

## **Gendering the Disability Discourse: Disabled and Independence in Indian Cinema**

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### **Abstract**

The concepts of care, support and assistance are of vital importance to disabled and non-disabled alike. This article uses frameworks from the Indian women's movement and disability rights movement to interrogate the gendered construction of disability and its cultural reproduction, particularly through Bollywood cinema in India. A selection of films released between 2005-2014 are used to demonstrate how within a span of a decade attempts were made to create a space for newer dialogues on disability in the public conscience. Using the critique of care and the idea of dependency from disability studies and the feminist idea of 'ethic of care' the paper analyses the complexities of framing 'a right to care'. The difficulties of choosing between state-funded institutional structures, home care, community-based rehabilitation and care through voluntary organizations are analyzed. The author argues that these questions have not been adequately addressed either in the theoretical discourse or in popular imagination as can be gleaned from the films that have attempted to address rights of the disabled.

**Key Words:** Disability Studies, feminism, care, personal assistance, caringscapes

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## Gendering the Disability Discourse: Disabled and Independence in Indian Cinema

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This paper looks at a selection of Bollywood films released between 2005 and 2014 that deal with the subjects of disability, stigma attached to disability, and care for the disabled. The selected movies are *15 Park Avenue* (directed by Aparna Sen, 2005), *Guzaarish* (directed by Sanjay Leela Bhansali, 2010), *Barfi!* (directed by Anurag Basu, 2012), *Ship of Theseus* (directed by Anand Gandhi, 2013) and *Margarita With A Straw* (directed by Shonali Bose and Nilesh Maniyar, 2014).

Although these films attempt to move away from conventional depictions of disability, they remain largely in step with the gendered notions of care. These movies too situate the woman as the caregiver in her various roles of mother, wife and daughter. *Ship of Theseus* (2013) proves to be the only exception, where a man takes on the role of caregiver. The family is often the primary and the sole site of care. Morgan (1996, p. 111) suggests that the 'caring nexus' both constitutes and is constituted by the ideas of family and gender. Care work is generally undertaken by women, and is believed to be part of womanly duties. In other words, to care is to be female.

Care is of critical importance to human existence. All people experience (both receiving and giving) care differently at different points of time. This experience of care is mediated by specific caste, class, gender and age locations. As a concept with multiple layers, care can comprise both feelings and tasks. Scholars have suggested that 'caring about' is concerned with the feelings whereas 'caring for' is the 'tasks' practical work of looking after others (Sevenhuijsen, 1998; Watson, McKie, Hughes, Hopkins, & Gregory, 2004).

Despite growing awareness, increasing justiciable rights, and greater sensitivity, stigma continues to be attached to disability and the disabled body. The concept of stigma includes notions of social disgrace and ritual pollution. It bears medical connotations (with an emphasis on physical disabilities), in addition to its religious significance. As Coleman writes,

It appears that stigmatization occurs only when the social control component is imposed, or when the undesired differentness leads to some restriction in physical and social mobility and access to opportunities that allow an individual to develop his or her potential. This definition combines the original meaning of stigma with more contemporary connotations and uses. (Coleman, 2006, p. 149)

Thus, a stigma reduces the person from a complete individual to a compromised one; and because stigmas arises in specific social contexts at a particular time, it is perennially in a state of flux. Coleman (2006, p. 147) writes that 'two of the most common ways in which non-stigmatized people convey a sense of fundamental inferiority to stigmatized people are social rejection or social isolation and lowered expectations'.

Shame is intrinsic to this process of stigmatization and it results in the stigmatized person's quest for acceptance. As Goffman (2006, p. 134) writes, 'Those who have dealings with him fail to accord him the respect and regard which the uncontaminated aspects of his social identity have led them to anticipate extending, and have led him to anticipate receiving; he echoes this denial by finding that some of his own attributes warrant it'.

Hughes (2009) looks to Julia Kristeva's conception of the abject – that which is a threat to life, identity, and order; that which arises from prohibition or taboo, like the horror of the corpse. Therefore, the 'abject' disabled body is seen as dirty and dangerous, and is consequently shunned by the mainstream.

Further, management of the bodily emissions are crucial in the making of the 'abject body'.

What one does with one's shit, snot, sweat, saliva, sick, wind, blood and pee is highly circumscribed by social norms and controlled by an elaborate and highly codified system of 'manners' and one is expected to be autonomous in relation to the management of one's corporeal waste. (Hughes, Mckie, Hopkins & Watson, 2005, p. 266)

### **The Feminine Space of Care in Feminist Politics**

Feminists are increasingly asking for greater value and resources to "underpin care work in the labor market and the family. The priority is to enhance the experience and/or remuneration of carers" (Watson, Mckie, Hughes, Hopkins & Gregory, 2004, p. 339). However, caring for the disabled is the most marginalized within the field of domestic labor. Of course, caring has not been recognized as work for a long period of time as it has been naturalized into the role and idea of the woman.

Care is often understood as a feminine ethic according to Carol Gilligan (1995). It is an ethic of "special obligations and interpersonal relationships". Selflessness and self-sacrifice are seen as essentials of care, separate from the individual autonomy, freedom, justice, and contractual obligation.

However, it is also the case that in a society that has historically shunned abject bodies, caring for the disabled does not count as work because care for the disabled serves those who are identified as 'burdens' on the nation's resources and its economy. The call to count household work within the economy is based on the argument that woman's domestic labor allows for the smooth functioning of the economy. Thus, domestic labor is seen as productive. The disabled person is seen as removed from the site of work and thus unable to contribute to the economy. Therefore, woman's labor in caring for the disabled is seen to be non-productive.

The feminist ethic of care has brought with it the realization that even though custodial care is increasingly entering the market, it continues to be gendered and poorly remunerated. It has also led to demands that governments acknowledge the importance of custodial care and provide financial compensation to unpaid caregivers, generally women, who perform this labor. Lanoix (2010, p. 139) further suggests that

a better awareness of the actual responses to custodial care needs would facilitate the formulation of policies that adequately address the real needs of care receivers and take into consideration the risks and burdens that caregivers, both paid and unpaid, face... help clarify the actual status of care and help identify the barriers to recognizing the right to care as a social right. (Lanoix, 2010, p. 139)

The location of care within the family results in the unpaid caregiver being dependent on her personal resources and the state's benevolence such as those provided by tax breaks, concessions and other such benefits. As Lanoix (2010, p. 145) argues,

If care is seen as a private responsibility, then the unpaid caregiver can only accept, gratefully, whatever aid is provided. This gives the support the state is providing an aura of rescue while it implicitly relies on the unpaid caregiver's labor. This manner of putting forward the response to care needs makes the state's help impermeable to charges that it is not doing enough or that services are not good enough. (Lanoix, 2010, p. 145)

In stark contrast, stands the paid caregiver, the outsider who occupies a position in the margins of the family. She comes to the care receiver's home (which acts as her work space) to provide care for the stipulated number of hours at pre-determined times either daily or at allotted periods during the week in return for a nominal salary and occasionally, food and lodging.

Keigher (2000, p.141) argues that the caring labor falls disproportionately on women, poor immigrants, and people of color. Further, he suggests that these inequities must be understood in terms of who gets to do what for whom and who is expected or permitted to do what for whom. Watson, McKie, Hughes, Hopkins, and Gregory suggest that, "Given the low pay and poor term and conditions of many paid female care workers it is likely that many of them will find it difficult to access anything other than state provided, means-tested care services in later life." (2004, p. 334)

However, within the disability rights perspective, care is identified with (institutional) 'confinement, limited social engagement, partial citizenship, disempowerment and exclusion. To be cared for is to be in deficit and to have one's competence as a social actor denied or questioned... This position reflects the historical invalidation of disabled people's lives and bodies and it does so largely irrespective of gender. Social policy constructs male and female recipients of care as burdens and a drain on scarce resources' (Hughes et. al, 2005, p. 261). In fact, as Jenny Morris (2001) writes

feminist research divided women into "carers and their dependents" and made invisible the experiences of women who need such support. Disabled and older women were identified as "other" and not included in the feminist analysis of women's experiences. Instead, the researchers identified an "equal opportunities" issue for non-disabled women whose economic position suffers because of the unpaid caring work they carry out within the family. Some non-disabled feminists suggested that disabled and older women should therefore be consigned to residential care. (p. 6)

## **The Physical Space of Care: Institutional and Community Settings**

Historically, the idea of institutionalization of the disabled has been promulgated in order to better their lives. The argument has been that by insulating themselves within their own communities, disabled people can erase the markers of their 'differentness', and flourish in the company of similarly disabled others. Although institutionalization creates a space for the disabled within the mainstream, it consciously avoids any interaction with the latter. In fact, the involvement and participation of family members in the institution was discouraged, as it was believed that it hampered their assimilation within it. In fact, institutionalization was proposed only when the family failed in its duty of caregiving.

However, understanding the demand for institutionalization in these terms turns the spotlight away from society's deep discomfort with disability. Institutionalization emerged as an alternative when it was realized that stigma and ostracism faced by disabled people from mainstream society hampered the all round development of disabled persons.

However, recent studies have revealed that unpaid caregivers continue to be involved in providing care to institutionalized family members. Keefe and Fancey (2000) revealed that in the setting of the institution, this caregiving took on a different form.

Unpaid caregivers can be involved in direct care, such as feeding their family member, or they can perform indirect care, that is, making sure the needs of the family member are well addressed... However, unpaid caregivers are also integral to forming a link between the person who is institutionalized and the staff... Much of the direct labor performed by unpaid caregivers is emotional labor, since the institution takes over the major tasks of physical care. Emotional labor involves being in communication with and being supportive of the care receiver. (Lanoix, 2010, p. 147).

Another critical task performed by the unpaid caregiver within the setting of the institution is to maintain the social identity of the institutionalized individual. Previously, their cutting off from the society and their subsequent institutionalization would result in their 'social death'. As Lanoix (2010, p. 148) writes, 'unpaid caregivers play a vital role in fulfilling the institutionalized person's social needs since unpaid caregivers not only embody part of that person's past history but also because they are a vital link to the outside world where the ties that the institutionalized person had are still evolving'.

Disability rights activists have opposed institutionalization on the grounds that it leads to the social death of the incarcerated. Further, institutionalization erases the possibility for them to participate in the public sphere and thus, invisibilizes their existence.

However, institutionalization is also often detrimental to the interests of the paid caregivers, usually women as Nirmala Erevelles' (1996) work reveals. Interestingly, the identity of both unpaid and paid caregivers is formed through the axis of class, caste, race, gender and disability, both within institutional as well as community settings.

Further, the limited allocation of state resources for the provision of institutional services creates a distinct 'ethic of service'. Erevelles observes,

this seeks to attract voluntary workers who would freely offer their services for the needy and the suffering. However, the "ethic of service" that typifies the work performed within a voluntary organization is itself an idealistic concept, because at this historical moment, the pool of workers "able" or "willing" to offer their labor power for no wage is very small. Therefore, there is the need to allocate some part of capitalism's surplus to pay the wages of these workers. However, given the limited resources in the service sector, and its status as non-profit, there is plenty of justification for providing a "nominal wage" and "minimal" work related benefits as compared to other institutions/organizations which are aimed at profit maximization. (Erevelles, 1996, p. 527)

The ethic of service promoted by the voluntary organizations feeds into the existing notions of selfless service that is at the core of the feminine ethic of care. The poor pay given to these female carers is also justified on the grounds that it does not require learning a specific skill set as these skills are 'natural' to a woman.

The opposition to the practice of institutionalization has led to the emergence of community care policies. Although hailed by disability rights activists, community care has been criticized by some feminists as the 'community' is often identified with the site of the 'family', where the sexual division of labor continues to flourish. Further, Community Based Rehabilitation (CBR) has failed in the rural areas as it has not been contextualized properly.

Gopikumar and Parasuraman call for a reimagining of community. 'Somehow, institutions are vilified irrespective of their chequered pasts because of the difficult functions they were to perform, while the "community", which often reeks of callousness, has been overestimated and deified. Maybe we begin to open up to the thought of hospitals as communities and of community itself as an institution?' (2013, p. 71).

### **Re-Envisioning Care: Personal Assistance and Caringscapes**

Thus, the disability rights movement has put forward the demand for personal assistance. The aim is to shift the balance of power between the cared for and carer in favor of the disabled person.

Personal assistance is carefully constructed in opposition to the feminist ethic of care. The ideals of the latter can be detrimental for those who suffer from psychological disabilities linked to relational abuse. These 'destructive relationships can obstruct their healing. In this instance, traditional ideals of autonomy and independence can serve as guide posts in their moral experience, affording direction and support' (Donner, 1997, p. 385; Nicki, 2001, p. 98). A sharpened, healthy egocentrism can help them to be more available, in the long term, for positive, loving relationships, and can thus further their moral development (Nicki, 2001, p. 98; Nicki, 2002, p. 270).

Self-care is concerned with the activities and actions that an individual needs to perform in order to attain an adequate quality of life. In other words, these are the activities of daily living (ADLs). Custodial care refers to the help individuals need to carry out these activities. However, the prevalent disabling attitude in society views those who require help with the physical tasks of daily living as dependent.

As the dependent partner in the relationship, the care receiver is understood to be a passive recipient of care, merely taking all that is given to him or her without a complaint. Such an understanding of the care relationship negates any contributions that may be made by the dependent to the relationship. However, as Albert Memmi (1979) has revealed all dependency relationships always involve an exchange between the caregiver and the care receiver and vice versa. Both parties are providers, albeit what they are providing is different. According to Memmi, the contributions of the care receiver are often erased because of the context in which the care receiver's contribution arises. This erasure is more complete in the context of custodial care where care needs are identified precisely but the relation of care itself is not given any formal attention (Lanoix, 2010, p. 141).

As mentioned earlier, the state enters the care economy through the caregiver, her needs and failures. As Lanoix (2010, p. 145) writes,

services are initially directed at the unpaid caregiver's lacunae, and then as a result of the negotiation with the unpaid caregiver, to the care receive.... It entrenches the care receiver as a dependent individual who does not warrant public help because she has needs but, rather, because she has become an excessive burden to another individual, who, in many cases, is a working-age adult... Denied is the possibility that custodial care is a social right of citizenship originating from the care receiver herself rather than through a negotiation with an intermediary such as a family member. It also puts the care receiver in a state of double dependency since her needs are responded to through the filter of an unpaid caregiver's availability: she depends both on an unpaid caregiver and on public resources. (Lanoix, 2010, p. 145)

This depersonalization of the disabled care recipient through the actions of the state and the caregiver is challenged by disability rights activists who argue that independence lies in exercising control over how help is provided to you, and not in the idea of doing everything for yourself.

With this view of independence in mind, the disability movement has articulated the need for a 'Personal Assistant' (PA) as opposed to the figure of the 'carer'. The former seeks to break the link between care and dependency. As Watson et al. (2004, p. 336) write, the PA works for and with the disabled person and does not need expressions of gratitude. The PA provides assistance, support, and help for the disabled person similar to the PA of a businessperson. The disabled person is thus no longer an object of care but a recipient of assistance in a neutral manner.

The concept of personal assistance gave rise to demands for cash-for-care schemes. The state responded by presenting these schemes as an issue of free choice. In other words, the disabled and/or old people and/or their families now have the option to choose among

different kinds of care and care providers. This situates autonomy and control with the disabled individual who is no longer the object of care. Instead, he is the active subject who makes his own decisions.

Scholars suggest that cash-for-care schemes will benefit both the disabled individual and the personal assistant in other significant ways. It will result in intense competition among the different care providers, thus improving the quality and efficiency of care. It may also lead to the recognition of (formerly unpaid) informal care, because such schemes allow beneficiaries to compensate or employ their relatives.

However, the conceptualization of personal assistance in the disability rights perspective couches it in mechanical, instrumental terms and this may underplay the reciprocity and emotional involvement invested by both parties in the relationship. Second, the empowerment of the disabled person does not offer protection from exploitation to the assistant. The discourse of direct payments and PAs has been devoid of a language of mutuality, partnership and interdependence (Watson et al. 2004, p. 338).

The concept of Caringscapes (Watson et al, 2004) encompasses the complex and diverse ways in which people deal with the day-to-day challenges of organizing and conducting caring work. Pathways of caring are often restricted by the availability and accessibility of caring resources and services. Sometimes they may be routinized into conventionally gendered pathways. “Caringscapes” are not static and planned caring ‘routes’ must sometimes be amended. They also shift in response to changes in mobility and communication. “Caringscapes” would involve several of the following activities or experiences: planning, worrying, speculating, prioritizing, ensuring quality of care, accessing care, controlling or paying for care, shifting patterns of work, job (in)security, moving home, managing family resources, supporting school work, or being involved in the school or care group. (Watson, et al, 2004, pp. 340-341).

In the case of those who have mental health issues, the decision about care or assistance becomes more complex. Writing in the context of the mental health bill, Gopikumar and Parasuraman (2013, p. 70) suggest that when informed consent is not achievable, the judicious move in the best interest of the individual may be to temporarily suspend the right to self-determination and opt for care and recovery.

### **Disability Stigma and Care in Bollywood Cinema**

Movies are both an extension and a representation of society. While depicting lived realities, they can mediate understandings of those experiences and can be instrumental in either propagating or shattering stereotypes. Moving beyond stereotypes and mere representation of communities, movies can also raise pertinent questions about and reflect upon the issues of the time. Increasingly, post their theatrical run, movies are finding an afterlife in both popular and academic discourse.

Aparna Sen’s *15 Park Avenue* (2005) captures how social rejection and lowered expectations for disabled can even occur within the family. During a family gathering, Meethi



(a woman diagnosed with schizophrenia) asks her sister if she can hold the newborn baby. This is a cause for anxiety/ Anu, Meethi's older sister and carer, sits her down and ensures that the baby is carefully placed in her lap. The family is nervous and tells Meethi repeatedly to not drop the baby.

Meethi's schizophrenia isolates her from her family, the very site where one expects her to find companionship and compassion. Despite her age, she is not recognized as a competent adult (due to her disability) and fears are expressed over the possible harm that she could cause to the baby. Coleman (2006) suggests that people experience the fear of contagion even when they know that the stigma cannot be developed through contact. 'This fear usually stems from not knowing about the etiology of a condition, its predictability, and its course' (Coleman 2006, p. 148).

This scene also establishes Anu as Meethi's primary caregiver. In this, Anu is aided by the hired help, Charu. However, their tension and dilemmas are also subtly hinted at in the scene.

Director Aparna Sen further explores this idea in the following scene. Meethi seeks to unite with her 'family', and decides to run away from home in the dead of night. Just as she is about to step out into the dark night, her sister Anu spots her from the gallery of the first floor and foils her plans. In the ensuing tension, Meethi ends up urinating on the carpet, an act that she was unconscious of until Anu draws her attention to it. Forced to wake up in the middle of the night and clean the house, house-help Charu complains. She says, "Chi, chi, chi", an expression of disgust that suggests that Meethi should feel shame. She also implies that Meethi would not have soiled herself if she were to listen to their advice and drink less water at night. Charu is reprimanded by Anu, who says that Meethi is 'helpless' to control her body, and that the soiling is a result of medication. Anu also says, "It's okay baby, Charu will help you change" leading to Meethi's outburst about being a grown woman and not a child.

Aparna Sen deftly turns the spotlight on the issues of care (both emotional and practical labor), autonomy and infantilization of the disabled through this scene. On the one hand, it identifies Anu strongly as the caregiver performing intensive emotional labor. As the caregiver from Meethi's immediate family, the character of Anu plays to the existing conventions of the unpaid female family member performing that role. On the other hand, it also identifies Charu as the paid caregiver, performing the everyday tasks of practical, often 'dirty' labor (cooking, cleaning, administering medication).

Thus, the carer represents the civilizing forces of prohibition and order. This scene also brings into play the questions of caste and class, and juxtaposes Anu against her employee Charu. At the same time, the scene also constructs Meethi as passive, helpless and childlike, dependent on her caregivers to lead a dignified life. It also records her defiant protest against this construction of her identity. Symbolically too, this scene depicts the distance between schizophrenic Meethi and lower-class paid help Charu who looks 'up' at professor Anu (who is standing on the first floor).

The location of care within the arena of domestic labor is underscored in Anurag Basu's *Barfi!* (2012). In spite of his impairment, Barfi is portrayed as an independent young man.

Infact, Jhilmil as the autistic loner requires constant care and supervision. But marriage brings with it a massive change. Jhilmil provides care to husband Barfi, and enjoys her new role.

It is also important to note that although the paid caregiver may also perform emotional labor, she is often kept at the margins of the family. The following scene from *Guzaarish* (2010) interrogates this position held by the lower-class paid caregiver. Director Sanjay Leela Bhansali challenges the understanding of care within the disability rights perspective here. Disability rights activists challenge the concept of care for its unidirectional flow of power (i.e., from the care giver to the care receiver). Instead, Bhansali etches Ethan as a quadriplegic with a strong independent mind of his own (who single-mindedly opts for euthanasia).

For instance, Sofia comes over to former magician and present-day quadriplegic Ethan Mascarenhas' place to provide him with care services. She picks up the morning newspaper and is stunned and hurt to read the headline about Ethan's plea for euthanasia. As part of her daily chores, she reads out the newspaper headlines to her employer in a stern voice.

Ethan realises that Sofia is upset and hurt, so he apologises to her and he says he owed her an explanation. She cuts him off saying he does not owe her anything since she is merely his caretaker nurse. She also informs him that should he feel that he does not need her services after submitting the petition, he should let her know and she will submit her resignation. It is clear that she is offended that he did not inform her of his plans despite her having been in his service for the past twelve years.

Yet, the idea of care is repeatedly emphasized upon in each frame of the movie, and in fact, Ethan's dependency on Sofia and others is depicted to make a legitimate plea for euthanasia in the eyes of the audience, both within and outside the movie. Thus, moments where Ethan, an elite Indian man asserts his decision-making powers are rare and in fact, almost a site of subversion in the text.

In *15 Park Avenue*, Anu, in her role of Meethi's primary caregiver, has put her life on hold in order to look after her sister. As per the codes of the feminine ethic of care, she cannot complain about the lack of support from other family members, nor portray herself as the self-sacrificing do-gooder

Sanjeev (Anu's boyfriend) asks Anu why she always puts her own happiness last. Anu says that placing Meethi in an institution is not an option. A closer reading of the text suggests that Sanjeev acts as the voice for Anu's outburst. In fact, Anu's rebuttal highlights the feminization of care, where it is unthinkable to associate care work with the male members of the family.

The protagonist of *Margarita with A Straw* (2014), Laila is perhaps one of the strongest and most independent disabled women represented in Hindi cinema. She is comfortable in public places and moves around on her own, operating her wheelchair. She writes lyrics for her college band in Delhi University and performs on the stage with them. Later, she goes on to pursue a course in creative writing from New York University and moves in with her girlfriend in New York. Even when she needs help to perform any activity, she is not afraid or ashamed to

ask. *Margarita with A Straw* depicts Laila's journey to self-discovery, becoming assertive and comfortable in her own skin.

However, the movie also establishes Laila's mother as her primary and unpaid caregiver in the opening scenes itself. She performs both the emotional and physical labor, even uprooting her life in Delhi to accompany Laila to New York and help her settle in the new city.

Laila comes back to Delhi during her holidays. Her girlfriend accompanies her on this trip. She decides to disclose the truth about her relationship and her sexuality to her mother who has cancer and has become the care-receiver. It is against this backdrop that Laila wants to talk to her mother about being "bi" or bisexual. Her mother misunderstands and thinks Laila wants to talk about how she has become a "bai" or a maid on account of having to care for her mother. The scene highlights how in popular discourse, the physical tasks of care-giving are equated with the menial jobs undertaken by poorly paid maids.

It is interesting to note here that although Laila's family is shown to be a happy, close-knit one. Her father and younger brother are supportive of her. Yet, the physical labor associated with care-giving is performed by the women in the family. First, by Laila's mother and then in a role-reversal, by Laila. Selflessness is a defining characteristic of the care-giver, both the paid and the unpaid one in the feminine ethic of care.

This is highlighted in *Guzaarish* (2010) when Ethan's apprentice Omar suggests to Sofia, his caregiver that she should take a break. He says that he knows she has not taken a single day off in the past twelve years. He suggests that she take half a day off to visit her family, go to the beach, watch a film, or just do anything that is not care work. He reminds her that she need not feel guilty for taking time off, since she deserves it.

Omar's words stun Sofia into silence and the audience is told of her selfless and thankless service. However, this is naturalized into the responsibilities of a wife as she ultimately marries Ethan. This also foregrounds domestic labor as intrinsic to a woman's selfless love for the family, as Sofia is repeatedly shown to be in love with Ethan even in the absence of an acknowledgement or promise of commitment on his part.

Sanjay Leela Bhansali also explores the concept of personal assistance and the autonomy of the disabled individual in *Guzaarish* (2010). Ethan refuses the medication that he is meant to take. So Sofia begins the process of administering the medication by injection. He protests the medication, and insists that he is not mad, that he merely got angry. Sofia silently continues to administer the medication and ignores his protestations.

On the one hand, Bhansali argues for the need to create a space for personal assistance within the realm of care through Ethan's exhortations to be allowed to take his own decisions. The mind-body dichotomy is also carefully constructed: the super-achiever quadriplegic's usual rationality is questioned when he demands the right to euthanasia. His subsequent actions are termed as 'emotional drama' and the caregiver and doctor are framed as rational, acting on Ethan's behalf for his own good when his actions are deemed as irrational.

In the case of those who suffer from psychological disabilities, this idea of personal assistance and right to self-determination is further complicated and often negated as highlighted in the following episode from Aparna Sen's *15 Park Avenue* (2005). In Anu's absence, Meethi's mother asks for Charu's advice on how to care for Meethi. Charu suggests the services of a tantric. Meethi initially misunderstands the events to be a wedding and is excited to conform to gender roles, even asking for a dupatta. Within seconds, she begins to plead for mercy and help as the tantric beats her and pulls her hair.

Schizophrenic Meethi's voice is continuously sidelined and the decisions about her treatment are taken by other family members and caregivers. Aparna Sen explores the contrasting conceptions of care and treatment held by lower class, uneducated caregivers and by upper-class, educated caregivers. However, in emphasizing the violence done on Meethi's body in the tantric episode, one loses sight of the violence inherent in modern medicine, and its imposition and invasion in her body and mind without her consent.

The conception of 'Caringscapes' makes its way into celluloid through Anand Gandhi's *Ship of Theseus* (2013). Aliya's blindness does not make her dependent on her husband, Vinay or other colleagues. Neither does she employ a help to assist her with leading a dignified life as a disabled. Instead, the couple is shown to live a regular life, working, cooking, loving and bickering while taking her blindness into account.

Aliya's profession is also an unusual choice for disabled characters in Bollywood. She is a photographer navigating the hustle and bustle of Mumbai, its streets and markets. She is aided by technological advancements in the field. In fact, Aliya relies on her walking stick, camera and other equipment to lead an independent life. Additionally, Vinay provides a detailed description of the pictures to her later and based on this, she chooses which photographs to retain.

Anurag Basu makes a strong case for institutionalization of the disabled, suggesting that they will find greater understanding, companionship and compassion among their own, as opposed to the outside world in his movie *Barfi!* (2012).

Six-year-old Jhilmil was left in the care home, Muskaan, by her maternal grandfather after her alcoholic mother tried to kill her autistic daughter. She spent a happy childhood at Muskaan. Despite their misgivings, the staff at Muskaan sent her back to her family at their request. Her caregiver Ms. D'Souza remarks that one needs great love and patience to care for Jhilmil. Both Jhilmil and her family struggled to coexist and ultimately, she ran away from her home.

In fact, Barfi, who was shown to be a jovial young boy who grew up as part of the community, shifts to Muskaan after he marries Jhilmil. This suggests that while disabled couples may be ostracized by mainstream society, they might find a safe haven within institutional settings.

Although Jhilmil and Barfi have non-disabled staff at their service at Muskaan, Jhilmil continues to act as Barfi's unpaid caregiver, undertaking the activities that have been naturalized into the duties of a woman: knitting for, feeding, and taking care of her husband, Barfi.

## Conclusion

Stigma and shame play an important role in marking out and creating the disabled citizen in contrast to 'normal' citizens. Generally, this results in the disabled persons facing social rejection and/or isolation and thus, they are often kept within the confines of the home (in order to avoid public embarrassment for the family). Traditionally, a site of compassion, the family here becomes distanced, the responsibility of providing care falling on the female members of the family. In fact, both the emotional and practical care is seen to be part of a woman's duty and thus, it is not recognized as work and goes unpaid. Even in the case of paid care work, the axes of class and caste decide who gets to care about and who gets to care for the disabled.

The feminist ethic of care threw light on the fact that even when there is custodial care, it continues to be gendered and poorly paid. It calls for financial compensation in cases of unpaid care work. Interestingly, even within institutional settings, the unpaid caregiver (generally, a female relative) continues to play an important role and often acts as the link between the care receiver and the staff, and the society.

On the other end lies the disabled care receiver whose autonomy is discarded. Instead, the care receiver is infantilized. With the intention of changing this scenario, disability rights activists have called for Personal Assistants to change the relationship and power dynamics between the care giver and the care receiver in favor of the disabled care recipient. The idea that guides the concept of Personal Assistants is that independence lies in exercising control over how help is provided and not in the idea of doing everything oneself.

Hospital wards are intended as cooperative spaces in which both the family members and the medical establishment can cultivate the patient towards recovery. As Das and Adhlakha say

This strategy is dictated, in part, by the shortage in public hospitals of qualified staff and other resources...Such practices augment the ward's character as a public space, and patients and their relatives can often develop a spontaneous sociality over the duration of an illness. It is also one of the important spaces in which the state enters the everyday life of poor and low-income families (Das and Adhlakha, 2001, pp. 521-522).

In fact, the shift from hospitals to in-home care has witnessed the loss of many key services (such as personal care, equipment and medications) for the care recipients. Now, the costs for such services have to be borne by the individuals.

Some of these concerns have begun to creep into cinema, with wider kinship networks being recognized in texts like *Guzaarish* (2010) and *Barfi!* (2012). This is a far cry from older texts like *15 Park Avenue* (2005). At the same time, there is a need to understand the resentment and social isolation that may creep into caregiving as it is naturalized into a filial or spousal duty.

History is replete with examples where the stereotypes operating about stigmatized individuals were modified under specific conditions. As Coleman (2006, p. 146) writes, 'when

stigmatized people have essential information or possess needed expertise, we discover that some of their attributes are not so different, or that they are more similar to us than different.’ This too is a historic moment where the able-disabled individuals are being welcomed by society. The stories are making way to the screen, but we must reject the ablest mindset that many replace older negative representations with new forms of representations that stigmatize and box individuals.

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