

Voicing the Unspoken: Congenital Diseases, Female Sexuality and Contemporary Indian Cinema

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Abstract

Disability had always been a purely medical concern until the emergence of disability studies as an academic discipline, which placed emphasis on the social, cultural and political factors that make it a construct. Popular culture, especially cinema, used to uphold the age-old notions of disability being a curse and punishment. Only able-bodied men were portrayed as autonomous beings. The dichotomous representation of the disabled as either pure and angelic, or evil and monstrous has been questioned by disability studies. The present paper examines how the contemporary Indian cinema depicts the persons affected with congenital diseases by focussing on two films *Margarita with a Straw* and *Peranbu*. It is an attempt to study the gendered experience of disability, as both the films have female protagonists. The usually unspoken and unexplored issue of disability and sexuality is also examined in the study along with the role of socio-cultural and economic factors in formulating the disabled identity.

Keywords: congenital diseases, disability, autonomous bodies, sexuality, identity, crip theory

The emergence of disability studies as a field of academic discussions and deliberations has brought about a change in the approach to disability, from being treated as a matter of pure medical concern to a product of social injustice. Martha Stoddard Holmes states: “Medicine tends to consider disability as a problem that needs repair or cure and locates disability in individual bodies/ persons and conditions rather than in a complex of social, cultural and political relationships” (104). But disability has social/cultural implications and it is rather a construct, the impacts of which change from culture to culture, and from place to place. Most ancient societies treated disability and deformity as a curse, a punishment for the sins of their previous births or that of their forefathers. This stigma that ostracises the affected ones and keeps them away from auspicious occasions can be seen deep-rooted in the Indian culture. As a result, they are denied a dignified life, with choices of their own or agency to lead their lives as they want. Disability studies focusses on the social meanings and symbols that exist in every society in connection with disability, undermining the widespread notion that only able-bodied human beings are quality people and autonomous beings.

Popular culture plays a decisive role in shaping one’s views regarding diseases, especially the rare ones, where the common man’s notions will depend wholly on the representation available in those cultural narratives. The pervasive image constructed by the diverse cultural channels including literature, film and television rules our awareness related to health and illness. Holmes vehemently criticises the representation of disability in literature, both classic and popular: “Stories both popular and classic engrave the idea that disabled people are not only atypical in body or mind, or both, but also radically alien as a result, and in largely negative ways” (117). Analysing the earlier

representations in literature and media, one can see that very often these images are drawn with heavy strokes of the brush, exaggerated, sympathetic or melodramatic, far from being realistic and normal. As Martin F. Norden argues in *American Narrative Films and Disability: An Uneasy History*, “the film industry has relied heavily on, and perpetuated, long-standing stereotypes to inform its characterisations, mainly to generate feelings of pity, awe, humour or fear among able-bodied audience” (137). Hence, the cultural representations of diseases being powerful sites of meaning-making, the academia should approach it seriously. Imaginative and novel visual culture can invigorate one’s capacity to think differently and transformatively about health and illness.

The present paper tries to explore the representation of congenital diseases in selected contemporary Indian films. It attempts to examine whether any paradigmatic shift has occurred in the approach of media towards disability and sexuality. The concept of health and wellbeing being a cultural construct, the nuances of it vary from place to place, depending on numerous factors like race, class, gender and ethnicity. Diseases cause illness to the person, disease being the physiological state whereas illness constitutes the experience of it. Apart from causing illness to the person, disease affects people’s response to that individual, changes his/her perceptions about him/herself, and influences the very identity of the individual. Diseases often make one ‘the other,’ ‘non-normative’ and ‘the deviant’ who is excluded from the core circle of the society. The films taken for the present study are *Margarita with a Straw* (2014), a Hindi film directed by Shonali Bose and *Peranbu* (2018), a Tamil movie directed by Ram. The paper probes into the role that these films play in constructing an image in the audience regarding these diseases and how the experiences of disease and disability differ according to socio-cultural and economic factors.

Able-bodiedness is a temporary identity, and being human, all of us would, at least temporarily, shift to the disabled identity. But those

who are born with congenital diseases cannot entertain such a hope. Even a temporary shift to an able-bodied identity is a non-existent reality for them. As disability per se is correlated with inferiority, congenital diseases usually result in the social exclusion of the affected. *Margarita with a Straw* and *Peranbu* deal with protagonists having Cerebral Palsy, a congenital disease rarely portrayed in Indian films, and these narratives, through the medium of popular culture, help in drawing the attention of the public to the problematics related to these diseases and the condition of the people who suffer from this. As Tobin Siebers argues, “disability is not a physical or mental defect but a cultural and minority identity” (4). The condition of their body pushes them to the margins, underlining the fact that disability is more an elastic social category than a biological property. Both the films under consideration throw light upon a phase of life often left unspoken and unexplored in erstwhile disability narratives. The protagonists, Laila of *Margarita with a Straw* and Paapa of *Peranbu*, are teenage girls just awakening to sexual awareness, and the films very boldly portray their struggles while they pass through that phase. Laila is a college-going student who later pursues her higher studies in New York, whereas Paapa, whose greatest wish is to wear a uniform and go to school, is diametrically opposite to her.

The lived experience of disability is depicted in recent films in a realistic manner, divesting it of the unrealistic sympathetic colours attributed so far. *Margarita with a Straw* exhibits a paradigmatic shift in the approach towards a disabled girl by treating her as an individual with an agency to make choices, with an identity of her own, with her own preferences and priorities, without being a dumb puppet waiting for the sympathy of the society. Laila is able to challenge the sympathetic attitude that society in general shows towards the disabled, so that she would get accepted and acknowledged for her intelligence and talents. She revolts against the judges who place her music band first in the competition claiming that “when we heard that the lyricist was

a disabled girl, we had to give the award to her college” (25: 34). The disgusting sympathy underlying the words, explicitly communicating that she is preferred not for her merits, but as a means to showcase their magnanimity, makes her leave the stage without receiving the prize. *Peranbu*, on the other hand, unravels the life of a father-daughter duo, who find life extremely troublesome in a society entirely hostile towards them. Paapa has to confront the stigma related to disability from her kith and kin who ask Amudan to leave the place with her. Lack of compassion from society and absence of systemic support make Paapa’s life vulnerable and insecure.

Intersectionality plays a vital role in the marginalisation of the disabled. The predicament of the affected and their families results from multiple oppressions of interlocking structures. In this regard, Tom Shakespeare et al comment: “People with impairment are disabled by the twin processes of discrimination—economic, social and physical, and prejudice—cultural, attitudinal, psychological” (3). The gap in the living conditions of Laila and Paapa reveals the role of socio-economic background in disability as an experienced reality. Laila, hailing from a well-off middle class urban nuclear family, benefits from her position compared to Paapa, who is the daughter of a driver, and whose mother had deserted her for another man, with no secure financial background to rely upon. The fear expressed by other family members doubting whether their children would begin to behave like Paapa, and the complaint from the residents’ association about the noise that she makes, force them to leave for a calm and secluded place in the village. Driven to move to the city following a set of disheartening incidents, Amudan finds it difficult to manage Paapa, as he cannot leave her alone safely. When she gets ill-treated in the residential home where she is admitted, he is left with no option other than to lock her up in the room while going for work. The social and economic backwardness results in Paapa being denied proper healthcare, counselling and therapy which is inevitable to improve her condition and provide psychological

assistance. Leading a lonely life away from her peer group denies her the opportunity to explore herself, her talents and develop her own identity. The urban rural divide gets reflected in the gap that one finds in the condition of Laila and Paapa.

Gendered experience of disability matters because of the cultural marginality suffered by women in general in the Indian scenario. To make matters worse, a disabled girl child adds to the woes of the family, as marriage, which is usually considered as the ultimate goal for a girl child, seems to be a blurred possibility for her. The sexual maturity at the age of puberty causes more issues to a disabled girl child than a boy. *Peranbu* very deftly portrays this problem of handling such a child in the most vulnerable period of her life. Amudan and his Paapa have to manage it on their own without the support of a woman, which becomes difficult as the girl refuses to permit him to change her napkins once she develops notions regarding sex and gender. As the doctor says, “she has learnt that her father is a male” (1: 30: 31). The curiosity regarding her reproductive organs leads Paapa to explore the body parts of the doll, which Amudan finds shocking. As it is a complex and complicated matter, society conveniently ignores the sexuality of disabled children. It is Vijayalakshmi, their temporary maid, who helps him realise that it is normal for her to have all feelings and emotions like other adolescents, and he will have to respect that: “Paapa is not a kid anymore. She has all the feelings that a grown up woman has” (1: 12: 09).

The efforts to assimilate the disabled into the social structure have materialised to an extent through centuries, underlining their right to a life with dignity. But, catering to their material needs and empathising with them alone do not suffice in acknowledging their identity as an individual. The society usually shuts its eye towards their sexual awakening and tends to consider them as asexual. Parents also concentrate on providing material facilities, as living with a disabled kid with meagre systemic support itself is a hazardous task.

Every human being learns the basic lessons of sexuality through his/her interactions with the society, their peers especially. Being denied the proximity of their more 'normal' peers due to myriad reasons, this education is scanty or even 'bad' sometimes. The exclusion from healthy social relationships adversely affects the emotional and mental growth of the individual. Marriage and sexual gratification through that seems a possibility, even though not a prospective, for men, as the patriarchal society conjures up to find a woman somehow to take care of him, offering money, food or shelter. Hence, it is evident that even in disability, women are again discriminated against and marginalised, and there is a tendency in the society to conveniently consider them as 'asexual' beings. Disabled anthropologist Robert Murphy states: "The sexual problems of the disabled are aggravated by a widespread view that they are either malignantly sexual, like libidinous dwarfs, or more commonly, completely asexual, an attribute frequently attributed to the elderly as well" (83). Even when the entire family tries to make a dignified life possible for Laila by providing her quality education, gives her time to pursue her passion, respects her autonomy in making decisions for herself, her sexual needs are not addressed at all. The experiments with her disabled friend and porn sites are her only resort, and once her mother finds this out, she reacts violently, thinking it evil and unnatural. Society usually nurtures the notion that the disabled should be grateful for and contented with the material comforts offered to them. Agencies as well as families are unwilling to engage with this problematic as it is embarrassing for them, as they are ill-at-ease in handling this issue. Once Paapa's sexual awakening is identified by Amudan as an unavoidable reality, he comes to terms with it and badly wants to get a sexual partner for her, but the society does not have an option to provide such a service. He even goes to a brothel asking for a male prostitute for her, but gets slapped on his cheek for being a father who tries to violate the chastity of his daughter.

The role of family becomes crucial in the physical, mental,

emotional, psychological and academic wellbeing of the disabled person. Laila is blessed in that respect to have well-informed parents, especially her mother who is the superpower behind her achievements. She has taught Laila music from the age of seven, arranges to have all material comforts and technological devices to make her life easy, drives her to college every day and fights against all odds including her own colon cancer to see Laila scaling new heights. Paapa on the other hand yearns for the love of her mother who had taken care of her until she was eleven, and is bewildered to be left with her father who has just returned from abroad. The animosity shown by the extended family and society makes it intolerable for her mother who decides to leave her. The occasional sanctuaries that Paapa finds, like the White woman and Vijayalakshmi, leave her adding to her distress. It is Meera, the transgender who finally brings light into the darkness of Paapa's and Amudan's lives alike. Fragmented relationships and shattered families wreak havoc upon the lives of the disabled than they affect "normal" children, as physically and emotionally they are more vulnerable than others.

Crip theory focusses on embodied experiences of disability and how certain identities are excluded while others are normalised and accepted as natural. Russell Shuttleworth and Linda R. Mona define crip theory as "an interdisciplinary critical disability theory that strongly aligns and allies with queer theory's interrogation of the categorisation of 'normal' and abject forms of embodiment, identity and pleasures" (8-9). Crip theory moves across boundaries and brings in other exclusionary identities that aggravate the crises faced by diverse disabled identities. Laila's homosexual relationship with Khanum, a blind girl, and her revelation to be a bisexual had been shocking for her mother who has been a fighter throughout for the sake of her 'not normal' child. When she tells Laila, 'this is not normal,' Laila reminds her that "that's what the world said about me too" (1: 25: 18-1: 25: 28). The deviation from 'normalcy' regarding body is more acceptable

to her mother than the deviance in sexual orientation that questions the heteronormative standards of the society. *Peranbu* also poses the question of the queer, with the transgender Meera coming to the life of Paapa and Amudan. The movie ends with the marriage of Amudan and Meera, again thwarting the conventional stereotypical notions regarding gender and sexuality.

In short, contemporary Indian cinema views disability in more realistic and progressive terms, deconstructing the age-old stereotypes of the sweet, innocent, asexual angel or the obsessive avenger. There is a paradigm shift visible in *Margarita with a Straw* from the dependent disabled to the independent autonomous being, who is aware of her sexuality and sexual orientation even. At the same time, reality being multiple and heterogeneous, Laila is not a generalisable symbol representing the entire disabled community. Intersectionality plays a prominent role in the marginalisation of the disabled, and hence *Peranbu* portrays yet another reality, where Paapa has to bear the brunt of the social, economic, cultural backwardness of the place and the people. It can be inferred that the educational, cultural and economic divide becomes instrumental in the individuality and independence they develop. Depicting female protagonists as disabled, the directors underline the gendered experience of disability where women are pushed to the fringes, suffering from the predicament of multiple oppression. The unexplored and underexplored issues of disability and sexuality are highlighted and brought to the forefront of discussions by the directors. The essentiality of a systemic support to provide healthcare, physical as well as psychological, and ensuring availability of equal opportunity to all irrespective of class, race, caste or gender, is communicated to the audience through the bold portrayal of Laila and Paapa. Cinema being a powerfully influential medium, both the movies educate the public about the need for rehabilitating the disabled and providing proper care to them. Congenital diseases should not be a hindrance to the dreams of the affected and their families. Laila shows the autonomous human

being that one can aspire to be, whereas Paapa shows the abyss that one may fall into, without the society to support. To be brief, one can say that Indian cinema has successfully sexualised the so long desexualised disabled women.

Works Cited

- Holmes, Martha Stoddard. "Disability in Two Doctor Stories." *Health Humanities Reader*, edited by Therese Jones et al, Rutgers UP, 2014, pp. 102-120.
- Margarita with a Straw*, directed by Shonali Bose. Viacom 18 Motion Pictures, 2014.
- Murphy, Robert. *The Body Silent*. Phoenix, 1987.
- Norden, Martin F. "American Narrative Films and Disability: An Uneasy History." *Health Humanities Reader*, edited by Therese Jones et al, Rutgers UP, 2014, pp. 136- 148.
- Peranbu*, directed by Ram. Shree Rajalakshmi Films, 2018.
- Shakespeare, Tom et al. *The Sexual Politics of Disability: Untold Desires*. Cassell, 1996.
- Shuttleworth, Russell and Linda R. Mona, editors. *The Routledge Handbook of Disability and Sexuality*. Routledge, 2021.
- Siebers, Tobin. *Disability Theory*. U of Michigan P, 2011.

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