Original Article

Cervical cancer in Bangladesh – community perceptions on cervical cancer and cervical cancer screening.

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Running title: acceptability of cervical screening in Bangladesh

Summary

We investigated the awareness of, and the attitude towards screening for, cervical cancer in Bangladesh. We performed a qualitative study using Focus Group Discussions (FGD). The framework approach to qualitative analysis was used. The study was performed in the catchment areas of Addin hospital, Jessore, Southern Bangladesh (peri-urban) and LAMB hospital, Parbatipur, North West Bangladesh (rural). 220 men, women and adolescents participated in 28 FGD.

Awareness of cervical cancer was widespread. Knowledge about causes was often inadequate. The perceived consequences of cervical cancer were numerous and awareness of the need for cervical cancer treatment was present. Barriers to accessing care include: low priority for seeking help for symptoms, limited availability of health services, and cost. Most women were unaware of the possibility of screening via speculum examination which was considered acceptable to women (and men), as long as the examination was done by a female health care provider in an environment with sufficient privacy.

In conclusion, adequate gynaecological services are not available or accessible for most women in rural and peri-urban Bangladesh. However, awareness of cervical cancer is widespread. Screening for cervical cancer in these communities is acceptable if done by a female health care provider under conditions with sufficient privacy.

Keywords: cervical cancer screening, low resource setting, perceptions, acceptability

Introduction

The world wide annual incidence of cervical cancer is estimated at 493 000 cases. More than 270 000 women die of cervical cancer disease each year. At least 80% of cases occur in developing countries (Parkin 2006), and in these countries, it is the most common cancer in women.

Cervical cancer can be prevented by relatively inexpensive screening and treatment technologies. Abnormal cervical tissue can be detected and treated before it progresses to invasive cancer.

There is worldwide agreement that screening programmes for cervical cancer are a necessity (Ngoma 2006) and furthermore, there are clearly defined management approaches that can be applied even in resource poor environments to diagnose and treat gynaecological diseases including irregular bleeding and cancers of the genital tract in particular cervix cancer. (ACCP 2004)

Programmes that use technically simple screening tools such as Visual Inspection with Acetic Acid (VIA) are the recommended screening approach. (ACCP 2004, Goldie et al 2003, JHPIEGO 1999, Nene et al 1996, Sankaranaranyan et al 1998) However, the uptake of screening in many developing countries is still poor. (RTCOG and JHPIEGO 2003, Sangwa-Lugoma et al 2006) Reasons for this are not well documented. A few studies have suggested that there is a lack of knowledge and awareness among women with regard to cervical cancer in general and screening opportunities in particular (Gichangi et al 2003, Kidanto et al 2002, Soew et al 1995). Lack of knowledge among men (as key decision makers) and a negative attitude of men towards screening or treatment of cervical cancer is thought to be another key factor contributing to poor uptake of services. (Singh et al 1998)

The limited information from Bangladesh that is available indicates that cervical cancer is the most common cancer among women of reproductive age.

There are currently no population screening programmes for cervical cancer in Bangladesh. Furthermore, there is a lack of information about what Bangladeshi women know about cervical cancer, and what approach to screening for cervical cancer is feasible and acceptable to both men and women. Bangladesh has an estimated population of 136 million people. It is one of the most densely populated countries in the world. The annual income per capita is 1770 USD. Life expectancy is 61.7 years for women and 62.3 years for men. About half the population consists of children under 18 years of age. The adult literacy rate is 50% for men and 31% for women. The fertility rate is 3.1 children per woman. The main religion is Islam (83%) (http://HDR.UNDP.org/statistics/data)

In this study, we assessed perceptions and understanding of cervical cancer symptoms, prevention and treatment options, as well as the acceptability of a cervical cancer screening programme with the aid of Focus Group Discussions (FGD) in two Bangladeshi communities. Using this approach our aim was to derive understanding based on group discussion from the community as opposed to testing a preconceived hypothesis or theory (Pretty 1993).

Material and Methods

The study was carried out in two different areas in Bangladesh. FGD were held in the catchment populations (about 500 000 per facility) of two health facilities; Lamb Hospital (Parbatipur) in rural northern Bangladesh and Addin Hospital in Jessore

(urban/peri-urban). Both hospitals provide community primary care with a focus on poor women and children. They do not currently provide any form of screening services for cervical cancer.

Topic guides and questions were developed with health care providers during a one week multi disciplinary workshop in Bangladesh. These were tested using groups of non – health care providers (both men and women) and adapted using correct local terminology.

Community health care workers were trained in the conduct of FGD and at each site five pilot FGD were conducted. The topic guide was revised (simplified) and further training provided.

FGD were conducted in the two communities. During other community health related activities in the month preceding this study, both communities were informed about planned FGD and invited to participate. All participants were self selected from within the community and did not receive any payment. FGD generally took place in the shade outside or on the veranda of a health facility but never in a space that could be perceived as intimidating or uncomfortable. Groups were constituted such that they were culturally acceptable and to obtain a maximum of information from both men and women in the community. All discussions were held in an appropriate local setting in the community and conducted in the local language. Each group had two moderators who were of the same sex as the participants.

A total of eighteen FGD were conducted with married women in the age range 20 – 49 years (eleven), postmenopausal women (three) and teenage girls (four). The opinions of men as key decision makers were also sought and FGD held separately with married men (five) and teenage/unmarried men (five). (Table 1) Each FGD received a code (either "a" or "L" followed by a number).

In general each FGD consisted of between eight and twelve participants; in four cases there were larger numbers of people participating (up to eighteen). A large number of people in each community showed an interest in joining the groups and the team felt it would be counterproductive to refuse them the opportunity to participate.

The slight limitation of the larger group size was considered less important than ensuring the 'credibility' of the data (Pretty 1993). Discussions were generally lively and appeared frank.

All discussions were taped, transcribed and translated into English. A framework for data analysis was developed, using the research questions and new issues arising (Ritchie and Lewis 2003). This was then used systematically to identify major and minor themes and interrelationships.

All members of the research team were involved in the analysis to enhance the 'confirmability' of the findings through bringing a range of perspectives to bear on the data. (Pretty 1993)

Ethical Approval was obtained from the research committees of both hospitals.

Informed consent was sought from all individuals participating in group discussions after the purpose of the research and specific activity for which participation was being solicited was explained. The names of participants were not recorded to further protect privacy and confidentiality.

Dissemination was via feed back to health care providers at each site and via a central workshop.

Results

Data collected from 28 FGD with in total 220 participants were analysed.

Given the potentially sensitive nature of the subject, the willingness to participate in the discussions as well as the openness with which topics were addressed was remarkable. We report on the results by topic – where there is variance between the groups this is noted. In cases of agreement between the groups this is not restated in the text.

Knowledge of cervical cancer symptoms

Among both men and women there is general and accurate knowledge about cervical cancer symptoms. Cervical cancer is referred to as 'an ulcer on the neck of the womb'. Symptoms attributed to cervical cancer include white vaginal discharge and abnormal vaginal bleeding.

However, knowledge about causes of cervix cancer is not always accurate. Frequent intercourse, intercourse during menses, (prolonged) use of the Intra Uterine Device (IUD), contraception other than IUD, and unclean clothes were all mentioned as possible causes of cervical cancer.

Perceived consequences

There is general awareness that cervical cancer is lethal if left untreated. Other consequences include deterioration in the atmosphere at home because of inability of a woman to perform her duties, anger directed to the women by her husband when she is not well and unable to have intercourse, and loss of income due to inability to work. According to women, the ultimate consequence may be that other members of the family ban a woman with cervical cancer from the house. Interestingly, men mainly mention physical consequences. Social consequences such as expelling the woman from the house, remarriage, bad atmosphere in the house, are only referred to once.

"I had ulcer in the uterus and the doctor advised me to undergo an operation. But I can't tell my husband or mother-in-law. They won't keep me then." (FGD#a2)

Knowledge of treatment options and barriers to seeking care

There is general awareness that gynaecological diseases and more specifically cervical cancer can be treated. However, even when women had managed to gain initial access to formal health services and knew what their treatment needed to be this could often still not be obtained. Reasons given included

- low priority given to seeking care for symptoms
- lack of money
- lack of appropriate care. Women are often asked to undergo further examinations and tests before treatment is commenced. There were several reports of women who had blood tests and ultrasound or X-rays performed, but not speculum examination, even if complaints were of a gynaecological nature.
- lack of appropriate services at close proximity.

Acceptability of examination

The general consensus of women (both rural and urban) is that examination is needed and welcomed to treat and prevent cervical cancer, without specifically talking about a speculum examination which most women have never experienced. Men similarly expressed that they felt that without appropriate tests and examination a proper diagnosis could not be made and therefore treatment might not be adequate.

Adolescent girls perceived the process of examination prior to treatment as a "modern approach" as long as examination is done in an environment with sufficient privacy.

"Examining us is absolutely necessary. How will you identify the disease if you didn't examine?" (FGD#a2)

Rural women talked about examination being embarrassing.

Men were in favour of examination in general, and seemed to have an accurate concept of screening for disease as a possibility to prevent worse.

Men did however place the responsibility of awareness of need for care and initiative to seek care primarily with women themselves. Furthermore, they stressed the importance of availability of female health care providers.

"It is convenient for us (the men) if women took their own initiative. They have their own privacies and embarrassing issues. If a man goes to a woman to learn or see a private matter then it becomes a disgraceful affair for that woman." (FGD#a10)

Although examination was generally acceptable to both men and women, there were also misconceptions. In some cases women expected the examination itself to constitute a cure.

"Now examining is absolutely necessary for me. The sooner I have my examinations done the sooner I'll be healthy again. We already know that death is waiting for us. There is no harm having our examinations done." (FGD#a2)

Acceptability of a speculum examination

Despite the high incidence of gynaecological complaints and symptoms, only two (1.4 %) out of the 159 women who participated had ever undergone a speculum examination. Both women were of child bearing age and recalled their experience as beneficial.

"I haven't seen the machine but it is used together with a small light, a machine/instrument they insert and then they see with the light. After they have looked I was given medicine. I have used the medicine and the pain went away that I had."

(FGD#L11)

Prior to discussing the topic of speculum examination in more detail, the FGD moderator explained what the examination comprised of, and showed a speculum to participants. Married younger women were curious and had clearly never seen a speculum before but there was a clear consensus that instruments were cleaner than using 'hands'.

"We (....) believe in medical science. Using hands has harmed a lot of women but with an instrument we can have easy examinations and stay safe, which is good for us." (FGD#a8)

Older women shared the view that using hands (i.e. performing a manual vaginal examination) was dangerous. Older women did not report experiences themselves of having a speculum examination but had anecdotal reports of women who died in childbirth because "hands" were used in the "birth passage" and felt that this was not safe.

Although adolescent girls agreed that examination would be helpful and would provide information, they expressed fear and thought the examination might be frightening and embarrassing.

"They will get frightened (...). Many women will not allow it for shame/embarrassment. Those whose disease is serious must have the exam. Why will we not have it- we must have it. Everybody wants to live; no one wants to die."

(FGD#L2)

Some older women and rural women also expected that women would be frightened but most expressed high motivation.

The speculum was also associated with the procedure of dilation and curettage (D and C), and there was some concern as to whether the speculum would be used for termination of pregnancy.

There was general consensus among women and girls that a speculum examination was acceptable and less frightening if the procedure was well explained beforehand. Married men, although agreeing that such examination was necessary, felt that the uptake of speculum examination by women would be low unless it was clearly a life saving procedure and that unless suitably counselled, women would be likely to panic and refuse examination.

"Of course they will be afraid, and most village women are uneducated. They will be embarrassed, and they might say, 'it is my disease, let it stay within me- let your instrument stay with you!' (...) Brother, as I said before, it needs to be explained beforehand- what is this test and why is it needed." (FGD#L14)

The majority of young men agreed examination with a speculum would be beneficial to screen, detect and then correctly treat disease. They had not heard of it before and saw it as a new and modern examination tool.

"I think with this instrument detecting the diseases early instead of detecting them late will benefit citizens. But only if this instrument can really find out the ulcers or other complications in the vagina with ease. A doctor could prescribe medicines accordingly and after timely taking the medications one could hope to be cured". (FGD#a13)

Generally rural young men thought women would be frightened and would need a lot of explanation and reassurance, but expected the majority of women to agree to be examined in the right environment. A minority of young men thought examination would be wholly unacceptable to women.

"Actually women in our country are very sensitive and they don't want to show or examine their infected organs to anybody. They completely disagree to do tests on those sexual organs." (FGD#a14)

Conditions for a speculum examination

All participants of all ages and gender suggested that the two key requirements for gynaecological examination of women were a female health care provider and privacy.

'A homey environment' was the term most commonly used. This was generally defined to mean a quiet and secluded room with privacy and confidentiality

maintained by a provider with a professional attitude who provided up to date and specialised care and information.

Furthermore, there was general agreement that proximity of services was important with women advocating for house to house visits and men asking for a clinic in each village. Services also need to be free or of 'reasonable' cost.

"Since we are poor people we can't travel far for examinations. It would be great if a female doctor, inside a closed door, did the examinations. Then we could have told our problems intimately. We could have shared all our problems." (FGD#a1)

The problem of the unavailability of services was continually raised:

"And if the environment were little homely that would've been great, but can't find such place. I want my examinations done in secret without even telling my husband. If such place around us within a reasonable cost I wouldn't have given a second thought." (FGD#a2)

Preference for type of health care provider

Adolescent girls expressed feelings of shyness and embarrassment and explained that it was socially seen as unacceptable to discuss feminine diseases with a male and/or be examined by a male health care provider. There was general agreement that they would not access care if this was provided by a male provider and that their mothers also did not do so. A minority (of women) said if the condition was very serious and there was no other option a male provider would be accepted. Married men seemed to

have given the matter a lot of thought and wished to see a service run wholly "by women for women":

"And there needs to be a woman doctor, for women a woman doctor- for men a male doctor. If we take a woman for treatment and there is a male doctor, he will not be able to do her examination, there is no rule for this anywhere. But if it is necessary for her treatment we can let a male do an x-ray or ultrasound or ECG." (FGD#L14)

There was considerable disagreement among men as to whether a male doctor would be acceptable. After lengthy discussions, the majority of men felt that examination by a male doctor was acceptable in case of a life threatening situation and/or if there was only a male doctor available. Men realised that women themselves might not wish to go to a male doctor but they felt this should be overcome:

"But treatment is necessary for these diseases for which they need to go to doctors but in our country most of the doctors are male so they hesitate to go to them. But numbers of female gynaecologists are very limited so women should step forward to help themselves." (FGD#a14)

Regardless of gender, both men and women noted that health care providers needed to be friendly and professional and maintain confidentiality.

Discussion

To our knowledge, this is the largest study from a resource poor country that has investigated the community perceptions and knowledge of cervical cancer, the acceptability of screening for cervical cancer and the conditions that need to be met to make such screening acceptable to both women and men.

Given the potentially sensitive nature of discussions surrounding 'women's diseases' we have found the method of using FGD to both effective and informative. All participants were very willing to discuss this 'difficult' topic. An important advantage of FGD is that it presents an environment that is comfortable and socio-culturally more acceptable than one-to-one interviews which may be intimidating. A potential disadvantage of FGD may be that controversial issues may not be discussed. In this study we were careful to constitute FGD groups such that these were culturally acceptable and it was possible to discuss all topic areas with ease.

In both communities there is considerable general knowledge about cervical cancer and both women and men demonstrate awareness of most symptoms that are related to cervical cancer. However, this knowledge is not accurate with regard to all aspects of the disease. Beliefs regarding cause of cervical cancer are generally inaccurate. Men have stronger and more elaborate views on causes of cervical cancer than women.

In contrast, women are more aware of the consequences of cervical cancer than men. The current consensus in both communities is that once cervical cancer has been diagnosed, cure is not possible. Knowledge of prevention/screening and treatment options for cervical cancer was found to be very limited. This lack of knowledge was also found by others (Ayinde and Omigbodum 2003, Gatune and Nyamongo 2005, Gichangi et al 2003, Wellensiek et al 2002) and is probably related to limited access to and availability of these services.

In all 28 FGD of our study participants elaborated on the fact that appropriate health care services are not available and/or not accessible.

On the other hand, even when a well organised and technically feasible screening programme is in place, uptake rates can be very low. A study performed in Thailand on the feasibility and acceptability of a VIA screening programme reported that even after intensive information campaigns the uptake of screening was only 17% among eligible women (RTOCG 2003). Reasons for this low uptake were not given.

Another factor contributing to low uptake of screening services may be the low priority given to seeking health care for symptoms related to cervical cancer (Holroyd et al 2004, Singh et al 1998).

In contrast, in a recent publication from Congo, a remarkably high uptake of screening (1571/1699 or 92%) was reported (Sangwa-Lugoma et al 2006). In this paper the high uptake was attributed to 'commitment' of the local health care workers to provide this service.

The unavailability of health care services specifically addressing 'women's diseases' in the populations we studied is perhaps best illustrated by the absence of any knowledge about options for screening for cervical cancer. With the exception of two women, no-one had ever heard of or seen a speculum nor undergone a speculum examination. Once the FGD facilitator had demonstrated the speculum and explained what a speculum examination comprised of, the examination was considered acceptable to both women and men. It is of note that, in comparison to a classic PV examination, i.e. "with hands", a speculum examination is perceived in this population as more hygienic, more 'modern' and therefore more acceptable.

The community had clear, realistic and well expressed ideas about conditions necessary for gynaecological examination. These include privacy, confidentiality, information and professionalism. There is a strong preference for a female health care provider, and this is compatible with other studies (Fylan 1998, Holroyd et al 2004).

It is striking that among a population where gynaecological symptoms are common, awareness of cervical cancer is high and willingness to undergo gynaecological examination present, gynaecological examination is rarely performed. Other investigations such as blood tests, ultrasound and X ray are done more commonly. Financial incentives that are absent for simple gynaecological examination and strongly in favour of other diagnostic tests may play a role in health care providers' choice of diagnostic tools.

Despite promising results of HPV vaccination trials several research questions remain to be answered (Lowndes and Gill 2005):

- -how often and how many times should vaccination be repeated?
- -apart from its beneficial effect on HPV infections and CIN, does vaccination also reduce the incidence of and mortality due to cervical cancer?
- -at what age should women/girls be vaccinated?
- -should we also vaccinate boys?

Furthermore, the currently available vaccines are costly and require refrigeration as well as clean needles for the injection. Hence, implementation in developing countries may not be realistic until a cheaper and more practical vaccine (i.e. inhalation or transdermal alternatives) are available (Roden and Wu 2006).

It is anticipated that, in order to reduce the huge worldwide burden of cervical cancer mortality, effective and feasible screening programmes will be needed for the next few decades. These screening programmes should incorporate community perceived needs and expressed pre-requisites for acceptable screening programmes. Failure to address the needs and beliefs of the community will result in a low uptake of services.

We conclude from this study that there is both unavailability and inaccessibility of adequate services for women with gynaecological symptoms in general and cervical cancer screening in particular. The situation is likely to be similar in many other resource poor settings. This unmet need must be addressed as a matter of urgency in consultation with local communities.

Ethical clearance

Ethical Approval was obtained from the research committees of both hospitals.

Informed consent was sought from all individuals participating in group discussions after the purpose of the research and specific activity for which participation was being solicited was explained. The names of participants were not recorded to further protect privacy and confidentiality.

Conflicts of interest

We report no conflict of interest.

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Table 1 overview of Focus Groups Discussions

type of participants	number of FGD's
postmenopausal women	3
women of child bearing age	11
adolescent girls (<20 yrs)	4
married men	5
adolescent men (<20 yrs)	5