

“Happiness of Us Alone”: Exploring the Debate about Prenatal Diagnostics and Parental Choice

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Abstract

The paper will explore the issues surrounding disability primarily through the analysis and critical study of “Happiness of us Alone” and “Koshish”. Both the films deal with issues surrounding parental choice and caregiving with respect to disability. The first part of the paper briefly introduces the issues of caregiving and disability through Rabindranath Tagore’s Story “Subha”. The paper then goes on to discuss the current debates on parenting and caregiving through Ghai and Johri’s paper on prenatal detection of disability. This will be followed by a discussion of the 1961 Japanese film “Happiness of us Alone” and the 1972 Indian film “Koshish” which bring to the fore, issues of disability rights and experiences of parenthood and caregiving.

Key words: prenatal detection, caregiving, disability, Tagore, “Subha”, deaf and mute, community

Rabindranath Tagore’s short story “Subha” begins with an account of Subha, or Subhashini, a mute girl’s life in a small hamlet. Subha is withdrawn into her own world owing to her speech impairment. Faced with enormous social bias Subha knows that her parents are worried about her uncertain future. Her mother looks at her with aversion and as a blot on her own self. For her father she is a liability. Yet it isn’t as if the girl cannot communicate all-together. It is nature that fulfills her want of speech, and she is able to communicate with her cows, who in-turn know Subha’s touch. Social circumstances and a fear of ostracism from their community force the parents to look for a bridegroom for her in a different town. Her helplessness is highlighted in her vehement resistance towards marriage which is expressed through tears. This, however is understood by no one around her and she is forced to leave her home, village and her beloved cows, due to sheer parental pressure and social convention.

The story, apart from being a poignant exploration of the theme of isolation and fear, opens the debate about parenthood and caregiving of disabled children especially in impoverished households. Subha’s parents are burdened by the prospect of her marriage. They, like Subha, face stigma and hostility from the community which they belong to. The urgent decision to marry Subha off and send her to a distant land is a calculated one. While parental

caregiving of disabled children comes with its own physical demands; the mental pressure and strain are also faced often by caregivers. Subha's parents Banikantha and his wife can therefore either be interpreted as selfish and cowardly, but Tagore tries to confront the readers with Banikantha's mindset. In a traditional rural society, parents are often blamed for congenital diseases of their children. Her mother's being "ashamed" of Shubha stems from such social bias often internalized by parents. The choices available to her parents are therefore already constrained by the financial pressures they face in addition to the social stigma and fear of further ostracism. The tragic end of the story forces the reader to rethink the social aspects intrinsically associated with disability and its perception. Tagore therefore offers a poignant commentary on the negative social attitude towards disability which may percolate into parents and caregivers as well.

Recent debates concerning prenatal detection and genetic testing further complicate the social attitudes towards disability in the present day. Although genetic testing is not applicable to hearing and speech impairments per se, the very idea that there can be an ableist bias associated with parental choice and caregiving is a big one. In order to understand this debate, one can first look at the concerns of disability activists and scholars in this context.

Disability Studies in India: Global Discourses, Local Realities edited by Renu Addlakha, published in 2013 revolves around various issues concerning disability in the contemporary times. By bringing in various narratives of individuals with disabilities, and caregivers, the essays in the book try to pose various methodological questions concerning the political emergence of disability studies in India. Concerning the debate about caregiving and disability, an essay in the book by Anita Ghai and Rachna Johri entitled "Prenatal diagnosis: Where do we draw a line?" comments on the intersectionality of disability and gender rights particularly surrounding the debate about the right to consider prenatal diagnosis of disability as an ethical ground for the termination of pregnancy.

To begin with, the debate about prenatal detection of a congenital medical condition is mostly associated with intellectual disabilities in general and Down's syndrome (DS) in particular. Prenatal tests are often conflated with the detection of Down's syndrome, essentially because other intellectual disabilities are mostly not diagnosable prenatally. But the debate surrounding the termination of pregnancy with the possibility of Down's syndrome is not only concerned with DS in particular but other disabilities which may be prenatally discovered in near future. Ghai hints at such possibilities becoming important issues in ethics concerning genetic technologies which will make numerous choices possible. The debate regarding prenatal detection of birth abnormalities therefore remains to be a crucial one and the social construction of disabilities, both physical and intellectual has a significant bearing on the issue. It is for this reason, that Ghai and Johri in their essay connect the subject of prenatal diagnosis of disabilities with the wider area of social attitudes towards disability. Ghai argues that while the discursive construction of pregnancy with a potentially disabled child is such that instead of assisting and facilitating prospective parents to make informed, autonomous decisions, medical professionals tend to adopt a directive approach by projecting the termination of the pregnancy as not only an advisable, but also a routine, "usual" and a highly necessary procedure. The ableist social bias makes the decision to rear a child with a disabled body look illogical and ridiculous. This

attitude, Ghai and Johri argue borders upon a larger ableist social bias. While individual choice, they conclude, must be promoted, what needs to be addressed is the scenario in which this choice takes place in a particular social space in which disability does not have a negative connotation. This social bias needs to be first challenged in order to have a more nuanced perspective towards prospective children with disability. Furthermore, the Authors rightly concede that the disability community in India is involved with issues of basic survival and that there is as yet no space for discussion of the implications of new reproductive technologies. Nonetheless, the issues raised by them are of particular importance given the changing scenario in the area of new genetic technologies.

Parental attitude and Disability

In this section I compare and contrast a Japanese Film and an Indian film with respect to debates about parental choice and caregiving. In the 1961 Japanese Film “Happiness of Us Alone” directed by Zenzo Matsuyama, the dilemma faced by a deaf-mute couple are vividly shown with respect to the choice of whether to start a family at all. Faced by social and economic turmoil, in postwar Japan the two characters Akiko and Michio fight all odds to have a lifestyle and family like everyone else. Their firstborn dies owing to an accident which is escalated and proved fatal due to their inability to hear his cries. Akiko in fact contemplates killing herself because she feels that she isn’t able to take care of the child suitably. The film however finally ends with their apparent victory at having succeeded in their ordeal of parenthood when their second born son writes an essay about his parents. Radical and path breaking for its times, the film however projects a bitter confrontation between the deaf-mute and the “normal world”. In one of the scenes, Akiko describes her life as full of suffering and pain. Michio implores her to not give up as neither of the two can survive alone. They should help each other, or they will “lose” to “normal” people.

This element of anger and hostility towards the so called normal world seems to affirm the bias that the disabled or the physically impaired have no place in a “normal” society. If they have to survive, they may have to fight for their own place. This however may not be a favourable proposition with respect to disability rights. As the Indian poet and filmmaker, Gulzar also affirms. “The (Japanese) film revolved round the theme of creating a special and separate world for the disabled, an idea which appeared to me to be very reactionary.”(Mondol 2017). Nevertheless, the critically acclaimed film does show a realistic picture of disability by showing the everyday life of these two people. The impairment of the protagonists is only one of the aspects of their rounded characterization. The debate of parenthood and disability is also touched upon by the film, though not in a very sustained manner. Nevertheless, the film does bring to the fore, important questions about disability and parenthood.

Analyzing the Indian Film “Koshish” with Respect to Parental Care and Disability

Inspired by the above discussed Japanese film, “Koshish” deals with the issues of disability and parenthood, but handles the subject in a slightly different manner. The protagonists, here are Hari Charan and Aarti, both hearing and speech impaired, who struggle to make a livelihood. Despite all odds the two get married and decide on having a family of their own. They are frequently shown to laugh, joke and argue with each other. Aarti and Hari are distinctly different from

Akiko and Michio. In a scene Hari plays a prank on a sleeping man by whistling loudly in his ear. The fact that disability is not a problem in itself is shown effectively in the film. Aarti and Hari, despite fighting odds do not necessarily view their lives as an endless confrontation with the “normal world” as Akiko and Michio.

Initially, Aarti has her reservations about having a family at all, as she believes that Hari’s and her own child will also be born with a hearing impairment like themselves. Hari on the other hand vehemently argues that their child will be able-bodied. This also throws off balance, the assumption that the negative attitude towards the possibility of having children born with congenital disorders may a tendency of only the able bodied. Despite having hearing and speech impairments themselves, they may nevertheless prefer to have an able-bodied child. In one of the scenes, the duo become increasingly anxious believing that their child is indeed born with a hearing impairment. Hari becomes extremely worried over the hypothetical possibility of their child being born deaf. This instance however may not be interpreted as a negative attitude towards disability in general. Both Hari and Aarti are themselves at a loss in forever trying to fit into a social structure where their disability is always a deterrent in their ability to communicate with the people around them. It is these struggles which make them perhaps ambivalent about the possibility of having to raise a child with the same impairment as theirs. The last scenes of the film exhibit this standpoint more clearly. The film ends with the scene in which Hari’s son, Amit is faced with the choice to marry someone with congenital deafness. Amit agrees to be married to her and the film ends on the final note that the “Koshish” or the effort continues. The idea projected here, is that it is not confrontation, but an assimilation that is a more appropriate way to make effective changes with respect to disability.

While “Happiness of us alone” ends with the couple’s son writing about his parents in an essay in school, which heralds a new beginning for Japan, “Koshish” on the other hand ends on a different note. The writer-director Gulzar affirms that he did not want to portray disability and disabled as separate from the rest of the world. “I wanted to prove that the disabled are part and parcel of society”. The film thereby goes well beyond its Japanese counterpart in its sensitization on the issue of disability. It pushes for the cause of the inclusion of the disabled community within the society, not as a separate independent whole as the Japanese film. The final scene in “Koshish” is therefore an effort towards creating a legitimate place for disability in the otherwise unfriendly “normative” world.

Irrespective of the positive social attitude represented in the film, the film nevertheless throws off balance, the assumption that the ableist parental choice is only restricted to able-bodied parents. The anxiety that Aarti and Hari face is representative of the fact that irrespective of their own identification with disability, their choice as parents may still be ableist. These debates become important when one is faced with the new issues that have arisen due to the recent advances in prenatal diagnosis. Yet one has to also notice that such choices become harder in the absence of community support. An important aspect of adopting a positive social attitude that Ghai envisions is intrinsically associated with not only assimilation but also consolidation of the disability community, including caregivers. What parameters are chosen to make the decisions about prenatal diagnosis choices will definitely depend upon the social attitudes to disability as Ghai points out. But the consolidation of disability community as well as caregivers

is an important issue that has to be taken into account. A positive social attitude towards disability will be a prerequisite to ensure a balanced perspective towards reproductive technologies in future.

References

Journal Papers

Acharya, Kruti. "Prenatal Testing for Intellectual Disability: Misperceptions and Reality with Lessons from Down Syndrome." *Developmental disabilities research reviews* 17.1 (2011): 27–31. PMC. Web. 9 Apr. 2018.

Asch, A. "Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy." *American Journal of Public Health* 89.11 (1999): 1649–1657.

Wright, Joyce A. "Prenatal and Postnatal Diagnosis of Infant Disability: Breaking the News to Mothers." *Journal of Perinatal Education*, vol. 17, no. 3, 2008, pp. 27–32., doi:10.1624/105812408x324543.

Blogs

Mondal, Sayantan. "Gulzar's 'Koshish' was inspired by a Japanese film, but it is no unthinking remake" Scroll.in, December 13, 2017, scroll.in/reel/860661/gulzars-koshish-was-inspired-by-a-japanese-film-but-it-is-no-unthinking-remake

Newspaper Articles

Caden, Sarah. "Down syndrome and the debate on abortion" *Pressreader*, 4 Feb 2018. www.pressreader.com/ireland/sunday-independent-ireland/20180204/284734862071410

Film/Video

Gulzar. "Koshish." YouTube, uploaded by Shemaroo, Feb 7, 2011. https://www.youtube.com/watch?v=w5o8d76khkA. Accessed April 10 2018.