

Livelihood, food security and well-being of persons with disabilities in Bangladesh during the COVID-19 Pandemic

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Background

The COVID-19 pandemic is taking a toll on the lives of people across the borders. Persons with disabilities are one of the most vulnerable population groups that suffer the most during such pandemic situation. Persons with disabilities are at increased risk of COVID-19 infection because of multiple reasons: many of them cannot maintain social distance and separation from caregivers, most of them have limited access to COVID-19 related information and poor access to water, sanitation and hygiene (WASH) facilities.¹ Lack of adequate health related information, inadequate social assistance, poor physical and psychological well-being, poverty, food insecurity and improper livelihood facilities and complete dependence on family are triggers for poor quality of life for persons with disabilities during the COVID-19 crisis.² However, even before the onset of the COVID-19 pandemic, for people living with disabilities there have always been existing significant challenges and discrimination in terms of achieving adequate and equitable inclusivity in all areas of their lives; including personal and social life, education, employment and being treated justly.³ For, females, particularly those who are poor, the situation is worse.

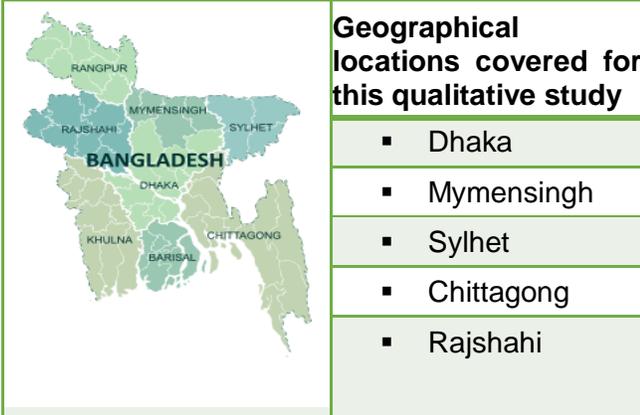
In response to the COVID-19 crisis, Government of Bangladesh (GoB) has initiated many interventions and programs (eg. Mass aid services), however, whether persons with disabilities are benefitting from these services still remains to be explored. To better understand the life conditions of persons with disabilities during COVID-19, this rapid qualitative research assessment focused on the dimensions of livelihood, wellbeing and food security of persons with disabilities across 6 sites of Bangladesh.

Methods

An exploratory qualitative rapid research assessment took place during 15th April 2020 to 15th May 2020. The research took place in 6 different geographical locations of Bangladesh among 27 persons with different types of disabilities. Among them, 14 were male respondents and 13 were female. Data were collected through telephone interviews because of the lockdown and mobility restrictions in place due to COVID-19.

This research brief draws on the evidence generated from interviews with 27 respondents. The respondents were purposively selected from an existing research at BRAC James P Grant School of Public Health (JPGSPH), BRAC

University, from a sample (n=5,000) of nationwide survey on sexual and reproductive health and rights (SRHR) of persons with disabilities that covered all the divisions of Bangladesh. The nationwide research (pre-COVID-19) covered 12 types of persons with disabilities as per Bangladesh government classification for disability detection survey. However, the qualitative research during COVID-19 was able to cover 5 types of disabilities, based on their communication ability over telephone. The types of disabilities covered were physical disabilities, visual impairment, mild hearing impairment, cerebral palsy and multiple disabilities.



The in-depth interviews were conducted by experienced researchers of BRAC JPGSPH, BRAC University who had prior experience in working with disabled populations. In-depth interview guidelines were used which covered major themes like awareness, knowledge and practices regarding COVID-19, preventive measures being taken by them and their family members and information related to livelihood,

food security and social protection during COVID-19 situation.

Summative transcriptions were generated for each case and a data matrix was formed to analyze the data. Finally, thematic analysis was done to generate findings from the obtained data. Clearance from the Institutional Review Board at BRAC University was sought to conduct this research and ethical guidelines were maintained at all times.

Findings

Knowledge about COVID-19 and practice of preventive measures

All 27 of the respondents had knowledge regarding the spread, symptoms and health impact of COVID-19. However, the knowledge about the preventive measures and understanding the need for prevention varied based on their source of information, socio economic status, gender and educational attainment.

Their main sources of information were radio, television, newspaper, relatives and neighbors. Respondents obtaining information from radio, television, newspaper showed better knowledge than the respondents relying on relatives and neighbors. Many of the respondents who were relying on their neighbors, relatives and family members as the source of knowledge had inaccurate information. Such example is given below, where a respondent shared her fears and

mistrust if she sought care from outside the home. This 35-year-old female with physical disability said,

“I have got fever for 10/15 days; I feel pain in all body. I need to go to doctor, but neighbors suggested me not to go the doctors, if I go, they will inject me to die in suspect of that disease (corona)”.

On the other hand, being a male, having higher educational attainment and better socio-economic status had a positive impact on the respondents’ knowledge because they had access to multiple sources of knowledge. Apparently, they were found to be better informed about prevention and treatment of COVID-19.

Many respondents from poorer socio economic backgrounds and less education, had huge gaps in knowledge regarding the necessity of maintaining social distance. They believed it to be government-imposed rule which they needed to maintain, rather than a prevention method to keep them and others safe. A 32 years old male with physical disability said that,

“There is curfew going on. If you go out the law enforcement people force us to wear mask or maintain distance and wear masks. You will be beaten if you don’t obey the rule”.

This shows a certain level of mistrust and a lack of understanding of the preventive guidelines

which were being widely promoted in the country.

Despite the level of knowledge about spread and health impact of COVID-19, very few of them practiced the proper measures that are required to ensure safety during COVID-19. The reasons as reported were many, including: dependence on caregiver, having poor accessibility, poverty, nature of the job which did not allow for distance, income insecurity and varied misconceptions about COVID19. A 26 years old male with visual impairment said,

“I am the sole rice winner of the family and need to go out for work. Moreover, due to my blindness I cannot move alone rather my cousin holds me to walk. Neither staying home nor social distancing is feasible for me”.

Similarly, another 34 years old male with visual impairment said,

“These safely measures are not planned for us. You can enjoy staying home only if you have food at home and access to service. You have no idea how difficult it is for me to go to market without transport and support.”

Another Sole rice winner male with physical disability said,

“I can’t help going out as I have to earn on a daily basis. Pulling rickshaw wearing a mask is a difficult job. I wear those when I see the

police. At home there is poverty and outside there are corona and police”.

This shows how poverty meant that many chose between the dilemma of managing food and evading hunger and COVID19. For many there was limited choice as they needed to survive. Most viewed the guidelines of distancing or staying at home as luxuries only the better off could afford to follow. For them it was about survival. Being already disabled and vulnerable, this was another crisis that they needed to manage, and for them the choice to work was a pragmatic decision given the very real financial constraints in their lives.

Income loss, impoverishment during the COVID 19 pandemic

Most of the respondents were involved in informal economy, with a few of them being the non-earning member of the family. Many of the males were daily wage earners and most of the females were self-employed (ie. Small tailoring works, tea shops etc.) or homemaker.

| Employment category covered | |
|------------------------------------|--------------------------------------|
| Female | Male |
| Tutor | Agriculturalist |
| Shopkeeper | Businessman (Poultry, Wholesale etc) |
| Tailor | Rickshaw puller |
| Maid | Daily wager |

| | |
|-----------|---------|
| Student | Student |
| Housewife | Beggar |

Other than one Poultry businessman all of the respondents informed that they along with their families, were going through complete to partial income loss. Most of them didn't have any savings. One out of 27 respondents had mentioned about having savings while the rest were depended on 'luck', 'loans' and 'help'. A 25 years old visually impaired widow woman shared:

“I have borrowed money as well. With all these I may manage a few more days not more than that.”

Along with this, there seemed a fear of not being able to pay the debt because even after the pandemic ends, there will still be lack of financial resources in their lives due to disability whereas the interest on the loan credit will keep increasing.

Daily wage earners and small shopkeepers have been facing extreme difficulties too, as they are depended on jobs which cannot ensure physical distancing. For a few of them who are trying to continue their jobs, they have been doing it with huge health risks.

A 19 years old female with physical disabilities who runs a tea stall mentioned how things are still better for them despite the pandemic

because she owns a tea stall. However, her fears lie with the aspect of physical distancing

“I know that letting customers get inside the house is risky now. But if someone comes and takes tea twice or more and if someone buys a few products, that allows my family to arrange one meal for everyone. According to her, ‘If such a situation continues for 2-3 more days, it will be unimaginable what will happen! I wonder how I will survive; how will I manage my family for survival!’”

It is already very difficult for a person with disability to gain respect and acceptance in the family and society due to the financial dependence they have on other family members. In this case, the respondent discusses how COVID19 will put her financial independence in jeopardy.

Respondents from lower middle-income class families are in a double dilemma as they can neither seek help nor bear with the poverty. A 55 years old visually impaired male who belongs from a lower middle-class economic background mentioned:

“Even though we are poor people, we cannot really go there and say we need these things, you know, because we are not very poor! My father was a government service holder. We are living in hardship, but cannot go for our personal reasons, for fear of our respect and dignity”

Such situations are extremely difficult for persons with disabilities belonging to the lower-middle or middle class families who have already established a stable lifestyle (of respect and dignity) regardless of the ridicule and taunts from the society and/ community. But in times like this, where the job security, income and savings are in such unstable situations, they have to seek help from others, which then creates an internal dual between their need and self-respect. There is also a constant fear of going back to hearing the ridicule and taunts of the community.

Relief, social security and safety net

Out of 27 respondents, most were unaware of any aid or relief provided either by the government or non-government organizations (NGOs). Though some respondents got food item relief from some unofficial sources such as local leaders and social service groups and individual donations, only a few of them heard about the general stimulus package and within this only 2 of the respondents received relief from the government through municipality, local government and local police. One of the respondents said:

“You have to be in good connection with the local leaders to get relief; I am a woman, that too disabled I have no connections with anyone, so no relief for me also”.

Most of them did not get allocated aid due to political bias, discrimination on the basis of

gender and/or disability. A 35 years old married woman with physical disability mentioned during the interview that:

“Member-chairman gives aid to people like rice, potato, oil etc. I heard this from area (neighbors) people, I do not get this kind of information by myself, as I don’t go out often (I am a woman), I didn’t receive any help till now”.

Another problem which came out of the discussions was the lack of disability sensitive relief and aid distribution. Most of the respondents especially the ones with physical disability had a hard time availing the services due to the inaccessibility of these relief and aid distribution services.

Most respondents with physical disability informed that food aid was being distributed near their area but the distribution point was far from their homes. Because of the disability and the lack of any caregiver in the house, they were not able to reach there and could not avail the aid services. On the other hand, their relatives, who barely needed those services, availed those aid facilities (a package of essential food items). The frustration of being invisible and helpless to do anything as they were dependent on others, was clear during the interviews.

It was also reported that the allowance allotted for the persons with disabilities has been postponed. So, the social safety net program has

come to a halt making it harder for them to survive this crisis situation.

“I don’t know about social safety and security for us during a crisis. I only know about the monthly allowance that we get after three months, but at this moment I did not get any allowance. I have heard that one donation has arrived at the social welfare office for us.”

Effect of COVID-19 on the food security status of households that have disabled members

More than one third of the respondents reported having persistent food insecurity. This is directly relating back to the income loss during COVID-19 lockdown from 23rd March 2020 to 30th May 2020. Different coping strategies were adapted by the respondents to mitigate the crisis. Many of them reduced consumption of protein like fish or meat instead relying lentils. Respondents in rural context relied on leafy vegetables available around their yards but respondents living in urban settings with no access to any of this, ate potato instead. However, decreasing food quantity, meal skipping and starving seemed evident in both urban and rural settings. A 25 years old female with physical disability said,

“Rice with dal, that’s what we all eat in every meal. My husband went out a few days ago and bought some potatoes, so we got to have mashed potatoes for some meals. We are not

having any fish/meat or vegetables for quite a long time..... As there's no income and the stored food is almost over, sometimes my mother doesn't eat thinking one of her children will be able to eat next time. My siblings are doing the same. To sum up, we are trying to utilize two meals worth of food into three meals".

Another 35 years old married woman with physical disability mentioned:

"This time also my brother-in-law helped me for monthly bazar, he bought me rice, oil, lentil, vegetables like calabash etc. After this month I don't know how I will manage.

Lockdown and limited transportation in some places were reasons as to why respondents who were disabled and did not have support from caregivers (i.e neighbours or others) could not visit nearby markets at all. Respondents living in rural or in distant geographic locations mentioned this challenge repeatedly during the interviews. A 55-yearold male with physical disability said:

"I used to go to the bazar near my home, now they do not have that due to lockdown, I have to take a ride to the distant big market to get groceries, that costs more money and I can't walk much due to my problem (ie. Impaired legs).

The financial instability acted as a barrier for many of the respondents to stock or pile food

items in their households. The situation was worse for respondents with physical disability, as mentioned earlier and do not have a caregiver to support. A 35 years old male, auto rickshaw driver with physical disability mentioned:

"Now the food prices are even rising. If you have money you can enjoy avoiding the 'corona' sitting at home. I am the sole rice winner of the family. How can I sit at home when my family is starving! Every morning, when I worry about all these, I think that I should go out with my auto rickshaw. But because of the locked down situation, I can't. The food we have now will run out anytime. I'm going to bed with that thought in mind, and the same thought wakes me up."

Physical and mental health of persons with disabilities and health service accessibility

Chronic health issues like heart diseases, chronic pain is deteriorating due to lack of care, mobility and caregiver support.

Regular check-ups are disrupted for many of the respondents due to their own financial crisis, lack of transportation and limited service availability.

Strict law enforcement also acted as a barrier to service access. Very few of them ventured outside their homes (with support) to buy prescribed medicines as they were very afraid of law enforcement agencies and being punished for leaving the home. One Female with multiple disabilities said:

“Everything is closed, nothing is like before. I cannot go outside for a walk, that’s why my waist pain has increased. My leg is getting numb. If I could walk, I would feel better. But now it is very painful for me”

Respondents who have lost their jobs or have their family members lose job due to COVID-19 are dealing with frustration and restlessness. Some of them are also suffering from sleeplessness because of the mental stress of staying at home for such long periods and the overall uncertainty of their future. The news of this pandemic especially the rumors of death, dying and ‘isolation’ if one has a ‘cough, fever’ was increasing tension and fears among the most of the members of the households, deteriorating both mental and physical health.

Coping strategy for better mental health and psychosocial well-being

The level of emotional and mental distress among the respondents was evident in the interviews as many despaired of their situation and were fully aware of the double burden of not only being poor but also being disabled. For men, the role of rice winners and feeling like a failure to the family was a persistent worry. For women, anxieties about their future, their children and family’s future were foremost on their minds.

Most of the respondents mentioned about different ways to calm their minds and hearts

during this crisis situation. Prayers, fasting, reading religious scriptures were some of the ways of coping. A 17 years old female with disability said:

“Prayers are the only way; nobody can help us. Nobody will help us, only God will”

A sense of being left behind and not trusting support from external sources, some of the respondents have also started to spend time with others especially the neighbors and family members to get some social comfort and feel secure. Other ways of managing anxiety were to be on social media (ie, facebook) and watching TV and listening to the radio. Some of the respondents, mostly living in peri-urban areas mentioned about using TV, Radio, Social media as ways to divert their mind and remain entertained. Indoor games (ie, ludo, cards, etc) have gained popularity too especially in areas where people live in bigger families.

Conclusion

This study further supports the claims of many national and international agencies that persons with disabilities are most vulnerable during any pandemic or crisis. This pandemic highlights that we need move beyond the individual determinant of health and look at the structural and social factors and inequalities that impact on the lives of the most vulnerable. As mentioned earlier, historically persons with disabilities have lacked proper inclusion in education,

employment and social sectors and generally remain invisible.

During these pandemic shocks, the crisis, combined with their vulnerability has exacerbated the person, emotional, mental, physical, social and economic aspects of their lives. Counselling support and targeted aid and services are required to combat the immediate impact of COVID-19 on persons with disabilities.

Designing policies and strategies to have more inclusive education, cash stipends, provision for subsidies in transportation, priority access to health services can alleviate the damage that persons with disabilities are facing during the pandemic.

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