Situation of Obstetric Fistula in a Marginalized Teagarden Community of Bangladesh: A Qualitative Study

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ABSTRACT

Aims: This study aims to explore why and how difficult it is for obstetric fistula patients living in the underprivileged teagardens community of Bangladesh.

Methods: It was a qualitative study conducted in 10 teagardens with approximately fifty thousand population. Five case studies followed by five Focus Group Discussions (FDG) were conducted in places where obstetric fistulas were identified.

Results: The mean age of the women was 41 years and the mean duration of suffering was 19 years. All of them got married before the age of 15 and became pregnant in the following year. One woman was divorced, two were separated and two were living with their husband. Only one of them received treatment from a tertiary center but did not continue due to economic constraints; rest of them were never exposed to any treatment or care. They believed that it would be recovered over time. All of them were neglected in their society and were deprived from all social and religious activities in the community. FGDs findings represent that poverty, lack of knowledge and perception are the significant barriers.

Conclusions: Underprivileged communities in the teagardens in Bangladesh are far behind in terms of access to quality health care services. Obstetric fistula is particularly still being under reported and undermined and focused intervention is required to eliminate fistula among them.

Key words: barriers, community, obstetric fistula, referral, teagarden.

INTRODUCTION

Obstetric fistula is a key public health concern globally. Around 2 million women are suffering from it and 50000 to 100000 new cases are found yearly[1,2] among which it is much higher in Bangladesh than other developing countries.[3-5] A national study in 2003 showed that the prevalence of fistula was 1.69 per 1000 women in Bangladesh.4 There are limited resources in the developing countries, so the burden of the disease is not well addressed.[6] Evidences show that the prevalence of obstetric fistulas is higher in the places where health care is poor, limited or absent.[7] In Bangladesh, a large number of women suffer from life threatening and chronic health problems including obstetric fistula due to pregnancy and childbirth every year.[3,8,9] Young women with poverty are mostly affected with these complications.[8,10] Treatment of obstetric fistulas is complex, therefore quality maternal health care services can improve overall situation.[11] Recent maternal morbidity validation study in Bangladesh in 2016 showed that the prevalence of fistula reduced to 0.42 / 1000 women[12]. However, the underprivileged women in teagarden community in Bangladesh are highly vulnerable to high maternal mortality.[13,14] Those teagarden women are mostly illiterate and have a limited knowledge on maternal health care. Most of the deliveries are conducted at home by untrained birth attendant, prolonged and obstructed labour being common consequences.[14,15] As there is very limited research on the burden of the disease,[16] this study aimed to look at the situation of obstetric fistula in the teagarden community of Bangladesh.

METHODS

A qualitative study was performed from May 2018 to July 2018 in purposively selected ten teagardens of two sub-districts of Moulvibazar district. It was implemented by Centre for Injury Prevention and

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Awareness meetings were held at each teagarden with the local community of the teagardens and field level healthcare providers covering approximately 50,000 population on the occasion of International day to end obstetric fistula. The meetings were conducted by the health department of sub-district. The community leaders, pregnant women and their guardians, religious leaders, elected community leader of local government, teagarden workers including male and community volunteers of the project participated in those meetings. The objectives of the meeting were to make people aware about fistula and also provide information about suspected fistula cases from their community to the field level health care providers or to the community the volunteers. Following the meetings, teagarden community volunteers with the support of government health care providers, identified 20 suspected cases during households visit. All women were primarily screened using a checklist of questionnaire for primary diagnosis as suspected fistula cases by diploma midwives and 14 positively screened women were referred to the primary health care centre for final diagnosis. All 14 women were examined by gynecologist; among those 14 women five were diagnosed as obstetric fistula patients [Table-1].

Table-1: Checklist to identify suspected fistula cases.

Questions	Answer	
	Yes	No
1. Either the women had continuous urination or feel pressure of urination?		
1a. If answer of Q1 is yes, did it happen immediately after delivery of LB/SB?		
1b. If answer of Q1 is yes, did it happen after operation of lower abdomen?		
2. Either the women's vaginal tear occurred up to rectum or she couldn't control defecation?		
If the answer is YES to Question 1, then the women will be sent for final diagnosis for fistula		

After confirming the diagnosis, the diploma midwives used a guideline to conduct in depth interview of the women to write the case study on story of each of the women suffering from obstetric fistula [Table-2].

Table-2: Content of the guidelines for detailed case stories collection and FGD conduction.

Areas of discussion	Contents
Demography	Age of the women Profession of the women Profession of the husband Income sources Education
Maternal history	Age at first marriage Age at first pregnancy History of complication during delivery
Fistula related issues	When first recognized herself with complication? Types of complications? What did she do after complication was identified? When was she first diagnosed as fistula case? Did she receive any treatment? How? Why didn't she receive treatment?
Challenges and Barriers	Any challenges in the family and society faced with this problem? Types of challenges? Any barriers to receive treatment? Types of barriers at family and society? What steps were taken to overcome the barriers? Expectation of support in medication and rehabilitation?

This study also performed five FGDs with the community people of each identified cases. A total number of 47 participants were present in these FGDs with the age range of 18-50 years. Among them, the relatives of

the fistula patients, community leader/Panchayat member, neighbors, women and men of the communities also participated. Two trained research associates were assigned to conduct the FGDs at the field and guideline was pre-tested before data collection [Table-3].

During the FGDs, one research associate facilitated the discussion whereas the other took important notes. Informed consent was taken from each of the respondents starting the FGDs. FGDs were recorded using voice recorders upon permission from the respondents. The hand notes of the interviewers, and research associates prepared during FGDs were transcript in local language and translated to English. Peer debriefing was performed to maintain reliability of the data. Themes were identified after reading and re-reading of the data[17,18] and finally, analysis was performed thematically.

Table-3: Content of the guideline for FGD conduction.

Areas of discussion	Types of Prompts used
Perception on obstetric fistula and complication	What is the idea about obstetric fistula and complication? Where and from whom got the idea about the complication? Why the responder didn't get proper idea on obstetric fistula?
Practice of fistula management at Community	What community practices exists for fistula? What preparations are taken during fistula complication? Where & from whom the treatment is received during fistula complication?
Barrier of the community to practices on fistula	What are the social and family barriers at community in practicing fistula care and health care seeking for treatment of fistula? What do they recommend for the support of fistula affected women?

RESULTS

The result is splited into two sections. First section is concerned with the findings of the FDGs . The FGDs highlighted some key areas including percpetion and practice of the commnutiy people on fisutla, existing barriers and suggestions from the commnutiy regarding fisutla identification, care etc. In the second section, findings from each case with obstetric fistula is discussed.

Perception of the community

Teagarden community has no clear idea on fistula. Most of the participants of FGDs had never heard the word fistula. They are completely unaware of the fact that it is a serious maternal health problem and a chronic morbidity. Participants had no idea about the causes of fistula either. A few community people mentioned about the leakage of urine or faeces as a problem. According to them, it happens because of God's will.

> "I didn't hear the term fistula earlier. But I know when one woman in my community was suffering from uncontrolled urination and finally identified as fistula in a hospital. I don't know why this occurs. This may be due to lack of cleanliness and menstrual hygiene management", said one of the neighbors of the identified fistula case

Practices of the community

Community people perceived that this type of disease can recover automatically. They had no idea about where the treatment facilities are available. All participants mentioned that the teagarden community calls or meets the village doctors (untrained) if any complications and also visit the traditional healers. During any serious complications, they visit the teagarden facility (dispensary) for primary care. They usually do not go out of teagarden seeking health care from the recommended government facilities.

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> "We do not have any idea about the right place for fistula care. We, the teagarden people normally

depend on traditional healers for any treatment or any complications. If we don't recover, then we go to the teagarden dispensary for treatment", said one of the relatives of a womam diagnosed with obstetric fistula.

Barriers in the family and society

The fistula affected women faced barriers in the family and society. The husband does not want to stay with his affected wife. The patients themselves feel uneasy as continuous urination occurs. She needs to change her dress 2 to 3 times a day. They also face problem in the society as the community people don't want to communicate. Cases were unable to continue work in teagardens due to such problems.

"We have lots of barriers for fistula management. The main barrier is the ignorance, poverty, communication and transportation. The fistula affected women face lots of problem in her family and society. She even can't work easily in the teagarden", said one of the Panchayat members during FGDs.

Suggestions and feedback

All participants in the FGDs wanted to know details on fistula disease, how it occurred, who can identify a case of fistula, where to transfer the woman and how it can be cured. They were also interested to know how fistula can be prevented. The participants suggested for a mass awareness and advocacy in the teagarden community on genital fistula prevention. In addition, they wanted to know more details on how the identified cases shall be treated and reintegrate into the society.

"We need mass education and awareness programs on fistula and its prevention in our teagarden community. As we are poor, we need full support for treatment of diagnosed cases of fistula", said one of the Panchayat members (local leader).

Fistula case reports

The case reports looked at the factors which were responsible for development of fistula and challenges they faced in the family and society. Early marriage and early pregnancy were identified as key factors for development of obstetric fistula. Other key factors included not seeking care during pregnancy and obstructed labour as delivery was conducted by untrained birth attendant at home. All women suffering from obstetric fistula are not seeking any health care due to ignorance. All five cases were illiterate and were the teagarden workers. The age range was between 30-50 years. All got married before the age of 16 and got pregnant in the following year. The duration of suffering from fistula varied from 8 years to 20 years [Table-4].

Table-4: Basic information of the cases identified.

Case	Age			Education	Profession	Para	Gravida	No of child	Duration of suffering (Years)
	Present	Age of marriage	1st Pregnancy						
1	35	15	16	Illiterate	Teagarden worker	3	3	0	10
2	50	15	16	Illiterate	Teagarden worker	1	1	0	20
3	38	14	15	Illiterate	Teagarden worker	3	3	0	19
4	50	15	16	Illiterate	Teagarden worker	2	2	1	15
5	30	16	17	Illiterate	Teagarden worker	2	3	2	8

Details of case findings

First case was a 50-year-old woman, and a teagarden worker, who got married at the age of 15, and got pregnant the following year, when she had a complicated and prolonged labour. During her first labor, when she arrived in the district facility unconscious, she delivered a stillbirth. She identified the leakage of urine after she returned back to home, she felt it was usual and happened because she had a stillbirth. She did not expose the matter initially to anyone. Later when she exposed her problem to the family, she was neglected by her husband and family members, no one took her disease seriously and brought her to seek any treatment. She is still working in the teagarden with this morbidity; she changed her clothes two to three times in a

day. She thought she might recover automatically but it persisted. Her husband left her and he re-married. She feels very shy, neglected and humiliated in the community and she is living with no hope.

Second case was a 38 years old woman working in the teagarden. She got married at the age of 14 and got pregnant the next year. She delivered a stillbirth at home by an untrained birth attendant. In the following two months, she got pregnant again; delivery took place at home by an untrained birth attendant. The baby survived for next two days only. Within one year, she got pregnant again. At sixth month of her pregnancy, she had severe abdominal pain at midnight. The traditional birth attendant was called and she tried long at night to deliver the baby, but she failed. At hospital, she delivered a stillbirth once again, by cesarean section. She had leakage of urine after two weeks and was unable to identify the reason. She did not seek any treatment due to serious negligence, ignorance of the long term morbidity, economic barriers, social challenges and family restrictions. At present, she is staying with her husband, however often facing family violence. Everyone blamed her for this illness. She changed her clothes 4-5 times in a day. She wanted to be cured.

The third case was a 35 years old women, working in the teagarden, married at the age of 15 and got pregnant immediately. Her first delivery was a stillbirth. After two years, she again became pregnant. When the labor pain started in the night; she waited at home for about three hours and then went to the teagarden facility. She delivered a stillborn baby by caesarian section. After one week, she started to leak urine. She did not have any idea on where to go, where to seek treatment and she was afraid to seek medical attention due to serious money constraints. As a result of her illness, her husband left her and he re-married. She is now completely alone, living and working in the teagarden.

The fourth case was a 30 years old woman working in the teagarden. She got married at the age of 16 years. She got pregnant the following year and had livebirth. After two years' gap, she was pregnant again. During the time of her delivery, traditional birth attendant was called and she tried for about five hours to deliver the baby. Unable to deliver in the district hospital, she was referred to the tertiary medical college hospital. She got admitted in the tertiary hospital in the afternoon and delivered a stillbirth through cesarean section. Later, she developed leakage of urine and it persisted. She took a number of medicines and was treated traditionally for her illness for a few years, however it wasn't cured. She stopped the traditional treatment and remained untreated. Her husband left her and she is now living alone with her morbidity.

The fifth case was a 50 years old woman who got married at the age of 15. The first child was born after one year of her marriage. During her second pregnancy, she came to teagarden facility when her labour pain started. She got admitted in the tertiary facility after around fourteen hours of her labour pain. Caesarean section was performed there. She started having leakage of urine when she was back home. She thought that the problem will get cured automatically. At first, she had hidden it and ignored this complication. She did not know the place where she could receive treatment for this. She changed her clothes 4-5 times a day. She is still with her husband. However, her husband has another wife. She did not receive treatment due to lack of understanding, ignorance, transportation, and economic crisis.

DISCUSSION

These findings represent that there is serious lack of information, knowledge and perception about genital fistula in the community. Therefore, the community is unable to identify fistula as serious maternal health morbidity. The community is also unaware of where and how the treatment can be obtained or how it can be prevented. The case studies highlighted that, in all cases, women had child marriage and early pregnancy. Obstetric fistula occurs as a result of delivery trial conducted by the untrained birth attendant at home and long hours of waiting before being referred to the referral facilities. It was also found that these women were illiterate. Hence, when they identified their problems, four of them did not go for any treatment from the right referral facility. One of the studies mentioned that community misperception and negligence about the disease restricted them to get treatment.[19] Other study highlighted the barriers in the society that also restricted the women to get treatment.[20] The community suggested for a mass awareness and advocacy to improve the knowledge on fistula and its prevention; similar recommendation was suggested in another study.[7] The teagarden community is far behind in terms of quality health

care services and also living with poverty making it hard to reach treatment areas. Obstetric fistula is dominantly higher in the rural commnutiy with low scoio ecnomic condition.[21] Recent maternal mortality survey has shown that 3% of all deaths are due to obstructed labour. It was observed that over 50% of deliveries are still taking place at home by untrained birth attendant22 which is one of the major predisposing factors of obstetric fistula along with early pregnancy and prolonged labour.[23] Economic constraints, ignorance, misperception, deprivation, societal stigma and barriers were found as key factors for not receiving or seeking treatment by the affected women.[19,24,25] In the teagarden community, women are working in the garden for whole day and have a limited access to quality health care services. Social myth, religious customs, behavior and practices restrict the women to go to the facility for maternal health care.[13,15]

CONCLUSIONS

Obstetric fistula is still emerging as cause of maternal morbidity in Bangladesh; women living with low socio economic condition being mostly vulnerable. This study clearly represents that the disease is still undermined; the women were found with fistula after the awareness programme. A clear pathway of identification of cases and referral to the recommended facility for diagnosis could help to explore the real magnitude of the problem. Mass awareness and advocacy is needed in the areas hard to reach to find out the fistula cases and also to advocate the community on prevention. United Nations is mandated to eliminate fistula within a decade. This study explored the needs of the community and also showed the best possible ways of fistula awareness and knowledge building that can be done in the rural community to prevent burden of fistula in Bangladesh.

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