Barriers and Facilitators for Wheelchair Users in Bangladesh: A Participatory Action Research Project

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ABSTRACT

Purpose: *People who use wheelchairs face a range of physical, social, and economic barriers to regular participation in their communities. These barriers may be more acute in countries such as Bangladesh which are affected by poverty and often lack the physical infrastructure or resources necessary to create inclusive or accessible environments. This research aimed to identify: (a) the barriers and facilitators to accessibility faced by wheelchair users in Bangladesh; (b) how these barriers affect the inclusion of wheelchair users in Bangladeshi society; and (c) what could be done to improve accessibility and inclusion for wheelchair users in Bangladesh.*

Methods: *This participatory action research (PAR) project used Photovoice and semi-structured interviews to identify barriers and facilitators to accessibility for people who use wheelchairs in Bangladesh.*

Results: *Participants mentioned a number of barriers in public spaces, such as roads, missing or inadequate ramps, inaccessible restrooms, and negative attitudes. There were also participants who had made their home environments more accessible with accommodations such as ramps, arrangement of space, and low countertops/work spaces. Women wheelchair users seemed to face greater barriers to access, as compared to men, in a range of community spaces and activities. Participants' recommendations for improvement targeted government stakeholders and included greater focus on road infrastructure, particularly during flooding in the rainy season, and modifications to the public transportation system.*

Conclusion: *A key goal of the study was to identify barriers and facilitators, and use the information gathered to promote social change on the ground. Future*

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research and action should encourage more people to get involved in removing barriers for people with disabilities, in Bangladesh as well as globally.

Key words: *wheelchair users, participatory action research, Bangladesh, Photovoice, accessibility*

INTRODUCTION

The World Health Organisation (2010) indicates that approximately 65 million people worldwide require the assistance of a wheelchair. Strong evidence from around the world demonstrates that people who use wheelchairs face a range of physical, social, and economic barriers to regular participation in their communities (e.g. Schonherr et al, 2005; Balbale et al, 2017). These barriers may be even more acute in countries affected by poverty, such as Bangladesh, as these countries often lack the physical infrastructure or resources necessary to create inclusive or accessible environments for wheelchair users.

Global human rights treaties, such as the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) have emphasised the importance of "identification and elimination of obstacles and barriers to accessibility" (United Nations 2006, Article 9) for persons with disabilities. Many countries have espoused this commitment to identification and removal of barriers at the national and local levels through national policies on disability. In spite of policy commitments, disparities remain for wheelchair users globally, particularly in the developing world(Burns and O'Connell, 2012). In order to translate policy commitments to action, research may assist in the identification of barriers at a local level and in the communication of these barriers and remedies to policy-makers and other relevant stakeholders. People with disabilities themselves are in the best position to identify these factors, as they encounter the barriers and facilitators to inclusion on a daily basis (Newman and SCI Photovoice Participants, 2010).

This manuscript details the results of a participatory action research (PAR) project that aimed to identify barriers and facilitators to accessibility for people who use wheelchairs in Bangladesh, and to take action to remedy barriers and promote facilitators identified. Specifically, answers were sought to the following research questions:

(a) What are the barriers and facilitators to accessibility faced by wheelchair users in Bangladesh?

(b) How do these barriers affect the inclusion of wheelchair users in Bangladeshi society?

(c) What could be done to improve accessibility and inclusion for wheelchair users in Bangladesh?

Bangladesh is one of the most densely populated countries in the world (1070 population/km^2). Recent reports indicate it has a gross national income (GNI) per capita of US$1,314 (National Institute of Population Research and Training and International -NIPORT, Mitra and Associates, 2016). Bangladesh has a relatively high incidence of spinal cord injuries and other disabilities - due to falls from heights, traffic accidents, and physically demanding and hazardous occupations - that require the assistance of a wheelchair for mobility (Rahimi-Movaghar et al, 2013; Villanueva et al, 2017). The Government of Bangladesh has demonstrated strong public support for the inclusion of persons with disabilities in mainstream society. This support includes a national policy on disability, the Persons with Disabilities' Rights and Protection Act 2013, which is in line with the principles of the UN CRPD (Women with Disabilities Development Foundation, no date). Additionally, Prime Minister Sheikh Hasina has made numerous public proclamations related to the rights of persons with disabilities, including outlining government efforts for greater identification of people with disabilities and provision of social protections and financial support, along with access to health and education facilities (News Bangladesh, 2016).

In spite of a promising political environment for people with disabilities, research still indicates that many people with spinal cord injury (often wheelchair users) in Bangladesh rarely leave their homes, have reduced opportunities for employment, experience poverty, and have secondary conditions such as pressure ulcers (Hossain et al, 2016). Additionally, evidence demonstrates that people with spinal cord injury in Bangladesh report low total community integration and life satisfaction (Ahmed et al, 2017). Researchers have also indicated that people with spinal cord injury, many of whom use wheelchairs, have moderate rates of depression and report limited quality of life (Hossain et al, 2016) as well as lower self-efficacy (which has been linked to depression) (Villanueva et al, 2017). In the light of this situation, there is a necessity for better identification of barriers in the hope that policy-makers and service providers may then direct their attention to facilitate effective interventions and improve the quality of life for this population (Hossain et al, 2016; Ahmed et al, 2017).

METHOD

Study Setting

This study was conducted in different urban and rural regions in Bangladesh.

Study Design

In alignment with participatory action research practices of actively involving representatives of the participant population in all phases of the research process (e.g., Chevalier and Buckles, 2013; Wickenden and Kembhavi-Tam, 2014), Bangladeshi wheelchair users were engaged in all components of the research, from study design and method selection, to data collection, data analysis, and dissemination. It was determined that Photovoice (adapted from Wang and Burris, 1997) would be an appropriate first phase to gather information relevant to the research questions. To expand upon and verify findings in Phase 1, and to gain a richer, detailed description of experiences of wheelchair users, the Photovoice phase was followed by semi-structured interviews in Phase 2.

Phase 1: Photo Taking and Protocol Development

Data Collection

Data for Phase 1 was collected by the three members of the research team who use wheelchairs themselves. Prior to commencing data collection, researchers received training on research ethics and safety, digital camera use, and strategies for taking successful photos. Then, over a period of approximately four months, they took their cameras with them and photographed any barriers and facilitators they encountered in daily life. They would ask for permission before taking photos where any other person was identifiable. Often, photos were not of people but of situations or items (e.g., ramps). Sometimes the researchers would hand over their cameras to a friend or bystander to take pictures of the researchers demonstrating a barrier or facilitator (e.g., trying to wheel up a particularly steep ramp).

During data collection for Phase 1, the team held weekly (and in later months, bi-weekly) meetings to discuss progress of photo taking and to solve any issues as a group. At these meetings, each team member would display his or her favourite photos, on an overhead projector, to the group, and describe: (a) what is depicted in the image, and (b) why they took the image and/or why they believe the image

is relevant to the study research questions. As the meetings progressed, the team identified and documented themes that they saw commonly emerging across photos and across researchers. They would also identify and discuss gaps or experiences that were not yet depicted in the photos but which they believed would be important to capture in the days to come.

Data Analysis

On completion of the photo-taking period, the research team met for a final review of the photos that were identified as the "best" or most representative photographs over the previous weekly or bi-weekly team meetings. They worked as a group to sort and categorise all the images. At the end of this exercise, they had identified nine major categories: Roads, Leisure, Toilets, Transportation, Household Accessibility, Gender, Impact of Inaccessible Space, Ramps, and Sidewalks. These categories guided the development of questions for inclusion in a semi-structured interview protocol that would be used in Phase 2 of the research.

Phase 2: Semi-structured Interviews

Data Collection

Team members who use wheelchairs conducted semi-structured interviews with other wheelchair users. Interviewer choice was intentional, in the belief that interview respondents might be more comfortable or could speak more openly and frankly with people who were also wheelchair users. Before conducting the interviews, team members received training in research ethics, interviewing and interview techniques. Once they were comfortable with the interview questions and confident about their interview technique, the three interviewers went into the community to conduct approximately 6-8 interviews each with other people who use wheelchairs. Participants were included in the study if they (a) used a wheelchair on a daily basis; (b) were older than 16 years of age; (c) spoke Bangla fluently; and (d) were willing to provide informed consent to participate in the study.

Participants were recruited using the network of the Centre for the Rehabilitation of the Paralysed (CRP) in Savar, Bangladesh. CRP is a multi-service centre that specialises in providing support to people with spinal cord injury, and has a range of both inpatient and outpatient services for those who use wheelchairs.

Interviews were conducted at a time and location most convenient to the respondents (at CRP-Savar, Chapain, Arapara, Mirpur, Dhaka). Interviews lasted from 20 - 60 minutes, and were conducted, audio recorded and transcribed in Bangla. Interviewers asked respondents to reflect on their experiences related to the themes from Phase 1 as well as any additional barriers or facilitators not identified in the initial themes. Table 1 presents the interview protocol.

Table 1: Interview Questions

1. Could you please tell me about your experience with disability?
→ (probe) When did you get your disability? How long have you lived with a disability?
2. Could you please tell me about how you manage your daily activity and movement as a person with a disability?
3. Tell me about your experience on the roads that you use in your day-to-day life.
→ (probe) What is the type of surface of road that you use regularly (e.g., mud, brick, cement)? How does the type of surface impact you?
→ (probe) Can you tell me about how you use the roads during monsoon season?
4. What about travelling on the sidewalks/footpaths – how do you use these?
→ (probe) What barriers do you face to using footpaths/sidewalks?
5. Tell me about your experience using ramps in your daily life?
→ (probe) How do you use ramps in indoor situations? How do you use ramps in outdoor situations?
→ (probe) Have you ever encountered ramps that you couldn't use? Could you tell me about that?
6. Tell me about your experience using washrooms?
→ (probe) What do you need to be able to access a restroom? How often do you get this? Where?
→ (probe) Could you talk about using washrooms outside of the home?
→ (probe) Have you ever not attended a location or participated in an activity because you knew you couldn't use the washroom?
7. Tell me about your experience using public transport?
→ (probe) What kind of transportation do you use?
8. What are the differences between male wheelchair users and female wheelchair users for activities of daily living?
9. How easy is it for you to navigate your home?
→ (probe) What makes it easy/hard for you?
10. Could you tell me about any effects that your disability has on accessing leisure activities?
11. How does accessibility in your environment impact your life?
12. Is there anything else about accessibility that we haven't already talked about but you would like to share with me?

Data Analysis

The community researchers first participated in two workshops on how to conduct data analysis. These workshops included practice exercises related to categorisation and coding of content. As researchers conducted semi-structured interviews, the research team would come together in regular meetings to share progress, problem-solve any challenges, and identify interesting points or emerging themes. Once all the interviews were transcribed, the Bangla-speaking research team members met to code the transcripts together in Bangla. The research team reached consensus on preliminary themes identified in the coding, and these were then applied independently by four Bangladeshi researchers to all of the transcripts. They met again to discuss their findings, and further reflect on the codes assigned and themes that had emerged. After the group came to a consensus, one Bangladeshi researcher assigned final codes to all Bangla transcripts. During the write-up of the results, the researchers identified a representative quote in Bangla, had this translated into English, and then back translated from English to Bangla to confirm accuracy of the translation.

Ethical Considerations

Prior to conducting this study, ethical approval was obtained from the Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB), Queen's University, Canada and CRP's Ethical Review Board.

RESULTS

In total, 20 wheelchair users (10 male, 10 female) were interviewed. Participants were between 20 and 48 years of age, and had all been educated to at least secondary school level. While some reported that they had a disability for at least 3 years, there were others with disability for as many as 29 years. The majority of participants (14) were living in urban areas. Most of the participants lived with family members (e.g., husband, wife, father, mother, sister, brother, children), and most of them were assisted by their relatives in activities of daily living. Details of participants' demographic information are provided in Table 2 below. The results have been organised along three major themes: Major Accessibility Barriers and Facilitators, Effect of Barriers on Daily Life, and Recommended Improvements.

Table 2: Participant Demographics

Age in Years	Gender (M/F)	How long with disability (in years)	Highest level of education achieved	Location of home (rural or urban)	Profession	Who do you live with? (Do they provide assistance in ADL to you?)
32	F	19	HSC	Urban	Service	Husband. (Sometimes.)
28	F	19	Class-VIII	Urban	Service	Mother and husband. (Both help her in household work.)
24	F	6	Bachelor	Urban	Student	Living in student hostel. (Sometimes roommates help her.)
20	M	3	HSC	Rural	Student	Father and mother. (Manages ADL by himself)
23	M	21	HSC	Rural	Jobless	Father, mother and brother. (Everyone helps in activities of daily life.)
28	M	6	Bachelor	Urban	Student	With sister and sister-in-law. (Friends and family members help.)
27	M	10	SSC	Rural	Jobless	By himself.
25	M	20	HSC	Urban	Business	Father and mother. (They help him with his ADLs.)
26	M	9	HSC	Rural	Business	By himself.
22	F	7	HSC	Urban	Student	By herself.
23	F	8	HSC	Urban	Service	Living with her husband. (Her husband helps her with ADLs.)
28	M	27	HSC	Urban	Service	Living with his family.
21	F	9	SSC	Urban	Jobless	Living with her family.
48	M	29	MBA	Urban	Service	Living with his family. (Everybody in the family helps him.)
33	M	22	Class-VIII	Rural	Jobless	Mother. (Everyone helps him.)
33	F	31	Class-VIII	Urban	Student	Mother and brother. (Everyone helps her.)

28	F	12	Class-VIII	Urban	Service	Husband. (Everyone helps her.)
40	M	13	Class-VIII	Urban	Service	Wife and son. (Everyone helps him.)
35	F	29	Class-V	Rural	Tailoring	Husband (Everyone helps her.)
27	F	5	HSC	Urban	Service	Mother, father and brother. (Everyone helps her.)

Major Accessibility Barriers and Facilitators

Accessibility barriers identified by the interview participants primarily included barriers within the built environment. Participants confirmed the findings of Phase 1 of the research and identified barriers in infrastructure related to roads, sidewalks and ramps, transportation, and restrooms.

Roads, Sidewalks and Ramps - Participants reported that they experienced the greatest challenges to accessibility during the rainy season, when many roads became flooded. They stated that flooded roads make it *"difficult to move"* in their wheelchairs. Moreover, they said they did not want to navigate when the water on the roads was deep as they could get wet, dirty, or sick as a result. Participants also reported that flooded roads concealed great hazards to wheelchair users – such as open holes, broken tarmac, or uneven pathways that could lead to falls and/or injuries.

> *"Many of our roads are flooded when it rains. We cannot get out from our homes. When water drains away from the road, the sticky mud will remain. Those roads become inaccessible for wheelchair users as there are holes and many different problems arise."*

Apart from challenges related to roads in the rainy season, one participant shared that she did not feel she was in control of her wheelchair on uneven roads. A number of other participants pointed out challenges on busy roads where there were both big (trucks) and small (rickshaws) vehicles to be avoided and limited to nil access to sidewalks (*"footpaths"*) to help the wheelchair users stay out of harm's way. On the subject of sidewalks, participants complained that these were elevated above street level, making it impossible to roll onto in a wheelchair. Others complained that shop owners set out their wares on the sidewalk, so that it was not possible to roll through on a wheelchair.

Although participants mainly shared barriers, some of them also mentioned how roads were facilitators for their accessibility. In particular, concrete urban roads were seen to be conducive to accessibility.

> *"Since I was inside a municipality, I had no problem with the road. As we used to travel in a van, it was not a problem. The road was absolutely good, not too bad. Being home inside a municipality, I used concrete roads."*

Additionally, many participants stated that they were able to move and navigate inaccessible roads with help from others, such as family members or paid helpers.

Ramps - Linked to road infrastructure, many participants also reported the importance of ramps to help them navigate their environments.

> *"Suppose I go somewhere where I need to say in a guest house. If there is no ramp or if they accommodate me in a room on the 1st or 2nd floor, then it will be almost impossible for me to stay there."*

Participants not only noted the presence or absence of a ramp as a facilitator or barrier, but they also remarked that not all ramps are created equal: they lamented about ramps that were in *"poor condition"* or too steep to wheel up independently.

> *"The ramp made at City Centre (shopping mall) is too high. It needs two people to go up the ramp, one in the front and one in the back. The ramp needs to be wider and start much further back."*

Inappropriately constructed ramps were a major feature pictured in many of the photos taken by the researchers in Phase 1 of the study.

Transportation - Participants reported using a range of transportation options to navigate their daily lives: from rickshaws to CNGs (auto rickshaws), to public buses and private vehicles. A majority of participants reported that they *"cannot use"* public transportation, either because of physical inaccessibility, such as needing a ramp to get up into the bus independently, or due to negative attitudes, such as when a transport conductor ignores the wheelchair users or refuses them entry even when there are vacant seats on the bus.

> *"I can't use public transport. Sometimes it is seen that public transport does not even stop for people who use wheelchairs like us, don't give time for us to get in. If we get in, we need help to be lifted up to get in."*

Participants reported that large crowds of people were also a great barrier, as it became near impossible to compete with people pushing to access the bus and they would be left behind.

Participants mentioned their preference for using private vehicles to move around the community; however, a number of them reported that they did not have the financial means to be able to do this. Some participants reported that they were able to use rickshaws and autorickshaws/CNGs, whereas others reported that they could not get into these forms of transportation with their wheelchairs.

As with the use of roads, many participants stated that getting help from others, either from a family member or hired 'helper' or from the driver or conductor of a public transport, was an important facilitator in their being able to get around and use transportation.

> *"To use public transportation, I need the help of others. I can't get in without the help of others. There are many problems. I can't get in by myself. The wheelchair needs to lift after folding, it is very difficult. I need to take help of others all the time to get in. The vehicles are crowded so it is difficult to get in."*

Although many participants stated that getting help from others was a facilitator, for one participant the fact that she always needed help from others to get into public transportation was actually a barrier to going out of her home.

> *"To go anywhere, I need public transportation but I cannot use public transportation. It is very difficult… and to go anywhere, I create a burden for other people. They also have their work. They can't help me all the time."*

Toilets - Most participants stated that the restrooms in their homes were accessible due to adjustments and adaptations such as adding ramps, bringing in stools, and widening the doorway.

> *"I have an accessible bathroom. I can do everything myself. When I am at home, I usually do not face any problems."*

Outside their homes however, accessing toilets was a challenge for every participant. It was commonly reported that many toilets were impossible to access, either because there were stairs or a step up into the restroom without any ramp, or because the door was too narrow for the wheelchair to fit through. If they were able to get through the door, participants reported that common lower commodes ("squat" toilets) were more difficult to use than the high commodes.

Challenges related to restrooms not only included physical inaccessibility, but also the level of cleanliness within. Participants reported that when the restrooms were physically inaccessible, they needed to lower themselves onto the floors, but the lack of cleanliness made it unsanitary and unhygienic.

> *"Get down directly from the wheelchair seems risky to me… Bathrooms are very dirty and my wheelchair gets stuck at the door."*

Most participants could clearly and easily identify the features of restrooms that were facilitators in terms of accessibility. Many participants identified that access to restrooms with ramps, wide doors, high commodes, and ample space for moving about within, greatly facilitated their willingness and ability to participate in their community. Participants also reported the convenience of toilets that had low taps and wash basins for easy hygiene. A number of participants specifically mentioned the Mirpur National Stadium and the CRP as locations where they found environments particularly accessible for persons with disabilities both in terms of toilets and ramps.

Attitudes - Going beyond the categories identified in the photographs, interview participants also discussed attitudes as being a major barrier to accessing society. Some participants reported that attitudes vary, with some people treating them just like everyone else, and others treating them differently because they use a wheelchair.

> *"I live in a village. There are some people who do respect me as a person with disabilities and some people who treat me like 'who are they, they are disabled, are they human?' Some people give value, some not."*

A couple of participants described pitying attitudes as barriers to their participation in the community: They stated that they avoided going out of their homes and to public places like the market because they did not want to face people who treated them with pity. Others reported that people around them discounted their perspectives and point of view, and this became a barrier.

> *"We face obstacle both in movement and in speaking – no one wants to accept our opinions. They always dishonour recommendations by saying 'a disabled person cannot say anything meaningful'."*

Many participants lamented that attitudes created a barrier for them in terms of accessing opportunities for education and employment. For example, one participant shared that her family blocked access to education for her, because

they did not think it was an appropriate use of resources for the future of a wheelchair user. Another participant believed that attitudes were a barrier for wheelchair users to procure employment or to advance in the workplace if they are employed.

> *"If a person in a wheelchair goes for an interview, the authority does not take it positively. They think wheelchair means beggar or something like that… If a disabled person does get a job, they are deprived of a promotion. They are doing excellent performance but they are treated negatively."*

Sadly, a participant who was self-employed stated that because he was a wheelchair user, people in the community would steal from him, making assumptions about his incapability to demand payment and effectively denying him access to dignity and income.

> *"My business has become bad… Those who eat, don't pay. I could not go to them. If they are willing to pay, then I get the money. Otherwise, I have no ability to get my money back."*

These then are the major barriers and facilitators, and participants went on to discuss the effect these had on their daily lives.

Effect of Barriers and Facilitators on Daily Life

Participants reported a range of issues connected to the barriers they identified.

A couple of participants stated that they sometimes remained in their homes for up to 4 days at a stretch, and one participant mentioned only leaving home once or twice a week in the rainy season. A number of participants referred to being *"trapped"* or *"prisoners"* due to the road conditions.

> *"In the rainy season, I do not leave my home. From morning to evening, evening to night, night to morning, I spend all the time in my room. It feels like years later when I am able to see the sky, take a breath of fresh air. I always say that I am a prisoner surrounded by walls. Cannot see the sky, cannot feel the sunshine."*

Apart from road conditions, almost all the participants reported that inaccessible toilet facilities caused significant isolation from their communities in a range of different sectors. Finding an accessible toilet would be a major preoccupation during any outing outside the home. Some participants reported missing education or employment opportunities due to inaccessible toilets. One participant reported that he was unable to attend school regularly due to the

inadequate restroom facilities, and only turned up for exams; even so, it was challenging. Another participant reported dropping out of school at eighth grade due to accessibility issues.

> *"I studied up to the eighth grade. I did not continue my studies because our school is not accessible to wheelchairs. Also, there is no ramp. My school is far away from my home. When I entered my classroom, there are stairs. It is very tough for me… In these circumstances, I don't feel any interest to continue my studies."*

Participants mentioned that they missed out on a range of social and leisure opportunities in their communities, including attending concerts, going to shopping malls, visiting relatives, and participating in cultural events, largely due to inaccessible toilets.

> *"I do not go outside. I mean, I don't go to my relatives' house. I don't go anywhere, I don't travel anywhere. I have three sisters, they invite me to go but I don't. Because I have one problem: if I need to use the toilet, then where do I go? … My brother does not come to see me, but he phones me and asks me to go to his place but I don't go."*

Some participants shared instances where inaccessible toilets had caused them health problems such as urinary tract infections.

> *"I went to a programme related to people with disabilities and I went there in the morning. I became too restless because I couldn't go to the toilet there. Later, I returned at 8 pm. My urine got stopped that time and then I need to spend 3000 taka (US$36.15) for medical treatment…"*

In addition to losing opportunities for education and employment due to poor toilet facilities, some participants also blamed the missed opportunities on a lack of ramps in these community spaces.

It was revealed at the interviews that wheelchair users also face barriers that are related to their gender. Some participants raised issues of gender-based violence and personal security for women wheelchair users, reporting that they believed women in wheelchairs were at greater risk for violence. One participant also observed that female peers would be left by their husbands on getting injured, but *"if a man became disabled, then he is still in the village, his family is still with him"*. In Bangladesh, it is not typical for non-related males to touch women. Therefore, women wheelchair users faced even greater challenges when going out of home because if they needed assistance to be lifted or transferred, they could not ask the people around them for help. For

this reason, women wheelchair users seemed to be doubly disadvantaged in the matter of navigating their communities.

> *"(For) a female, it is not possible to move in the road, which is easy for me (a male). Our society's system is like this… You can see that when any person in a wheelchair gets into the roads, others stare at him with questions in their eyes and this will normally be double for females."*
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> *"The problem of women is more than men. If she wants to go somewhere, she cannot go without her own people. In this situation, a male person can take any person to go somewhere. A male disabled person can complete his toilet anywhere but a female cannot do so."*

As alluded to in the above quote, a number of participants highlighted how females face even greater barriers, in particular when it relates to toilet accessibility. Barriers relate to biological differences, which make it easier for some men in wheelchairs to relieve themselves discreetly and from a sitting position, unlike women, or to issues of modesty for women which are more tied to gender norms. This means that even though both men and women experience reduced access in the community, for women this reduction is often even more acutely experienced.

> *"I do not go to social events because I have difficulty accessing them. Once, I visited an event but faced many problems in using the toilet. In an emergency situation I soiled my dress. So, now I don't take part in programmes."*

Interestingly, on the subject of facilitators, a large number of participants reported experiencing greater independence and accessibility in their home environments, as they had made modifications and removed barriers to make life *"easy"*. Modifications often related to construction, creating accessible toilets, and using ramps to help access different spaces in the home.

> *"In my home, I am independent. I do all my tasks like move around, use the toilet, use the tube well, etc. By setting up a ramp, it is very easy for me to do my work."*

Home modifications ranged from very simple arrangements such as ensuring clear spaces and limited clutter and creating simple ramps, to more complex or expensive modifications including renovating or constructing new homes or moving spaces to create a more accessible home environment.

> *"I made my house terraced so I can move alone. Before, I did not have a concrete house. That time I was facing lots of problems. Last ten years I was living in one room. I could not move to another room… But now my home is accessible for people with disabilities to move easily. Besides, I made a ramp also. So it is very easy for me. I feel happy."*

Coping

In spite of the many challenges, participants also reported developing a range of strategies to cope with the barriers, thereby enabling them to navigate daily life outside their homes. These strategies included personal adaptations, requesting help from others, and explaining accessibility in utilitarian terms to others.

In relation to personal adaptations, one participant remarked that although his movements are restricted in the rainy season, *"but, if any kind of need arises* (when he needed to get out), *I just carry some water to wash my hand and start my journey again".*

A number of participants reported coping with inaccessible restrooms by using a urine bag.

> *"I buy a small plastic bag. When I go out, I urinate in the bag. In this way, I manage to solve the problem of going outside. I couldn't enter the restroom many times. I might get stuck and have to urinate at the door. I mean, this is a bad situation to get into and there are many restrooms like this."*

Another noted that she takes off her shoes and puts them on her hands to navigate dirty restrooms. Yet another participant reported that he fasts when he goes outside the home so as to avoid using the restroom.

> *"When I go outside, I do not take food. I fast. I try not to eat food outside. Always, I think if I get any pressure then what will I do because the toilet is not accessible for a person who uses a wheelchair. If I face any problems, it is very embarrassing. That is why I usually won't take any meals."*

To try to overcome and navigate barriers, many participants reported that they need to interact with people in the wider community. To that end, participants discussed accessibility and their needs for accessible environments with the community, using language related to universal design, noting that accessible environments are good for all people, not just people who use wheelchairs.

> *"I would like to say that a person without disabilities goes up stairs and I use a ramp to go up. But the person without disabilities can go up the ramp so it is not necessary to build separate stairs… then he can go up and I can also go up, I will not be disadvantaged."*

Furthermore, participants counteracted actions emanating from pity or sympathy by standing up for themselves and explaining to people that they were fine, and that people with disabilities can do just as well in life as anyone else.

> *"Everybody used to ask about my disability and show their sympathy. It would be hard for me. But now, if anybody comes to show their sympathy, I tell them that there are lots of people like me. Still, they are alive, some of them are working in very good positions. I am inspired from them. I believe we can work even better than a non-disabled person."*

DISCUSSION

This article shared the results of a participatory study that sought to understand barriers and facilitators to accessibility for wheelchair users in Bangladesh, and the effects of those barriers on daily life. Participants mentioned a range of barriers in public spaces, such as roads, missing or inadequate ramps, inaccessible restrooms, and negative attitudes. They also experienced living in highly accessible home environments, by making accommodations such as ramps, arrangement of space, and having low countertops/work spaces. Women who used wheelchairs seemed to face greater accessibility barriers as compared to men, in a range of community spaces and activities.

The findings of this study indicate that people who use wheelchairs in Bangladesh are denied access to basic human rights, as enshrined in the UN CRPD (United Nations, 2006), such as accessibility (Article 9), living independently and being included in the community (Article 19), personal mobility (Article 20), and education (Article 24), among others. Given that the Bangladeshi government is a State Party of the CRPD, future action must seek to remedy and address these gaps in the implementation of the CRPD in the country. This study also provides empirical evidence and concrete examples of how women with disabilities experience dual disadvantage, often termed "double discrimination" (Habib, 1995) by gender and disability scholars. This study's findings indicate that future government and civil society efforts to improve and promote the rights of persons with disabilities in Bangladesh must take on a gendered perspective in order to effectively address the challenges of the whole population.

Global literature indicates that many people who use wheelchairs, such as those with spinal cord injuries, will require varying degrees of assistance to perform activities of daily living, such as eating, dressing, and mobility (Nas et al, 2015). Many of those who provide caregiving duties are often family members who engage in caregiving and assistance to their family member, with little training or support(Nogueira et al, 2013). In this study, many participants highlighted the need to rely on others to help navigate their environments. This reliance on others was sometimes communicated in terms of it being a facilitator (e.g., *"if I have someone to help me, I don't experience any challenges"*) and sometimes a barrier (e.g., *"if I need to rely on or bother someone in order to move around, I will simply avoid moving around"*). This indicates a tension as well as a potential future area of exploration, as interventions to support inclusion and social participation of wheelchair users must not only focus on the built environment, but also on personal assistance, assistive technology, and health promotion and fitness (Myers et al, 2002). Future research could seek to understand the role of informal and formal caregivers and helpers for persons who use wheelchairs in Bangladesh, including how personal assistants, aides, and carers are recruited, supported, financed, trained, etc., as well as understanding their experiences, perspectives and needs as it relates to supporting persons with disabilities.

It is interesting to note that although many of the themes of the study were captured in the initial phase of the study (Photovoice), one major theme – attitudes - was only uncovered during the second phase of the study, after researchers had an opportunity to probe deeper into the experiences of wheelchair users in Bangladesh. This may indicate that although Photovoice is an important and useful tool for participatory research approaches, it may be necessary for studies using this tool to probe more deeply and integrate different data collection methods to provide a holistic perspective of the issue under study.

Finally, in discussing the results of the current study, it is of utmost importance to highlight the agency and ingenuity of participants in creating accessible home environments. Many people discussed the specific accommodations and adaptations they were able to make in the environments over which they had control, such that they were able to live, participate, and interact at home on an equal basis as peers who did not have disabilities. In the light of this, it is suggested that any future efforts to improve public accessibility in Bangladesh should actively and meaningfully involve wheelchair users in the development and implementation of solutions – indeed they are the true experts and many

have already proven that they are able to successfully and sustainably identify, remove, and mitigate barriers that they face in their environments.

Limitations

First, although this study was conducted among participants from urban and rural regions in Bangladesh, most of the participants were recruited based on their connection with CRP (e.g., service user, employee, former client). Thus, the population studied may be skewed towards people who are familiar with disability rights and accessibility by virtue of their engagement with this organisation and the services it provides. Additionally, although recruitment was structured to include a diversity of perspectives, many participants came from the capital city of Dhaka, and thus the perspectives of city-dwellers may predominate. Also, because photos guided the questions that were selected for interviews, this study may have been skewed towards the more observable environmental issues, rather than less tangible barriers and facilitators. In spite of this limitation, interview responses were still able to uncover some intangible components (e.g., attitudes, gender).

CONCLUSION

This study provides an insight into some of the barriers and facilitators faced by wheelchair users in Bangladesh and the effect that these barriers have on their lives. However, this study is only the initial effort, since the goal was not only to identify and study these issues but also to use the gathered information to promote social change on the ground. In addition to sharing the results with an academic audience, the plan is to disseminate the results of this study in a range of accessible formats for stakeholders and change-makers, including people with disabilities, community members, and policy-makers, through a series of photo exhibitions, posters, and discussions in Dhaka and surrounding areas. It is hoped that future research and action will encourage more people to get involved in removing barriers for people with disabilities in Bangladesh and globally. Everybody has a responsibility to act.

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