SAGE Open

Violence Against Women With Disability in Mumbai, India: A Qualitative Study

Nayreen Daruwalla, Shruti Chakravarty, Sangeeta Chatterji, Neena Shah More, Glyn Alcock, Sarah Hawkes and David Osrin

Violence Against Women With Disability in Mumbai, India: A Qualitative Study

Nayreen Daruwalla[1], Shruti Chakravarty[1], Sangeeta Chatterji[1], Neena Shah More[1], Glyn Alcock[2], Sarah Hawkes[2], and David Osrin[2]

Abstract

We conducted open-ended interviews with 15 women with disability who had reported violence in a preceding survey. Emergent themes included a lack of acceptance by families, the systematic formation of a dependent self-image, and an expectation of limited achievement. Emotional violence was particularly emphasized, as was perceived structural violence stemming from social norms, which led to exclusion and vulnerability. Violence in the natal home was an issue that had been relatively uninvestigated.

Keywords

violence against women, India, Mumbai, disability

Background

> I think our society gives too much importance to what is considered normal. Normal as in, if someone is physically fit or is married . . . whatever their thinking may be, they will be considered normal and they will be given importance. But, if there is disability . . . then this is considered wrong and there is no acceptance from society . . . (D01, 30 years, visual impairment)

Social norms in India are influenced by values such as productivity, the right to private property, and patriarchy (Ahmed-Ghosh, 2004). Much is made of the rule of law, the institution of marriage (Goel, 2005), the family as a social unit, and the importance of religion. The family—able-bodied, heterosexual, and engaged in socially acceptable livelihoods—is the fundamental social unit. The history of the Indian women's movement has been one of focus on poverty, caste, and employment, issues such as dowry and *sati*, population control and female feticide, sexuality, and domestic violence. Its agenda has not, generally, included disability. Critical feminist analysis of disability in India was initiated by, among others, Renu Addlakha (Addlakha, 1998, 1999, 2001, 2005, 2006; Addlakha & Das, 2001; Davar, 1999; Dhanda, 2000; Ghai, 2002a, 2002b; Hans, 2003). These feminist scholars challenged the disability movement and the women's movement.

An idea common in India is that disability represents a personal flaw. Able-bodied people are the "corporeal standard" (Kumari, 2009), and—from a moral perspective—disability arises as a consequence of karmic misdeeds:

Impairments are deserved and intrinsically punitive. Two other perspectives on disability are also common. From a charity or welfare perspective, disability speaks to an idea of victimhood with which campaigners against violence against women are familiar. The individual with disability deserves sympathy and is dependent on the assistance of others. From a biomedical or rehabilitative perspective, disability encompasses defects that require clinical intervention. Pervasive as they are, these models are outmoded in disability discourse. The United Nations Convention on the Rights of Persons With Disabilities (UN CRPD) recognizes that disability can be seen as a collection of hindrances to participation in society, a product of the interaction between people with impairments, attitudinal, and environmental barriers. This model locates disability in relation to structures rather than with the individual. A rights-based model broadens this position by promoting acceptance of diversity through nondiscriminating environments and inclusive social processes, to level the playing field by tackling the visible privileges of the able-bodied. Finally, in a cultural model, disability represents a pervasive system that, through stigmatization of impairment, informs our notions of self, family, society, and sexuality. Garland-Thomson argues that the system defines

[1]Society for Nutrition, Education, and Health Action, Mumbai, India
[2]UCL, London, UK

Corresponding Author:
David Osrin, UCL Institute for Global Health, Institute of Child Health, 30 Guilford Street, London WC1N 1EH, UK.
Email: d.osrin@ucl.ac.uk

the relationship between bodies and their environments and prescribes a set of practices that produce both the able-bodied and the disabled (Reproductive and Sexual Health Issues, 2010).

If women with disability do not physically measure up to able-bodied standards, neither does society expect them to do so. In many cases, they are not expected to adopt the roles of wife and mother. Women with disability do not, however, quietly acquiesce to this. They may struggle against negative stereotyping in an attempt to develop a positive sense of self within bodily and societal limitations, a struggle that does not often leave space for celebration of difference and pride in one's individuality (Addlakha, 2006). In a series of narrative interviews with young people with disability, gender was a defining element of the disability experience, but meshed with elements such as class and caste, family composition and dynamics, and geographical location. Experience of segregation and inclusion influenced informants' opinions on marriage and family life and their social behavior, and, although the charity model of disability was slowly giving way to a human rights model, the transition was far from complete (Addlakha, 2007). This study presents the findings of a series of follow-up interviews with women with visual or locomotor impairment.

Method

Setting

The study was carried out in Mumbai by the Society for Nutrition, Education and Health Action (SNEHA), a non-governmental organization. It was one of the three—in India, Bangladesh, and Nepal—that formed a project on understanding violence against marginalized women in south Asia (Dutta, Weston, Bhattacharji, Mukherji, & Joseph, 2012).

Design and Procedures

During an initial survey interview, we asked women who reported an experience of violence if they would be interested in participating in a later in-depth interview. We were able to generate a subsample within the strata used for the survey. Two pilot interviews were carried out to develop a better understanding of the process, and subsequent interviews were conducted by four senior researchers. Beginning with a topic guide to key areas of interest, respondents were asked to recount instances of violence and locate them within their wider experience. The guide included open-ended questions about the respondent's self-perception (e.g., her body image and personality), family environment and social networks, sources of psychological and social support, perspectives on life as a woman in India, the idea of violence, experiences of violence, and responses and coping strategies. Interviewers used spontaneous probes to clarify information and to explore in more detail other aspects of respondents' narratives.

Data Management and Analysis

Each woman was interviewed once, at a location of her choice, typically in her home or accommodation, an office, or—less frequently—a public space. We took written consent. Interviews lasted an average 70 min, were digitally recorded and transferred to secure files on a password-protected computer. Original audio recordings were deleted after transfer and access was restricted to the study coordinator and data analysts. Interviews were transcribed verbatim and translated into English (Easton, Fry, & Greenberg, 2000; McLellan, MacQueen, & Neidig, 2003), following a predefined protocol to ensure consistency of transcription. Transcripts also included the researcher's observations of the interview setting, the reactions and behavior of the respondent, reflections on the interview process, and additional information not captured digitally. Respondents' names and other identifying information were removed or replaced with pseudonyms. Transcribed, anonymized interviews were imported into NVivo version 7 qualitative data analysis software (QSR International), on a secure computer. The master list was prepared with anonymous codes and was stored in a locked cupboard.

The analysis was carried out through a series of meetings and online discussions that emphasized the extraction of themes from the data. We followed an iterative process, using findings from initial interviews to inform subsequent lines of inquiry. We examined the qualitative data using a framework approach, incorporating some principles of grounded theory for initial coding (Green & Thorogood, 2004; Lacey & Luff, 2007). From the outset, members of the research team read and reviewed the transcripts of all the interviews to familiarize themselves with the data. We kept analytical notes on our reflections on them, to include in the analysis and to inform further data collection. We developed an initial thematic framework from both a priori and emerging issues and used open coding to identify, examine, compare, and categorize individual pieces of data. We followed this with axial coding, whereby the codes and categories were rearranged to look for connections and associations between them (Strauss & Corbin, 1990). The involvement of multiple researchers helped us question our coding framework, propose new codes, and offer alternative interpretations (Barbour, 2001). As a result, we were able to refine our framework as further data were collected, discussed, and analyzed. These data, in the form of summaries and interview extracts, were copied into a table to compare and contrast themes and categories across cases. We then used this information to write a series of more detailed descriptions, interpretations, and explanations of our main findings. We used an ecological framework to conceptualize women's experiences of violence (Heise, 1998; Krug, Mercy, Dahlberg, & Zwi, 2002). Designed to understand the origins of gender-based violence, the framework emphasizes the reciprocity between people and their environment, recognizing the complex interplay between

personal, situational, and sociocultural factors. It considers individual development and personality, interactions between individuals and the subjective meanings they assign to them, the formal and informal social structures that influence an individual's environment, and the broader cultural values and beliefs that permeate and inform the other levels.

Research Governance and Ethical Issues

The study was overseen by a steering group and approved by the joint Institutional Ethics Committee of the Anusandhan Trust and the University College London Research Ethics Committee. We prespecified in the study protocol that participants should freely choose to be involved, at a time and place of their selection, and could withdraw at any time. Interviewers were trained in discussing sensitive issues and mechanisms put in place for referral for support. The research team identified organizations that would be accessible to participants and could provide timely and appropriate services. Investigators were equipped with the contact details of organizations across Mumbai who had consented in writing to accept referrals. All such referrals were documented and followed up to meet the requests made by respondents. A protocol was followed for action in cases of violence, abuse, or distress. Clarity on the responsibility of the researcher for inadvertently provoking any action by respondents was also established.

Results

We interviewed 15 women with disability. Twelve had visual impairment, 2, locomotor impairment, and 1 had both. Eight were between the ages of 18 and 30, four were in their thirties and three were older. Five were married. Ten women were Hindu, 4 Muslim, and 1 was Christian. Five came from poorer socioeconomic strata, 4 lived in hostels, and others lived with their natal or marital families. Two had not had any formal schooling, 3 had attended up to the 10th standard, and 10 beyond. Nine did not have a job, although 1 of them ran a small home-based business, and 2 others were learning vocational skills.

Childhood and the Self

Many of the respondents had grown up around able-bodied siblings and friends and described their childhoods as "stable." Some reported not being particularly aware of their impairment in childhood, and interacting with their siblings on an equal footing. As they grew older and were influenced by other people, however, they began to feel different.

> We [brother and I] used to play with friends' children around us. I never thought I was blind. But only when my father used to say when I passed from one room to the other, when his friends used to come he used to say, "She can't see." I did not know English much, but there was some association. Because whenever I

passed my father used to say this. But what is that "she can't see" I could not understand, but there was some association with that. But I didn't know what it was. (D03, 50 years, visual impairment)

Most of the women with visual impairment had attended "sighted" schools with teachers who were supportive of their needs. In contrast, women with locomotor impairment reported feeling more isolated and had their schooling disrupted because of the need for medical treatment and time in hospital. Institutional discrimination in the form of unequal access to education was reported by a few respondents who struggled to gain admission to regular schools or to take exams. This was usually due to an inability to accommodate the girl's needs, a fear that she might have an accident, or concerns that "she won't be able to keep up with the normal students." In the family environment, women described early experiences of feeling "not accepted," first, because of gender, and then because of disability: "When I was born there was no acceptance. First of all she is a girl, and then she is blind." They described how their parents' disappointment at having a daughter was compounded by the discovery that she also had a physical impairment:

> I was born normal but [even] from then only I was not accepted. Before me [were] three daughters, so there was no happiness, no enthusiasm when I was born. Then, when I was two or one-and-a-half years, I got polio. After getting polio I was completely unacceptable. Completely unacceptable. They did not accept me and then they sent me away to my maternal grandmother's house. (D08, 43 years, locomotor impairment)

Few of the respondents reported severe physical violence during childhood. Although being hit on the legs by a teacher, smacked by a mother for disobedience, or being yelled at by a father were events that "put a lot of fear into us," they were considered "very, very minor incidents of violence." More common were neglect and verbal abuse, at home and at school, largely driven by attitudes to disability.

> My mother and father did not pay me much attention. Sometimes my aunt would look after me. When I fell ill, she admitted me to the hospital but no one from my family came to look after me. (D14, 20 years, locomotor and visual impairment)

The impact of such events on women's self-perception meant that some "began to believe it." While some parents took measures to protect their daughters from accidents, others denied them the opportunities enjoyed by other siblings because they "did not see the need for me to go out or have things." Derogatory comments from peers and family reflected a belief that disabled children were incapable and unemployable:

> In my childhood, there were comments I faced from my family. It was verbal. I remember [my father's sister] used to call me

"phutki" [damaged] . . . In school also we had to listen to comments like, "Blind people are going to become beggars only—that is your future." So that used to make us feel like, really we are not capable of anything . . . " (D01, 30 years, visual impairment)

Parents who felt that a daughter with locomotor impairment was of little use seldom offered encouragement or considered ways in which they could help her overcome the challenges of living with her impairment. In extreme cases, parents thought that disabled daughters were better off dead:

[My father] felt what should he do with me, she is very nice, but what to do with her? They never thought about me in a way that I could do anything on my own and that we can help her to do that. They could not understand that responsibility. They never wondered what I want to do; they did not think that I would be able to do anything. He used to feel that dying was the best possible option for me. (D08, 43 years, locomotor impairment)

Less extreme measures for dealing with the stigmatizing effect of having a disabled child in the family included keeping her out of sight:

I remember my father's sister . . . she was very bad. When guests would come she would not let me come out, I could not meet them. She would make me sit in one corner. She would not let me go in front of the guests so that they would not come to know that there is a blind child in the house. (D01, 30 years, visual impairment)

Sexual "misbehavior," usually by members of the extended family, was not unknown and ranged from "gazing" to inappropriate touching. Episodes of sexual violence often went unreported, either because parents disregarded them or because they held their daughters responsible. In situations where the abuse was likely to continue, some women had felt that their only option was to leave home:

I don't go home now. My Mama's [maternal uncle's] gaze was not good. I tried to inform my mother but she just wouldn't listen to me. I also told my grandparents in Bombay about my Mama. They told me to stay away [from him]. I haven't gone home now since eighth standard. (D12, 24 years, visual impairment)

Importantly, in the context of childhood, sexual violence was constructed not only as the act itself, but also in terms of the unwillingness of parents to acknowledge it:

By seventh or eighth standard . . . there were instances of [sexual] misbehavior with me [at home] around that time, but I could never share. When it first happened I told my mother about it, but she said that it must be my fault that it happened. So after that I never told her anything . . . when someone misbehaves with you and you tell your family and they don't believe you, that is also violence. Both are violence: the misbehavior and the not believing. (D10, 20 years, visual impairment)

Many of the experiences in childhood continued into adulthood. Accounts of physical abuse and mistreatment in adulthood were less common, though, than other forms of violence. In light of a widespread popular belief about physical violence that "such things happen in all families," the focus on articulating other forms of abuse suggested that women found them equally distressing. The anticipation of possible physical violence, especially within the marital home, the temporal nature of injuries caused by it, and the incomprehensibility of inflicting psychological, emotional, and economic violence on a wife might explain why respondents emphasized them in their narrative accounts. When physical violence did occur, it was usually in a milieu of emotional, psychological, and economic violence.

Respondents' constructions of their identities were influenced by social constructions of disability, their own experiences of living with a physical impairment, and the attitudes and behavior of those they interacted with. Emotional, psychological, and physical self-violence could not be understood as isolated acts; they were as much impacts as they were behaviors. Self-defeating beliefs and negative constructions of the self were common, particularly among women who had endured persistent physical or psychological violence. Being constantly spoken down to or treated as disabled tended to lead to an internalized stigmatization of one's own disability. Feelings about the impact of their physical impairment on their family, and being made to feel a burden, led some women to self-blame and a sense that "I am the problem." Within marriage, strategies to deal with the pressure of bearing children, together with fears about them inheriting an impairment, included anticipating separation from the husband to bring up a child alone.

At least three respondents reported contemplating or attempting suicide. One was motivated by the fact that her family had considered her disability so undesirable (beside her gender) that her father had wanted her to die, and another explained that

. . . if I was a burden on everyone, if I was causing all my loved ones so many problems I should just go away from the scene. Then I attempted to kill myself but it was my misfortune that I survived. (D08, 43 years, locomotor impairment)

Intimate partner violence

Women's experiences of domestic violence included emotional and verbal insults, withholding money, threats of abandonment or physical violence, and actual physical violence. They were rarely one-off occurrences and typically involved a combination of several types of violence over a period. Spousal alcohol use, forced marriage, disputes with in-laws and the tendency for husbands to take their mothers' side, and suspicions of infidelity were described as key factors. Although the respondents themselves did not perceive their disability as a causal factor, it was an additional dimension to their experiences of violence:

My husband drinks. He never paid the rent of the house we were living in. For 1 year he did not give rent and all the things in my house were taken away. I lost everything I had brought from my maternal home. Is this the way to manage a married life? . . . You tell me, does he have no responsibility? I have been married to him for 9 years. I was 17 years of age. I was blind and my parents were in a hurry to get me married off. He is a sighted man. When he married me he knew I was blind. Then why did he marry me if he can't behave properly towards me? (D11, 28 years, visual impairment)

The most vulnerable women seemed to be those who were married off at an early age by parents who no longer wanted to take responsibility for them or were concerned about their ineligibility as wives: the families of able-bodied men often had strong reservations, such as a belief that the marriage would fail, "a fear of the unknown," or the perception that a disabled person's home is a "sad house." These stigmatized attitudes sometimes continued after marriage:

Right from the beginning, she [my mother-in-law] and her family were against their son marrying a blind girl. There was no acceptance . . . My mother-in-law told them [her family], "She is not married to my son." (D11, 28 years, visual impairment)

The husband's authoritative role in the household was a commonly described feature of marital relations, and even a supportive husband "keeps control of everything."

My husband keeps control of everything. Sometimes he will ask me to spend. My daughter got married. I wanted to give something to her. She wanted a pair of bangles. I said we will give her. When there is a need and there is a happy occasion we should give her. If we can't give at this time then what is the point of having that money? I felt very bad. At that time I couldn't give her anything. She spent her money. Having my own income I couldn't give. I felt very bad. It's a feeling of complete helplessness . . . (D03, 50 years, visual impairment)

Minor marital conflicts, quarrels, and attempts to hurt each other emotionally were not usually considered violent, although physical violence was more likely if a wife's behavior transgressed acceptable gender norms or caused suspicion:

 . . . He beat me up till I was bruised. He had never beaten me like that before. We used to have verbal quarrels but this was very bad . . . When he got suspicious of my friend he beat me up very badly . . . He had never beaten me like this before. He dragged me out of the house and beat me. I was in a state of panic and shock. (D11, 28 years, visual impairment)

Violence in the natal family

Respondents were vulnerable to violence from natal families in a variety of ways. Women who had defied their family's wishes—for example, by marrying across religions—described suffering psychological and physical violence, typically from a father or brother. Although it was difficult to know the degree to which disability might have been related

to the violence, it was evident that gender and physical impairment were used to make violent threats:

They started hitting me. At that time I was sitting on this slab with wheels and I fell down. When I got up, they hit it again and it went towards the steps, but I stopped it. I would have got hurt . . . My youngest brother said that they could harm me more than this, they would harm my child also, and told me not to complain to the police, they also told me that they had more strength than me. (D08, 43 years, locomotor impairment)

Other forms of family violence included abandonment and exclusion. Women perceived the stigma associated with their impairments and the resulting social exclusion as acts and impacts of violence, as they caused them to be and feel excluded. Similarly, women who were deprived of agency experienced a reinforced sense of "being" disabled and feelings of isolation and helplessness:

When [my brother and his wife] go out they don't take me. They leave me back, alone [starts crying]. They just leave me and go away. When I tell them they say, "We will not take you. What will you do?" There is nothing I can do. They do go away leaving me here . . . [They say], "I don't like to take you out with me. I won't take you." I am alone. I don't have a choice. If I had a choice I wouldn't live in this house. But I don't have a choice. And they make sure that I realize that. [They say] "Aye, you are handicapped. Do as I tell you. Eat what we tell you to. Live like we tell you to." Kabool [I accept]. There is nothing I can do, right? When my father was alive, all of us brothers and sisters did everything together. I never felt I was handicapped [crying]. I never felt like that. But now every moment they make me feel that I am handicapped. Now I have begun to feel that, yes I am handicapped. (D07, 57 years, locomotor impairment)

Stigma was typically related to being ashamed of having a disabled person in the family or being "worried about what people will say." Discrimination often originated from the common belief that disabled people "don't have the capacity" to do things, or the view that, "she is blind so she is useless." The notion that disabled people are more prone to accidents led some parents—albeit with genuine concern to protect their daughters—to deny them the opportunity to learn mobility techniques or travel by train, even if they expressed a desire for independence. Exclusion from family affairs often continued into adulthood. Besides a feeling of neglect, this was interpreted as ostracism:

[My younger brother and his family] never say, "She is a member of our family. And this is a family function so she must be taken along." The fact that you [younger brother and his family] don't take me along means that you don't consider me a part of your family. You neglect me . . . My brother's son came from the US. Everyone went to the hotel to eat. They did not take me. Why? Because his wife told them, "I feel ashamed of her." So everyone left me and went to the hotel. And I understood that they do not consider me family. (D06, 57 years, locomotor impairment)

Experiences of violence from family members did not depend on physical acts or overtly abusive behavior, and were often more subtle:

> [My family] would never say a word, an abusive word, but they made you feel like that . . . You can make out in the way someone welcomes you and even if someone does not welcome you but just negates you. Negating you is just terrible. And then on my birthday, to come and wish me happy birthday when they negated me at every other time. When no one has even spoken to me before my birthday for 4 days, especially when my heart is dying to talk to you, to be loved by you, then how would I feel? (D08, 43 years, locomotor impairment)

Violence in public spaces

Physical challenges and perceptions of women with disability as defenseless made them easy targets. Verbal and physical sexual harassment by strangers occurred in public spaces, trains, and buses. Women were vulnerable to exploitation because of their dependence on others for support and, possibly, as a result of men perceiving them as sexually available:

> Harassment happens in public. People have behaved badly [with me] while traveling in public transport. Or under the excuse of helping me people have done weird things. Even in private transport there is harassment. Recently an incident happened and so I remember. I took an auto to reach college and just at the gate of the college he [rickshaw driver] touched me here [points to her breasts]. (D10, 20 years, visual impairment)

Behavior that would usually be unacceptable in public might be spuriously legitimized by the need to "help":

> . . . In most cases, the men, they hold our hand, they run their fingers over us. When we tell them to hold the stick, they say directly, "Why don't you let us hold your hand?" . . . Then sometimes they touch us, put their hands around our shoulders while passing us or crossing us. They sometimes make dirty comments. (D01, 30 years, visual impairment)

Violence from society

Discrimination targeted specifically at disability was inherent in many of the respondents' narratives. Structural forms of violence included inequalities in access to work opportunities in private or public institutions, and some respondents had been denied jobs and social support. General discriminatory attitudes of potential employers toward women with impairments were often explained as concerns that they would not be able to "keep up" with colleagues, would be less productive, or would be incapable of completing the work.

> The government departments that I have had to work with initially were resistant and didn't want to take me on . . . I would always be confronted with questions, "What can you do? Why are you here?" (D05, 35 years, visual impairment)

In the absence of accommodating environments and facilities for people with disability, women were usually expected to manage on their own. They often felt that requests and complaints were met with indifference or were not taken as seriously as they would have been if they had not had an impairment.

> I was searching for a job as well as pursuing some courses I thought would be useful. However, the response I heard from people made me feel that there is no use to all my education. I began to feel that blind people have no option but to keep studying all their life. Despite having education nobody wants to give a job to blind people. (D01, 30 years, visual impairment)

Some women perceived that institutional discrimination was directed at their disability more than their gender:

> Usually the police are very rude and indifferent to the blind person. Suppose something happens, then the police will say to the blind person, "How will you recognize a person? How can we catch the person?" (D03, 50 years, visual impairment)

Disability was an additional layer of violence on top of widespread gender bias, a double-discrimination. Respondents felt that people often assumed them to be incapable of doing everyday activities, fulfilling expected gender roles and participating in education or work life. This perception included the belief that they were "dumb" and not to be taken seriously. Some people also considered women with disability to be a burden, or as individuals deserving pity or sympathy:

> I think people feel that if you are a girl and you are blind, you have no brains and you cannot understand anything. I mean, I don't know, how do they think like this? There is no respect. And the opinion about girls is also not great to start with. Then they wonder how will a girl accomplish anything? So in the context of a blind girl this factor of what will she achieve in life is very high. Then they say, "Arre arre, bichari [oh, poor thing] . . . She looks beautiful but she is blind." And I feel, what is the connection between looking beautiful and being blind? (D10, 20 years, visual impairment)

The impact of violence

Naturally, physical violence led to a fear of further beatings and a sense of vulnerability. Social exclusion and isolation from the family, neglect, and being made to feel a "burden"—"I am the problem"—led to psychological and physical distress, and more than one respondent had attempted suicide:

> I become hysterical. The thought stays in my head—it doesn't go away. I keep thinking, they are neglecting me, they are neglecting me. My blood pressure rises. I try very hard but the thought doesn't leave my head. My nature is like this. I cannot change it. I feel really very bad. I cannot control myself. Life is miserable. Nobody is fighting for me. (D07, 57 years, locomotor impairment)

Notions of disability that reduced women to deficiencies related to their physical impairment ran the risk that, "one then doesn't want to try, and becomes quiet and loses interest." These attitudes played an important role in influencing how respondents viewed themselves and what they felt they were and were not able to do. Although many felt that they were capable of cooking and traveling alone, any negative self-perceptions they held were likely to be further reinforced by a lack of encouragement and autonomy:

> I can do everything. I can even cook. I clean. I manage myself. So how can I be handicapped? Let me give you an example: breakfast and tea is made in the house for everyone. The same breakfast and tea is made for me. So food is made for everyone. They are not handicapped but food is made for them right? Then why do they say to me that food and tea is being made for me because I am handicapped? Then it takes on a different implication: that we have to do it for you because you cannot do it for yourself. (D07, 57 years, locomotor impairment)

Another effect was a reinforcement of beliefs such as "I must be disabled." The cumulative impact of attitudes and behaviors was experienced in at least two dimensions. It was detrimental to the woman's self-confidence and was likely to result in a deprivation of opportunities:

> . . . Even a handicapped person has ability, and people treat them in this way then a handicapped person will not want to even use that much ability that she has. (D08, 43 years, locomotor impairment)

Responses and Coping

While some women strove to prove themselves capable, or to "be like normal women," others restricted their mobility and life choices.

> It's definitely restricting, it's limiting. There are also certain restrictions and limitations that I have also imposed on myself. For instance, I have not . . . even though I have gone through mobility training, I have not chosen to travel on my own, and so I still have somebody who travels with me. So it is sometimes a lot . . . anxiety-provoking, since I am dependent on somebody for help. (D05, 35 years, visual impairment)

The pressure of proving oneself to be accepted and treated with some degree of normality fell on the women themselves:

> In experiences with education I decided that I have to prove myself and my capabilities. Since I have a disability, I am left with no option but to prove myself and I did that. So all the hard work that I could do, I did, without complaining. So I coped fairly well with my studies. (D01, 30 years, visual impairment)

Some women used problem-focused coping strategies to carry out tasks that would usually be done by sighted people, partly to prove themselves. Others worked to limit their

distress by accepting, for example, family requests to restrict their mobility.

> My sister-in-law says you are not supposed to take any unwanted risks. That is the reason I don't go out of the house. She also says to avoid the risk. Till the moment it is possible to avoid the risk. (D02, 38 years, visual impairment)

Discussion

In qualitative interviews with women with disability, the common motifs were an idea of not being accepted by their families, childhood formation of a dependent self-image, and an expectation of limited achievement. Respondents' constructions of their identities were influenced by social constructions of disability, their own experiences of living with impairment, and the attitudes and behavior of those they interacted with. Violence was rarely one-off, and usually a combination of emotional and physical abuse over time. Structural violence was a pervasive concern. Women's narratives were characterized by difficulties in resolving their identities against concerted disapproval and internalized guilt.

One of the central findings was the complexity of the idea of violence. First, women who did not report physical violence nevertheless articulated many of their experiences as violence, the most obvious examples being their descriptions of the structural violence inherent in social norms. There is a taxonomic challenge here: Is the concern of a woman with visual impairment that she will not be able to complete a PhD—because of logistic and social challenges—a violent experience? At what point does the lived experience of inequity become violence, and is there a danger of the debate becoming a competition for what counts? Second, we formed the—somewhat provocative—impression that for some women, the psychological effects of nonphysical violence were more pervasive. Perhaps this reflects the general toleration for domestic violence in Indian homes (Special Cell for Women and Children, 1997, n.d.). Women with disability who had been physically abused nevertheless dwelt more on the cognitive and emotional effects of marginalization and on the ambiguities in their loved-ones' attitudes: physical assault is a nonambiguous form of communication.

By extension, the interconnectedness of forms of violence causes problems in framing our idea of it. The ecological model had the benefit of being simple to understand, but we struggled to fit women's accounts neatly within it. For example, a suicide attempt is a clear example of self-directed violence, but it arises from negative ideation linked with low self-worth, emotional violence and marginalization, and broader social mores. To fail to acknowledge each of these levels of violence would be to miss important contributors to a woman's well-being. It also has implications for recommendations. Clearly, social change is necessary if we are to validate the experiences of marginalized women and prevent

violence against them: change at the level of policy, culture, community, and familial behavior. What is more challenging is to decide where to put the emphasis.

Women with disability often felt excluded from mainstream activities. Growing up with impairment, many had been left out of family functions, religious festivals, sports, and extracurricular school activities. They had also been teased and had limited numbers of friends. One of the outcomes of a marginalized existence was invisibility, silence being an epistemic form of violence. Women with disability described experiences in which family members had negated their identity or existence. This negation extends to all levels, up to the Government, which responded only after nationwide protests from disability groups that they should be included in a census and counted as citizens of India (Ghai, 2000a).

Most of the campaigns against violence have focused on its occurrence in the marital home. Our findings suggest that the supposedly protected environment of the natal home has often been a site of violence. While women in general may be prone to higher incidence of violence in natal homes than their male siblings, women who are seen by their families as different from the norm have faced particular violence in an effort to minimize their perceived deviance. Our study shows that women with disability faced violence in the form of neglect, control, restricted mobility, forced marriages, and lack of autonomy.

Conclusion

Women faced pressure from their natal families to conform, and described experiences of having to "prove themselves capable." Gender roles frame women's stay in their natal homes as a precursor to their being given away to marital homes. For women in general, and particularly for women from marginalized communities, sustained efforts to promote independent living would go a long way in resisting family violence. Campaigns around violence and laws protecting women from it, education and career guidance, sexuality education, and housing schemes all need to be geared toward equipping women to make life choices that protect them from violence, live without fear of exclusion and discrimination, and resist oppressive norms.

Contributors

All authors contributed to the design of the study, criticized drafts of the report, and read the final version. N.D., Sh.C., S.C. and N.S.M. did the interviews. G.A. oversaw qualitative analysis. N.D., Sh.C., S.C., G.A., and D.O. wrote sections of the first draft of the paper. D.O. was responsible for subsequent collation of inputs and redrafting. S.H. conceived the study and was responsible for multisite inputs. N.D. supervised the project and is guarantor for the paper.

References

Addlakha, R. (1998). Nisha: Who would marry someone like me. In A. Bhaiya, & L. F. Lee (Eds.), *Unmad: Findings of a research study on women's mental and emotional crisis: The voice of the subject* (pp. 60-93). New Delhi, India: Jagori.

Addlakha, R. (1999). Living with chronic schizophrenia: An ethnographic account of family burden and coping strategies. *Indian Journal of Psychiatry*, *41*, 91-95.

Addlakha, R. (2001). Lay and medical diagnoses of psychiatric disorder and the normative construction of femininity. In B. V. Davar (Ed.), *Mental health from a gender perspective* (pp. 313-333). Delhi, India: Sage.

Addlakha, R. (2005). Affliction and testimony: A reading of the diary of Parvati Devi. *Indian Journal of Gender Studies*, *12*, 63-82.

Addlakha, R. (December, 2006). *Body politics and disabled femininity: Perspectives of adolescent girls from Delhi (India)*. Paper presented at The International Conference on a World in Transition: New challenges to gender justice, Gender and Development Network and Centre for Women's Development Studies, New Delhi, India.

Addlakha, R. (2007). How young people with disabilities conceptualize the body, sex and marriage in urban India: Four case studies. *Sexuality Disability*, *25*, 111-123.

Addlakha, R., & Das, V. (2001). Disability and domestic citizenship: Stigma, contagion and the making of the subject. *Public Culture*, *13*, 511-531.

Ahmed-Ghosh, H. (2004). Chattels of society: Domestic violence in India. *Violence Against Women*, *10*, 94-118.

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *British Medical Journal*, *322*, 1115-1117.

Davar, B. (1999). *Mental health of Indian women: A feminist agenda*. New Delhi, India: Sage.

Dhanda, A. (2000). *Legal order and mental disorder*. New Delhi, India: SAGE.

Dutta, D., Weston, M., Bhattacharji, J., Mukherji, S., & Joseph Kurien, S. (Eds.). (2012). *Count me IN!* Research report on violence against disabled, lesbian, and sex-working women in Bangladesh, India, and Nepal. New Delhi, India: CREA.

Easton, K. L., Fry McCornish, J., & Greenberg, R. (2000). Avoiding common pitfalls in qualitative data collection and transcription. *Qualitative Health Research*, *10*, 703-707

Ghai, A. (2002a). Disabled women: An excluded agenda of Indian feminism. *Hypatia*, *16*, 34-52.

Ghai, A. (2002b). Feminism and disability. *Hypatia*, *17*, 49-66.

Goel, R. (2005). Sita's trousseau: Restorative justice, domestic violence, and South Asian culture. *Violence Against Women*, *11*, 639-556.

Green, J., & Thorogood, N. (2004). *Qualitative methods for health research*. London, England: Sage.

Hans, A., & Patri, A. (Ed.). (2003). *Women, disability and identity*. London, England: Sage.

Heise, L. (1998). Violence against women: An integrated ecological framework. *Violence Against Women*, *4*, 262-290.

Krug, E. G., Mercy, J. A., Dahlberg, L. L., & Zwi, A. B. (2002). The world report on violence and health. *Lancet*, *360*, 1083-1088.

Kumari, C. F. A. (2009). *Contours of ableism: The production of disability and abledness*. Basingstoke, UK: Palgrave Macmillan.

Lacey, A., & Luff, D. (2007). *Qualitative data analysis*. National Institute for Health Research Design Service for the East Midlands. Yorkshire and the Humber, UK.

McLellan, E., MacQueen, K. M., & Neidig, J. L. (2003). Beyond the qualitative interview: Data preparation and transcription. *Field Methods*, *15*, 63-84.

Reproductive and Sexual Health Issues. (2010). *Sexuality and disability in the Indian context*. Working Paper. New Delhi, India: Talking About Reproductive and Sexual Health Issues (TARSHI).

Special Cell for Women and Children. (1999). *Shades of courage. A study on section 498A of the Indian Penal Code*. Mumbai, India: Tata Institute of Social Sciences, Akshara.

Special Cell for Women and Children (n. d.). *Because the personal is political: A documentation of the work of the Special Cell for Women and Children*. (1984-1994). Mumbai, India: Tata Institute of Social Sciences in collaboration with Bombay Police Commissioner.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research. Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Author Biographies

Nayreen Daruwalla has a background in psychology and social work. Her primary interest is in interventions to address gender-based violence. She directs the SNEHA program on prevention of violence against women and children.

Shruti Chakravarty has been working in the field of gender, sexuality and mental health for the last 10 years in the non-profit sector in India. She is a researcher, counsellor and social worker.

Sangeeta Chatterji has a background in social work and social sciences. She is a researcher with an interest in violence against women, gender, sexuality and non normative identities.

Neena Shah More has a background in social work. Her primary interest is in community-based interventions to improve women's and children's health, and she directs the SNEHA programme on community resource centres.

Glyn Alcock is a researcher with a background in medical anthropology and experience of international health and development in Latin America, Africa, and India. His interests include medical pluralism and health care provision, health-seeking behaviour, and the use of mixed-methods to study urban health issues.

Sarah Hawkes is a UCL Reader in Global Health and Wellcome Trust Senior Fellow in International Public Engagement. She leads a research group looking at the link between empirical evidence and policy responses in sexual health.

David Osrin is a Wellcome Trust Senior Research Fellow in Clinical Science. His research focuses on urban health, particularly of women and children in India.