

Documenting the challenges of conducting research on sexual and reproductive health and rights (SRHR) of persons with disabilities in a low-and-middle income country setting: lessons from Bangladesh

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ABSTRACT

Research has shown that persons with disabilities require greater sexual and reproductive health (SRH) care and services than persons without disabilities. However, this need is often neglected in most of the low-and-middle-income countries including Bangladesh. There is also a dearth of research and data relevant to this issue. A nationwide mixed-methods research has been conducted to explore persons with disabilities' specific sexual and reproductive health and rights (SRHR) needs, health seeking behaviour related to SRH and barriers in accessing SRH services, along with the associated factors that influence their SRH outcomes. The purpose of this paper is to discuss the challenges encountered by the researchers while conducting this research and the strategies adopted to resolve those challenges. Some of the challenges experienced by the researchers include development of appropriate tools with questions on sensitive SRHR topics, obtaining informed consent, difficulty to maintain privacy while exploring sensitive SRHR issues and communication difficulties when interviewing individuals with intellectual and sensory impairments. The mitigation strategies include iterative revisions of all tools based on multiple pretests in different filed sites and expert feedback, strategic rapport building and maintaining appropriate contextual etiquette while conducting the interviews. The reflections discussed in this paper will assist future researchers in understanding potential field challenges they might encounter in similar low resource settings while conducting research on SRHR and similar sensitive issues among marginalised population groups, such as persons with disabilities.

BACKGROUND

Any individual with long-term physical, mental, intellectual or sensory impairments which hinder their full and effective participation in society on an equal basis are presently labelled as persons living with disabilities.¹

Summary box

- Sexual and reproductive health and rights (SRHR) of persons with disabilities is one of the least prioritised issues in Bangladesh despite the fact that persons with disabilities require greater sexual and reproductive health care and services than persons without disabilities.
- The purpose of this paper is to discuss the challenges encountered by the researchers while conducting a nationwide research on SRHR among persons with disabilities in Bangladesh and the strategies adopted by them to resolve those challenges. Challenges include development of appropriate tools with questions on sensitive SRHR topics, obtaining informed consent, difficulty to maintain privacy while exploring sensitive SRHR issues and communication difficulties when interviewing individuals with intellectual and sensory impairments.
- Mitigation strategies include iterative revisions of all tools based on multiple pretests and expert feedback from health professionals, strategic rapport building and maintaining appropriate contextual etiquette while conducting the interviews.

Persons with disabilities are among the most disadvantaged groups of people, with poor health, education and employment outcomes. They are more exposed to abuse, discrimination and exploitation compared with persons without disabilities.²⁻⁴ According to the World Report on Disability, it is estimated that 15% of the world's population are experiencing some sort of disability and the prevalence of disability is higher in the lower income countries than in the higher income countries.⁵

Bangladesh is a lower middle-income country in South Asia with a total population

of 165 million.⁶ National estimates suggest that about 9% of the population in Bangladesh live with some form of disability.^{7,8} Over the years, different ministries of the Government of Bangladesh including Social Welfare Ministry have taken several steps to eliminate the risks and vulnerability of persons with disabilities. The 'Persons with Disability Welfare Act 2001' and 'Persons with Disabilities Rights and Protection Act 2013' both reflect the efforts from the highest policy level of the Government of Bangladesh to address the unmet needs of persons with disabilities. Though these policies briefly expressed interest in meeting the sexual and reproductive health and rights (SRHR) of persons with disabilities, until now very little attention has been paid to this issue.

Sexual and reproductive health (SRH) is a very sensitive and stigmatised topic around the world. Moreover, when it comes to the SRH of persons with disabilities, it gets more stigmatised. Society has mostly overlooked the idea of sexuality for persons with disabilities. The SRH of persons with disabilities are mostly perceived as that they are either asexual or hypersexual and incapable of reproduction and unfit choice as a sexual or marriage partner.⁹ As a strong perception prevails on this matter, most of the people even the persons with disabilities themselves, feel discomfort discussing sexual matters in the context of disability.¹⁰

Another reason for SRHR of persons with disabilities to lag behind in policies and practice is the gap in research on this topic.¹¹ A limited number of research have been conducted so far on this issue globally and almost a non-significant number in the context of Bangladesh. This lack of research can be assumed to stem down from the cultural and context sensitivity of the issue as well as the challenges to conduct research with persons with disabilities. Due to the limited number of studies, researchers are not fully aware of the possible challenges they might experience while conducting research on SRHR among persons with disabilities. This void in documentation and knowledge makes it tough to propose strong policy recommendations and conceptualise effective policies. The cascade of these events negatively impacts the development of the persons with disabilities into having a more inclusive and less vulnerable society.¹

This study aims to address this knowledge gap by conducting a nationwide mixed-methods research among persons with disabilities to better understand their SRH needs, SRHR, knowledge about SRHR, SRH sufferings, perception around sex and sexuality and barriers in accessing SRH services in Bangladesh. There were multiple challenges the researchers experienced while conducting this nationwide research and they had to adopt appropriate innovative strategies to mitigate those challenges. The aim of this paper is to document those challenges and share the mitigation strategies in order to improve and facilitate further research on SRHR issues of persons with disabilities in similar context.

The research

A sequential explanatory mixed-methods study design was adopted to conduct this research where persons with any kind of disability were included as study participants. A mixed-methods design was embraced because this kind of design provides greater flexibility to draw a comprehensive conclusion based on the research findings. The independent institutional review board of BRAC James P Grant School of Public Health (JPGSPH), BRAC University comprehensively evaluated the study protocol especially the study design, study tools, consent form, procedures of enrolling participants, privacy and safeguarding of research participants and researchers, data confidentiality and storage and gave ethical approval (2018-044-IR) to it after they find everything satisfactory.

Even though the study comprise of both qualitative and quantitative components, this paper exclusively focuses on the challenges that researchers have faced during the quantitative part of the study.

Under the quantitative component, a cross-sectional nationwide survey was conducted among persons with disabilities covering whole Bangladesh. A minimum sample size of 5760 was determined to be appropriate to provide national and subnational (divisional) level estimates. However, researchers were able to collect data from 5000 persons with disabilities. The response rate for this survey was found to be 87.1%. The survey followed a multistage cluster sampling procedure for recruiting the respondents (all 12 types of persons with disabilities as per Bangladesh Government classification)¹² from eight administrative divisions of Bangladesh. A brief summary of sample size calculation is provided in the online supplemental material.

All challenges discussed in this paper are based on personal experiences of the research team. To record the experience, the research assistants were given a set of nine open-ended questions to document the field challenges experienced by them during data collection. A total of eight field coordinators were responsible for cross-checking and assuring that the information provided by the research assistants were correct. Different strategies were adopted by the researchers to mitigate the challenges; series of group discussions have led the team to figure out the most effective mitigation strategies for each of the following mentioned challenges.

CHALLENGES EXPERIENCED BY THE TEAM AND ADOPTED MITIGATION STRATEGIES

Development of tools

A comprehensive survey questionnaire was developed using validated tools from multiple sources, such as 'Rapid Assessment of Disability',¹³ 'Household Income and Expenditure Survey',⁸ 'Asking Young People about Sexual and Reproductive Behaviours',¹⁴ and 'The Washington Group of Questions'.¹⁵ Although the initial draft questionnaire was developed based on the validated tools and information from the literature review, the process

of finalisation of drafted tools took couple of months and proved to be challenging. Different issues posed challenges during the development of tools and their translation to local language, such as certain etiquettes needed to be maintained and certain terms needed to be avoided while formulating the questions to ensure acceptability of the questions to the study respondents. For example, respondents were asked 'Do you face any difficulty to perform your daily activities?' instead of asking 'What is wrong with you?' A lot of consideration and thoughts had to be invested into generating questions around sensitive SRHR issues and subsequent modifications were done to make them culturally appropriate. For example, respondents were asked 'Have you ever been to any romantic relationship?' if yes then 'Were you physically intimate in that relationship?' instead of directly asking 'Did you have sex with your partner/lover?' Here, asking direct question about sex or even using the word sex can be considered inappropriate because anything sexual count as a taboo topic in Bangladesh.

Given that most people with intellectual disabilities and those who have a severe impairment could not communicate themselves, the research team had to seek help from their identified caregivers to get responses of several questions. However, questions on knowledge and perceptions about different SRH issues were not asked to the caregivers as their perception or knowledge could not define the knowledge or perception of the respondents. Furthermore, questions on sensitive topics such as sexual desire, sexual dysfunction or sufferings from sexually transmitted diseases were not asked to the caregivers because this was not deemed to be ethically appropriate considering the fact that these are respondents own experiences, thoughts and feelings.

To mitigate the challenges, and to have stronger, comprehensive yet context sensitive tool, multiple visits were made to different government departments, disabled people's organisation (DPOs) and non-governmental organisations (NGOs) to consult relevant staff who have substantial experience of working on disability and SRHR issues. These visits and consultations helped the research team better understand the etiquettes of asking questions to persons with disabilities along with how to facilitate discussions on sensitive SRH topics. Two brainstorming workshops with diverse stakeholders from government and non-government organisations (DPOs and NGOs) also helped the research team develop a strong insight about the gaps in the tools. For example, the research team learnt from the stakeholders that barriers to accessing SRH services for persons with disabilities can be of different types such as physical barriers (inaccessible hospitals and other healthcare facilities), attitudinal barriers (negative attitudes of healthcare providers, caregivers and family members regarding SRH of persons with disabilities), communication barriers (failure of healthcare providers to communicate and consult with persons with disabilities) and financial barriers (high cost of medicine and expensive health services). All

these types of barriers were later incorporated in the tools as per their suggestion. Extensive feedback was also obtained from experienced researchers who have worked on disability and SRHR issues in Bangladesh and elsewhere.

Difficulty to reach the respondents and obtaining informed consent

To identify persons with disabilities, lists prepared through the Disability Detection Survey by Department of Social Services (DSS) and Ministry of Social Welfare (MoSW) of the Government of Bangladesh were used in this study.¹² However, in the lists, comprehensive correct information of the registered persons with disabilities, for example: full address or contact information were sometimes missing, as these were not being updated regularly. In few data collection sites, researchers could obtain only a handwritten list which was 5 or 6 years old. As a repercussion, sometimes reaching a respondent in a locality became very difficult. To mitigate these challenges, the lists provided by the DSS, MoSW were cross-checked with local DPOs and necessary corrections were made.

After locating the respondents, gaining access to them in order to conduct interview almost always involved going through the gatekeepers or caregivers. A significant number of respondents were dependent on other family members for their livelihoods and for performing daily activities. Therefore, even though they are adult, they could not show the complete authority to take part in the study which led the research team to convince the gatekeeper or caregiver along with the person with disability for the consent. It involved an additional stage of providing the gatekeepers with all the detailed information about the study and rapport building.

Difficulty to maintain privacy

Maintaining privacy during the process of data collection was one of the major challenges encountered by the research team. As mentioned earlier, many of the study respondents rely on family members for performing daily tasks. For those respondents, the caregivers or family members were around most of the time and therefore the respondents did not have much privacy of their own. However, the sensitive nature of the study questions requires privacy and when the researchers used to request for a separate room or privacy, questions about their motive were raised by many of the family members or caregivers. As persons with disabilities are considered vulnerable to discrimination and abuse, often the family members did not feel comfortable to allow the researchers to talk to them privately.

To mitigate this challenge, interview process and the study objectives were explained to the parents/caregivers in detail and permission was sought to conduct interview in a private place. In order to ensure privacy and security of the respondents, researchers took extra precautionary measures. They used to change sensitive questions or skip those for some time, when any family members suddenly

came too close or entered the room. For example, when the researcher was talking about sexual behaviour or experience of violence with the respondent and if he/she noticed that someone is coming to them or could hear them, they used to change the topic to something else such as rights of persons with disabilities. The researchers tried their best to ensure privacy and security of the respondents while collecting data from them. Almost all the interviews took place in private room and when a private room was not available, a safe place was identified as per respondent's choice. Information related to experience of violence, the perpetrator(s), sufferings as a result of experiencing violence and coping strategies of the respondents were collected carefully maintaining proper privacy and confidentiality so that sharing this information does not pose any further challenges to the respondents as well as to the researchers. The researchers also provided additional information to the respondents about health and judicial support services in cases they ask for it.

Exploring sensitive sexual and reproductive health and rights issues

Discussing different aspects of sexuality such as sexual function, desire, satisfaction, sexual relationship and abuse are considered as taboo in the context of Bangladesh. People do not understand the necessity of sound SRH for overall well-being of a person. Stigma and superstitions surrounding the topic makes people uncomfortable to discuss about it. They had very minimal knowledge about SRH and displayed a very negative attitude towards it at times. As a repercussion, respondents were not comfortable opening up and used to hide their perceptions. In few of the data collection sites, respondents got offended when they were asked about their SRH. Moreover, several respondents were reluctant to share their history of abuse, no matter if it is verbal, emotional, physical or sexual. To overcome this challenge, the researchers built rapport and trust with the respondents to help them open up in sharing sensitive information. Besides, gender compatibility between the researchers and respondents was always maintained. Female researchers collected data from the female respondents and male researchers collected data from the male respondents. However, when the respondent was male but his caregiver was female, assistance from a female researcher was sought so that the caregiver feels comfortable talking about the SRH of the respondent. In addition to that, sometimes, researchers shared their own stories to make the respondents comfortable. Many a times, they had to give examples of different incidents surrounding sexuality or SRH to make the respondent understand about it. However, anyone uncomfortable or unwilling to disclose any information were not forced to do so.

Communication challenges

The major challenge experienced by the research team during data collection was communication difficulties in the form of interpreting verbal responses, lack of skills in sign languages when dealing with persons with sensory impairments and difficulties of the respondents to share their accurate view or perspective due to limited cognitive ability.

Persons with mild to moderate speech impairment or hearing impairment were interviewed with average level of difficulty; however, it was hard to interview persons with severe hearing or speech impairment. At least one researcher who knows universal sign language was present in every team to interview persons with hearing or speech impairment. However, it was found that, a majority of the respondents with hearing or speech impairment were not familiar with universal sign language. Instead, they communicate with personalise sign languages, which in most cases only the caregivers or close friends used to understand. There were instances where the respondents wanted to say something but could not express it properly due to communication barrier.

To mitigate this challenge, assistance from the caregivers were taken, in the presence of the respondents. Questions with dichotomous responses were asked to the respondents directly with the help of the caregivers. However, questions related to experience of violence and sexual behaviour were not asked to the respondents in front of the caregivers to ensure their safety and privacy. Furthermore, while interviewing persons with mild to moderate hearing impairment, researchers spoke loudly and slowly to allow sufficient time for the respondents to lip read. Furthermore, if a respondent was able to read but cannot communicate, they filled up their own questionnaire with the assistance of a researcher.

Many of the persons with intellectual disabilities who have mild or moderate level of impairment could take part in the interview process on their own. For interviewing them, simplified questions were used. Succinct instruction and concise explanation of all the questions were given to them so that they can provide appropriate response. Researchers also adopted informal methods such as gesture, symbol system and photographs to make them understand the questions. In addition, help from the caregivers was sought. Researchers used to help them understand a question first and then caregivers used to repeat it again in their own form of language so that appropriate response could be obtained. However, persons with severe intellectual disability were not interviewed as they could not understand the questions nor did they respond. Their different thinking process and understanding level would not allow them to think intensively about various critical aspects and many a time they replied, 'I have never thought about it'. In such cases, the researchers relied on the caregivers. Nonetheless, sensitive questions related to experience

of violence or sexual behaviour were not asked to the caregivers.

DISCUSSION

A good number of research studies on various issues related to disability can be found in the literature; however, research related to a sensitive topic such as SRH of persons with disabilities is limited in number. This paper shared some of the challenges experienced by the researchers while conducting a nationwide research on SRHR among persons with disabilities in Bangladesh and the strategies adopted to resolve those challenges. The reflections discussed in this paper will assist future researchers in understanding potential field challenges they might encounter in similar low resource settings while conducting research on SRHR among persons with disabilities.

One of the major challenges faced by the researchers while conducting interviews with intellectually challenged individuals and individuals with sensory impairments is the communication difficulty. According to Singal, engaging persons with disabilities is crucial while conducting interviews; however, it imposes challenges.¹⁶ Author mentioned the challenge of the inability to express for persons with disabilities and the researchers' failure to use alternative methods of communication to establish a dialogue with persons with disabilities who cannot communicate in a conventional way.¹⁶ New technologies such as speech generating devices can be used to communicate with people who have little or no functional speech to communicate.¹⁷ The discussion presented in the paper on communication challenges and ways to mitigate them would be useful for any future research among persons with disabilities.

Development of culturally appropriate tools for persons with disabilities on sensitive issues such as SRHR was a significant challenge for the research team. A good number of tools can be found in the literature but most of them are appropriate for western culture. It was hard to find validated tools which are appropriate for Bangladeshi culture. A study conducted by Aswan *et al* in Malaysia documented similar challenges where the researchers had to rely on tools of international global based studies, although, those tools to a large extent are not culturally appropriate.¹⁸ Our learnings from this present study suggest that it is important to consult with different stakeholders from relevant departments of the government, academicians/researchers and NGO/DPO personnel when developing the tools and the tools, once drafted should be pretested multiple times to increase the acceptability among the persons with disabilities.

The challenge of getting a good quality database to access persons with disabilities has been documented by many authors in the past. Robson and Evans in a comprehensive review of international data sets of developing countries mention that existing data sets are fragmented most of the time, even the definition of disability is

inconsistent.¹⁹ One study in India have found that the number of persons with disabilities identified through census and sample surveys are quite different and the authors argued that it is because of the definitions used to define impairments.²⁰ In this study, we utilised the disability detection survey database maintained by the DSS, MoSW of the Government of Bangladesh. Until now, more than 1.7 million persons with disabilities are enlisted in the database and this is an ongoing process.¹² While accessing persons with disabilities for interview, at times we have found that the information available in the database is not correct and the list has not been updated regularly. Our learning is that it is a good idea to verify the information available in the database with local DPOs and NGOs who work closely with persons with disabilities in those areas before starting any field work.

Securing family members and caregivers as a guide during research was found to be useful and it helped the research team in accessing the respondents and get permission for the research. Furthermore, age and gender of the researchers can also help to get more thorough information from the respondents about sensitive issues such as marriage, relationship and sexual desire. When the respondents get the researchers as their same age group, they more likely think of them as peers, which help them to open up in a more comfortable manner.¹⁶ Gender compatibility between the researcher and the participant is also crucial just as age in SRH research.²¹ Furthermore, in research about sensitive topics like SRH, respondents might feel comfortable to fill-up the questionnaire by themselves. Therefore, universal design of research is recommended to use during research so that persons with disabilities can take part in the research in their preferable way without facing any difficulties.²²

CONCLUSION

This paper delivers essential knowledge and insight required by future researchers who are going to conduct research on sensitive issues such as SRHR with a marginalised group, persons with disabilities in a low-and-middle-income country setting. Even though developed countries are focusing on this area for research, low-and-middle-income countries like Bangladesh are still lagging behind. Furthermore, a nationwide community-based study on a sensitive issue with a vulnerable population group in a low resource setting brings a bunch of challenges for the researchers. The learnings from the challenges and the insight of this paper will appease future researchers to be aware of those challenges and get prepared from beforehand.

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the manuscript, and finally, AA adds the discussion section based on the overall findings. TH, RA and SR gave comprehensive feedback on the manuscript and TH and AA address all the feedback and finalise the manuscript.

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Supplementary material

The sample size for the quantitative survey is calculated with an aim to provide national and sub-national (divisional) level estimates. For having a nationally representative sample of persons with disabilities, this survey will follow a multi-stage cluster sampling procedure with two-stages of selection, where a random sample of clusters will be selected in the first stage from each stratum and persons with disabilities will be selected in the second stage from each cluster.

To ensure stratum specific estimate, the minimum sample size (sample of persons with disabilities) for each stratum is calculated using the formula for single proportion¹ and considering a prevalence of 11%² with 95% confidence level and 3% margin of error with design effect 1.55 (considering intracluster correlation coefficient as 0.024). The calculated sample size for single stratum is found to be 648 (Equation 1). After considering the finite population correction factor and a potential non-response rate of 10%, we fix the final sample size at 720 for each stratum. For the whole of Bangladesh, the final sample size is calculated to be 5,760 (720×8 stratum).

$$n_0 = \frac{Z^2 * p * q}{e^2} * deff \dots\dots\dots (1)$$

Where,

n₀= Initial sample size

Z= the z-score and the value of z for 95% CI is 1.96

p= 11% of PWDs had suffered Urinary tract infection (UTI)

q= 1-p

e= margin of error, 3%

deff = 1.55

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