

BRIEF REPORTS

The Double Burden: Barriers and Facilitators to Socioeconomic Inclusion for Women with Disability in Bangladesh

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ABSTRACT

Purpose: Recent evidence suggests that, globally, women with disability suffer multiple forms of discrimination and exclusion from mainstream society when compared with their female peers and men without disability. In Bangladesh, which is a grossly overpopulated low-income country in South Asia, women with disability have poor health outcomes within a gender-biased cultural context. This study aimed to define the current barriers and facilitators to socioeconomic inclusion for women with physical disability living in the community in Bangladesh and to highlight the impact of these barriers on health.

Methods: Semi-structured in-depth interviews were conducted with 15 women who had either a spinal cord injury or amputation, and who had been discharged for at least 3 months after inpatient admission. Mixed purposeful sampling (a mixture of typical case sampling and criterion sampling) was used to recruit the study participants. A thematic analysis was conducted to extract themes from the data. The social determinants of health framework and the International Classification of Functioning (ICF) model were then used to contextualise the data.

Results: Five major themes were identified including: exclusion from formal education, exclusion from the work force, exclusion from public facilities,

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exclusion from marriage and increased risk of violence and exclusion from community activities and social groups. Facilitators to inclusion include: provision of accessible buildings and transport, community-based advocacy services and vocational training services.

Conclusions: *The combination of physical disability and female gender presents multiple complex barriers to inclusion in the socioeconomic and cultural life of Bangladesh. Practical interventions through both up-scaling and expansion of disability-specific programming and sustained policy implementation are required to facilitate individual empowerment and better health outcomes for women with disability.*

Keywords: *Exclusion, disability, women, Bangladesh, physical disability.*

INTRODUCTION

Globally, the right of a person with disability to be included in the socioeconomic life of a country has been largely ignored (UN, 2007; WHO, 2011, 2013).

Popay et al (2008) define exclusion as, “Unequal power relationships interacting across four main dimensions - economic, political, social and cultural - and at different levels including individual, household, group, community, country and global levels. It results in a continuum of inclusion/exclusion characterised by unequal access to resources, capabilities and rights which leads to health inequalities”.

The UN Convention on the Rights of Persons with Disabilities (2006) was developed to encourage all countries to protect the rights of all people with disabilities and offer them specialised opportunity for personal development and societal contribution. In accordance with UN recommendations, Bangladesh was one of the first countries to ratify this convention in 2007, indicating an intention to focus on the rights of all Bangladeshis with disability (NHRC Bangladesh, 2013).

However, despite this formal commitment, there exists a double burden for women with disability in Bangladesh. Firstly, this is represented by gender and how being female can often mark a preconceived life course including early marriage, limited education and exclusion from the formal workforce (Rahman, 1993; UNICEF, 2010; Ferdaush and Rahman, 2011; NHRC Bangladesh, 2013).

Secondly, a woman with disability can be deprived of opportunities regarding marriage and childbearing, community inclusion and any kind of work (either

domestic or paid) which compounds her isolation (Hussein, 2008). She is also more likely to suffer violence during her lifetime than a woman without disability (Hussein, 2008; Mitra et al, 2011; CREA, 2012; NHRC Bangladesh, 2013; Hassan et al, 2014). This double burden is underpinned by fundamentalist ideas regarding traditional gender roles and poverty, therefore compounding unequal power relationships and exclusion mechanisms reflected within disability specific health inequalities globally (Foley and Chowdhury, 2007; Ferdaush and Rahman, 2011; Simkhada et al, 2013).

Ill informed attitudes and routine discrimination against women with disability can be seen across multiple realms of Bangladeshi society, including the physical, political and cultural environments (Salah, 2003; Jalil, 2012). These modes of discrimination catalyse poorer health outcomes for this population (Hosain et al, 2002; Foley and Chowdhury, 2007).

In 2011, it was found that a gender gap of 13% existed between prevalence of disability in women (22.9%) versus men (9.91%) between the ages of 18-65 years (Hussein, 2008). This gender gap is markedly higher than in other countries in the region, such as Pakistan (6%), Lao PDR (<1%) and the Philippines (1.6%). Moreover, the likelihood that these women will have opportunity to engage in paid work is less when compared to men and women without disability; hence it is statistically less likely that a person with physical disability (particularly if it is a woman) in Bangladesh will escape poverty than it is for a person without disability (Foley and Chowdhury, 2007; Tareque et al, 2014).

This data was collected via the World Health Survey and conducted through the provision of individual household surveys. Surveys were designed with the definition of disability being shaped by the ICF model which includes physical structure and function limitations, activity restrictions, participation limitations and environmental and personal factors contributing to the overall state of health for the individual (WHO, 2013). However, it should be noted that surveys were more in depth for lower income countries such as Bangladesh than for higher income countries such as the Philippines, and therefore data is more likely to represent a slightly higher gender gap and disability prevalence rates than those who received less detailed surveys (WHO, 2011).

Foley and Chowdhury (2007) describe a cultural climate whereby merely the label of disability for persons within Bangladeshi communities can prompt a chain of 'exclusion mechanisms that reinforce each other'. These culturally embedded

mechanisms are found to proliferate the sequence of poverty and increased risk of ill health (Yeo and Moore, 2003; Foley and Chowdhury, 2007; Kashyap, 2013). Further, Bangladeshi culture is dominated by patriarchal ideals that force increased dependence of women on men (Blunch and Das, 2007; Nokrek et al, 2013). There remain substantial gaps between participation in health, education and employment for adult Bangladeshi women as compared to males. Therefore, disability for women creates amplified deprivation across all areas of the socioeconomic spectrum (Titumir and Hossain, 2005; WHO, 2013). This impeding cultural climate can be seen in other countries within the South Asian region, such as Nepal. Dhungana (2006) describes both the causes of disability and barriers to inclusion for Nepalese women with disability to be results of cultural and societal oppression and ignorance targeted at females. It was found that mechanisms for disability, particularly for women, are related to gender discrimination, poverty, a lack of state security systems, negative attitudes amongst communities, inadequate family support and failed government systems (Dhungana, 2006). This evidence reflects regional problems such as gender inequality, poverty and human rights violations for persons with disabilities.

Despite the implementation of the 'Bangladesh Persons with Disability Welfare Act – 2001', there is little evidence that the policy has manifested as community change over the past decade (Sultana, 2010; Sense International, 2013). In 2013, the 'Rights and Protection of Persons with Disabilities Act' was introduced, which mandates the issuing of national identity cards, enrolment in regular schools, reservation of seats on all forms of transportation, equal opportunities in employment and protection of inherited property rights (Sultana, 2010; Sense International, 2013). Similar to the earlier Act of 2001, without practical intervention and rapid mass scaling up of inclusion programmes, this Act of 2013 may well be as unsuccessful as its predecessor.

Moreover, corrupt Government officials and police can be perpetrators of exclusion and abuses for the vulnerable, which reflects tribulations common within the Bangladeshi political environment and represents another complex barrier to inclusion (Habib and MdHabibur, 2002).

Wilkinson and Marmot's (2003) social determinants of health framework demonstrates the sensitivities of health to the socioeconomic, cultural and environmental conditions and therefore is useful in contextualising the results of the study. The framework also describes the social gradient of health which refers to a global phenomenon whereby health inequalities affect the entire population.

It demonstrates that where people are positioned on the social hierarchy impacts not only the way in which they develop, but also determines their vulnerability to ill health (Wilkinson and Marmot, 2003). The framework addresses the core aspects of life which are directly linked to health, such as stress, early life, social exclusion, work, unemployment, social support, addiction, food and transport (Wilkinson and Marmot, 2003). Therefore, the framework clearly contextualises the impact of socioeconomic exclusion from these key aspects of life on health and demonstrates how disability can further impede these aspects, particularly in a low resourced environment (Wilkinson and Marmot, 2003).

Despite the regional evidence regarding the barriers and facilitators to inclusion for women living with disability, there is a clear gap in available and timely evidence which describes the: 1) Lived experience for women with disability in Bangladesh, 2) Barriers to socioeconomic inclusion, and 3) The facilitators for socioeconomic inclusion for women with disability living in Bangladesh. This research aims to describe some of the specific mechanisms which propagate inequality and ill health for women with disability in Bangladesh, and to show how these mechanisms have developed and still remain a barrier within this cultural context. Although the results of the study cannot be generalised to the wider Bangladeshi population, in gaining further understanding of the situation for the women included in the study, ideas of how to combat these barriers and enhance the facilitators may be generated. The authors anticipate that these recommendations will be of use to local (CRP) and international organisations working in the disability sector in the region.

METHOD

Setting

This study was conducted in November and December 2014. Data was collected through the outpatient departments of Prosthetics & Orthotics and Spinal Cord Injury (SCI) at the Centre for the Rehabilitation of the Paralysed (CRP), located in Savar (approximately 35km north-west of the capital city of Dhaka), Bangladesh. CRP is the only organisation which offers specialist medical and allied health intervention for adults and children with SCI in the country and is one of few organisations to offer specialist rehabilitation services to persons with amputation. Clients may access services for free if they demonstrate that they have no means of funding their own care. Alternatively, a fee is charged relative

to the client's income. Therefore those who have increased disposable income are expected to contribute to their own healthcare costs.

Sample

The study is based on semi-structured in-depth interviews of 15 women, who were recruited through mixed purposeful sampling (a mixture of typical case sampling and criterion sampling), with the assistance of outpatient clinicians (Prosthetists and Physiotherapists).

The inclusion criteria: females between the ages of 15 and 40 who had acquired either a spinal cord injury or amputation via a traumatic cause and had been discharged for at least 3 months after inpatient admission. Researchers excluded women with congenital disability as they aimed to capture the perceptions of inclusion both before and after disability onset to inform differences between gender discrimination and disability discrimination.

Procedure

Fourteen interviews were conducted in Bengali using an interpreter, and one interview was completed in English.

Each woman was interviewed once and an information statement regarding the research aims and processes and consent forms were provided in Bengali. Every participant had the ability to provide signed consent and agreed to recording of the interview via Dictaphone, with written notes to be taken at the session. The interviews ranged from 45 - 90 minutes and translations were made immediately via the interpreter to allow for live discussion, clarification of ideas and probing during the interview (Murray and Wynne, 2010). Transcription in English was completed following the interview and each respondent's name was removed and replaced with a number and letter code.

Analysis

The analysis regarding the extraction of themes from the data took place face-to-face at CRP with the local authors and via email and Skype with Sydney University staff (Professor Robert Cumming and Dr.Cynthia Hunter). An iterative process was established whereby open coding was utilised to recognise and analyse emerging themes and categories (Sobo, 2009; Green and Thorogood, 2009).

The data was summarised and key interview extracts were placed in a table, allowing a contrast of themes and categories across all participants (see Table 1.0). The social determinants of health framework was then used to further conceptualise the results of this process (Wilkinson and Marmot, 2003). That is, all determinants (excluding addiction) are mentioned by the participants, including aspects of stress, early life, social exclusion, work, unemployment, social support, food and transport which therefore demonstrates the correlation between the determinants and disability inclusion. The framework allows these aspects of the participants' experience to be understood within a context of health specifically, either immediately or as the potential for longer term effects on health. This understanding is underpinned by the concept of the social gradient and how ill health will promote a further descent down the gradient.

Ethics Approval

The study was approved by the Sydney University Human Research Ethics Committee (project number: 2014/725) and the CRP Research Ethics Committee. The study protocol specified that participation was completely voluntary and participants could withdraw at any time.

The primary researcher is a dual national (Australian and British) registered Occupational Therapist with extensive experience in interviewing women with disability and discussing sensitive and confidential information. Post-interview debriefing was made available through the CRP psychology service; however no participants pursued this.

RESULTS

The major themes derived from the data for discussion include: barriers to formal education, barriers to the workforce, barriers to public facilities, barriers to marriage and increased risk of violence and exclusion from community activities and social groups. (Please see Table 1.0 for themes, categories and the codes assigned.)

Table 1.0: Themes, Categories and Codes

| Themes | Sub categories | Codes |
|--|--|--|
| Exclusion from Education | Poor environmental accessibility; Familial dependence; Familial support; Teacher discrimination; Student discrimination; Lack of inclusion policies; Misconceptions regarding the capacity of women with disability | Gender discrimination, poor disability awareness, Bangladeshi culture, society, disability access, disability policy, discrimination, family support, girls' education, gender bias |
| Exclusion from Paid Work | Inaccessible working environments, e.g. stairs, no lifts; Government corruption; Inability to go outside of the home and seek work; Perception that women with disability have no capacity to work; Physical impairment; Disability preventing work; Male priority | Gender discrimination, poor disability awareness, male dominance, male priority, environmental accessibility, female inferiority, Bangladeshi culture, traditional gender roles, community expectation, male genetics, corruption |
| Exclusion from Public Environments and Transport | No accessible buses in Bangladesh; Extra charge to bring wheelchair on the bus; Uneven roads, muddy roads in rainy season; No accessible public buildings, markets; Doctor discrimination; Exclusion from community gatherings; Unreported sexual abuse; Poor disability awareness; Misconceptions regarding efficacy of females with disability; NGOs raising awareness | Gender discrimination, poor disability awareness, disability access, disability policy, family support, infrastructure, sexual abuse, abuse, vulnerability, neglect, superstition, wheelchair access, family support, corruption, fear |

| | | |
|--|--|---|
| Exclusion from Traditional Marriage practices and Violence | Abandonment of wife after the accident; Family-in-law rejection of wife; Shame brought to the family-in-law; No arranged marriage offered for woman with disability; Dowry disputes; Financial abuse; Inability to complete household activities; Women should stay inside the home and only males are fit to go outside the home; Unable to have children; Males viewed as higher priority in society due to their perceived increased earning capacity; Traditional gender roles | Shame, guilt, abandonment, 'normal woman', Bangladeshi culture, society, family-in-law, mother-in-law, rejection, increased dowry for marriage, other woman, no children, will not accept, disrupted normal life course, cannot earn money, cannot contribute to familial unit cope, torture, beating, vulnerable, murder, taking money, large dowry, corruption, unprotected, guilt, shame, family beating, dowry, poverty, fear, depression |
| Exclusion from Community Activities and Social Groups | Poor understanding of disability; Poor understanding of causes of disability; Low education levels in villages; Discrimination against women | Superstition, curse, advocacy groups, disability-specific education, disability awareness, local support groups, mental health, physical health, motivation to engage, misconceptions, children, bullying |

Characteristics of Participants

Table 1.1 provides characteristics of 15 women with disability who were interviewed.

Table 1.1: Characteristics of Participants

| Background Characteristics | Frequency | Percentage (%) |
|-----------------------------------|------------------|-----------------------|
| Type of Injury | | |
| Amputation | 5 | 33.3 |
| Spinal Cord Injury | 10 | 67.7 |
| Mobility Status | | |
| Wheelchair dependent | 9 | 60 |
| Independently ambulant | 6 | 40 |
| Age in Years | | |
| 20-25 years | 5 | 33.3 |
| 26 – 32 years | 7 | 46.7 |
| 32 – 40 years | 3 | 20 |
| Area of Residence | | |
| Urban | 8 | 53.3 |
| Rural | 7 | 46.7 |
| Education Level | | |
| No education | 1 | 6.7 |
| Primary | 14 | 93 |
| Secondary | 6 | 40 |
| Tertiary | 4 | 26.6 |
| Marital Status | | |
| Married | 9 | 60 |
| Single | 4 | 26.6 |
| Widowed | 1 | 6.7 |
| Abandoned by husband | 1 | 6.7 |
| Religious Identity | | |
| Muslim | 14 | 93.3 |
| Hindu | 1 | 6.7 |
| Worker Status | | |
| No paid work | 6 | 40 |
| Paid work | 9 | 60 |
| N | 15 | |

Barriers to Formal Education

The barriers include poor societal attitudes regarding female disability, poverty, teacher and student discrimination and poor physical accessibility within educational institutions. Women reported feelings of frustration, prejudice and oppression due to the primitive beliefs often held within their communities regarding traditional gender roles and the common perception that educating a woman with disability is futile. Women in the study described barriers mostly related to high school, college and university level institutions. One woman (40 years old) reported that she had never attended school at all due to both her injury in early life and her gender in the context of rural poverty. These barriers directly correlate to the concepts of individual functioning outlined within the ICF (WHO, 2013). That is, women describe environmental barriers as aforementioned to be impeding their level of participation and activity and more specifically, reducing their capacity to engage at all (mostly as teenage and adult learners).

“People around me, they think: what is the point of you studying further? You are a woman so you should stay in the room (even though I am tutoring and teaching children). My father says don’t teach the children, I will give you money. You don’t need to study anymore, please just stay in the house. This makes me lonely and frustrated” (D9, 21 years old, SCI).

“First of all I am a woman so I cannot complete my study so this is another problem. Also there is the problem that I am disabled” (D15, 20 years old, amputee).

Most women who had been involved in secondary and/or tertiary education reported difficulties related to teacher and student discrimination, which is associated with poor disability awareness and the absence of disability inclusion policies. Other students often excluded the women from study and social circles, thereby increasing their dependence on family.

“I face more difficulty in study life because in college no students support me so family member needs to move me to class, the teacher doesn’t give me extra time so it’s more difficult. After I complete college I wish to do further study but there is no university to take disabled people so it will be difficult for me to do this” (D9, 21 years old, SCI).

Support of family within this environmental context is identified as a facilitator for engagement in education. That is, given the extensive barriers to engagement, e.g., teacher and student discrimination and poor building accessibility, the support of family means that engagement is still possible. All the women reported

poor physical accessibility of educational institutions. Some women reported this had prevented them from completing their studies altogether.

“I cannot sit the examination at school because the hall was [on the] fourth floor and so I could not get to the examination” (D12, 35 years old, SCI).

This starkly highlights the relationship between the environment, activity and participation. In this example, basic structural problems, e.g., no wheelchair access, prevented the completion of high school, which in turn prevents any form of further education and significantly impacts job prospects. The wider implications of this relate to poverty and general increased vulnerability, both of which will contribute to an increased likelihood of poverty and ill health. This example suggests that effective facilitation methods to reduce these barriers include increasing accessibility of educational institutions to enable students with limited mobility.

Feelings of disappointment and injustice were common. Only those who had the support of at least one family member were successful in completing the level of schooling they had aimed for.

“If I was able, I could go to school and college, but my disability will be a problem regarding transport; everything [at school] is not accessible for me” (D8, 29 years old, SCI).

Transport is defined as a barrier to participation in education. To fully understand the impact of transport problems for this particular participant, one must consider what the inability to finish high school may mean for future health and socioeconomic inclusion. This extends to the determinants of health such as work, unemployment and poverty, and the subsequent negative impacts for her health in the context of her position on the social gradient and compromised well-being (Wilkinson and Marmot, 2003). Paradoxically, this example suggests disability-friendly public transport as a facilitator to educational inclusion.

Barriers to the Workforce

Access to employment is impacted by perceived inefficiencies of women with disabilities as compared to women without disability and particularly men (with or without disability). Study participants have depicted a society that often fails to recognise that women with disability have earning capacity; a society which traditionally prefers males to participate in the workforce. According to most

participants, women with disability are usually expected to stay within the home and complete domestic duties, or sit idly and not participate at all.

“Of course if I were a man I could work even if I had a disability, but I’m not. Our society always favours the man, not woman. If I can get opportunity to work, then I can do just like a man, no problem, but it depends on the society” (D3, 24 years old, amputee).

“I have a dream to be banker, if I was a man then I know my dream would come true, but I don’t get any opportunity from society and other people; if I was a man then I would have lots of opportunity” (D9, 21 years old, SCI).

“If I was a male, then I can do anything, I can go outside and do other jobs, right now I am making clothes in my house, but if I was male I could have a shop at a local market. But because I’m female it’s not possible for me to go outside in the market and work in the shop” (D11, 40 years old, SCI).

These reports highlight that the interaction between gender and disability compounds exclusion from the workforce for women in this study. The women also described physical accessibility issues as barriers to inclusion in the workforce.

“There is no access for disabled person in the bank because most of the banks in our country are upstairs so if I got the qualification to become a banker then I think the bank will not offer me the opportunity to work there” (D9, 21 years old, SCI).

“The government has a disabled quota for jobs as a primary school teacher, but every time there is an exam [an aspect of the job application process] it is upstairs, like on 2nd or 4th floor so I cannot get to the exam” (D9, 21 years old, SCI).

Some women mentioned government corruption as a key barrier to gaining employment.

“I don’t get any opportunity because there is lots of corruption. If the government sends a new wheelchair to the district, then they will send the chair to sell at the market and we don’t get anything. The government don’t offer any job or any opportunity; there is no opportunity for disabled. The government says there is opportunity but there is not” (D9, 21 years old, SCI).

“In my district there is lots of corruption including the minister and chairman members, so every union in Bangladesh have opportunity to get a job for disabled person but in our district the non-disabled person will take those jobs” (D5, 29 years old, SCI).

The majority of women engaged in paid work attributed this to either employment provided by CRP or financial assistance to begin their business provided by either CRP or another local organisation such as the National Council of Disabled Women, Bangladesh. This indicates that gender specific, local disability support can facilitate employment and protect women from discrimination in the work force. Women also reported that the environmental accessibility and inclusive community attitudes contributed to their success at work and social life, as well as to improved mental and physical health.

“In CRP women get more priority than males. Outside of CRP males get more opportunity for work than females. I am living in CRP and many women are using wheelchairs so they support us, so this impacts positively on my health” (D6, 26 years old, SCI).

Barriers to Public/Places

Most women reported difficulty in accessing public/places due to inaccessibility of transport and public buildings.

“[The bus is] not accessible for using the wheelchair and no available seat on the bus for me. I use bus, the bus driver helps, but he takes more taka [money] from me” (D5, 29 years old, SCI).

“If I return to society [from CRP] I feel difficulty to move, because in my district there are problems like narrow roads and when the rains come the roads become muddy” (D4, 23 years old, amputee).

“I don’t like any health clinic in the district because I have so much problem using the wheelchair” (D15, 20 years old, amputee).

These difficulties were often compounded by fear of verbal and sexual abuse in public places.

“[I am] fearful of getting teased and fearful of any kind of sexual abuse from man. But [disabled] man, they don’t have this kind of fear to go outside” (D5, 29 years old, SCI).

“When the female go outside, the community people are saying so many negative things. But if male go outside they do not face any negative or prejudiced words” (D13, 30 years old, SCI).

Two women reported they had a family member who was able to accompany them in public and therefore they did not identify with the difficulties regarding

public access. This indicates that familial support acts as an effective facilitator for participation in public life.

“As my family is very supportive, then this kind of situation is not a problem for me; my family are always with me, by getting their support then nothing is difficult for me” (D7, 22 years old, SCI).

Barriers to Marriage and increased Risk of Violence

The opportunity for inclusion in marriage in Bangladesh is often dependent on the female’s family and the family’s willingness to arrange a partner. All but one participant identified marriage as a central cultural practice in which women with physical disability can often be either excluded or at a higher risk of abuse and abandonment than women without disability. Common reasons for this were that the father would often relinquish his responsibility regarding arranging a marriage after the daughter sustained a disability; the likelihood that another family would not want an alliance with a family whose daughter had disability; unaffordable dowry (provision of valuables in exchange for marriage); the high risk that men may marry only for dowry payment and then abandon the woman soon afterwards; high risk of inter-partner abuse or abuse by the husband’s family; and, the potential inability of the woman to either bear and/or raise children. Exclusion from marriage and childbearing has a negative effect on future life prospects in this societal context and further jeopardises an individual’s health and well-being. This is most often an issue specifically affecting women, as men may marry more than one wife; however, women usually cannot have more than one partner in their lifetime.

“No, I will never get married ... lots of family they don’t accept the disabled person for their son to get married. Even when they are getting married, maybe a few months later the husband is living with his wife and then going away; my family did not make the arranged marriage after the injury. My family are just thinking, maybe they could not find another family to get married with me” (D5, 29 years old, SCI).

“Because of the injury the boy did not agree to marry me. Although he did wait for me for two years, but because I did not become normal he married another woman” (D9, 21 years old, SCI).

“Nobody wants to get married to a disabled woman. But if they do get married, the man needs lots of dowry usually” (D15, 20 years old, amputee).

Women regularly reported that abandonment, physical and financial abuse were understood to be common in the marital life of the female population with disability. They reported that due to police corruption, crimes against women with disability often remained unpunished.

“In my own Upazilla [district], the husband, husband’s mother and husband’s brother, they killed the wife. I think this was due to dowry issues, three Lak taka [3896 USD]. Police were told but they did not take any steps. The victim will get ignored because the culprit will provide more money than the victim to the police” (D15, 20 years old, amputee).

“Both the husband and the family members beating the disabled woman, sometimes husband, sometimes the husband’s family members. Because when someone gets married to the girl in our society, they think the girl should do all of the household work, so when she can’t do that properly then the violence happens” (D13, 30 years, SCI).

Exclusion from Community Activities and Social Groups

Most women reported discrimination from their local (original) community. All of them attributed this to a poor understanding of disability, leading to misconceptions that women with disability were ‘cursed’ or had committed an offence against God. This form of exclusion impacted their mental health significantly, resulting in reports of depression.

“75% of neighbours around me, they treat me differently. Some people in my society try to avoid me and they say, ‘nobody eat from her!’ because of me losing my hand” (D2, 29 years old, amputee).

“I think if I died at the time of the accident then this would have been better. Then the people cannot treat me differently” (D15, 20 years old, amputee).

Generally, women expressed their dissatisfaction with the lack of disability information available in their local areas. However, those who had received advocacy services reported improvements in mental and physical health, motivation to earn money and increased capacity to care for their children. This indicates that local advocacy and education services act as effective facilitators to inclusion.

“Now the situation is improving, at first many people are avoiding and neglecting me but now I got support from the Upazilla [district] disability foundation. I had the

president talk with my father and mother and they taught them about amputation and now the situation is improving for me” (D2, 29 years old, amputee).

DISCUSSION

Common motifs emerged throughout the interviews. Feelings of loss related to traditional and contemporary roles that are less likely to be achievable, such as: 1) motherhood and professional roles, 2) an expectation of limited achievement in the course of life due to inequalities rather than the disability itself, 3) feelings of incapacitation by rigid societal constructs rather than due to the disability itself, and 4) women identify as part of a repudiated minority population whereby inequality and deprivation is inherent.

High levels of discrimination and violence against women with disability have been reported across various South Asian and South-East Asian developing countries. De Alwis (2010) describes this double burden of gender and minority (disability) within Bangladesh, India, Nepal and Cambodia. Most specifically, gender-related violence is defined as both a cause and consequence of disability in the region. Common gender-related practices such as abandonment of female children, child marriage, dowry and honour crimes reflect a culture which traditionally favours males more than females, irrespective of disability. This demonstrates that disability is a catalyst for increased discrimination, violence and exclusion in what is an already biased environment (Thomas, 2011; Simkhada et al, 2013).

Women’s narratives were commonly characterised by feelings of frustration because of routine deprivation of opportunities through lack of support. All the women identified concerns for their future health and economic security, given that their ability to participate in the mainstream workforce was significantly limited.

Across the Asia-Pacific region, women with disability remain less educated and therefore demonstrate higher rates of unemployment when compared to their male peers (Thomas, 2011). These inequalities are also attributed to lagging efforts across sectors such as human rights law and the sensitivities of Government intervention programmes (Thomas, 2011). Therefore, exclusion from society is compounded by neglect within the larger political environment.

Poor mental health has been recognised as costing modern societies in terms of lost productivity or ‘misery cost’ and economic waste (Layard, Chisholm, Patel & Saxena, 2013). Evidence suggests that it is not only reasonable to expect poorer

health outcomes for the individual but this can have a dramatically erosive impact on local economies in terms of lost productivity and loss of participating individuals in the workforce. Thus, through various exclusion mechanisms, women with disability are transformed into economic and social burdens. This burden is borne by the society collectively and therefore causes the entire society to descend further down the social gradient of health (Wilkinson and Marmot, 2003).

By placing the major themes within the social determinants of health framework, it becomes possible to understand how issues such as poverty and disability impede health. Facilitators have been identified by the women themselves and relate to accessible environments and transport, local advocacy services, changes in community attitudes and vocational training services enabling increased financial independence. These facilitators can be seen as key areas for specific local programming and scaling-up of the current programmes that are in place. These facilitators are the key to creating change and enablement for women with disability. Not only does inclusion in socioeconomic aspects of life such as employment and education enable the individual to progress, but with more examples of women with disability becoming contributing members of society, attitudes in communities are likely to change as the community will become better informed and possibly more inclusive.

Authors call for not only the provision of gender-specific disability inclusion policies (which are implemented with conviction) and programming to address the aforementioned facilitators, but also the inclusion of women with disability in all aspects of policy and programming design. Women such as those of the study sample demonstrate invaluable knowledge and experience of facilitators and barriers to socioeconomic inclusion, and therefore they should be utilised as leaders in the development of empowerment and enablement programmes instead of merely being recipients. In doing this, women are not only gaining employment but also the likelihood that programmes will be targeted in a meaningful, specific and contextually relevant way is infinitely increased (Austrian Development Agency, 2013). Therefore, programme and policy makers need to veer away from a top-down approach to inclusion by taking the true meaning of inclusion literally and incorporating it into each step of development (Austrian Development Agency, 2013).

Moreover, the disability inclusion policy set out by the Bangladeshi government requires constant monitoring and evaluation to ensure accountability. Policies which are in line with international standards do not enact change without

practical intervention and development that is congruent with changes in need. The UN's sustainable development goals are related to disability, such as: Goal 4 - Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all; Goal 8 - Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all; Goal 9 - Build resilient infrastructure, promote inclusive and sustainable industrialisation and foster innovation; Goal 10 - Reduce inequality within and amongst countries; Goal 11 - Make human settlements inclusive, safe, resilient and sustainable; and Goal 17 - Strengthen the means of implementation and revitalise the global partnership for sustainable development (International Disability Alliance, 2015). These are one set of measures against which progress can be monitored (International Disability Alliance, 2015), however government accountability must be incorporated into current local policies to ensure sustainability, avoid the concealment of corruptive practices and mismanagement of resources (International Disability Alliance, 2015). Furthermore, local laws related to disability inclusion must be supported by allocated funding to implement the outlined changes in policies. The development of disability-led monitoring and evaluation committees is one way in which practices can be monitored and the focus on government responsibility can be ensured.

CONCLUSION

The women who were interviewed for the study demonstrated that the combination of physical disability and female gender presented multiple complex barriers in their experience of socioeconomic and cultural inclusion. Efforts to empower this population through community education and advocacy-based initiatives, vocational training opportunities and the provision of accessible public environments and transport, would promote more independent living and thereby improve community integration and better health outcomes.

There is evidence that women with disability are particularly in need of employment opportunities so that they will be able to view themselves as able contributors to society, gain financial independence and this in turn will help combat misconceptions regarding disability.

Increased support through community-based programmes that embody the principles of the Rights and Protection of Persons with Disabilities Act 2013 would be pivotal in transforming community perceptions of women with disability. In order to remove barriers to participation, the government and civil society NGOs

need to mutually provide programmes and policies which address the facilitators to inclusion for this population, and match these with sustained funding.

Limitations

As participants were recruited through the outpatient services of CRP, the study sample reflects a group of women who have access to basic healthcare as well as to some financial support. The experiences of ultra-poor women and women of very high socioeconomic status have not been captured. Also, since most of the study participants have had some education, the study does not really analyse women who have been totally deprived of education. Despite this, the results of the study demonstrate that the experiences of women with disability in Bangladesh are congruent with experiences of the double burden for women in the South Asian region.

ACKNOWLEDGEMENT

Sincere and heartfelt thanks to the brave women who agreed to take part in this study and share often intimate details of their lives. The authors thank the staff of the Centre for the Rehabilitation of the Paralysed for their participation and support during the planning and data collection phase. Many thanks to the interpreter team for their dedication, time and the sensitively rendered assistance during the interview process. Thanks also to the Sydney University Human Research Ethics Committee for raising valid questions in the planning phase which improved the quality of this research.

The authors declare no potential conflicts of interest regarding the research or the authorship of this article.

REFERENCES

Austrian Development Agency (2013). Persons with disabilities inclusion: Human right and mandate guideline on including persons with disabilities in ADC project cycle management. Vienna Austria: Austrian Development Agency; December, 23.

Blunch NH, Das MB (2007). Changing norms about gender inequality in education: Evidence from Bangladesh. World Bank South Asia Region: Sustainable Development Department; Report No.: 4404.

Creating Resources or Empowerment in Action – CREA (2012). Count me in: Research report on violence against disabled, lesbian, and sex-working women in Bangladesh, India, and Nepal. New Delhi: CREA; Report No.: 09042013.

De Alwis RDS (2010). The intersections of the CEDAW and CRPD: Integrating women's rights and disability rights into concrete action in four asian countries. Wellesley Centre for Women (US): 126.

Dhungana BM (2006). The lives of disabled women in Nepal – vulnerability without support. *Disability and Society Journal*; 21(2): 133-146. <http://dx.doi.org/10.1080/09687590500498051>

Ferdaush J, Mustafizur Rahman KM (2011). *Gender Inequality in Bangladesh*. The Centre for Research and Action on Development: Dhaka.

Foley D, Chowdhury J (2007). Poverty, Social Exclusion and the Politics of Disability: Care as a Social Good and the Expenditure of Social Capital in Chuadanga, Bangladesh. *J Social Policy and Administration*;41(4): 372-385. <http://dx.doi.org/10.1111/j.1467-9515.2007.00559.x>

Green J, Thorogood N (2009). *Qualitative Methods for Health Research*. Sage Publications: London. <http://dx.doi.org/10.1136/qshc.2007.023119>. <http://dx.doi.org/10.1136/qshc.2008.029397>. <http://dx.doi.org/10.1136/qshc.2008.029447>. <http://dx.doi.org/10.1136/qshc.2008.028837> PMID:19188456 PMCID:PMC2629853

Habib MohaammadZ, Md. Habibur R (2002). Human Rights, Civil Society and Nongovernmental Organisations: The Nexus in Bangladesh. *Human Rights Quarterly*; 24(4): 1011-1034. <http://dx.doi.org/10.1353/hrq.2002.0055>

Hassan T, Muhaddes T, Camellia S, Selim N, Rashid SF (2014). Prevalence and Experiences of Intimate Partner Violence Against Women With Disabilities in Bangladesh: Results of an explanatory sequential mixed-method study. *J Inter per Violence*; 29 (17): 3105 – 3126. <http://dx.doi.org/10.1177/0886260514534525>. PMID:24860077

Layard R, Chisholm D, Patel V, Saxena S (2013) In Helliwell J, Layard R, Sachs J (eds) *World happiness report, 2013*. UN Sustainable Development Solutions Network: New York. PMCID:PMC3776229

Hosain GM, Atkinson D, Underwood P (2002). Impact of Quality of Life of Rural Disabled People in Bangladesh. *J Health Popul & Nutr*; 20(4): 297-305. PMID:12659409

Hussein A (2008). *Report on Women with Disabilities in Bangladesh*. Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV): Dhaka.

International Disability Alliance (2015). *Disability indicators: SDG Advocacy tool kit* [Online] Available at: <http://www.iddconsortium.net/resources-tools/disability-indicators-sdg-advocacy-toolkit> [Accessed on 9 September 2015].

Jalil MA (2012). Disabled people's access to public sector employment in Bangladesh: Why so little changes?. *Int'l J. Sust. Dev.*; 3(9): 87-92

Kashyap A (2013). *Bangladesh: Three terrible exclusions* [Online]. Available at: <http://www.hrw.org/news/2013/08/02/bangladesh-three-terrible-exclusion> [Accessed on 2 August 2015].

Mitra S, Posarak A, Vick B (2011). *Disability and Poverty in Developing Countries: A snapshot from the world health survey*. World Bank: Washington DC. Report no.: 62564.

Murray CD, Wynne J (2010). Using an interpreter to research community, work and family. *J Comm. Work and Fam*; 4(2): 157-170. <http://dx.doi.org/10.1080/713658930>

- National Human Rights Commission, Bangladesh (2013). *The Convention on the Rights of Persons with Disabilities: A Study on Bangladesh Compliance*. NHRC: Dhaka Bangladesh.
- Nokrek P, Alam MA, Ahmed M (2013). *Livelihood challenges for extremely poor disabled people in the southwest coastal region of Bangladesh*. Shiree: Dhaka: Shiree. Report No.:12.
- Popay J, Escorel S, Hernández M, Johnston H, Mathieson J, Rispel L (2008). *Understanding and Tackling Social Exclusion*. World Health Organisation (WHO) Social Exclusion Knowledge Network: Lancaster UK.
- Rahman O (1993). Excess mortality for the unmarried in rural Bangladesh. *Int J of Epidemiol*; 22(3): 445-56. <http://dx.doi.org/10.1093/ije/22.3.445>. PMID:8359960
- Salah U (2003). *Disability Situation & Impact of ADD work in Bangladesh* [Online]. Available at: http://www.independentliving.org/docs6/uddin20_0309.html [Accessed on 5 August 2015]
- Sense International (2013). *New Bangladeshi Disability Act Helps to Improve the Lives of Millions* [Online]. Available at: <http://www.senseinternational.org.uk/news/new-bangladesh-disability-act-helps-improve-lives-millions> [Accessed on 8 October 2015]
- Simkhada PP, Shyangdan D, Van Teijlingen ER, Kadel S, Stephen J, Gurung T (2013). Women's knowledge and attitude towards disability in rural Nepal. *J Disability & Rehabilitation*; 35(7): 606–613. <http://dx.doi.org/10.3109/09638288.2012.702847>. PMID:22823929
- Sobo E (2009). *Culture & Meaning in Health Services Research California*. Left Coast Press: Walnut Creek CA.
- Sultana Z (2010). Agony of persons with Disability – A comparative study in Bangladeshi. *J Politics and Law*; 3(2): 212-221. <http://dx.doi.org/10.5539/jpl.v3n2p212>
- Tareque MI, Begum S, Saito Y(2014). Inequality in Disability in Bangladesh. *PLOS One*; 9(7):1-10. <http://dx.doi.org/10.1371/journal.pone.0103681>. PMID:25075513 PMCid:PMC4116223
- Thomas P (2011). *Implementing Disability-inclusive Development in the Pacific and Asia*. Development Studies Network: Canberra Australia
- Titumir RAM, Hossain J (2005). *Disability in Bangladesh: Prevalence, knowledge, Attitudes and Practices*. The Centre for Research and Action on Development: Dhaka.
- United Nations (2007). *Report of the United Nations High Commissioner for Human Rights on progress in the implementation of the recommendations contained in the study on the human rights of persons with disabilities*. UN Human Rights Council: Geneva, Switzerland.
- United Nations General Assembly (2006). *Final report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*. United Nations: Geneva, Switzerland.
- United Nations International Children's Emergency Fund (2010). *Women and Girls in Bangladesh*. UNICEF: New York.
- Wilkinson R, Marmot M (2003). *The Solid Facts: Social Determinants of Health* (2nd ed), World Health Organisation (WHO): Copenhagen. [http://dx.doi.org/10.1016/s0305-750x\(02\)00218-8](http://dx.doi.org/10.1016/s0305-750x(02)00218-8)