

On Being Woman, Other and Disabled: Navigating Identity

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Abstract

This article addresses disability in a Middle Eastern context. It interrogates disability and identity from a Bedouin perspective. The author relays her experiences with a physical disability and society's stigmatization of different bodies. More often than not, this usually creates psychological traumas and a complex terrain of emotional tensions when dealing with society's oppression of individuals with disability. The author engages with a discursive discussion of the struggles of navigating spaces of shame, the traumas of stigma, and ultimately healing in finding a voice that is separate from the collective.

Keywords: *personal narrative, disability, shame, identity, Bedouin, women, autoethnography*

Narrating Identity

This essay is part of a long coming-out process. As a woman with a disability, I have struggled with hiding my illness and remaining silent about it. Because I am a woman who comes from a Bedouin tribe, there are specific notions and stigma concerning disability that arise when I choose to claim my disability. There has been little scholarly attention focusing on Eastern perceptions and understandings of disability. There is hardly any work discussing specific and qualitative and/or ethnographic experiences of Arab women with disability. This essay attempts to be corrective of this lack of attention to perceptions of disability outside of the West. I shed light on an altogether different understanding of disability and what it means to be a disabled 'Eastern' woman, using my own experience as a starting point as well as a feminist disability studies theoretical framework.

Growing up, I was always reminded that I was a woman, that I was not a man, my rights were not equal to a man's, my experience of life would be restricted and limited, and that I would not have access to the public sphere. I was also a hybrid, born to a Bedouin father and a Palestinian mother. A hybrid identity immediately cast me as 'other'; as a mixed-breed woman, neither fully Bedouin, nor fully Palestinian. My identity as a hybrid was unusual for my Bedouin father's culture, because marrying from outside the tribe was highly frowned upon. At the age of seven, my father sat me down, and explained that I was now a 'woman'. And not just any woman, for that matter, because my identity was tied to the tribe's; I did not represent myself, I was not an individual, but rather, I was a symbol, a representative of the tribe itself. As a child, my sense of identity was largely eradicated. About a decade later, I was diagnosed with Multiple Sclerosis (MS), an illness that called into question every definition of 'self' that I had acquired over the years. I was now a woman, and a hybrid, with a disability.

It goes without saying that in a heteronormative, ableist global culture, the experience of illness and disability is already marginalizing. In smaller communities, and specifically tribal communities, ideologies of exclusion are even more intense and bodies are regulated in different ways. I do not claim to speak for a general Middle Eastern perspective, nor do I wish to homogenize or overlook all the different cultures within the Middle East. My experience as a woman living with MS has been affected by the public sphere and I have been negotiating different labels for my identity. For what does it mean to be woman, and does it by definition mean a heterosexual non-disabled woman, and what does it mean to be defined as ‘other’ and what of the elusive category of the ‘disabled’? Must my experience of disability necessarily constitute a visible disability? These three disparate and marginalized identities (of being a woman, a hybrid, and disabled) have shaped my sense of self, a self that is always in a state of transformation and ambiguity.

Negotiating Disability Definitions

First, I would like to consider the usage of the term ‘disability’. In his groundbreaking study *Enforcing Normalcy*, Lennard J. Davis explains that this term includes those ‘who are regarded as having a limitation or interference with daily life activities such as hearing, speaking, seeing, walking, moving, thinking, breathing, and learning. Under this definition, one now has to include people with invisible impairments such as arthritis, diabetes, epilepsy ... multiple sclerosis, heart and respiratory problems, cancer...and so on.’¹ Davis reminds us that we need to think of disability ‘as a descriptive term and not as an absolute category’.² I use the term in the same way that Davis urges us to use it – it becomes an inclusive category, one that is not fixated on the extent of disability, but rather, the presence of it.

In the same vein, Rosemarie Garland-Thomson situates disability as a social construction and examines the disabled body’s position in the world. She asserts that ‘[d]isability, perhaps more than other differences, demands a reckoning with the messiness of bodily variety...Disability is defined not as a set of observable, predictable traits – like racialized or gendered features – but rather as any departure from an unstated physical and functional form, disability highlights individual differences.’³ As such, disability cannot be restricted to medical definitions. Impairment usually means the condition itself, while disability may constitute the lack of functionality caused by the impairment itself. the Susan Wendell’s highly acclaimed work *The Rejected Body* puts forward a few ‘good’ definitions of impairment and disability, recognizing that speaking of disability and disabled individuals is a complex issue and demands recognition of people’s lived realities as well as a language that is adequate and accommodates different experiences of disability. Wendell summarizes a few characteristics of possible definitions:

Good definitions of impairment and disability should recognize that normal (i.e., unimpaired) physical structure and function, as well as normal (i.e., not-disabled) ability to perform activities, depend on some extent on the physical, social, and cultural

¹ Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (New York: Verso, 1995), 8.

² Davis, 8.

³ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 24.

environment in which a person is living, and are influenced by such factors as what activities are necessary to survival in an environment and what abilities a culture considers more essential to a participant.⁴

Given the pervasiveness of society and the environment's effects on the lives of people living with disabilities, it becomes necessary to situate different cultural and social understandings of disability. Race and gender cannot be ignored when articulating disability experiences. Recent scholarship addresses identity politics and is concerned with situating lived experiences of disability. What is it like for women with disabilities living in different societies with particular understandings (and stigma) of disability? *Disability in Local and Global Worlds* maps these very specific experiences of disability in different parts of the world, bearing in mind what makes these experiences similar and different. The editors of this collection state that they 'are interested in people's own experiences of what is disabling in their world rather than some universal definition.'⁵ Disability studies requires a cross-cultural theoretical understanding, shifting between ethnographies, anthropology, autobiographies, and a dialogue between activists, individuals with disabilities, and scholars.

Feminist disability studies calls for the intersection of gender and disability, and recent scholarship is urging for race to be included in the discussion. Intersectionality becomes the only possibility in engaging with gender and disability. Nirmala Erevelles defines a transnational feminist disability studies perspective as a:

perspective that engages gender and disability and their intersection with race, class, and sexuality within the material context of the post/neocolonial state...this perspective maps both the continuities and discontinuities across different historical periods that have both separated and connected women along the axes of race, class, disability, sexuality, ethnicity, and nationality, by foregrounding not just discursive representations but also the material (read actual) conditions of their lives.⁶

Similarly, I argue that transnational feminist disability studies is the only way disability studies can become inclusive. Disability definitions and stigma vary from culture to culture and are either challenged or reproduced by scholarly research. This paper, then, is only a glimpse into a Bedouin-Middle Eastern perspective, grounded in my own experiences, and by no means do I claim to speak for all Bedouin and/or Middle Eastern women. In a sense, this paper is inspired by critical autoethnography as a method of qualitative and self-inquiry. Critical autoethnography is about reflecting on one's lived experience by examining the effects of culture and institutions that govern us. Critical autoethnography is not a simple telling of one's own story but rather engages with multiple discourses of thought and looks at the lived experience through different lenses. According to Linn and Pruyn:

⁴ Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996), 22.

⁵ Benedicte Ingstad and Susan Reynolds White, 'Introduction: Disability Connections', in *Disability in Local and Global Worlds*, eds Benedicte Ingstad and Susan Reynolds White (Berkeley: University of California Press, 2007), 11.

⁶ Nirmala Erevelles, *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic* (New York: Palgrave Macmillan, 2011), 141.

Critical autoethnographers view their work as a means of pointing out the *politics* of their positioning, explicitly acknowledging the inevitable privileges and marginalizations they experience...They do so by creating accounts of intersectionality, a term coined by legal, feminist, and critical race theory scholar Kimberlé Crenshaw. Intersectionality calls to attention to how oppressive institutions, attitudes, and actions in cultures including racism, xenophobia, sexism, heteronormativity, classism, religious and spiritual fundamentalism, ageism, and ableism do not function independently but instead are connected and mutually influencing (5).⁷

As the above definition illustrates, I have recognized the significance of telling the story from a specific standpoint, through the body, from the body, and exploring race, culture, and social structures that come into play when negotiating what it means to live with disability. I stand as both the observer and the traumatized, the silent body and the researcher, and the authoritative voice on my experiences attempting to derive meaning and formulate an identity I can claim.

Disability Narratives and Belonging

For the purpose of this essay, I want to discuss Nancy Mair's work and its role in guiding me through Disability Studies, disability, and writing. Nancy Mairs writes of her experience with MS in *Carnal Acts*. When I first read Mairs's work, I found myself trying to make sense of the feelings of shame which were suddenly replaced by – dare I say it – pride. I was proud to be connected in some way to Nancy Mairs, the writer, this woman who was reclaiming her womanhood, her disability, her 'voice' as she so elegantly puts it. Mairs's work spoke to me on many levels. She was able to describe the experience of having MS in a way that no medical terminology had managed to do, and no neurologist had taken the time to explain to me. Mairs's description of the mechanisms of MS is as follows:

The hypothesis is that the disease process, in which the protective covering of the nerves in the brain and spinal cord is eaten away and replaced by scar tissue...is caused by an autoimmune reaction to a slow-acting virus...In effect, living with this mysterious mechanism feels like having your present self, and the past selves it embodies, haunted by a capricious and meanspirited ghost, unseen except for its footprints, which trips you even when you're watching where you're going...and weights your whole body with a weariness no amount of rest can relieve. An alien invader must be at work. But of course it's not. It's your own body. That is, it's you.⁸

MS, then, almost seems non-existent, a ghost that attacks your body, its exact origins science and medicine are still unable to identify. All we know is that it is degenerative, and the body attacks itself. Because it is my body which has somehow decided to plot against my corporeal self, my ethereal self and my self-image is shaken. This 'self' of mine is called into question. MS itself originates in the central nervous system, the brain, the greatest powerhouse, yet it manifests itself mainly as bodily symptoms. The brain, then, destroys the body, or is it the body that is destroying the brain?

I find MS an almost always ambiguous state of being, ambivalent, unclear; a

⁷ Linn, Holman Jones Stacy and Marc Pruyn, *Creative Selves / Creative Cultures: Critical Autoethnography, Performance, and Pedagogy* (London: Palgrave Macmillan, 2018), 5.

⁸ Nancy Mairs, *Carnal Acts: Essays* (Boston: Beacon Press, 1996), 83-4.

hybridized disease, if you will. MS is, sometimes, a disability that manifests itself during numerous times of one's life, and may or may not disappear momentarily. You may lose function of your hearing, eyesight, and may identify as 'deaf' or 'blind' for the time being, until you regain functionality. Not everyone who loses one of their senses will identify as disabled. Not everyone with invisible symptoms will identify as disabled, and, to complicate this further, one may identify as disabled because of invisible symptoms which others do not perceive as a disability. With MS, a disease that presents multiple symptoms, it is nearly impossible to always claim a 'disabled' identity on the MS continuum. For instance, when I attended an MS support group, I found that I was not only the youngest woman at the meeting, but I was also part of the minority that was still able to walk. Everyone's disability status/impairment differed; and, of course, this is not to discredit any of these disability experiences. Disability experiences are always diverse and there is a whole spectrum of ability/disability. I was not in a wheelchair, and I did not use a cane, yet I could not feel my legs at all because they were numb. But that was an invisible ailment, and I felt both guilty and selfish, for I had felt as though my own pain had to be measured next to theirs. I did not feel like I belonged and that I had no place amongst those who were really suffering, those who were truly in pain. What did I know of their pain? How would I connect with them, how would I belong with them? I felt varying degrees of shame, of not belonging, and this was further intensified with the way my family (and to a larger extent society) dealt with illness. The reason I had sought out an MS support group was namely that I was in great need of a place to belong to; I felt the incessant need to belong to a community. What hurt me the most was when other MS patients told me I was too young (ageism of course) and thus I would not suffer as much; that I should feel blessed. As I tried to find myself amidst the community, I realized that illness and disability were negotiated in different ways.

Illness and/or disability (or any affliction) may be understood in various religious and superstitious ways. Superstitious beliefs insist that illness is caused by black magic, demonic possession of the 'weak' self, or by the 'evil eye'. Superstitious ideologies such as these work to exclude the weak (and yet also deviant body) from the social order and the tribe. Illness and disability may also be recognized as a form of punishment of the individual. In Islamic theology, disability has been interpreted in various ways. Mohammed Ghaly's *Islam and Disability: Perspectives in Theory and Jurisprudence* examines the intersections of disability and Islam, and of a concept of a loving and merciful Allah. Ghaly's study is one of the extremely rare examinations of the concept of disability in the Muslim and Arab world. Ghaly emphasizes that 'disabilities *may be* but need *not necessarily be* the result of committing sins ... Disabilities or misfortunes as punishment befall those who...make no effort to return to the straight path, declare no repentance to God and continue their disobedience.'⁹ As such, upon recognizing that illness must have a reason, the family or those closest to the individual urge him or her to find Allah, to go back to a 'straight path' and avoid whatever sin committed in the past.

As an eighteen-year-old struggling with MS, I could not fathom the reason for my sudden illness. What sinful act could my body have committed? I had lost function

⁹ Mohammad Ghaly, *Islam and Disability: Perspectives in Theory and Jurisprudence* (London and New York: Routledge, 2010), 44.

of both my hands and legs, upon waking up one morning, a morning after I had graduated from high school. Some family members proclaimed I had been affected by the dreaded 'evil eye' (since not every Bedouin girl graduates high school, and my privileged position was one that supposedly sparked envy). Another understanding, perhaps with less negative connotations, is the one that my mother chose to embrace. It is one of purification and it dictates that illness/disability is a way for the self to become whole, to be purified, cleansed; in other words, the ill/disabled body is marked as a chosen one. Ghaly refers to this as an 'elevated rank', one that brings the sufferer closer to heaven: 'Disability as a form of affliction and concomitant suffering were seen as possible means of attaining a lofty rank in a Paradise that would have been unattainable by good deeds only.'¹⁰ The disabled or ill person becomes the chosen someone, someone who is unaware of the blissfulness of this affliction.

Suffering is seen as necessary for reaching the best rank in Paradise, thus emphasis is placed on the afterlife. This view is supposed to be consoling and refreshing, and is adopted by most individuals. The more thankful one is for the disability/illness, the better the reward. Once you inquire as to why this has happened to you out of all people, then you are questioning your chosen status, and pushing the reward further away. My mother urged me not to ask Allah why this had happened to me, and just fully accept the condition. I spent a decade living with MS and fighting every day, on both a physical and an emotional level. My identity was constantly negotiated. I was unable to find a solid reason or a justification for my illness. Mostly, I felt overwhelmed.

Bloodlines and Bodies

As a Bedouin woman, my individual identity was closely tied to the collective and the idea of 'asl' or bloodline and purity. In *Veiled Sentiments*, Lila Abu-Lughod examines the concept of bloodline in Egyptian Bedouin societies. Abu-Lughod's work is crucial for explaining critical concepts of Bedouin ideologies. I adopt Abu-Lughod's theoretical framework to consider the same concept of purity in Bedouin Middle Eastern society and culture. Abu-Lughod defines 'asl' as 'nobility of origin or ancestry.'¹¹ Although I was a hybrid, and my mother was not Bedouin, my identity was largely my father's. As Abu-Lughod explains: 'Children take their father's tribal affiliation, although their mother's affiliation affects their status.'¹² My status as a hybrid remains affected, I am othered, but at the same time, I carry a Bedouin, collective identity. Negotiating such conflicting ideologies had always been difficult, but even more so when MS decided to add itself to the mix.

Illness in a Bedouin context is primarily regarded as a subject to be avoided, and disabled subjects, especially women, are to be silenced. Abu-Lughod reminds us of the Bedouin code of honor: 'The final element in the Bedouin network of honor-linked values is self-mastery, one aspect of which is physical stoicism. Bedouins think physical pain and discomfort should be borne without complaint.'¹³ Mastery over the mind and body is crucial in establishing a good, moral self, a self that is fit to belong within the

¹⁰ Ghaly, 46.

¹¹ Lila Abu-Lughod, *Veiled Sentiments: Honor and Poetry in a Bedouin Society* (Berkeley: University of California Press, 1999), 41.

¹² Abu-Lughod, 53.

¹³ Abu-Lughod, 90.

pure and noble tribe. The identity of the disabled person, or the disabled woman, is called into question. To come out with the illness, to speak out, to claim the illness, is to taint the purity of the tribe's collective identity. This brings shame to the family, and by extension, the tribe. This idea of shame in illness stems from a concept of ideal femininity, ideal purity (*asl*), and the lack of mastery over the body. Women occupy lower positions on the social hierarchy, and people with illnesses or disabilities are even more excluded and marginalized.

I had to learn to absorb all these different public understandings of my MS and find my own personal reasoning to this new identity that had become me. Rosemarie Garland-Thomson reminds us that '[t]he ways that bodies interact with the socially engineered environment and conform to social expectations determine the varying degrees of disability or able-bodiedness.'¹⁴ I began to understand that my MS not only threatened and confused society, but it also marked me as a deviant and disabled body, as inferior on social hierarchies. My presence itself was unsettling, and my illness had become an issue to keep quiet about. If I had failed to perform my identity as a perfectly healthy, able-bodied, pure-blood woman, then I had also shamed the family and the tribe.

Perhaps my experience in a Middle Eastern, Bedouin culture caused a greater level of stigmatization when linked to ideologies of purity and *asl*. As such, my MS was to be hidden, concealed from the public sphere. People were never to know, and if I was going through a physical exacerbation, I was to avoid being seen in public. In *The Wounded Storyteller*, Arthur Frank reminds us of the double-burden that the person with the illness or disability must carry:

When adult bodies lose control, they are expected to attempt to regain it if possible, and if not then at least to conceal the loss... Thus the work of the stigmatized person is not only to avoid embarrassing himself by being out of control in situations where control is expected. The person must also avoid embarrassing others, who should be protected from the specter of lost body control.¹⁵

Frank writes from a Western perspective, but I find that this experience of stigma is universal; that the person suffering from illness or disability feels the same burden in different cultures (regardless of the intensity of the burden and/or shame). I was to maintain, as much as possible, a decent, 'normal' healthy image of a woman who was part of a certain family, and a family that was part of a 'noble' tribe. Not only was the experience of disability and illness difficult, but it was also complicated with cultural notions of normalcy.

Disability and Identity

Claiming the identity of a disabled woman has its consequences. Common beliefs about a disabled woman included various manifestations of lack: a disabled woman cannot hold a job, no man could possibly want to marry her, she cannot have children, and if

¹⁴ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 7.

¹⁵ Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago and London: University of Chicago Press, 1997), 31.

she does, then she would somehow pass the disability onto them. Disability for a young woman can be emotionally crippling. The social stigma and being denied basic needs leave one outcast from the community and the family. The idea that you have failed to satisfy society's expectations and the family's marks you as incomplete, lacking, and as undesirable. The disabled female identity intersects with other social expectations of womanhood, namely reproduction and the ability to be a fully functional wife and a mother. The disabled woman fails to meet the definition of a 'good woman', one that is socially productive; in other words, fertile and possibly capable of breeding decent individuals. Associating with a disabled woman produces fear of contamination. It is a blurring of boundaries between abled/disabled, healthy/unhealthy. Disability is thus seen as polluting agent that is to be avoided. At a certain point in my life, I met someone who wished to marry me, until he informed his family that I was affected by MS. Needless to say, the reaction was an utter refusal of their son marrying into a family that had bred this disabled woman. Illness and disability marked me as unacceptable and not fit to be a wife or a mother.

The fear associated with illness revolves around not knowing what the condition entails, and whether contagion is possible. Because MS is a disease of the CNS, most people assume it is hereditary and that it is also a mental illness. I was perceived as not only disabled, but also dangerous, a threat to future generations and a body that would require constant care. As for the man who wanted to marry me – he felt that he did not mind sacrificing his youth for me. This so-called 'sacrifice', this concept of martyring one's self in the pursuit of a disabled woman, simply did not appeal to me. I was nowhere near severely disabled, if anything, I suffered from slight 'impairment' and yet I had been denied the right to start a family with this specific person. I realized that regardless of the extent of disability, prejudice and discrimination against women with disabilities and/or illnesses constituted a whole new type of social disability. This cultural treatment of disabled women did not only affect me personally, but I quickly learned that there were many others who were subjected to the same social stigma.

Although Rosemarie Garland-Thomson speaks of western societies, she is right in maintaining that the disabled women 'must sometimes defend against the assessment of their bodies as unfit for motherhood...disabled women are often denied or discouraged from the reproductive role.'¹⁶ Women are socially required to be capable of fulfilling many roles: maternal and familial duties, to be able to earn sufficient income to help support the family, and also to give birth to healthy children. In tribal communities such as my own, once one of the tasks is incomplete, then the woman's value decreases. I spoke to several women who were married before MS decided to take control of their bodies. After being diagnosed with MS, they found no support from their husbands. A few were abandoned and divorced, while others had to suffer from a different kind of fate: having her husband re-marry. Since Islam allows polygamy, some men found that it was their right to re-marry and find a suitable and healthy woman instead. This did not mean complete discarding of the first wife, however, she was to share her husband with another woman, and give up her position and status within the family home. The new, healthy, able-bodied wife occupied a higher rank, while the disabled woman became even more marginalized and excluded. I was devastated when I spoke to these women, who soon became my friends. They had succumbed to their fate,

¹⁶ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 24.

accepted their multiple losses, and found that the husband reserved the right to re-marry, given that she had failed to satisfy him. Their sense of identity as women, as sexual beings, as complete and autonomous individuals, had been replaced with shame, feelings of failure, and acceptance of loss.

This acceptance of loss does not come from successfully embracing a new identity and a new body, but rather, from accepting the blame for this dysfunctional body. These women feel at fault. Society's discrimination and uprooting of ableism is internalized within the self. As a disabled woman, she is denied social status, rendered invisible, and deemed sexually undesirable. Robert McRuer argues in *Crip Theory* that compulsory heterosexuality is synonymous to what he terms 'compulsory able-bodiedness'.¹⁷ In a society that considers heterosexuality the only acceptable sexuality, it comes as no surprise that the discourse of ableism is as dominant and oppressive. There is no other alternative to living.

Although I understood that my gender and disability did not constitute my entire identity, I was still aware of the repercussions of claiming my body and illness. My identity was inextricably linked to my family and my tribe. Coming out with an illness is a process that is not purely personal, but affects the family and the tribe. The tribe itself extends across national borders. Kinship is based on sharing the same blood, the same roots, and as such, a bond that transcends nationalities and gender. For instance, a Kuwaiti tribe will share the same *asl* with a Saudi tribe, and by theory of kinship, they form a very strong, familial bond. As such, every action affects the entire tribe. One individual's reputation and honor affects the collective, and vice versa. There have been numerous occasions where I have tried to 'come out' with my MS, and instead, faced reprimanding from my family. My action of claiming my identity as an MS patient, my speaking about it, was considered selfish, because I was not supposed to shame the family. The burden was mine to carry silently and deal with as invisibly as possible.

The disabled or ill body is the rejected body, the one made to feel ashamed, the body that is almost forced to conjure the negative feelings of both shame and guilt. Sara Ahmed, in *The Cultural Politics of Emotion* defines shame as the 'intense and painful sensation that is bound up with how the self feels about itself, a self-feeling that is felt by and on the body.'¹⁸ She argues that if one feels shame, then the 'desire to cover and to be covered presupposes the failure of cover; in shame, one desires cover precisely because one has already been exposed to others.'¹⁹ Shame, then, is inextricably linked to the experience of exposure, and rejection. Ahmed also aptly tells us that 'family love may be conditional upon how one lives one's life in relation to social ideals...Shame secures the form of the family by assigning to those who have failed its form the origin of bad feeling ('You have brought shame on the family').'²⁰ Shame was an emotion I wished to rid myself of, but at a very high cost. If I had brought shame on the family, what had I brought onto myself?

¹⁷ Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York and London: New York University Press, 2006), 2.

¹⁸ Sara Ahmed, *The Cultural Politics of Emotion* (New York: Routledge, 2004), 103.

¹⁹ Ahmed, 104.

²⁰ Ahmed, 107.

Moving Forward and Healing

Questions began formulating and my perception of my identity started to develop over time. Part of my academic career is my vexed interest in disability studies and I have struggled to find illness narratives from the Middle East, or narratives that I can relate to. As a way out of the traumas of living in a society that diminishes my agency as a woman living with a disability, I ended up writing my own illness narrative. It was a crucial part of my personal healing and to allow others in the same boat of marginalization to connect with this lived experience of disability in the Arab world, specifically Kuwait. Another reason I wrote the book was my scholarly and academic calling to address this gap in literature, a collection of short stories entitled *Notes on the Flesh*.²¹ *Notes on the Flesh* deals with love, disability, and identity in the Middle East. The protagonist of the book, Sara, is a recreation of my previous self, freshly diagnosed, and still learning the languages of disability and ableism. Sara serves as a stand-in for my experiences, however, she also represents the voices of marginalized identities. Other characters in the book must contend with their illness and their failed love lives. Love presents itself as a theme throughout the text. In the face of disability, what happens to love? How does one navigate a new relationship while also maintaining a sense of autonomy? How does society (in this case, Kuwaiti society) deal with different bodies and women with disabilities? Each hero and heroine of the various stories struggles with an ableist society that demands better bodies, better lives, and coherent identities. My characters are based loosely on people I have met during my quest to find a support group for disability. These voices are the unheard ones and I needed to articulate them. Because there is a lack in Arabic literature dealing with disabled female protagonists, I decided to correct this gap in the literature by writing from my body and other diverse bodies with different disabilities and overlapping identities: gender, social status, educational level, mothers, daughters, and significant others.

Illness and disability remain taboo subjects, in the same way that sexuality and the body is still a dangerous territory to discuss in Arabic cultures. The body is always shamed, whether it is 'healthy' or 'unhealthy'. It is regarded as an immodest part of our selves, a part that should be covered, hidden, and avoided. The body in Arabic and Islamic cultures is one that should remain covered, both literally and symbolically. Any form of exposure is shameful and it is the mind that needs to be elevated and addressed. But a form of exorcism is in order. I choose to write about my disability, my body that has 'failed' to live up to society's expectations. I choose to rid myself of shame, and I hope that, one day, my narrative will change the reception of women affected by illness in marginalized communities.

It goes without saying that I do not claim to speak for or represent all women with disabilities in the Middle East. This is, again, a personal narrative, an autoethnographical account, a story that has been informed by my interest in feminist disability studies. At this point in my life, I am starting to build a new sense of self, and see myself as an individual, claiming autonomy that is not altogether based on the collective; and finding new ways of expressing a sense of belonging. This embodied agency is a fundamental part of my academic career and pursuit of a change in global and feminist disability studies. By writing about the traumas of the stigmatized disabled body, I am able to find a voice amidst the shame and exclusion. I am writing myself and

²¹ Shahd Alshammari, *Notes on the Flesh* (Malta: Faraxa Publishing, 2017).

my body into the larger narrative and finding a sense of liberation from the oppressive social structures of society.

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Despre a fi femeie, alteritate și dizabilitate. Navigarea identității

Rezumat

Acest articol abordează problematica dizabilității în contextul Orientului Mijlociu, punând întrebări despre dizabilitate și identitate dintr-o perspectivă beduină. Autoarea relatează experiențele personale legate de dizabilitatea fizică și de stigmatizarea de către societate a corporalității diferite. În cele mai multe cazuri, aceasta cauzează traume psihologice și creează un teren complex pentru tensiuni emoționale în cazul în care individul are de-a face cu opresiunea societății asupra persoanelor cu dizabilități. Autoarea se angajează într-o analiză discursivă a luptei de a învinge spațiile rușinii, traumele stigmatizării și, în final, de a ajunge la vindecare și la găsirea unei voci care să fie separată de cea colectivă.