LOOKING AT LESIONS: LEPROSY AS A CASE STUDY

KIMIA HEYDARI

A few years ago, I worked at a leprosy care facility associated with the Center for Research and Training in Skin Diseases and Leprosy at Tehran University. I spent my days shadowing the doctor who treated patients and learning about multidrug therapies, the cure for leprosy that the World Health Organization and pharmaceutical company Novartis distribute free of charge in countries like Iran (WHO). This 'cure-all' drug renders leprosy non-communicable and non-infectious, which means that it's no longer a widescale public health threat. However, our research at the center focused on treating permanent damage from the disease that had occurred before drug administration; namely, we looked at patients' leprous lesions and disfigured limbs.

The doctor who served as my mentor explained that the bacteria *Mycobacterium leprae* nibbles away at the soft tissue inside and outside a patient's body. Because of how *Mycobacterium leprae* disables a patient's nervous system, leprosy sufferers cannot always fully register pain. Patients often came to the clinic with irreparable burns and lesions caused by unintentionally leaving their hands on the stove. Since they felt no pain, their flesh could burn or deteriorate extensively before they noticed the damage.

In a low voice, the doctor reminded me, "What you will see will not be pleasant. You do not have to stay in the room." The nurse led an emaciated woman into the room. Wrapped in chador, the Islamic veil that some women wear in Iran, Zahra sat by the side of the bed.[1] From my seat beside my mentor, all I could see of the woman were her hands, with stubs instead of fingers. After applying pressure on Zahra's fingertips for circulation checks, my mentor explained to Zahra, "While there is minimal blood flow in your fingertips, there is no sensation in them. Be careful not to burn yourself again. Pick up these gloves at the pharmacy so you can wear them when you cook. Try not to leave your hands on heated surfaces like the stove."

Zahra's fingertips were not the main issue that my mentor had to address; it was the lesions on her forearms and legs that had brought her to the clinic. My mentor had to ask a few times for Zahra to loosen her grip from the heavy cloths and chador she held around herself. What hid beneath Zahra's chador was deeply disturbing to view. I scuffed my eyebrows together and averted my eyes toward the door, silently praying that Zahra would not recognize my reaction at the sight of her leprous lesion.

Psychology can easily explain why I turned away in repulsion from Zahra's lesion: psychologists argue that a lesion is indeed a site of pain, which is an intolerable sensation. Accordingly, in his research paper regarding the emotions that human beings experience when looking at lesions, psychologist Tom Kupfer argues that when observers see an injury they vicariously feel the injury (959). Vicarious pain is the sensation of pain that another person's lesion inflicts on the person viewing it. One might justify turning away in repulsion from a lesion as a result of a biological reaction of sharing the unbearable suffering of others.

However, I argue that turning away from the lesion is not as simple as a biological response of a knee-jerk. Besides, if Zahra felt no pain, a psychologist's model of vicarious pain—the sympathetic sharing of suffering—only scratches the surface in explaining the reason I turned away from her lesion. There is a much more complicated reason that Zahra's lesion was repulsive. Even though I stopped looking at it, I still felt deeply disturbed. I tried to reason that down the line, I would get used to what I saw. This was the beginning of my desensitization, a process that some in healthcare undergo to become used to the sight of lesions. Yet what belonged inside Zahra's body was leaking on the outside, transgressing the border that her crippled skin was supposed to cover up. Could it have been the borderlessness of the lesion that made me turn away? And how does this borderlessness feed societal measures in stigmatizing leprosy?

Theories regarding the concept of abjection further unveil reasons that I found Zahra's lesion repulsive. In her book *Powers of Horror*, philosopher Julia Kristeva defines the abject as "what disturbs identity, system, order. What does not respect borders, positions, rules" (4). My repulsion in turning away from the lesion relates to how my body, confined within my skin, became threatened at the sight of a leprous lesion, one that was not enclosed by the borders of Zahra's skin: her lesion was abject.

Intact skin allows for the creation of borders that tell where one body stops and another starts. These clear borders collapse when encountering the sight of a lesion. The leprous lesion threatens the meaning that society associates with skin, the border that separates individual bodies and identities from one another. In her article "Corporeal Cuts," gender studies professor Margrit Shildrick focuses on how our understanding of self changes with surgical and non-surgical incisions. However, with regards to lesions brought on by bacteria in dermatological diseases such as leprosy, she peripherally notes that "weeping, bleeding, leaky skin is a matter of some abhorrence" (33). What bleeds is fluid and can thus travel beyond the borders of one's skin. Shildrick's "leaky skin" reveals that what is supposed to stay contained inside one person's body can threaten another person's skin and body. And upon viewing Zahra's lesion, my view of my own body, bordered in by skin, collapsed.

Zahra, the human being with the lesion, faded into the background of my vision, as my most important task at hand was to avoid the sight of the leprous lesion that threatened the borders separating my body from hers. Zahra collaborated with my repulsion toward her lesion: she continuously pulled the heavy cloths of her chador over her body, trying to make herself and her lesion as small and invisible as possible. Sociologist Erving Goffman offers multiple definitions of stigma, including that of the ancient Greeks, as "bodily signs designed to expose something unusual and bad about the moral status" of stigmatized people (1). What Goffman refers to as a bodily sign—in this case the leprous lesion—is what Shildrick calls "a matter of some abhorrence" (33). Goffman makes the stark observation that "we believe the person with a stigma is not quite human" (5). In this line of thinking, I come to "believe" that a person with leprosy is "not quite human." But is it that I "believe?" Or am I under the influence of an impulse to cut off the abject?

Reacting in repulsion toward the abject lesion, while also reifying the border between self and other, transforms the affected human body into an object, something that is no longer a human being. This reaction of turning away perpetuates the belief that those suffering from the visible lesions of leprosy are not only not human, but that they are objects to be pushed and maintained outside the borders of society. The repulsion toward the leprous lesions intensifies the persisting stigma surrounding leprosy.

Fueled by repulsion toward the abject, this personal decision to turn away from leprous lesions and objectify those who carry them has lifetime consequences for people affected by leprosy. In his book *People Are Not the Same*, scholar Eric Silla uses first-hand accounts of leprosy sufferers in Mali to shed light onto the experiences of those living with the lesions, disfigurements, and other effects of the disease. Silla illustrates an exceptional facet of leprosy, noting that "Unlike fatal or short-term afflictions, leprosy last[s] a lifetime, steadily limiting one's ability to work and live with others" (73). In contrast to "fatal" and "short-term" diseases, leprosy leaves its sufferers as objects of abhorrence, psychologically scarred for the entirety of their lives.

Although my mentor and other individuals who undergo medical desensitization training may not show extreme reactions toward leprous lesions, my own decision to turn away was a choice that many in society will mirror when coming into contact with leprosy. With every action there is a reaction. Explaining the action of turning away from the lesion without discussing the reactions of the people who bear the leprous lesions is impossible. In covering their lesions, those who suffer from leprosy protect themselves from becoming objects that repel onlookers.

My mentor explained to me how unwilling the patients were to force themselves out of their homes, risk presence in public, and travel to the leprosy center. More often than not, when patients did seek out medical aid, their limbs were already so deformed that there was little the center could do but prescribe topical ointments. Beyond our patients' lost sense of pain, their reluctance to seek out treatment for their lesions resulted in care that could not meet their bodies' deteriorated state. Using first-hand accounts, Jacqueline J. Bonney discusses why leprosy patients can be extremely reluctant to seek medical aid. Bonney reveals that "[p]eople affected by leprosy find it difficult, for example, to get treatment for non-leprosy related disorders from private hospitals if they have visible signs that mark them out as having leprosy" (98). Even though their treated leprosy is no longer infectious, those with visible signs of leprosy—the lesions that Goffman calls stigma—often cannot be treated outside of leprosy colonies, plots of land removed from cities that house those suffering from leprosy.

Sometimes people remain in leprosy colonies at their own will, as evidenced by Bonney's example of a man who did not want to work outside of a colony because "[h]e dreaded someone commenting, dreaded the possible confrontation and the possibility that people might find out he had leprosy" (99). Some sufferers of leprous lesions decide to remain within these separate communities as a way to protect themselves from becoming objects of repulsion again. But remaining separated from society keeps many from seeking out aid for their lesions. Untreated, their lesions worsen, and they are constrained to a lifetime of disability in leprosy colonies.

On a regional and global scale, the World Health Organization has long prioritized the reintegration into society of those suffering from leprosy (Lockwood). Leprosy is no longer infectious and the lesions that the disease leaves on patients' bodies should not trap patients outside the borders of society. Those experiencing these second-hand effects of leprosy do not deserve to remain in substandard living situations: that is unjust. We must work toward a society that is welcoming to rather than repelled by those suffering from leprosy.

Besides moving hospital wards and care centers, reintegration depends on how individuals in society decide to approach the abjection that arises from the sight of the lesions. In coming into contact with the abject leprous lesion, the human inclination is to reify the borders between self and other that the lesion endangers as quickly as possible. Immediately averting the gaze from the leprous lesion is the fastest and most efficient way of doing so; however, this reaction wreaks havoc on the lives of those with leprosy. Philosopher Josh Dohmen furthers Kristeva's concept of abjection, stating:

> The abject, by dissolving imaginary boundaries, returns the subject to the level of imaginary identification, reveals the ambiguity of one's borders, the incompleteness and contingency of one's identifications, and can thus contest and even revise one's identifications. The danger, though, is that in response to the abject one instead reconsolidates one's imaginary boundaries, violently rejecting, and thus performatively recreating, that which is abject. (769-770)

Dohmen's view of boundaries and borders, such as those of the body, is that they are "imaginary," meaning that they are made through the thoughts and actions of human beings. Repeated human action and thoughts have shaped our boundaries out of ambiguity, conjuring repulsion for those identifications contingently deemed abject. Repulsion to the abject is not a predetermined reaction. Dohmen sees encounters with the abject as opportunities to "contest and even revise one's identifications" (769). The abject, though disturbing, is an opportunity to contemplate and redefine, rather than to immediately reinstate, the borders between oneself and the other. Redefining borders is a process that takes contemplation and time and is hindered by immediate responses of repulsion. Attempting to understand the abject allows for the possibilities of non-alienating responses toward the abject. The abject will continue to threaten human beings and their view of the borders that separate their bodies from others. Besides expanding their awareness about the abject, onlookers bear the responsibility to consciously revise their reaction toward the abject, in order to reevaluate and improve their reactions over time.

Day in and day out, I worked, wondered about lesions, and went on guilt trips about my reactions toward lesions belonging to the first set of patients. For a while, when I explained my reaction toward Zahra's lesion to family and friends, they did not discourage me from doing so. In fact, most did not think it was a big deal. I still wonder if my mentor—the doctor—felt no repulsion toward the lesions or if she was able to process her repulsion in an alternative way that I did not yet know about. After desensitization training, would I be able to do the same? And was my guilt telling me that I should have known better and not reacted the way I did?

I still struggle to answer these questions, but my guilt led me to investigate alternatives to turning away in repulsion from the sight of a lesion. In reflecting on my response to the patients' abject lesions, I was forced to recognize my contribution to the subconscious perpetuation of the stigma that surrounds leprosy. I was caught off guard as I read and reread the following verse: "I will gift another pair of earrings to the beautiful leper woman" [زن زیبای جذامی را، گوشواری دیگر خواهم بخشید] (Sepehri 215). This verse from twentieth-century Iranian poet Sohrab Sepehri's "A Message on the Road" [و پیامی در راه] challenges the definition of the borders of society, namely the position of the diseased and disfigured: here, the "leper woman" who is burdened by lesions. The word "leper" in Sepehri's poem still reminds readers about the leprous lesions that the woman bears. Furthermore, his conscious inclusion of "leper" is a unique move toward freeing this term from the historical stigma that accompanies it in many languages, including Farsi. Sepehri ascribes to Dohmen's ideal that abjection is based in imaginary boundaries and can be revised. He offers earrings, objects of beauty, to the woman, the human being whom he views as beautiful and worthy of beauty. More importantly, in Persian culture, earrings are metaphors for reminders. The Persian axiom "آویزه گوش کن" translates into "hinge a piece of advice to your ear." Sepehri first unhinges the history of constant repulsion and objectification that the woman has endured because of her lesions and then hinges a reminder about the woman's personhood. In contrast to the cloth that our patient Zahra continuously hid herself with, the earring, both literally and metaphorically, encourages the woman to uncover herself and be present in society despite the leprous lesions she suffers from.

While the lesion is abject and disturbs the borders between self and other, it belongs to a human being. In reifying the borders of our own identity through our repulsion toward abject lesions, we suppress the identity of those who bear lesions. Sepehri states that he will gift *another* pair of earrings. This repetition is an attempt that must be continued over and over again in order to transform skin into something other than the absolute border of one's body. Sepehri involves the reader in an activity of border crossing that reaches out to those suffering with leprosy. By understanding that Sepehri has made gifts of earrings before, readers are caught in his cycle of repeated border crossings, and they cannot immediately turn away from abject lesions in repulsion. In fact, this conscious repetition challenges and reconstructs borders in a manner akin to the desensitization training that some doctors and others involved in healthcare undergo.

Sepehri sets an example for Dohman's view of abjection, demonstrating that the abject is an opportunity to redefine borders rather than to reinstate them. By acknowledging societal abjection toward the lesions of those suffering from leprosy, Sepehri challenges and changes the borders of beauty in order to accommodate the reintegration of a woman who has been marginalized and objectified because of her disease back into society. Sepehri invites those uninvolved in medicine to realize the ways in which their repulsion toward leprous lesions subconsciously perpetuates the stigma surrounding leprosy.

Based on the knowledge of abjection that I currently have, I wonder how different Zahra's visit to the leprosy center would have been had I controlled my reaction to the sight of her lesions. The guilt I felt after turning away from her lesions—and from her as a human being—served as a guide that directed me to explore abjection and the underlying mechanisms that go into the moment of repulsion.

Understanding abjection is no 'cure-all' treatment for leprosy like the Dapsone that the World Health Organization distributes globally. However, awareness about and the embrace of abjection helps people realign their biases and adjust their reactions toward their surroundings. Looking at lesions with a knowledge of abjection helps us realize how thoroughly we have drawn, retraced, and highlighted the borders between bodies. Knowledge about the abject is crucial because it not only allows us to recognize our repulsions in vivid light, but also helps us realize that repulsion toward the abject is under our control and that we are the ones who define borders in the first place. We are responsible for our actions and are not helpless at the sight of abject entities. In de-stigmatizing diseases with visible markings on the body—leprous lesions in particular—we can start reconsidering the ways in which we respond to the abject and to other people.

NOTE

1. Patient's name is not disclosed; Zahra is a pseudonym.

WORKS CITED

Bonney, Jacqueline. "Responding to the Socio-Economic Implications of Leprosy." *Leprosy Review* vol. 82, no. 2, 2011, pp. 98-102.

Dohmen, Josh. “Disability as Abject: Kristeva, Disability, and Resistance.” *Hypatia*, vol. 31, no. 4, 2016, pp. 762-778, doi:10.1111/hypa.12266.

Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. Penguin Books, 1974.

Kristeva, Julia. *Powers of Horror: An Essay on Abjection*. Trans. Leon S. Roudiez. Columbia University Press, 1982.

Kupfer, Tom R. “Why Are Injuries Disgusting? Comparing Pathogen Avoidance and Empathy Accounts.” *Emotion*, vol. 18, no. 7, 2018, pp. 959-970, doi:10.1037/emo0000395.

Lockwood, Diana N J. “Leprosy Elimination—a Virtual Phenomenon or a Reality?” *BMJ*, vol. 324, no. 7352, 2002, pp. 1516-1518, doi:10.1136/bmj.324.7352.1516.

Sepehri, Sohrab. “A Message on the Road” [و پیامی در راه]. *Eight Books* [هشت کتاب]. Trans. Kimia Heydari. Gofteman Andeeshe Moaser Press, 2010.

Shildrick, Margrit. “Corporeal Cuts: Surgery and the Psycho-Social.” *Body & Society*, vol. 14, no. 1, 2008, pp. 31-46, doi:10.1177/1357034x07087529.

Silla, Eric. *People Are Not the Same: Leprosy and Identity in Twentieth-Century Mali*. Heinemann, 1998.

“WHO and Novartis Extend Agreement to Treat Millions of Leprosy Patients with Free Medicines.” *World Health Organization*, 15 Sept. 2016, www.who.int/neglected_diseases/news/WHO_Novartis_agreement_to_treat_leprosy_patients/en/. Accessed 21 Nov. 2018.

KIMIA HEYDARI '22CC is a John Jay Scholar and studies English and Biology. She grew up in Tehran and Toronto, and likes to leave a paper trail of Persian poetry as she moves from one place to another. She is a peer fellow at the Writing Center at Columbia, teaches alongside Peer Health Exchange in Harlem, and leads tours at the Hirshhorn Museum of Modern art in DC.