when he went for

radiological treatment at the hospital, he noticed that not all doctors evince the

same sense of power and dignity:

> The medical personnel of the [radiological] department included an unusually large number of Orientals [sic]. This wasn't too surprising, for many minority practitioners undertake specialties like this that are a step removed from the public, and thus from racial prejudice. My only uneasiness about this arose when I couldn't understand the English of the Japanese doctor who was marking my back for radiation. I assume that he got it right, for better or for worse, my spine was indeed radiated from one end to the other. (Murphy 1990, 39)

Here, Murphy comes to recognize how the fear of racism—both from patients and

colleagues—may have shaped the career choices of East Asian and perhaps also

Southeast Asian medical practitioners. Radiology is seen as a safe choice perhaps

because it is usually set up in the basement, and hence may shield the non-White

practitioners from other colleagues. Furthermore, radiology may also feel less

socially exacting because there tends to be less interaction between patient and

practitioner and hence fewer potential issues with a language barrier. (As a side

note, I have learned from anecdotal evidence that many Taiwanese-born doctors had to make painful changes to their career paths upon moving to the United States in the early 1980s. Many had chosen a prestigious path such as cardiology in Taiwan. Yet, because they felt lacking in language and social skills as adult immigrants, they made emotionally and technically difficult switches to specialties such as anesthesiology and pathology, which they perceived as lower prestige yet less draining in terms of interactions with native English-speaking patients and colleagues.)

While Murphy notes how racial otherness can undercut the status of doctors, rendering them as less than racially normative patients and colleagues, Liberman highlights how being a woman leads to a painful sense of otherness even among medical practitioners working in the most prestigious of medical institutions. At the time that Liberman was diagnosed with breast cancer at age 47, she had been working for 17 years at Memorial Sloan-Kettering Cancer Center in New York, a prestigious cancer center to which she unabashedly refers as "the best hospital in the world" (Liberman 2009, xi). Besides her clinical practice, she was also a prolific researcher, publishing more than 100 scientific papers and co-authoring a book (Liberman 2009, 11). Given her trust in Memorial Sloan-Kettering and, perhaps, her fear of antagonizing colleagues, she refrained from getting second opinions regarding her diagnosis and treatment plan from the staff at other hospitals, instead using her long-standing social network within Sloan-Kettering to find suitable practitioners in the fields related to her diagnosis.

Before I discuss her recognition of the more other than other character of the woman doctor, I briefly digress to Liberman's interesting reflection on her initial sense that her professional status as a doctor specializing in cancer would render her immune from it: "I must have thought that being a doctor, wearing that white coat, confers immunity—like cancer is something that happens to other people, and couldn't possibly happen to me" (Liberman 2009, 2). Even more interesting, her sense of immunity drove her to ask her physician/colleague about the percentages that her stage IV lymphoma could be cured. Assuming that, of all people, Liberman should know that there is no cure for lymphoma, her colleague appeared to find the question entirely ludicrous. She even found her usual use of statistics to make prognosis unacceptable to her need to be cured: "50% chance that he could bring the lymphoma into remission . . . That means . . . a 50% chance that . . . I'll die" (Liberman 2009, 6). When the fact of her physical vulnerability finally hit home, she not only felt helpless and lost but also came to critique her previous ease at telling her patients to "not think too far down the line" and to "take things one step at a time" (Liberman 2009, 7).

Despite her overwhelming sense of the contrast between being a powerful doctor and being a dependent and emotional patient, Liberman nevertheless reminded herself that even when as a doctor, she never felt all powerful due to the sense of exclusion she and her female colleagues experienced in their male-dominated working environment. Frustrated by the power asymmetry between female and male practitioners in the hospital, she joined the cancer center's Women's Task Force and she later became a leader:

> We found that women were significantly more likely than men to say that they are unclear about promotion criteria, that they lacked a mentor or had a mentor who hindered their career, and that they struggled with issues of work/life balance. We suggested creating an ongoing office to address woman faculty issues. The Program for Women Faculty Affairs (PWFA) was created in October 2005, and I was chosen to be the Director (Liberman 2009, 12).

Liberman's experience validates Acker's (2006) argument about the intersection between race, class, and gender in the working of instrumental organizations: despite being equal in professional status and being white, women doctors feel excluded by the male-centered organizational culture. Furthermore, as Acker avers, women physicians still feel overly pressured by their family responsibilities, and women are dealing with those issues alone. It also echoes Ridgeway's (1997) argument that, because of gender typing of definitions of technical competence in formal organizations, women tend to be perceived and treated as less competent than men, even though they may be not just equally well trained, but may actually have better performance, as evidenced in the hundreds of articles produced by Liberman.

To sum up, the recognition that the socially privileged status of being a doctor can mean less to a person's identity than that individual's so-called ascriptive statuses does not merely challenge our egalitarian belief that achievement matters more than ascription (Merton 1938). It further challenges the sociological argument that doctors enjoy the institutional perk of dominance over their patients, equality among peers, and the power to define what is normal and abnormal because of their professional training (Conrad and Schneider 1980; Freidson 1970; Parsons [1951] 2012). More importantly for my purposes, it shows how nonnormative statuses, especially in racial and gender terms, can render even healthy people so other than

other that they are regarded as polluted or abnormal. In certain contexts, the

abnormality attributed to the bodies of racial and gender others can even legitimate

categorically based violence initiated by people of normative status. Hence the

ironic fact that one can actually suffer bodily pain without being really sick, but just

by being socially defined as sick. In the next two sections, I will explore how authors

use the examples of racial and gendered violence to remind themselves that being ill

while also being high SES and, in most cases, white in the United States may not,

after all, be the worst.

**Comparing Illness with Categorically-based Violence: The Case of the Nazi
Holocaust**

The second way authors come to challenge illness identity discourse's

tendency to regard the social distribution of resources as powerless in shaping

biology is to point to collective violence targeting particular vulnerable categories of

otherwise healthy people. In the memoirs surveyed, the Nazi Holocaust and violence

against women are most frequently mentioned as comparators against which to

understand the authors' experiences. Through reminding oneself of the existence of

collective violence, authors come to recognize that status-based differences in

resources do more than shape ill individuals' sense of well-being by varying the

degree to which they can access healthcare and control to some extent the meaning

of their illness. Even more portentously, they are reminded that status-based

differences in resource can and too often leads to great harm and even death for

otherwise biologically healthy yet under-resourced people around the world. The

recognition that otherwise healthy people can be deemed fit for bodily punishment

due to their perceived social deviance (often but not always accompanied by a lack

of material resources) serve to remind the authors that, as socially privileged

citizens of post-war liberal societies such as the United States, being ill, or even

being in great pain and facing probable or certain death, may really not be the worst

that could happen.

In this section, I explore two ways that authors cite the Nazi Holocaust to

contextualize their suffering as ill people. First, I draw upon Lucy Grealy's

Autobiography of a Face (1994) to show how she uses the experiences of

concentration camps inmates to reappraise her harrowing experiences in hospitals.

Next, I review Susan Gubar's discussion in her *Memoir of a Debulked Woman:*

Enduring Ovarian Cancer (2012), of how the post-traumatic memories of Holocaust

survivors can result in physical symptoms to remind herself that sicknesses caused

by biology, however difficult to endure, are at least morally neutral as opposed to

illnesses caused directly or as a side effect of inhumane treatment by other humans.

Grealy's memoir points to the way in which knowledge about the experiences

of Jewish inmates in Nazi concentration camps helps her better cope with her

experiences as an ill person in the post-World War II United States. Grealy was

diagnosed with and subsequently underwent surgical and chemical treatment for

Ewing's sarcoma in her jaw at age 9. She came out of the treatment with a visibly

different jawline and became the target of relentless stares and bullying at school

and whenever she was outside of her home. In the hopes of getting back what she

felt was a normal-looking face, she further underwent several painful cosmetic

surgeries. While the memoir is ostensibly about her sense of marginalization

because of her facial difference, a no less important portion of her memoir is about

the suffering inherent in cancer treatment as well as surgical facial reconstruction.

Her portrayal places a special emphasis on the embodied effects of both surgery and

chemotherapy, which she regards as a kind of punishment. Here is a memorable

portrayal of her experiences after absorbing necessary toxic chemicals for the first

time:

> It was an anatomy lesson. I had never known it was possible to feel your
> organs the way you feel your tongue in your mouth, or your teeth. My stomach
> outlined itself for me, my intestines, my liver, parts of me I didn't know the
> names of, began heating up, trembling with their inner warmth, creating
> friction and space by rubbing against the viscera, the muscle of my stomach,
> my back, my lungs. I wanted to collapse . . ., but I couldn't. The injection had
> only begun . . . My head began to hurt. Not sure if my brain was shrinking or
> swelling, I squinted around the office, not in the least surprised to see a yellow-
> green aura surrounding everyone, like some macabre religious painting.
> (Grealy 1996, 66)

Even though Grealy was writing about an event that happened during her childhood,

she has a vivid somatic memory of how the first chemo session felt like. Although

she understands the use of poisonous chemicals to kill cancer cells, she resists what

she sees as the tendency of medicine to treat chemotherapy as a technical

procedure. Rather, Grealy regards the experience as a sort of live torture, as

evidenced in her metaphor of anatomy lesson." Rather than learning about the

human anatomy through books, pictures, or dissections of other human bodies; she

actually felt dissected by the chemicals running through her throat to her body.

Besides the physical pain, the chemicals seem to have also distorted her perception,

making others in the room where she was administered the chemicals appear as a

"macabre religious painting."

Despite the obvious pain and trauma of passively going through cancer treatment, and then later facial reconstruction treatment, Grealy emphasizes how she came to make light of her embodied suffering as an ill and disabled person by comparing her experiences with that of Jewish inmates of Nazi concentration camps. This realization dawned on her when she came across Eli Wiesel's and Primo Levi's autobiographies in social studies class during high school:

> I had already read a great deal about the Holocaust, but now we were reading first-person accounts by Eli Wiesel and Primo Levi in social studies. I was completely transported by their work, and the more I absorbed of their message, the more my everyday life took on a surreal quality. Now everything, *everything* seemed important [emphasis in original]. The taste of salt and peanut butter and tomatoes, the smell of car fumes, the small ridge of snow on the inside sill of a barely open window. I thought that this was how to live in the present moment, to resee the world: continuously imagine a *far worse* reality [emphasis added]. At these moments, the life I was leading seemed unimportant, uncomplicated. (Grealy 1996, 187)

According to Grealy, through reading about and empathizing with the suffering of Jewish inmates in concentration camps, she came to limit her sense of the worstness of her own challenges. Not only that, she came to develop an aesthetic perception of the everyday, as Frank and Ensler do with regards to trees. She regarded formerly mundane physical sensations—the taste of salt, the smell of car exhaust, the sight of a tiny landscape of snow—as joyful and lovely, rather than a drab background to her suffering. Although Grealy does not specify how she came to realize that the lives of the Jewish inmates in Nazi concentration camps were far worse than hers, I offer two explanations. First, Grealy comes to see her sense of being an outcast in society to be as due to an objectively real illness and the only possible treatment for that illness. In contrast, the Nazis labeled as deviant and/or physically unfit the people they sought to separate and ultimately eliminate from society, i.e., gender non-

conforming, Roma, communists, Jews, and others (Proctor 1990). In other words, she may have come to regard the causes of her stigma as more rational than that imprinted on the bodies of the otherwise biologically healthy yet socially outcast people in Nazi Germany. Second, Grealy may have come to regard her experiences as an inmate in the hospital in a more positive light. At the very the least, no matter how powerless a sick person is in relation to the physical pain produced by a medical institution, that person is in principle free to refuse treatment. Moreover, doctors were focused on returning her in reasonably good health to her former life, even though harming her body was a necessary part of that process. In contrast, inmates in Nazi concentration camps were never meant to return to normal society, but rather to labor until their bodies were fully wasted or simply killed through the most efficient means available (Bauman 1989).

While Grealy compares her experiences with that of Jewish inmates in Nazi concentration camps, Gubar (2012) compares her illness with the embodied trauma suffered by Jewish survivors. In Chapter Two, we saw that Gubar was shocked to find that, in spite of her recognition of bodily vulnerability as a human being and an aging person, she had wrongly assumed that she was immune to ovarian cancer. Even more ironically, she was dismayed upon realizing that the aftereffects of the treatment were worse than the symptoms she had experienced before the surgery. A paradigmatic form of silent killers of women her age, Gubar's late-stage ovarian cancer had been asymptomatic. Her bodily suffering only surfaced when she underwent the surgical removal of significant portions of organs affected by cancer. Her pain and sickness after the surgery even made her wonder aloud whether it

would have been better for her to die naturally from cancer rather than go through the supposedly life-saving procedure.

While deeply affected by her experiences of bodily suffering from debulking and its post-surgical complications, Gubar was able to limit her sense of the worstness of her surgically caused pain by comparing it with the pain caused by traumatic memories suffered by Jewish survivors of the Nazi Holocaust. While recounting her diagnosis, Gubar mentions that she had actually harbored a lifelong dread that something bad would happen to her body. Towards the middle of her memoir, Gubar uncovers the root of her longtime sense of physical vulnerability as stemming from memories shared by her parents, both German-born Jews with relatives who died during the Holocaust:

> What good can anger or fear, self-pity or dread achieve, once it becomes clear that disaster surrounds us and those we cherish all the time, that there remains no place exempt from its malice? It was a lesson I had a learned as a child growing up with refugee parents. Uprooted and impoverished, my father and mother perpetually mourned the deaths of their relatives of their prior lives in Germany (Gubar 2012, 117).

Gubar first renegotiates her dread of physical suffering by contextualizing illness as just one of the many "disasters" that "surround us and those we cherish all the time." What is it about her parents' traumatic memories that made Gubar more able to accept the physical suffering she associates with debulking? To begin, Gubar may have felt relieved that her bodily trauma from the surgery is due to real biological causes, and further, the surgery was meant to save her—albeit with the side effect of unthinkable pain. In contrast, her parents' psychological trauma were caused by having escaped from Nazi Germany at the cost of leaving loved ones and entire communities to suffering, death, and destruction. Moreover, the traumatic

memories had real effects on the bodies and lives of her person, not unlike a biological illness. According to Gubar, her parents led miserable and emotionally stunted lives even after becoming citizens of the United States. Her father committed suicide during her childhood. Her mother, in contrast, led a long but bitter life, creating even more misery for her daughter.

To briefly conclude this section, Grealy and Gubar show how each came to limit their sense of worstness of their illnesses through the work of contextualization. In contrast to the work of biographical contextualization of illness in order to limit the sense of criticality related to illness, Grealy and Gubar contextualize their illnesses at the social if not the global level. Basically, they came to recognize that, in spite of all the misery suffered by ill (privileged) citizens of post-war United States, they may actually be a lot better off than otherwise biologically healthy victims of the Nazi regime. In this way, they come to complicate illness identity discourse's emphasis that no one is immune from illness by adding, "low-status people are more prone to suffer illnesses related to the experience of systemic violence." In the case of Jewish victims of the Holocaust, their Jewish identity was used by the Nazis as a pretext for, and defining quality with which to rationalize, extreme violence, rendering them outsiders to normality and hence pathological. Even though many Jewish victims had resources such as money and knowledge, they lacked the power to protect themselves from state violence.

In the next section, I explore how authors may come to limit their sense of worstness of their illness by comparing their illnesses to the embodied suffering of

biologically healthy women living in male-dominated societies such as the United States.

Comparing Illness with Categorically-based Violence: The Case of Misogynist Representations of the Female Body

Earlier chapters demonstrated how authors such as Kat Duff, Eve Ensler, and Cheryl Kephart reveal that their illness emerged from lives already disrupted by experiences of sexual assault. All implicitly or explicitly define their experiences of rape as causal antecedents to their illnesses. Moreover, Ensler and Kephart use the memories of rape to help cope with the disruptiveness of their illnesses. In contrast, no male author mentions sexual violence against women and men, past personal experiences of rape (whether as victims or victimizers), or accusations of sexual assault. In this section, to follow up on the last section, which links violence against racialized others with the prior pathologization of their bodies, I explore how female authors reconcile themselves to their experiences of illness by reminding themselves of the cultural cause of violence against women: the pathologization of women's bodies in misogynist cultures.

I draw upon Mairs's *Waist-High in the World: A Life among the Nondisabled* (1996) and A. Manette Ansay's *Limbo: A Memoir* (2002) to explore the ways in which authors come to regard the pathologization of the otherwise female body through standards of female beauty and religion as worse than the real pathology of the ill body.

Nancy Mairs's memoir compares her impairment from multiple sclerosis with that the experiences of able-bodied women under the yoke of the commonsense standard of female beauty. Her recognition of the comparability of these experiences comes via a non-linear route. In the initial phases of her illness, she typified a version of feminism centered on women maintaining their traditional roles in the household while also pursuing interests beyond the family:

> Like many young women of my generation, the first to aspire to "have it all," I vastly overextended myself when I was younger, and by the time of my diagnosis, I wore so many hats I could hardly hold my head up: wife, mother, teacher, graduate student, political activist, not to mention cook, housekeeper, family correspondent, redecorator, needlewoman, digger of pet graves . . . (Mairs 1996, 33-4)

Based on her experiences of illness crisis, Mairs points to the unspoken assumption behind the early feminist ideal that women should be active both in the private and public spheres of social life: that one's body will remain healthy and capable to take on any and everything. To her, despite the moral rightness of feminism's goal of enabling women to freely choose participation within and outside the family, the unspoken assumption that women are equally able to do whatever they choose is not only unrealistic, but also damaging to the woman who is unable to live up to an expectation to be active in all spheres of life. Having internalized that ideal, the necessity imposed by her MS to limit her professional, familial, and domestic activities have made her coping more difficult: "Over the years, I've had to pare back . . . [,] and relinquishing, or at least revising, each role has wounded and shamed me (Mairs 1996, 33-4). Moreover, Mairs's sense of "overextending" herself in light of her effort to live up to the feminist ideal of "having it all," situates her biological

susceptibility to multiple sclerosis as partially triggered by her effort to live up to the feminist ideal.

Despite her critique of how the aspirations of feminism overlooked the inherent vulnerability of the biological body, Mairs returns to her feminist roots when she came to recognize the similarity of her experiences with those of biologically healthy women. In fact, she comes to regard the cultural pathologization of the healthy women's body as worse than the actual pathology of the disabled person's body. For Mairs, the most insidious form of pathologization of the healthy woman's body occurs through the imposition of impossible standards of female beauty:

> None [of my female relatives] could be considered vain . . . Their dissatisfaction with their bodies seems as natural to them as their menses or hot flashes, simply an element of womanly existence.
> Even if I hadn't developed MS, I would probably view myself with some distaste. (Mairs 1996, 45)

In this quote, Mairs comes to limit her sense of distaste for her own disabled body by pointing to otherwise healthy and able-bodied women's sense of shame of not fitting the cultural norm of beauty. The cultural power of the impossible standard of beauty is such that, even though her relatives are not vain, they are nevertheless rendered overly conscious of the distance between their bodies and the cultural standard of beauty. More ominously, Mairs even finds that her relatives do not simply pathologize their bodies for not being beautiful enough. They come to pathologize natural biological processes alongside their supposedly not-beautiful-enough bodies: their "dissatisfaction with their bodies [that to them] seems as natural . . . as their menses or hot flashes." With the recognition that otherwise

healthy and ablebodied women regard themselves as impaired by misogynistic understandings of the female body, Mairs seems to come to regard the cultural pathologization of the disabled body as "more rational."

A. Manette Ansay further finds similarity between the patriarchal pathologization of the female body, the Nazi pathologization of the Jewish body, and the Christian definition of woman's body as sinful. Ansay is an award-winning novelist and professor in an MFA writing program. Before she settled on writing as a professional career, she had aspired to become a pianist but was struck by a mysterious illness, mistakenly diagnosed as multiple sclerosis. After being bedridden in her parents' home, she eventually regained mobility with an electric wheelchair. The cause of her illness remains uncertain.

Like other authors, Ansay begins her memoir with accounts of helplessness in the face of her illness, and then adds in the middle memories of critical events that happened to others and to herself before the illness. For example, Ansay remembers the long-forgotten yet highly traumatic experience of finding out about the Nazi pathologization of the otherwise healthy Jewish body. As a member of a German Catholic community in the Midwest, Ansay had grown up with relatives who tried to exonerate Nazi Germany by arguing that American accounts of World War II were "greatly exaggerated" (Ansay 2002, 96). Nevertheless, such pro-Nazi apologists did not deter her from reading Chaim Potok's *The Chosen*, which she happened upon during sixth grade. She was so intrigued by the mention of Adolf Hitler in *The Chosen* that she actually borrowed a copy of Hitler's *Mein Kampft* from her grade-school library. She was traumatized after finding out the meaning of the

word "vermin," which Hitler matter-of-factly uses to describe a Jewish man. The

horrendous consequences of applying a word connoting germ-carrying animals to a

group of people dawned on her when she learned of Hitler's order to eliminate the

Jews, resulting in the deaths of at least six million and untold damage to additional

people, families, communities:

> Fear seized the back of my neck . . . I jumped up and sat down and jumped up
> again. . . . The next day, after school, I took it [Hitler's *My Struggle*] back to the
> library. . . . That was the year I increased my piano practice from one to two
> hours each day. That was the year I decided I didn't want to be a heart surgeon
> anymore. . . . I stopped going to the library. I didn't read another book, beyond
> what a teacher assigned, for the next ten years.
> *Vermin*: even now, that word holds its power, moves from my mouth like some
> living, whiskered thing that brushed against me in the dark. (Ansay 2002, 96-7;
> emphasis in original)

Typical of authors who cite past critical experiences to limit their sense of their

illnesses as total crises, Ansay does not explain why she includes this traumatic

memory in the middle of her memoir. Yet, the temporal marker "even now" reveals

her intention to remind herself and her audience that there is something about

falsely defining a biologically healthy body as pathological ("vermin") that is

decidedly worse than the real pathology of the biologically sick body. While Ansay

does not explain why she gave up her dream of becoming a heart surgeon, it may

coincide with recognition of the collaboration between medicine with the Nazi

regime, which regarded the extermination of Jewish people and other pathologized

groups as a mere large-scale public health operation (see Proctor 1990). Ansay thus

recontextualizes the way she understands her own bodily experiences in view of

how Jewish people living during the reign of the Nazis were pathologized as less

than human.

While being more direct in her comparing her illness with the experiences of Jewish victims in the Holocaust, Ansay is more indirect in comparing the pathology of the sick person and the cultural pathologization of the female body, especially in the domain of Christianity. As an adolescent, Ansay's view of her otherwise healthy body was informed by her Catholic upbringing:

> If God was perfection, then my adolescent female body was an exaggeration of *im*perfection. The only course of action was to abandon myself whenever possible, to become by choice an empty vessel, like the Virgin Mary, for whom I was named, and upon whom I . . . was encouraged to model myself. (Ansay 2002, 103)

In this quote, Ansay embodies the version of Christian theology criticized by feminist theologians for its uncritical reinforcement of the patriarchal pathologization of the female body (Daly [1973] 1993). The Catholic pathologization of women's body is based upon the prior assumption that God is male. In this way, the female body is seen as imperfect in relation to the supposed perfection of the male body. Moreover, though the Catholic reverence of Mary, Ansay argues that women in the Catholic world can only be either those who give in to the temptations of the flesh, or women who do not simply deflect the temptations but also sacrifice themselves by becoming selfless caregivers to their families.

Conclusion

In this final empirical chapter, I explore how authors engage in the second form of the reflexive practice of normalization, i.e., to come to recognize that being ill is neither outside of normality nor necessarily the worst thing. They do so by bringing together illness identity discourse and the resource theory of health,

emphasizing the robust role of the status-based distribution of resources in shaping the well-being of both the healthy and the ill.

In the last chapter, in their debunking of the resource theory of health through the assumption that no one is immune from illness advocated by illness identity discourse, authors come to regard the biological as not simply independent but also dominant over the social. This ontological view informs a view of society as fundamentally divided by the arbitrary forces of biology, separating people as healthy and ill regardless of their social statuses or command of resources.

The problem with this turn from the resource theory of health to illness identity discourse, however, is not only conditioned on an asymmetric understanding between the social and the biological, merely reversing the relationship proposed by the resource theory of health. It is further problematic in obstructing the ill person's need to normalize her illness, i.e., to both regard the ill world as less separate from the healthy world and to regard illness as not necessarily the worst. To begin, the view that society is fundamentally divided by biology rather than social differences wholly separates the healthy and the ill. The healthy are seen as wholly blissful in their not being ill, regardless of their differences in social status and resources. In contrast, the ill are seen as wholly immersed in crisis. Even more problematically, the ill person's need to normalize her illness is thwarted at the practical level by a fatalistic sense of being determined by biological forces. This is so because it blocks awareness of the ways in which collective action in the form of equalization of resources may prevent and ameliorate the vicissitudes of biology.

This analysis has identified two types of surprising experiences that remind the illness memoir authors that the social is not after all wholly dependent upon the biological. First, even though they recognize that the socially privileged person's large pool of resources cannot protect her from or even allay the embodied suffering of chronic illness, they nevertheless find that categorical based differences in resource is quite important to a person's sense of control in the midst of dealing with irreversible and incurable illness. This is especially true in reference to access to healthcare and the meaning of one's illness. When an illness is linked to nonnormative statuses such as being perceived to be a gay man (in the case of HIV/AIDS), the diagnosis of such an illness may render patients more other than other ill people.

Alternatively, even though illness memoir authors recognize that the embodied suffering such as that imposed by many chronic illnesses cannot be prevented or fully treated by means of resources, they come to recognize that socially defined categories renders some otherwise healthy groups of individuals more likely to suffer from categorical violence such as the Nazi Holocaust and violence against women. Collective violence is made possible through the imbalance of resources such as prestige and power between people of normative and nonnormative statuses. The lack of prestige of racial and gender minorities reaches its extreme in attempts to define their healthy bodies as pathological. The lack of power of these minorities is manifested in their lack of control of the process of political decision-making and means of collective violence, which makes them vulnerable to violent acts on the part of the majority.

The recognition that individual sense of control during illness varies according to one's pool of resources, as well as the connection between status-based differences in resource and collective violence, does not merely remind authors that being ill as a socially privileged citizen in societies such as the United States may really not be the worst thing. Further, it reminds them of the role of collective agency in spite of our inability to prevent and cure disruptive chronic illnesses. Through collective acts to redistribute resources in a more equitable manner, we may not only reduce the sense of passivity that comes from lacking access to healthcare and from being regarded as more other than the average ill person. At the same time, collective acts to equalize resources may prevent or allay categorically based discord and ultimately slaughter.

To conclude this chapter, I think it is also important to emphasize an important limitation to the authors' reflection on categorically based violence. While I fully agree with their recognition of the importance of racial and gendered violence, I feel that authors have tended to take an implicitly American- or Western-centered view of what kinds of suffering matters the most. For example, they tend to also leave out categorical violence related to Western-led colonialism and imperialism. Nor is there much reflection upon state violence committed in the name of other sorts of definitions of the people, including the working class and the nation. Obviously, there has to be a limit to the kinds of collective violence that can be fitted in a memoir about illness. However, the fact that authors tend to compare their illnesses mainly with Nazi racialized violence and gendered violence evince a particular understanding of "us" among authors and their audiences. As Clarke

(2006: 19-21) argues through his study of cultural understandings of disasters, the

sense of badness of a particular event of suffering is often due to a sense of

similarity between the sufferer and the self, rather than objective factors such as the

numerical count of victims.

Chapter Six

Concluding Remarks

Empirical Findings

My dissertation analyzes memoirs of chronic illness as cultural sites of reflexive identity construction. Specifically, drawing upon 40 critically acclaimed illness memoirs published between 1980 and 2017, I explore how authors of illness memoirs make sense of their experiences and identities by reflecting upon what Everett Hughes calls the contradiction of status that they commonly face. Authors tend to embody both the non-normative status of being ill and the normative status of privileged individuals, i.e., mostly white, highly educated, successful, professionals, e.g., professors, doctors, actors, authors, activists, etc. Through the reflexive work of making sense of the contradiction of the status of being both privileged and ill, authors of illness memoirs become sensitized to two opposite, culturally powerful, and still under-studied assumptions about the relationship between social privilege and illness: "privileged people are immune to illness" and "no one is immune."

The assumption that "privileged people are (more) immune to chronic illness" often serves to essentialize social inequality through medicalized language: equating privilege with the normative biological status of health, and vice versa. The "privileged people are immune from illness" assumption is not simply a myth that reinforces difference in privilege, however, but is actually supported by two competing discourses of public health. What I call the responsibility theory of health

accounts for the association of privilege with health alluding to privileged people's supposed tendency to adhere to the value of responsibility towards one's own health. The resource theory of health, in contrast, seeks to explain the association by emphasizing privileged people's access to a greater pool of resources, such as money, power, prestige, knowledge, and social connections.

The alternative to the presumptive association between privilege and immunity is the assumption that no one is immune. This assumption is supported by what I call illness identity discourse. Basically, illness identity discourse argues that biology autonomously divides people into two categories, regardless of their social privilege: healthy and ill people. In this view, healthy people are insiders simply because of their biological luck of not yet becoming ill, while ill people are outsiders from the normal world simply because of their illness. In view of this dualism between insider and outsider, I call the process of becoming ill, estrangement. Moreover, illness identity discourse tends to emphasize that, given our inability to control the onset and the development of chronic illness, and the illegitimate social stigma of the ill, the difference between healthy and ill people is regarded as the most fundamental dividing line in society. Or, being ill is the worst.

Even more interestingly, while authors generally find the assumption that no one is immune useful in making sense of his or her becoming ill "in spite of" of his or her privileged status, they also come to critique the assumption for making it hard for them to normalize their illness. By this I mean the process of coming to both recognize that healthy and ill people as not wholly distinct, and to recognize that illness per se may actually not be the worst kind of suffering. The assumption that

no one is immune to illness can render normalization difficult by overemphasizing the role of biology in the determination of embodied well-being. It may thus easily lead to the wholesale denial of differences in privilege in the shaping of embodied well-being, which is what the responsibility and resource theories of health emphasize. This recognition tends to lead to the reflexive effort to create a middle ground between the contradictory assumptions and the discourses that support them.

In view of the double-edged character of both the assumption that no one is immune and that the privileged are immune, I construct two heuristic conceptions of reflexive practice. The reflexive practice of estrangement seeks to invalidate the commonsense association of privilege with illness while validating the assumption that no one is immune. The reflexive practice of normalization, in contrast, seeks to balance the presumptive association of privilege with immunity and the assumption that no one is immune.

In the memoirs, the practice of estrangement tends to precede the practice of normalization. Estrangement tends to happen in the early parts of the memoirs, where authors recount their encounter with sudden and drastic changes to their bodies and their social lives. It mediates the privileged person's estrangement from the normative world of the healthy (which tends to take for granted the association of privilege with immunity) and becoming a member of the nonnormative world of the ill (which tends to take for granted the assumption that no one is immune) through the onset of illness. Normalization, in contrast, tends to happen in the middle or later parts of the memoirs, when the authors have better knowledge of

what it is like to be ill. This second practice seeks to both bridge the worlds of the ill and the healthy, as well as to come to limit their sense of the worstness of illness. In order to do so, they seek a new balance between the previously debunked presumptive association between privilege and immunity and the assumption that no one is immune.

In order to explore how authors engage in the two reflexive practices, I draw upon Schutz's concepts of boundary crossing and shock. Basically, reflexive practices are catalyzed when the person finds herself shocked by unexpected experiences. The shock signals the contradiction between emergent experience and the experiential boundary underlying a particular assumption. For example, a privileged person's shock at becoming ill "in spite" of her responsible living signals that she assumes that privileged people are immune to illness simply because of their responsible living. The shock does not need to be all negative, however. One can cross the experiential boundary underlying an assumption and be pleasantly surprised. For example, an ill yet privileged person can be pleasantly surprised to find herself bridging social differences that she previously thought as unbridgeable.

Reflexive practices do not simply depend on shocks related to boundary crossing. More importantly, they require work on the part of the person to move from the shock to actual reflection. That is, the person needs to make the effort to ask herself the reason for the shock, and from this, perhaps coming to challenge the validity of the very assumption. At the same time, reflexive practices tend not to be random or entirely individual. Rather, as my data show, they tend to be rather formulaic. This is not only due to the fact that shocking experiences in a particular

domain tend to happen in certain ways. For example, in the domain of chronic illness, the sense of being suddenly attacked by illness and, from this, the sense of being plunged into a personal and social crisis is common. It is also due to the possibility that people doing the reflection in particular domains may share similar values and resources. This is especially the case for authors of chronic illness memoirs, who are oftentimes highly educated professionals with a large pool of resources. Moreover, reflexive practices may become scripted when they are shared through communicative practices such as memoir writing.

Engaging in the practice of estrangement, authors come to challenge the presumptive association between privilege and immunity—as encapsulated in the responsibility and resource theories of health—and adopt the assumption that no one is immune, which is embodied in illness identity discourse. They do so by pointing to two main kinds of shocking experiences that alert them to the possibility of crossing the experiential boundaries underlying the assumption that privileged people are immune from illness. First, they point to the obvious contradiction between the assumptive association between privilege and health and their being privileged yet also ill. In particular, they emphasize that they became ill when they felt the healthiest and most resourceful. Second, the authors point to the shocking experience of interacting with healthy people as privileged yet ill individuals. In Chapter Two, we find that authors often find healthy people distancing themselves from the authors through the language of responsibility. Healthy people either impute irresponsibility to explain their illness or demand authors to act responsibly, i.e., not being overly emotional or dependent because of illness. In Chapter Four,

moreover, we find authors surprised by healthy people's attending to their being ill, while ignoring their privileged status. While there are obviously negative responses to such acts of reducing the privileged yet ill person to a mere sick body, some authors are pleasantly surprised at how their illnesses helped them bridge social differences they did not think were bridgeable.

Engaging in the practice of normalization, authors come to challenge illness identity discourse, and the underlying assumption that no one is immune from illness. The challenge is based on authors' recognition of the problem posed by illness identity discourse with regards to their need to normalize their illness, i.e., to both recognize that the ill are not so different from the healthy and to recognize that illness per se may not necessarily be the worst. Through its view of society as fundamentally divided by the forces of biology, which randomly enables some to remain healthy while making others ill, illness identity discourse obstructs recognition of the similarity between the worlds of health and illness. The experience of healthy and ill people are seen as entirely dependent upon their biological state, such that the healthy are seen as homogeneously blissful and the ill as homogeneously in crisis, regardless of differences in mental power and resources among them. In other words, the worstness of illness cannot be limited in such a fatalistic view of society.

In spite of the problems posed by illness identity discourse, the practice of normalization does not simply revert to the responsibility and resource theories of health. After all, these public discourses support the problematic assumption that privilege leads to immunity. Rather, in their practices of normalization, authors seek

to partially reinstate the two public health discourses' emphasis on the role of personal (mental) and collective agency in the distribution of embodied well-being in society.

With regards to personal or mental agency, authors point to shocking experiences that alert them to both the variability of mental power within the categories of health and illness, and the similarity of mental power between individuals in both categories. Among the ill, the authors find that ill people are not invariably totally overwhelmed by their illnesses. Some are able to limit their sense of criticality of the illness by contextualizing their illnesses in what turns out to be already traumatized personal lives. Others come to find the possibility of looking at daily life in a wholly new light precisely because of the disorienting effects of illness. Moreover, authors find that while some healthy people can learn to empathize with the ill, many ill individuals still have a lot to learn about empathy towards "fellow" ill individuals. The lesson from these surprising experiences is to not get bogged down by the commonsense yet also highly limited definition of mental power as responsibility. Rather, the mind has more dimensions than responsibility, such as contextualization, aesthetic perception, and empathy. Moreover, given the right conditions, the mind can develop these other dimensions.

With regards to the resource theory of health, authors obviously come to reject the association of resources with immunity to illness. What they do take from the resource theory of health, however, is the robust role of resources in the shaping of well-being among the healthy and ill individuals. For one, contrary to the stipulation of illness identity discourse, authors come to recognize that, because of

differences in status and resource between ill individuals, the level of well-being among ill individuals is not equal. This is driven home both by their embarrassment at recognizing their obvious advantage over underprivileged ill individuals in terms of access to healthcare, as well as their anger at being treated as "more other than other" because of the gendered or sexual meanings of their illnesses. Moreover, authors point to their shocking recognition that difference in resources among the healthy can actually lead privileged healthy people to not just define the bodies of underprivileged healthy people as pathological, but also to deem the latter's body fit for punishment or "treatment." Specifically, they point to the collective violence against Jewish people during the Nazi era and violence against women.

In the next two sections, I explore two broad implications of the authors' practices of estrangement and normalization. First, I look at how the reflexive practices of estrangement and normalization in the domain of chronic illness may be informed by epistemic strategies in identity politics in other domains of social struggle. Secondly, I explore the practice of normalization as the authors' reassertion of their privilege as well as their selves.

The Two Reflexive Practices as Two Sides of Illness Identity Politics

The reflexive practices of estrangement and normalization studied in this dissertation should not be regarded as wholly internal to the domain of chronic illness. Rather, these two practices would be more accurately understood as informed by two contrasting epistemic strategies found in identity politics in other domains of social struggle, such as race, gender, sexuality, etc. The practice of

estrangement mirrors the identitarian strategy of attacking meritocratic

individualism's tendency to overlook arbitrary differences that allow some to be

individuals while disqualifying others. In contrast, the practice of normalization

mirrors internal critiques in identity politics, which seek to avoid the identitarian

mistake of slipping from arguing for the relative autonomy of a difference in

question—in our case, being the difference between health and illness—in relation

to other differences to arguing that the difference between health and illness is

more fundamental than other differences.

To understand how identity discourse can be re-adapted from other domains

of social struggle to the domain of chronic illness, we need to get a basic sense of

how identity discourse began in racial struggles in the United States and then

increasingly affected other domains of social struggle. According to Skrentny (2002),

identity politics began with the birth of African American identity during the Civil

Rights Movements, which sought to challenge white domination masquerading as

meritocracy. At the same time, African American identity was also useful to justify

the autonomy of racial politics from Marxist or class-based politics. In view of the

success of African American identity politics, the construction of similar liberation

or political movements on the part of, for example, other communities of color,

women, the LGBTQ communities, were basically modeled on the discursive and

thought strategies through which African American identity was constructed in the

1950s and 60s. Like African American identity discourse, the discourses of identity

in the latter domains also attack meritocratic and Marxist theories of society that

overlook the apparently more fundamental differences of gender, race, sexuality,

and so on. Interestingly, the language of identity is also increasingly adopted by the right, especially since the rise of the so-called conservative backlash, where being white, male, Christian, heterosexual, etc. is seen as an identity being aggressively silenced and excluded by the progressive left. Increasingly, the identity of the disabled person is recognized as a legitimate participant in identity politics. In contrast, the identity of the ill person has yet to be fully recognized. I thus argue that Illness memoirs, like first-person accounts in other domains of social struggle, serve to legitimate illness identity through sharing personal experience (for a classic account of how first-person accounts of African American women served the construction of Black feminist identity, see Hill Collins 1991).

Authors' critique of the responsibility theory of health can be easily read as the re-adaptation of the identitarian critique of meritocratic individualism in other domains—in particular, race—into the domain of chronic illness. By the meritocratic view of society I mean the view that anyone can become entitled to well-being by responsibly working towards the largest possible pool of resources. The meritocratic view posits itself as superior to feudal society, where well-being is not founded upon merit but accidents of biology or birth. African American identity discourse invalidates the meritocratic view of society by arguing that the individual able to succeed in the meritocratic game is assumed to be white. In contrast to the preconception of individuals as white, African Americans as a whole are defined as other to individuality. To African American identity discourse, the non-individuality of African Americans is the result of their systematic exclusion from resources. Yet, the white-biased definition of individuality tends to overlook the racially based

asymmetric distribution of resources, choosing instead to blame African American

individuals apparent lack of responsibility.

Similar to African American identity discourse's critique of the meritocratic

individualism in the domain of race, illness memoir authors basically find that the

cultural definition of the individual makes the problematic assumption that the

person needs to remain permanently healthy. Yet, like differences such as race,

gender, and sexuality; the difference between health and illness works in an

arbitrary manner, such that who gets to be healthy or ill is a matter of biological luck.

Moreover, rather than being honest about the association with individuality with an

untenable view of biology, healthy people actually work to cover up the random

ways in which people are biologically rendered ill. This act of covering up biology is

done through the normative expectation of the individual to be wholly responsible

for her own biology. Rather than acknowledge the limit of mental control of one's

biology, self-claimed individuals thus accuse the ill of their putative irresponsibility

before and after illness onset.

In the practice of estrangement regarding the resource theory of health,

moreover, authors of illness memoirs essentially adopt the identitarian strategy of

arguing that the difference between health and illness is more fundamental than

other differences. The reason lies in their sense that socially salient differences such

as race, class, gender, sexuality, etc. merely focus on the ways in which well-being is

shaped by the status-based distribution of resources such as money, power, prestige,

knowledge, and social connections. To illness identity discourse, the effect of

resources on well-being is superficial, whereas the effect of the random distribution

of health and (chronic) illness on well-being is deep. The deep effect on well-being of biological uncertainty can be seen in the way that, given the limited power of biomedicine in preventing and treating chronic illness, illness often acts as the ultimate social leveler. Besides indiscriminately attacking both the privileged and underprivileged, illness also has an overwhelming effect in determining a person's identity. While healthy, the privileged person enjoys a great leeway in determining her identity, as in the case of Crosby's identification as femme butch. When one becomes ill, however, illness often becomes the person's master identity, whether the person likes it or not.

As emphasized in my study, the identitarian logic informing the practice of estrangement is double-edged. It is positive in uncovering the non-obvious assumption that the meritocratic individual has to remain healthy indefinitely. Yet, the negative side of the identitarian logic is the difficulty that it poses for the ill person to normalize her illness, in particular, to recognize that healthy and ill people are not so different, as well as to recognize that illness is not necessarily the worst. Illness identity discourse tends to regard the social world as fundamentally divided by non-controllable biological processes, thus healthy and ill people are rendered wholly different in the mental level because of their biological difference. More importantly, illness identity discourse tends to over-emphasize the worstness of its preferred form of suffering, hence making the person unable to both perceive differences in suffering among the ill, as well as possible forms of suffering among the healthy, specifically racial and gender violence.

In light of the double-edged character of identitarian thinking in the domain of chronic illness, authors' practice of normalization can be read as informed by recent internal critiques of identity politics. Rather than regarding society as fundamentally divided by healthy and ill people, they not only come to argue for the intra-categorical variation among healthy and ill individuals, but also the inter-categorical similarity between healthy and ill individuals. This is made possible firstly the authors' emphasis in learning to limit their sense of criticality of their illnesses through the work of contextualization. At the same time, the role of personal agency enables some healthy individuals to "uncharacteristically" be empathetic towards the ill, while making some ill individuals "uncharacteristically" unempathetic towards "fellow" ill individuals. Further, the recognition of intra-category variation and inter-category similarity is made possible by the authors' recognition of the intersection between social and biological processes. To the least, they come to recognize that social differences among the ill create robust differences in well-being, especially with regards to access to healthcare and the symbolic meaning of illness. Even more, they come to recognize that social differences can actually independently create embodied suffering among healthy people.

To sum up, in this section I explore how identitarian logic and the internal critique of identitarian logic respectively inform the practices of estrangement and normalization. In the next section, I further explore how the practice of normalization produces a symbolic boundary among ill people: ill individuals who are capable of becoming distanced from their illness and thus recognize other forms

of suffering in their lives and in the world, leading to a sense of "cosmic acceptance" (Gerson, personal communication, 2018), and those who are incapable or unwilling to thus distance themselves from their illnesses. I argue that this distinction dangles between authors' reassertion of privilege and self.

The Practice of Normalization: Reassertion of Privilege or Self?

In the authors' practice of normalization, there is often an implicit distinction between ill individuals who truly know what it means to normalize their illnesses and those who do not. There are two types of ill individuals who do not know the meaning of normalization. One type of ill individual follows the positive psychology view to regard their illnesses in a positive light, whether or not they really feel that their illnesses are really occasions of spiritual growth. The second type of ill individuals are simply stuck within the fold of illness identity discourse, unable to see both that the healthy and the ill are really not that different, and that being ill per se may really not be the worst.

In contrast to these two types of individuals who do not know the true meaning of normalization, authors portray themselves as in the know. Rather than denying or being stuck in the notion of illness as the worst, authors argue that normalization means the limiting of the sense of worstness of illness through the work of contextualization. The contexts through which one can limit the worstness of illness can be biographical or societal (or even global). Biographically, the ill person can come to recognize that, in spite of the obvious badness of their illnesses, their own lives have already been scarred by critical events such as rape and life-

destroying alcoholism. While authors do not mention the possibility, the ill person

can even come to limit their sense of worstness of illness by anticipating related or

unrelated critical events to happen in the future.

At the level of society (or the globe), the ill yet privileged person can come to

limit her sense of the worstness of her illness by recognizing that underprivileged ill

individuals can really have it worse than them. This is especially the case when it

comes to access to health care and the worse symbolic meanings of certain kinds of

illnesses. Even more astonishing, authors argue that true normalization means

being able to look across the aisle, and recognize that otherwise healthy people can

come to suffer from bodily pain and symbolic pollution simply for being

underprivileged. This recognition that healthy people can suffer bodily and symbolic

pain for non-biological reasons often serves to remind authors that at least their

bodily and symbolic pains are rooted in biology. In comparison, the former kind of

suffering is seen as worse because of it being rooted in artificial considerations of

status and resource.

Authors' implicit and explicit distinction between ill individuals who know

the true meaning of normalization and those who do not can be easily read through

the lens of the Bourdieusean resource-based theory of aesthetic perception. In

Distinction ([1979] 1987), Bourdieu argues that the disinterestedness in modern

aesthetics is really the effect of being born into middle- to upper- class backgrounds,

rather than the product of the person's inclination and will. Middle- to upper- class

individuals can afford to perceive reality in a disinterested way not simply because

their parents were able to pay for their costly aesthetic education. More

fundamentally, they become able to regard reality aesthetically because they are financially unencumbered, and hence do not have to be concerned about reality in the way a working-class person does.

Following the Bourdieusian logic, ill individuals who claim to know the true meaning of normalization can be seen as capable of taking a disinterested view towards illness. In contrast, ill individuals who do not know the true meaning of normalization are too caught up in their illnesses, whether they actively deny or are wholly focused on the illness.

From the Bourdieusean lens, moreover, ill individuals who claim to know the true meaning of normalization, i.e., the authors, may be simply naturalizing their social superiority over less privileged ill people through their claim of attaining a disinterested view towards their illnesses. As already mentioned in Chapter Three, the difference between disinterestedness and interestedness towards illness may simply come down to differences in resources. For example, the aesthetic perception developed during illness cannot be fully appreciated unless we remember that these authors are already versed in humor and artistic perception gained prior to their illness. In other words, there is a transposition of cultural capital onto the domain of chronic illness. Moreover, the very ability to remind oneself that there are many other forms of embodied suffering, in particular, racial and gender violence, should be understood as a transposition of sociopolitical knowledge from other domains onto the domain of chronic illness. Both artistic and sociopolitical knowledge are elements of the cultural capital that socially

progressive professionals such as the illness memoir authors bring into the domain of illness.

Furthermore, the very fact that authors enjoy the luxury to reflect upon illness identity in such disinterested manner points to the way their socio-economic status allows them to be disinterested. This is most obvious in the dual fact that they can afford to access high-quality healthcare without financial hardship, and avoid bankruptcy when they are too sick to work. Their financial privilege, based on prior savings and investments, excellent insurance coverage, as well as the fact that most of them seem to be able to keep their professional jobs in spite prolonged absences mandated by their illness, means that they can afford to stay at home to rest and be reflective about their illness. Obviously, this does not mean that they are not suffering bodily and symbolically while recuperating at home or writing in the hospital. It is only to underscore that the capacity to distance oneself from one's illness often requires a stable material infrastructure that is part of these memoir writers' social privilege.

Yet, even though authors may indeed come to reinforce their privilege through portraying themselves as knowing the true meaning of normalization, we need to also be cognizant of the way in which this self-portray embodies the reassertion of a self that is previously damaged by illness. As authors who were born into privilege emphasize, the fact that they were able to reproduce their parents' positions, and moreover, find great satisfaction in their present lifestyle, is not an automatic process of social reproduction. Besides the obvious role of strategy, authors emphasize their sense of commitment to living an independent

and honorable life. To them, their sense of self is what separates them from other people who were also able to reproduce their parents' position and lifestyles, but nevertheless feel empty in spite of their worldly success. In the same vein, we could also appreciate the immense effort and commitment put into the work of limiting the worstness of one's illness by contextualizing it in one's and others' lives. This recognition that one does not simply suffer now and alone, as well as that everybody else suffers all of the time, albeit in different ways, can be seen as a form of "cosmic acceptance" (Gerson, personal communication, 2018) that can be learned through reading the memoirs and committing oneself to such stance. In other words, while normalization can be significantly facilitated by resource and status, it can nevertheless be relatively independent of authors' resources and privileged statuses.

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