Acceptability of chemoprophylaxis for household contacts of leprosy patients in Bangladesh: a qualitative study

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Accepted for publication 06 April 2011

Summary

Objectives: Chemoprophylaxis with single dose rifampicin is a promising intervention to prevent leprosy in close contacts of patients. However, application in control programmes often requires disclosure of the leprosy diagnosis, which is still a stigmatised disease in many countries. Promoting control and treatment of stigmatised diseases without contributing towards stigma of the individuals involved can be very difficult. The objective of this study was to assess the social acceptability of disclosure of the diagnosis and the attitude towards taking prophylactic medicines in a leprosy endemic area in Bangladesh.

Design: Qualitative study through focus group discussions with 136 healthy men and women from different age groups and religions, coming from two rural villages and an urban area in northwest Bangladesh, and 14 health workers with extensive experience with leprosy patients.

Results: The participants would not object to disclosure of the diagnosis to household members and nearby family if they were diagnosed with leprosy. However, many participants were not willing to share this information with their neighbours and other social contacts due to stigma of the disease. All healthy participants were willing to take chemoprophylaxis if any of their close contacts were
diagnosed with leprosy, even after explaining that full protection against leprosy was not guaranteed.

Conclusion: It can be concluded that chemoprophylaxis for household contacts of leprosy patients is an effective and socially acceptable addition to the current leprosy control programme. Chemoprophylaxis for other categories of contacts likely to benefit would only be feasible, without disclosure of patient information, if given in the form of mass campaigns for the whole population in the area.

Introduction

Chemoprophylaxis in chronic infectious diseases such as tuberculosis, is of established benefit when given to people who are known to be at an increased risk of the disease. Trials with rifampicin used as chemoprophylaxis for contacts of leprosy patients have shown it to be effective. In a large trial in northwest Bangladesh (COLEP study), a 57% reduction in incidence among contacts was reached in the first 2 years after prophylactic treatment with a single dose of rifampicin. Rifampicin was provided to household contacts, neighbours and close social contacts after the leprosy patient had taken the second dose of multidrug therapy and could be expected to be non-contagious. People not closely related to the leprosy patient or not living in the same household, benefited relatively more from this prophylactic treatment with a single dose of rifampicin. However, household members of patients are at highest risk of being infected with Mycobacterium leprae. Physical distance to a patient and severity of the disease (leprosy classification) were identified as risk factors associated with transmission of Mycobacterium leprae while the contact characteristics ‘blood relationship to the patient’ and ‘age’ were identified as risk factors for the development of clinically apparent disease.

The WHO recently suggested in their ‘Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy, 2011–2015’ that the use of chemoprophylaxis as a tool to prevent the occurrence of new leprosy cases among household contacts should be explored further. One important issue for further study is the acceptance of chemoprophylactic measures by leprosy patients and their potentially benefiting contacts. Although many will appreciate the preventive effects of this kind of treatment, leprosy patients could object to disclosure of their diagnosis to others. Disclosure of the stigmatised diagnosis of leprosy to community members may have a major impact on the social life of people affected by the disease. Although mass distribution of rifampicin in a whole village without identifying the index case would be possible, disclosure of the diagnosis is a necessary step in the provision of targeted chemoprophylaxis to household members or close contacts of a patient, who have the highest risk of getting infected. This aspect was not addressed in the COLEP study, since only patients who did not object to disclosure of their diagnosis were included in the study. However, about 25% of those new leprosy cases registered in the period the COLEP cohort was being enrolled did not participate in the trial and were also not related to any of the cases included in the study. Although there were several possible reasons for not participating in the study (e.g. not present in the house at enrolment time, only temporarily in the study area, living less than 100 metres from a COLEP patient), the main reason was a refusal to participate. Another possible issue may be the difficulty of motivating healthy contacts of patients to take prophylactic medication.
In this qualitative study by means of focus group discussions, we assessed the social acceptability of disclosure of the leprosy diagnosis and the attitude towards taking prophylactic medicines in a group of healthy individuals in the same leprosy endemic area in northwest Bangladesh where the COLEP study was carried out. A focus group discussion on the same subject was conducted with a group of 14 staff members of the Leprosy Mission Bangladesh (TLMB) who all had extensive experience with leprosy patients in the hospital, rehabilitation projects or leprosy control programmes in the same area.

Methods

STUDY AREA AND POPULATION

The study was carried out in March 2009 in the leprosy endemic districts of Nilphamari and Rangpur. The large (3951 km²), mainly rural area has approximately 4.5 million inhabitants and is one of the poorest parts of Bangladesh.7,8 The new case detection rate for leprosy was 1·3 per 10 000 inhabitants in 2008, with a child rate of 10·5% which indicates an active transmission of Mycobacterium leprae. The new case detection rate in this area dropped remarkably over the last decade, from around 4·0 to 1·3 per 10 000 inhabitants. However, a study based on active case finding in 2002–2003 showed a prevalence of previously undiagnosed leprosy of 15·1 per 10 000 inhabitants, which was about six times higher than the reported prevalence rate.9 Therefore, the disease is still quite common in this region and many people are familiar with it.

Focus group discussions were conducted in two rural villages and one urban ward. In collaboration with field staff of the rural health program (RHP) of TLMB, locations were selected where there was a trained RHP volunteer available. The local RHP volunteer facilitated in the logistic management of the discussions, obtaining consent from the village leader, recruiting participants and organising an appropriate venue.

Participants from poor as well as better-off families were invited for the discussions to ensure representatives from different socio-economic backgrounds. The two main religions in the region (Muslim and Hindu) were represented in all groups. In each location separate group discussions were held for adult women, adolescent girls, adult men and adolescent boys (adult: above 20 years of age and adolescent: between 12 and 20 years of age).

DATA COLLECTION

Staff members from RHP facilitated the focus group discussions. Before the start of the study they received training and instruction from an experienced local social scientist from the International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B) in Dhaka, and the international researcher; besides written guidelines in Bengali and English were provided. For good rapport a female staff member facilitated the female discussion groups, while a male one conducted the male discussions. The Bangladeshi social scientist and the international researcher were present in the different discussions to observe and to assist the facilitator when necessary. The discussions were held in the local language (Bengali) and recorded with one or two tape recorders. Additional notes were taken on observations and the context under which the discussions took place.

The group started with a general introduction and discussion about social contact structures. Thereafter the facilitator gave some brief information about leprosy and confirmed
that everyone was familiar with the disease. The facilitator explained that a study with chemoprophylaxis showed promising effects in the prevention of leprosy, but that these medicines do not give full protection against disease.

A topic list was used to structure the discussion. However, the facilitators were instructed to give participants the opportunity to raise new issues as well.

ETHICAL APPROVAL AND CONSENT

At the start of the focus group discussion the subject, purpose and procedures of the meeting were explained to the participants. After this explanation participants gave their verbal consent for the discussion. Ethical approval for this study was obtained from the Bangladesh Medical Research Council under reference: BMRC/NREC/2007-2010/2107.

ANALYSIS

The staff members who facilitated the interviews transcribed the recorded interviews in Bengali. Afterwards these transcriptions were translated into English by a researcher from ICDDR.B in Dhaka, supervised by the social scientist and the international researcher. The software programme N-vivo (version 8, QSR International), was used to conduct a thematic analysis.

Results

DEMOGRAPHIC INFORMATION

In total 150 people participated in the study, 136 participants from the villages and urban ward and 14 staff members (Table 1).

There was an almost equal representation of Muslims and Hindus among the participants. The adult male and female participants had an average age of 41 and 38 years respectively, while the adolescent boys and girls were on average 18 and 16 years old. Adolescent participants in the study had a higher educational level than adult participants. Most of them, both male and female, had received secondary education. Only half of the male adult participants in rural as well as urban areas had secondary education, while the majority of the

<table>
<thead>
<tr>
<th>Group</th>
<th>Site</th>
<th>Number of participants</th>
<th>Minimum Age</th>
<th>Maximum Age</th>
<th>Average Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult male</td>
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<td>70</td>
<td>44</td>
</tr>
<tr>
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<td>30</td>
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<td>Urban</td>
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<td>25</td>
<td>60</td>
<td>38</td>
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<tr>
<td>Adult female</td>
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<td>23</td>
<td>25</td>
<td>65</td>
<td>38</td>
</tr>
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<td>11</td>
<td>17</td>
<td>20</td>
<td>19</td>
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<tr>
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<td>Rural</td>
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<td>11</td>
<td>20</td>
<td>17</td>
</tr>
<tr>
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<td>15</td>
<td>20</td>
<td>18</td>
</tr>
<tr>
<td>Adolescent girls</td>
<td>Rural</td>
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<td>12</td>
<td>17</td>
<td>15</td>
</tr>
<tr>
<td>Staff TLMB</td>
<td>Male</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff TLMB</td>
<td>Female</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>150</td>
<td>11</td>
<td>70</td>
<td></td>
</tr>
</tbody>
</table>
female adult participants in urban areas had only primary education and in rural areas no education at all. Most rural male adults as well as adolescents were involved in farming, whereas urban participants were involved in a variety of jobs ranging from day labourer to running a small business. Almost all female participants who were not going to school were housewives; in rural areas however, all females were also involved in farming.

Two main themes were extracted for analysis: the attitude towards taking prophylactic medication and the attitude towards disclosure of a leprosy diagnosis to household members, neighbours and others.

ATTITUDE TOWARDS CHEMOPROPHYLAXIS

All participants were positive about taking a prophylactic drug in the event of someone in their household, family or neighbourhood having leprosy, even when they were told that the medicine could not give 100% protection. There were no differences between male and female or adult and adolescent participants. Many people were already familiar with taking medicines as a precaution against other diseases; several people mentioned the example of prophylaxis for lymphatic filariasis.

Rural male adult:
- “It is good to take a medicine. We don’t have any problem with that”

Rural female adult:
- “Of course we will take the medicine. We are also taking the medicine for filariasis, because we know we will be protected from the disease when we take the medicine”

Urban female adolescent:
- “Health workers in our area give medicine for different diseases. Our parents are taking these medicines and allow us to take them also. They do not have any objection for that”

The participants of the discussion groups anticipated that their household members, other family and nearby neighbours would have no problem with taking a prophylactic medicine as well. Taking medicines for all kind of problems and complaints is well accepted in the area and everyone regularly uses medicines.

Also staff of TLMB with extensive experience with leprosy patients think that everyone will agree to take prophylactic medication.

TLMB staff:
- “Yes, people in this area will support this and take the medicine”
- “Most of the people in this area also come to take medicines to protect them from filariasis”
- “In the COLEP study many people came to us to ask for the medicine spontaneously”

ATTITUDE TOWARDS DISCLOSURE OF A LEPROSY DIAGNOSIS TO OTHERS

Participants were asked to imagine whether they would have any problem with informing household members, neighbours and other social contacts about their diagnosis if they were to be affected by leprosy (Table 2).
Disclosure of the stigmatised leprosy diagnosis is necessary in order to give targeted prophylaxis to household contacts and other selected close contacts of patients. All participants agreed that household members and nearby family should have this information in order to detect early signs of disease and to receive maximum protection in the form of a prophylactic medicine.

Rural female adult:
- “It can be told to our household members, but not to other relatives”
- “In our family, all family members help each other. So we will do what is the best for all of our family members”

Rural male adolescent:
- “I have to tell my parents about my problem for my own good. They will help me”

Rural male adult:
- “It will create problems if my household members don’t know anything about it. For example: if we dine together, my son or grandson may eat my leftover food. If I have a disease, I will not let them eat my food. But it will look odd if I don’t offer food to my grandson who stays with me. I have to tell my family about the disease, so they will know why I am doing this”

Urban male adult:
- “If I have any problem, my family should know about it. It is important that our family knows about the disease so that they can be aware and take precautions”

The urban groups were also happy to have their neighbours or other nearby contacts informed about their disease if they had leprosy.

Urban male adult:
- “First of all, my family needs to know. Then I will tell my neighbours that I have this disease and that there is a medicine for them to take as prevention. If anyone of them also has leprosy, it is important that they get treatment too”

Table 2. Attitude towards disclosure of information about the leprosy diagnosis towards others

<table>
<thead>
<tr>
<th>Group</th>
<th>Site</th>
<th>Disclosure of diagnosis to family</th>
<th>Disclosure of diagnosis to neighbours or others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult male</td>
<td>Urban</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
<td>+</td>
<td>+/+–</td>
</tr>
<tr>
<td>Adult female</td>
<td>Urban</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
<td>+</td>
<td>–</td>
</tr>
<tr>
<td>Adolescent boys</td>
<td>Urban</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
<td>+</td>
<td>+/+–</td>
</tr>
<tr>
<td>Adolescent girls</td>
<td>Urban</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Staff TLMB</td>
<td>+/+–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>+</td>
<td>+</td>
<td>+/+–</td>
</tr>
</tbody>
</table>

+ = positive attitude, – = negative attitude, +/– = some of the people were positive and some reacted negatively.
Urban male adolescent:
• “We don’t have any objection to tell others about this disease. We can’t hide this disease; the disease will spread if we hide it”

In rural areas people were more reluctant, and only some of them agreed that their neighbours or other nearby contacts should be informed. In the rural adult female groups the participants unanimously objected to informing their neighbours and other contacts, while in the rural adult male and adolescent boys groups there were objections as well. The reasons for not informing neighbours or other social contacts all had to do with the stigma of the disease. Participants mentioned that they were afraid of embarrassment, humiliation, social isolation and problems in finding a marriage partner.

Rural male adult
• “Maybe it is not good to inform the neighbours, they should not know in detail. It is a matter of embarrassment”
• “It will be a problem for our children, they will not get married”
• “It is common that people say: ‘Do not go to that house because he or she has leprosy’. That person will be hurt by hearing this, but other people will be protected”

Rural male adolescents:
• “I don’t want to tell my neighbours about the disease, because they might hate us. It will be good if they don’t know”

Rural female adult participants:
• “We will not let other people hear about it, but there is no problem if our family knows it”
• “There are many people who will not talk to a person who has leprosy, will not walk beside her, will not touch her”

The more educated adolescent participants had fewer objections to disclosure of information than the older generation. Only rural adolescent boys were reluctant to disclose information. Some girls mentioned that they themselves were happy to give information about their diagnosis, but that they thought their parents would not agree.

Urban female adolescent participant:
• “What we are trying to say is that we want to tell everyone, but our family might not agree to that. Other people will be aware of the disease if we tell them. This is good for the society. We are educated and therefore we have this way of thinking. People who are illiterate will not tell anyone about the disease. They think that telling other people will cause damage and problems in their marriage”

The group of experienced TLMB staff members said that most patients would not object to disclosure of the diagnosis to their household members, but would object to disclosure to others. However, they also have experience with patients who have problems with telling household members about their disease.
Chemoprophylaxis for leprosy in Bangladesh

TLMB staff:
- “Sometimes the family doesn’t love them anymore the way they used to do if they tell about the disease. This happens to many people. We have learned from our patients that family members don’t eat with him anymore or don’t want to share their clothes. Sometimes the family don’t want to spend money on this member anymore”
- “I think this is not a common picture. They will not face any problems in their household unless they become disabled. Then it will create some problems, but this is the minority. However, the majority of patients will not like to tell their neighbours or other contacts about their disease”
- “At present we have two female patients who do not want us to go to their home places, because they don’t want their husband and other family members to know about their disease”
- “I have another female patient who doesn’t want us to go her house, because she thinks it will create problems for her marriage”

Discussion

Prophylactic treatment with a single dose of rifampicin is known to provide protection against leprosy in close contacts of patients. In our study we found a positive attitude towards disclosure of the stigmatised leprosy diagnosis to household and nearby family members in order to provide them chemoprophylaxis. Participants from rural areas, especially the less educated adult participants, were not happy to share information on this diagnosis with neighbours and other social contacts as they feared social isolation when people knew about their disease. All participants had a positive attitude towards taking medicines as prophylaxis should one of their close contacts have leprosy, despite the fact that they were informed that this would not give them full protection against disease.

The study was performed among healthy individuals from three different areas in leprosy endemic districts of Bangladesh. Although the groups were not randomly chosen, we ensured that the two main religious groups in the area, as well different educational and socio-economic backgrounds, were represented. This resulted however, in a relatively high percentage of Hindu participants. Half of our participants were Hindu compared with only 10% Hindus in the general population of the area. However, we do not expect this difference to influence the outcomes of the study.

A possible limitation of the study is that only individuals without leprosy were consulted. It might have been difficult for them to imagine that they had leprosy, although the disease is widespread in the study area and thus many people might have been confronted with this disease. The advantage of interviewing healthy people is that community ideas and attitude towards leprosy are assessed. Since healthy people (contacts of patients) are also the target group for prophylaxis, their attitude towards leprosy and towards taking medicines as a preventive measure against this disease, whilst being symptom-free, is valuable as well. Furthermore, we also obtained information from TLMB staff who had extensive experience of working with leprosy patients in the area and thus could give examples on how patients actually react.

Despite enormous cultural diversity, people in a diverse range of endemic countries are confronted with social discrimination when diagnosed with leprosy. Although diminishing due to increasing knowledge about effective treatment options, fear and cultural beliefs about
the disease still cause negative community behaviour towards patients, especially those with visible impairments.\textsuperscript{10,11} Many patients in India and Nepal experience negative behaviour within their community and sometimes within their own family.\textsuperscript{12–14} As a result many of them try to hide their disease. In Brazil decentralisation of health services for leprosy was not successful, since many patients do not want to take treatment for leprosy close to their homes, as they are afraid that they could be recognised. Some of them had not even informed their household members about their treatment.\textsuperscript{15}

The fact that many leprosy patients are reluctant to inform others about their disease can hamper disease control and cause late detection of the disease, when irreversible nerve damage and disabilities have already occurred. The same is described for other stigmatised diseases such as TB, HIV/AIDS and mental illnesses. Controlling and treating these diseases without contributing towards stigma can be very difficult. It may be necessary for health workers to take restrictive measures towards patients with infectious diseases in situations where public health risks are involved. For example, it might be necessary to isolate infectious patients from others. However, segregation or actions of health staff can cause negative community behaviour towards the patient, even continuing after the infection risks are eliminated or the disease is treated.\textsuperscript{16}

Although chemoprophylaxis for contacts of leprosy patients can be an effective addition to the current leprosy control programmes, we have to keep in mind the balance between controlling the disease and contributing towards stigma. In this study we found a positive attitude towards disclosure of the stigmatised leprosy diagnosis within the household and close family in all discussion groups, while TLMB staff reported problems with this as unusual. Household contacts of leprosy patients are the group at highest risk of getting infected.\textsuperscript{2} Therefore chemoprophylaxis for household contacts of leprosy patients would be an effective and feasible option in disease control in Bangladesh and possibly also in nearby countries in the South Asian continent such as India, Nepal and Pakistan. Many participants in our study had objections to disclosing a leprosy diagnosis to contacts outside their own household. Informing other social contacts in the neighbourhood is likely to contribute towards stigmatisation of the individuals involved, but this may differ elsewhere in the world. When more people need to be protected, prophylaxis for a whole village or urban neighbourhood without disclosing information about a specific patient could be an option. This can be combined with more general health education about leprosy, which is the usual practice in leprosy control.

\section*{Acknowledgements}

We thank the staff of the Rural Health Programme of TLMB in Nilphamari for their dedicated and hard work for organising and conducting the focus group discussions and especially for transcribing the data. Special thanks also to Ms. Shahela Anwar from ICDDR,B for translating all data into English. We gratefully acknowledge financial support for the project from the Netherlands Leprosy Relief.

\section*{Contributors}

JHR, LO, QN and SF were involved in the design of the study, while QN, DP and SF were involved in implementing the study in the field. Analysis, interpretation, and writing were
done by SF with input of all other authors. The corresponding author SF had full access to all data in the study and had final responsibility to submit for publication.

Funding
The Netherlands Leprosy Relief funded the study. The study sponsors had no role in the study design, data collection, analysis, and interpretation of data, and writing of the report.

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