Impact of Disability on Quality of Life of Rural Disabled People in Bangladesh

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ABSTRACT

This study examined the impact of disability on the quality of life of disabled people in rural Bangladesh. A primary healthcare specialist conducted a door-to-door survey in two villages in Bangladesh to collect socioeconomic and demographic information on the villagers and for identification of disabled people. Information on disability and how it affected their life was also obtained either from the disabled people or from their caregivers by interviewing them. The study revealed that disability had a devastating effect on the quality of life of the disabled people with a particularly negative effect on their marriage, educational attainment, employment, and emotional state. Disability also jeopardized their personal, family and social life. More than half of the disabled people were looked at negatively by society. Disabled women and girl children suffered more from negative attitudes than their male counterparts, resulting in critical adverse effects on their psychological and social health. A combination of educational, economic and intensive rehabilitative measures should be implemented urgently to make them self-reliant. Collaborative communication between professionals and parents, behavioural counselling, formation of a self-help group, and comprehensive support to families will reduce their suffering.

Key words: Disability; Quality of life; Inequalities; Impact studies; Bangladesh

INTRODUCTION

The World Health Organization has defined health as “a complete physical, mental and social well-being and not merely the absence of disease or infirmity.” The concept has more recently been extended to include health-related quality of life (1,2). According to the international classification of impairments, disabilities, and handicap, impairment is concerned with physical aspects of health, disability has to do with the loss of functional capacity resulting from impaired organ, and handicap is a measure of the social and cultural consequences of an impairment or disability (1). Disability affects physical health, social relationship of people, life in the realms of family, friends, and neighbours, psychological state, and level of independence (3). The consequences of disability can have an impact at personal, interpersonal, family and social levels.

Although disability is as old as the human race, the issue of disability and the experiences of disabled people have received little consideration in general academic circle (4). These issues have been marginalized, and only in the disciplines of medicine and psychology, has disability been given an important place. People with disabilities remain at the margins of society as one of the impoverished groups (5). The International Year of Disabled Persons in 1981 stimulated much interest worldwide in disability. UNICEF has estimated that four-fifths of the disabled people of the world live in developing countries (1). The overall low levels of
development and inadequate health and social welfare services have all contributed to the persistence of poor quality of life among the disabled people in these countries, particularly in Bangladesh. It is generally agreed that more information on the extent of the impact of disabilities is required to formulate future policies aiming at improving the quality of life of disabled people (6,7).

The quality of life of disabled people has been studied in developed countries. As the various health indicators of population are improving in developing countries, attention should now shift to improve the quality of life of the marginalized and under-privileged groups. In Bangladesh, where life is difficult for many able-bodied people, disabled people are more likely to face much greater problems in the absence of a disabled-friendly environment. They are less likely to be educated, employed, or rehabilitated. Social segregation of disabled persons is extremely widespread (8). Moreover, social welfare services do not still provide special privileges for the disabled. As a result, most disabled people usually face insensitivity, cruelty, and often pity. The dominance of a medical model of disability has tended to ‘blame the victim’ which, as Imrie states, shows people with disabilities as ‘inferior, dependent and of little or no value’ (5). This discrimination prevents or confuses thinking about solutions. Although some changes in approach have taken place, there is still a need for major changes if disabled people are to be integrated comfortably within mainstream society.

Attempts have been made to publish a series of papers on disability in Bangladesh. One paper on the prevalence and pattern of disability and another on the use of healthcare by disabled people have already been published (6,9). The present paper reports the results on impact of disability. Disability affects the different facets of life of a person, and this life is often complicated by negative forces, such as ignorance, prejudice, negativism, and insensitivity. The study attempted to explore and understand disability, particularly in the light of its psychological and social impacts. The results of this study are expected to help us understand in detail the impact of disability on the quality of life of disabled people in rural Bangladesh. This, in turn, will guide policy-makers in framing laws and prioritization and allocation of resources to create a disabled-friendly environment in Bangladesh.

MATERIALS AND METHODS

A house-to-house survey was conducted during 1991 in two villages of Manirampur upazila (subdistrict) under Jessore district of Bangladesh. Manirampur upazila is served by a 31-bed government hospital with eight qualified physicians. The two villages, Parala and Bahirgharia, are situated about 5 km east of Manirampur upazila headquarters and are similar in terms of various sociodemographic aspects, such as housing, income, education, etc., having a total population of 1,906 residing in 376 households. Many of these households are extended families. Most people in this area are Muslims, and their main occupation is farming. Some non-government organizations (NGOs) work in the field of microcredit in this area. These two villages are, thus, representative of a modernizing Bangladesh, with rural character, strong family bonds, and limited access to modern amenities. While results from these two villages may not be as readily generalizable as results from a large-scale cluster sample, data obtained from these two villages are much more likely to be valid and accurately reflect what is actually happening in the selected villages.

A qualified primary healthcare specialist conducted the fieldwork over four months. Collection of quality data on a sensitive issue, such as disability, requires time and cultural sensitivity on the part of the researcher, and trust on the part of respondents. To develop a good rapport with the villagers, the researcher stayed in the study villages during the whole data-collection period, i.e. from August to November 1991. The study population included all disabled people who were the usual residents of the villages at the time of the study which was carried out in three stages. First, a house-to-house survey was carried out in the two villages using a structured questionnaire to collect socioeconomic and demographic information from the villagers and for identification of disabled people. In the second stage, information on disability and how it affected their life was collected either from each disabled person or from his/her caregiver using an interview schedule with both open- and close-ended questions. Disabled people who were children or who had substantial problems with communication were not interviewed directly. The third stage involved the collection of in-depth qualitative data through 10 informal focus-group discussions and 12 personal interviews on a sub-sample of both able-bodied and disabled people. In addition, observations made in the villages were used for supplementing this information. The respondents were assured that information so collected would not be disclosed to any other people.
International classification of impairment, disability, and handicap was used by the researcher to define disability (1). The term disability was defined as “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.” Types of disability were also classified according to their classification into ‘seeing difficulties,’ ‘hearing difficulties,’ ‘movement difficulties,’ ‘learning difficulties’ (mental retardation), ‘speech difficulties,’ ‘strange behaviour’ (mental disorder), ‘fits’, ‘feeling difficulties’ (sensory), and ‘others’, such as alcoholism, drug dependency, severe malnutrition, severe dyspnoea, advanced stage of cancer and tuberculosis, etc. (1). This survey estimated the impact of disability through measuring certain aspects of quality of life using the standard instrument, SF-36 (Short Form-36). This instrument is widely used throughout the world, and its validity and reliability is widely established (10). We used only nine items from that form and added some other questions of our own.

Most questions relating to the impact of disability were investigated using a series of open-ended questions and were later regrouped. All the questions were not, however, asked to all respondents due to their inherent inappropriateness. Effect on schooling was asked only to those disabled people who were aged 5-30 years. It was not asked to older disabled people as there was no primary school in that area 30 years ago. Effect on employment was asked only to those disabled people who were male and were aged over 12 years. In this rural community, since women are not usually involved with any regular or salaried jobs, questions relating to employment were asked to men only. Questions relating to ‘effect on marriage’ and ‘changes in family perception’ were asked either to the disabled people or to the caregivers of the younger disabled and to those who had a severe communication problem. Our experience from other studies indicate that, by 10 years of age, children with disabilities learn that it is less desirable to be disabled (11). Reasons for emotional problems, changes in community activities, and changes in social attitudes were asked only to those disabled people who were aged over 10 years and those who did not have any severe communication problem.

The association of independent variable ‘gender’ with different dependent variables was tested using chi-square and odds ratios to measure its association. As most variables were regrouped as categorical variables, we analyzed data using chi-square, measuring the p values, and Fisher’s exact test was also used for statistical significance where a cell value was less than five. All were set at p<0.05 for statistical significance. All statistical analyses were performed using SAS software (12).

RESULTS

As mentioned earlier, the prevalence and patterns of disability found in this study have been described elsewhere (6,9). In total, 162 disabled people were identified in the study area. This study revealed that disability could have devastating effects on the life of disabled people. These effects may either be at the personal level, at the family level, or at the social or community level.

Education

Fifty-seven disabled persons were eligible to respond to this question. The problem reported by or on behalf of 41 disabled people (71.9%) was related with school attendance—either being unable to attend school due to disability (n=15), or being compelled to leave school due to disability (n=26).

Employment

Sixty-nine male disabled people were eligible to answer this question. Fifty-five (79.7%) reported that disability had some negative consequence on their employment. Nineteen disabled people (27.5%) who were employed could not earn as much as did people who were not disabled. Eighteen disabled people (26.0%) were forced to change their employment either voluntarily or because they had lost their previous employment. Another 18 (26.0%) had been unemployed (either dismissed or had not been able to work).

Marriage

This was considered for all the disabled people. One hundred twenty-two disabled people (75.3%) responded that disability had no obvious effect on the marital status of any members of their family, while 40 (24.7%) stated that disability had affected the marriage prospects of one or more family member(s). Of these 40 disabled people, 19 (47.5%) were unable to marry, and 9 women were either divorced or separated due to disability (Table 1). Seven people reported that disability had been responsible for the delayed marriage of one of the other members of their family. The presence of a disabled female in a family (37.2%) was 3.93 times more likely to be reported to have
had an effect on marriage in the family than the presence of a disabled male (13.1%), and this difference was statistically significant (p=0.0007, $\chi^2=11.25$, 95% confidence interval (CI) of odds ratio (OR)=1.69-9.28).

Table 1. Impact of disability on marital status

<table>
<thead>
<tr>
<th>Effect on marriage</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male (n=11)</td>
</tr>
<tr>
<td>Cannot marry</td>
<td>5 45.5</td>
</tr>
<tr>
<td>Delayed marriage</td>
<td>4 36.3</td>
</tr>
<tr>
<td>Effect on siblings</td>
<td>2 18.2</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>0 0</td>
</tr>
</tbody>
</table>

$\chi^2=11.25$, 95% CI of OR=1.69-9.28, p=0.0007

Table 2. Reasons given for emotional disturbance

<table>
<thead>
<tr>
<th>Reason for distress</th>
<th>Frequency</th>
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<tbody>
<tr>
<td></td>
<td>Male (n=56)</td>
</tr>
<tr>
<td>Guilt over disability</td>
<td>11 19.6</td>
</tr>
<tr>
<td>Afraid of complications</td>
<td>10 17.9</td>
</tr>
<tr>
<td>People do not interact</td>
<td>10 17.9</td>
</tr>
<tr>
<td>Cannot earn</td>
<td>14 25.0</td>
</tr>
<tr>
<td>Will never be an able-bodied person</td>
<td>8 14.3</td>
</tr>
<tr>
<td>Cannot perform household chores</td>
<td>1 1.8</td>
</tr>
<tr>
<td>Others</td>
<td>2 3.6</td>
</tr>
</tbody>
</table>

$\chi^2=0.28$, 95% CI of OR=0.52-3.97, p=0.59

Emotional problems

This was considered for 125 of the disabled people, excluding 23 children aged ≤10 years and those exhibiting strange behaviour (n=14). Of the 125 people, 103 (82.4%) reported a variety of emotional problems (Table 2). The males were 1.43 times more likely to have emotional problems (84.8%) than the females (79.7%), but it was not statistically significant (p=0.59, $\chi^2=0.28$, 95% CI of OR=0.52-3.97). The main cause that 25 disabled people (24.3%) mentioned for their emotional disturbance was grief and guilt arising from their disability itself. Another group of 17 (18.4%) reported that their ‘inability to earn’ was the main cause of emotional distress. In this group, the males as expected outnumbered the females (male=14, female=5). Inability to perform household chores was an important concern among the females.

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$\chi^2=0.28$, 95% CI of OR=0.52-3.97, p=0.59

Family perceptions

Perception of the family was examined for all the disabled people. Seventy-six disabled people (46.9%) were not considered by their families to pose significant problems, and 86 (53.1%) posed different types of problems to their families. Thirty-five (40.7%) of the 86 disabled people were considered to exert a problem for the family because of the extra care they needed.

Community activities

The question on participation in community activities was asked to 125 disabled persons. Sixty-two disabled people (49.6%) said to be normal participants in most community activities, such as sports, shopping, ceremonies, functions, and religious festivals. The remaining 63 (50.4%) were said not to be participating normally in community activities (male=30, female=33). The females were 1.52 times more likely (55.9%) not to participate in community activities than the males (45.5%), but this difference was not statistically significant (p=0.32, $\chi^2=0.98$, 95% CI of OR=0.71-3.29).

Social attitude

The same 125 disabled persons were asked about social attitudes towards them. Forty-nine persons (39.2%) felt that they were treated noticeably differently from non-
disabled people (Table 3). Of the 49 people, 12 (24.4%) reported that they felt embarrassed by unnecessary sympathy shown to them, and 8 (16.3%) stated that they were frequently addressed in derogatory terms, and 8 replied more strongly that society simply hated them. The females (44.1%) were 1.47 times more likely to suffer from negative attitudes than their male (34.8%) counterparts, but this difference was not statistically significant ($p=0.38, \chi^2=0.76, 95\% CI of OR=0.67-3.23$).

**Table 3. Changes in social attitude**

<table>
<thead>
<tr>
<th>Experience</th>
<th>Frequency</th>
<th>Male (n=23)</th>
<th>Female (n=26)</th>
<th>Total (n=49)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>Over-sympathetic</td>
<td>7</td>
<td>30.4</td>
<td>5</td>
<td>19.2</td>
</tr>
<tr>
<td>Treated as being unimportant</td>
<td>7</td>
<td>30.4</td>
<td>4</td>
<td>15.4</td>
</tr>
<tr>
<td>Avoided</td>
<td>4</td>
<td>17.4</td>
<td>6</td>
<td>23.1</td>
</tr>
<tr>
<td>Teased</td>
<td>3</td>
<td>13.1</td>
<td>5</td>
<td>19.2</td>
</tr>
<tr>
<td>Hated</td>
<td>2</td>
<td>8.7</td>
<td>6</td>
<td>23.1</td>
</tr>
</tbody>
</table>

$\chi^2=0.76, 95\% CI of OR=0.67-3.23, p=0.38$

**DISCUSSION**

This study analyzed the situation of social status of disabled people of rural Bangladesh through four months of close observations on the villagers. It was thought that quantitative data along with some qualitative observations would bring out important issues that need to be identified to satisfy the research questions.

The findings of the study showed that the working disabled people were earning much less, and some of them were even dismissed from their jobs. This result corroborates the findings of Keir who has shown that disabled people are often targets of prejudice and discriminatory practices in areas of employment (13). Modern rehabilitative services with proper training and appropriate remedial education are generally aimed at bringing them back into the work force. The improved economic productivity of a group of disabled people might change people’s perceptions about disability in general. Special employment programmes in the form of cottage industries could be implemented through local government or by NGOs to rehabilitate them.

Our study has shown that disability has markedly reduced the possibility of education. Of the 69 eligible disabled persons, 18 (26.0%) attended school of any sort, and of those who attended, 62% dropped out of their classes. Among the dropouts there were disproportionately more girls. This result is worse when compared with another study where more than half of the children dropped out before completing the 5th grade (14). In our study, we found that all children with disabilities were attending the same regular classroom with virtually no extra help or resources made available either to them or to their teachers. It is encouraging that some NGOs in Bangladesh have established some integrated programmes through supplying resource materials and teachers to ordinary schools (15). In this way, special education can be taught to them in the same

Disability had considerable devastation effect on the marriage prospects of disabled people. The situation was worse for females. In our study, females were more likely to suffer from problems, such as ‘cannot marry’ and ‘breakdown of marriage’ than their male counterparts. We also observed that, in some cases, a huge dowry was paid to some bridegrooms. A study by Palgi has shown that spouses of eastern origin were more rejected by their husbands after a disability than spouses of western origin (16). Females in Bangladesh generally have a lower status and are not as actively involved in income-generating activities as males, and neither do they control family resources. Thus, disability, apart from being negative, is also a potential barrier to marriage, especially for women.

Disabled people gave a wide range of reasons for their emotional disturbance arising from disability. Emotional problems, such as grief, depression, suicidal tendency, and economic dependency, were related either to disability itself or to their own or other people’s reaction to disability. These people needed psychosocial rehabilitation which is a relatively new approach for assisting people with disabilities, particularly when there is an emotional problem to adjust to living (17). People with disabilities have individual physical, emotional, social and intellectual needs and different personal bases
of knowledge, skills, experiences, and attitudes that all together form a unique set of preconditions. Service providers should be asked to enhance clients’ expectations to help them view themselves as capable of progress and to support the process of growth (18). Thus, people need a psychosocial rehabilitation model that upholds social supremacy rather than a medical one in which treatments are limited to the provision of medication to reduce symptoms.

As in other studies on disability conducted in developing countries (19,20), a large number of disabled persons in our study felt that their family considered them as a burden or that there had been a change in the way they were treated by their family. Our study also revealed that the poorer families expressed a more negative attitude towards disabled people. The more understandable and seductive impetus behind this trend is that of the financial pressure occasioned by the growing burden of disability. The full provision of such care by government funds appears to be impossible for a poor country. But then what is to be done? The answer lies in our traditional family values. Family care is widely believed to be superior, more kindly, and sensitive, and is more compatible with the kinship and family integrity that already exists in this part of the world. Along with this existing congenial atmosphere, the government should provide some financial support.

More than half of the disabled people in our study stated that they were viewed negatively by society, and only a few felt that they were viewed positively. As in other studies, it was found that the outward appearance (for example, cerebral palsy, loss of a limb, burn deformity) of a disabled person has a significant effect on this negative attitude (19,20). Negative attitudes resulted from the commonly-held belief that some disabilities, such as mental retardation, cerebral palsy, etc., were the result of divine punishment, and they blamed their fate. This fear and lack of understanding about disease processes exposed them to social segregation, leading to considerable emotional distress. As a result, they lost interest and became more isolated. These negative attitudes towards persons with disabilities are a significant obstacle to their successful integration in society.

Some of the above findings clearly indicate that various impacts of disability were clearly equal in males and females. The pain of disability is sex-blind, but this does not mean that the issues were the same for males and females. Neither does it mean that the rehabilitative services were equitable to all. It has also been seen in other studies that the economic rationalization on healthcare spending is also not equal, although women work more in rural areas of developing countries (21,22). Sen has further clarified that it is not the time spent but the value of women’s time in the South Asian region that is perceived to be of lesser value (23). It is the deeper social and cultural values concerning females that contribute to their greater seclusion and worse condition with more deprivation in all aspects. One can state that a disabled woman would probably be the least likely to have a good quality of life.

An important issue relating to qualitative data was to examine how people felt about disabled individuals. It was observed that people in general believed that those with disabilities had suffered a terrible tragedy and were forever bitter about their misfortune. How accurate are these perceptions? The study found that there was no difference in terms of happiness, frustration, or satisfaction between disabled and non-disabled persons other than the ratings of difficulty of life. The degree of difficulty did not increase their feeling of frustration with life or lower their feeling of satisfaction or happiness. They agreed that there were periods of loneliness and depression before making adjustments. Some disabled people reported that their families were generally supportive initially, but with time the attitudes changed to negligence. This finding was not different from that of Yuker (24). Most disabled persons viewed their disability simply as a fact of life and accepted themselves as they are. It is only at the stage when poor health becomes associated with death or fear of death that their happiness becomes difficult or impossible. We also observed that many disabled people were not only quite happy, but even derived some happiness from their ability to cope with their difficulty which can be seen in the case report. During the four-month stay in the study area, it was also observed that women were more sympathetic and considerate to disabled persons than males. It was also seen that people with learning disabilities (mental retardation) and strange behaviour (mental disorders) were the most common targets of prejudice and discriminatory practices. This finding is in line with that of Pal et al. in India (25). Many respondents reported that adjusting to societal attitude was the most difficult. It was also observed that non-disabled people avoided contact with disabled people.
CASE STUDY

Wahed was congenitally blind. It was very difficult for his parents to accept that their only son was disabled. He did not attend school nor did he receive any special training. He said, “My parents still believe that my blindness was due to their fault...not fulfilling the commitment of sacrificing two khasis (goats) in the name of God at the local dargah (mausoleum) that my parents committed after the death of their first son.” He added, “My parents took me to various types of local faith healers and only at age five I was first taken to an ophthalmologist, but it was too late.... So, they decided to involve me in religious-related activities. My parents thought it would be better to engage me in a local mosque. I started praying five times a day, and I soon became the mouzzin (who calls for prayer) of the mosque. I started spending the whole daytime in the mosque.” He continued, “I am happy at least in one sense that I am taking care of God’s house (mosque). I think God will forgive our sins as we have dissatisfied Him earlier. In this way, I would like to pay the price. I will spend the rest of my life serving God.” His parents feel proud of him for becoming a hujur (religious leader), and they are happy that Wahed can now earn money for survival, particularly through religious activities (milad), pani pora (chanted water), and selling amulets. Wahed is now living happily with his parents. He recently got married and has a one-year-old son. He further added, “People who used to call me earlier in derogatory term as Kana (blind) Wahed now call me choto hujur (little priest). I really feel proud of it.”

Our findings showed that the plight of disabled people could be best explained by the ‘minority group’ model. The ‘minority group’ paradigm is based on a sociopolitical definition of disability as a product of interaction between the individual and the environment (26). In the other ‘functional limitations’ model, no attention is devoted to the possibility that the external influence of negative perceptions is the primary source of the problems that people with disabilities encounter (22). This disadvantaged minority group is facing one of the highest rates of poverty, unemployment, welfare dependency, and a pattern of segregation in education and social activities that parallels the practice of apartheid. This model suggests that exterior forces impose severe restriction on various types of abilities rather than to suppose personal defects or deficiencies. These are the problems that must be addressed first to enable disabled people to lead a satisfying life.

This study has some limitations. It was a cross-sectional study, so it was difficult to ascertain what the cause is and what the effect or the temporal relationship is between the two events. However, reverse causality could be excluded as those possible (outcome) impacts can hardly produce disability itself. There was also always a risk of potential confounders, such as age, gender, and socioeconomic status, that could explain the difference between the groups. Given these limitations, this study provides preliminary data and generates hypotheses that can be more formally tested by quantitative methods at a later time.

As a means of enhancing the quality of life of disabled people, we suggest that our emphasis should be directed towards changing the attitude of society. One solution would be to increase contact between disabled and non-disabled people. There is evidence that contact with disabled persons results in the development of more positive attitudes (27,28). What is clearly known is that good attitudes and experiences should begin at the earliest possible age. If there is any difficulty in acceptance, an articulate parent of a handicapped child can express his/her feelings about possible ridicule and misunderstanding to the parent and student groups in school. This will gradually increase their (disabled children’s) acceptance without being forced. Going on trips together and sharing leisure activities, holidays, birthday parties, and other special events are positive efforts. This sort of direct exposure will help influence the feeling about handicapped people. Parents of disabled children should also form a self-help group to exchange views among themselves. Actually, when exposure is denied, it becomes more difficult to accept handicapped people as part of the environment around us.

The Government of Bangladesh has signed the Universal Declaration of Human Rights, but the country cannot meet the needs of disabled citizens due to economic constraints. Several NGOs in Bangladesh have been working with disabled people to make their life socially and economically more productive. Disabled people should be made aware of their rights, privileges, and existing laws. Involvement of mass media is very important for a general disability awareness programme for the entire nation. A small amount of disability benefit...
allowance in the form of a financial incentive could be offered to them by the state. In general, most services, including health, education, social welfare, and institutions within the country, have to be adapted to the needs of people with disabilities, and laws should, accordingly, be framed. The model of a community-based rehabilitation programme can provide the impetus for an attitudinal shift from the restorative tradition and unite rehabilitation workers through a cohesive framework. A special behavioural counselling programme could be offered to parents through this community-based rehabilitation programme. Like Nilesh (29), we would also like to caution that all community-based services must be community-driven or directed with proper empowerment, and their work should be devoted to spending time listening to their community or clients or advocating their interests.

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