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Reclaiming Womanhood: Sexuality, Violence and Women with Disabilities

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Abstract

This paper addresses the issue of sexuality and violence and how they are inextricably linked in women with disabilities. Perceived by the family as well as the state to be vulnerable to sexual violence in terms of assault and rape, what remains under-examined in case of women with disabilities is the violence that is committed by not regarding them as sexual beings with desires for emotional and sexual fulfilment. By depriving them of roles that are available to able-bodied women and considering them as non-sexual beings, their humanity and dignity is compromised. Drawing from the field work with women with disabilities, the paper argues that despite family support, institutional rehabilitation and government initiatives, issues of sexuality, sexual identity, companionship, and reproductive rights of disabled women are often glossed over. The paper locates female experience of disability and sexuality in the larger context of feminist debates about the female body and argues that a rights-based approach will address the needs and aspirations of disabled women. Additionally, the paper also examines specific articles of United Nations Conventions on the Rights of Persons with disabilities (UNCRPD) that acknowledge the needs and aspirations of women with disabilities and their right to have a home and family.

Keywords: gender, violence, disability, sexuality, rights

Introduction

The silence around questions of sexuality within disability studies has been broken by a range of scholars both within feminist and disability studies and has opened up areas that were considered peripheral to both medical and social model of disability analysis. (Addlakha 2007; Garland Thomson 2002; Shakespeare 2000). Over the last two decades, there has been a growing concern about the centrality of sexuality while addressing the rights of the persons with disabilities that emphasize moving beyond the earlier models of rehabilitation. Tom Shakespeare, one of the early scholars to draw attention to question of disabled sexuality, cites Liz Crow:

> I've always assumed that the most urgent disability civil rights campaigns are the ones we're currently fighting for—employment, education, housing, transport, etc…For the first time now I'm beginning to believe that sexuality, the one area above all others to have been ignored, is at the absolute core of what we're working for…. You can't get closer to the essence of self or more 'people-living-alongside-people' than sexuality, can you? (Shakespeare 165)

Recent theoretical interventions in disability studies have drawn attention to the limitations of social model of disability that turn away the attention from the issues of embodiment and focus on socially constructed attitudes to disability. While persons with disabilities suffer stigmatization more because of societal factors than because of their impairment, the attitudes towards women with disabilities in particular are more exclusionary and makes them doubly disadvantaged, because of their gender and disability. The salience of gender in disability analysis is noted by Nilika Mehrotra (2006) who argues that disability is gendered, culturally constituted, and socially negotiated. The issue of sexuality also has a gendered dimension, especially in a country like India, where sexuality of women with disabilities and their reproductive rights are often glossed over even within disability rights movement (Addlakha 2007). While the discussion of sexual and reproductive health rights of women with disabilities have begun to gain visibility in research, it is still overlooked in policy making, planning and implantation of welfare schemes. This paper addresses the question of sexuality by juxtaposing the personal narratives of women with disabilities that are silent about issues of sexuality along with an examination of few recent court cases that deal with sexual violence against disabled women and how the state appropriates disabled women's sexuality. Additionally, the paper also looks at the specific articles in UNCRPD 2008 which take cognisance of the needs and aspirations of women with disabilities and how this has impacted research and analysis.

Theoretical Framework

Women's experience of disablement has more to do cultural expectations of the female body and the traditional roles that they are expected to perform in family and society at large. There is an idealization of female body and any deviation from the normative prescriptions of femininity excludes women from being desirable and acceptable. This holds true for able bodied women also who are shamed for being dark complexioned and overweight and may have difficulty in finding suitable matches. Given these idealized notions of desirability, disabled women become doubly disadvantaged and find themselves excluded from the general category of women. Questions of companionship, intimacy and sexuality are relegated to margins, rather they remain unacknowledged by the family. In the Indian context, where arranged marriages are fairly common, the onset of disability excludes them from the realm of womanhood and this causes more pain than the fact of having an impairment. Thus, as discussed above, those cases where disabled women have access to traditional roles of being a wife and a mother, they tend to have a positive self-concept and feel more fulfilled. Quite ironically, these traditional roles confine women in a patriarchal society and they seek to liberate themselves from it. Women with disabilities thus may experience "role lessness" (Fine and Asch 1988) as roles of nurturance associated with motherhood and wifehood may not be made available to them. Feminist theory has at length examined the commodification and eroticization of female body, but what women with disabilities face is 'asexual objectification,' that they are asexual beings and questions of sexuality are outside their domain. Combining disability framework with insights of feminist theory yields rich insights to understand the gendered dimension of disability and scholars like Rosemarie Garland Thomson, have dealt with it in an early essay titled "Integrating Disability, Transforming Feminist Theory" where she argues that feminist disability theory goes beyond traditional issues associated with disability like accessibility, health, prosthetics, beauty etc. and address "broad feminist concerns as the unity of the category 'woman,' the status of the lived body, the politics of appearance, the medicalization of the body, the privilege of normalcy, multiculturalism, sexuality, the social construction of identity, and the commitment to integration" (259). The issues related to mainstreaming and integration of women with disabilities and acknowledging their aspiration for home and family was an important takeaway from my interaction with them.

In the Indian context, where women's movement has won impressive victories, the issues of disabled women remained side lined until recently when there is an acknowledgment of their plight both in policy documents and even in theoretical discussions of disability. According to the Report of the Working Group on Empowerment of Women for the XI Plan*,* prepared by Ministry of Women and Child Development, disabled women are considered "incapable of fulfilling the normative feminine roles of homemaker, wife and mother." The plan document, for the first time acknowledges that:

> The majority of women with disabilities in India suffer the triple discrimination of being female, being disabled and being poor. Indeed not only are they a socially invisible category but their plight is worse than both men with disabilities and other non-disabled women. (91)

It was only in the eleventh plan that women with disabilities came to be regarded as a distinct social category. It was acknowledged that they do not have fulfilling relationships, cannot do household chores efficiently, and keeping their vulnerable position in mind recommends a host of initiatives to mainstream them like creating a separate wing for women Disability Commissioners' office, allowing representation in state and central co-ordination committees, appointing disabled women as field workers and project facilitators to incorporate their concerns and enhance their visibility.

Women's experience of disablement offers crucial insights into the gendered dimension of disability and how embodied differences between women with disabilities and men with disabilities shape their experiences of the world. I was part of the research project conducted by Women's Studies Development Centre, University of Delhi, which required me to gather lived experiences of women and girl children with locomotor disabilities. Supported by Amarjyoti Rehabilitation and Research Centre, Delhi, a non-profit organization working for the orthopedically disabled, the study focussed on the lives of the orthopedically disabled women and girl children and multiple levels of disadvantage they face due to their gender and disabilities. The project involved interviewing women and girl children and documentation of their lived worlds and experiences about how disability had impacted their lives. The purpose of using gender as a primary analytic category was to examine the specificity of experiences of women with disabilities and seeing them as separate from, but related to their single minority group of women and physically disabled. As there is little or no understanding of how such women live their daily lives, an attempt was made to uncover the misunderstood and neglected world of their experience. The field work focused on the intersection between gender and disability in areas such as employment, education, health, and family life. Since most cases were drawn from lower income groups, the research also explored how class intersects with gender and makes them a doubly disadvantaged group. The larger objective of the research was how disability had impacted their chances and choices in their lives. Further, since the samples were drawn from a rehabilitation centre, the project also entailed examining the impact of institutional support and how it brought about changes in their lives in terms of providing them with different kinds of aids, opportunities for vocational training and employment and improved the quality of life.

Life-Story Model

Since the project required writing short life-sketches, the primary data collection was done through extended personal interviews, as most women were initially reticent to talk about their personal lives. The semi-structured, open-ended interviews became the principal means by which the active involvement of the respondents was solicited and also data collected about their lives. The research required engagement with the women and building connections so as to avoid the alienation between a researcher without disabilities and the researched. Though being a woman did help, it was not enough. It was shared cultural patterns and beliefs that put women at ease and talk about their experiences. Being a gender segregated study; interviewees were asked what is different for men with disabilities and women without disability to their experience as women with disabilities. A majority of women felt that men with disabilities are also subject to social stereotyping and face similar barriers but “they are still men after all” and can benefit from their status as men. Women with disabilities face double discrimination because of cultural and social prejudice.

Being a woman researcher without disabilities, my primary efforts to collect data were often fraught with anxieties as I was often perceived as an intruder, a professional ‘data collector’ on disability. Thomas G. Couser’s (2004) analysis of the ethics of representing ‘vulnerable’ subjects, for instance, those who are old, suffer from an illness, and those who are socially and culturally marginalized provides relevant framework for the research. While Couser is primarily concerned with representation of people who are connected to the biographer, either as family members, or other "trust-based relationship," and his concern with the ethics of representation in life writing is relevant for the such studies. In drawing attention to the methodological and epistemological challenges that arise in life writing, Couser alerts us to the danger inherent our desire to represent the “vulnerable subject.” According to him, writing about the lives of those who are sick or disadvantaged bestows a responsibility and care must be taken to "resist objectification" when representing them. While Couser draws on the works of many scholars like Joseph Shapiro (1994), Susan Wendell (1989) and Rosemarie Garland Thomson (2002), what is particularly useful is the "social model" of disability that he outlines and is relevant in the Indian context. Couser observes that, "Individuals with disabilities are handicapped or disabled by a physical environment that disadvantages them and a culture that excludes or stigmatizes them" (180). Fieldwork with women with disabilities made me realize that women were marginalized not just by the fact of having a disability but that they were excluded from the mainstream culture and normative expectations of gender. While Couser does not address the gendered dimension of disability, his insights are valuable for they draw attention to the challenges of representing vulnerable subjects. In collecting data on disability which was drawn from the rehabilitation centre, I faced similar representational challenges and wondered whether an able-bodied paradigm of knowledge can do justice to the experiences of disabled women. Representing the experiences of these women was a difficult task as there was fear of romanticizing them by projecting them as either extraordinarily brave or as helpless victims. The fact that these women received institutional support and were in the process of rehabilitation did imply their special needs and reflected concerted social efforts to integrate them into the society.

Marriage and Sexuality

The discussion of disabled female sexuality remains largely an underexamined subject in the Indian context and is addressed in relation to marriage and childbirth. Disability studies scholars have highlighted that having a disabled girl child is considered a liability by the family and there is a feeling of shame and embarrassment associated in acknowledging their presence. Also, it is widely believed that the presence of disabled girl children will hinder the marriage prospects of female siblings (Ghai 2003; Bhambani 2009). With a "strong son preference" in many communities in India, and birth of a female child is almost like a burden (Patel 2003). With such societal attitudes, if the female child is born disabled or suffers an impairment later, then it is considered a curse for the family and the parents' initial reaction is "she'd have been better dead than disabled for life" (Ghai 2003; Mehrotra, 2006; Addlakha 2008; Vaidya 2016). The female experience of disablement and the alienation experienced within the families undermines the self-concept of these women. Women with disabilities are excluded from the normative expectations femininity and are perceived as incapable of taking care of their bodies, without any desire for intimacy and privacy. Thus, there is a premium on making them economically self-reliant as they are likely to remain single and without companionship.

During field work and interaction with women, what emerged is an uneasy silence on issues of sexuality, reproductive rights, motherhood, and marriage. It is these silences that I want to highlight in the course of this paper. While most women were vocal on how rehabilitation had brought about changes in their lives and provided them with employment opportunities, they were reticent to talk about their personal lives. The process of rehabilitation was very central to shaping their confidence and self-concept. However, it would be erroneous to assume all disabled women under rehabilitation felt the same. Their sense of self-worth was dependent heavily on the support of their family, education, employment, marriage, and motherhood. Being financially independent was the top most priority for these women and their families as they were likely to remain single and hence had to fend for themselves. The parents of girls with disabilities also stressed the importance of education and vocational training as it would increase their employability. Most women skirted the issue of companionship, sexuality, and reproductive autonomy, but it figured tangentially in the context of marriage. One of the major anxieties was regarding the marriage of disabled women. Most women felt that finding a suitable match for the women with disabilities was extremely difficult. In a culture where arranged marriage is almost a norm though there is trend in increasing case of love marriages women's physical appearance is of utmost advantage and women with disabilities are perceived as outside marriage market. The question of companionship outside marriage does not arise as it is socially and culturally unacceptable. In any case, women with disabilities are not expected to have relationships and the families also do not entertain such possibility as they are largely are perceived as asexual. To some extent, women also internalize this notion and focus on education and employment as if that is the only aspect crucial to their well-being. The whole process of rehabilitation is also geared to make them independent and does not acknowledge that women might have emotional and sexual needs which would make them feel more secure and fulfilled. Though the women did not admit it explicitly, it was more than obvious that marriage, child bearing and nurturing were crucial to their self-esteem and important to integrate them into larger society. Women who were happily married and had children had positive self-concept and body image as is the case of Laxmi. While there are socio-cultural constructs and fears behind women with disabilities discouraged to marriage with the fear that their disabilities may be transmitted to the children,

> Laxmi, (23) who was stricken with polio in both her legs and could not walk at all, found institutional support enabling as it provided her with necessary aids to enhance her mobility and gave her vocational training in watch repair. Having learnt to ride a tricycle Laxmi became a self-reliant. Laxmi stands out amongst other women, because she found love in Laxman, who also suffered locomotor disability, and worked with her in the same repair unit. After a year of friendship, both decided to get married and then a year later were blessed with a baby girl. Marriage and motherhood boosted Laxmi's self-confidence as her family had always thought she would not get married because of her disability.

Motherhood

As with Laxmi's case, in my interaction I learnt these women did not want to be perceived as incapable of being good parents and unable to take responsibility regarding their lives and their children. Urmila had a very low self-esteem, as she was not allowed to look after her children.

> Urmila is reticent to speak about her motherhood and marriage. With her one hand amputated because of an accident in the water mill, she found difficult to go about her daily work. Though she was married of early by her family children to a man who did not have a steady job, her two children were taken by her in-laws on the pretext that she was incapable of looking after them. Guilty that she has not been able raise her children, she feels by depriving her of her 'role' as a mother, her emotional needs and personal dignity have been compromised.

Depriving women with disabilities of traditional roles associated with womanhood like caring for the family and motherhood affects their self-esteem. In a patriarchal society, these roles are central to women's self-concept since they are readily available to able bodied women. In fact, at times women are forced to succumb to marriage and motherhood much against their wishes and must struggle to study and work. Thus, women without disabilities are oppressed by imposition of normative constructions of femininity, disabled women are oppressed by exclusion from them. The case of Pushplata highlights, the insecurity of disabled women regarding marriage.

> Pushplata suffers from severe congenital disorder that has restricted her bodily movements. Though with treatments her situation improved and she could move on her own, she could not get married, as her family disapproved of the man she had chosen,

> since they felt it was not the right choice and she would not be taken care ofwell in another family. Pushplata acquiesced to the wishes of the family, but wonders if she will be able to find someone else.

One important aspect of rehabilitation centre is that women are able strike a bond with men who are afflicted with a similar kind of impairment, and some of these friendships result in marriages. Like Laxmi, Nazma also met her husband Tarique at the centre.

> Afflicted with polio, Nazma could not complete her graduation degree because she had to get her leg operated, but she did a multigrade teacher training, and became a special educator. Nazma's desire to marry Tarique was not met with approval from her family since he also suffered impairment in one of his legs and they assumed he would not be able to good care of her. But Nazma persisted and the family finally agreed. A year later Nazma was blessed with a baby girl. She feels happy and content.

Despite being economically self-reliant, what emerges from these examples is that a sense of well-being and fulfilment is experienced by women who feel mainstreamed in society by marriage and childbearing. Thus, denying the opportunities of traditional roles associated with womanhood is an act violence as much is physical abuse, social, and familial neglect. There are numerous court cases, that bring to light the problem of sexual assault on women with disabilities in the Indian context where the state also perceives the sexuality of women as a threat and seeks to regulate it.

If we were to examine the court cases dealing with violence against with women with disabilities, especially cognitive disabilities, it is found that it is largely sexual in nature and their sexuality is regulated by depriving them of bodily autonomy and reproductive rights by forced sterilization and abortion. Thus, while women with disabilities are considered outside the folds of femininity, they remain vulnerable to sexual assault and rape and this is borne out by court cases dealing with violence against them. One important aspect that emerges in many instances is that disability renders them incapable of taking care of their bodies and their need for privacy. Most importantly, they are regarded as incapable of making reproductive choices and fulfilling responsibilities associated with motherhood. Cases of forced sterilization and abortion highlight that at times such practices are authorized by the state itself and in the 'best interest' of women. Since women with disability are prone to sexual assault and rape, sterilization may save her from unwanted pregnancies. For example, in the famous Pune case in 1994, the Maharashtra government recommended hysterectomy operations on mentally challenged women on the ground that they have "no sense of hygiene" during menstruation (Rajan 2005). In Sucheta Srivastava v. Chandigarh Administration, the Punjab and Haryana High Court allowed the abortion of a mentally disabled woman against her consent, even though medical experts cautioned that such abortion would have adverse impact on the health of the mother. However, the Supreme Court stayed the order of the Punjab & Haryana High Court, and held that "the right to reproductive choice flows from the right to liberty under Article 21 of the Constitution" (Fox Mandal). The court noted that taking away a woman's choice regarding her own body would amount to infringement of her right to privacy. While there has been a greater awareness about women's reproductive rights over the years but such practices continue, and women with disabilities claim that the denial of their mothering rights through forced sterilization or general discouragement by doctors and family members not to have children is an experience of oppression. This is not to overlook repeated case of rape, molestation of women with disabilities. The most horrific instance is the rape of a mentally challenged girl in a Mumbai local train as other co-passengers looked on. No one came to rescue the girl (Telegraph Online 2002). These instances highlight that there must be greater awareness about the sexuality in women with disabilities and if they feel violated, they should be able to complain and get legal help if required. At the policy level, there needs to be a more inclusive framework so that women have access to be redressal mechanisms.

Human Rights Framework

Much of the concerns of disabilities studies have now begun to be acknowledged within human rights framework. The adoption of the of the UNCRPD, the Convention of the Rights of Persons with Disabilities and its optional protocol by the United Nations General Assembly on 13th December 2006 marks a historic moment in the global recognition of disability. Till date over100 members, including India have signed it. The CRPD is a major step in the recognizing the needs and aspirations of the disabled population which continues to be on the margins. The recent convention marks a significant move from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing them "subjects" with rights, who are capable of making their own informed decisions, claiming their rights and be active members of society. The Convention is designed as a human rights instrument with a clear, social development approach.

Articles 22 and 23

There are specific articles in CRPD that take into cognizance the needs and aspirations of women with disabilities. Article 22 titled “Respect for Privacy” guarantees the right to privacy that is crucial in relation to women with disabilities and includes privacy in family, home, correspondence, honour and reputation, and personal, health and rehabilitation information. Recognition of the right to privacy is important as it is linked to a number of other rights and entitlements, like right to home and family, health, reproductive autonomy, etc., whose implementation may be become more effective with the recognition of this right. The recognition of the right to privacy for women with disabilities ensures provides legal safeguards to the protection of their rights. Women with disabilities have been denied roles associated with womanhood, including the role of being a mother. The Article 23 of the CRPD titled “Respect for Home and Family” provides for this right. The article mandates that law should recognize the right to home, family, marriage, family, parenthood, and relationships on an equal basis with others for women with disabilities. The article also addresses the issues of both bodily and sexual privacy. Women with disabilities are often deprived privacy in relation to their bodies and the right to reproductive autonomy appears to be more restrictive for them as compared to non-disabled women. As discussed earlier, the fact that women with disabilities are denied their sexuality is itself a violation of this right. Women are often not given opportunities to engage in intimate relationships and there is a denial of their sexual needs, preferences, and identity. In case of institutional rehabilitation, this would mean that sexual needs and identity of women are recognized and respected. Recognition of right to privacy for women also includes privacy in personal hygiene and self-care within the home. Recognizing the motherhood of women with disabilities, the Act should also prohibit giving away a child of a disabled woman in adoption without her consent. As we have seen, with the adoption of the legal approach in the CRPD, the best-interest approach cannot survive and non-medical hysterectomy, forced abortion, etc. cannot be performed on disabled women without their consent. The law must recognize the reproductive autonomy of women with disabilities and their right to retain their fertility. The fact that even courts have authorized forced sterilizations and abortions, as discussed above, indicates that mere recognition of legal capacity of women with disabilities in the legislation might not be enough. The legislation should explicitly prohibit forced sterilization and abortion, and make the violation of this provision a punishable offence.

By recognizing the sexual needs and identity of the women, the right to retain their fertility and have a home and family, UN convention recognizes and honours the aspirations of women with disabilities. This in a way legitimises their right to roles associated with womanhood which women themselves are reticent to articulate. In 2007, India signed the UN convention on rights of persons with disabilities and in 2016, it passed the "rights of persons with disabilities bill" that widened the ambit to include a diverse group of people suffering from different kinds of disabilities. The new legislation identifies twenty-one categories of disability as compared to seven in the 1995 law and includes some new gender specific clauses that recognizes women with disabilities as a distinct group. While this is a welcome step, change in social attitudes especially around sexuality and sexual rights of women with disabilities might take longer in countries like India where these subjects are often considered non-issues and to a large extant taboo. Women themselves are uncomfortable talking about these issues as it emerged in my interactions with them and they discussed it tangentially in the context of marriage. The stereotype of women with disabilities as either non-sexual or hypersexual beings have led to their victimization and increases their vulnerability. By refusing to treat them as "normal" women and with needs and aspirations that move beyond social, infrastructural, and political inclusion, there sexual and emotional well-being has been compromised. Theoretical discussions about such issues have gained traction within disability studies and a right based approach makes the state responsible for safeguarding the rights of disabled women. This also marks a shift away from the medical model of disability to social, cultural and political environment that shapes the everyday lives of disabled women.

Conclusion

Focussing on how disability renders women out of the normative expectations of femininity and roles associated with womanhood, this paper has drawn attention to the need of moving beyond recognizing sexual violence only in terms of physical assault and molestation. Ignoring the emotional and physical well-being associated intimacy, sexual fulfilment, and desire for motherhood also amounts to violence and damages the self-esteem and confidence of women.

Women mostly internalize these notions and focus on making themselves economically self-reliant as if that alone would ensure their well-being given that they are likely to be alone. According to Anne Finger

> Sexuality is often the source of our deepest oppression; it is often the source of our deepest pain. It is easier for us to talk about and formulate strategies for changing – discrimination in employment, education and housing—than to talk about our exclusion from sexuality and reproduction. (Finger 8)

The reticence to talk about issues related to sexuality emerged clearly in my research and interaction with women with disabilities and they were more forthcoming in addressing issues related to family support, vocational training, medical and prosthetic support provided by the rehabilitation centre. The gaps and silences around the issues of marriage, bodily privacy, intimacy, and motherhood led me to probe further on these issues. Through life sketch/life-writing model, the disabled women render us visible the often misunderstood and neglected world of their experience. Representation of disability in these short sketches that emerged from the field work is both a matter of speaking for as well as speaking about. Even the silences in their narratives provide an entry point to explore the social, cultural, and environmental factors responsible for their exclusion from discourse of sexuality. While official reports and statistical data provide numbers, and documents the plight of women with disabilities, to listen to their story in their own voice give insights into an area of experience that remains opaque and misunderstood and this approach can be helpful in making interventions and formulating policies.

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