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Cripping Care: Gender, Disability, and the Medical Gaze in *Naseema: The Incredible Story*

Athira. S

Abstract: *This article examines the intersection of disability, gender, and healthcare in Indian women's autobiographical writing, focusing specifically on Naseema: The Incredible Story by Naseema Hurzuk. It argues that such autobiographies challenge dominant biomedical discourses and offer alternative frameworks for understanding care, health, and agency. These narratives, often marginalized in mainstream medical or literary discourse, confront the clinic with stories grounded in emotional labour, gendered embodiment, and social resistance. Using the lens of disability studies and feminist narrative theory, this paper analyzes how Hurzuk's narrative articulates resistance against reductive medical gazes and reclaims narrative agency through lived experience. The text critiques ableist assumptions within both clinical and social settings, offering insight into the complexities of patienthood and survival for disabled women in India. By locating disability within socio-political contexts, Hurzuk's story redefines recovery not as a return to normativity, but as an ongoing negotiation with structural barriers and inner resilience. In doing so, such narratives enact what scholars' term "crip epistemologies," proposing new ethics of care rooted in interdependence, activism, and radical hope. This article contributes to conversations in narrative medicine, feminist disability studies, and postcolonial health humanities by centering patient narratives that resist erasure and demand visibility.*

Keywords: *Disability studies- narrative medicine- gender and health- Indian autobiography- patient narrative- feminist disability theory*

Disability narratives have long been overlooked in medical and literary canons, particularly when authored by women in the Global South. Indian autobiographies written by women with disabilities are especially rare, and their inclusion in scholarly discourse offers a necessary intervention into the domains of both narrative medicine and feminist theory. *Naseema: The Incredible Story*, the translated autobiography of Naseema Hurzuk, emerges as a powerful critique of the biomedical model that seeks to pathologize and contain disabled bodies. By articulating her life as a continuous negotiation with physical, social, and institutional barriers, Hurzuk challenges the clinic's authority over the meaning of disability.

The concept of “Cripping the Clinic” — drawing on disability theorist Kelly Fritsch’s notion of “crip time” and Alison Kafer’s critique of the medical-industrial complex — refers to the reorientation of clinical authority through lived, embodied experiences. In the context of Indian women’s life writing, this involves contesting dominant narratives of cure, normalcy, and bodily control. Instead, autobiographies like Hurzuk’s foreground the affective, socio-cultural, and political dimensions of healthcare and patienthood. This article seeks to explore how such feminist disability narratives offer alternative modalities of care, challenge normative biopolitics, and ultimately reimagine agency beyond biomedical determinism.

Resisting the Clinic: The Gendered Gaze on Disabled Bodies

In *Naseema: The Incredible Story,* the clinic is not a place of restoration but of repeated trauma and invisibility. Hurzuk’s autobiographical voice documents the physical and emotional pain of repeated misdiagnoses, delayed treatments, and invasive procedures — experiences that highlight the failures of the Indian medical system, particularly for disabled, lower-middle-class women. “I told every doctor who treated me, ‘When I take a bath I can feel the heat of the water on the upper part of my body but lower down, I can’t make out whether it’s hot or cold’” (Hurzuk 107). Despite her articulations, her symptoms are often dismissed or misunderstood — a pattern familiar in feminist critiques of the clinic, where women’s pain is systematically minimized or psychologized.

Moreover, the gendered dimension of disability in India renders Hurzuk hyper visible and invisible at once — visible as a subject of pity, and invisible as a subject of agency. The expectation of marriage and normative womanhood is frequently weaponized against her. An astrologer's prediction that she would never marry becomes, for Hurzuk, a moment of ironic reflection rather than despair: "'But, of course, you haven't inferred that from my wheelchair, have you?'" (Hurzuk 52). Her narrative challenges the assumption that femininity must be linked with normative physical ability, beauty, and heterosexual marriage.

Narrative Agency and "Crip" Reclamation

The term "crip," once a slur, has been reclaimed by disability activists to signify a radical stance against able-bodied and able-minded normativity. In narrating her story, Hurzuk enacts a form of "crip reclamation" — not just asserting the legitimacy of her body, but exposing the violent architecture of exclusion that the abled world imposes. This is evident in her insistence on documenting everyday acts of defiance: returning to education despite paralysis, creating an NGO (Helpers of the Handicapped), and mentoring others with disabilities. These actions reposition her as a figure of resilience and resistance, rather than a passive recipient of care.

Narrative agency is central to this process. Hurzuk refuses to be spoken for — by doctors, family, or society. Her self-authored narrative becomes a space of epistemic resistance, aligning with Arthur Frank's idea of the "wounded storyteller" who reclaims agency by telling their own illness narrative. Rather than following the traditional "restitution" model where the patient is cured, Hurzuk's story adopts the "chaos" and "quest" narrative modes — acknowledging suffering while also emphasizing transformation and community care (Frank 115–134).

Beyond Biomedicalism: Towards an Ethics of Interdependence

The dominant biomedical model, with its focus on cure, fixity, and individual autonomy, fails to account for the interdependence central to disabled life. Hurzuk's story foregrounds this interdependence — with her family, peers, doctors, and later, the larger community of disabled people she helps mobilize. Feminist disability theorists like

Rosemarie Garland-Thomson and Eva Kittay have argued that interdependence, not independence, should be the ethical cornerstone of care.

When Hurzuk writes of her sister Rehana tenderly dressing her wounds, of her community members assisting in daily tasks, she does not present this care as a loss of dignity, but as a redefinition of it. The care is mutual, reciprocal, and generative. Her organization, Helpers of the Handicapped, is itself built on this ethos. It challenges the charity model of disability by centering empowerment and mutual respect, rather than paternalistic aid.

In one powerful moment, Hurzuk recalls being taunted by fellow students who treated her with mockery. Instead of withdrawing, she uses the moment to reflect on the cruelty of normative systems: “When half your body is dead and the other half lashed with endless pain, how can you not cry and keep smiling?” (Hurzuk 43). Yet she continues to participate, perform, and teach. Her pain does not define her limits — her ethical and communal commitments do.

Gender, Sexuality, and Embodied Resistance

Another crucial theme in Hurzuk’s narrative is the intersection of gender, sexuality, and disability. Feminist disability scholars have critiqued the erasure of disabled women’s sexuality and reproductive autonomy. For instance, the asexualization of disabled bodies often strips them of their right to intimacy, desire, or romantic aspirations.

Hurzuk tackles this invisibility head-on. While she notes that she was told she would “never marry,” she transforms this stigmatization into a narrative of self-ownership. Her narrative does not romanticize loneliness but articulates a robust interior life that finds fulfillment in activism, friendships, and work. This aligns with Alison Kafer’s assertion that disability futures need not follow heteronormative trajectories but can instead open up space for “crip temporality” — a way of being that disrupts normative life scripts of marriage, childbearing, and productivity (Kafer 27).

By centering her affective world — from her bond with Rehana to her mentorship of children with disabilities — Hurzuk’s life narrative embodies what Robert McRuer calls "compulsory able-bodiedness." By refusing this compulsion, she not only affirms her own embodiment but creates a space where others can do the same.

Patient Narrative as Activist Testimony

Autobiographies like *Naseema* function as activist texts as much as they are personal accounts. They serve as testimonies that demand structural change in policy, healthcare, and education. Javed Abidi, in his foreword to the book, notes that disability in India has never received the political attention it deserves — a reflection of both bureaucratic apathy and societal neglect. Hurzuk's narrative, then, is not just a story of personal triumph but a damning indictment of systemic failure.

Patient narratives in narrative medicine are often used to humanize healthcare professionals' understanding of illness. But feminist disability narratives go further — they challenge the very foundations of medical ethics, care protocols, and healthcare delivery. They ask: Whose pain matters? Whose body deserves care? Whose voice is heard?

Hurzuk's life and work respond to these questions by transforming her own suffering into systemic intervention. Her organization fights for access, dignity, and policy reforms — making her narrative a living archive of resistance. As Rukmini Sekhar notes in the editor's introduction, Naseema's life is "pain, fresh air, inspiration, and a new world" (Sekhar xviii).

Conclusion

Naseema: The Incredible Story not only exposes the structural violence embedded within clinical and social institutions but also reimagines care through feminist, ethical, and crip perspectives. Hurzuk's narrative challenges the notion of disability as a personal tragedy in need of correction, asserting instead that it is a socio-political condition demanding recognition and redress. Through her acts of storytelling, organizing, and resilient survival, she redefines patienthood as a space of radical agency and collective transformation. By centering lived experience over clinical abstraction, this narrative urges a paradigmatic shift from paternalistic models of care to participatory, justice-driven frameworks that address the complex entanglements of gender, disability, and health. Narratives like

Hurzuk's are not supplementary to medical knowledge—they are foundational. They offer blueprints for building a more inclusive, compassionate, and equitable society.

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Author bio

Athira. S is Research Scholar, T.K.M College of Arts and Science, Kollam. She has won recognition among the younger generation of scholars for the originality of her ideas and the energy of her presentations .