



Lorna Hummel

Querying and Queering Caregiving:
Reading Bodies Othered by Illness via
Porochista Khakpour's *Sick: A Memoir*

Ever since I can remember, I dreamed of escaping.
Escaping *what* was always the question... (Khakpour 39)

The word diaspora is often reductively defined as an escape, “the dispersion of any people from their original homeland.” Leah Lakshmi Piepzna-Samarasinha’s poem, “diaspora,” from her volume *Bodymap*, names diaspora differently: “to be in diaspora, maybe you are always a ghost always missing something...”. Through my experience with diaspora and transnational studies, especially thanks to Gayatri Gopinath, I have come to define diaspora much more broadly, something more akin to the “ghost always missing something” that Lakshmi describes. Gopinath expresses a “dissatisfaction with standard formations of diaspora that inevitably foreground the nation as the primary point of reference,” and thus proposes an alternative cartography (Gopinath 4). This new kind of theoretical mapping “rejects dominant cartographies that either privilege the nation-state or cast into shadow all those spaces, and gender and sexual formations, deemed without value in the map of global capital” (4). This mapping extends to queered, othered, and alternative bodies and formations (physical and psychological), including those othered by illness and disability. For Gopinath, and for the purposes of this study, “‘queerness’ here names a state of being out of place and disoriented in the landscape of heteronormativity” (21). This notion of disorientation is often expressed by individuals with “unruly” bodies, bodies that defy the heteronormative definitions of health and wellness and refuse to be disciplined into normative ways of “well-being.” One such voice is evident in Porochista Khakpour’s 2018 memoir, *Sick*, labelled on the back cover her

“grueling, emotional journey” as a woman, an Iranian American, a writer, and a chronically ill person. The memoir thus navigates her queer diaspora: her attempted escape from the hegemonic constructs that define her existence as a disabled-and-suffering woman of color.

Khakpour’s *Sick* is a brutally honest depiction of “escaping” from what is deemed home—the place, space, and body already prescribed. Her memoir conveys her long battle with illness which ultimately results, after \$140,000+ spent on medical bills, in a diagnosis of late-stage Lyme disease. The narrative relies heavily on the movement from place to place, chronicling her family’s flight from Tehran and the Iran-Iraq War, to “Tehrangeles,” an Iranian community in Los Angeles, then to the dreamlike New York City, Santa Fe, small-town Pennsylvania, Germany, et cetera. Throughout it all, she navigates a search for self, a becoming, or alternatively, an escape from the heteronormative body/space/place she cannot fully occupy. The memoir intimately describes the physical and psychological symptoms of Lyme, in addition to her addiction patterns and other encounters with illness, in order to confront the misconstrued notion that bodies are faultless and flawless houses for our beings. Susan Wendell, in her article “Toward a Feminist Theory of Disability,” asserts, “disability is not a biological given; like gender, it is socially constructed from biological reality. Our culture idealizes the body and demands that we control it. Thus, although most people will be disabled at some time in their lives, the disabled are made ‘the other’” (Wendell 104). Wendell argues that chronic illness be recognized as a disability, and so too does Khakpour. Her narrative describes Lyme disease as one “that many in the medical profession, unless they specialize in it, find too controversial, too full of unknowns, to fully buy it as legitimate,” othering her because of her biological reality (Khakpour 21). Thus, though she is the accumulation of her own (dis)embodied experiences, she is denied full inhabitation of her body, over and over again, because of caregivers’ hesitancy in assigning a diagnosis of Lyme, or for that matter, any diagnosis at all.

Even long before Khakpour’s official diagnosis, and her endlessly repeated hospital stays, she felt a discomfort in her body. When her body met with chronic illness and disability, she “grew to feel at

home” (6). The cover image depicts Khakpour herself, lying down, eyes wide but fixed and sure, mouth closed, nasal cannula hooked in place behind her ears, thick black hair fanning around her head. In this image, and in the memoir itself, she is confronting her audience with this stare and with the spill of pills that border her name and existence and the title of the book, challenging caregivers’ denial of her “othered” body and creating a space for herself via the health humanities. Early in the memoir, Khakpour voices, “I am a foreigner, but in ways that go much deeper... under the epidermis and into the blood cells” (Khakpour 6). Her body is “foreign,” strange, as it resists heteronormative modes and diagnoses. In a *New Yorker* review of *Sick*, Lidiya Haas writes that “pain and disease are what they are—they resist meaning and the narratives that make it. Other people’s sicknesses, as bodily phenomena, must be imagined or taken on trust, since they can never quite be transmitted across the gap” (13). So many bodies and persons fall into this gap because they are queer, queer to their friends and family and queer to caregivers and healthcare providers. This “gap” deserves to be explored, in order to pay attention to the persons and queer bodies that have fallen into its cavernous mouth, and to be bridged, by establishing a framework, or a transnational net rather, of adequate caregiving. Such a framework can draw from Gopinath’s vision for a queer optic, which “brings into focus and into the realm of the present the energy of those nonnormative desires, practices, bodies, and affiliations concealed within dominant historical narratives” (Gopinath 4). Why is it that nonnormative bodies such as Khakpour’s are consistently denied existence by the Western and hegemonic optic, in other words, the heteronormative way that providers *see* patients? She experiences so many different symptoms, and attempts treatments with an array of formal practitioners and intimacy with a number of informal caregivers. But despite her attempts, she is largely ineffectively cared for, due to her “queer” existence as a woman of color navigating chronic unhealth, and her insufficient care for herself. Through this study, I hope to name the *what* that Khakpour is escaping from, to shed light on her and other patients’ experiences of “queering” via disease and healthcare, and to analyze and critique caregivers’ perceptions of queer bodies, thus querying (or queering) caregiving for “others.”

Articulating a Framework for ‘Querying & Queering’

Performing an aestheticized practice of queer diaspora in Khakpour’s memoir demands that we look at illness as queering, especially for a young woman like Khakpour. Michele Lent Hirsch’s book, *Invisible: How Young Women with Serious Health Issues Navigate Work, Relationships, and the Pressure to Seem Just Fine*, greatly contributes to this notion of queered embodied experiences. Hirsch herself shares commonalities with Khakpour; she too was diagnosed with Lyme disease, in addition to thyroid cancer and mast-cell activation syndrome, among other health difficulties. Also, like Khakpour, she uses the pages of her book to explore the intersection of gender and health, between femininity and illness/disease/disability. While *Sick* is a memoir, *Invisible* is an accumulation of personal health narratives, Hirsch’s included, interviews, and research studies. Hirsch seeks to answer the following question: how are women shaped by disease, and how do they shape the disease to fit their otherwise maligned bodies? She notes, “disability is largely about the world’s failure to make space for you,” articulating the same kind of disembodied disgust that Khakpour speaks toward. The Kirkus review of *Invisible* states, “At a moment when women’s experiences in the workplace have come to the fore, Hirsch’s eye-opening study of gender-based disparity surrounding illness will hopefully help spawn a similar reckoning for women’s health” (“Kirkus Review”). Khakpour’s *Sick* also calls for this reckoning, but broadens it, confronting caregivers with non-normative, non-masculine bodies such as hers and Hirsch’s.

Engaging with Khakpour, and Hirsch supplementally, points to the gendered experience of illness, disease, and disability, and thus is intimately and intricately linked to feminist theory and phenomenology at large. Wendell, as mentioned above, is one of the early writers on the intersection between feminism and disability. She speaks at length toward the ongoing difficulty that othered/queered/disabled bodies have in placing themselves in the heteronormative world around them, ultimately arguing that feminist theory can free the disabled other from the stricture of disability and the social constructs that surround it.

Gopinath’s argument for the queer body is similar to Wendell’s plea—both are grounded in the need for

body equality. Wendell also fell ill due to a disabling chronic illness, so she and Khakpour share the same “othered” ground. In her much-later study, “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities,” she continues to explore terms of definition for “disability” and disabled persons. Here Wendell asks, are illness and disability necessarily always *evil*? Western medicine tends to paint ill and disabled bodies in this way, as if the way to reckon with those bodies is to overwrite the illness, “healing” them of their otherness. The solution, she says, is not so black and white. Rather, ill and disabled persons should be met where they are, recognized as human even in the light of suffering. Her argument converges with Gopinath’s: as the aesthetic practice of queer diaspora “provides us with a critical model of engaging with difference: a model that does not see past difference, but opens the possibility of forging alliances in and through it” (Gopinath 29).

Queer diaspora problematizes prescriptions of “normative” embodiment, as does feminist phenomenology, thus this analysis requires engaging with Lisa Folkmarson Käll and Kristin Zeiler’s anthology *Feminist Phenomenology and Medicine*. The text is compiled of essays from many different perspectives that each speak toward different medicalized modes of being. Abby Wilkerson, one of the essayists, best describes what it means to apply phenomenology to medicine.

Because phenomenology addresses meaning “at the level of the life-world” and contextualizes this lived experience in the interactions of “embodiment and culture,” it opens up a critical space for assessing the life impact of medicalization through attention both to how normality and its boundaries are defined and to the nature of subsequent interventions into departures from normality. (Käll & Zeiler 156)

These “departures from normality” are what I am interested in. Khakpour’s diasporic body and narrative departs from normality, thus it is “queer” and “other” to the medicalized and heteronormative optic. The stakes of *Feminist Phenomenology and Medicine* are such: “to advance more comprehensive analyses of issues such as bodily self-experience, normality and deviance, self-alienation and objectification” (Käll & Zeiler

2). Käll and Zeiler, and each of the chapters therein, thus speak directly toward Khakpour's "bodily self-experience;" she is a feminist and woman of color trying to navigate the hegemonic of American healthcare, all the while feeling distanced from her own body, without a home. While dealing with issues of embodiment and situatedness, the book also "examines normative cultural practices and structures of meaning that situate different bodies in different ways and with different conditions, and seek to lay bare the constitutive conditions of experience" (Käll & Zeiler 2). This study also seeks to investigate areas that are not typically deemed "medical"—sexuality, bodily appearance, and norms of beauty—each of which factor heavily into Khakpour's othered and queer narrative.

Sick offers a painstakingly personal portrayal of just what it means to be "sick," and what all accompanies that label. There are two specific essays within *Feminist Phenomenology and Medicine* that are serviceable in this query, Linda Fisher's "The Illness Experience" and Wilkerson's "Wandering in the Unhomelike: Chronic Depression, Inequality, and the Recovery Imperative." Fisher voices the need for a phenomenological approach in studies on illness, especially in studies on *the experience* of illness. Fisher deems that the illness experience, purportedly subjective, is "heavily colored by the reception, construal, and treatment of the individual in the wider social context" (Käll & Zeiler 39-40). *Sick* provides us with exactly that, as the care and attention she is given by others, caregiver or not, restructures her own experience with illness. Her self-perception is so greatly based upon how she is received and perceived by others, especially those she trusts with the knowledge of her body and illness(es). Fisher queries why illness is framed "not just as the compromise but the negation of health [...] In this manner, health is defined in opposition to illness, as the absence of or resistance to this ever-threatening Other, the negative foregrounding and delineating the positive" (31). Khakpour does not just have a disease, she *is* ill; her body becomes what Fisher calls this "ever-threatening Other." While her illness experience does not draw significantly from the actual voices and writings of an outsider, what Fisher calls "a view from without," her experience is fractured and framed by the care given to her mind and body, or the lack thereof, what

Fisher calls “a view from within.” *Sick* provides us with this view from within, not only relating her sense of self to her bodily experience but entrenching that experience within the broader sociocultural context. This analysis inherits the kind of phenomenological approach that Fisher elucidates, explaining how Khakpour’s memoir portrays “a view from within,” thereby commenting on society at large.

Wilkerson’s “Wandering in the Unhomelike,” as the essay title conveys, speaks to this unsettling “othering” as well, specifically in the context of depression. Through frequent use of bodily metaphors drawing from Delmore Schwartz’s poem, “The Heavy Bear Who Goes With Me,” she conceptualizes the illness experience of depression, focusing her argument with a Marxist lens to demonstrate how depression meets with “broader social power dynamics” (Käll & Zeiler 155). She employs Heidegger to construct her framework, whose concept of “being-in-the-world, in which objects’ meanings depend on their role in human projects,” speaks directly toward an experience of depression (156). Heidegger points to boredom and anxiety, both symptoms of depression, “unhomelike phenomena” by which “the world resists meaningfulness” (156). For Heidegger, unhomelikeness “suffuses embodiment, illustrated well by the bear, lumbering and slow yet always capable of annihilation, a creature whose presence would seem to render home itself unhomelike” (156). Wilkerson’s application of the unhomelike is evident in Khakpour’s embodied discomfort that she voices throughout *Sick*. This discomfort, though multi-faceted, is ultimately rooted in her illness and *dis-ease*: “Every part of my body felt like its wiring was all wrong, I felt like a foreigner in a hostile country, never adjusting or accepting that this was what it had all come to” (Khakpour 108). At several points throughout the narrative, she voices a kind of lost and home-less feeling, not knowing if she was “depressed, addicted, messed up from [a car] wreck, or something else;” she feels foreign to her own self, not just to those around her, thus she partially others herself because of her experience with disembodiment (63). Her body is unhomelike, not just for her, but for friends and family, and even for healthcare providers too—her body’s deviance from health into illness, what Fisher

calls “the ever-threatening Other,” is uncanny and unhomelike, even to readers like me and you (Käll & Zeiler 31).

The Medicalized Aesthetic: Seeking Formal Care

Khakpour’s illness experience was significantly shaped by what I am calling the medicalized aesthetic, in other words, the optic/way-of-seeing employed by formal caregivers and healthcare providers. When she is, perhaps, at her lowest point, symptoms of every kind ravaging her body and mind, she admits:

I became someone whose main job was trying out medications and going to the doctor. It was like shopping in a way [...] I tried acupuncture, I tried an ayurvedic center, I tried multiple healers, I tried nutritionists. At one point I was seeing three different sleep specialists who all seemed fairly invested in hiding how stumped they felt. I spent every penny I had searching for the energy to keep seeking. (Khakpour 104)

This section will evidently speak toward the many healthcare providers that Khakpour sees and seeks. Her experiences of formal caregivers and the care that they give inform her illness experience and her sense of selfhood and identity. Even as she states, “*I think there is something wrong with me physically,*” the providers she sees are confounded by the cacophony of her symptoms and thus fail to truly listen to her narrative (Khakpour 104).

Western medicine operates under a strictly heteronormative optic, permitting illness, of course, but largely for the purpose of restoring health, turning illness “off.” Nearly all of Khakpour’s formal caregivers subscribe to this optic, the standard way of *seeing* patients, not finding validity in her story and symptoms because they “fall outside of the purview of official archives” (Gopinath 8). Both Linda Fisher and Susan Wendell speak toward this rendering of illness, especially by those situated within the medical hegemonic. Fisher notes, “whether such negative social framings of illness are latent or on the surface, whether mild or strong, they serve to constitute illness and the ill person as Other” (Käll & Zeiler 31).

Illness thus “serves the normative function of designating what counts as normality and the desirable status quo” (31). Disability is identified similarly, as it is largely socially-constructed. Illness and disability are even further complicated by gender—it is ill and disabled women who “struggle with both the oppressions of being women in male-dominated societies and the oppressions of being [ill or] disabled in societies dominated by the able-bodied” (“Toward a Feminist Theory of Disability” 105). As femininity has historically implied a lack of power, both these terms, illness and disability, connote weakness. Feminine, ill, and disabled bodies are evidently less *visible*, even to such caregivers as these. Consider again the cover of Khakpour’s memoir—her gaze commands the space of the narrative as her eyes and expression are challenging the medicalized optic that would dare pin her body down as something to be pointed at, defying with a look all those who’ve labelled her as “sick.” I also invite us to consider the cover of Hirsch’s *Invisible*. This image very fittingly demonstrates the diminished visibility of women with chronic illness. In the medicine cabinet, split by the opened door of the mirror, half of a woman’s face looks back at us. Her face already obscured by shadow, the mirror of the medicine cabinet (representing the medicalized optic that I’ve been speaking toward), fractures her sense of self. And behind the mirror are three plastic pill bottles, with their indistinct prescription labels, trying to return her unruly body to a normative existence. This medicalized mirror alters the way that a young and chronically ill woman sees herself; her identity has changed because of what physicians and providers have diagnosed and prescribed. Hirsch’s *Invisible* and Khakpour’s *Sick* present the oft-obscured eyes and perspectives of those on the other side of the normative optic, giving identity and body and emotion to those patients that only serve as statistics, to those ‘real’ persons acting their way through commercials for prescriptions.

The optic for chronic illness, especially those illnesses that are muddled by difficult or unreliable methods of diagnosis, is even more debilitating. Chronic Fatigue Syndrome, Somatization Disorder, Chronic Depression, Chronic Lyme Disease—each of these illnesses functions beneath the *knowing-ness* of medicine. When Khakpour is first pulled into sickness, experiencing a tumult of symptoms simultaneously,

she tells her editor, “*Chronic fatigue* [...] *that’s what they are saying*. But no one was saying it and there was no ‘they’” (Khakpour 107). The “they” is a signifier for some greater body of knowledge that has the ability to name, and thereby signify, what Khakpour is experiencing. The “they” conjures up an image of a presumably wise group of medical experts, all hetero, white, and male, physicians and researchers gathered around her very “other” body, pointing to a cold collective of data and statistics that implicates her body into a gendered and complex diagnosis. The “they” would not understand Khakpour’s body, that she “doesn’t look like what [they] might expect. That [she’s] a brown Middle Eastern woman” instead of privileged and white like the bodies that fill their studies (129). She finds illness turns her body, literally and imaginatively, “white—thin and pale to the point where everyone congratulates me at my sickest as I transform to a white woman in appearance [...] Every part of me in illness becomes the white woman of their dreams” (129). This is how “they” and their medicalized aesthetic frames Khakpour and women like her. This is the typical narrative of Chronic Fatigue Syndrome, among other chronic illnesses, and Khakpour, in her confused scramble for a diagnosis, defers to what the “they” might be saying, thereby subscribing to the medicalized aesthetic that surveils ill bodies and minds.

In their 2009 study for the *Journal of Women’s Health*, “Implications of Gender in Chronic Lyme Disease,” Gary Wormser and Eugene Shapiro identify one of the difficulties in their study as the “relatively small number of patients with post-Lyme disease who were available to be *analyzed*. This is likely because very few patients actually develop significant long-term functional impairment after a true episode of Lyme disease” (833, emphasis added). Their study ends with the following conclusion: “This finding suggests that illnesses with a female preponderance, such as fibromyalgia, chronic fatigue syndrome, or depression, may be misdiagnosed as chronic Lyme disease” (Wormser & Shapiro 831). Instead of attending to the narrative to the persons within this study, Wormser and Shapiro take to the normative optic and diagnose and *analyze* based upon statistics and probabilities. Similarly, in the article, “The Overdiagnosis of Lyme Disease,” the authors write, “the greatest diagnostic problem demonstrated in this

study was distinguishing Lyme arthritis, encephalopathy, or polyneuropathy from chronic fatigue syndrome or fibromyalgia” (1815). Khakpour speaks to these kind of studies in her essay, “On Place”: “It is no coincidence then that doctors and patients and the entire Lyme community report—anecdotally of course as there is still a frustrating scarcity of good data on anything Lyme-related—that women suffer the most from Lyme” (166). In her own theorizing and through her narrative voice, she highlights the “normality” of chronic illness for women, and how that chronic illness is often mistaken for mental illness because “women simply aren’t allowed to be physically sick until they are mentally sick, too, and then it is by some miracle or accident that the two can be separated for proper diagnosis” (166). Due to the nature of these studies on Lyme, and of their field in general, they subscribe to the medicalized aesthetic that traps othered and ill, thereby queer, bodies beneath the framework of medical diagnostics and statistics, a trap that has persisted for decades upon decades. The medical rhetoric for physicians and practitioners and researchers rests on the history of hysteria, a history in which women who were physically ill, especially those chronically physically ill, were deemed to have poor mental health as well. This mindset persists even today, in these kinds of studies, and thereby in the minds of women like Hirsch and Khakpour, because they are at the hands of these physicians and practitioners and researchers who continue to ascribe to a hysteric kind of rhetoric.

Consider Samira, who Hirsch introduces as a “twenty-nine-year-old woman of color/femmedrogynous person of color” who was diagnosed first with polycystic ovarian syndrome (PCOS), then post-traumatic stress disorder, then hypothyroid, then severe irritable bowel syndrome, then insulin-resistance due to complications of PCOS (Hirsch 130). Her body and medical chart are the cumulative results of her illnesses, not able to be separated from her illness experience;

Despite this combination of serious—and diagnosed—health issues, Samira cannot get doctors to listen.

“I live with chronic pain,” she writes, “but am refused any form of reprieve from my practitioners. They don’t see the pain, exhaustion, anxiety, or depression that have become a part of my conditions [...] I’ve dealt with homophobia and misdiagnosis”—and, it seems, the common belief that her pain isn’t worth treating or even real.

The history of ignoring or disbelieving women’s pain is centuries old. The problem is so vast that it’s almost too unwieldy, too pervasive throughout history, to summarize briefly. (Hirsch 130-131)

Unwieldy—this is what by-the-book practitioners use to describe bodies like Samira and Khakpour’s. They are unruly and slippery and too risky to listen to, so caregivers that ascribe to the medicalized aesthetic choose to be ignorant, or rather, subscribe to the stony incomprehension that chooses only to listen to medical journals and texts, without the patient narratives necessary for fostering empathy and understanding. Gopinath asserts that an “unruly vision” is essential for inclusive accommodation and thus to properly care for queered and othered persons.

One of the most othering symptoms, according to Khakpour and the women of Hirsch’s *Invisible*, is fatigue and all that accompanies it. Wendell, in her study “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities,” reminds us, “fatigue is one of the most common and misunderstood impairments of chronic illness” (24). Fatigue resists the typical categorization that other symptoms fall easily into; “it is more debilitating, it lasts longer, and it is less predictable [...] Reasonable precautions may help prevent it, but it resists control” (“Unhealthy Disabled” 24-25). The normative medicalized aesthetic depends upon control, so a symptom like fierce and unyielding fatigue unsettles even the most scrupulous of physicians/providers. Khakpour frequently mentions “Dr. E,” an infectious disease specialist, one of the few physicians she sees regularly. He is one, due to his specialty in “unruly” diseases, that has a grasp on the “impossibilities” of Lyme disease. When she started experiencing such fatigue, he warns her that “almost always, as the spirochetes multiply and infiltrate the body, the Lyme sufferer loses the ability to sleep. *It’s*

usually a particular type of insomnia, he said, *the kind that really ruins people. It's not the type of insomnia the general public can begin to fathom*" (Khakpour 101). Fatigue renders already strange bodies *unfathomable*, especially in the light of a neoliberal and hyperproductive capitalist era. Fatigued persons cannot be appropriately productive, thus they are inherently worth less, compared to "healthy" and "productive" peers.

As Khakpour navigates doctor's office after doctor's office, seeking some kind of diagnosis or reprieve, one provider she trusts is a nurse practitioner who "was an expert in women's health," Firoozeh, who also, "by strange coincidence, happened to be Iranian" (Khakpour 149). Khakpour in this instance of meeting Firoozeh diminishes her own symptoms, asking, "Why do you think there is something definitely wrong?" [...] She looked at me like I was crazy" (149). Firoozeh eventually named her diagnosis as something very near to "Diabetes 1.5," not a true diagnosis, but something outside of and beyond diagnostic criteria, beyond what I've called the *knowingness* of medicine. While descriptions of Khakpour's relationship with Firoozeh are limited, I am interested in exploring it because she attends to Khakpour's body much more intimately and frequently than do any of her other formal caregivers. She and Khakpour, in their existence outside of the white/hetero West as Iranian Americans, share what Gopinath calls a region of (un)belonging. Firoozeh is also a woman of color who had to navigate very masculine and medicalized spaces, attempting to situate herself in a landscape that is largely hostile to women, especially to women of color, and even more so to women of Middle Eastern descent. Firoozeh's body is also queer to society around her because of her origins, personal or familial, another victim of the disorientation that is "the by-product of dominant constructions of national and communal (un)belonging" (Gopinath 8). While she did not fully grasp the root of Khakpour's difficulties with unhealth, she took her seriously, believing in her story and her symptoms and her body as other formal caregivers had not. Khakpour mentions a handful of other Iranian-American providers, all men who do not attend to her body and disease effectively. While their experiences of Gopinath's region and cultural (un)belonging may be similar, gender and societal seat and illness interrupt the intimacy available to them, thus they failed to grant her

the concerned care that Firoozeh did. In Khakpour's words, after having moved back to New York, her other healthcare providers "seemed as clueless as I was, my body a mystery they couldn't solve. I started to feel rejected by them, sensing their dread when they'd greet me, feeling the frustration in their bodies as they pored over yet another batch of bloodwork" (Khakpour 174). Their dread arises out of the normative optic that deems Khakpour's body and bloodwork queer, that optic that hopes to see a body that can be tactfully replaced into a healthy and normative state of being.

Instead of subscribing to the normative medicalized aesthetic, illness narratives like Khakpour's are advocating for a queer optic, a way of seeing and caring for patients that does not belittle their experiences with its rigid constructions of health. This revitalized optic queers its own way of seeing. Gopinath identifies the goal of her study as the creation of "a shared queer visual aesthetic that mobilizes new ways of seeing both regions and archives, and that puts into play, through an affective register, an intimate relation between the two" (4). Patients, as persons, emerge out of a personal region and archive, thus their illness experiences are embedded both in where they come from, where they find home, and their archive of memories, what *beyond* illness shaped their body and mind.

Finding Home in the Other: Relationships Of- and Without-Care

In addition to the "they" that diagnose and prescribe and surveil over bodies like Khakpour's, there is another "they" present in *Sick*, those unlicensed and supposedly supportive voices of her informal caregivers. It is important to thus engage not only with the formal caregivers in her narrative, but with the relationships she carries throughout as well. While formal caregivers and healthcare providers can validate one's illness via diagnosis, family, friends, and lovers are those who validate one's sense of being. Such people have both the ability to affirm one's sense of self even in the midst of a debilitating diagnosis, like Chronic Lyme Disease, and the potential to further fracture and further Other. *Sick* is thus muddled by many informal caregivers, including a long list of boyfriends, friends who flit in and out of Khakpour's

life, and her parents back in Los Angeles. Khakpour reflects on these relationships, saying, “The deal with so many chronic illnesses is that most people won’t want to believe you... you make them uncomfortable. Your existence is evidence of death, and no one needs to keep seeing that—especially not the people who gave birth to you” (Khakpour 82). Even fathers and mothers and friends can other their kin in an instance of illness. They are hopeful in the expectation that illness will soon dissolve, and the son/daughter/friend will return to health and “normality.” Chronic illness defies these borders and boundaries set for bodies, thus making us as friends, parents, and partners, uncomfortable. Every phase of Khakpour’s health “seemed to have had a [person] attached to it [...] they serve as echoes of [her] memory, as witnesses, as invisible testimony” (139). Made into a ghost by illness, she is trying to find that “something always missing” in *someone* (Lakshmi).

Sick is very self-aware, sure of its sorrows and confusions and even contradictions. Khakpour thus admits to her heavy, and often unhealthy, reliance on relationships, her most notable reflection on this just after she ends a near-abusive relationship with Ryan:

I realized that for years now, every stage of my life had been calibrated by romantic relationships—including the measurements of health and wellness. Being alone suddenly, at this point in my life, made me feel especially unanchored [...] As much as I didn’t want to admit to that dependence, it felt like I had lost a soul mate and needed a placeholder. (Khakpour 137)

She very quickly turns to a colleague, Jacob, after the breakup, a man whom Ryan had always been suspicious of for his “eye” for Khakpour, deepening her friendship with him until it, very quickly, reaches sexual and emotional intimacy. Out of earnestness, Jacob asks her to move in with him that very fall, so that they could “practice,” Khakpour very sure of what he meant. She describes this as the “most Adult relationship” of her life, full of great hope and the promise of a “real life” (Khakpour 140). Ryan became the “Bad Boyfriend” while Jacob very readily became the “Good Boyfriend,” the new informal caregiver in a long lineage of informal carers who, each time, Khakpour thought was the one who could care best

(140). Jacob was the most serious of Khakpour's carers and lovers, thus why I take particular interest in his role in the narrative.

Hirsch, in her personal reflections in *Invisible*, as opposed to the stories she draws from other voices, accentuates the very danger of vulnerability in the illness experience. Jacob proposes to Khakpour and their engagement persists through a series of long-distance stints, but ultimately falters due to his alcoholism; his vulnerability prohibits caring for Khakpour in her vulnerability. In a way, Jacob idealized Khakpour's sick body, and had since the beginning of their friendship, with him driving her to appointments when Ryan was no longer there to do so. He idealized her for her bodily dependency/ despondency, and she him for his method of caring and his dreaming of her in his future. They failed each other because they did not properly confront the queer innate in both of their bodies. Jacob was too distanced, as had been each of her lovers, their relationships founded on need instead of want; Khakpour finds it unclear if all of those men "were caretakers or protectors of additional stressors when life would hand me its trials, trials these men couldn't access as they were primarily trials of the body" (152). Khakpour here identifies her distinct challenge in heterosexual relationships—the men, primarily white, with whom she assumes intimacy are unfamiliar with her queerness, as a woman, an Iranian American, and a sick person.

Hirsch also explains such distancing in relationships well, evident in her personal narrative and in her stories from other women. While not exclusive to hetero- relationships, "there seems to be more of a precedent for cisgender men rejecting women for their health [...] those deep cultural forces and beauty standards and gender roles were still there in the relationship, pinning [women] down" (Hirsch 12, 11). Queer and "sick" bodies are often Othered, even in very intimate relationships beyond the misogyny of medicine. Thus there lays a kind of danger in dating.

You're a woman who's barely out of high school or college, or you're thirty and supposedly at your sexual peak. You're in pain [...] or your immune system is weak, or it's overly strong, or there's a

tumor or a faulty valve [...]. You are strange to your ‘healthy’ friends, who perhaps want to understand, but can’t...

And on top of that, what you keep hearing whether you’re single or partnered is that you’re already in danger of being ditched. (Hirsch, back cover)

Hirsch says she herself is “more gay than straight,” having had several relationships with women, but she does not expound on these, does not offer how these women attended to or cared for her body. And neither does Khakpour, who also identifies as gender queer. In her brief but notable chapter, “On Lovers Lost and Found,” she asserts her queerness but doesn’t fully claim it: “(... Because I am afforded heterosexual privilege in dating men so often, I tend not to rush to mark that box (the LGBTQ “box”). Perhaps it’s also because I feel overwhelmed by all my marginal identifiers. But I question that omission; to leave that out would be disingenuous too)” (Khakpour 239). Despite her three notable relationships with women, she writes her queerness in parentheses, not even claiming her writing as words that deserve a rightful place in the narrative. In doing so, she is othering herself and her alt-sexual body, in order to comply with what is deemed heteronormative, in order to not be further othered.

There are other relationships within *Sick* that demonstrate informal caregiving beyond lovers and boyfriends, best evident in Khakpour’s mother and father. As she begins the memoir, she admits there is one thing she has always known: “I have been sick my whole life. I don’t remember a time when I wasn’t in some sort of physical or mental pain” (27). Part of this mental sickness emerged in her childhood and her family’s flight from Iran amidst the tumult of the Islamic Revolution. Her parents, members of the “educated, progressive, Western-friendly upper class,” could not have lasted there (27). Khakpour describes her first memories are from this time of flight, memories of pure anxiety from seeing her parents so panicked. She cites storytelling as her method of survival, “furiously she told stories to distract” and pull them out of their trauma (27). These memories are what Gopinath calls one’s archive, the collective of memories that continue to shape one’s future no matter their distance from the present.

Khakpour's archive is marred by the traumatic transplant from Tehran to Tehrangeles. What I find even more curious—her earliest memory of storytelling demonstrates caregiving. She attempted to care for her parents while they were in deep grief over the move far away from home to a place where they became victims of Gopinath's regional (un)belonging. As her childhood begins with caregiving, the rest of her life as we see it leans heavily on that thread. Several providers diagnose her with PTSD throughout her narrative, citing this early experience as one that could cause significant psychological repercussions later in life. Khakpour was the one providing care, denied an attentive and appropriate home and care from her parents, thus she seeks home and attentive care throughout her illness experience, in largely unhealthy ways.

Khakpour's mother is evidently no longer an unattentive mother. She scoops her daughter out of Chicago and then out of Germany in the midst of severe relapses to bring her back home to Los Angeles. But she is not a perfectly healthy mother either. She too is bound by what Khakpour calls her "Western-friendly" vision, the optic that Others and distances her daughter's illness experience. Already displaced and disposed in her existence as an Iranian woman living in the United States, she cannot fully empathize, or other herself further, to meet with her daughter's queer symptoms. Khakpour explains that her mother validated her illness only once, saying she looked truly sick—"To be seen, to be heard, to exist wholly, whether in beauty or in ugliness [...] felt like another big step to wellness" (Khakpour 82). This recognition is a form of love for Khakpour, the kind she felt she never received as a child navigating a new (and unhomelike) home. America was not homelike to her parents either, as her illness greatly distorted their vision for what an American life might be like.

They were supposed to have money, I was supposed to have health, and all of that was supposed to be tied up in the same bundle. Health and wealth. I think the only thing that consoles them is the fact that it seems like a big chunk of Americans are also without those things. All my life, I've

heard my parents and relatives say *America is a sick country*, in every meaning of the sentence possible. (Khakpour 83)

America has denied them the American dream, that hopeful promise that is most readily available to heteronormative and white persons. A hope not so readily available to Iranian Americans in a post-9/11 and hypervigilant West. It is not that they are poor, but members of a fragile middle class where substantial health difficulties can lead to bankruptcy. They do not expect America to be a country that lacks adequate and accessible healthcare, finding it unbelievable that illness cannot be easily and seamlessly “fixed.” Khakpour’s parents are, in part, assigning their daughter blame for her otherness. They are shocked, nearly disappointed, when she seeks admission to the hospital’s psychiatric unit near her home in California, appalled that she would choose to publicize her already queered, woman-of-color, body as something *sick*. Her parents are not the only ones to accuse her in such a way. In the midst of crippling poverty, she sold a few family heirlooms to a pawn shop owned by an elderly Iranian man. As he takes her things, he tells her, “my boy in medical university; my girl, married and with baby. Your fault for being a starve of an artist, daughter” (Khakpour 121). In their “Western-friendly” vision, her parents, and this Iranian man of their generation, subscribe the heteronormative optic that Gopinath warns against, the optic that expects persons and bodies no matter their origins or health to be neatly categorized and subsumed into American perceptions of normality. They are thus negatively contributing to Khakpour’s illness experience. Fisher reminds us that there are many instances “where the ill person is seen as not only responsible but morally blameworthy for their illness, the illness seen as their fault, even as deserved” (Käll & Zeiler 30-31). Even when such blame is not assigned, “there is still frequently an overriding moral negativity and anxiety about illness, a negativity and anxiety, once again, that can extend to the ill person herself, even if unwittingly” (31). The Othering of a person, who is queer in gender or of body or of mind, can truly fracture, cracking through the sense of one’s self. The informal caregivers of *Sick* are just as essential and informative to Khakpour’s illness experience as are her formal caregivers. In their intimacy,

her friends, boyfriends and lovers, and parents all “can at least tell you I existed. They might not have thought of me much, but they can tell you I was real. Sometimes too real” (Khakpour 239).

Regional (Un)Belonging: Caring for the Self

“I sometimes wonder if I would have been less sick if I had a home.” (Khakpour 168)

The above reflection from *Sick* captures Khakpour’s embodied and emotional longing for place. This analysis begins with her dream of escaping, and this thought articulates what she is escaping from and where she hopes to escape to: she yearns to leave physical and psychological troubles of the body behind and find some a kind of a home, a body that is more homelike. Thus this third analytical portion of my chapter regards the care that Khakpour affords herself. Her method of caring is via region, as she seems to think that a new location (whether New York or Northern California or Santa Fe, what she longingly names the “Land of Enchantment”), a new physical home, will help ease her body away from discomfort (Khakpour 145). She structures her novel around place, naming each chapter after the locale in which the chapter’s happenings *happen*. She begins the novel with the question, *what?*, but moves into the novel to ask, *where?* Where can she find her home, her sense of herself, and her health, or alternatively, the absence of Lyme relapses?

Gopinath writes of region in *Unruly Visions*, stating, “A turn to the regional is quite often a turn to the personal and the autobiographical. Evocations of the region often take the form of deeply affective, personal explorations of regional belonging or alienation” (6). Khakpour is navigating this very personal search and escape for a regional belonging, as she is alienated and othered in every place that she has sought home: “When the body feels out of place it will cling to anything that looks like life. Cities. Homes. Peoples. Lovers. Love is the only good way many of us know how to feel alive” (Khakpour 239). This is why she continues to “escape” from every place that she settles into, only keeping hope alive for New York and returning there repeatedly despite the harshness of the city, the lack of intimacy in its busy

streets. The city is not any kinder to her than the polluted cloud over L.A. or the arid desert of New Mexico, she is still rendered vulnerable even when hiding in the ever-buoyant city of the American Dream, the dream that her body precludes her from.

Her formal and informal caregivers do not privilege her voice or her body to be vulnerable, and that is what Alondra Nelson, Columbia University's Dean of Social Science, cites as problematic in one's attempts to achieve wellness:

What's especially challenging, Nelson says, is that human suffering, human vulnerability, is usually what we turn to when we want to find the universal thread that unites human beings. [...] When that very vulnerability, and that very sense of suffering, is put into question, it makes it very difficult, I think, for people to get well. (Hirsch 130)

Khakpour thus finds herself foreign and without belonging in every place (and in every person) that she escapes into: "There was never a home for me [...] Only recently do I wonder if that has to do with being considered 'foreign' [...] How could I recognize myself if no one else could?" (Khakpour 167). Her body and illness(es) are unrecognizable to informal caregivers and undefinable to her healthcare providers, thus she is distanced from her own sense of self and made further vulnerable through their perception of her and her illness(es). Her archive is not one that felt homelike, therefore she is exactly the queer diasporic body that Gopinath describes. For many such persons, "the region as 'the place where you're from' is an ambivalent site, where one's queerness is both formed and nurtured but also disciplined and repudiated" (Gopinath 12). Khakpour articulates feeling foreign and "queer" as a young girl, out of place in her body and in her home. Her original region, rooted in the archive of her family's flight from Tehran, othered her from the beginning, and continues to do so, as her embodied queerness is disciplined and contained by her parents and the city of L.A. itself.

All of this points to her failure to fully care for herself. She admits, "I am not a poster girl for wellness. I am a sick girl. I know sickness. I live with it, in some ways, I keep myself sick" (Khakpour 229).

Her history of inattentive caregivers has turned her body into “the ever threatening Other” even to herself, keeping her from self-care and the “space to suspect” her symptoms, rendering in her “a sort of dazzling indifference, a mute button almost creating a lovely white noise, its antipresence so very present like another hole in [her] life” (Käll & Zeiler 31; Khakpour 98). Her queer diaspora seeks escape from this antipresence, begging for a queered aesthetic that allows her body to be *present*, even in illness. Wilkerson’s “Wandering Through the Unhomelike” asks for this as well, that disability be permitted to be “central to the human condition, rather than a departure from it” (Käll & Zeiler 162).

While Khakpour has difficulty adequately caring for her body through region and through the hands of others, her writing is an act of care in itself. Her memoir places a mirror in front of the medicalized aesthetic, asking for a reframing of the aestheticized picture that figures sick and disabled persons. She writes a queer diaspora out of the hegemonic optic and into a new kind of “archival practice that excavate(s)” stories like hers from the fray (Gopinath 6). Though “language is a sticky thing, especially when we try to capture what’s happening in our bodies and in our culture,” Khakpour commands her language, not withholding any detail of her illness experience but fully exposing it, disorienting her audience with every thought and action, even if aberrant or shocking (Hirsch ix). Even if caregivers and onlookers can deny her body, they cannot deny the reality of her words. Her memoir provokes the questions, “Whose bodies count? Whose bodies do we systematically inconvenience or overlook?” thus demanding that her pain “count” (Hirsch ix). The difficulty of pain, and therefore also of any illness, disease, or disability, especially one that is so unequivocally Othered, lays in its unsharability. Pain is at risk of inexpressibility, its triumph what Elaine Scarry names “the absolute split between one’s sense of one’s own reality and the reality of other persons (4). Though Khakpour’s memoir is still subject to this unsharability of pain, it greatly diminishes that space between a pained person’s reality and the reality of those around her. Her narrative of body and its space and its symptoms functions as the bridge between pain and the imagination of the other, in this case, the caregiver. *Sick* is thus realizing and legitimizing the

experience of a chronically ill person, with all of her physical and psychological and social suffering, imparting just what it is to be “sick” in the eyes of healthcare providers and informal caregivers, and even to oneself.

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