

Beyond the Ramp: Caregiving, Cosmology, and Gendered Selfhood in Shivani Gupta's *No Looking Back: A True Story*

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ABSTRACT

No Looking Back: A True Story (2014) by Shivani Gupta, is an autobiographical novel. It deals with her transformation after a fatal car accident that left her tetraplegic. It presents her own experience of acquiring disability following a car accident, also documenting her journey towards becoming one of the best-known disability access experts in India and finally her widowhood. Generally, the novel can be read either in the spatial politics of the built environment or in the general western frameworks of trauma and resilience, the exercise of power in the context of informal caregiving relationships, the Hindu cosmological vocabulary through which disability is socially interpreted namely that of karma, pity and ritual purity, the gendered arc of courtship, marriage and widowhood that shapes the memoir's closing moves. A close reading of the novel from the perspective of disability studies, combined with an intersectional and stigma theory, demonstrates that Gupta's story does not follow a linear, redemptive trajectory that is assumed by models of adaptation and post-traumatic growth but it instead constitutes a negotiation with cosmological explanations of disability and with the unevenness of caregiving itself. The analysis explores two conflicting models of care, contextualises the frequent motifs of almsgiving and ritual exclusion within India's karmic understanding of disability, and reads the memoir's trajectory from courtship to widowhood as a critique of an adaptationist model that assumes only one direction of movement. The article concludes by reflecting implications for training for special educators and rehabilitation counsellors.

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Introduction

Shivani Gupta shot to fame with the publication of her novel *No Looking Back: A True Story* in 2014. She portrays her life experiences and achievements that can inspire millions of disabled

individuals striving to follow in the footsteps of Shivani Gupta. The text narrates her meeting with a car accident and becoming tetraplegic at the age of 22 while she was travelling abroad to pursue her post-graduation. The two decades after this story, her hospitalization, a long and

torturous period of physical and psychological adjustment, her professional retraining as an access consultant, courtship, marriage, and finally, widowhood, are presented quite impressively in the novel. Shivani struggles with the determination to regain control of her life and her body to get an identity of her own. The memoir is divided into five books: "Rebirth," "Discovering the Spirit," "Learning to Fly," "Gaining Acceptance," and "Another Journey," and preceded by a prologue and an epilogue. Shivani struggles hard to regain control over her life and her body and moves forward without any hesitation to overcome her disability and acquire an identity of her own. Thus, the novel is a deeply moving and motivating account of Shivani that portrays surviving the challenges of disability. Shivani Gupta has acquired national and international acclaim and honour, and been conferred with the Helen Keller Award (2008), the CavinKare Ability Mastery Award (2008), the National Role Model Award (2004), the Neerja Bhanot Award (2004), the Red and White Social Bravery Award (1999), and the Sulabh International Woman of the Year Award (1996) for demonstration of her personal courage, resilience, for her service and achievements in the disability sector.

Theoretical Framework

The theoretical framework of the present study is based on three bodies of work. The first is the sociological literature on disability stigma in India. One aspect of the study by Misa Kayama, Christopher Johnstone and Sandhya Limaye on how disabled youth in India "adjust" their presentation of self in social interaction is the belief in karmic causes of disability, such as past misdeeds, their own or those of a family member. It is a live explanatory frame, even among educated, urban respondents, and one that works in parallel with, rather than in simple opposition to, medical and rights-based understandings of disability.

The second body of work is the disability studies literature on life writing as a genre of self-determination. According to Thomas G. Couser's statement:

in disability autobiography, disabled people counter their historical subjection by occupying the subject position. In approaching this literature, then, one should attend to the politics and ethics of representation, for the "representation" of disability in such narratives is a political as well as a mimetic act" (Couser quoted in Sati, 330).

Shivani Gupta's account of Putul's exploitation of her is an example of a narrative reclamation from a relationship in which she, at the time, had comparatively little power, if autobiography is where a disabled narrator can "speak for" as well as "about" disability (Couser quoted in Sati 330), then Gupta's account of Putul's exploitation of her is itself an act of narrative reclamation over a relationship in which she had, at the time, comparatively little power.

The third relates to the rehabilitation psychology literature on psychosocial adaptation, which has recently been summarized in Hanoch Livneh's updated conceptual framework. Hanoch Livneh views the process of adaptation to chronic illness/disability as a "gradually unfolding process" (172) despite its "not universal (trans-situational and across CIDs (Chronic Illness and Disability) progression" (175), as once thought by models centered on stages. Reviewing the longitudinal results across the three groups of spinal cord injury, cancer, and cardiovascular patients, Hanoch Livneh reports that there is evidence of reactions like anxiety and depression "generally observed to subside over time," (175) but there is a smaller body of evidence that shows "fluctuations in experienced reactions (depicting a curvilinear trend over time)," (175) including instances in which "heightened anxiety and psychological distress were reported in anticipation of a later life event, following an earlier downtrend of reactions" after the initial onset (Livneh, 175). This reading focuses on the curvilinear finding, rather than on any previous stage in Gupta's model, to describe how his narrative does not follow the unidirectional trajectory of "growth" that Waseem Akram and Brinda Veerappa's selected frameworks suggest, but rather returns, years after the initial injury, to the depths of widowhood, to a form of the same

existential questioning that was present in the hospital chapters.

Caregiving as Power

In the context of disability of a person, family and paid caregivers are treated as background, the supporters, whose hands transport Gupta from bed to wheelchair in Someshwar Sati, the escort figures in the scenes, whose focus is architecture or psychology, in Waseem Akram & Brinda Veerappa. But caring in *No Looking Back* is the place where its own drama is played out repeatedly, and the memoir plays out at least two oppositely structured dramas of caring.

The first one is Putul, who is Shivani Gupta's caretaker during the years she is cultivating her relationship with Vikas Sharma. Someshwar Gupta says that Putul witnessed their first kiss and that she told her parents about the relationship, which they both knew about (117). This is what prompts Gupta's father to tell Putul to "keep out of my personal life," and Vikas's parents to tell their son to "stay away from Gupta" (117). The caring experience is not an add-on to the courtship story, but the way in which courtship becomes apparent to both families, and indeed on Putul's terms and not Gupta's. The blackmail is without quoting Gupta's own words, as it can be seen from the passage that it was not some vague sense of "privacy", but the very concrete threat of exposing a relationship that the family did not approve of and that would have a lasting impact on the way Vikas's parents viewed Gupta for the first time.

Caregiving is a complicated relationship to read as neutral, or simply an enabling relation, because of the intimacy that is needed to be able to assist another person in their daily functioning, and because of the opportunities for coercion that arise in such a relation, since the person who needs assistance is dependent on this relation to function. In the smaller register, anticipating this asymmetry, Someshwar Gupta describes nurses who operated mechanically:

I was very conscious about these women seeing my naked body, even if they were nurses. To top

it all, the screens had gaps in the corners, and anyone could see inside. I kept requesting them to keep me covered with a sheet as I couldn't lift my hands to do so myself, but I doubt if they even heard me. They operated mechanically. After the sponge, they tried changing my sheet. They were not sure how to change the sheet since the doctor had given strict instructions not to turn on me. They discussed this for not more than a few seconds and told me they would change the sheets later. (27)

From the start of the story, bodily exposure and unconsented care are thus recurring features of care, whether institutional or paid.

The second, structurally opposite caregiver is Ritu who has a much earlier appearance in the narrative than either of the previous studies indicates. Vishwakarma's review does not mention Ritu until in the memoir's final section, when Ritu supports Gupta after the accident kills Vikas. This is complicated by direct references to the text, Ritu is already an established member of Gupta's family during her university days, assisting her with tasks that require a lot of hands but which Gupta cannot do "model making became a family exercise, my father and Ritu helping me out" (151) — and in the opening pages of the Prologue itself, in January 2011, a year after Vikas's death (3). Ritu, then, is not just a caregiver who comes to fill the void left by widowhood, but rather a presence that has been around for several years that just carries on. The author states:

Ritu was going to accompany me to the reunion—I needed assistance in getting in and out of the car. It had become a familiar drill by now. It was nineteen years since I had become disabled, depending on a carer 24x7 to help me with just about everything. Ritu had been with me for nine of those nineteen years and was now more a friend than a paid employee (2)

The contrast this article makes is not between an early, exploitative carer and a later, redemptive one, as a linear interpretation of Vidya Vishwakarma's synopsis would suggest, but between two sets of caregiving relationships that coexist and differ in kind, with Gupta for

decades. Someshwar Sati's architectural reading is not equipped to address a threat that comes from within the home, not from the street or an office building; Waseem Akram and Brinda Veerappa's resilience framework, which focuses on the protagonist's psychological trajectory within themselves, rarely has to examine either of these relationships in such detail. Putul and Ritu argue that the memoir does not offer a simple, universal conclusion on paid versus unpaid care. It is a care relationship whose moral contours are flexible and do not follow the natural contours of dependency.

Karma, Pity and the Economy of Charity

The strangers who understand Gupta's wheelchair in cosmological sense rather than in medical or infrastructural terms are the subject of the memoir's recurring scenes. A woman presses a twenty-five paise coin into her hand, thinking that she is a beggar, outside a temple in Haridwar, where she has gone on a family trip "for blessings" (63). As for the woman giving her money, Shivani Gupta remembers the moment when she was confused, "Why was she giving me money?" and then realized what had transpired, "She had thought me a beggar only because I was disabled" (63). This kind of scene is read by Someshwar Sati mainly as a manifestation of "the object of the pathos of the charitable gaze" theorized by Bill Hughes (70), which involves the disabled body as an object of pity for the giver, which is a reflexive confirmation of the giver's own virtue. That reading is correct but incomplete; considered as a gesture of secular pity, the coin is more legible in the context of the broader literature on disability in India, which reads the gesture as more karmically than secularly. Misa Kayamaa, Christopher Johnstone and Sandhya Limaye's study of disabled adults in urban India reveals that the Hindu "theory of Karma" that posits that current impairment is linked to "past misdeeds" of the individual or family has influenced local conceptions of disability and some families who believe in this theory may seek "ritualized practices" to cure impairments rather than medical treatment (Kayama, Johnstone, & Limaye, 465). According

to the same study, "others' pity" is a common experience for disabled people in India, and sometimes they receive money from people who think that this will help them to achieve their own good karma, which makes them feel dependent (Kayama, Johnstone, & Limaye, 465). Within that context, it is understood that almsgiving brings benefit to the giver, and that the hardship that it alleviates is the residue of a past misdeed by the recipient. Gupta's Haridwar coin is a small, exact example of this, and a gap between the giver's cosmology and her own, which a charitable gaze framework can't explain.

The second cosmological scene is more explicitly found at the Kanyakumari temple, where Shivani Gupta is denied access to the temple in her wheelchair "as it was considered impure" (119). She is carried inside by one of her colleagues for darshan of the deity, one of the most humiliating and embarrassing experiences of her life, as everyone ogled her as she was carried (119–120). In this context, it is not almsgiving but ritual purity that is the motivating factor; the wheelchair itself, and consequently the body it carries, is a source of contamination that must be protected from sacred space.

Shivani Gupta's cosmological register is juxtaposed with the contrast she makes between Delhi and Salisbury, England, where she finished her professional training. She writes about the other wheelchair users she met in the United Kingdom, and how they were treated, and found that there was not an ounce of sympathy or charity:

It was in Salisbury that I understood the true meaning of rehabilitation. I also understood disability a little better—that being disabled wasn't a big deal. All the patients at the rehabilitation centre projected an attitude of being regular people who happened to be using a wheelchair. There was not an ounce of sympathy or charity that their demeanour invited. It was amazing to be there—an absolute eye-opener. (76–77).

In Delhi, however, she is greeted by the bystanders who lament in amazement before questioning, "Chhi chhi! See, such a young and

pretty girl in a wheelchair—who will marry her now?’ Such remarks made me feel sad for myself for a while. But as I got used to hearing them, I would think: ‘Yeah, I know I cannot get married...but who wants to get married anyway?’ There were numerous instances wherein I was told off at offices—they said I should not have troubled myself to visit personally, I should have sent a representative. My physical presence to them seemed like a burden.” (76) A question of pity coupled with an explicitly gendered concern for marriageability, which will be discussed further below. There is a complementary reading to Someshwar Sati’s here. It is not a dichotomy between a modern, rights-respecting West and a premodern, charity-bound India, but one that the memoir itself is likely to reproduce and that postcolonial critique should not take for granted. It’s, in other words, a juxtaposition of two different explanatory frameworks for how a body can become disabled and what, if anything, must be done for it: a broadly secular and rights-based one, and a cosmological and karmic practice. While it’s easy to see Someshwar Gupta’s professional trajectory as a personal endorsement of Western ideals, it is perhaps more accurately described as a practical argument against the karmic charitable model – a model that she and Vikas have consistently rejected, and in very explicit and assertive terms, by stating that:

We were frustrated by the deep roots that charity had taken in the disability sector, wherein most non-governmental and governmental organizations considered making provisions for the disabled as ‘God’s work’, jeopardizing any chance of real inclusion. We set out to bring change within the sector as well as outside the sector. (174)

This is no different from the moment of public recognition that even Shivani Gupta has experienced. She received the Neerja Bhanot Award in 2004, and she was pleased to find that the organizers had made arrangements for her to enter the auditorium, as they were aware that she was interested in accessibility, but the ramp turned out to be “actually wooden planks nailed together over the staircase, dangerously steep, and I couldn’t make use of it” (158–159). Shivani

Gupta’s own interpretation of the episode is accurate. She says that there are people with “a lot of goodwill ... to promote access for all; what was really missing was the understanding of how to provide it (159). Her elsewhere insistence that “the last thing that a disabled person wants is charity” (175) and her hope to see disability treated “as a mainstream developmental issue rather than a charitable one” (175) are direct rebuttals of the same goodwill without competence economy that the temple, Haridwar, and award ceremony scenes all stage in different registers.

Professional Expertise as an Answer to Cosmology

Shivani Gupta’s reply to the rhetorical and charitable description of her disability is not only rhetorical, but institutional as well. She picks up a series of qualifications along the way such as an invitation to a training programme organised by the United Nations Economic and Social Commission for Asia and the Pacific, on “Non-Handicapping Environments for the Disabled and the Elderly” (115), a two-year diploma in architecture technology, as the awarding institution did not consider her ‘age and disability’ a disqualification (144), and a master’s degree in inclusive environments from the University of Reading in the United Kingdom, which she studied alongside Vikas and was admitted to in 2004 (156–157). This career path is not about “career” or “empowerment” alone, but about replacing a secular, credentialed and auditable standard of access with a discretionary, merit based one of charity, and the even more discretionary one of ritual purity (as Gupta’s stated goal is that access be a basic right, “the right to be able to access all places with the same ease and dignity” as a non-disabled person. (119). An access audit is a technical document that can be measured against a standard and, in principle, enforced when alms are given at the giver’s discretion and confirms the giver’s virtue, and when a wheelchair is deemed impure in a temple. The professional register of the middle books of the memoir is thus not a separate register, but the critique of karmic pity.

Marriage, Widowhood and Gendered Selfhood

Shivani Gupta was only on the outside of the disability experience: “Disabled for me, until now, had been ‘them’” (45) prior to her accident. Her coming to understand of herself as disabled is not incidental colour but a social verdict that Gupta must metabolise, for the “who will marry her now?” refrain is a constant. (76) While Wasim Akram and Brinda Veerappa suggest that the memoir can be read from the perspective of gender, they do not apply this to any passage, and this article argues that the best way to read gender in the memoir is to see the arc from courtship to marriage to widowhood. Shivani Gupta’s relationship with Vikas Sharma remains unaffected after Putul blackmails her (117) and after two years of being physically separated from Vikas, who works in the United Kingdom (UK) (The culmination of this is marriage, which happens about four months prior to the couple’s first family holiday with Vikas’ parents, which they had planned for 13 August 2009 (208). The marriage is not a rescue story, but rather a story of two professionals who have invested in accessibility together, have trained together, studied together at the University of Reading, UK, and ultimately built the organisation AccessAbility together. She explains the motto of this organization:

I can never emphasize this enough: Vikas and I were a team. It was our education together that laid the foundation for the organization we would set up in the future and gave us the power to think differently and not to accept things as they had always been. It gave us the courage to stand up for what we believed in. AccessAbility, our organization, was an outcome of this. (168-169)

This plot is completely reversed in the memoir’s final movement. On the way to Manali for the family vacation, an oil tanker ran into the family’s car head-on, “about three hours short of Manali” (212). The narrative states that the man’s father-in-law died at the scene, a phrase that is used to describe the death of a man but is understated: “Magistrate Sahib was no more” (216). Vikas had internal bleeding and was operated on a day late

“due to doctors’ negligence” (219), and after a week of struggling to survive, “gave up” when he developed septicemia and multiple organ failure at the age of thirty-three (220). Shivani Gupta’s own report of the news is devoid of embellishment: “Vikas was dead. An incomprehensible reality” (221). After eight months of suffering from her own injuries in the crash, Shivani Gupta writes, “two questions plagued me. What is life? Why do I live?” (229). This recurrence is significant considering Hanoch Livneh’s finding that some psychosocial reactions to chronic illness and disability are not linear but rather show a “curvilinear” trend over time. (176) The two frameworks selected by Waseem Akram and Brinda Veerappa are Abraham Maslow’s self-actualization and Richard G. Tedeschi and Lawrence G. Calhoun’s post-traumatic growth, both of which are centered on moving forward, towards integration or flourishing. That’s not the story of Gupta. After 20 years and a career, marriage, and public recognition, she’s brought back to the same question she faced at the start of the book by widowhood.

The coping mechanisms, resilience strategies, empowerment and agency analysed by Waseem Akram and Brinda Veerappa without referring to the Posttraumatic Growth Inventory developed by Richard G. Tedeschi and Lawrence G. Calhoun, which was designed to measure a set of outcomes (New Possibilities, Relating to Others, Personal Strength, Spiritual Change, and Appreciation of Life) that, on its own account, Shivani Gupta’s narrative appears to have already secured well before Vikas’s death (455). The instrument is difficult to apply to a second trauma onto a pre-existing adapted life, as in Richard G. Tedeschi and Lawrence G. Calhoun’s sample, women reported about twice the amount of growth as men after experiencing severe trauma, which suggests that women may be more capable than men of learning or benefiting from difficult life experiences (Tedeschi & Calhoun, 468). Shivani Gupta’s story, which reaches widowhood after 20 years of just such growth, doesn’t just add another layer to it. Instead, it reverts to unanswered questions, indicating that the

Posttraumatic Growth Inventory's (PTGI) cross-sectional outcome of the trauma is not necessarily additive across successive traumas in an individual's life.

The final act in the memoir (which began in April 2010, when Shivani Gupta was in Leh, Ladakh, to help develop an accessible travel package for disabled travelers) is better understood as an extension of the same professional identity Shivani Gupta had developed before his death, rather than a resolution of that recurrence. This is a much less rectilinear and certainly less redeemed form than either of the previous studies' frameworks would suggest, and it is the form that gendered, relational readings of the memoir (those that take marriage, dependency, loss, rather than architecture or trauma, into account) are better suited to capture.

Implications for Special Education and Disability Studies Practice

The reading provided here is not just literary or cultural analysis but has practical implications. Culture is not entirely absent from special-educator and rehabilitation-counsellor training programs based on adaptation models such as Hanoeh Livneh. The model explicitly includes the contextual factors "sociocultural status," which is defined as the presence of available support systems, social integration, family roles and, not least, "cultural meaning of health and illness" (173). The category exists. What it does not and by its own logic cannot provide is content; by naming "cultural meaning of health and illness," it names a slot to be filled in, not the karmic, alms-based, purity-conscious meaning system that Gupta's narrative fills it with, in specifically Indian, Hindu, and urban terms. The training programme which is developed from a text like *No Looking Back: A True Story*, does not fix the absence in the model, but rather fills in a variable which the model, by necessity, leaves abstract. The "caring" and "karmic" and "gendered" aspects of alms-giving, rather than the more commonly mentioned scenes of physical inaccessibility, would give practitioners the tools to see that the alms that are given outside a temple, the wheelchair that is ritually

unclean, the caretaker who becomes a threat rather than a help, and the matter of who will marry a disabled woman are not peripheral colours, but rather are the very stuff that a variable like "cultural meaning of health and illness" must be for it to be of any use in practice.

In light of the above argument, we may propose additions of three practices to a special-education and/or rehabilitation-counseling curriculum based on a text like *No Looking Back: A True Story*. First, the trainees may be asked to determine from a series of passages assigned to them, which of the three explanatory systems— medical, rights-based, or karmic-cosmological — a given character or bystander is working from, as a practitioner-client encounter in an Indian context may involve more than one of these explanatory systems, sometimes within the same family. Second, perhaps the Putul and Ritu episodes were used specifically to discuss the ethics of paid and informal care settings, rather than simply "having support" as a positive outcome that is set up and then ignored. Third, the widowhood chapters in the memoir provide a check on any training program that assumes that psychosocial issues surrounding disability are over once the disability has been addressed in early adulthood. Gupta's return in her forties to the same questions she had in her twenties, for example, indicates that later life experiences, which are not necessarily related to the original disability, can trigger psychosocial issues that were previously thought to be resolved.

Conclusion

When read together, Someshwar Sati's architectural analysis, Wasim Akram and Brinda Veerappa's psychological survey, and Vidya Vishwakarma's narrative synopsis make *No Looking Back: A True Story* one of the texts that can be read through multiple, non-competing scholarly approaches. The four readings discussed here are mutually related and collectively constitute a fourth reading that is neither explored in either of the two research articles nor hinted at in the recent book review. Shivani Gupta's story about the coin she received outside a temple in Haridwar, the blackmailer

who took care of her, the wooden ramp which she was not allowed to use and the question she was left with after her husband passed away, ‘What is life? Why do I live?’ (229) does not fall into either of the two narratives – one of architectural failure that is triumphed over by professional skills; the other of linear psychological development. It is rather a tale that is continually revisited in terms of the incomplete

business of interpretation, who is allowed to interpret the meaning of a disabled body, and on what terms? The unfulfilled need of a special education and disability studies readership is precisely what literary testimony can offer, in addition to a generalized clinical model.

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