Negotiating Desire with Disability in *Skin Stories*

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Abstract

The last few decades have seen a proliferation in disability life narratives that situate disability as a complex social, cultural, political and embodied position. A study of the intersectionality between disability, gender and sexuality alongside caste and class stratums enables an in-depth understanding of the sociocultural, historical, and political context of disability experiences. This paper engages with the personal narratives of persons with disabilities put together in an edited book of essays, *Skin Stories: Essays on Sexuality, Disability and Gender* (2019), wherein the disabled individual is no longer a vulnerable passive object, rather an active desiring sexual subject. The paper proposes to read the writing of these stories as an act of resistance against misconceptions about disability and also examines how these narrative help bring forth a counter narrative on ableism.

Keywords: Disability, life narratives, sexuality, intersectionality, desire

Disability in India is met with a deep rooted social, cultural and political hostility. Disabled persons are seen as medical anomalies, helpless victims and a lifelong burden for the family and society. While personal tragedy and charity models of disability evoke feelings of pity and fear, the medical model of disability pathologizes the body and aims at finding a cure for the 'defect'. The social model of disability, however, takes the focus away from an individual's impairment as a biological condition and reads disability as a social construct—result of legal and social oppression. Disability rights activism till recent few decades had been primarily concerned with addressing disability

discrimination rather than in explaining the actual living conditions of people with disabilities—like periodic or chronic pain, or experiences of distress and rejection in emotional and sexual relationships. Society and media endorse the sexually ableist agenda and fail to acknowledge that persons with disabilities have similar physical, emotional and sex desires. Disabled bodies are considered as asexual—neither sexually desiring nor desirable.

The last few decades have seen a proliferation in disability life narratives that contest the understanding of disability as vulnerability and situate disability as a complex social, cultural, political and embodied position. This article engages with the personal narratives of persons with disabilities put together in an edited book of essays, *Skin Stories: Essays on Sexuality, Disability and Gender* (Anasuya, 2019), wherein the disabled individual is no longer a vulnerable passive object, rather an active desiring sexual subject claiming agency for themself to voice concerns against the denial of social, economic, political, cultural and interpersonal rights. Nidhi Goyal (2018), a feminist disability activist from India, while on one hand welcomes deliberations on sexual rights of girls and women with disabilities as 'a ground-breaking step forward', she also expresses her concern on the invisiblisation of disabled women with regard to their sexual rights and related issues. Goyal questions:

> So where were the women with disabilities? How were their existential realities more compounded because of their multiple identities? Why were they invisible in the disability rights movement? How deep was the ungendering of persons with disabilities rampant in the country? (p. 169)

Personal reminiscences in *Skin Stories* address this gap and focus on the corporality and psychological underpinnings of (un)gendered lives of persons with disabilities with an aim to take forward disability advocacy in India. *Skin Stories* should be read as a quest to understand the struggles and challenges experienced by disabled persons (and women in particular). *Skin Stories* affirms disability as a diverse and complex phenomenon, and contests its classification in absolute categories. This paper traces the trauma and antipathy persons with disabilities experience due to reduction of their identity to that of desexualised entity. The paper reads the writing of their personal stories as an act of resilience against misconceptions about disability on one hand and

 ISSN: Print 2229-6557, Online 2394-9244

desire for love, dating, sex and relationships on the other. Reclamation of one's personal story is also therapeutic as it enables disabled persons to deconstruct the dominant understandings of disability and bring forth a counter discourse on ableism.

Fiona Kumari Campbell (2018) argues that disability studies needs to shift its focus from practices and production of disablism to a more nuanced exploration of epistemologies and ontologies of ableism. An emphasis on disablism reinscribes an able-bodied lens towards disability that categorizes disability as an 'other' and leads to internalization of ableism. Ableist normativity fails to acknowledge diversity in human being-ness and works simply on the binaries of inclusion and exclusion. Such ableist trajectories render 'corporeal otherness' as "the 'disabled', 'perverted' or 'abnormal body', instead of the more neutral designation 'variable' bodies" (Campbell, p. 40). Bodies, and thereby identities are thus classified into absolute categories to reiterate an ethos of compulsory abled-bodiedness. Unmana Datta refutes the philosophy of compulsory abled-bodiedness to emphasize the tenet of 'temporarily able-bodiedness' and asserts, "...bodies cannot be conveniently categorised into abled and disabled. That abilities can ebb and flow, morph and disappear and reappear... even the healthiest body may not always remain so" (2019, p. 48).

Disability is often regarded as a uniform and homogeneous group. Popular depictions fail to acknowledge the diversity within the disabled community. *Skin Stories* successfully transcends the cliches on disability representation and brings forth personal accounts from a wide spectrum of permanent/temporary disabilities, ranging from visual disability to hearing and speech impairments, locomotor disabilities to mental illnesses like PTSD, OCD, Hypochondria, Clinical Depression, Anxiety Disorder, Borderline Personality Disorder and Trichotillomania, and various other illnesses causing chronic fatigue and pain such as Chronic Fatigue Syndrome and Endometriosis. Also, inclusion and visiblisation of disability related issues in women's rights movements and other movements is rather tokenistic and rarely results into amplification and strengthening of voices from the disability community. Through the various personal narratives in *Skin Stories*, Anasuya (2019) claims for inclusion and visiblization of the concerns and demands from persons with disabilities and disabled women in particular, in the mainstream euphoria of empowerment:

> And as another International Working Women's Day creeps up on us, we push past the sinister pinkwashing it is shrouded in and reiterate that this desire for more is political. To be seen as employable and not to be dismissed because our bodies have different demands, and because we make these demands known. To have our pain acknowledged for its own sake, not via the lens of reproductive ability. To be seen as deserving of research that can look towards finding a cause, and a cure. (p. 57)

Nandini Ghosh (2018) argues, "disability is experienced in, on and through the body" and adds, "the bodies that women experience are always mediated by constructions, associations and images which most patriarchal sociocultural formations accept and endorse" (p. 102). Ableist discourse, patriarchal power and gaze construct the notion of an idealized normative feminine embodiment, which is considered as inferior to male embodiment, and internalised by women in order to seek acceptance as sexually desiring and desirable subject. Personal narratives in *Skin Stories* help us to understand how disabled identities, especially that of women, are constructed due to a complex interpenetration of oppression and affliction. *Skin Stories* investigates "the ways in which the representational systems of gender, race, ethnicity, ability, sexuality and class mutually construct, inflect and contradict one another and intersect to produce and sustain ascribed, achieved and acquired identities" (Ghosh, 2018, p. 102). Goyal (2018) asserts, "marginalizations and identities are like a web, complex and linked" and cannot be "stripped in layers" (p. 168). *Skin Stories* explores negotiation between disabled female bodies and imperatives of socially and culturally constructed identities. Christina Thomas Dhanaraj (2019) talks about the politics of devaluation that she has to persistently struggle with, owing to her caste and disability, and the enormous toll it has on her mental health. While sharing her experiences of the politics around dating and forming romantic relationships as a Dalit and disabled woman, she says :

> ...within the Indian context, caste continues to play an important role in determining the value of a woman in romantic partnerships.... It is safe to assume that the modern-day ideal is also a *savarna* or a *savarna*-passing woman, that is, typically, light-skinned and able-bodied... and embodying the qualities of what is considered to be feminine. The farther one is from this ideal, the more undervalued she is perceived to be. (Dhanaraj, 2019, p. 19).

 ISSN: Print 2229-6557, Online 2394-9244

She calls for state and community-sponsored interventions to prevent and resist structural violence and discrimination against Dalit women. She argues in favour of redefinition of mental health discourses on trauma, body image, and disability using the caste lens. It is important to note that psycho- social problems like depression, stress, lowered self-esteem, and social isolation experienced by women with disabilities often remain unacknowledged and unaddressed (Nosek & Hughes, 2003).

Skin Stories explores diverse processes that shape and influence experiences of disabled women with respect to social–cultural constructions of the ideal female body. "All girls internalize, from a young age, this notion of the normal body, the preferred body and the valued body—imbued with particular physical qualities, acceptable attitudes and modes of behaviour and social expectations" (Ghosh, 2018, p. 104). Corporal aspects of body such as size, shape, weight, skin colour and associated characteristics define the ideal female body and subsequently categorise the disabled female body as inactive/passive, asexual/hypersexual, incompetent/unproductive, and incapable/incomplete for normal life. Disabled women internalize standard norms on ideal female body and find their own bodies as deficient, not beautiful, desexualized and a source of shame. Manjiri Indurkar (2019) shares her apprehensions about dating and forming sexual relationship because she is an overweight woman having mental illnesses like OCD and hypochondria. She writes:

> I am worried that my illness makes me unlovable. I am worried that my weight makes me unfuckable.. .. I am afraid you might not like the boil scars on my breasts, or my skin pigmentation.. . I am worried .. . you will give me pity sex. (pp. 59-60).

Parvathy Gopakumar (2019), a child amputee, reminisces her experiences of trauma, shame and denial. She recollects, how she struggled hard to accept her new body; the sight of her bare stump would send chills down her spine, she wore full-sleeved clothes all the time to conceal her disability, and her reflection in the mirror without her prosthetic hand would make her uncomfortable about her new reality. While on one hand, she familiarizes the readers with the challenges she experienced in her day-to-day activities, she also highlights the immense mental health difficulties that people with disabilities often experience due to the negative stereotypes on disability. She deliberates, how her prosthetic hand dominates her sense of self-esteem in matters of love, romance

and dating, "I am not lovable, and this dating thing won't work for me" (2019, p. 65). Nevertheless, she concludes on the note of acceptance and celebration of her disabled body,

> I have taught myself to love that part of myself as well. The hollow part of my prosthetic arm is where I hoard chocolate at times, and I love applying nail polish on the silicon fingernails these days, because why not? (2019, p. 34)

While heteronormativity is seen as a culturally ubiquitous phenomenon, persons with disabilities are either desexualized or infantilized, and considered as incapable of having sex or good sex. Shakespeare et al. explain that disabled people are viewed as lacking sexual potential or potency (1996, p. 10). Eunjung Kim (2011) defines desexualization as "a process that separates sexuality from disabled bodies, making it irrelevant to and incompatible with them because... disability is believed to lead to sexual incapacity" (p. 482). Margrit Shildrick (2007) explains that desexualization happens to people with disabilities in all stages of life. Disabled people are denied the right to lead active sexual lives and also not considered fit to participate in hetero-normative institutions like marriage and parenting. Malini Chib (2019) questions the desexualized representations of disabled persons in media that lead to enforcement of asexual stereotypes in real life. Chib points at the retorts that disabled persons receive from able-bodied people, "'Sex? You? But you are disabled!'" and asserts, "You see, people forget that the most sexual organ in the human body is the brain. If it is intact, I believe that we will think of sex.. ." (2019, p. 85). O'Toole and Bregante (1992) criticize the society for considering disability and sexuality as incompatible concepts (p. 273) and claim 'disabled people are actively sexual' (p. 279). Milligan and Neufeldt (2001) argue, 'basic drives or the desire for love, affection, and intimacy' don't get eliminated with disability (p. 92). Amla Pisharody, who has BPD, in the middle of all the complexities due to her sudden and constant mood swings, her ever changing notion of her self-worth and unpredictability of her behaviour, proclaims, "I absolutely love having sex.. . Sexual intimacy makes me feel powerful, like I can conquer anything" (2019, p. 82).

Societal assumptions render desires and experiences of disabled people with diverse sexual orientations invisible. *Skin Stories* should be read as an important step towards recognizing sexual diversity and need for freedom to explore sexual choices by/among persons with disabilities.

 ISSN: Print 2229-6557, Online 2394-9244

Goyal (2018) shares her experiences of having met with absolute refusal and condescension during her research to identify women with disabilities with different gender identity and sexual orientation, and highlights the hierarchy that actors belonging to one marginalized community have towards the other even in rights-based movements. Anonymous in *Skin Stories* elaborates on the complexity of navigating through the disability groups without revealing her queer identity, "It is there where I feel most understood, yet I still harbour a secret" (2019, p. 15). Given that non-normative sexualities have a history of invisibility in literary and cultural depictions, these narratives in *Skin Stories* initiate a dialogue on questions around compulsory sexuality, heteronormativity, visibility and invisibility to offer new insights about debates on hetero- and homosexualities, asexualities, transsexualities, BDSM and queerness. Queer disability studies theorist Alison Kafer (2003) asserts that the constructions of disability and non-normative sexuality are imbricated, each supporting and feeding off the other. Queerness and disability threaten to disrupt the institutions of heterosexuality and able-bodiedness. Queer disability narratives invite shame and stigma, and often get relegated to the margins. Anonymous shares her experiences of negotiating with her feelings of shame and stigma attributed to her so-called deviant lesbian desires, "And my shame is the biggest way in which my PTSD and lesbianism are linked" (2019, p. 14). Coming out with her queer disability narrative helps her to deal with the claustrophobia she has been experiencing because of her queer disability identity. Queer sexual preferences/practices are medically pathologized and abstinence is prescribed as the only alternate way to straighten the sexual deviance, as Anonymous notes, "I spent several sessions talking to a dismissive professional... who only suggested medical intervention when she found out that I was a lesbian" (2019, p. 15).

Regulatory medical discourses play a significant role in constructing the disabled queer sexualities as non-normative. However, there should be more creative possibilities for exploring diverse sexual identities and practices. These diverse sexual orientations/identities/practices should be respected as chosen identity, and also be included in the mainstream sexual discourse. It is equally important to explore the adaptations that are made/challenges that are experienced in the non-Western disabled queer narratives within the culturally specific gender dynamics of South Asia. Challenging and resisting the gender norms

that pathologize queer sexuality, Upasana Agarwal affirms her identity, "I am queer and gender non-conforming and a survivor. These are my lived realities" (2019, p. 27). Agarwal problematizes the much celebrated and polarized representation of disabled queer love in media: "Headings sensationalize love, and all of our trauma is clubbed under the over-hyped, misrepresented Article 377" (2019, p. 27). Similarly, Rachelle Bharathi Chandran writes about her experiences as a Dalit, non-binary person reaching out for and not finding access to mental healthcare facilities for non-binary people. She demands for a specific vocabulary (free from prejudices) to voice the concerns and stories of non-binary persons. She elaborates on her ambiguous relationship with her body that is more often than not viewed through an ableist and gender binary lens. Chandran's caste identity adds another layer of marginalization to her experiences of subjugation:

> How can I as a Dalit person ever feel comfortable talking about caste to a therapist who repeats every word except caste? How can I feel comfortable discussing my NB personhood, problems with school or work, when every one of these are marked with my Dalit identity? (2019, p. 166)

As stated earlier, marginalizations and identities are like a complex and interwoven web, and inclusion of certain marginalised communities in other marginalized groups is only tokenistic, Chandran discusses the reasons and consequences of the invisiblisation of voices from non-binary communities, "It is to be living in a country that never has spaces for us. Our people have to hide their identity for fear of discrimination, so we don't even recognise each other and are isolated and alone." (p. 166). Both Agarwal and Chandran urge to bring the conversations back to addressing issues relating to mental health and creating sensitive and empathetic spaces to delve into the lived experiences of rejection and ostracization of disabled queer and non-binary people. These personal narratives raise significant questions about intersectionality between disability, gender, sexuality and human rights that need to be addressed in the mainstream disability activism.

Dominant social, linguistic, and cultural interpretations of sexual desires/practices/orientations tend to desexualize and marginalize the lived experiences of disabled persons. Further, the daily lived experiences of disabled women in India often get shrouded under the depictions from

 ISSN: Print 2229-6557, Online 2394-9244

the West. *Skin Stories* is a significant initiative in bringing the focus back to the Global South. *Skin Stories* should be read as an important step furthering the cause and concerns of the disability and gender/civil rights groups in India and beyond, offering hope and scope for acceptance of diverse/hetero/homosexual desires of disabled persons. Personal reminiscences in *Skin Stories* explore the positive and resistant modes of expression to carve and create more open spaces for expression and understanding within the Indian context. These narratives are informed by the demands/claims of disability rights movement in the region and should be read as productions of social/physical environment, politics of gender and sexuality, lived realities/experiences, and disability, each intersecting with each other. These narratives on one hand report the devaluation of disabled sexual subjectivity as an outcome of disability oppression and impairment, and on the other challenge the disability stigma by portraying disability identity as neither damaging nor negative. Instead, the assertion of disability pride leads to a sense of self-worth.

Skin Stories also validates the disability communities/groups as significant sites for solace, healing, (re)discovering, affirmation and resilience for persons with disabilities to accept, assert and claim their diverse/sexual and disability identity. *Skin Stories* can be read as an important contribution to the ongoing theoretical, conceptual and methodological development of disability studies in India at intersections with gender and sexuality. However, most of the personal accounts in *Skin Stories* come from persons with disabilities living in the urban spaces. Given that the medical, charity and social models of disability prevail simultaneously in the Indian socio-cultural milieu and interact with each other in such a way that the perception of disability and related issues floats between these various models of disability, there is a need to retrieve the lived experiences of persons with disabilities from the rural/non-urban parts of the country as well. The ideological constructs on disability, gender and sexuality are rather more conservative and rigid in rural/semi-urban ndia and offer very little scope for expression. Although expected to conform to 'feminine' norms, disabled girls are excluded from gendered notions of sexuality as "disabled femininity is constructed, nurtured and contested within the domains of the socio-cultural valuation of bodies and the ideas around the activities and practices in which such bodies are to be implicated" (Ghosh, 2018, p.

115). A Western rights-based paradigm fails to account for local cultural constructs of disability resulting in the domination of Disability Rights Movement by elite and English-educated scholars and activists, and therefore, marginalization of local grass-root level-experiences and realities. The need of the hour is to create a disability culture that would help in bridging the gap between the disability experiences from the urban spaces and rural hinterlands in South Asia.

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