Chapter-3

Mothering the Disabled: Empowerment Beyond Grieving

Trajectories of Care

The birth of a disabled child leads to several challenges for a family thereby leading to the reconfiguration of relationships within the family. This, in turn, affects the physical as well as the psychological well-being of the parents of children with chronic disabilities (Raina et al., 2005). Parents of children with rare diseases also experience stress on account of their lack of knowledge of and competence in giving care to a child with such diseases. Besides, such parents also experience social isolation, and the emotional crisis resulting from the apprehension that the child may not grow in a normal way (Dellve et.al, 2006). Further, in such situations the care required by children with different disabilities may vary, but it has been established that the caregiving required by children with disability far exceeds the typical requirement of mothering a child with normative needs (Read, 2000). As mothers, women are expected to perform the gendered role of caregiving at the expense of negating their own individual growth, and for mothers of children with disability this responsibility of caregiving increases substantially. Being the primary caregiver of a child with disability, a mother is burdened with the role of the guardian, nurse, and therapist (Aneja & Vaidya, 2016). Thus, in the family, it is the mother who experiences greater emotional and psychological turmoil than other family members (Smith et al., 1993). This caregiving responsibility combined with existing gender roles compel women to take care of the household and other family members while coping with the other difficulties (Parks & Pilisuk, 1991; Gray, 2003; Ersoy & Bulus, 2019; Vadivelan et al., 2020). The special care associated with mothering the disabled involve acquiring specialised knowledge

of the diseases and the needs, forming extensive collaboration and association with health professionals, and performing skilled health care delivery (Traustadottir, 1991; Hill & Zimmerman, 1995). As a result, maternal health is affected on account of the physical disability of the child (Frey et al, 1989), the mother also develops physical problems such as muscle disorders, back and neck hernia, and there can also be trouble in her marital relation, often leading to divorce and separation (Tekindal, 2015; Vadivelan et al., 2020). Often these mothers have to leave their jobs to take up full time care responsibilities, leading to the loss of one's social and economic support system (Leiter et al., 2004). Moreover, parental burnout and chronic sorrow are common in such mothers because of the anxiety, shame, guilt, and alienation resulting from the negative social perception and exclusion.

The chapter analyses how the cinematic representations have gone beyond the maternal paradox and have captured the alternative self-care practices adopted by mothers of disabled children while also caring for their child. Through a thematic analysis of *Margarita with a Straw* (Bose, 2014), *The Sky is Pink* (Bose, 2019), *Jalsa* (Triveni, 2022) and *Salaam Venky* (Revathi, 2022), this chapter maps the trajectories of care and examines the alternative mothering strategies adopted by mothers of children with disabilities. A critical examination of these on-screen mothers provides an insight into the individual care needs of the caregiver and the care receiver. Finally, the chapter posits how these mothering practices can be seen as an important starting point in developing a deeper understanding of the individual care needs of the caregiver and the care receiver.

Maternal Paradox and Culture of Care

In our culture of care, mothers play an important role, wherein by adhering to the gendered notion of care, they are expected to externally direct their act of care.

Motherhood can be a praxis, an institution, and a lived experience. However, “The dominant portrayal of what is, and what it means to be a 'mother' remains locked within a reductive and imaginary prism of white supremacy, heteronormativity, and sexism” (Story, 2014, p. 1). Normative family structures and practices are historically and institutionally embedded, drawing on ethnocentric images and discourses of good mothers as being married, middle-class, heterosexual, living in a nuclear family structure, economically dependent and child focused. The good mother is framed within these normalising discourses that have historically positioned groups of mothers outside these norms as the other, failed, deviant, invisible and unworthy of mothering (Rich, 1976). The idea of an ideological mother has been prevalent both in western countries and in India. However, mothering practices go beyond these hegemonic definitions of mothering and motherhood. Scholars in motherhood studies have paid attention to the racist and heteronormative ideological structures of motherhood, but not enough attention has been paid to the experiences of mothers of disabled children. While the care work done by mothers in general are invisibilised and are associated with their gender roles, the additional care responsibilities of the disabled child and their impact on maternal health are further ignored (Francis, 2010; Khanlou et.al, 2017). The maternal paradox faced by mothers of disabled children is that they are blamed for the disability of their children, while at the same time they are glorified so that they continue as the primary caregivers of their children (Khanlou et al., 2017). Again, within the disabled community these mothers occupy a liminal position because they are not disabled. However, their proximity to disability on account of their roles as primary caregivers gives them special competence as compared to others, making them activist mothers who are capable of bringing change for their children and other disabled people. The undervaluation of such mothers leads to their maternal paradox.

The mother blaming faced by these mothers on account of the health complications of their children stems from several scientific and psychoanalytic studies, and, as a result, these mothers are socially labelled as bad mothers for having failed to ensure the healthy birth and upbringing of their child (Francis, 2010). Psychoanalytic studies blamed mothers for behavioural "disorders" like autism in children. The "autistic withdrawal" in children was associated with the cold and disengaged mothering (Bettelheim, 1967). Although the myth of the refrigerator mother has been debunked through advances in medical science and growing awareness (Grinker, 2007; Feinstein, 2010;), most of these mothers continue to go through self-doubt, guilt and blame themselves for failing to uphold the societal standards of being the good mother. Initially, psychologists and psychiatrists used large-scale quantitative methods to study the impact of the children's disabilities on maternal health. They used personality tests and questionnaires and were based mostly in the UK, US, or Sweden, and focussed on different forms of disability or chronic illness (Ryde-Brandt, 1991; Joesch & Smith, 1997; Hoare et al., 1998; Olsson & Hwang, 2003). While some of the research did indicate that the disability in children had a significantly greater impact on the mother than the father, or sometimes even led to divorce and separation, not much in-depth attention was paid to this (Veisson, 1999). When qualitative studies were conducted, they mostly focused on the familial struggle while caring for a child with disability, and did not highlight the impact on maternal health and wellbeing, rather they focused on the collaboration between health and educational professionals in providing support to these families (Snell & Rosen, 1997; Dale, 1996; Ainbinder et al., 1998; Sloper, 1999; Case, 2000; Knox et al, 2000; Murray, 2000; Dowling & Dolan, 2001). A significant number of works were also done on the various forms of disability and the challenges encountered by families having such children with disabilities; such as Autism (Seltzer

et al., 2000), Down Syndrome (Hauser-Cram et al., 1999), and developmental delay (Gowen et al., 1989). Some of the qualitative works focused on maternal narratives (Read, 2000; Home, 2002; Tarrant, 2002; Malacrida, 2003; Redmond & Richardson, 2003; Todd & Jones, 2003; Ryan 2005). Scholars in the US and UK were the first to draw attention towards the journey of mothers with disabled children (McDonnell, 1991; Kittay, 2001). While these works gave voice to mothers of special child, and provided in-depth insight into the lives of their child and their struggles with the lack of infrastructure, and the need for attention from the government to bring in social change, very few have managed to highlight the experiences of mothers and the alternative mothering practices that they adopt. Of them Tarrant, who is mother to a child with Asperger Syndrome, in her *The Maternal Metamorphosis,* speaks of an evolutionary journey, where one gradually adjusts to living with a child with autism, and how they develop confidence and "maternal intuition" over years of hardship and struggle (Tarrant, 2002, p. 80). Being herself a mother of a child with disability, her work with other mothers could offer a more nuanced understanding of such mothers and their mothering practices. Kittay too mothers a child with disability and advocates the need for co-mothering to cater to the varied needs of her child, while continuing her profession, mothering her other child, and other everyday activities. This form of mothering she termed as "distributed mothering" (Kittay, 2001, p. 13). Home's study with 39 Canadian mothers with attention deficit hyperactivity disorder highlights the gendered nature of care prevalent in Canada and seeks social change through action research. Todd & Jones (2003) explore the impact of the notion of 'good mothering' on self-perception, and how it determines a mother's relationships with the professionals. The researchers emphasised how on account of this, the participants were hesitant in sharing their needs, to not appear to be selfish before the professionals.

Mothering the Disabled: The Real and the Reel

Motherhood studies is an emerging area in India and is yet to develop an understanding of the alternative mothering strategies adopted by mothers with disabled children to navigate their care trajectory. Women in India are often blessed by elders with "*putravati bhavo"* (may you bear sons) and attain respect and recognition on giving birth to valorous sons (Aneja & Vaidya, 2016). It is considered that motherhood's actual contribution is to maintain patriarchy through the triple instruments of control over reproduction, sexuality, and sexual division of labour (Krishnaraj, 2010). In this patriarchal pact, certain ideologies and conduct of motherhood are privileged and are preferred over others, "the preference for sons over daughters, and ability over disability; the desexualisation of the maternal body, its appropriation as commodity, its being posited as a "lack" and an ongoing reluctance to grant it the position of subjectivity and agency" (Aneja & Vaidya, 2016, p. 18). A study conducted in two Indian cities has highlighted a greater amount of stress among parents with children with disabilities (Gupta et al., 2012). However, the study focussed on parents in general and did not focus specifically on mothers. The study conducted by Banga and Ghosh (2017) is an important contribution in the study of childhood disability and caregiver adaptation in India, and it also focuses on mothers in particular. However, their study limits itself to studying quantitatively the affiliate stigma common among mothers caring for children with Specific Learning Disability. Aneja and Vaidya's *Embodying Motherhood: Perspectives from Contemporary India* (2016) examines the experiences of mothers caring for a disabled child, as well as mothers who themselves are disabled. The study records the experiences of these mothers in challenging the dominant discourses and breaking stereotypes. However, while the study focuses mostly on the challenges these mothers have to face while practicing motherhood, not much attention

has been given to the techniques that they can adopt to care for themselves. Importantly, none of these studies on motherhood has examined the correlation between changing motherhood discourses in India and their cinematic representations.

According to the Dwyer, cinema in general, and Hindi Cinema in particular is an important tool in examining the social imaginaries and the public perception in India; because it plays a pervasive role in shaping public discourses. Hindi Cinema, becomes a "collective imagined text" which accurately represents the everyday world of the ordinary people (Dwyer, 2010). Hence it is important to examine the impact of cinematic representations of mothering the disabled with a view to developing a deeper understanding of the evolving culture of care. Julie Elman (2017) in her work on the representation of disability in popular culture in the US has identified certain recurrent tropes in their portrayal of a disabled person such as the "inspirational hero" or an "object of pity" or as the "sinister and evil", ugly pirates, criminals, witches, villains, or ugly old women; the "eternally innocent," which is commonly associated with intellectual disability; the "victims of violence"; the hypersexual or the asexual being; or the undesirable person incapable of sexual or romantic interactions. Similarly, Chakraborty (2021) notes that these were also prevalent in India, and here disability is seen mostly-

> as a supernatural punishment (*karma*) which is worse than death, or the disabled as evil crook (e.g. *Jeevan Naiya,* 1936; *Mehboob ki Mehendi,* 1971; *Sholay* 1975; *Dhanwaan,* 1981; *Omkara,* 2006; *Haider*, 2014); as a comic interlude (e.g. *Judaai,* 1997; *Mujhse Shaadi Karogi,* 2004; *Tom, Dick and Harry,* 2006; *Pyaare Mohan,* 2006; the *Golmaal series* 2006, 2008, 2010); as heroism (e.g., *Dushman,* 1998; *Aankhen* 2002; the *Krrish* series, 2006, 2008, 2010); or innocence (e.g., *My Name is Khan*, 2010; *Barfi*, 2012; *Koi… Mil Gaya*, 2003); as an object of pity and dependence (e.g., *Dosti,* 1964; *Khamoshi: The Musical,* 1996; *Fanaa,* 2006); and as social maladjustment (e.g., *Gora Aur Kala,* 1972; *Ram Tera Desh,* 1984). (p. 95)

In post 2000, Hindi Cinema has witnessed a surge in films that represent the lives and experiences of people with disabilities instead of them being part of the subplot (Mohapatra, 2017). These films include *Koi... Mil Gaya* (Roshan, 2003) *Iqbal* (Kukunoor, 2005)*, Guzaarish* (Bhansali, 2010)*, My Name is Khan* (Johar, 2010), *Barfi!* (Basu, 2012) and *Kaabil* (Gupta, 2017) and others. However, only a handful of films have depicted the experiences of families caring for disabled children. It started with *Black* (Bhansali, 2005) which portrays the journey of a blind and deaf child. *Taare Zameen Par* (Khan & Gupte, 2007) remains a landmark film in Hindi Cinema for its contribution towards generating mass awareness about disability care. *Paa* (Balki, 2009), *Margarita with a Straw* (Bose, 2014), *The Sky is Pink* (Bose, 2019)*, Jalsa* (Triveni, 2022), and *Salaam Venky* (Revathi, 2022) are other films which depict children with disabilities who are greatly dependent on their mothers for care. This phenomenon has also included a shift from the on-screen portrayal of homogenised mothers to the depiction of mothers who are rescripting the contours of mothering and caregiving through the strategic negotiation of the stereotypes in unique ways. This shift of Hindi Cinema towards creating more spaces for women-centric films can also be attributed to the changing socio-cultural scenario (Anwer & Arora, 2021; Karandikar et al., 2021; Paunksnis & Paunksnis, 2020; Arora, 2019; Manzar & Aravind, 2019). Informed by these important shifts in the mothering practices being depicted through Hindi Cinema, the chapter examines representations of sociological as well as psychological trauma that mothers experience while offering special care to their children with disabilities. Most importantly, the chapter takes note of the process of empowerment that these mothers go through as they cope with their grief.

Empowered Mothering through Mothering the Disabled

Mothers of disabled children go through a non-linear journey as they overcome parental burnout and chronic sorrow to practice empowered mothering. As has been discussed in the previous sections, mothers across cultures continue to be shamed and are blamed for the poor health of their children. As a result, they continue to feel guilty for having done something unwittingly to cause the disability in the child (Kandel & Merrick, 2003). It is to absolve themselves of the guilt, which often is deep rooted, and make up for their "lack" and "deviant" self, that these mothers with disabled children take up the challenge of becoming the "warrior-hero". The warrior hero mother is expected to "battle to attain resources and possible cures for their children" (Sousa, 2011). The extended family, health and education professionals, and other people in the vicinity refer to the importance of mother's love, and its all-encompassing capability to overcome all challenges, emphasising the role of mother in caring for the child and taking up their care work. (Aneja & Vaidya, 2016). The study highlights how scientific as well as cultural discourses simultaneously blame and glorify mothers of disabled children; they blame the mother for the pathological condition of the child and, at the same time, glorify her so that she is coerced into assuming roles that are beyond the regular roles of her being the mother. Thereby "shifting the historical burden on mothers from causing the intellectual disabilities (or any disability) of their children to curing them" (Sousa, 2011) While most of these studies focus on mothering children with intellectual disabilities, the films being discussed in the chapter deal with cerebral palsy in two cases, Duchenne muscular dystrophy (DMD) in one and Severe Combined Immunodeficiency (SCID) in another. Cerebral palsy involves motor and learning disability and DMD and SCID are genetic disorders; DMD leads to progressive muscle degeneration and SCID causes life-threatening problems with the immune-system.

The challenges faced by the mothers may differ in each of these cases, as they should for everyone, but each of them goes through life-altering experiences. Most of these parents are at the risk of developing parental burnout, when they "lack the resources needed to handle stressors related to parenting" (Mikolajczak et al., 2019). It is a state of intense exhaustion where a parent finds him/herself becoming emotionally detached from their children and doubts their competency as a good parent (Roskam et al., 2017). Parental burnout is caused because of prolonged response to chronic and overwhelming parental stress (Mikolajczak & Roskam, 2018). Parental burnout can lead to escape ideation, child neglect, and parental violence, and can have implications worse than job burnout (Mikolajczak et al., 2019). However, one of the most common causes of developing parental burnout is having one or more children with special needs which interferes with the healthy functioning of the family (Gerain & Zech, 2018; Lindahl Norberg, 2007). Parents are required to provide continuous and systematic childcare support to their children. They may experience loss of energy, physical fatigue, mental breakdown, anxiety about the future of the child, and a breakdown of relationships with their partner and other family members and friends, leading to isolation and loneliness. While parental burnout is a common phenomenon and affects both parents, mothers are more vulnerable to it. Mothers of children with developmental disorder experience endless sorrow, regret and a sense of guilt caused by their child's disability. This situation may very often lead to a loss of their personal autonomy (Sadziak et al., 2019). The endless sorrow caused in such mothers is called chronic sorrow (Olshansky, 1962). Chronic sorrow is a psychological response in parents with disabled children, but it is different from grief and depression and it could be permanent, periodic, or progressive (Burke et al., 1992; Eakes, Burke, and Hainsworth, 1998). Chronic sorrow stems from the realisation that the child has a lifelong disability or illness, or their inability to meet

developmental milestones when there are relapses in the disease, or recurrent hospitalisation, or they become more dependent on medical support, and they long for a desired child (Bowes et al., 2009; Gordon, 2009; Hewetson & Singh, 2009; Patrick-Ott & Ladd, 2010). Like parental burnout it is mothers who are more prone to developing chronic sorrow (Mallow & Bechtel, 1999; Hobdell, 2004). Their chronic sorrow may take the form of emptiness, guilt, and self-blaming (Fraley, 1986; Hummel & Eastman, 1991), fear (Fraley, 1986; Hobdell & Deatrick, 1996), sadness (Hobdell, 2004), and depression (Hobdell & Deatrick, 1996). However, while parental burnout is a result of the care work undertaken for the child and often creates emotional distancing from the child, chronic sorrow is a psychological state on account of the child's incapacity to live a healthy life and a concern for the child's future.

Studies suggest that there is a great deal of correspondence between the parents' coping with their child's disability and the Kübler-Ross (1969) grief elaboration theory in terms of the parents' journey through denial, anger, bargaining, depression, and acceptance (Calandra et al., 1992). The crisis builds up over a period and gradually they gather the courage to overcome the grief. Acceptance is an important part of this coping process. Some of the most common coping techniques adopted by such mothers include seeking social support, planful problem solving, escape avoidance, and positive reappraisal (Paster et al., 2009). However, in India, seeking social support is difficult and comes with affiliate and family stigma; these are common among caregivers, especially mothers (Banga & Ghosh, 2017). Here, practicing empowered mothering can be an effective tool of self-care. Empowered mothering comes from the idea that both mothers and children benefit when the mother lives her life and practices mothering from a position of agency, authority, authenticity, and autonomy (O' Reilly, 2008). Mothers who practice empowered mothering no longer view childcare as solely the

responsibility of the biological mother, nor do they consider round-the-clock mothering as a compulsory requirement for raising children. Empowered mothering is characterised by maternal agency, which involves the capacity to influence and take control of one's life. It liberates mothers from the overwhelming pressure of practicing intensive mothering constantly. Instead, it encourages active involvement from their partners, friends, and family in the caregiving process. The primary goal of empowered mothering is to bestow upon mothers the essential attributes of "agency, authority, authenticity, autonomy, and advocacy-activism," which are often denied to them in patriarchal motherhood (Hallstein et al., 2020, p. 30). Practising empowered mothering with a disabled child is difficult because the child requires special care, depending on the level of disability. Very often because of the stereotype and shame associated with disability, parents are not able to seek assistance from friends and extended family. Also, people need to have basic training, literacy, understanding, and skills to offer special care, many parents do not have the financial capability to afford such trained caregivers. However, they gradually reach a state of "constructive adaptation to the fact of having a child with disability" (Sadziak et al., 2019, p. 8). The scope for mothers with disabled children to practice empowered mothering is very limited, and only a few privileged could delegate their tasks to caregivers or other family members. Most of the mothers give up on their career, or cut down their work to take care of their child, because of the lack of "adequate childcare services and educational provisions" (Kingston, 2007, p. 116) However, some mothers are able to develop "informal careers", where their caregiving skills become a means of employment (Olesen, 1989) where they take up therapy and special education as professions, turning the adversity into opportunity (Aneja & Vaidya, 2016), and others believe that their child's disability has made them better persons, more patient, accepting, kind, and helpful towards other

people. Many of these mothers also become advocates for their children, voicing their concerns as a person with disability, and some also rise above and become maternal activists, acting independently or along with support groups, demanding the rights of the disabled (Ryan & Cole, 2009).

***Margarita with a Straw* (2014)**

Margarita with a Straw begins with close shots of Shubhangini preparing breakfast and getting her family ready for the day. We soon see her driving her husband and her children to their respective workplaces and schools and college in a camper van. She is indeed "bold yet gentle, strong yet domesticated." (Chakraborty, 2021, p. 102). As much as she is seen being involved with her family, we see her a little more involved with her disabled daughter, Laila. Shubhangini has also put in effort to style and design their lives in an accessible way with a power wheelchair and an accessible camper van for Laila, but Laila's college is not sufficiently accessible. Most importantly, unlike others, Shubhangini is convinced that Laila's cerebral palsy is only a bodily impairment, and it does not negatively impact the brain or Laila's intelligence. Shubhangini has largely overcome the initial inhibitions of mothering a child with disability. She does not in any way show an ableist approach, and believes that Laila, like any other child can fulfil her dreams. This same confidence is not present in her husband, who has very little contribution in the day-to-day activities of Laila; so, Shubhangini becomes the primary caregiver of her family. Shubhangini's approach to mothering is not an intensive one, nor is she ever unnecessarily protective of Laila, she gives her space and freedom to go about her life at college. Of all the mothers in this discussion, Shubhangini is most confident about her disabled daughter. So, when Laila gets an opportunity to study abroad, Shubhangini comes out in her support and decides

to accompany her, even when her husband is not willing to send Laila to New York for higher education.

When she starts living in the US, there is a shift; as soon as she finds herself spending more time with Laila, she becomes more protective and alert about Laila's wellbeing in general. It could also be that Shubhangini, who otherwise has a traditional outlook towards life, feels overwhelmed in the foreign setting. Her discovery of Laila watching porn, or Laila's selling off her heirloom jewellery to get an iPad further aggravates Shubhangini's apprehensions about Laila's ability to continue living in the US without her mother's supervision. At this crucial point, she feels a dilemma- "she must choose between seeing Laila as a child who needs her and accepting that Laila is her own person" (Chakraborty, 2021, p. 102). She feels assured when Laila brings home Khanum, whom Shubhangini sees as a friend and as someone who would be able to take care of Laila in her absence.

Khanum does take care of Laila, but she is more than just a friend, Khanum helps Laila to discover her sexuality and makes her realise that she may be a lesbian or bisexual woman. After her mother, Laila depends on Khanum for reassurance and care, and Khanum starts mothering her. Khanum, a confident young woman who was disowned by her Bangladeshi-Pakistani parents at the age of fourteen, following her coming out as a lesbian, is now a transnational activist. Khanum bolsters her confidence and helps her claim her body and its beauty and her autonomy. Laila has a hard time in college as a growing young adult, she battles her insecurity and tries to make friends with 'normal' people; she explores her sexuality through masturbation, casual sex with men, and her relationships with Dhruv and later with Khanum. Through these experiences we see Laila growing up and claiming her identity while redefining the physical and ideological barriers that have resulted in the "imposition of asexuality" which denies

the accessibility of sexual culture to disabled people, especially to a woman. Although she is shamed and chastised by Dhruv and Khanum for her supposed promiscuity, Laila urges the necessity of these experiences for her to sufficiently discover herself and her sexuality. Shubhangini, however, gives Laila the space and independence to discover herself, even after her initial inhibitions, she is able to allow Laila to continue on her own in the US.

For Shubhangini, it comes as a shock, when Laila comes out as a bisexual. As much as Shubhnagini loves Khanum and invites her to their place, it is difficult for her to accept Laila's bisexuality, and she feels betrayed; she stops talking to Laila and is visibly angry. Her disappointment is cut short when she is admitted to the hospital for her treatment of cancer. Even when she is accommodative about Laila's individual space, she is unable to accept her desire for and curiosity about sex and sexuality; her reaction to Laila's confession about her sexuality is an extension of the disdain she felt when she discovered Laila watching porn. Given her traditional Indian outlook, Shubhangini's outburst is understandable. Her disappointment is even greater because, until then, she had perceived Laila as her asexualised disabled child who needs her care and attention for every day-to-day activity. So, the anger and the silence thereafter are her way of accepting Laila as an individual with her bodily autonomy. She also feels concerned that Laila being disabled might be taken advantage of in her absence, and it is the first and only instance that we get a glimpse of her chronic sorrow. Post-hospitalisation Shubhangini realises she does not have much time left with Laila, so she forgives her and asks her to go back to the US, presuming the US would be a haven for her disabled bisexual daughter. Shubhangini's perception of the West sees it as lacking the ableist and homophobic tendencies present in India. Shubhangini becomes the means through which "the film subtly affirms Western exceptionalism by

geographically positioning ableism and inaccessibility in India and representing New York City as a haven for the disabled… NYU and The Big Apple seem like a land of plentitude-magically free of ableist prejudice, broken elevators, poorly kept sidewalks, or cabs that don't stop for wheelchair-users…. (the film also) positions homophobia as an ongoing problem of unenlightened non-Western attitudes." (Elman, 2017, para 9)

By the end of the film, Laila loses both her mother and Khanum, both women whom she loved dearly, and both of whom who helped her love herself. But the film does not end on a note of pity and sorrow. Instead, we see Laila taking herself out for a date, albeit with a little help from her father. She looks happy and confident with herself, sipping her favourite margarita with a straw. This image of a happy and confident girl after her mother's death is a reversal of the usual story where we mostly see the mothers mourning the untimely deaths of their children, as in *The Sky is Pink* and *Salaam Venky!* Instead, Shubhangini's ability to allow Laila her personal space and her acceptance of Laila as a separate individual has allowed Laila to grow and live a life on her own terms, even when she is not in the US.

***The Sky is Pink* (2019)**

The Sky is Pink is the journey of a couple who bring up a disabled girl child, along with a son, without any disability. Both the parents are seen equally invested in the care work. However, they have moments of marital discord on account of the caregiving responsibilities. While Niren (the father) and his family never explicitly blames Aditi (the mother) about the child's disability, however there is a tension between the couple, regarding who is genetically responsible for the disease of their daughters. Niren is quick to doubt her fidelity when a medical report suggests that their son may not be their child. They go through an "ideological crisis" as they overcome the instant shock of accepting the reality of their daughter and begin to live with her reality (Kandel &

Merrick, 2003, p. 744). Both adopt different means of caring for the child, which also becomes a reason for their occasional discord. While Niren trusts the doctors blindly, Aditi decides to do her independent research and develop her own understanding of the disease and its possible treatment and side effects. They had lost a daughter previously, and the guilt of losing her was equally present among both; and each blamed the other for the death. This form of blaming and feeling of guilt creates an ambivalence among parents. It is on account of risk like this that they had planned on not getting a child after Ishaan. So, when Aisha was diagnosed with SCID, both put in equal effort, trying to save her in their individual ways as they met a "reality crisis" in terms of finding a bone marrow donor, finding financial support, and having necessary knowledge; but they put in equal effort to overcome the crisis (Kandel & Merrick, 2003, p. 744). Niren donates his bone marrow and arranges for crowdfunding, as Aditi stays away from family in far-off London to cater to the health needs of the child. Niren and his family care for their son, Ishaan, in India. Separated from the family, Aditi becomes fiercely protective of Aisha and fastidiously monitors her health. She also records every moment with Aisha, not only to send to Niren but also because she fears that she may lose her daughter.

Aisha's disability and ill-health take a toll on her parents' relationship. Aditi develops parental burnout when she has to single-handedly care for Aisha in London; she has marital discord with Niren. Even when he shifts to London, their life does not become any easier. Both have to work in shifts to support the family while caring for their children. This too has a negative impact on their relationship- they rarely get to spend time with each other. Aditi is again burned out when Aisha develops pulmonary fibrosis later in life. Aditi monitors Aisha's condition sleeplessly for nights and has to be hospitalised following a mental breakdown. This ambivalence and inability to accept

reality results in chronic sorrow. On realising Aisha's death is near, Aditi decides to offer her all such experiences that she may miss out on after her death. This includes letting her date her crush, gifting her a pet, taking her for adventurous sports, and publishing her book. Gradually, she begins mourning Aisha even before her death- when she realises that it is their last Christmas with her. She oscillates between denial and acceptance. After Aisha's death she completely isolates herself, even withdrawing from her husband, which leads to their brief separation. It is difficult for her to cope with the loss, even when she has been preparing for it for years. For Aditi, the chronic sorrow is not only about losing Aisha but also about losing her identity as Aisha's caregiver.

Aditi had given up her job after she came back to India, and the family became financially stable. But this also meant Aditi had very little to do outside caring for Aisha. So, the loss of Aisha also leads to her loss of identity as the caregiver.

Aditi does not become a professional activist, but she takes up the role of speaking out for Aisha. She is the one who makes the major medical decisions with respect to Aisha, often going against the advice of the doctors and Niren. Aditi has the last words when it comes to having the child or not, as well as not going with Aisha's last operation. Aditi arrives at her decisions based on her research and informed understanding. She had understood with her first child that the biggest hurdle while mothering a child with disability is not having enough knowledge about the child's condition, so she leaves no stones unturned when Aisha is diagnosed with SCID. For Aditi, this knowledge is a form of empowerment, which helps her take special care of Aisha over the years and create some of the most beautiful memories with her. Although Aisha does practice intensive mothering by being always present for Aditi, and fulfills all her needs and desires, she never hides crucial information regarding Aisha's health. This honesty and

courage make Aditi a strong and powerful mother who possesses agency, authority, and authenticity as a mother. Most importantly, as a mother, she understands when it is time for her to let go of Aisha. The last operation would give Aisha a few more days, but it would take away her dignified existence. This acceptance of her reality was her real empowerment as a mother. Aditi also encourages and inspires Aisha to reach out to people to share her journey with disability. Aisha's story is inspired by a real-life motivational speaker and the author of *My Little Epiphanies,* and Aditi even pre-releases the book so that Aisha can look at her book before her death. For Aisha, her mother is an uncompromising feminist who makes some life-changing decisions. However, Aditi's inability to separate her needs from Aisha's becomes a hindrance; she forgets to take care of herself and her needs when she takes care of Aisha, so she feels the pain of losing Aisha even more than others, because with Aisha, she also loses a part of herself.

***Jalsa* (2022)**

A single mother, Maya, in *Jalsa,* acquires the custody of Ayush after proving in court that her husband is incapable of raising a child with special needs. As a mother she is overprotective of her child; she co-mothers her child with her mother and with the help of an aid, Ruksana. Maya's overprotectiveness is on account of caring for Ayush without the support of her husband and overcoming the "ideological and reality crisis" by herself (Kandel & Merrick, 2003, p. 744). Being a working mother, she installs a camera to interact with Ayush and monitor him from her office. We can also see her being fastidious about Ayush's health and rebuking her mother for her lapses. The camera monitoring Ayush reveals her deep-seated fear of becoming a bad mother by not practising intensive mothering. She also tries to make up for her absence by employing a paid caregiver. Maya strategically navigates social perception by having a

home in a high-rise building, a safe cocoon for Ayush far away from the prying eyes of the neighbours and equipped with modern technology to prevent trespassing. Even when the whole world has access to Maya's life as a journalist, she goes to lengths to ensure the security and safety of Ayush, by keeping him away from the public eye. Like Shubhangini, Maya has absolute maternal agency when it comes to Ayush and any decisions regarding her health are taken by her independently, while Aditi has to fight for it sometimes. However, all of them are overprotective and caring for their child which directly or indirectly stems from their fear of negative evaluation by the society in general, and their family in particular.

Maya develops burnout very early on; the mental stress of bringing up a disabled child without a spouse while also being a working mother takes a toll, and she commits an accident. She runs over a girl while driving back late at night after a long day at work, on account of a lapse in attention. Maya spirals down as she is bogged down by guilt and anxiety because if she is caught, not only would that affect the image of her news channel and her authenticity, but it would also put Ayush before public scrutiny, making his future insecure. Her several outbursts before her mother and her business partner are a result of the burnout that collects within her, which she is not able to voice out. In a poignant scene, she angrily lashes out at Ayush and blames him for making her life difficult. It might apparently seem inappropriate for a mother to blame her son, but she is already burnt out and anxious about herself and his future in her absence. Such blaming of the child is common among parents who fail to process the disappointment of giving birth to a disabled child, who would not be able to fulfil their hopes and ambitions. While Maya is overprotective of Ayush, she is also frustrated with him and disappointed with herself for failing as a mother. Ayush's slow development also affects Maya's career and ambitions (Kandel & Merrick, 2003, pp. 743-744). In the

case of the birth of a child with a disability, parents are not able to mourn the symbolic loss of a normative child (that was not born), while simultaneously trying to care for a child that exists and thereby demands additional care. Since there is no actual separation between the parents and the child, they do not get an opportunity to conclude the bereavement process, and they seem to be in a state of ambivalence. The chronic sorrow in *Jalsa* is not only present in the form of Maya's ambivalence. We also see it in the anguish and grief of Ruksana, whose child Alia becomes disabled as a result of the accident. For her to accept that her daughter would not be able to lead a normal life anymore brings her sorrow and great distress. She goes through her social media posts and realises how much of her she has not known. That way, she blames herself for not being with her the night of the accident; she also tries to punish the boy with whom she thinks Alia spent the night, and finally she seeks revenge when she realises it is Maya is responsible Alia's accident. Her chronic sorrow drives her to seek revenge by almost killing Ayush. In the last scene, both Maya and Ruksana are seen negotiating their grief as they sit silently by the shore of a receding sea, while their boys lie together on an abandoned boat, singing aloud the song of life.

Maya does not perform intensive mothering. She fails on several levels, but at the same time, she also seems to be the most humane of all the mothers being discussed. She falters when she is bogged down by stress, and she is strong enough to admit her flaws and shortcomings. Maya commands authority at the office, where she holds power over others, like a matriarch. It is at her work that we find her enjoying herself. She also has a commanding presence at her home, where her mother, Ayush, and Ruksana are afraid of her temper; however, here, she is mostly frustrated and controlling. She loses control only after the accident; she knows ethically that what she does is wrong, but she also knows she has to flee from the site; otherwise, it would jeopardise Ayush's life if she

were arrested. When she comes to know it is Ruksana's daughter who came under her car, she supports her financially and does everything in her power to help her access top-class medical facilities. Finally, when she masters enough courage, she confesses her guilt. For her, the real act of courage is to face Ruksana and surrender before her. For Ruksana, it is an act of empowerment to accept her daughter's acquired disability and not seek revenge. It takes them every ounce of courage to understand what the other is going through, and Ruksana, being less privileged than Maya, has a more difficult battle before her to care for a daughter with disability, with fewer financial resources and far less knowledge of medical and technical discourse. However, this mishap, makes both better human beings-more accepting, kind, and patient towards themselves and others.

***Salaam Venky* (2022)**

Sujata (played by Kajol) has to divorce her husband and give away the custody of her daughter so that she can provide the necessary care to her son with a disability, Venky. She is also portrayed as an overprotective mother who has acquired sufficient knowledge about her child's disability so that she can make informed decisions regarding his health. Much like Maya, Sujata has to overcome the "ideological crisis" single-handedly as well as the "reality crisis" by accepting the disability of her son and separating from her daughter, as well as finding resources for the treatment of Venky (Kandel & Merrick, 2003, p. 744). She moves to an Ashram and Venky grows up in the spiritual environment of an Ashram which deeply influences him. Although Sujata fights against all odds to bring up Venky, she faces her real challenge when he asks her to fulfil his last wish of donating his organs and to seek his right to die with dignity. As a mother, Sujata is faced with a moral dilemma; her role as a good mother expects her to protect and care for her son and not file a petition seeking his death. At the court, the

public prosecutor questions her integrity and accuses her for being a mother who might be seeking the death of her son to trade his organs. It is not unusual for mothers with disabled children to encounter such kind of shaming and they are blamed for their inability to take care of their children and family (Kandel & Merrick, 2003). The film highlights the challenges of a single mother bringing up a child with a disability while adhering to the societal expectation of being a good mother. The film also brings into media discourse the need to provide these mothers and other family caregivers with institutional support.

Another important concern this film brings forth is the debate on euthanasia, which is prevalent in several parts of the world. The debate is equally significant in India given that it cuts across various issues- legal, ethical, spiritual, and public health. Article 21 of the Indian constitution safeguards the Right to Life of its citizens; euthanasia, which is a form of suicide, is therefore incompatible and inconsistent with the right to life. A welfare state has a maternal relationship with its citizens; it is entrusted with the responsibility of protecting its citizens, so when someone petitions for his/her right to die with dignity, the state faces a legal as well as an ethical conflict, much like the mother (Math & Chaturvedi, 2012). People opposing euthanasia argue that pushing for euthanasia would eliminate the aged and the chronically ill; the state would also stop investing in healthcare leading to commercialisation of the health sector; the patient may be mentally ill or depressed and may not actually be seeking death in a healthy state of mind; opportunistic relatives could also use it as a means of inheriting the property or of indulging in organ trading. So instead of mercy killing, this group emphasises on the state's role in providing care to the terminally ill patient and supporting the caregivers. There is also emphasis on the need for palliative care for these patients to alleviate their pain, so that they can live the rest of their lives with

dignity (Sinha et al., 2012; Math & Chaturvedi, 2012). Those supporting euthanasia have cited the example of terminally ill patients who require long-term intensive care from their caregivers which not only becomes an emotional, psychological, and physical burden and drains their time but it becomes extremely expensive to continue treatment. Sometimes, the patients refuse care, to die with dignity, besides the patients do not wish to be a burden to their family caregivers any more (Sinha et al., 2012). *Salaam Venky* knits together all these arguments and offers a balanced representation of the State, the caregivers (doctors and mothers), the patient, and other stakeholders. Passive euthanasia has been legalised in India under strict guidelines only in 2018, while the film is set in and around 2004. Media in general and films like Salaam Venky play a major role in raising awareness and generating discourses around such complex medico-legal issues**.**

Sujata never considers her caregiving responsibilities as a form of burden; however, as Venky's organs start failing, he no longer wants to depend on medical support to continue what he feels is an undignified life. He also feels that his existence has become a burden for his mother and prevents her from living life to her full potential. Initially, Sujata disapproves of Venky's last wish, yet she files a petition in court, and with the help of media intervention, she and her lawyer garner support and awareness regarding euthanasia and organ transplants among the masses. Much like Aditi, Sujata's life too revolves around Venky as she performs intensive mothering, and the only possible way she knows to live her life is to live as his caregiver and live for him. However, they do not receive a favourable verdict at court. The judge recognises the sincere and courageous stand taken by Venky; however, he states the jurisdiction of law and how the public health care system is not in the position for an immediate overhaul.

However, Venky dies a peaceful death soon after, in his mother's lap, as she sings him a lullaby. Sujata fulfils his last wish by donating his eyes to Venky's childhood friend and lover. For Sujata, who has lived the best part of her life fighting all odds to keep Venky alive, it is an act of empowerment to let him go. The film personifies death as a character with whom the mother indulges in a conversation. In their final rhetoric of wit, Sujata realises that it is in the best interest of Venky that she should allow him to find a peaceful death. Venky's longing for a life that would let him pursue his dream of being independent of any assistance is pensive and makes her realise why Venky finds it easier to die than to continue living with assistance and support. Sujata's empowerment also lies in her ability to become his voice when she seeks justice at court; she also becomes his representative, and like Aisha and Ayush, Venky becomes the changemaker that society needs.

From Maternal Paradox to Empowered Mothering

Aditi, Shubhangini, and Sujata, live their entire lives as primary caregivers of their children. Although Maya delegates her caregiving duties and has a job outside her caregiving responsibilities, she has no less of a burden on her shoulder. It is difficult to understand for whom the journey is more difficult- Ruksana, whose child acquires disability after her accident, or the others who are born with a disability; it also cannot be measured who is blamed more for the disabilities of their children. However, for all of them, the journey of mothering a disabled child remains a lonely affair where only a few receive help from their partners, family, and friends. It also becomes even more difficult when such mothers also have to cater to the needs of another child who may or may not be disabled.

For those like Shubhangini, they start to mould their lives around their disabled child and continue their day-to-day activities after constructively adapting themselves. But

often, mothers are not able to fully cope with their children's disabilities, as in Aditi, who continues to live in chronic sorrow even after Aisha's death, or like Maya, who develops parental burnout while trying to switch between her roles as the caregiver and as the breadwinner of the family. This apprehension about their future and the fatigue of continuously being present for their children do take a toll on these mothers and their physical and mental wellbeing. Most often, societal perception overlooks these hardships and continues to blame these mothers for their inability to adhere to the culturally sanctioned idea of the good mother who gives birth and brings up a socially acceptable, healthy child. At the same time, these mothers are glorified by the medical discourse so that they continue as the primary caregivers who consider all the needs of their children single-handedly. Though these mothers problematise such expectations, they are in no way larger than life characters; they have their lapses, and they go through a non-linear journey of parental burnout and chronic sorrow, leading to moments of empowerment. It should also be noted that most of them belong to the upper-class, upper-caste privileged section of society, so it is comparatively easier for them to make their lives accessible for their disabled or chronically ill children, which may not be possible for those like Ruksana, who is a house-help living in a slum in Mumbai. If not for Maya's help, she would not have been able to afford Alia's treatment, or, for that matter, save her. It is also not clear how Sujata provided for the expensive treatment of Venky, but it is surmised that the ashram they were part of helped her significantly. Indeed, with financial security, taking care of medicine and resources becomes easier, but the societal stigma and negative evaluation continue. It is also to be noted that in most of these cases, the fathers are either absent or have nominal roles in the lives of these children. Apart from Niren, the husbands are not supportive, so a part of the challenge for them is also to perform the role of both parents. Maya and Sujata separated

from their husbands because of the disabilities of their sons, which led to marital strife. Mothers like Aditi and Sujata also face the crucial challenge of having to choose between their children's life and death. As a mother, it is beyond them to watch their children gradually die before them, but it is equally difficult for them to watch them go through excruciating pain as they continue to be on life support systems.

Yet, these women gather courage, take charge of their lives, and, in the process, help their children too. Aisha, Laila, Ayush, and Venky grow up as young individuals who are much more than the disability through which society chooses to perceive them. This perspective of empowerment comes to them through their strong and empowered mothers who dared to challenge the culturally sanctioned norms of mothering. Each of them lays out their own rules and becomes the changemaker in their own unique ways. While Maya and Sujata decide to co-mother their children with friends and other family members, Aditi has to seek professional help to overcome her sorrow and burnout. Maya does not go to a professional, but her confession at her office and her final encounter with Ruksana help her find closure. The calm, receding sea at the end of *Jalsa* signifies the long battle Maya and Ruksana have been fighting with themselves and with the world. Both understand the difficult situation they are in, and both now need each other for their sustenance. It is safe to say that these caregivers require care and institutional support beyond the informal support of their family and friends. Institutional support may help them build a life outside of their caregiving responsibilities and separate their needs from those of their children, thereby allowing them to see their children as separate individuals even when they may be partially or fully dependent on them. This may also lead to raising awareness and eliminating social stigma around disabled children and their mothers.

Hindi Cinema is yet to tell us Ruksana's side of the story- the journey of a mother caring for a disabled child with very little formal education who is not financially privileged to afford the care of a child with a disability. Nor has Hindi Cinema represented a disabled mother on screen who herself requires care and therefore is often considered incompetent to care for her child, although there is a glimpse of this when Laila takes care of her mother at the hospital when Shubhangini is treated for her cancer. These films analysed in this chapter successfully represent the trials and tribulations of mothers offering special care and have dismantled the homogenised representation of mothers on screen. This has opened avenues for acceptance of such mothers in real life, where their struggles will not only find recognition but might also find a forum to advocate for and address their demands and interests. These mothers not only require the support and understanding of their family and friends, but they also require adequate institutional support from the government, in the form of creche, special schools, and more affordable and accessible special care services. They also need special care services, which might help them take care of their mental health as they continue to be the primary caregivers of their children for such a prolonged period. The representation of more such mothers from the margins on screen will not only reflect the positive changes in society but also accelerate such changes