

Ethical Dilemmas in Conducting Research on Reproductive and Sexual Health Issues in Rural Bangladesh

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The Study

- **Aim of the study:**

To understand rural married men & women's sexual and reproductive health concerns, needs & their access to service providers.

- **Study site:**

8 of the 19 unions of Chakaria, a remote rural upazila in the south-eastern costal area of Bangladesh.

One of the low performing areas in terms of health and family planning performance indicators.

- **Employed a Mixed Method Approach**

The Study

- 700 married males were interviewed from 1000 randomly selected households, &
- 455 married females from 500 randomly selected households were interviewed
- The final phase of the research involves 60 in-depth interviews (20 M, 20 F & 20 service providers), who will be selected purposefully from the quantitative survey

The Topic

- SRH health matters remain as a sensitive and silent topic in Bangladesh.
- Sexual and reproductive diseases are not only caused by any viral or bacterial infection, but there are multiple social and cultural norms, understandings and taboos associated with it.

The Topic

- Furthermore, sexual behaviour is usually monitored and regulated with social stigma and discrimination faced by many who are found to be suffering from or susceptible to sexual and reproductive diseases.
- Therefore, research on sexual and reproductive health issues demand great care about ethical issues.

Aim of This Presentation

- To share the ethical challenges encountered during the data collection and
- how we took measures to overcome some of the ethical challenges and
- some of the remaining unresolved dilemmas

The Ethical Dilemmas

Some of the key challenges that emerged were:

- Coping with the sensitivity of the issue
- Obtaining informed consent
- Maintaining confidentiality and
- Finally addressing the issue of what benefits does such research provide to the community

Coping with the Sensitivity

- The data collectors were well informed about the social and cultural issues BUT
- None of them had any prior experience
- The community was not used to

Measures:

- ✓ Extensive week-long training
- ✓ Practice interviews
- ✓ The order and phrasing of the questions
- ✓ Males to interview males and females to interview females

Obtaining Informed Consent

Verbal Vs written informed consent

- We obtained verbal informed consent

The Challenge was to ensure that verbal informed consent obtained properly

- Training
- 5% respondents were re-interviewed
- Contract with the data collectors

Obtaining Informed Consent

- **Individual vs Group informed consent**

If research findings/conclusion affect a group

- affect the people who were not approached for an interview or even
- the people who refused to participate in the study

Is it really possible to obtain a effective group consent?

We obtained individual informed consent

Obtaining Informed Consent

- However, we struggled with **methodological and ethical conflict**
- Our data collectors informed us that (too much) emphasis on informed consent often made the environment very formal
- This raised the question whether informed consent can bias the data because in a formal environment, respondents may try to give answer that they think will be perceived as correct by the interviewers

Maintaining Confidentiality

- **Recruiting data collectors** imposed huge dilemma
- Initial plan was to recruit data collectors from the other parts of Bangladesh BUT
- Study site has its own dialect which is difficult to understand for outsiders
- We had to recruit local people
- However, confidentiality was safeguarded by ensuring that data collectors selected did not conduct research in their own locality. Furthermore, data collectors were also trained on the importance of maintaining confidentiality.

Maintaining Confidentiality

- After training the data collectors we believed that data collectors understood the importance of confidentiality
- However, it was later observed that some of them were sharing SRH narratives among themselves as they thought it was okay to share findings among the research team
- We immediately explained the codes of ethics and made it clear that this behavior was not acceptable

Maintaining Confidentiality

- Although they assured us that they would always maintain confidentiality, we were still in a dilemma as to whether in fact they would follow our strict **confidentiality rule after office hours**
- We had no way of ensuring that they did not share any interesting details and disclosing the identity of the respondents among their friends **after their contract was over with us**

Maintaining Confidentiality

- We did not know how to deal with the fact that what **if the respondents themselves leak information**
- We did not want to let other community people know that we were doing study on sexual and reproductive health issues because this may stigmatize our respondents as assumptions would be made that they are suffering from sexual diseases

Maintaining Confidentiality

- Though we requested our respondents not to share the interview with others, we understood that a number of them leaked the information as few people tried to help our data collectors to find people with STIs
- Our data collectors explained them the methodology of selecting a respondent and the ethical issues and politely refused to interview the people they pointed out

Maintaining Confidentiality

- **Finding a private place to interview the respondents was also a difficulty job.**
- The community people were very inquisitive. Often neighbours and family members wanted to be present and hear the conversation.
- In few cases even the respondents also thought that it was okay to interview them in front of others (friends, relations).

Maintaining Confidentiality

- But, we instructed the data collectors to ensure that interviews were done in complete privacy and
- Respondents were requested to ask others to leave them during the interview period.
- In some case, with the help of the respondents, interviews were rescheduled to ensure privacy.

What happens to the community?

- A particularly thorny issue relates to what happens to the community where the research took place once the research is over.
- The returns of research does not perceive in terms of their immediate benefits.
- Benefits from this research would result from a lengthy process.
- Research findings would enhance our understanding of society, which circulates to benefit the whole group.
- But, is this enough?

What happens to the community?

- We referred the respondents suspected as having STIs to the nearest government and NGO health centre.
- The study findings and recommendations will be presented among the govt., private and NGO health service providers of the study area.
- Furthermore, it is hoped that the research will provide baseline data towards the provision of gender and culturally sensitive reproductive health services within the BRAC rural health program through their Community Health Workers.

Conclusion

- An increasing number of studies conducted on sexual and reproductive health issues question the direct benefits to the community.
- We continue to grapple with a number of ethical challenges raised by these types of studies.
- We should move for research ethics, which will take in to account and remain sensitive to contextual and cultural issues.

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