

CONTACT FGD, Chandauli, 2018

FG-CC:

1- 27 Years –Male	Block – Sahabganj
2- 48 Years – Male	Block – Sahabganj
3- 43 Years – Male	Block – Sahabganj
4- 19 Years - Male	Block – Sahabganj
5- 40 Years - Male	Block – Barahani
6 –35 Years – Male	Block – Barahani
7 –32 Years – Male	Block – Barahani
8 –62 Years – Male	Block – Barahani

District Name – Chandauli

IR- My name is XXX and I came from an NGO which is working in collaboration with government of India on leprosy disease. We expect your contribution, we will take some of your precious time and ask some questions which you can refuse if you don't know the answer of any question and you can leave this procedure whenever you want to, if you are agree so please do your signature on the paper.

FG-C1- Yes.

FG-C2- Yes sir.

FG-C3- Yes.

FG-C4- Yes.

FG-C5- Yes

FG-C6- Yes, I agree.

FG-C7- Yes.

FG-C8- Yes, sir.

IR- Do you know any patient suffering from leprosy disease?

FG-C1- Yes, my brother was suffering.

FG-C2- My daughter-in-law she is of 30 years.

Jitendra- My uncle is suffering from a leprosy disease; he is of 65 years his toes get distorted.

FG-C4- My brother and my uncle is suffering from this.

FG-C5- My grandfather, he is of 60 years.

FG-C6- My brother he is 18 years old.

FG-C7- My mother she is of 70 years.

FG-C8- My younger brother's daughter

IR- What do you know about leprosy disease? What are your thoughts about it?

FG-C1- Leprosy is caused because of the diet.

IR- What do you mean by diet, like including meat and such kind of food?

FG-C1- By eating anything impure, lack of hygiene.

FG-C2- White colored spots occur on body which gets numbness.

IR- In which parts of body it could be occurred?

FG-C2 - All over the body.

FG-C3- Numbness occurs and patches can be seen all over the body and cuts cannot be felt.

IR- What do you mean by numbness, is it completely or partial numb?

FG-C3- In a complete way.

FG-C4- My brother was having the spots, these spots having numbness, he was not able to feel anything there, and these spots are different from the body skin.

FG-C5- In leprosy disease large spots occur and nothing can be felt on pinching, it can also happen on face and chest.

IR- Do he feel pain on that parts?

FG-C5- No.

FG-C6- In this disease blisters can occur anywhere in the body. White spots occur on neck and back and if burns then no sensation feel on it.

IR- It only takes place on neck and back or on all over the body?

FG-C6- All over the body.

FG-C7- We were not knowing about the leprosy disease in the starting but after the spots are developed and numbness occur and then we consult to the doctor he says that this is leprosy disease.

FG-C8- Diet is the reason of leprosy disease because of which hands and legs get numb and nothing can be felt on touching.

IR- Do you know what are the symptoms of leprosy disease?

FG-C1- Spots and patches can be seen all over the body and nothing is felt on pinching.

IR- Where can these spots can occur and where does it happen to your brother?

FG-C1- It can occur all over the body but my brother was having on his chest.

FG-C2- White spots and numbness on the body.

IR- Partial or complete numbness?

FG-C2- Partially.

FG-C3- White spots occurs on the body, numbness, sometimes the fingers do not work and gets decay

IR- It does not work partially or completely?

FG-C3- Condition gets very worse and the person becomes incapable.

FG-C4- White spots and boils occur; my brother was having on his shoulders and it was itching also.

FG-C5- White spots occur in which itching also occurs.

FG-C6- Spots and patches are seen all over the body.

FG-C7- Initially spots are seen then their edges starts increasing then the nerves starts swelling and blisters occurs and numbness can be felt while touching.

IR- Does it completely gets numb?

FG-C7- Yes, blisters are formed and the patient cannot sit near fire.

FG-C8- Spots and patches occur which gets numb.

IR- How does Leprosy disease caused?

FG-C1- Leprosy disease is caused due to bad lifestyle, unhealthy diet, unhygienic living and staying near to the patient is also the reason.

FG-C2- It spread due to unhealthy diet and also because of the lifestyle of a person.

IR- What do you mean by the diet?

FG-C2- It happens because of the deficiency of nutrients in the body.

IR- If we include fish and meat in our diet then this disease will not occur?

FG-C2- If the nutrients will be sufficient then it will not happen otherwise any disease can be caused.

FG-C3- Lifestyle, diet and unhealthy food is the reasons by which it occurs.

IR- What do you mean by unhealthy food?

FG-C3- Unhealthy food means stale food or eating without washing hands.

FG-C4- Uncle was saying that he was gone somewhere and suddenly spots and patches were formed on his body rest I don't know anything.

FG-C5- This disease is caused due to deficiency of protein in the diet in our body.

FG-C6- This leprosy disease is spread because of the diet, stale food should not be eaten as it contains bacteria.

FG-C7- There is no exact or particular reason for leprosy disease like cough, cold and TB so, any disease can be caused.

IR- Tuberculosis is caused by a bacteria similarly does this disease is also caused by bacteria?

FG-C7- I don't know about this, I eat the same food which my mother eats but my mother is suffering from this disease and I am not so, I can't tell the exact reason because everyone's lifestyle is almost same.

FG-C8- This leprosy disease is a game of nature and reward of your doing, he is suffering from leprosy disease but I am not.

IR- What is the meaning of the word kamaayi, which you just said?

FG-C8- It's all nature's game and reward of our work did in the last life that he is suffering from the leprosy disease and I am not.

IR- Could leprosy disease treated?

FG-C1- Yes, it can be treated through medicine this is available at the health centre.

IR- The disease can be treated with the medicines which you get at the health centre?

FG-C1- Yes, leprosy disease is treated with the medicine and it is free of cost at the health centre.

FG-C2- Yes, it is treated in the hospital.

IR- In which hospital allopathic, ayurvedic or to the private doctor.

FG-C2- It is free in the government hospital.

FG-C3- Yes, it is treated in the government hospital.

IR- How is the treatment done?

FG-C3- Free of cost the medicine is given for 6 months through which it is cured.

FG-C4- The medicine is given at the PHC through which the disease is cured.

FG-C5- Yes, the disease is cured and the medicine is available free of cost in the hospital.

IR- The medicine is only available in the government hospital or somewhere else?

FG-C5- If it is available for free at the government hospital then why should we go somewhere else.

FG-C6- Yes, medicine is provided free of cost in the government hospital.

FG-C7- Yes, the medicine is available at the health centre through which leprosy is treated and it is very effective.

FG-C8- Everyone say like this but the medicine is not that effective, there is not much relief to my niece even after taking the medicines for 4 to 5 months.

IR- Medicine was for how many months?

FG-C8- Medicine was given for 6 months.

IR- Can you tell me what type of responsibility do the people in the community carry towards the leprosy patient or what are their responsibilities?

FG-C1- The most important responsibility towards the leprosy patient is they should be informed that there is a treatment of this disease and should be taken to the hospital so that the disease does not transfer to someone else.

FG-C2- This is the responsibility of the people of the community to tell the patient that the medicine for this disease is available free of cost in the government and if possible they should take the patient to the hospital.

FG-C3- The responsibility of the villagers is to go to the hospital and tell the names of the leprosy patient in our village so that the hospital staff can organize a camp for distributing the medicines.

FG-C4- There is a doctor in our village who did the checkup of my brother and told me to take him to the government hospital for the checkup and then take the medicines, so this is a responsibility of everyone to bring the patient to the hospital.

FG-C5- The responsibility of the people of community is to inform the patient's family members to take the patient to the health centre to get the medicines and to have medicine time to time and also take care of the hygiene.

FG-C6- The responsibility of the society is to take the patient to the hospital and with the help of their family provide food and medicines to time.

FG-C7- Responsibility of the society is to provide medicines to the patient and ask to have the medicine.

IR- What if the patient does not want to eat the medicine?

FG-C7- Try to feed him medicine any way.

FG-C8- It is the responsibility of the family as well as the society to provide medicines to the patient and should not do any kind of discrimination.

IR- Can you tell how do the people of the community behave with the leprosy patient?

FG-C1- The villagers don't want to stay with or nearby them and tell them to maintain the hygiene so that the disease does not spread to others.

IR- What is the reaction of the patient when the villagers behave like this with them?

FG-C1- Leprosy patient thinks of going and doing the proper medication so that the disease does not spread to others.

IR- Do the people of the village has different behavior towards them?

FG-C1- Some people isolate them and the patient think to get the proper treatment done so that it does not transmitted to others.

FG-C2- They suggest patient to have medicine but do not stay away from them but still they think that this is a communicable disease to better stay away from them.

IR- Have you ever thought this way to maintain the distance with them?

FG-C2- I have never thought this way but the villagers think not to eat anything given from that family.

IR- What will be the reaction of the leprosy patient after knowing this?

FG-C2- Patient struggles with all the problems and keep on doing all the work but that feeling of inferiority comes in the mind.

FG-C3- Only some people have different behavior with them, they want to talk to them but stay away from touching the body.

IR- Then what do the patient thinks?

FG-C3- Patient gets the feeling that people are maintaining distance so they feel inferior.

FG-C4- In our village we treat the patient normally rather than behaving in a different manner.

FG-C5- The leprosy patient is treated normally because if we will badly behave with them then their morale will be break down.

IR- Do you have different behavior with them?

FG-C5- Feelings come to the mind to eat separately and maintain distance from them but don't do that.

IR- what is the behavior of the patient?

FG-C5- The patient thinks that if I had not suffered from this disease then everyone would have behaved normally with me.

FG-C6- The people in the society create distance from them due to which the patient gets the feeling of inferiority in the mind.

FG-C7- Those who don't know about the leprosy disease of the patient they behave normally but after knowing they maintain distance from them due to which the patient feels sad but the behavior of the family members remains normal towards them.

FG-C8- Leprosy patient is provided with separate bed to eat and sleep because this is a communicable disease so leprosy patient is treated similarly like the tuberculosis patient and see all this patients themselves maintain the distance so that it does not get transferred to anyone else.

IR- Will you reveal the leprosy disease in front of the community and why?

FG-C1- Yes, I will tell so that they get alert and if someone is already infected then they should go and get the medicines.

FG-C2- Will not tell to anyone, what is the need of telling anyone.

FG-C3- Yes, will tell so that they can get good medication/treatment and everyone should get to know how this disease is caused and what its symptoms are.

FG-C4- Yes sir, I will tell because if anyone suffering from it nearby can go and get the medicine.

FG-C5- Yes, will tell so that the people in the community maintain the hygiene due to which the disease will not spread.

FG-C7- I will not tell because the people in the community find us inferior and will distance themselves.

FG-C8- Will tell to some specific person in the community so that I can get advice from them in order to get better treatment.

IR- Thank you so much for all this information.

Declaration

It is hereby certified that above shown translation work has been completed by undersigned as per the discussed terms & conditions.

Dr . Pravesh Dwivedi

FGD Health Worker Chandauli, baseline

Responder FG-H:

- 1- Age – 45 Years, Male, NMA, CHC Block - Dhanapur
- 2- Age- 27 Years, Male, BMW, Block - Barhani
- 3- Age – 50 Years, Male, NMS, Block - Niyamatabad
- 4- Age – 36Years ,Male, BMW, Block- Chakiya
- 5- Age – 45 Years, Male, NMS, Block - Sahabganj
- 6- Age – 52 Years, Male, NMO, BLO Office, Block - Chandauli
- 7- Age – 62 Years, Male, NMA, Block - Chandauli
- 8- Age – 55 Years, Male, NMA, Block - Niyamatabad
- 9- Age – 37 Years, Male, NMA, Block - Sahabganj

IR- My name is XXX. We have started work in Chandauli on Leprosy, the PEP ++ Programme is going on in this area. The study which we are conducting is about Leprosy. The information provided by

you will be kept confidential. We will record your responses which you are going to share with us this is really helpful for this study; it will be useful for our study. Now please introduce yourselves

10- (names removed)

IR- Thank you very much. We hope for your co-operation and with your permission, shall we start now?

RE- Yes yes, please start

IR- **My first question is, do you know any leprosy patient in your area ?**

FG-H1- We know, of course we know.

IR- In which way do you know them and how much do you know them?

FG-H1- We know them very closely. We know the leprosy patients who come to us very closely, just like family.

IR- Would you like to tell us something about it?

FG-H1- The names are noted in the registers. If you ask me now, I will not be able to recall the names.

IR- So do you visit them, or it is they who usually visit you?

FG-H1- We visit them, and they visit us too. We visit them every two to three months for MB, and for PV as well. We make at least 1-2 visits during the treatment

IR- At least two

FG-H1- As per rules, we require to make six visits, but we make at least two home visits

IR- Alright

FG-H1- We enquire about their condition and how they take the medicines.

IR- Anything else?

FG-H1- That's all.

FG-H2- We treat the leprosy patients who visit us, like family. We meet them every month. If they happen to stop their medication during in the midst of treatment, which happens quite often, then we are required to take medicines to their homes. They have our contact number and they can call us any time, day or night. We then take medicines to their home.

IR- Right

FG-H2- I don't remember the exact names, but all the names are available in the register.

IR- Would you like to add anything, you must know some leprosy patients

FG-H3- All the leprosy patients who come to Niyamatabad, face social stigma in their social structure. We first inform them what causes leprosy, how it can be treated and how many days they need to take the medication. After giving them all this information, we give them the medicines. With the MB patients who visit us, we need to have at least 3 contact hours, and six visits. We have to take whatever social or economic measures that are necessary. We make arrangements at the block level.

We have 4 PB and 13MB patients as per the March report.

If you want names, there is XX, XX, XX and XX, who are MB patients. XX is a little better now. Among PB patients we have XX, XX, XX. These patients take their medicines regularly. There is no problem. They stay in regular touch with me. They have my number. I do not face any problems here. If there is any one with a disability, then I give him relevant information about POD, whatever will benefit them.

IR- Alright.

FG-H3- We give them all the information, guide them and motivate them. We tell them about the different organizations where they can get their surgery done. In some of these places they get monetary assistance.

IR- Alright.

FG-H3- They get free food there. And they can call us any time they have a problem, because they have our numbers. We sit together and have tea, chat and laugh with the patients who come to us in the hospital. We try to understand their problems and give them advice that will benefit them.

IR- Alright. You had used a technical word right now

GF-H?- Yes

IR- Stigma. What is that?

FG-H3 -*soshak dosh* (same written in Hindi)

IR- How yes,yes.

FG-H3- In our society, is seen as a result of sin and bad *Karma*. But this disease has no relation to that. This disease is caused by micro bacterial Just like diseases such as TB , and there are other diseases which are caused by viral infection, the same way this disease is caused by micro-organisms. It can be treated to regular medication, and the medicines are available with us. It is supplied to us by the Government of India. 99% bacteria can be killed with its help. If they take it everyday, they do not acquire infections and can live with their family.

IR- Alright. Is there anything else you would like to add?

FG-H3- No

IR- You tell me please, do you know any leprosy patients?

FG-H4- Yes , very closely.

IR- How well do you know them?

FG-H4- I know their family too.

IR- Right

FG-H4- I know what work they do and about their condition

IR- OK

FG-H4- The leprosy patients usually live in poor conditions. They are mostly from very poor families. They cannot buy medicines from the private shops. They just manage to arrange for two square meals a day.

IR- And what else do you know about them? How many patients are here right now?

FG-H4- In my place there are a total of 16 cases, out of which 9 are MB and 6 are PB.

IR: ok would you like to share anything else

FG-H4: Sir, I can give you the names of the patients too. We visit their homes too. One family which lives in North Madahua, has 3 MB patients. You had visited them.

IR- Yes yes

FG-H4- There is Vinod, Pramod and Gopal.

IR- Are they from the same family or the same village ?

FG-H4- They are brothers from the same family

IR-OK

FG-H4- And in Maduhua itself, there is another patient, Gita . She is a PB patient.

IR- Now Anand ji, please tell us

FG-H5- Our work is to keep in touch with leprosy patients. We provide medicines to some patients and we visit the homes of some patients. We maintain a healthy contact at their home.

IR- Do you know any leprosy patient?

FG-H6- There is one leprosy patient, whose name I can recall, Sunil Kumar. I am posted at the headquarter. Many leprosy patients come here. We counsel them about the treatment, about the right dosage and regimen of medication and we also encourage them to bring family members who may have leprosy. If the disease is not severe then we ask them to take medication for 6 months, and if it is severe, we ask them to continue for a year. We also tell them the side effects which may occur, due to the medicine. We send them to the CHC and the PHC and if anyone is disabled, we tell them about physiotherapy.

IR- Do you know any leprosy patient?

FG-H7-This month we have a new patient, Anees. When a patient comes to us, we explain to him about leprosy, we register his name and check if he is a leprosy patient. If he is a leprosy patient, then we put him in either of the two categories that is six months and 12 months treatment. Then we do their ST and PFT tests, give them their medicines and explain to them that if they miss their medicines, the disease will get aggravated, and they may face physical disability. Then we note their mobile numbers and give them our contact numbers, so that they can call us if they need to. We visit the homes of the patients to make healthy contact. If there is a family member who has leprosy, we provide medicines to her too. Every 2-3 months we make follow up visits to find out if they are taking their medicines regularly. We explain that if they discontinue medication, the problems will increase

IR- Do you know any leprosy patient

FG-H8- Yes. We get patients at our PHC, and we help them. If the patient has an ulcer, then we bandage him using betadine. If the patient is poor and does not have money then we help them. One patient needed to get a differently abled certificate from the district, but did not have money. We helped him. He now gets a pension of 2500 from the government. If the patient gets medication on time, then 99% of the bacteria are killed. Wherever the patient may be from, we provide them with medicines and a kit with cotton wool, bandage, betadine and fitkiri(alum) etc. We also show them exercises.

Do you know any leprosy patient? How well do you know them?

FG-H9- Yes I know some leprosy patients. Rambriksh, Mohan, Birbal, Mahendra, Mithilesh pandey. All of them are disabled.

IR- What do you know about leprosy as a disease?

FG-H1- Spots on the skin having numbness are a sign of leprosy. Later it causes pain and may even lead to disability.

IR- What do you know about leprosy?

FG-H2- Leprosy is a chronic disease. It is contagious and is caused by microbacterium leprae. Initially one can see patches on the skin with numbness. If the patient does not undertake medication, it may lead to disability. They have pain in the nerves and a tingling or prickling sensation. They cannot do work normal everyday.

IR- What do you know about leprosy?

FG-H3- It is caused by microbacterium lepre. The parts where patches occur do not have any hair and sweat.

IR-What do you know about leprosy?

FG-H4- This disease is caused by the bacteria, *microbacterium leprae*. It affects the body slowly. It may remain active from 6 months to 13 years. There is no fixed period. It depends on the body's immunity. One can experience numbness wherever patches appear.

IR- What do you know about leprosy?

FG-H5- This disease is caused by the bacteria, *microbacterium leprae*. This disease spreads from infected persons who have not been treated. It spreads slowly over a long period of time. Slowly spots appear, followed by numbness. It destroys the sweat producing cells, due to which the patient does not sweat wherever he has these patches. If timely treatment is provided, disability can be prevented.

FG-H6- It is caused by the *microbacterium leprae* bacteria. It affects the nerves and the skin, causing numbness and loss of sensation, and loss of body hair (on affected areas). If it affects the facial nerve, then the patient finds it difficult to close his eyes. If it affects the fingers, then the fingers bend, and if it becomes severe then the fingers may become ulcerous and deformed. We detect leprosy by examining the nerves. If leprosy is detected then we ask the patient to visit the PHC, and start treatment as soon as possible. We also tell them that if they do not get correct treatment, it may cause disability. We help patients to obtain disability certificates. We tell them that there is no shame in being a leprosy patient.

IR- What do you know about leprosy

FG-H7- It is caused by *microbacterium leprae* bacteria. It affects the nerves and skin. When it affects the nerves, we categorise it as MB case and treat patient for a year. If there are 1-4 patches, then we categorise him as a MB case and provide treatment for 6 months.

IR- What do you know about leprosy?

FG-H8- It is caused by microbacterium leprae bacteria and it affects the nerves and skin, causing skin patches and numbness. We spread such information through posters and banners. The Pradhan should be able to identify the symptoms of leprosy. In 1985, nobody used to touch the water of Barhani. They believed in myths.

FG-H9- It is caused by microbacterium leprae. It affects the nerves and skin. Information is the best precaution. If timely treatment is not provided, it may lead to physical disability.

What are the symptoms of Leprosy?

FG-H1- Numbness, spots and patches. When a patient comes to the hospital with complain to skin patches, if in the check-up leprosy diagnose it affects the nervous system also if the treatment is not given in initial stage it may lead to disability.

FG-H2- The first symptom is that there is numbness in the patches. We can call it leprosy only if the patches are red, prominent and there is numbness.

FG-H3- In the first stage, patches appear which, with numbness and absence of sweat. When nerves get affected, then disability may be caused. Disability is the last stage

FG-H4- Spots appear on the skin which is lighter than the skin's color. These have numbness, loss of hair, and such patches do not itch.

IR- What are the symptoms of leprosy?

FG-H5- There are usually 1-3 patches on the skin. In the early stages, there be mild loss of sensation. These will be followed by complete numbness, absence of sweat, and loss of hair in the affected part. There may be pain and swelling in the hand. These are all symptoms of leprosy.

FG-H6- There are three types of symptoms for leprosy. 1- slightly white or copper color patches with numbness. 2- presence of microbacterium leprae 3- Nerves becoming tender and thick. Any two of these need to be present.

FG-H7- There are reddish yellow spots on the skin, which are partially numb. This disease affects the nerves and leads to disability

FG-H8- In leprosy, the patches appeared. The centre is pinkish and numb. These are the signs of leprosy.

FG-H9- The first symptom for leprosy is the sensation of tingling and numbness in skin patches and spots. These spots are copper color with redness. If timely treatment is not provided, it leads to pain and may ultimately cause disability.

FG-H1- It is caused by *microbacterium leprae*

FG-H2- It is caused by *microbacterium leprae*. It is caused by other person's coughing and sneezing.

FG-H3- *Microbacterium leprae* is considered the cause of leprosy

FG-H4- It spreads through *microbacterium leprae*

FG-H5- When an affected leprosy patient sneezes, he may transmit bacteria to another person's body. If a person has low immunity, he is susceptible to the disease.

FG-H6- Leprosy is caused by *microbacterium leprae*. It spreads through droplet infection. When an infected leprosy patient sneezes, he transmits the bacterial to the other person's body.

FG-H7- Leprosy is caused by *microbacterium leprae*. A person acquires leprosy when an infected case sneezes. The bacteria are transmitted to the other person when he breathes in. If the person's immunity is low, then the bacteria starts dominating.

FG-H8- It is caused by bacteria. If the patient starts medication early, then the bacteria are killed, if he doesn't then he becomes disabled.

FG-H9- Leprosy spreads through a bacteria called *microbacterium leprae*. It spreads through the respiratory route. The bacteria released through coughing and sneezing of an infected person may affect persons with low immunity.

IR- How is leprosy treated?

FG-H1- Earlier there was monotherapy its complete treatment called MDT.

FG-H2- Through MDT or Multi Drug Therapy. There are separate regimens for adults and children.

FG-H3- It is treated through multi drug therapy. Prednisalone also be given alongside. If it diagnose early it can be to cured early.

FG-H4- Through MDT. There are two types of drugs under MDT, one for adults and the other for children. In MDT one drug is Arsin and the other has dapsone and clofazimine. For PB patients, medication is for 6 months and for MB patients it is for 12 months.

FG-H5- Leprosy is treated through MDT. It is a combination of several drugs, that is why it is called MDT. There are two types of MDT, for adults and for children. And there are two classification of this medicine, one for PB which lasts for 6 months and the other for MB which lasts for 12 months.

FG-H6- Leprosy is treated through MDT. It is the acronym for Multi Drug Therapy. It can be classified into two types, one for PB and the other for MB. PB requires 6 months medication while MB requires 12 months medication. Alongside, patients are given a supporting drug like prednisalone. In some cases the leprosy patients may be provided physiotherapy or oil and water treatment. All this is a part of MDT.

FG-H7- Leprosy is treated through MDT. Its full name is Multi Drug Therapy. It is divided into two types, for PB and MB. In PB, medication lasts for 6 months and in MB it needs to continue for 12 months. For PB, 600 mg Arsin), 100 Mg Dapsone is given, while for MB, 300 mg clofazimine along with 100 mg dapsone as booster is given. They also provide medicines for gas.

FG-H8- Ever since MDT has come on the scene, treatment has become very effective. For PB the treatment lasts for 6 months and for MB, 12 months medication is required.

FG-H9- Treatment is provided through MDT. It has a combination of three drugs- dapsone, arsin and clofazimine.

IR- What is the responsibility for the community towards leprosy?

FG-H1- They have the responsibility to provide co-operation and to avoid myths as there are several myths about leprosy that don't sit with them they should remove these myths and should help them to take their medication.

FG-H2- They (the community) should behave well with leprosy patients, not discriminate or stop them, and if the patient faces any problem then they should co-operate.

FG-H3- If the community is aware then they can send persons whom the skin patches appears, to the hospital and encourage them for treatment. This is the responsibility of the society. They can encourage patients to continue medication and they should also say that it is not a result of any supernatural cause or a consequence of patient's sins but caused by a bacteria.

FG-H4- The community's responsibility is to encourage the patient to take his medicine. They should demonstrate the desire to know about the disease, about how it was acquired, so that it does not spread to others.

FG-H5- If the community comes to know about a leprosy patient, they should send him to the hospital so that timely treatment can be provided.

FG-H6- Society has a responsibility to not discriminate against any leprosy patient and encouraging them to take medication. These days the popular slogan is – MDT Khao, Kusht Mitao (Have MDT and eliminate leprosy)

FG-H7- The society has a responsibility that to take persons with leprosy to the hospital for treatment, behaving well with such a person and not discriminating against him. They should socialize with him, as this will encourage the leprosy patient to seek treatment.

FG-H8- If there is any person with leprosy, they should take him to to hospital and get it treated. They should come to the PHC and inform about such a person.

FG-H9- The society has a responsibility to bring anyone they find with leprosy to the hospital and get him treated. They should all stay together. Gandhi ji used to serve and care for leprosy patients.

IR- How do people in the community treat leprosy patients?

FG-H1- If the leprosy patient is normal then they socialize with him. If he has become disabled, then discriminate avoid contact. There is lack of right information. Sometimes even after giving the correct information, people attribute it to supernatural causes. This is their misconception.

FG-H2- I believe there is still great need to promote and publicize information. When people find out that someone is a leprosy patient, they maintain distance from the person. But if the person becomes disabled, he is made to leave his house. All this is due to lack of correct information.

FG-H3- Educated people are not affected. But in the context of Chandauli, much of the district is rural, and there are few educated people. When people come to know about the disability (of leprosy patient), they keep a distance, and look down on them. Even today people are disgusted by leprosy.

FG-H4- The educated community does not discriminate, but those who are not educated they do discrimination. If there is a leprosy patient, he is made live out of the society. Earlier they loathe more, but now there has been a slow increase in awareness among people.

FG-H5- The people in the community know that there are chances of getting infected by a leprosy patient. So they keep their distance from him. Even when they know that the person has been treated. If society aware that leprosy did not spread after being treated, they would not discriminate against the person.

FG-H6- The educated in the community do not discriminate. But if they are not educated they discriminate

FG-H7- The educated community treats leprosy as any other disease. They people who believe in old customs they keep feeling of hatred. Society should made aware not to develop feeling of hatred.

FG-H8- If it is a normal leprosy patient, then no one discriminates. But if he has a disability, then people discriminate. They believe in supernatural causes.

FG-H9- People in the community show good behaviortowards leprosy patients and encourage them to take medicines

IR- Thank you very much for sharing this information.

Declaration

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Dr . Pravesh Dwivedi

In-depth interview – Index FGD, Chandauli, baseline 2018, perception study

Code, FG:

1-- 26 Years –Female	Block –Chandauli
2- 34 Years – Male	Block – Chandauli
3- 55 Years – Male	Block – Chandauli
4- 26 Years - Male	Block – Sahabganj
5- 28 Years - Male	Block – Chandauli
6 –32 Years – Male	Block – Sahabganj
7 –42 Years – Male	Block – Chandauli

IR- Do you know any leprosy patient?

1. Yes, if someone is suffering from this disease named leprosy, spots and patches will be appeared like this.
2. Yes, I know one of my neighbors in my village have red spots like this, he is suffering from leprosy disease and taking medicines for it.
3. There is one person who is having pain at different parts of the body itching is also there in some parts means having pain at some place that's it.
4. No, I don't know, I mean I am suffering from this disease so I know only about me and when I got this leprosy disease I took the medication from the Barahani block where doctor told me it's a white spot will be fully numb means it's a leprosy disease and also told me about its symptoms too.
5. When I had problem in my legs I went to the doctor where he saw and told me that this is leprosy disease and its medicines will be given for continuous 6 months then I came to know about leprosy disease.

IR- Did you know any leprosy patient earlier?

6. No, was not knowing about this earlier but I was knowing that if there is any kind of stains or spots over the body then it has to be shown as it is leprosy disease.
7. Yes, I know, I will tell you about myself I have suffered from this disease 5 years back, I was not having any information that its medicines was also available, Once a man told me about a government hospital named Lehara. I went there and from there I was referred to Sahabganj block, when I came here I received the medicines and got well.

IR- Were you knowing about any leprosy patient earlier then this?

8. Yes, I know someone but he had taken the allopathic medicines from some medical store and now he is cured. If I talk about myself my legs got numb and color got change then I came to know that its medicines is been given in the block in PHC Chandauli from where my treatment is going on and 4 months since now there is huge relief.

IR- Were you knowing about any leprosy patient earlier then this?

9. Yes, my neighbor his whole head has turned white, yes half.

IR- What do you know about leprosy disease?

1. What I know about leprosy disease is that those who suffers from this disease then work, I mean that particular place gets patches and spots means when you look at that particular place it looks very disgusting.
2. The very first symptom is numbness of the skin but there is no pain in the wounds and these are the symptoms of this disease.
3. Leprosy disease is that in which spots occur at different places creating trouble then white patches are formed, when it is cured from one affected area it occurs at some other place, all this happens.
4. Leprosy means occurrence of spots and white patches, heating sensation in case of any wounds or injury and this sensation also remains while sleeping and numbness will also be there.
5. Leprosy is, if there is any kind of spots and patches or there is numbness then that comes in leprosy disease.
6. Leprosy is a non-communicable disease, it does not spread by touching sharing food, this happens through a bacteria. In leprosy disease numbness can be felt and can be recognized by the presence of white patches. Suppose white patches are not called as leprosy but white patches with the feeling of numbness is called as leprosy.
7. Initially the numbness starts and then slowly discoloration of the skin takes place, this is what happens.

IR- Can you tell me any of the symptoms of leprosy disease?

1. Yes, the fingers get distorted and gets numb, like nothing can be felt in that area whether you rub that area same is the thing in this also.
2. There are growth of patches either of yellow colour or white colour and also feels numbness, this has no effect while sleeping.
3. Means this is a naturally formed, happens through the nerves and because of infected blood.
4. White patches and numbness occurs.
5. Numbness is the symptom/sign of this disease, if there is any kind of patches or spots on the body that should be immediately checked as that can be the symptom of leprosy disease.
6. Leprosy is a type of disease in which nothing is felt on touching but in case of any injury or wound there is excessive pain. The symptom is if it got hurt a little then nothing will be felt but if it got hurt suddenly then excessive pain will be felt.
7. Similarly numbness, discoloration of the skin, rashes then wounds.

IR- Now tell how leprosy disease is caused?

1. Leprosy disease caused through bacteria while sneezing and coughing, because of the bacteria while sneezing it comes out and enters to the body of the other person.
2. Similarly it occurs because of sneezing, this disease is caused by micro bacteria leprosy.
3. After coughing when we breathe out the air it happens because of that, if we are sitting nearby or in front of the infected person.
4. Also caused by infected water, sneezing and also through the air.
5. We were unaware of the leprosy disease, but people here tells us that it is caused through the bacteria while sneezing and coughing.
6. Leprosy disease is caused by bacteria, if the bacteria is already in someone and we are in front of him and he sneezed then the bacteria will enter inside us and causes the disease.
7. I don't know.

IR- How is leprosy disease treated?

1. Through medicines.
2. Yes, through medicines.
3. Through medicines.
4. By having medicines, it will be cured.
5. Yes, it can be treated by the medicines.
6. The treatment of the disease can be done through the available medicine MDT, just one dose of it might kill the bacteria.
7. Yes, it can be treated in the hospital.

IR- What is the perspective of the society towards the person having leprosy disease, can you tell us? What is the responsibility of the society towards that person?

1. Their responsibility is to provide them proper medication so that they can get cured, stay healthy and others don't get in trouble/suffers because of them, it will be good for their family as well.
2. First of all they find that person inferior instead they all should collectively help them providing proper medication so that the disease do not spread further.
3. As I am suffering so I should take precaution for it, should consult the doctor and take medicines for it then only it will be cured.
4. Advice should be given to take medicines for it, so that it will end up without spreading and by doing of this the causing bacteria will washed up without spreading to others.
5. I don't know about the view point of the society but when I told others that there is some kind of disease after that their behavior towards me is same as before, it's responsibility of the society and has their own view point.
6. Its responsibility of society and even the people who had been cured from the disease to take the patient to the health facility by doing good behavior with them make them get better treatment and also tell them that this medicine is for free, they must told patients not hide the disease come forward for medicine.
7. Leprosy patient gets free medicines in the government hospitals so it is the responsibility to get the patient there, or we should take them there get them the medicines, they should not be hated, many people hate the people suffering from the disease so, they should not be hated and the government has various schemes for this.

IR – Do you know that the community behave differently with the people suffering from leprosy disease?

1. Yes, many people do that, they say that to take them for medication so that they can properly live with their family.

IR- Differently means how and in what other way do they behave?

1. Like some people think that they are suffering from the leprosy disease which is not good.

IR- How do you feel when the society shows this kind of behavior, what is your reaction?

1. It does not feel good.
2. Yes, they don't sit with us, they maintain distance from us and don't want us to come near them.

IR- Why do they behave like this?

1. They think that it can be transmitted to them that's why they maintain the distance.

IR- How do you feel when the people in the society do all this and give this kind of response to you?

1. We don't feel good.

3. Suppose someone is having leprosy disease, so who so ever is having knowledgeneeds to take patients to the district level doctors, people think that they will get this disease from the person who is already suffering from this disease, because of this they don't take them or don't tell them anything.

IR- Why do they do like this?

3. They do like this to make themselves safe from this disease.

IR- What are your reactions when they show this kind of behavior?

3- We people don't feel good,we think if I am suffering from this disease it will be cured and not spread to others. We take medicines.

4- They behave in a different manner, they maintain distance and are like why you are sitting near me.

IR- Which type of different behavior?

4- They maintain distance from us , they don't sit with us , they think it might be transferred from me or they don't come near to us, many people do like this and we really feel bad as we are not the ones responsible for the happening, people are very hesitant and are not like us. It can also happen to them so, we really feel bad when people talk like this.

IR- How do you feel when leprosy patients come and people behave with this type of feeling/attitude?

4- Feels really bad, they should be made aware and now common people are having the information related to it that it does not spread by touching or by sharing food.

5- According to me their behavior now also is same as before, I haven't seen any differences, and they see the person with loathe.

IR- What is the effect of their behavior that time on you as you are the patient?

5- This type of behavior should not be shown, it is a natural phenomenon it can happen to anyone and anywhere so they should not hate us but the culture/beliefs which is being followed over generations cannot be changed easily, it will change but it will take time.

6- I have never treated with differentmanner and even one of my friend told me to go and take medicines for it then I will be fine, he was also suffering from the same and now he is fine and I am also fine, I felt good that he did not say how will I go with you, no discrimination was done with me when everyone came to know that I was having leprosy disease, when anyone will ask then only I will tell them I myself will not go telling them about this.

7- See this type of disease should be hated not the patient, but society abandonthe patient having this disease which is not right..... the patients should be taken to the hospital.

IR- Which type of distance they maintain?

7- They think that they might get disease as well now also people say like this so, when they come to know they maintain distance with that leprosy patient.

IR- When people distance themselves creating discrimination, how do you feel then?

7- I really feel bad, everyone feel bad, and this is actually not good.

IR- will you reveal about your disease to others in the community?

1. Like I am suffering similarly someone else might be suffering, its medicines is available, can go to the government hospital and can take the medicine from their so that it will not cause to others, that person will get well, no one will get troubled and everything in the society will also stay fine.
2. I will not reveal it in the society but will go and tell in the hospital that I am suffering from leprosy disease.

IR – Why will you not reveal it to the society?

2- Because everyone will hate me, if I will tell them then they will stay away from me rather than staying close to me, they will not eat with me that why I will not tell them and I will go to the hospital tell the doctor take the medicine so that it is cured.

3- Why will we not tell them, when we will tell them then they will run away from us so, will go to the doctor take the medicine cure the disease then will reveal in the society that you can go there for the medicines and you will get well.

IR- You would like to say this and what else information would you like to give to the society?

3- Like we came to know similarly if someone has the information can tell others.

4- Yes, I would like to share so that it will not happen to others in the society, will tell to have MDT and remove the leprosy disease so that it will not spread, free medicines are given in the government hospital that will cure the disease and it will also not spread at home.

5- Yes, I will tell about the disease and I have also told about it and like I am having this leprosy disease they should not suffer from it, if they see any kind of the signs or symptoms they should go for the immediate checkup in the government hospital.

IR- Why do you want to tell the society?

5-Because if they will have the information then they will get the treatment on time and it will not get transferred to other and they will not get the disease.

6- Yes, I want to tell to the society and if someone is suffering from then I myself want to take the person and tell that this medicine can cure the disease so that the person can further tell others.

IR- What is the reason of revealing this in the society?

6- I want to reveal it to the society because this is very disgusting disease, I want to tell it so that our society stays healthy without getting disturbed with any kind of disease.

7 Elder people have a mindset of hiding about this disease but this is not right, it should not be kept hidden rather complete treatment should be done.

IR- Why would you like to tell the society?

7- So that the disease should not spread over larger area as it can be treated, we people think that this disease cannot be cured but it can be cured, just before it spread over larger area people should go to the hospital for taking the medicines.

IR- Have you heard about PEP++?

1. No.
2. No.

3. Yes, I have heard in Lucknow.
4. No, I have also not heard about it.
5. No.
6. No.
7. No.

IR- You people came here and gave your precious time, thank you so much for that!

Declaration

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Dr . Pravesh Dwivedi

In-depth interview – Contact / Age – 45 Years / Gender – Female / Block Name – Chandauli / District Name – Chandauli – C1F

IR: My name is Chandra Bali Maurya to eradicate leprosy disease I am doing interviews on the provision of medicine means to facilitate the medicine of leprosy disease, it has been started in your area, I would like to take your suggestion on this, are you ready to share information, and whole interview will take 15 to 20 minutes are you ready?

C1F: Yes, I am ready.

IR: Could you tell me something about leprosy disease?

C1F: No, I don't know about leprosy disease.

IR: ok, could you tell me for what reason this disease can occurs means what could be the reason due to which he caught the disease?

C1F: I don't know how this disease occurred to him, it's kind of white spots on skin and some people say that she must have touched infectious person white spot that is why it occurred that is what we thought

IR: Ok, ok

C1F: He might have gone to the doctor and might have told to the doctor that the area became numb, then doctor did check-up then we came to know that he is suffering from leprosy disease.

IR: ok means numbness and spots

C1F: Yes. He is taking pills for spots to avoid problem as I am a girl and it will create problem for me also?

IR: From where did you get information regarding leprosy disease?

C1F: When we came back with check-up then we came to know that this is leprosy disease.

IR: ok when he got the disease then you came to know about the disease.

C1F: Yes, yes

IR: He is suffering from leprosy disease?

C1F: Yes

IR: It seems like you have not listened about this disease in your school or college.

C1F: Sir I listened about the white spot, a man was suffering from it.

IR: Have you listened about the disease during you studies

C1F: Yes, I have heard about it but how is it, what is it? I didn't know about it.

IR: From where have you got the information regarding the leprosy disease?

C1F: Leprosy disease awareness is also broadcasted on the Television.

IR: Ok, ok

C1F: Yes, this is leprosy disease.

IR: Could you tell the thoughts the community is having regarding the leprosy patients

C1F: In our village there is no discriminative thought regarding the leprosy patients, even in Muslim caste there is no discrimination.

IR: Ok there is no discrimination regarding anything?

C1F: Everyone says that this is just a disease it will be cured soon.

IR: Does this disease affect you in any manner?

C1F: No not at all.

IR: Does it affect the society?

C1F: No, it does not affect.

IR: if the symptom of leprosy is visible then does it make any difference in behaviour of your neighbours, family members and relatives or at society level

C1F: No there is nothing such in our family

IR: Does this leprosy disease can occur to anybody?

C1F: see, I don't know about this but people say that this is a contagious disease.

IR: Does this leprosy disease can occur to anybody

C1F: no this is not so this leprosy disease can't be occurred to everyone.

IR: If there is medicine available which helps to prevent people from leprosy disease then how would you feel? The people who are getting infected by leprosy disease if they get cured by one medicine then how would you feel?

C1F: I will feel good I will definitely go to take that medicine.

IR: If the medicine of leprosy made available then how would you feel and what will be your thought?

C1F: My thought is that this disease may not be occurred to anyone.

IR: Ok, ok

C1F: and who so ever is suffering from the leprosy disease may cure from the medicine.

IR: Ok, means you will take that medicine?

C1F: Yes, for sure I will take.

IR: Ok, thank you for all the information you have given.

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Dr . Pravesh Dwivedi

In-depth interview – Contact / Age – 40 Years / Gender – Male / Block Name – Chandauli / District Name – Chandauli - C2M

IR1 - My name is Meenu singh. I am interviewing people regarding the provision of medicine to stop leprosy. Are you interested to share your thoughts with us .Any knowledge you want to share.

C2M - I used to take medicine from health centre .

IR - Alright! It will take some time from you to tell me about this. Can you give me some time for the interview about this disease, leprosy ?

IR2 - It will take 20 to 30 minutes.

IR1 - Just only for a while. It will hardly take 20 to 30 minutes . Can you give some of your time?

C2M - What?

IR1 - I will ask you some questions .

C2M - Oh !

IR1 - It means I will take some information about this disease . Can you give some of your time ?

C2M - Yes ! I can .

IR1 - Ok then ! Your name ?

C2M - Munib kumar

IR1 - Ok ! What is your relation with patient ?

C2M - He is my brother.

IR - Your brother . Ok can you tell me something about leprosy ?

C2M - Leprosy. . . I do not understand .

IR1 - Ok .

IR2 - The disease that your brother have. . . . Do you know anything about that ?

C2M - Yes ! He has shivering in his leg .

IR1 - Shivering in leg .

C2M - Hmm. . . .

IR - Shivering . . . What else ?

C2M - His two fingers are Sensationless .

IR1 - Sensation less ok . It means that you know about the symptoms of this disease . As you just now told that his leg is Sensation less .

C2M - Yes . My brother was telling me .

IR1 - Yes .

C2M - So his leg remains Sensation less .

IR1 - Ok .

C2M - He leg shivers when he walks .

IR1 - He feels Shivering .

C2M - Yes ! Yes !

IR1 - ok .

IR1 - Hmm then do you know anything about the reason of this disease ?

IR2 - Mean how did it happen ? What is the reason ?

IR1 - Is your brother knows what is the reason ?

IR2 - Do you have any idea that how it happened to your brother ? Please tell something .

C2M - He went to banaras , he thought it was sprain in his leg . His leg swelled then he got the plaster done at health centre chakia .

IR1 - Ok .

C2M - Yes .

IR1 - Then sensation less of his leg , how and when did it happen ?

C2M - It was 2017 .

IR1 - It happened in 2017 ?

C2M - Huh .

IR1 - Ok .

IR2 - In 2017 , what was the month ? It was summer , winter or marriage season ? Do you remember something about the season or month ? Any idea ?

C2M - It was summer .

IR2 - Summer

IR1 - It was summer .

IR2 - Ok .

IR1 - Ok so from where did you get the information about leprosy ? I mean from where did you know about leprosy ?

C2M - Dinesh ji from health centre came .

IR1 - Ok

C2M - So he was telling . . .

IR1 - Yes .

C2M - that white spot. . . .

IR1 - Yes .

C2M - and Sensationless - ness. . . .

IR1 - Yes .

C2M - must have been there .

IR1 - Ok it means that you got knowledge from health centre .

C2M - Yes .

IR1 - Hmm yes . Can you tell me about the thought of people of your community about leprosy ?

Can you tell me about perception of the people about leprosy in your community .

C2M - Hmm .

IR1 - The place where you live ,the people of your neighborhood , what do they think about this disease ? Can you tell something about it ?

C2M - No . They all think fine .

IR1 - What do they understand ?

C2M - Very well .

IR1 - Very well ?

C2M - Yes .

IR1 - You need not to be worried . Your all information will be safe .

C2M - No ! No ! Not worried .

IR1 - We will keep the information secret and whatever we are asking or whatever we are recording , we will remove it . It is only for information purpose .

C2M - Ok Ok .

IR1 - And whatever information that you will provide us , it is very important for us . We will spread the awareness among people . If we will be able to know something then it is good right .

C2M - Yes Yes .

IR1 - It will be good for our country and society.

C2M - Yes .

IR1 - Now you should tell us at ease that you said very well. . . . What exactly people think about this disease ? What kind of feeling people have about leprosy .

C2M - Their thoughts are good .

IR1 - They have nice feelings .

C2M - Yes .

IR1 - It is a very good thing .

IR2 - Have you ever found any change in anybody's behaviour because of this disease , leprosy ?

IR1 - When you brother faced this problem .

IR2 - Did people say something ?

IR - Some people. . . . Mean did anyone behave in a different manner with you ?

C2M - No ! Nothing like this have happened till now .

IR1 - Nothing like this .

C2M - No .

IR1 - They did not behave differently .

C2M - No .

IR1 - Ok whenever you visited someone at their home , did you face any problem at that time ?

C2M - No .

IR1 - Did it cast any effect on you when you came to know that it could be synonyms of leprosy ? How you felt when your brother got this disease ?

C2M - Yes I will surely feel .

IR1 - Yes .

C2M - I felt . No !

IR - No ?

IR2 - Mean ?

IR1 - When your brother. . . .

IR2 - No ! When your brother got disease ,

C2M - Yes .

IR2 - then how you felt ?

IR1 - What were your feelings ?

IR2 - Yes that your younger brother got this disease . This madam is asking you about your feeling .

C2M - Oh .

IR2 - So how you felt ?

RE - This is what you are trying to say that how I felt , how did it happen , it happened because of food or something else ?

IR1 - Ok so you thought about how it happened or not happened.

C2M - Yes .

IR2 - How you felt mean?

IR1 - Mean that how you felt in your conscience about this disease, how you felt , what kind of perceptions built up in your mind when your brother got a disease like this ?

IR2 - You would have felt something. As people become uncertain about the future and usually think like "what will happen now " .

C2M - Yes Yes .

IR2 - How ?

C2M - I tried to figure out how it happened and how will my brother earn a living now .

IR1 - Can leprosy affect all type or age group of people ? If not then why not ?

IR2 - This disease. . .

C2M - Yes .

IR1 - The disease of leprosy. . . .

IR2 - The disease that madam is referring to. . . .

IR1 - This. . . .

IR2 - Disease can also affect other people around you .

IR1 - This disease can cast effect on people living in your neighborhood.

IR2 - Madam is saying that neighbors can get infection of this disease.

IR1 - This disease can spread means it can cast effect.

RE - No ! It can not spread if medicine is available.

IR1 - Oh .

C2M - Yes .

IR1 - It will not spread if medicine will be available . How will you feel about availability of a medicine which can help people save from leprosy ?

IR2 - If government provide you that medicine .

C2M - Yes .

IR2 - When people will consume it (medicine) in order to avoid leprosy , how will you feel ?

C2M - I will feel good .

IR1 - You will feel good . So would you also like to take that medicine ?

C2M - Yes I used to take my brother (to health centre) for medicine .

IR1 - Ok good .

C2M - I used to bring medicine from health centre whenever he forgot .

IR1 - Ok .

C2M - Yes .

IR2 - If

IR1 - If this medicine is being given to you , would you like to take this medicine ?

C2M - Sir I can have medicine only if I have disease.

IR1 - Have disease. . When?

IR2 - Mean?

IR1 - If you do not have disease then ?

C2M - Then what will I do by taking medicine ?

IR1 - What will you do !

IR2 - Suppose you are given such a medicine . . .

C2M - Huh !

IR2 - The disease that can happen even after 4 or 5 years . . .

C2M - Yes .

IR2 - to finish that disease if we provide the medicine in advance , then will you consume it ? Suppose for example , if someone can get disease after 2 to 4 years , then he has medicine in advance for safety .

C2M - Hmm.

IR2 - So will you have medicine so that this disease does not happen to you in future ?

C2M - Yes why will I not eat .

IR1 - So it means that if there is any chance of this disease in future then you will consume medicine for sure .

C2M - Yes .

IR1 - Ok good .

C2M - Yes .

IR2 Ok brother thanks . Namaste .

IR1 - Thank you sir . Brother .

IR2 - We felt good that we could get your important time .

C2M - Ok .

IR2 - Ok brother please sit .

IR1 - Please come brother. Brother you please be seated .

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Dr . Pravesh Dwivedi

In-depth interview – Contact / Age – 40 Years / Gender – Male / Block Name – Chahaniya / District Name – Chandauli - C3M

IR- Hello my name is Kamlesh Kumar I am from an organisation named Netherland leprosy relief, an interview will be conducted of you by this organization, the study which will be done by that we will come to know that how many leprosy patients are there in district Chandauli and now we will ask you some questions which will take around 25 to 30 minutes.

C3M - Yes....Yes

IR- Do you have time?

C3M -Yes, I have.

IR-You have to answer only those questions in recording about which you have information and this recording will be kept confidential this will not be told to any other person. This is being done for the purpose of reporting. I am going to read out some lines to you.

C3M - Yes

IR- I am announcing that I clearly know about this study that what it is about and what the study is and would like to understand the mode and motive of study. The questions I was asked were all answered by him and now there are no questions. I understand that during interview the questions which I have answered will not be shared by anyone and this recording will only be used for study purpose.

C3M -Yes Sir

IR- I am agree with this written form as you said you are agree and there is one more thing in this if you don't understand anything or don't know the answer of any question you can inform us that you don't know or don't understand. You are not bonded to answer all questions.

C3M – Yes

IR- Whenever you want you can exit from recording.

C3M – Ok

IR- Do you agree?

C3M - Yes

IR- I am interviewing to eradicate leprosy disease for the provision of medicine which will be going to start in your area. Are you interested to give your opinion about this?

C3M – Yes, Sir why not

IR – Ok what is your relationship with patient?

C3M - He is my brother

IR- Ok my question to you is that is the contact person is alright now? Can you tell me about leprosy disease how it occurs and what its symptoms are?

C3M – Sir, white spots occur and there is numbness in skin all over the body.

IR- Ok, tell us what all information do you have about leprosy disease?

C3M - Skin gets numb and white spot types occur this all happens.

IR- Ok, what are the reasons from which it occurs?

C3M - I don't about this that due to which reason it happen.

IR- Due to which reason people suffer from this leprosy disease

C3M - it might occur from lack of blood circulation due to which flow of blood stops in affected areas.

C3M – Symptoms are, first of all, white spots occur and then numbness occurs in skin and white spots also gets numb.

IR-Ok

C3M – Itching might occur.

IR- Ok my next question is that from where you got information about leprosy disease and how you come to know that this is called leprosy disease?

C3M - I came to know about it by leprosy patients.

IR- Do you meet with leprosy patients?

C3M -Yes, I met with patient.

IR-Ok when did you come to know about your disease?

C3M - Sir, when he started telling me then I came to know.

IR- How many days before?

C3M – It's been a years.

IR- Then what did he say to you, what he say to you about leprosy disease?

C3M – He they showed me that the spots were becoming enlarged but after taking medicine its decrease in size then we come to know that this is leprosy disease in skin diseases.

IR- Ok, did you know about the leprosy disease earlier?

C3M –Sir there is village nearby us named Nadi gram from there we took patient to the centre.

IR- Did you take them to the hospital?

C3M –Yes, the doctors sit two days in a week there, we use to take patient and the patients who didn't come to hospital we searched them and took them to the hospital.

IR-Yes

C3M - We use to suggest them that they should go to the hospital then also if they are not able to go to the hospital then we take them to the hospital this much we do

IR- Ok I mean to ask that initially from where did you get to know that how leprosy disease occur

C3M –Yes Sir I am telling you, we came to chahaniya here we got information about leprosy disease, doctors from chahaniya went to our area to our subcentres in saidpur and they also did advertisement there, they went there in a vehicle, they told that if you find any leprosy patient so take them to our sub centre or give us information.

IR-Yes

C3M - We will provide free medicines in our centre these all things were told there.

IR-Ok

C3M –So the disabled children who were not able to go to the centre by themselves we took them to the centre.

IR- That means you get the information from health centre for the first time.

C3M - Yes Sir

IR-Ok my third question to you is, can you tell me that what are the thoughts or perception of your community people about the leprosy patient who are in your community?

C3M – Look Sir, it is like if a person gets infected by leprosy disease then he wants to get cure and he tries to get cure and some people hide also.

IR- Ok does people hide also?

C3M –Yes, usually women hide, they think that if they will tell that they are suffering from leprosy then their dignity will fall or goes down it is something like that.

IR- Ok, do men also hide this thing or only women use to hide this?

C3M -No, it is like some men become careless that at the moment infection is less and will be cured by itself then so it is equal to hiding.

IR- Ok which type of people hides the most?

C3M - Women

IR- Ok the people of which community hide the most, which caste people hide about this?

C3M –Look the people who are in veil they do this work more means they hide the most as when new bride come to their house who is already having this disease the family people use to cover it and when it becomes more then they say that we have become disable and are not feasible to walk, when hand and leg stop working then they give information about disease.

IR-Ok I have one question for you that does it make any difference to you if someone is having sign and symptoms of leprosy disease or not

C3M – Yes

IR- Leprosy disease is there or not how does it make difference?

C3M – If there is sign and symptoms of leprosy disease in person then person will become the patient of leprosy disease and it is important to treat the patient by providing him medicine, and it is important to tell him about treatment, it is also important to give them suggestion.

IR-Ok

C3M – Yes Sir

IR- Means it will affect you.

C3M – It will affect Sir.

IR- Ok my next question to you is that does leprosy disease can affect all types of people

C3M - Yes Sir, it can affect anyone. Whether they are male or female anyone can be affected.

IR- Yes, whether they belongs any religion or caste.

C3M - No, there is no relation of disease with caste or religion, disease has no connection with it whether the person is from any caste or religion.

IR- No, some people have mentality that this disease maximum occurs in lower community people like people from SC, ST community people.

C3M – No, sir there is problem in peoples thinking disease does not identify any person caste or any religion

IR- Yes, Ok

C3M – Yes, Sir

IR- Ok, my next question to is that, for the help of people if the medicine is available to prevent them from leprosy disease then how would you feel?

C3M - Yes

IR- Means in future this disease will not happen to anyone then how would you feel?

C3M - I will be very happy Sir that people will be cured from this leprosy disease.

IR- Ok, if the medicine for this disease will be provided for free would you like to take it?

C3M - Yes, I will take it and will use it also.

IR- Why would you like to take it?

C3M - By taking those medicines I will distribute to the people who are suffering from leprosy disease in my areas.

IR- Ok, you will distribute it in your area but why would you use it?

C3M - No, then what is the meaning of using it for me then I would rather not take it.(hindi is bit confusing)

IR- No, suppose that it is infectious disease and it spread from one person to another then by now you will not get infected by it?

C3M - Why not, I could be infected

IR- So would you like to take medicine?

C3M - Yes

IR- Ok very good answer, answers that you gave were very important and it was really very nice talking to you.(hindi is not clear)

C3M - Yes

IR- Thank you so much, for your valuable time that you gave and thank you so much for talking to us.

C3M – Good bye

IR- Ok, good bye.

Declaration

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Dr . Pravesh Dwivedi

In-depth interview – Contact / Demography / Age – 36 Years / Gender – Male / Block Name – Sakaldiha / District Name – Chandauli – C4M

IR: My name is Ravindra Nath Sharma and I have come from NLR India.

C4M: Yes

IR: Who is working for eradicating leprosy, collaboration with Government of India.

RE: Alright.

IR: We want your support too.

C4M: Alright.

IR: Are you ready for it

C4M: Yes, I am

IR: It will take 30 min of yours.

C4M: Ok

IR: Whatever conversation we will record will be kept confidential.

C4M: Ok

IR: And after that if you don't like the conversation you can leave the conversation any time.

C4M: Ok

IR: If you are ready so please sign the consent from.

C4M: Ok,

IR: what is your name?

C4M: My name is XXXX.

IR: Ok Mr XXXX tell me something about leprosy disease?

C4M: ok

IR: Could you tell me about this leprosy disease and how does this disease occur?

C4M: Leprosy disease is a skin disease in which skin get dry from inside.

IR: Ok

C4M: This is all

IR: alright

C4M: yes

IR:Anything else?

C4M: It occurs in the blood and blood become (ATHUAA).(Hindi is not clear)

IR: Do you know the cause of this disease?

C4M: I don't know the reason and cause of this disease but once it occurs then only we came to know.

IR: Do you know the symptoms of this disease?

C4M:In the symptoms of this disease hand and legs become weak and this is called leprosy disease.

IR: Now tell me from where and from whom you get information of this disease?

C4M: I went to the facility I met with doctor there so he told me he infected with leprosy disease and he will get cured through medicines.

IR: So when did you get this information?

C4M: We got information from facility when we met with Doctor then I got information about the disease. We underwent treatment for long when we don't know about this disease.

IR: What did doctor tell you or what information does doctor give about leprosy?

C4M: Doctor told us to take medicine and to have proper diet so thats why I am having the medicines.

RE2: Doctor provided 3 months medicines

IR: He encourages you to tell.

C4M: Yes

IR: Did you know about it previously, from where you learn about it?

C4M: No Sir when I went to facility then I get to know that this is leprosy disease but other doctors were not able to tell that what disease is it.

IR: Could you tell me about the behaviour of the community

C4M: Ok

IR: Like what kind of perception does the society have about the leprosy patient?

C4M: They behave well.

IR: Yes

C4M:They felt it normal not bad.

IR: Yes, do you get affected if leprosy disease symptoms occur to anyone?

C4M: Ok

IR: will it affects you?

C4M: No it will not affect me.

IR: Does leprosy disease can affects anybody?

C4M: No

IR: Why not give some reasons?

C4M:It is not spread everywhere, leprosy occur due to filth.

IR: If the medicine for leprosy would be provided to you for the help of leprosy patient

C4M: ok

IR: how will you feel?

C4M: I will feel good;we will have medicine and get well soon.

IR: Would you like to takemedicine?

C4M: Yes, sure why not if I will not take medicine how will it get cured.

IR:Ok, you will take medicine too, the campaign which government is conducting to eradicate leprosy the government is providing medicine too to help in this campaign, what do you feel for this campaign?

C4M:I feel good for this, public will be fine through this, this is the only motive.

IR: Ok when medication will be providing, discussion will be going on with people then as a result of these, people's view towards leprosy patient will be change or not change?

C4M: Yes the change will occur surely

IR: What kind of change?

C4M: Proper change will be occurred if proper treatment will be done.

IR: Do you want more information regarding leprosy patient?

C4M: I didn't get more information regarding leprosy patient but if I get more information I will tell other regarding the leprosy and by observing symptoms of it I will tell anyone he or she will suffering from this disease.

IR: Do you want to tell us anything else?

C4M: Sure I will share with others, and then only they should know that I am suffering from this disease.

IR: Ok, fine it was nice talking to you.

C4M: Namaste!

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Dr . Pravesh Dwivedi

In-depth interview – Contact / Age – 30 Years / Gender – Female / Block Name – Sakaldiha / District Name – Chandauli - C5F

IR - Namaskar my name is Chandrabali maurya and I am interviewing people regarding the provision of medicine for eradication of leprosy. I am interacting with people , I am interviewing them. Leprosy that has occurred in your area , are you willing to share your opinion about it?

C5F - Yes.

IR - Ok. It can even take 15 to 20 minutes so whenever you want , you can deny to answer a particular question and not answer to questions you do not feel like answering them. Ok now can you tell me about leprosy? Please tell me. Can you speak a bit louder as your voice is very slow.

C5F - A few white spots appear.

IR - ok ok.

C5F - Area where spots appear becomes Sensationless.

IR - Oh ! ok.

C5F - Even Pinching at that area does not feel to the patient , affected area remains Sensationless.

IR - Ok. What else can be the reason? Do you have any idea?

C5F - This happens because of infection caused by virus.

IR - Ok. So does it happen because of infection?

C5F - Yes.

IR - Ok. Can anything else be the reason of its occurrence?

C5F - I do not know.

IR - Ok. So you do not have any idea?

C5F - No.

IR - What are it's symptoms? As you told about white spots and?

C5F - Yeah white spots along with Sensationless skin.

IR - Ok.

C5F - yes and some disability also occurs in hands like a leper.

IR - Oh.

C5F - Huh.

IR - Mean at advanced stage?

C5F - Yes.

IR - Do legs and hands start to turn disable?

C5F - Yes Yes.

IR - In your neighborhood as you said just now leper....

C5F - Yeah leper.

IR - Ok so do you people call this disease by other names also?

C5F - No we do not call a patient as leper but he turn into a leper till last of his disease as his face swells and the whole face looks bad.

IR - Ok so does this disease is known as leprosy only? As you said leper , so what people of village name this disease?

C5F - No we call this disease as leprosy only.

IR - Yeah that is what we call it but what people call this disease in village?

C5F - Yeah some people use word " leper " for it.

IR - Ok so people also use word leper.Ok so this disease happens at what age? Or it happens to people of all age , or people of young age or old age? How it happens? When it happens? Do you have any idea about it?

C5F - No I do not have any such idea. But patients of 15 to 18 , 20 , 25 age group are found more.

IR - Oh ! So does it not happen among children?

C5F - Why does it not happens among children. There is a child patient in my neighborhood only.

IR - It means it happens to people of all age group.

C5F - No.

IR - This disease has nothing to do with age. Ok fine now tell me , from where have you got the information about leprosy for the first time?

C5F - I got information from my own village.

IR - Mean when and how you got information?

C5F - Sir before 3 to 4 years.

IR - Ok so you got to know that there is disease named leprosy , before three years.

C5F - No no I knew about it even before that but I did not see any patient...

IR - Mean a long time ago when you were in school or when you were at your parent's home or in a gathering....

C5F - No when I was at my parent's home , there people used to call such patients as leper , but when I came to my husband's place....

IR - Yes.

C5F - then I came to know about it.

IR - So you heard that people use word " leper " , when you were at your parent's home.

C5F - Yes Yes.

IR - What you used to think about it as whether it was a disease or anything?

C5F - Sir I used to understand it as leper only though I could not get to see any patient of leprosy during that time , so I had no idea about how such patients look but I have seen many patients after coming here.

IR - Ok so people used to call patients as " leper "?

C5F - Yes.

IR - Ok so people used to consider it as a disease or they considered it as a spell or disaster?

C5F - Yeah people used to consider it as a problem related to spirit or ghosts.

IR - Oh so people used to see it as a ghost spell?

C5F - Yes Yes.

IR - Ok so at that time the people of your village....

C5F - Yes.

IR - they would have told you , then you could know.

C5F - Yeah they told me that it is leprosy.

IR - Can you tell about the thoughts and perception of the people of y community about leprosy? As you are saying about that leprosy patients and people take it as sine ghost's effect , so what society think about it? Whenever you go out and meet people , so what are their thoughts about? How people perceive this disease in your opinion? As you are telling that....

C5F - People see by this perception that this disease happens because of some ghost effect.

IR - Oh so this what they perceive?

C5F - Huh yes yes.

IR - Disease because of ghost...

C5F - They have this illusion.

IR - Ok they have illusion.

C5F - Yes people think all this.

IR - Ok so whoever suffers from this disease , people do....

C5F - Yes.

IR - not visit them. Is it the case?

C5F - Yes there are many people who think like this but situation has improved a lot from past.

IR - Is there any difference from past?

C5F - It improved a lot sir.

IR - Ok so it improved a lot from past.

C5F - Yes.

IR - Will it cast any effect on you , if anyone in your home have symptoms of leprosy? Mean , what is your relation with the patient in your home?

C5F - He is the son of my sister in law.

IR - So he is like your son.

C5F - Yes.

IR - So does it cast any effect on you that he has this disease?

C5F - No.

IR - When you come across a news about somebody's suffering from leprosy , what type of thoughts come in your mind?

C5F - No nothing like this.

IR - I am asking about your thoughts.

C5F - No. I do not think anything at such time.

IR - Ok. What else are it's symptoms or signs?

C5F - Sir as I already told you that white spots occur which become Sensationless after sometime.

IR - Ok.

C5F - Swelling also occurs. A girl had infection on her face , her whole face swelled completely.

IR - Ok. Your were telling that someone got this disease in your home and it is very light. Suppose if you are going to a tea stall....

C5F - Yes.

IR - And as soon as you start enjoying your tea , a leprosy patient , a little disabled , as were you were using word " leper' according to old time....

C5F - Yes.

IR - If such patient comes and sits beside you , how will you feel?

C5F - What kind of feel , his infection will not catch me.

IR - Ok.

C5F - I will have my tea and move after my purpose serves.

IR - Ok so it will not cast any effect on you?

C5F - Yes.

IR - Ok alright. Can leprosy affect all kind of people? Mean can people of all age group suffer from leprosy?

C5F - Yes.

IR - Ok of all age group?

C5F - Yes.

IR - No matter what kind of person is?

C5F - Yes.

IR - Ok how will you feel about availability of a medicine to save such people from leprosy?

C5F - I will feel good.

IR - Mean we are introducing a medicine , by which no body will be affected from leprosy after consuming it.

C5F - It is a very good thing sir.

IR - That medicine will be available for free but people have to wait in a line at government hospital in order to get medicine.

C5F - Yes.

IR - So will you go to collect the medicine?

C5F - Yes , if someone visits home , or I have to go to hospital , but I will take medicine.

IR - No i am saying that the medicine will be distributed in hospital in a line so will you also go to collect it?

RE - Ok if it will not be available at doorstep , I will have to wait in a line , or wait for even two days , even then I will collect medicine because I want my patient to get well anyhow.

IR - Ok.

C5F - Yes.

IR - So will you also take?

C5F - Yes.

IR - How will you feel?

C5F - I will find it problematic but if suffering is there then the only option is to bear it.

IR - Ok. Anything or any thoughts about you that you want to share?

C5F - No.

IR - Ok Then thank you.

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Dr. Pravesh Dwivedi

In-depth interview / Health care worker / Age – 45 Years / Gender – Male / Block Name – Sahabganj / District Name – Chandauli - H1M

IR: My name is Rajeev Singh, may I know your good name please?

H1M: My name is XXXXX

IR: On which post you are in(working)?

H1M: I am holding NMA post.

IR: From how many years you are working in sahibganj?

H1M: It's been around 10 years I am working in here.

IR: Have you ever got training on leprosy?

H1M: Yes, I got 4 month training earlier.

IR: Where did you get that training?

H1M: At Training centre of Shivpur .

IR: What do you know about the leprosy disease?

H1M: Leprosy is caused by *mycobacterium leprae* it can also be caused by close contact with leprosy patient, suppose if leprosy patient sneeze in front of me so the bacteria will enter in the body from breath if the immunity of the body is good then the bacteria will die and if the immunity is bad then it will enter the body and after the 8-10 years the symptoms of the leprosy starts appearing.

IR:Have you given such information to the people.

H1M: Yes, now we organise quiz in schools from which all children have come to know about the leprosy disease and in villages also we are spreading information about leprosy disease .

IR:If any Patient for the first time comes here to you and he has not taken the treatment then could you also get infection?

H1M: No, this disease can't be spread in first meeting;it will spread only frequently meeting with the leprosy patient. This disease can be spread only if the patient does not get treatment that is why it is said "Precautionary information about the leprosy disease is protection".

IR:What are the symptoms of leprosy disease?

H1M: First of all, mark will appear on the body those marks will be of rust(copper)colour or light colour from the body tone, first of all little numbness will occurs but later on full numbness will occurs, sweating will stop on that area, hair will fall from that area bacteria will destroy that area sweat gland.

IR: From where did you get all these information?

H1M: I get these information from training centre in chowka ghat, leprosy hospital is there,they show leprosy patient their practically.

IR: Do you know any leprosy patient around you?

H1M: Yes, in my childhood there was I washer man he was a leprosy patient.

IR: Do leprosy patients come to your centre?

H1M: yes

IR: Are you involved in diagnosis or treatment of leprosy disease if yes, then how?

H1M: first of all the check up is done of the patient if the report come positive then we register the patient and then medicine is provided to the patient.

IR: How much time you give to the patient?

H1M: We first examine the whole body of patient where the marks are then we do the check up.

IR: Do you decide that patient is suffering from leprosy disease?

H1M: No, doctor diagnoses it and tell us, we only find out PB and MB cases.

IR: How can you come to know about PB and MB?

H1M: If 5-6 patches is there then it is PB case and if more than this then MB case.

IR: when any leprosy patients come to your centre then what kind of behaviour your staffs do?

H1M: We do same and courteous behaviour with everyone we don't have awful thought about leprosy patient. It's been 20 year of my services and I have met with around 8000 patients, earlier I had been posted in the hilly area for 4-5 years in the area the number of patient was more.

IR: Will it make any difference to you if a person is having sign and symptoms of leprosy disease?

H1M: Normal treatment is given to the patient without any discrimination; I deal with the patient with a good manner if we do discrimination then how we will do treatment its being 30 years I am treating patient. Until we don't touch that patient how will we diagnose that the patient is suffering from this disease and his nerves are damaged.

IR: When you touch the leprosy patient during treatment how do you feel?

H1M: I diagnose patient properly by touching them to make sure that that what we diagnose is correct and proper and to avoid mistakes.

IR: Do you know about PEP++?

H1M: Yes, in our meeting discussion on PP++ was held several time I don't know much about it.

IR: Do you want share any information with me?

H1M: If any patient came to know about the leprosy disease in primary stage and start treatment then that patient will not be disabled, through advertisement and to spread information in the school we are trying conveying information in all the houses through children.

IR: Thankyou! for all the information.

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In-depth interview – Health care worker / Age – 40 Years / Gender – Female / Block Name – Sakaldiha / District Name – Chandauli – H2F

IR-We are supporting leprosy patient InLeprosy eradication program and we also want your support in this. It will take your around 30 minutes time, are you ready for this?

H2F - Yes Sir, my name is XXXXX. I am working as BHC at Sakaldiha and I am completely agreed with this program.

IR- Can you tell us about leprosy disease?

H2F - Yes Sir I can tell you, because of air pollution the environment have got polluted and due to this skin related problem get starts. It is a bacterial disease due to which slowly type of spot or rashes occur on skin, and skin got numbed which looks dirty and it is gradually effects our nervous system .It causes more effect on nerve system because this disease occurs on skin only.

IR– can you tell us the causes of this disease?

H2F – It is bacterial disease. As there are many factories running now days because of that the water get polluted due to which these bacteria spread everywhere and disease get started.

IR- what are the symptoms of leprosy disease?

H2F - small spots forms and the red rashes, red boils occurs in the body and the skin gets numb

IR- from where did you get knowledge about this?

H2F - We have got training in which they discuss about leprosy disease and we get information from field too we get more information from PHC and CHC public hospitals.

IR- In training what you have been told about leprosy?

H2F –we have been told In training about how to identify leprosy disease, bring patient to the hospital and how to treat the type of patients.

IR- when did you get information on leprosy disease?

H2F - I got training on leprosy in 2008 and I am working on this from last 10 years.

IR- Did you get information about leprosy from community or school or you get to know it by yourself?

H2F - Yes I get to know about it from school and community and when I went to the field I got complete information about it meanwhile we also get training on it.

IR- Do you know any leprosy patient in your community?

H2F – Yes, my aunty is suffering from leprosy.

IR- What were the symptoms of leprosy on her body?

H2F – Spot spread all over of her body and it affected her vein/ nerve due to which her finger get curved her treatment is going on, I myself took her for medication

IR- Do you know any patient who visits the health center for their treatment?

H2F – Yes I know one patient in who is in my field area.

IR- Did you ever participate in any leprosy eradication program?

H2F - Yes I have participated in such programs. I have not given medicine to any patients but I have taken patient to the health center. I have told patients how to take medicine, when to take medicine and also explain how many month patients have to take medicines.

IR- What is the opinion of health workers about leprosy patients?

H2F - We think good about them, this disease is not spread by touching any one. This disease doesn't spread by eating food with patient and it is not genetic disease.

IR- Do health workers treat leprosy patients differently?

H2F - No every patient is treated equally.

IR- How do you feel about leprosy patient who comes to you?

H2F - We have good feelings about them and we give them best treatment.

IR- Do you tell patient by observing signs and symptoms?

H2F – Yes we see the symptoms of leprosy on the patient body and accordingly provide them medicines

IR- Do you know about PEP++

H2F - No I don't know

IR- Thank you so much for your information

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Dr . Pravesh Dwivedi

In-depth interview – Health Worker / Age – 30 Years / Gender – Female / Block Name – Chandauli / District Name – Chandauli / H3F

IR- I am Anjali Singh. I need 30 minutes time from you to know about Leprosy. Can you please tell me something about Leprosy?

H3F - Yes, sure! Leprosy is a disease, which means it is caused by micro-bacteria! It gradually affects the body of the patient and he suffers from Leprosy disease. If he takes regular medicines and at the right time.....

IR- Yes.

H3F - Then he doesn't suffer from disablement. If the treatment is not given on time, then there is swelling in arms and legs. This swelling causes disabilities.

IR- What are the signs and symptoms?

H3F - It's symptoms are that there will be emerge spots on the body of reddish- yellow colour. There will be no hair on the spots and there will be no sweat on the spots. There will be no sensation of itching if the patient scratches the spot. This way we will be able to identify that it is Leprosy disease.

IR- Ok Ma'am! From where did you get this information about Leprosy and when?

H3F - I got this information about Leprosy when I was posted at Leprosy Office Department as a physiotherapist in 2015. I was trained there by DLO (District Leprosy Officer) and it was under his training than I got to know about Leprosy.

IR- Ok. Do you know any Leprosy patient in the community?

H3F - Yes.

IR- I mean do Leprosy patients come to your health centre for treatment?

H3F - We have NMA, NMS, PMW etc posted at our PHC and CHC's. At our DLO office we have HE, DLO, DIPTI DLO, HE and physiotherapists posted and the NMA, NMS, who are posted at PHC's and CHC's, they go for field visits and they provide treatment to Leprosy patients there. And those patients, who are not improving with the treatment, such patients also visit Leprosy Department.

IR- Ok! How many such patients do you know?

H3F - We know a minimum of 15 or 18 patients in each block.

IR- Do you also look after the diagnosis and treatment of Leprosy?

H3F - Yes

IR- In which manner!

H3F - Ma'am like if there is a Leprosy patient who has 5 or more patches we put them on multi drug therapy for a year along with PREDNISOLONE as support therapy so that the patient should not suffer from nerve damage causing him any disability and stop the disease at that stage only. If a patient has less than 5 patches then we put him on PB medicine for 6 months.

IR- Can you tell me what the health workers thinks about Leprosy patients?

H3F - For the past 3-4 years of my job I haven't seen any one in my office, PHC or CHC, neither the health workers nor the medical officers have any ill feelings towards the patient. In fact they give them treatment from time to time and go on field to spread awareness about Leprosy so that patients get proper treatment and prevent them from any disability and cure Leprosy and remain humble with them.

IR- So if there are two patients one with Leprosy and the other with a different disease, does the health worker behave in a different manner?

H3F - The health worker treats both the patients in same manner. If a person has some other disease, they treat them also. If the general patient is not responding to the treatment, they refer them to the District Hospital, PHC or CHC. They guide them properly, tell them that they are suffering from Leprosy and tell them that they can take medicines and their disease can be cured.

IR- I mean to ask is there any difference in behaviour for patients with different signs and symptoms?

H3F - Yes, if there is a general patient they deal with them in a different manner.

IR- Yes

H3F - Patients with Leprosy behave in a different manner, their nature changes as they have leprosy disease.

They become nervous feel inferiority complex because people in the society treat them in an inferior manner.

IR- I am asking about the health worker not the patient. RE- Ok health worker no.

IR- This doesn't happen

H3F - No, this does not happen.

IR- Tell me more about PEP++, like you were telling earlier.

H3F - PEP++ is a scheme of Government of India . It is a new scheme in which they hire the Health educator and research assistant in each block and with the help of NMA, NMS, PMW, DLO and Leprosy Office Staff at each CHC and PHC of each block; they will visit village to village of leprosy patients for the medication and treatment of Leprosy. They are providing information at the place of patients about the disease and give them medicines. If this scheme works well then this scheme will be further continued.

IR- So what do you think about this new scheme?

H3F - See in this new step of government I am also having the positive views about this scheme. It is a very good scheme. It is really a good campaign started by this scheme and Leprosy patients will be benefit with this. With the increase in Leprosy disease they have become disable if this PEP++ scheme continues, we will be able to control the disease and limit further disability in Leprosy patients.

IR- Is there any change in you since this PEP++ scheme has been implemented?

H3F - Yes, since this scheme has been started, many changes have been occurred in us. We go village to village and block area to organise camps and we call leprosy patients in camp.

IR- Is there any change in your behaviour towards Leprosy patients since this PEP++ scheme has started?

H3F - We are having the same perception for leprosy patients, after introduction of PEP++ as it was earlier.

IR- Ok is the availability of PEP++ affects your work?

H3F - Yes

IR- How does it affect?

H3F -One of the reasons for this is that from our department..... (IR interrupted)

IR- Has your work made easy with this PEP++?

H3F - Yes it has improved our working because this scheme has comes within our work area because our work comes under leprosy program under which this PEP++ scheme comes.

IR- Would you like share more information regarding this? RE- Yes, if you have any more information regarding this you can share with me.

IR- Is there anything else which you want to share with us, that you know and we are not aware of?

H3F - see I would like to share with you, there is not so much to share, All I want to share is that if there is any scheme in which we can help the patients financially because with some patients they have become disabled and it is impossible for them to earn money for their living. They can neither earn for food nor for their clothing. So I want that patients with Leprosy and disability should get full help, be it through pension for the disabled, medicines, MCR and care kit so that they should be fully aware and don't have to be dependent on anyone. Whatever knowledge we have about the disease, we should be able to share with them so that they feel good about themselves and should not feel nervous.

IR- Ok! Thank you for the information shared.

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Dr . Pravesh Dwivedi

In-depth interview – Health Worker / Age – 32 Years / Gender – Female / Block Name – Chahaniya / District Name – Chandauli - H4F

IR- My name is Anita Singh I want 30 minutes from you we want some information from you about leprosy disease so can you tell us?

H4F - Yes

IR- What is your designation?

H4F - I am LMO (lady medical officer)

IR- Since how many years you are working as LMO?

H4F - I am working on this position 3 or 3 and half years.

IR- Since when you are working with people who are infected with leprosy disease?

H4F - The people who came to me is few like not much leprosy patients visit to me some people who are infected with skin disease and after diagnosing them I found that the symptoms are of leprosy then I have referred them to lepro department otherwise I don't get much patient of leprosy.

IR- You must always have metwith some leprosy patients during one year.

H4F - If we take 3 years then for those three years continuously I get some of the leprosy patients.

IR- Can you tell me about leprosy disease what is the reason of this disease and what are its symptoms?

H4F - Yes OK, this leprosy disease is neuron pathological disorder as I told like the NODULES PAPLOSCOM and patches on skin and loss of senses also occur on skin and it occur through bacillus mycobacterium leprosy and mycobacterium laprae mitosis bacteria and what else I tell you

IR- From where did you get information about leprosy disease from whom and when? Who encouraged you about it, you got encouraged from school, community or by yourself.

H4F - I got information from medical college there only I study about it and got to know that what leprosy disease is then I practised here and saw the cases

IR- Do you know any leprosy patient in your community?

H4F - Patients who come to me for treatment I don't remember them, who they are but if they will come again then I will remember that I have treated that patient.

IR- Do you have leprosy patient in your health centres that are here for treatment if yes then how many of them you know?

H4F - Not monthly I would say but in year I get 2-3 patients of leprosy disease.

IR- Are you involved in diagnosis and treatment of leprosy disease if yes then how or in what manner?

H4F - Yes diagnosis and treatment, when patients come to me I did not provide them treatment directly I do the check-up and if I feel like or found the symptom of leprosy disease then there is a lepro department I refer them there do that there treatment could be done.

IR- Can you tell us about the thoughts of health workers towards leprosy patients?

H4F - Yes, the thought of health workers towards leprosy patients is, I did not see any difference that someone treat the patient as untouchable there is no such feeling of discrimination they surely get treatment and everything is done properly because their thoughts are good.

IR- Do your health workers do the treatment of leprosy patients differently from other patients? According to context of behaviour will it make any difference to you that a person is suffering from leprosy disease or he has sign and symptoms of leprosy disease or not?

H4F - Yes it does make difference we have to treat them affectionately and we have to make them understand that look, it will get cured we have to make them understand by talking with them positively in this way we should treat them.

IR- About touching leprosy patient important and early sign and symptoms and interest in check up and treatment of leprosy patients, how do you feel about it?

H4F – As I am doctor, and I do the treatment of every patient,so I don't feel any special difference

IR- Did you heard about PEP++ this is given to the person who are in contact of leprosy patients? Do you know that what is it and how it is given?

H4F - Yes, it is post exposure profile laxis I know little bit about it that is the person who takes care of patients and live with them like their family members, one dose of rifempsin is given to them.

IR- In this new step PEP++ what is your opinion?

H4F - In PEP++ the person who lives with patients they can work with confidence as there is a perception that they will also catch disease so this fear will get out of their mind and the lack of confidence which is there and the affection which they don't give/ provide to patient, the patient will start getting that.

IR- To get involved in this is there any change in your thoughts (does your thoughts change) towards leprosy patients if it is so then how?

H4F -I am not involved in this program. The program running earlier this the same like I don't feel any difference in both. Only patient family member feel some differences.

IR- Is achievement of PEP++ is effective on your work if yes then whether it has made you work easy or more difficult how it has affected?

H4F - I only know about the PEP++ that what is it?And this is the dose but I have not yet used it in that way , so that's why I can't say on this.

IR- Now do you want to share any other information with us about leprosy disease?

H4F -I want to get information from you people as of now as much you asked from me I can tell you.

IR- Thank you for giving your valuable time

H4F - Thank you!

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Dr . Pravesh Dwivedi

In-depth interview – Health Worker / Age – 52 Years / Gender – Male / Block Name – Sakaldiha / District Name – Chandauli - H5M

IR: My name is Raja Singh to eradicate leprosy disease I am doing interviews on the provision of medicine, it just started in your area, would you like to give suggestion on this, and the record of your interview will be kept confidential and will be used in the research only, and whole interview will take 20 to 30 minutes. Shall we start?

H5M: Yes, I am ready.

IR: You are working on which post?

H5M: I am working as NMA.

IR: What do you know about leprosy disease?

H5M: leprosy disease is a chronic disease; in starting leprosy disease seem similar to skin disease, yellow colour spots appear on the skin and become numb, in leprosy disease the nervous system gets effected and nerves got numb, and also it effects fingers.

IR: what are the symptoms of Leprosy disease?

H5M: Light yellow coloured and red coloured spot appeared on skin, numbness and hair fall occurs on affected area.

IR: From where you got this information?

H5M: I got this information on leprosy disease in the training at Dehradun.

IR: Have you given such information to the people?

H5M: Yes, I go to village and give information to the people that this is not due to ghost or spirit it's a kind of disease which can be cured by proper medication and treatment.

IR: Do you know any leprosy patient around you?

H5M: Yes, in your village there is a man who is leprosy patient whom I know very well.

IR: Do leprosy patient come to your health facility?

H5M: Yes, they do come at present we have 28 Leprosy patient registered.

IR: Are you involved in diagnosis and treatment of leprosy disease?

H5M: First of all, check-up is done of the leprosy patient and if the leprosy disease of the patient confirmed then after we register that patient and then we give medicine to the patient, if the case is of MB then we give treatment for 12 months and if the case is of PB then we give treatment for 6 months we also give instruction to the patient to take medicine regular, medicine should not be skip even for a day and if the finger got distorted we refer that patient to naini.

IR: When the leprosy patients come to your facility how your staffs behave with them?

H5M: Old perception of ghost and spirit for leprosy patient or it is a sin of past life is wrong, these kind of thought have ended, behaviour toward the leprosy patient of the staff is normal the way they treat other patient in the same way they treat leprosy patient without any discrimination and loathe.

IR: Does the treatment of leprosy patients done separately from normal patient, does the staff treat the leprosy patient differently?

H5M: No they behave with the leprosy patient normally no discrimination is made, like we provide medicine to the other patient in the same way we provide medicine to leprosy patient.

IR: If the symptom of leprosy started showing in someone does it affect you?

H5M: We do treatment of leprosy patient equally we do not do discrimination we treat them in a friendly manner if we discriminate then how will we do proper treatment it been 30 year we are giving treatment, Until we don't touch that patient how will we diagnose that the patient is suffering from this disease and his nerves are damaged.

IR: How do you feel when you give treatment to the patient by touching them?

H5M: To avoid wrong treatment. By touching the patient proper diagnose of disease will be done

IR: Do you know about PEP++?

H5M: Yes, I know, I got to know about PEP++ form district office through officer they told us that the team will go to the village and spread awareness to those who live nearby the house of leprosy patient and they will do the check up and suggest them to take medicine.

IR: Would you like to share any other information to us?

H5M: Yes, this programme is very good people will able to know about the leprosy disease earlier, we will try to eradicate leprosy disease before it spreads to other.

IR: Ok, thank you for the information

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Dr . Pravesh Dwivedi

In-depth interview – Health Worker / Age – 25 Years / Gender – Male / Block Name – Barahani / District Name – Chandauli - H6M

IR- My name is Raja Singh to eradicate leprosy disease I am doing interview on provision of medicine which has just started in your area. Are you interested in giving your opinion about this? The interview will take 20 to 30 minutes shall we start?

H6M - Yes

IR- On which designation you are working there?

H6M - I am working there as PMW.

IR- Did you get training for leprosy disease?

H6M - Yes of course, we got training in Lucknow, one and half years ago

IR- Since how many years you are working as health worker?

H6M - It's been Three years.

IR- How much time has been passed since you are working with leprosy patient?

H6M - In this also three years has been passed.

IR- You might have good experience.

H6M - Yes of course

IR- Could you tell me about leprosy disease that what is it? How it occur? And what are its symptoms?

H6M - Leprosy disease is long term contagious disease which is caused due to bacteria named *mycobacterium laprae* and it is spread by coughing and sneezing. It occurs to the person whose immunity is low. This bacteria takes time limit of 1 to 15 days to be doubled and in this lots of medicines are prescribed like MDT in which Refempicine, clozifimine, DEPSON all these medicines are given to the patients and pain occurs and we also prescribe TETMISOL. The important thing about this it spreadsthrugh coughing and sneezing.

IR- What are its symptoms?

H6M - The symptom of this disease is that whatever spot will be on the skin it will be protruded slightly outwards and it will be light red and numb, numbness will be surely there and the spot which is there or the patch which is there, no sweating will be on that area and also there are no hair these are its symptoms.

IR- How does it spread from one person to other?

H6M - This disease does not spread by touching it spreads by coughing and sneezing, numbers of bacteria come out while coughing and sneezing through which it attacks and it affects our nose biroza these bacteria attack in side of nose and bacteria gradually attacks the brain,through this initially patchesappears and if treatment is not done for two years it will result in disablement.

IR- From where did you get to know about leprosy disease first? And from whom did you get to know?

H6M - First of all when I got appointed then our DLO Sir, Agrawal Sir gave us training and I think it took maximum two month, our training held in DLO office we got knowledge from him about leprosy disease.

IR- When did it happen?

H6M - It's been 3 years and one and half years ago training was held in Lucknow. When I went to Lucknow then a State level officer told us about it.

IR- So do you remember that what did he tell you about leprosy?

H6M - For leprosy disease first of all, he told us about the symptoms then to do checkup it was told then what all medicine should be prescribed it was told, then how to work in field, how to do inquiry, how to do diagnosis all these things were told during two months of training.

IR- Do you know any leprosy patient in your community where you work, Is anyone working at centre is leprosy patient?

H6M - Yes, there are many.

IR- How many of them you know?

H6M - Out of these many of them I know

IR- To how many of them you are providing treatment?

H6M - This year now I have almost 18 patients, recently 17 to 18 patients have cured, 18 to 19 patients are there with us and in April one new patient has come.

IR- If we talk about over all how many patients you have treated till now?

H6M - If we talk about overall then in three years 150 patients have got treated.

IR- Are you involved in treatment and diagnoses of leprosy disease?

H6M - Yes.

IR- Then in what way, how do you do the treatment?

H6M - First of all, when patient comes to me, then we make him sit and explain him everything about leprosy disease it take about half an hour to one hour in explaining him about what disease he is suffering from, so that he can complete the whole course of medicine and whether the treatment will end by 6 months or it will take one year this thing are already informed to patient and we also tell the patient that the disease from which he is suffering from can tell about it to his family, relatives and neighbors and you can aware people that this can happen to them also if you are suffering with this disease then you should go to the hospital as soon as possible otherwise disablement will cause because of this, we get many patients from field there are some ASHA and ANM who also help us in this cause.

IR- Tell us one thing that what are the thought of health worker for leprosy patients?

H6M - If we say then there are both the thoughts there are good thoughts also and bad thoughts also both are 50-50% there are some staff who totally support us like if they went to field and the

saw any person suffering with leprosy disease or leprosy patient they make them sit on their bike and they bring them to the hospital and there are some people in the hospital who hesitate in writing name and address of the patient they do not pay any attention to the patient.

IR- If I talk to you about your thoughts then what is your opinion about this?

H6M - We should not see leprosy patient with inferiority complex, earlier the leprosy patient were thrown out of family and village but now its treatment is possible it is not such type of disease which cannot be treated so there is no need to throw the leprosy patient out of the house or village and one should not see the leprosy patient with inferiority complex now the conditions have improved much from earlier.

IR- Do health worker do the treatment of leprosy patient differently from other patients?

H6M - Like they do the treatment of other patients the same way they do the treatment of leprosy patient we do not do any discrimination and we make them believe that the medicine which we are providing to them will cure there disease permanently.

IR- Does it make any difference to you that a leprosy patient has come to you for treatment?

H6M - Not at all, it will not make any difference, I don't have such type of feeling.

IR- When a leprosy patient comes to you for treatment that has wounds, patches and decayof body parts how do you feel in treating them?

H6M - If such types of patients come to us and we ignore them for 6 months then they will become disabled and after they get disabled it is difficult for us to treat them we specially give suggestion to the leprosy patients that they should do exercise, and pay attention to cleanliness if they are provided by NCR or they are provided by self-care kit then how to use it all these things we explained to the patient I also provide my contact number to the patient so that if he feels any problem he can talk to me so this is how patient come to us. When this kind of patient come to us we do not do that we see the patients by seeing him for two minutes and asking him to go , we sit for 1 hour with them and tell them about the disease and apply ointment and bandage on wounds of the patient.

IR- Do you know about PEP++?

H6M - No, I don't know about it.

IR- Thank you, for giving such information.

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Dr . Pravesh Dwivedi

In-depth interview – Index / Age – 45 Years / Gender – Female / Block Name – Chandauli / District Name – Chandauli – I1F

IR- My name is Arti and her name is Anita Singh. We came from NLR leprosy India which is working for leprosy disease. We want to talk to you about leprosy we will record your thoughts and the talk between us will be kept confidential. After completion of the purpose this recording will be deleted so if you are ready then sign the form this session will take around 15-20 minutes during this session if you want to go without answering any question you can go.

I1F - it's alright

IR- Can you tell us about leprosy when you got affected by it?

I1F - Nine to ten months have been passed since I am suffering from leprosy. It has started from September (*bhado*). I went six months to block for treatment but I didn't get any relief then for 8 months I took medication from Ramnagar. I get some relief from there but after some time it spread overall body then I took medication from Nawabpur from there I got relief and doctor there use to sit both in government and private hospitals.

IR- what do you think due to which reason you got infected from this disease?

I1F - I don't know much about it ten years ago buffalo hit me and wound formed there may be because of that the leprosy disease has caused. Whatever be the reason the disease occurs.

IR- When you come to know that you are suffering from leprosy how did you feel?

I1F - I felt like numbness in my body and also felt like tingling and got numb. We are not getting proper medicine for leprosy disease anywhere and lots of money was spent on medicines.

IR- Do you know any person who is already suffering from leprosy?

I1F - No sir there is no such person in my family and not in my relatives also if it will occurs with any one will get to know.

IR- What is the behavior of society towards a person who is suffering from leprosy disease?

I1F -No, I did not hear anything and not even seen anything of such type. I will see myself only why I am going to look others .

IR- what is your opinion about leprosy prior to starts medication?

I1F - Doctor continued giving medicine and I took it no one told me from what disease I am suffering no one in my in laws house is suffering from this disease. I don't know how I got this infection.

IR- Did you informed in your house that you are suffering from leprosy?

I1F - I was not informed by any doctor that I am suffering from leprosy one of my brother is doctor who is doing his private practice he told me this is a kind of infection and will be cured only by medication otherwise it will increase. I took medicine for worth Rs. 500 for five days then I got a bit of relief , I did not get the sudden relief. Gradually it started to fester then I went to exorcist he provided me one medicine due to which it become wound from which blood and pus started coming out.

IR- Are you the head of your family

I1F - Yes I am head of my family. I am guardian of my family.

IR- Did you face any problem or complications from this disease.

I1F - It's my problem so I will only bear it. In this world no one stands for any one. As it has fallen on me then I have to do it. No one coming for me I can earn for my own self then only eat.

IR- When you suffered from leprosy did you tell any of your relatives that you are suffering from leprosy

I1F -No when I didn't know that I was suffering from leprosy then how I will tell to others I did not even tell to my family and children that I am suffering from leprosy, I was not knowing that I am suffering from leprosy.

IR- Have you ever talked or discussed about leprosy with your friends that what their perception about this disease is. What kind of this disease is?

I1F - No I have not discussed with anyone. I am medicating my wound. I did not tell anyone that I am suffering from leprosy, people say that which type of wound it is, it is not healing go and consult to doctor there is something wrong. It is something else.

IR- Did you ever talk to your partner openly about leprosy?

I1F - When I am suffering with leprosy what I will tell to my friends when I told them they said that get the treatment and it will be cured.

IR- when you come to know that you are suffering from leprosy then what your neighbors and relatives will say to you?

I1F – No, if I will not tell anyone that I am suffering from leprosy then what they will say to me

IR- Ok thank you so much for the information you provided.

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Dr . Pravesh Dwivedi

In-depth interview – Index / Age – 42 Years / Gender – Male / Block Name – Sahabganj / District Name – Chandauli - I2M

IR- Hi I am Rajeev Singh from NLR INDIA which is an NGO. I would like to ask some question about leprosy disease it will take 30 Minutes of yours, so that we can spread the knowledge and make people aware and change their perception and thinking towards this disease, so that they think good about this disease. If you are ready then please sign the form as your acceptance to this.

I2M - Yes I am ready.

IR- How many members are there in your family?

I2M - We are ten members in my family.

IR- When did you come to know about this leprosy disease?

I2M - Approximately a year ago I came to know about this disease. Initially I had medicines for six months and stopped for six months, it was then that I came to know about this disease.

IR- Where did you go first for the treatment of this disease?

I2M - First of all I had gone to the district hospital where they told me that the medicines will be available at the PHC.

IR- From which block are you?

I2M - I am from Sahabganj block.

IR- So it's been a year?

I2M - Yes

IR- Tell us for what reason this disease occurred?

I2M - I can't tell you the exact reason as how I got this disease. Initially, I had some pain in my finger and realized that without being hurt I am feeling this pain. Then I started feeling numbness in one of my fingers and thought that there is some problem in the blood or in the nerves. Then I thought of consulting and went to Chandauli where after check up I came to know about this leprosy disease.

IR- Alright

I2M - ?

IR- Can you think of a reason why did you start feeling numbness in your fingers?

I2M - I don't know the exact reason but yes it was pain that led me to think about it.

IR- Alright, pain started initially?

I2M - Yes , initially there was slight pain in this finger (RE is showing her finger to the IR) and I tried pinching on that same area but couldn't feel anything, whereas, I could feel the pinch on different parts of my body and finally came to a conclusion that only that particular finger was painning.

IR- Aright.

I2M - Then started feeling numbness in that finger and told my brother about it. He said it may be a sign of Leprosy and we should consult a doctor.

IR- Alright

I2M - We went to Chandauli and consulted a doctor there. He confirmed that it is Leprosy and prescribed medicines for six months after which it will be fine.

IR- How did you feel when you came to know that you have been diagnosed with Leprosy?

I2M - I didn't feel anything as many diseases affect our body. But one thing came to my mind that every disease needs proper medication whether it is Leprosy or T.B. and it can only be cured if we take proper medication.

IR- You are right.

I2M - If there is some disease then proper treatment is required to cure that. The doctor advised for six months of medication and on a regular basis I had taken those medicines. Now it's been six months I haven't taken any medicines and there is no problem.

IR- Yes, your disease has been totally cured.

I2M - Yes, but the part in which I was feeling numbness is still the same.

IR- Alright

I2M - And the doctor said that the disease is controlled! It will not spread further.

IR- Before this did you know anybody who had this Leprosy disease?

I2M - Yes there was a guy Sanjay Yadav in our village whose finger got distorted.

IR- Both hands or single hand?

I2M - All the fingers of one hand.

IR- Have you seen that guy ?

I2M - No, I haven't seen him but the Doctor at the PHC told us that he didn't take proper medication that's why all his fingers are distorted.

IR- Alright

I2M - The problem may increase if proper medication is not taken.

IR- How do people behave with him?

RE- Everyone behaves normally talks to him in a normal manner, there is no discrimination.

IR- How did the Pradhyaan behave?

I2M -It's fine. He use to go to his house, I have also seen him he behaves normal he doesn't have any ill feeling towards Leprosy patients.

IR- Ok! Do the Pradhyaan take part in festivals?

I2M - Yes he does.

I2M - He doesn't have any discrimination for Leprosy patients. IR- Have you told everyone in your family that you have this Leprosy disease?

I2M - Yes, everyone in the family knows about my disease. I have Leprosy and have taken treatment and medications for six months and it will be fine after that.

IR-What was the reaction and behavior of your family members towards you?

I2M - My wife?

IR- No other members in the family.

I2M -There is no change in the behavior. Everyone stays together.

IR- What is your role in your family

I2M -I am a farmer.

IR- Are you the eldest in your family?

I2M - No, I have an elder brother.

IR- Do you feel any problem due to this disease while working?

I2M - I have no problem at all.

IR-Do your friends know about your disease ?

I2M -Yes, Some of them know about how I got this disease and I am on medication but there is no discrimination in their behavior. We spend time together.

IR- Does anybody discriminates with you?

I2M - No, nobody discriminates with me.

IR- So what do your friends think about this leprosy disease?

I2M - See my friends don't have this disease, so why will they think about this disease.

IR- Do your neighbors know about your disease?

I2M - Not everybody, but yes some of them know about it.

IR- What is your neighbor's perception about this disease?

I2M - One who has this disease only he can feel and understand. IR- How was the behavior of your neighbors towards Sanjay Yadav who had this Leprosy disease?

I2M - When Sanjay used to talk to people, then it was never like that people don't talk to him. They were not concerned about his disease. There was no change in their behavior towards him.

IR- Do you speak openly about this disease with your neighbor?

I2M - Not so openly with everybody. I talked to a few people and they suggested me to consult a doctor and take six months medication.

IR- Does everyone knows about your leprosy disease?

I2M - Why should anybody be concerned with the disease I am suffering? Generally nobody shares his disease with anyone. They take treatment for whatever disease they are suffering from. Our house is located on the outskirts of the village so not many people know about my disease

IR- Alright

I2M - Then I was on medication and finally things are fine. So there is nothing to talk about this.

IR- Is there anything you want to share with us on your own ?

I2M - I have nothing to say Sir.

IR- Thank you for the information you shared.

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Dr . Pravesh Dwivedi

In-depth interview – Index / Age – 45 Years / Gender – Male / Block Name – Chahaniya / District Name – Chandauli - I3M

IR- My name is Raja Singh we are working together to eradicate leprosy disease through a program organized by NLR India. We would like to know the perception of people of Chandauli regarding leprosy disease to know this we would like to ask some questions from you how to prevent leprosy disease we would like to take your opinion this in which we will take 30 minutes, are you ready for this?

I3M - Yes

IR- Since when did you get this disease?

I3M - I don't remember exactly. There was pain in raising hand earlier, once I fell from motorcycle I got hurt my daughter said that go and consult doctor I said it will cure but it did not cure I went to doctor in terror for medication as I heard it is skin disease/ leprosy disease it came to my mind that I chop off my hand, but the doctor said that take medicine for one year and it will be cured.

IR- Can you tell us due to what reason this disease happen to you?

I3M - When I sat on chair it pinches (*दरती*)/ hurt this is why it happen or it might cause by touching infected person or in bank due to breath of someone's mouth, someone in crowd might be suffering from this disease that is why I got infected.

IR- When you heard that you are suffering from leprosy how did you feel?

I3M - It felt like chop off my hand or die immediately, no one in my family or relative ever suffered from this disease.

IR- Why are you feeling like to chop off your hand?

I3M - In my village one man was suffering from this disease due to which his hands got decayed I knew that he is as leprosy disease.

IR- What was the behavior of society towards that leprosy patient?

I3M - See brother, they loathe him.

IR- What did you feel about that that leprosy patient?

I3M - I felt very bad I hesitate to sit in society. I knew that, it is leprosy disease.

IR- What are your thoughts about leprosy disease?

I3M - Nothing, people said that it will be cured some people said that it is *Dinaay*. When I went to the doctor he said that it is distortion disease and said that he can provide medicine I would have to go to government hospital.

IR- Did you tell your family that you are suffering from leprosy disease?

I3M - Yes, my wife knows about it.

IR- What was the behavior of your wife at that time?

I3M - She said that it will be cured you should have consulted earlier to the doctor.

IR- What is your role in your family, do you face any problem in doing work?

I3M - Since I am suffering from this disease I am unable to do the work as compared to earlier.

IR- Is there any problem to the people who live nearby you due to this disease?

I3M - No it doesn't seem like they have any problem with this disease.

IR- have you told your friends about your disease?

I3M - No, not to anyone.

IR- Why didn't you tell your friends about leprosy disease?

I3M - I told them that it will cure then what is the need to say it repeatedly

IR – Do you freely talk to your friends about this leprosy disease?

I3M - Everyone says it will be fine.

IR- what kind of thinking do your friends have about the leprosy disease.

I3M - Friends said that it is a disease in which hands get decay. Now it is small, go and consult doctor soon.

IR- Do you tell your neighbors that you are suffering from leprosy disease?

I3M - No, I did not tell to anyone, only family members know that I am suffering from leprosy disease.

IR- What your neighbors think about leprosy disease?

I3M - They call it *kodhand* hate the patients.

IR- Is there anything that you want to tell us or share with us from your side.

I3M - No, Sir there is nothing to tell or share.

IR- Thank you so much for such information .

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Dr . Pravesh Dwivedi

In-depth interview – Index / Age – 35 Years / Gender – Female / Block Name – Sakaldiha / District Name – Chandauli - I4F

IR – My name is Manju lata am from NLR which is with collaboration with government, working for leprosy prevention program. We want to talk something with you if you will give us 30 minutes and the communication between us will be confidential and we will record it when you want you can stop the interview. We want to take information related to your leprosy disease.

I4F - Ok, it's alright.

IR – Tell us about your disease when it happened and how it happened?

I4F - No, I don't know one day I felt pain in my finger and now it been one year.

IR – Can you tell us due to which reason this leprosy disease happened?

I4F - I don't know anything

IR – When you heard that you are suffering from leprosy how did you feel?

I4F - What I should tell you, when I am working my hand is warm then I don't feel pain but when I finish my work, after some time my hand gets normal then pain starts.

IR –Do you know any leprosy patient previously?

I4F - No I don't know

IR – Have got some disease previously what are your thoughts about it

I4F - I underwent blood test and many other tests

IR – Did you tell your family that you have some disease?

I4F - Yes I have told everyone in my family everyone in my family knows about it even my relatives know that I am having this disease in my hand

IR – Can you tell me about their reaction?

I4F - Everyone talk to me eats with me and we go for outing together

IR – What is your role in your family do you face any problem in working

I4F - No I don't face any problem in working when I lift anything then pain occur when I raise my Hand up I don't feel any pain but when I put it down then pain occur

IR – Did you tell your friends that you are suffering from leprosy disease?

I4F - Yes I informed to all my friends that I am suffering from leprosy disease

IR – When did you get to know that you are suffering from leprosy disease?

I4F - No I continuously use to say to my daughter that my hand is paining apply any ointment or oil on it so that it get cure but it doesn't affect I get little bit of relief but it didn't get cure

IR – when you told your friends that you are suffering from leprosy how did you feel and what did your friends said?

I4F - They said that get the treatment and it will cure soon.

IR- Before you told to your friends that you are suffering from leprosy what was the presumptions of your friends about leprosy disease?

I4F - They uses to say that this is disease, go for treatment it will cure otherwise it will trouble you and your hand and legs will get distorted

IR – Do you talk freely with your friends about leprosy disease?

I4F - Yes, I talk about everything there is no discrimination

IR- Did you tell your neighbors about this disease of yours

I4F - Yes, I had talked to my neighbors that I am suffering from leprosy disease

IR – When you get to know about leprosy disease what was the reaction of your neighbors

I4F - There was no reaction they said that go to the hospital for treatment and checkup and your leprosy disease will be cure

IR – Do you talk freely about your leprosy disease?

I4F - Yes why not if I am sick then I will have to talk about why to feel sad and if a person is suffering from pain then he will discuss to everyone then the treatment will be done

IR – Thank you so much for your information

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Dr . Pravesh Dwivedi

In-depth interview – Index / Age – 65 Years / Gender – Male / Block Name – Chahaniya / District Name – Chandauli - ISM

IR: I have come from N L R India who is working on Leprosy disease, I would like to discuss about the leprosy disease with you, our communication will be recorded and will be kept confidential and will be deleted after completing our work, it will take 20 to 30 minutes to complete the interview if you are ready, shall we start our conversation

I5M: Means what you want to ask me? Whatever I know I will tell you ok you can start.

IR: Could you tell me when did you get this disease?

I5M: I don't know when I got this leprosy disease I was working in the fields from morning till the evening when I returned home then I felt itching and pinching in my leg. I am applying oil on it and have hot fomentation from fire In night and went to sleep. When I wake up in the morning it become wound.

IR: Ok

I5M: I showed it to doctor and that wound cured but after 2-3 month whenever it got hurt it bleeds

IR: Ok

I5M: But pain did not occur gradually after 2 or 4 years my fingers got numb then I showed it to doctor he told he that it a leprosy disease.

IR: Ok

I5M: Because of which this numbness has occurred in your fingers then I came to know that I got leprosy disease.

IR: Ok, when you came to know that you are suffering from leprosy disease how do you feel?

IR: Means when doctor called you then what did he tell you?

I5M: He said that white spots that have appeared on your skin it usually appears in leprosy disease.

IR: Ok, else what he said?

I5M: Doctor had told me that I am suffering from leprosy disease, I felt very bad that I am suffering from this disease because everyone loathe this disease and he also told me that I have to take this medicine for 12 month and I have to come to the hospital to take medicine.

IR: Ok

I5M: Then doctor had told me that I have to take medicine for 12 months from that day I am having medicine now there is no problem now it is ok but I can't tolerate the sunrays.

IR: Do you know anyone who is suffering from this leprosy disease?

I5M: No, I don't know anyone who is suffering from this leprosy disease but there are many people whose hand and legs are decaying after that I came to doctor

IR: Ok

I5M: Then doctor said to me that now you will be cure soon.

IR: What behaviour does society has for leprosy patient, how do they react as you describing what perception does community has for the leprosy patients?

I5M: They behaved very badly they used to say that he is leper stay away from him otherwise you will also get this disease.

IR: Ok

I5M: people says evil spirit was on him but doctor told me this is not because of ghost and spirit if you will do proper treatment you will be alright, you don't need to go to exorcist person , have faith in God now whatever God wishes will happen so I am having medicine in the name of God.

IR: what were your thoughts before your treatment done?

I5M: Earlier I was fit having no problems.

IR: ok

I5M: This leprosy disease has occurred after the birth of my 3 sons before that there was no problem.

IR: ok ok, have you had seen any leprosy patient in the village what did you think for them?

I5M: I saw them where I was doing farming there was a boy and a man they were suffering from this disease.

IR: ok

I5M: and he died I was so sorry to hear this before that I was having no problem.

IR: ok

I5M: In my village there was a boy who were suffering from the leprosy disease he was a harijan he used to sit silently everyone said about him that he is caught by some ghost or spirit then I told him that go to the doctor then doctor saw his condition he told that he has to take medicine for 12 months.

IR: ok

I5M: So then I come to know that it will take 12 month for me also doctor told me that it an infectious disease but when I got card then I read it, 'leprosy disease' was written there on the card, some people says usually it fall under 'kodhpan' leprosy, in which fingers get decay then I asked doctor my fingers will also decay then he told me that my condition is now better than previous, initially I didn't know that I am suffering from leprosy disease but it will recover soon by having pills.

IR: Initially when you came to know that this is leprosy disease so to whom did you tell in your home first?

I5M: Initially I did not know this is leprosy diseases so I didn't tell anything to anyone.

IR: Why did not you tell anyone did you have any kind of fear?

I5M: I have no fear from anyone.

IR: What kind of role do you have in your home due to your disease do you feel any problem while doing your chore.

I5M: Yes, I am the head of the family, but due to my disease I am unable to do work as like before.

IR: ok

I5M: I am unable to do work like before I used to do, now I am unable to lift heavy things as pain gets started and numbness is always there.

IR: Have you told about your leprosy disease to your friends, how your friends reacted after knowing about it could you tell me what kind of reaction they gave and how you felt after telling about your disease and did you expecting the kind of reaction they gave?

I5M: No, I have not told anything to anyone I just told everyone that there is some deficiency in my blood check-up of that is going on.

IR: Ok what else is did you tell?

I5M: When I said to the doctor he told me that you are suffering the leprosy disease in this disease fingers and hands get decay and white spots start appearing it will start occurring on your body and everyone start loathing you that is why I have not told it to anyone that I am suffering from leprosy disease.

IR: Ok

I5M: I do not tell it to my relatives and friends because I thought that I am suffering from this disease when they come to know about it they will loathe me.

IR: Have you tell it to your neighbour about your disease?

I5M: No, I have not told them till now people do ask me why your body became black and became so weak.

IR: Ok

I5M: I told them that I am suffering from typhoid I am having medicine of it and I got reaction of that medicine.

IR: What kind of thought your neighbours are having about leprosy disease?

I5M: They saw them with hatred and loathe lepers they don't even talk to them.

IR: Ok

I5M: They stay away from them, when they did not know about my leprosy disease they used to talk to me but noweversince they come to know about my leprosy disease they don't talk to me and they loathe me and they stay away from me.

IR: Ok ,Thank you so much for all the information you have given.

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Dr . Pravesh Dwivedi

In-depth interview – Contact > changed this to index patient! / Age – 27 Years / Gender – Female / Block Name – Chahaniya / District Name – Chandauli - 16F

("When my father took me for check-up and to get my medicine then they told that I am suffering from leprosy disease.")

IR: My name is Sant Kumar Maurya I have come from block chandauli I would like to ask you some questions it will take approximately 10- 20 minutes, are you ready?

IR: Tell me how leprosy disease can be spread?

I6F: My father was telling that this disease is contagious.

IR: Do you know about the symptoms of leprosy disease?

I6F: I don't know about the symptoms of disease but my father was telling that primary stage is normal and it is a contagious disease and also spread by eating leftover/half eaten foods.

IR: Ok, ok.

I6F: They did not allow me to eat.

IR: What kind of thought do you have regarding Leprosy disease?

I6F: What do I know about the leprosy disease, I live in village my father went to get medicine for me only he knows everything, doctor has told him everything and he does not tell anything openly for what reason it occurs.

IR: From where did you get information regarding leprosy disease?

I6F: I got information regarding leprosy disease from my father.

IR: How many days ago did your father tell you that you have caught by leprosy disease?

I6F: When my father took me for check-up and to get my medicine then they told that I am suffering from leprosy disease.

IR: Ok, Ok

I6F: I went to the government hospital for check-up then I asked what disease do I have doctor told me it's a leprosy disease.

IR: Ok, alright.

I6F: Its contagious disease.

IR: Ok

I6F: Before me my father was suffering from this disease but later it got heal up, doctor told us to be careful because it's a contagious disease and can be occurred to anyone by touching.

IR: Ok,ok

I6F: This was told by the doctor.

IR: what kind of behaviour does community have for the leprosy patient?

I6F: People say it's a disease it will be cure

IR: ok ,ok

I6F: Medication is going on and everyone is saying it is a disease and it will be cure.

IR: What do community people call to this disease?

I6F: They call it skin disease ('charamrog').

IR: As you are suffering from leprosy disease does it affect you?

I6F: Yes, it affects me a lot, which is why treatment is going on.

IR: How does it affect you?

I6F: That's what I am telling you; now infection has started spreading in body so it is getting numb now it started creating problem for me.

IR: What kind of problem you are facing?

I6F: People say that these white spots I got is looking weird it might affect my marriage in future, but treatment is going on to make it completely cure, in community some people are saying weird thing about me some people say that it due some evil spirit this all they think.

IR: Does it occur to any one?

I6F: It could be or could not be but God forbid this disease can't be occurs to anyone, only one person caught with leprosy disease I pray it could be cured and ended here, it could not spread to other I wish, my treatment is going on I am having medicine but my face is becoming black and I am feeling irritated all the time, I feel medicines of this disease are very strong, in this tension I left eating food, because of my family I was very tensed.

IR: Ok, do people help to cure this disease?

I6F: Yes some people give medicine

IR: People who give medicine by visiting here and there how do you feel about that?

I6F: I feel really good that people help us.

IR: Ok, you feel good

I6F: When people help us on behalf of government then I feel very good that they are giving medicine to eradicate this disease from its root.

IR: ok.

I6F: our government is also giving benefits to us to eradicate this leprosy disease from its roots and what else we want.

IR: That means you will take medicine

I6F: Yes, why not the person who is suffering from leprosy disease will definitely take medicine but the person who is not suffering why that person will take the medicine.

IR: Ok thank you, for all the information you have given.


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Dr . Pravesh Dwivedi

3th May, 2017

Interview 1: Kasopu 

“Abi” (Interview party English, partly Hindi)

23 y.o. m., student

Hindu, higher education

Has no close relationship with anyone who’s diagnosed with leprosy

Thank you so much for taking the time to talk to us today. As explained, we’re here to talk about leprosy, can you tell me a bit about the disease leprosy? Can you tell me what causes the disease?

I... Uh... I don’t understand. Could you repeat that question?

Of course, what do you think causes the disease leprosy?

I... Uh... I think...

If you rather speak in Hindi, that is fine too. Aakash is here to translate.

No, no, it is fine in English, but I don’t know what is cause. But, but I don’t see people with leprosy many. So, I don’t know always how it looks. It is difficult to say cause.

So, if I’m correct, you find it hard to say the cause, because you don’t or know people with leprosy?

Yes.

Ok. Have you ever had any education about leprosy or other disease during your school time?

No, never.

Ok. Do you think that leprosy can be caused by a curse of the gods, that it is a punishment from the Gods. Or maybe that it is a result of karma?

I think not. *Starts to talk in Hindi. Aakash:* He thinks it is due to genetics, to genes.

Ok. So leprosy is hereditary, it is caused by genetics and is a birth defect, if I understand you correct?

Yes.

How do you think that works? Do you think that a mother then gives the disease to a child, or uh, do you think that not everyone who’ve got the gene for leprosy gets leprosy. Can you explain how genetics work?

Normally, uh, normally if something like a disease like leprosy happens, to a male or female his or her father or mother... The disease is given from the parents

Yes

Then after, when the child borns, the child gets leprosy from his parents.

Due to the father and mother... So you think leprosy goes from a parent to the child?

Yeah.

Ok. And do you know...

And, and, also, if you touch.

If you touch?

If you come in contact with diseased skin. Then you get the disease.

Ok. So, via skin touch and via mother or father to child leprosy is transmitted?

Yes yes. The child gets the disease from his father and mother. Not because they are close in the room together, but via genes. Same as children get same look as their parents. Some children look a lot like their father or mother, you know. The disease he gets it from his father or mother. He's saying that it is all due to genetics. But, other people, can get leprosy from the child not via genes, but by touching the skin.

Thank you. And what do you think are the symptoms or signs that are associated to leprosy?

Like he has seen, wounds on the skin, wounds near the eyes...

Yeah...

And you know, the falling of the nails, the fingers that bend and disappear.

Yeah... Any more, symptoms?

No, I'm sorry, I don't know.

No, no, it is not a problem. I just want to know what you know about leprosy. If you don't know anything, or you don't know anything more, you can just say so. It's no problem at all. Just tell me what you know about leprosy. Do you think that leprosy is a disease that lasts for a life time?

Yes, for a life time. Any disease, if you will not care about it, you will not get prevention, so it will take more time to heal. It will be for lifetime. Otherwise, if you will take your prevention, then it will not be for all times. Temporary it will be, you know?

But do you mean prevention or treatment?

I think it is necessary for person to both prevent and treat or cure.

So, ok, both are important for staying healthy?

Yes, not only leprosy, but all diseases.

Ok, thank you. Do you think leprosy occurs in episodes? That sometimes one person only has got his symptoms for a month and then they subside and go away?

No, no, no... That problem, it is not a problem or disease you can say for a lifetime. Some small thing will remain in your body, like a bacteria or what you can say, or infection. Anything you can say will be left in your body

Yes

A minimum part.

A minimum part, so a small part will be left in your body?

It cannot be all prevented and treated and it will not... I can't control... You can prevent it for a period of time, but you can't clear it for the rest of your life. You know, it cannot be fully prevented, by medicine or anything. It can only be prevented for a period of time.

So, if I'm correct, please tell me if I understood it wrong, you are saying that if someone's got leprosy, and you give them medicine, you can cure the disease, but a small part of the disease will always stay in the body. So, do you think that anyone can really get rid of leprosy. So, if I, by this

small part, that is always in the body, you cannot cure leprosy, you will always be a little of leprosy? Like that?

Yes. The disease is too hard you know, and while preventing to this disease, you need to take a medicine of higher hard and higher mg.

High doses you mean?

Yes, strong medicine you will take, and while preventing it, you have to also see that you have not another part of your body affected by medicine. It may harm. So that is why you can't take a higher type of this medicine, as it may harm your other body parts. The medicine can do damage to other body parts, not only cure leprosy. I've seen it in people, they get wounds on their feet, because of injections. Same thing for leprosy, if you take a lot of mg, you get more wounds on body parts that have no leprosy.

Ok. Thank you for this. This was the first part of the interview. I will now continue with another set of questions. With whom do you associate leprosy, do you think everybody can get leprosy, or only weak people, only children, only elderly? How do you think that works?

Hmmm, I think ehh... It is not necessary that it will happen to children only. And not older, it can happen to anyone.

Can happen to anyone... Does it matter, do you think that someone's status, so if someone's poor or rich. Do you think that influences whether someone gets sick or not?

I think not. Maybe poor have less money for medicine. Poor people more percentage get attracted towards disease. Rich people don't, because rich people will get treatment *snaps fingers* too fast.

Ok. Like that. Do you think that people once they've got leprosy become poor and have no money?

No, he doesn't think like this.

I just asked you if you knew anyone in your community with leprosy, you answered that you didn't know anyone. Uhm, but for example, imagine there was someone here in this village with leprosy. Would you like to know it if someone's got leprosy or rather not if someone lives close to you?

He wants to know. He will treat. He will be go to go to meet him. He will see him, care for him.

So you would like to know if someone's got leprosy, because you want to take care of that person?

Yes, like that.

Ok. And can you tell me how the rest of your village would view or see people with leprosy? How do they in general think about people with leprosy? Do you know that?

...

Do you think that people in your community see leprosy patients as inferior, as less of people, as lower people?

Definitely, maximum. Discredit.

They see them as inferior?

Yes.

Can you tell me why they see them as inferior?

It becomes a mentality you know? That every person thinks that a person is infected with leprosy. We have to be aware of that. We have to protect ourselves we have to not come in contact with him. If you stand in front of a person you get sick.

So it is because of fear?

Yes, it is all about fear. Sometimes it happens that they remove that person from village and uhhh, things.

That they cast a person out of the village?

Yes, like that! Everyone fears that person.

Can you explain to me where that fear comes from?

Everyone is scared of getting sick. A sick person makes another person sick. So we don't want to come near.

Ok. So, as a summary, you say that because of fear of getting sick yourself, you avoid a person, cast him or her out of the village.

Nods head in agreement

Do you think that leprosy patients should be able to work or not?

If you will suffer from leprosy, he will be affected by some many weakness you know, he will not be able to work, his body is all weakness, so the system of the body will not work. The only thing that is left for a leprosy patient is to become a beggar.

Yes, for example if someone's got very severe leprosy I get that. But someone could only have some skin patches right? That person can use its hands and feet, than that person, should he be able to work according to you or should he also be a beggar and cast out?

I think... He must not do work. He shouldn't work, he can give leprosy to others.

Do you think a patient with leprosy is weaker than a normal person? Is that why he's got leprosy?

Yes. That is why he got leprosy. His body can't fight the disease.

Do you think that children or elderly get leprosy sooner than anyone else?

Yes, generally they weaker than other. All diseases they get sooner.

Ok. Correct me if I'm wrong. I summarize: You think a person with leprosy is weak, that's why he got leprosy, but because he has got leprosy, he becomes weaker, so it is a circle that's going on?

Yes. Exactly, maximum.

Ok. Thank you for that. Do people here in the community treat leprosy patients different than other people? Do they give them a different treatment? Or like you just said, they avoid people, they don't want to come near them.

Yes, they make fun of that person. They do gossip at their free time. You know, people in the villages have a lot of free time, so they do gossip about that person. We should be aware of him, do not come in contact with him. They make jokes at him.

Ok, so we can say that someone with leprosy is treated with less respect also, as they make fun of that person?

Yes, yes. Definitely.

And that is all due to the disease, not due to the person's personality, but due to the disease?

I think... I don't understand.

Ok. I'll rephrase, do people make fun of leprosy patients due to their disease, due to their leprosy, or do they make fun and treat them different because of who they are in their mind?

He says that the thinking of village and city not rural and urban areas are two different things. In villages you are good, you don't have any disease like this, oke? Then you are equal to all. But if you suffer from this disease either you are mayor or anyone of rich people, from this village, you will be seen as different eyes. You will be too worried. Good peoples even need to go from their home.

Even if you're a rich person, and powerful in the village?

Either who are you, it doesn't matter. This is the mentality of villages. And city... How he will say as he lives in villages?

Ok. Good, thank you. So, if I'm correct we can say that the different treatment leprosy patients get is a result of their physical manifestations, because you see they've got leprosy, so that's why they get treated differently?

Yeah, after seeing this all we treat differently.

And the different treatment is also the result of fear that people have for leprosy, right? That's what you said earlier. And what exactly is this fear about? What are people afraid of?

He's saying that they are having fear, because if they will they have fear that they will come in contact with them, either in touch or other, because they are not having the leprosy of how leprosy happens.

So it is fear of getting infected themselves?

They don't know how it happens, that's why they are panicking. Many times in our ancient times, like 100 years back, when any disease comes. Like this. Or any disease, which is bigger, you know, then if it happens to one person, they are not aware of that. So it happens then to the whole village and neighbor village also. That's why their mentality is like this.

So, people think it might become an epidemic?

Yes, definitely.

Ok. Thank you for that. How do you feel, you personally about the different treatment that people with leprosy get.

I think... Uh...

Do you think it is fair, unfair, deserved or undeserved.

Yeah... I think, ehm... I think it's fair people affected by leprosy do not get to life in the village.

Ok. It is fair people with leprosy get treated the way they do, can you tell us why it is fair?

Yeah, it is for the best of the village. Because then people in the village do not get leprosy. Some people think leprosy is for bad people and we don't want bad people with us.

Ok. I'm going to summarize this, please, if I am wrong, correct me. But, If I'm right, you think it's fair that people do not live in the village. Either because then they cannot give the disease to someone, but also because some people think only bad people get leprosy, and you don't want bad people living with you in the village?

Yes, yes, like that. It is all for the good village.

Earlier, when I asked you with who you associate leprosy, you did not mention that bad people get leprosy. Do you yourself think bad people get leprosy?

I don't... I don't know. Possible.

Ok. Well I'd like to talk a little bit more about treating leprosy. I know we touched upon it earlier already, but if I summarize what you told me. You feel that leprosy is curable, but a small part of the disease will always stay in the body. So, do you think that someone needs to take his medicine for a lifetime to suppress the leprosy, or is it just taking a few pills and that small part of leprosy won't come out.

I think that as I told earlier that is not a disease that is prevented for lifetime, only for period of time. You will do your treatment, take medicine, do your treatment and it will get prevented, only until you are taking your medicine.

So, if you stop taking your medicine leprosy will come back?

Yes. If you'll stop, it will come back.

So you need to take medicine for the rest of your life?

Yes.


Do you think medical treatment is the only way to go, or do you also think that medicinal herbs, or religious rituals, living pure and eating good food also contributes to curing leprosy?

Medical treatment, is important. But medicinal herbs too. Not religious rituals. Or living pure. Only medicine.

Do you think that curing leprosy is only dependent on the medicine or medicinal herb, for example the quality or efficacy of medicine, whether it works or not. Or do you think it is also dependent on one's adherence to the treatment, if he or she sticks to the treatment?

It is extremely important that medicine are taken. Not to high mg, but you must take it all the time. Discipline is important, you must take it at certain times a day for it to work. You cannot take it only in the morning all. You must take medicine more than one time a day. Discipline is too much necessary for taking medicine for the prevention of leprosy.

3th May, 2017

Interview 2: Kasopur 

“Som” (Interview partly English, partly Hindi)

21 y.o., f., student

Hindu, higher education

Has no close relationship with anyone who’s diagnosed with leprosy, but has seen people with the disease.

Can you tell me about the disease leprosy, or *kushta rogh*?

Leprosy is a type of skin disease, in this disease skin was damaged. And uh, that’s all.

Damaged skin. Ok. Do you know what causes the disease?

Yeah, eh, pollution. This is the cause of disease, and eh, ... yes.

Sorry, come again, what do you think is the cause of the disease?

Pollution.

Pollution of what? Of air, of water, of food?

Yes, water, food, air pollution.

Pollution thus causes the damage to the skin in leprosy?

Yeah, I think.

What do you think is in this pollution that might cause this damage?

In leprosy the skin is damaged and ... Uhhh... I don’t understand...

Do you think this pollution, what does this pollution consist of, what is in this pollution that makes the disease?

Like, uh, smoke, industrial smoke. The smokes comes from the plants and from the industries it is a bad pollution that causes skin damage. It also comes in your garden on your plants you eat.

Ok. And when this smoke comes on your skin, or you eat it via vegetables or you breathe it, and that causes leprosy?

Yes.

Thank you. What kind of symptoms or signs are associated to leprosy?

Leprosy has skin damage. Body parts are damaged, eyes can also be damaged.

What kind of damage to the body parts, what do you mean with that? Can you show or explain that to me? Or how it looks?

Holds her hands up like claws. Wounds, falling of the finger nails also.

Thank you, this helps! Do you think that leprosy can go from one person to another person?

No. It is non-communicable disease. But, because leprosy patient has bad health, other communicable diseases he can give to other persons. So, leprosy patient must be alone.

Do you think a leprosy patient can live in the village with other people?

No. He must live somewhere without people.

What do you think is the duration of leprosy? Do you think it is a lifelong disease, or is it only for a few months?

If you, if you... She is saying that if you will get a treatment of this disease, so it can be prevented, all symptoms. Otherwise, if you will not do a treatment, than it will not be prevented. Then, it will be for a lifetime.

So, if you get the right treatment it is a short disease, if you get no or wrong treatment it's for the rest of your life?

Yes. Exactly like that.

Ok. Thank you, that is good to know. Do you think also that leprosy sometimes can become worse, that it flares up a little bit, and then it becomes less. Or does that not happen?

I don't know. I'm sorry.

You don't know? It doesn't matter. If you don't know something, just be honest about it. It doesn't matter. I just want to know what you think about the disease. With whom do you associate leprosy? Do you associate it with children, do only children get leprosy, only weak, only poor people? Only rich, or elderly?

I think poor people and ... No only poor people.

And why poor people?

Because, the poor people get affected by leprosy due to it happen not so fast treatment. And prevention, they are dependent on the government medicals, medicines you know. They are not getting it properly. That's why they get affected more by this disease and by unclean environment. The poor people get affected due to it all.

I don't completely understand you yet, because you said that pollution causes leprosy, but everyone can get affected by pollution, right? So what makes that the poor people get leprosy sooner? Is it because they are less clean, or have no money to buy soap?

Both are reasons. They have no facilities and money and ehh... And less clean also, so dirtiness stays.

And because they have less money, they don't go to the hospital as often. Ok, thank you. Do you think weak person get affected by leprosy, like children or elderly people? Does it matter?

Yes, their bodies can't fight the dirtiness and pollution. So they get sick sooner and get leprosy sooner.

Ok.

Because, weak people mostly get affected by leprosy because of proteins. Something like that is not in their body, the amount is too low. It is not able to fight the dirtiness and pollution.

They don't have a good enough body for fighting disease?

Yes. They have some things not, like proteins.

Thank you. Do you think people become poor when they get leprosy, even poorer?

Poor it doesn't matter. If they know what is need of their body, and what kind of problem and vitamin and protein they need, than it doesn't matter. It's for everyone. Mostly, it is not necessary that a person is rich. It depends on the clean environment, if one lives in clean area away from pollution, he will not suffer from leprosy. Otherwise he will. Rich or poor, doesn't matter.

But do you think that as a consequence of leprosy, or that for example if someone gets leprosy, will he become poor, due to the disease? Do you think that he can maintain what he is doing if he gets leprosy?

No, not necessarily. If it is worse leprosy, he has trouble with his hands and other bodyparts. He can't work anymore and must ask people for money. He will lose his job.

Ok. Then we will continue with the last part of our questions. I asked you whether you know anyone in your community with the disease leprosy or *kushta rogh*, but you did see it in another village near here. Imagine that there would be someone in your village, who has got leprosy. Would you like to know that, or would you rather not know that someone has got leprosy?

First of all, they must get the proper medicine and facilities, they must cleaned and uh, be aware from clean lands and I will meet him or her, than I will give him the proper treatment. We must make him aware of how to prevent further disease and how to live with leprosy.

If I'm correct, you would like to know if someone's got leprosy so you could help him or her?

Yeah.

Is there also another reason you would like to know it?

No, only to help them to make sure the disease does not spread.

Can you maybe tell me, about how people in your community see a person with leprosy? How do they think of leprosy patients? Do they see them as inferior, as less of people or are they equal to themselves?

...

Do people in your community see leprosy patients as inferior, as less or a person. As someone who is not worth as much as other people?

I think as lesser people.

You think people see them as inferior, as a bit like *depicting lower status* a downgraded person?

Yes. I think. People with leprosy can give diseases they get due to leprosy, because they are weak, to others.

Can you tell me why people think leprosy patients are inferior or less of a person?

I don't know. I think it is because they are often dirty and poor. People don't like to come close.

Are leprosy patients capable of working?

Obviously, I think it differs per person. Most leprosy patients are dirty and poor. So, if they don't treat their leprosy it will go on, go on, go on. It gets worse. If it gets worse, working is not possible. No job for them. No one would want to work with leprosy patient, no one would like to have leprosy patients employed, no one would buy from leprosy patient. So, if leprosy is visible, they can't do work.

And if a leprosy patient can't do work, then what should they do?

It depends on the stage of leprosy, but they must beg and receive money from government or charity. Also, they cannot work like we do. They do less. So why would they live like we do?

Do you think a leprosy patient is weaker than a regular person?

Yes, obviously he is weaker. He was weaker at start of disease, and will get weaker due to sickness.

Do you also think that, as you just told me a weak person gets leprosy faster than a normal person, right?

Yeah.

Is it, because only weak people get leprosy, people see them as inferior?

Yes. These people did not treat their body right, and did not live healthy. That's why they got leprosy, because if they treated their bodies right, eat right foods with vitamins and proteins, they would not have gotten sick. The people should have treated their bodies right and cleaned it. They did not, it is their fault they got sick.

Thank you, we will continue with the last few questions. Do people in your community treat leprosy patients different than other people? E.g. do they gossip about a person with leprosy, or is someone treated with less respect if they've got leprosy?

I personally don't do these type of activities. But, you know, in village, people do treat leprosy patients with less respect. They must not live and come near to village. They might give other diseases to people living here it is thought.

And can you tell me how this less respect becomes visible, how do you see that? Can you give an example?

Like any guy that is affected by leprosy, anyone looks at him and thinks don't come near. Don't touch him, stay away. Because otherwise you also get diseases. Don't buy anything from him.

So if I'm correct, there is also a little bit of fear, people are afraid?

Yes. Definitely.

And what are they afraid of?

Of getting disease also. Not only leprosy, but extra diseases from leprosy patients. Also, people fear because they don't know about leprosy. Person affected by leprosy looks different, people don't want to get disease that makes you look different. You are not eligible then.

So, people in your village would avoid someone with leprosy?

Yes, maximum. He must not come to village.

Ok. Thank you. You said earlier that people affected by leprosy look different. And people are afraid that coming near them will give them a disease that will also make them look different. Can we say that mainly the fear of looking different than other people, makes them avoid leprosy patients, or are there any other reasons?

Other reason maybe because, as you know, I have already told you that they're affected by leprosy and other people know that if he will come in front of them, they are also affected by disease. Also, people are poor and dirty. Those people are not liked.

And where do you think the fear comes from? What is the basis of this fear?

It is a lack of knowledge, people don't know about leprosy. Also I know not much about leprosy.

How do you personally feel about people who treat leprosy patients differently? Do you think it is fair that they treat someone differently, unfair, is it deserved or undeserved? How do you yourself feel about that?

I feel that leprosy person should be helped. And must be told about medicine and prevention. But also, it is a person's own fault he has got leprosy. As I told you already, he not treat his body right. So if he had treated it right, he would not have leprosy. So it is deserved.

So you feel the different way people interact with leprosy patients is deserved, because they treated their bodies wrongly. So you feel it is ok people treat leprosy patients different, it is what they deserve and it is fair?

Yes. It is their fault, it is fair. They should first have treated their bodies good.

But, you would still help them?

Yes, because everyone must get help if he needs it. Facilities must be provided.

Do you think leprosy can be cured?

No. I don't think it can.

No? So a person with leprosy, will always have leprosy?

Yes. For the rest of his life.

Do you think medicine, or religious rituals, or medicinal herbs or living pure, are those ways of treating leprosy?

Yeah, most definility. I don't know what kind of medicine or medicinal herbs. But medicine from dokter give treatment for leprosy. But the disease will not go away.

And how do you feel about religious rituals for treating leprosy?

No, no, that will not help. You must go to doctor, get good food, treat body right, get medicine. That help.

Do you think it is important that one sticks to his or hers treatment plan, or can you just take your pills sometimes, and be done with leprosy symptoms?

I don't understand. Can you repeat?

I will try it in other words. Do you think leprosy pills are there for the rest of their lives, or can you take a few pills and then leprosy is cured?

I think pills are the best.

Ok. So they should take pills? But for how low do a person with leprosy need to take pills? For the rest of their lives, or only for a small amount of time? And then the leprosy is gone?

I think for the rest of their lives pills must be taken. Because leprosy is a disease that is lifetime.


And do you think that those pills must be taken at specific times of the day, or doesn't that matter?

I don't think it matters. You can just take some pills.

So, if you forget a pill, and you take it the next day, there is no problem?

No, no problem. I know people who forget their medicine for a week, and then take it all the next week double. No problem. It is ok.

3th May, 2017

Interview 3: Kasopu 

“Krish” (Interview in Hindi)

34 y.o., m., mayor

Hindu, secondary education

Has no close relationship with anyone who’s diagnosed with leprosy, but has seen people with the disease.

Can you tell me about the disease leprosy?

He’s saying about the leprosy that in the case of leprosy your body starts having different types of body, shapes changes, skins and nails are falling started, you know. You start getting weakness you know and loss of sensation also happening.

Loss of sensation, okay. That’s good, thank you very much. What do you think is the cause of this disease?

He’s saying about it happens due to unclean environment. He’s reminding us about what he told last week about open defecation, what he’s saying. About that, no open defecation, it eprosy will not be here. So bacteria are created by open defecation. And bacteria create disease.

Okay. Can you explain to me what the pollution of this dirtiness does in the body to make sure that leprosy comes about? How does he think bacteria work?

He’s saying about it’s all about air you know? And unclean environment, like plastic bags and pollution and all things. They are not getting decomposed totally, then after the insects or animals that are surviving in the environment, they’re having some bacteria on them. They drink the water and via the water people come in contact with bacteria. That’s slowly makes you a patients.

So if I’m correct, please tell me if I’m wrong. But if I summarize: due to pollution and open defecation bacteria in the ground and water they get picked up by mosquitoes, insects and other animals, the sharing of water or eating these animals, the bacteria comes into us, and that’s how leprosy comes about? Or when an insect stings you? That’s how leprosy is transmitted?

Yes, but also if people are religiously unclean themselves they are more vulnerable to get bacteria.

Ok, thank you so much. So religion can determine whether you get leprosy if I understand you correctly?

Not for 100%, but 50% is religion.

Ok. Thanks for that. Let me ask you something about the symptoms and signs of leprosy. You said nails falling, loss of sensation, wounds on the skin... Do you know any more signs?

No he don’t know more than those.

No worries, I’m just curious.

Wait, he’s saying about his nose that can get deformed.

Okay, that is good to hear. Thanks for telling me. What do you think is the duration of leprosy, do you thinks it’s a disease that’s there for the rest of someone’s life, or is it only for a short amount of time? In other words, would you call it permanent or temporary?

If it will get treated goodly, you know very well, then it’s not for a lifetime period. And if there will be no treatment for the disease, like any disease, it will be for a lifetime period.

And what do you think is a good treatment?

You should go to hospital with this disease. They give you medicine that help you get good again.

You also said that religion was involved in creating disease in the body, right?

Yes.

How do you feel about using religion in the treatment of leprosy?

I think it is necessary. You can go to temple and ask to get better, to get clean and be purified, pray to Lord Shiva. But if you have done bad in early lifes, you cannot change that. You must suffer consequences.

Do you mean karma with those consequences?

Yes. Karma gives disease.

Thanks, and with whom do you associate leprosy? Is it only poor people, or only children, only elderly, only rich people, only men, only women?

There is no difference for poor rich elder younger. It can hit anyone. But, the people that get leprosy have bad religion. They do not follow God's laws and lifestyle.

Leprosy can hit anyone, okay. Does it matter if a person is strong or weak, for example for leprosy... Do you think that a person who's stronger or weaker maybe get leprosy sooner?

He's saying that it creates fastly affects the weaker person. Because if you're stronger, it means your body is good. You can fight with the bacteria. But people who live in polluted areas are always weaker, so they cannot fight bacteria. So it happens to mostly weak peoples.

Weaker persons... So it does have got to do with fighting bacteria you think?

Yes.

Dji, dji, thank you for answering. I've already asked you whether you know anyone in your community with leprosy. Just imagine someone here in the village has leprosy, would you like to know that, or would you rather not know?

Yes, he will go, because he's social worker of this village, and mayor, so he will go. But, not as social worker or mayor he will go, but because he's a good person.

And, can you tell me how other people here in the village would see a leprosy patient? Would they also go, or would they think no, it's an inferior person, less of a person so I'd rather not go?

He's saying positively. Peoples are having no knowledge about leprosy that how it happens. So due to the lack of knowledge, some people will avoid.

Do they think people are inferior, less of a person when they got leprosy?

Yes, people think leprosy patients are dirty, and weak. So they are not regarded as much as other person.

So, they consider leprosy patients as dirty. But do they also consider leprosy patients unequal to themselves?

People do not. They are not equal they are less.

Not equal, ok. Do people in your community treat, they avoid a leprosy person, but do they also treat them different in another way? Do they gossip for example, or talk bad about them?

Definitely, because they talk bad. They don't like to talk TO him, but they do like to talk ABOUT them.

So, if I summarize it all we can say that a person with leprosy is treated with less respect?

Yes, people here in the village do not respect people with leprosy. But I do, I always help the sick.

Can you maybe explain to me where this less respect comes from and where the fear comes from, regarding leprosy patients?

Knowledge... It's all about knowledge. Peoples have lack of knowledge. If they have knowledge on how it happens, they would not do this. Then they would know how disease goes from one person to another, they wouldn't avoid. But now, if a leprosy patient would be in this house they would not drink water from this house, even though this is not correct. I think the problems are there, because people have visible leprosy. If leprosy was invisible, we would see them as normal, and normal we would treat them.

How do you personally feel about the different treatment leprosy patients or people with infectious disease receive?

He's saying that if you're talking about himself personally. He will be always available for every person, as a normal human being by nature, I must be available for every person suffering of any disease. I will take them to doctor, will have them sit with me, take medicine, take rest and be good. If patients is good, I will be good.

Can you think of anything that could be done to make sure that people in your community will treat patients with leprosy as more equal, or better?

If people know how leprosy comes, they dare to talk to them, then they know that leprosy patients are not dirty, but just less strong due to pollution. As I always say to the people, they must clean the environment, then green, and free of pollution. Then, nothing will happen. Clean environment, he always thinks about that.

8th May, 2017

Interview 4: Hamidpur 

“Jai” (Interview in Hindi)

30 y.o., m., gov empl

Hindu, higher education

Has no close relationship with anyone who’s diagnosed with leprosy, but has seen people with the disease.

File 5 and 6

Thank you for talking to me, I really appreciate it. Can you tell me about the disease of leprosy?

Yes, leprosy is not genetic. It happens from the uncleanliness and dirty environment. It is not from genetics. He’s saying that only.

So, if I’m correct, you think that leprosy is caused by an unclean environment?

Yes.

What in that unclean environment, can you pinpoint one thing exactly that causes leprosy?

Open defecation. In the open, animals are dead, and also these rot. Through that all leprosy comes. Everything that is unclean.

What kind of symptoms or signs do you associate with leprosy?

Loss of sensation he’s saying. Skin patches he’s saying. Wounds on the skin. He has seen this all.

Do you think that symptoms are worse in the beginning or in the end of the disease?

He’s saying some of them are happening at the beginning, some in the end.

What kind of symptoms do you think happen later on in the disease?

Loss of sensation happens late.

Ok. How long do you think leprosy lasts? Do you think it’s a lifelong disease, or only for a short amount of time?

It can be treated. But due to of not getting so much facilities in India here, and medicine correctly, it causes suffering. But leprosy symptoms can be prevented.

Thank you very much. With what kind of people do you associate leprosy?

It can happen to anyone, due to destiny. It’s destiny, it’s not necessary that it is him or here, it can happen to anyone.

I’m not completely sure I understand. What do you mean with destiny?

I mean, it is upon luck. Who’s luck is bad will get leprosy due to the unclean environment, who’s luck is good will not get leprosy due to unclean environment.

What determines whether someone is lucky or unlucky?

What you did and what you do. Yes, yes, they are unlucky because they did something wrong, they did bad things.

Bad things such as?

Yes, not going to temple. Bad persons, we don’t want them.

So everyone can get leprosy, or only unlucky children, elderly, rich, poor?

It can happen to anyone of any age.

I just asked you about whether you knew anyone with leprosy, that was not the case. Just imagine, that there would be someone with leprosy. Would you like to know that someone has leprosy?
Yes, he would like.

Can you tell me why?

He's saying that if he has some knowledge like that, he would go to him, as a social person and he will meet them and spread his knowledge, and tell them to go here for this medicine or there. As a normal human being.

Then I'd like to come back once more to the cause of leprosy. How do you think leprosy goes from one person to another, how is it transmitted?

Due to insects and mosquitoes.

So, it doesn't matter whether you are close to someone, whether you visit someone with leprosy. The transmission happens via mosquitoes, so you can just visit someone with leprosy and not get leprosy? Only via mosquitoes?

Yes, correct. It is like that. Exactly.

Thank you. What kind of problems would a person with leprosy here in your community encounter?

He's saying that the education level system or thinking and relation of the mind is not done in the village as compared to the cities. Okay? So people don't like to go to meet, to touch and many different things they don't want to do, due to the bad relation of the mind. Things like, avoidance and gossiping. This happens in the village due to unknowledgement.

Do you maybe think of any other problems, except for avoidance that might happen to people with leprosy?

He doesn't know. He feels he can't answer.

No worries. How do people in your community here view people with leprosy?

There is no leprosy here, so he cannot say.

Would people consider someone with leprosy or another infectious disease as inferior?

Yes, they are unlucky because they did something wrong. They did bad things. We don't want them. People who do bad things have lower status.

Do you think that leprosy patients are dirty?

Yes, they get the disease from an unclean environment. They must be more dirty than others.

What makes it that someone is more dirty than another?

As I said, it's because you did something wrong. Then you get bad luck. Then you get dirty. The more wrong, more bad luck, the more dirty.

Do you think people who've got leprosy have got a weaker body than healthy persons?

As I told earlier, it's all natural, about bad luck, then he get sick. The state of the body is determined by unluck and bad things. It is not only leprosy. This happens with any disease. Any disease can happen to anyone. The person who takes alcohol gets cancer, but also the ones who don't take alcohol. It's all about luck.

Do people in your community here treat patients that are suffering differently from other people, except for avoidance?

Yes. People gossip and make fun.

May I ask what kind of gossip happens, what do they say?

They say bad things. Because the sick person has done bad things to get bad luck and get sick.

Ok. So, you can say they are treated with less respect, because of what they've did?

I don't respect people who do bad.

But you did say you would visit the persons as a social person, to get them treatment?

Yes, because that is a good thing. Sharing knowledge on disease is a good thing. . Not going, not sharing is bad, I want to live good lives.

Would you visit a leprosy patient on any other occasion? Just for a regular talk?

No.

Ok. I see, so if I understand correctly and...

I said before, people get sick because of bad lives. I don't want to be with people who have bad lives.

Ok. Thank you for your explanation. You stated, and please correct me if I'm wrong. People here in the village are unknowledgeable about leprosy and infectious disease, because they don't know things they will treat people differently and they will avoid them?

Yes. They will.

Do you think there is also a bit of fear, that they fear themselves get infected? That that is part of the reason they avoid people?

No.

They don't fear their own infection?

No.

Ok. Do you think the different treatment a patients receives is differently, e.g. by avoidance?

yes. It is fair and deserved. Patients lived bad lives.

You stated that it's fair that a patient gets avoided, but you visit them anyway, you told earlier?

Yes, I don't know about the rest of the community, but I want good life. The rest of the village I don't know, they are of unknowledgement. So it's fair from community side.

Ok. Thank you for that. Now with the last questions... You told me that leprosy can be cured, but how would you cure it?

With medicine, from the doctor.

Would you take this medicine lifelong, or only for a short amount of time?

It is a talk about science, but the doctor gives you medicine for the symptoms. But the disease is always in your body and can be invisible because of the medicine. If you stop taking the medicine, leprosy comes back, so you must take it for the rest of your life.

Do you think it is important someone takes his medicine on time? Or is a gap or delay in treatment bad?

If you don't take medicine on time disease comes back. Also, if you take medicine later, symptoms are worse, so that makes it harder for the medicine to make the disease invisible. You can better take your medicine at start of disease, than later. And keep taking.

Ok. Thank you very much for answering my questions. I appreciate it that you took the time to talk to Aakash and me about leprosy. Is there anything you want to ask me, about the research or

leprosy in general?

8th May, 2017

Interview 5: Hamidpur 

“Weshna” (Interview in Hindi, translated immediately)

23 y.o., f., student

Hindu, higher education

Has no close relationship with anyone who’s diagnosed with leprosy, but has seen people with the disease.

File 7

Thank you very much for cooperating in this interview. I’d like to ask you a series of question. If you don’t know the answer, you can just say so. If you don’t want to answer, you can say so too. Could you tell me what you know about the disease, *kusht rog*, or leprosy?

She doesn’t know anything about it.

You have no knowledge on the disease?

No, I don’t know.

Ok. No problem. Could you maybe tell me, what do you think might cause *kusht rog*?

I don’t know... It happens due to touch. Coming in contact.

Coming into contact with whom?

With another patient, I think?

Ok. That’s how it goes from one person to another right? But could you maybe explain to me, what causes the disease in the first person. How does he or she get leprosy?

She’s saying, what she heard about that, is that it happens due to touch. More she doesn’t know.

Could you tell me who told you about this touching?

I don’t know, just people. When we talk with family and people. Also friends she says.

What kind of symptoms do you associate to leprosy?

Ehmm, she doesn’t know. Only white skin, and the pictures you showed and what you told, hands that go like this *shows clutched fists*.

Ok. Thank you. Do you know how long these white patches last, how long the disease lasts?

She’s saying that it gets treated, what she heard. So it stops when treated.

And, do you think that leprosy, once it is treated it is cured, it is gone?

Yes, she is saying that.

And what about skin touch, after a person is treated?

She is saying that with treatment, the disease is prevented.

Can you tell me how people should treat leprosy, what is the appropriate treatment?

She is saying that a person should go to the hospital. To get medicine from doctor.

Do you take this medicine for only a short amount of time, or for a longer timespan?

She is saying that, you take medicine for the treatment. Only for the treatment, and if it is treated, why take medicine for longer, for the life time? She is saying that she thinks you only take it for treatment, then it is gone.

Ok. The treatment is thus only of short duration, you think?

Yes, it is not lifetime like diabetes. Once the medicine cure the disease, it is gone.

Ehmm, what kind of people do you associate leprosy? Who do you think gets leprosy?

She is saying that it doesn't matter about age or being rich or poor. It can happen to anyone.

What do you think makes sure that someone gets leprosy? Is there anything that you think a person has or does that makes sure they get leprosy?

She is saying that it happens more to the weaker persons. Their body is not strong and cannot fight the disease. The disease affect the body most fastly.

I asked you whether you knew someone with leprosy, but you don't. If you could imagine that there is someone here in the village and community, how would you feel about a person that has leprosy?

She is saying that she would like to know who would have leprosy and she would go. She is saying that she can help the person. Maybe bring him or her to the hospital. Or maybe she can tell him or her that they should get medicine from the doctor. She wants to share her knowledge, but she does not know much.

Please correct me if I'm wrong, but you would like to know who has got leprosy, just to make sure you can help that person for example by making sure he goes to the hospital and gets treatment?

Yes, she is saying that. But also, because she knows little about the disease, she thinks that getting to know the person with leprosy, and knows what the signs of leprosy are, she can enhance her knowledge. She gets to know better.

Ok. That is very nice. How do you think people here in the village would look at a person who has got a disease like leprosy?

She finds this difficult to answer, because there are no people with leprosy in this village. But she has seen people with leprosy in other village and when she gets to college she has seen people with leprosy. She knows that other people do not see that person often. They do not go to the sick person for nice things, no drinking tea together or chatting. She does think that people also want to help and tell the doctor to go to the patient. Or tell the patient to go to the doctor.

Thank you. In general, do you think that people affected by leprosy are equal to other people?

She is saying that it depends on the thinking. On the thinking of the society. Also, if people with leprosy are high persons, like a mayor for example. Then, if they have leprosy, people do not think bad of them. But a person with no work, but he has leprosy, then people will think bad of them.

What do you mean by thinking bad?

People will think not go close. Will think that he or she have no good life, did not do good.

Do you also think that? That the person with leprosy have no good life?

She is saying that she doesn't think that a leprosy person has lived no good life. Some people in her village say that due to living bad, someone could get sick. She thinks it is about the body. If the body can't fight the disease, you get disease.

Ok. Do you think that you can do things to make sure you don't get the disease?

You need to eat well, drink good water and good food. You must go to temple a lot she says.

Do you think that going to the temple is good for your body?

She says yes. If you go to temple your body gets stronger. Because, if you pray in temple, you tell what you have done. If you say you are sorry for what you have done, it is no longer in your body.

Hmm, ok. Thank you. If we go back to the leprosy patients, do you think he or she should work?

Yes. If he or she can, she should work.

Could you tell me why?

She is saying, that if you work, you get money. Money makes sure that a good doctor can come and give you medicine. Also, you need money to get good food, to make your body strong again. They work for their surviving.

Would you go to the shop of a person with leprosy? Or buy items from him or her?

Yes. If he makes good things.

Would you also buy food from a person who has got leprosy?

No.

Could you tell me why?

She says, because if the person with leprosy would make good food, with vitamins, then he would not have got the disease. So his food must be not good.

Are you afraid that you might also get sick, if you eat food from a person with leprosy?

She is saying that she doesn't know how leprosy goes. How leprosy goes to other people. But if it is via touching, as she heard, then it must also go via food.

Ok. I would like to ask you, because I don't understand it completely, you would buy items from a person with leprosy you said?

She says yes.

But you would not buy food from a person with leprosy, because you think it is not good food, but also because it might give you leprosy yourself?

She says yes. If the food was good, he would not have leprosy. Also yes for getting leprosy.

Ok. But what is the difference between the items you buy from a leprosy patients and food you buy from a leprosy patient? It is both made by the same person?

Yes, but food you put in your body. It must be good she says. If he or she makes for example something else, like sheets on your bed, it is different. You don't put that in your body. Food can make you very sick also.

Thank you. I would now like to ask you, are you afraid of getting sick yourself? For example, by touching a person with leprosy?

I eat good. But, I would not go a lot to a person with leprosy. Because, if I go less, there is less chance I get leprosy.

There is one last subject I would like to ask you about, namely: What do you think are the biggest problem someone with leprosy has?

She is saying that for people with leprosy it is difficult to do work. She saw the pictures of the hands of the person with leprosy, she thinks, with those hands it is hard to work.

You also mentioned the white skin as a sign for leprosy. Do you think this also causes problems?

She says this depends on the thinking of people. If people are afraid of this, then yes. Then it is difficult to work also, because you can't get close to people. People will not go to you to buy.

Would people also avoid persons with leprosy in other situations? You already said that people would not do nice things, such as drinking tea.

Yes. She thinks that people with leprosy get avoided. Like, they have less friends. Also, I don't know people in my college with leprosy, so leprosy people also do not go to school I think. But school is very important. Without school, you won't get a good job or money. So, if you get leprosy before you go to school, you will not get a good job.

I see that you have to go, thank you so much for your time and for answering our questions!

8th May, 2017

Interview 6: Hamidpur



“Pete” (Interview in Hindi)

36 y.o., m., teacher

Hindu, higher education

Has a close relationship with someone who’s been diagnosed with leprosy.

File 8

First of all, thank you so much for cooperating with us.

It is my duty as a mayor. Of course I will help.

Can you maybe tell me about the disease leprosy?

He is saying that it is genetic. It is genetic in his thinking. It happens from parents to child, it comes via genes, from mother to daughter and from father to son. This is how it happens. A mother can’t give disease to her son, only if she has got a daughter and son that are twins. But, the very first one in the family that gets disease, is due to bacteria. Only if that person has bacteria, he gives the disease to the child via genes. So, bacteria must be in the body.

Ok. Thank you. So you think a combination of bacteria and genes cause leprosy?

He says genetic way, because he heard about that. But the first person of the family is affected by bacteria, and then it is genetic. But it is different, because only grandmother, mother, daughter give disease. Grandfather, father, son give disease.

What kind of symptoms do you think are associated to leprosy?

White patches, spots, skin melting, wounds, nails falling.

You know a lot, thank you. How long do you think leprosy lasts?

He is saying that is for a life time. You keep symptoms for life time. But you can stop disease, but some symptoms are there for a lifetime.

Ok. And with what kind of people do you associate leprosy? With children or elderly?

He is saying that it happens generally more to the elder ones. It happens. It starts sometimes in a person after 30 years.

Do you know why it happens more in elder people?

Due to the weakness of body. They are weaker and older.

Thank you so much. You told me you knew someone with leprosy. What kind of problems does a person with leprosy face?

Mainly in marriage. He can’t get married he says.

Other problems?

In society, people see him different. People will not touch him. Not go near him or go to his home.

So, avoidance?

Yes. People do not go to them he says.

Do you think it is difficult to get work for people with leprosy?

He's saying that the person will be unfit for work. So he must beg. Otherwise he can't get money. But, it depends. If the person has only white patches, he can work. But, if the person his hands are affected, then he can't work.

So, it depends on the stage of the leprosy, whether someone can work?

He says yes.

Would you like to know it if someone in your community is affected by leprosy?

Yes.

May I ask why?

He's saying, since he is mayor he is a social worker so he wants to help him. How it can be treated. He will get help. He wants no one in his village to suffer from any problem.

Ah, ok. Thank you. And how do you think your people in the village view someone with leprosy?

Not good. Dirty.

Can I summarize that as lower status?

Yes, in India, and in this village you can. People with leprosy are dirty, people think themselves are better than patient. They will not go to these people.

Does... You said that people in your community treat people with leprosy different? Like trouble in marriage, avoiding them, are unfit for work. Do you think other problems are present?

He says, it is all about social. People gossip for example. They talk about the patient badly.

Is a leprosy patients thus treated with less respect in your community?

Yes, he says, it is obvious he or she gets less respect. People are better they think.

The different treatment, the avoidance, and all those problems, no marriage, or no work, is that all due to the physical impairment due to leprosy?

Yes, they get fear from what they see. They see the leprosy, they see the nails falling and wounds. If people see this, they get fear, that they also get leprosy. If people do not see it, they don't have fear.

That was actually my next question, whether people fear leprosy patients. Where does this fear come from you think?

Because the leprosy is visible. The people are of unknowledge in this village. They are having a mind, yeah, a set-up of mind They think, if I touch them, I get the disease. People don't know a lot about leprosy. That causes fear.

So, do you also think teaching about leprosy might alleviate this fear, might decrease it?

Yes. Education is always good.

Do you know any other way of decreasing fear and change the behaviours of the people?

He's saying that only giving the treatment is good. If people see that the patient gets treated, they do not longer fear the disease. They see the doctor is helping.

Don't you think it could also be the other way around? Because people see that a person needs a doctor, they do not want to come near?

No. Every person needs a doctor sometimes. If they see that it gets treated it is good. You know, people see that the disease happens. Disease happens. People know that this disease have no treatment. If you do treatment, people will think it is better. He is saying that people will also think it is normal.

Ok. Thanks for that. So, actually when someone gets treated, people will not worry and...

Fear also comes from the name of leprosy he says, so if people see it is treated, that is good.

But what if people who already have got nails falling for example, and they get treated. Then you still see the leprosy, but it is treated.

People will still look at the hands. But they know the doctor also has seen it and gave treatment for it. So, then the patient is ok. Then there is no fear.

Ok. Thank you for your explanation. How do you personally feel about the different behavior towards leprosy patients?

He don't think it is fair. It is not deserved.

And may I ask why?

Everyone is everyone he says. He means that everyone is equal. If you got disease, if you got no disease. Everyone is everyone.

Ha, thanks. Then my last set of questions will revolve around treatment. Do you think leprosy is curable.

Yes, definitely he says.

Could you tell me how it could be treated or cured?

With medicine from the doctor.

Do you need to take this medicine for a short amount of time, or for the rest of your life?

He is saying that he said before. It is a lifetime disease, so you must take medicine for lifetime.

Ok. These were very clear answers. Thank you. Do you think a person can still give leprosy, to his or her children, when he is being treated with medicine?

He says, no. If he treated.

So, treatment stops that the father gives the disease to his son, and mother to daughter?

He says yes.

My last question to you is, whether you feel there are any other ways of treating the disease? You already told me about medicine.

Only doctors can treat the disease he says.

What kind of doctors do you mean?

Only the doctors in the hospital.

8th May, 2017



Interview 7: Hamidpur

“Bulari” (Interview in Hindi)

62 y.o., f., housewife

Hindu, no formal education

Has no close relationship with anyone who’s diagnosed with leprosy, but has seen people with the disease.

File 9

Thank you so much for helping me in this interview. At first, can you tell me what you know about leprosy?

Nothing she says.

Do you maybe know what causes the disease?

She is saying that she really don’t know.

That is no problem. Symptoms, are you aware of those?

No, I don’t know what leprosy is.

Ok. That is no problem. Leprosy is a disease, that if we do not treat it, can cause disfigurement. Also, early symptoms are white patches, and the loss of feeling in those patches. Does that maybe is a bit familiar to you?

I think, it is like *kodh* [dialect for leprosy]. It sounds like *kodh*. But I don’t know what is the cause of *kodh*, she says.

Yes, *kodh* is indeed a different name for leprosy. And it is no problem at all that you don’t know any symptoms. I just would like to know how you think about the disease and persons that have the disease. What kind of people do you think get leprosy?

Who’s luck is bad, will get it. People with bad luck have weak bodies. Age, whether you are poor, that does not matter.

Do you mean karma with luck?

Yes, she is saying it is all due to karma.

If someone gets *kodh*, or leprosy, is that for a life time?

She says that it is.

But do you think you can treat leprosy?

You can treat leprosy “*kodh*” with medicine. You don’t see the leprosy then. But, a minimum part of leprosy will always stay in your body. You can’t get it out. Not all. When you are weak again, the leprosy that you can see will come back. You can again treat it, but it will come back again.

If I’m right, you mean that you can never completely cure leprosy, the disease will hide in your body after treatment, but it will return?

Yes. A minimum part of leprosy will stay in your body after treatment always and the leprosy on your hands and feet can come back when your body is weak.

And what makes your body weak, so that the disease can come back?

Bad behavior, karma... But also bad food and bad water.

Ok.

But, she is saying that she does not know anyone with leprosy, so she does not know about treatment exactly. So, how can she say it so sure?

No problem. If there was someone here in the village with leprosy, would you like to know it?

She is saying she wants to know it. She is saying she will go and see.

Could you explain to me why you will go and see?

She is saying that as a normal human being, we neighbours, villagers are like a family. In happier moments we are together, so why not in sadder moments, times?

That is really thoughtful of you to say, it is beautiful!

She is telling about when the whole village was together. She is telling that she lost her son, he was of his age, almost 34. He had a car accident, two weeks ago. She is saying that what she has did, that God have given her this gift. What did she do wrong?

That is awful, my condolences.

She says it was like a gift to her, a shocking gift. He was hit by a car when he was on his motorbike she says. But, the whole village came together. She does not like to talk about it, she is sad, still so sad.

I understand. If you'd rather stop the interview, we understand. No problem if you do not want to.

She is sad, she says. She does not want to talk.

That is completely understandable

9th May, 2047

Interview 8: Ramnagar 

“Pryam” (Interview in Hindi)

72 y.o., m., ayurvedic health care professional (not a licenced physician)

Received no formal leprosy training

Hindu, *education unknown*

Has no close relationship with anyone who's diagnosed with leprosy, but has seen people with the disease.

File 10

First of all thank you very much for cooperating with me in this interview. Can you maybe tell me what you know about the disease leprosy?

He is saying that both high and low transmission happens. Leprosy comes in the old age alone, and lips will be affected for a lifetime. He's saying one medicines name 'sonto wakadji' (??). It's ayurvedic. It are seeds, and particles from seeds. Also, one oil, that you eat, 4 drops, and you have to also rub it on your body. This will help with leprosy. He's saying that one study in Mumbai, about leprosy is for a lifetime. There is no short timeperiod.

Could you maybe explain to me what you think causes the disease?

He's saying about more blood in the body... ..

Like high blood pressure?

Yes. He says leprosy is caused by high blood pressure.

Could you explain this a little bit further?

Leprosy is caused by high bloodpressure. But you get this bloodpressure by living bad. Living a bad life, you know, a bad bad life, with many sins in your previous lives makes you ill.

He's saying, you know, that, the circulation of blood in some peoples is too good, sometimes lower. That's why leprosy happens.

Ok. So if I'm correct, a too high blood flow, or blood pressure, causes leprosy?

Yes. Too high flow, or too low flow. Both he is saying.

And these disturbances in circulation are because you live bad?

Yes. Living with sins. It causes blood flow to disturb.

Thank you. Could you tell me the signs or symptoms associated to leprosy?

Of course he says. Of course he knows. He's saying 'soon bairee' [translates as insensitivity], white skin patches. Loss of sensation. He's saying same, if you put fire to it, you will no feel it, so loss of sensation.

Any other symptoms maybe, you mentioned the lips earlier?

Yes, the lips might get senseless. Also, there are so many symptoms, but he does not know them all. He only knows these. It's a skin disease, and the hair can fall out. Black hair might turn white. He's telling some other medicine, which you can put on the hair.

You told me that leprosy is a disease for the rest of your life. Do you think that in some phases of life, or sometimes leprosy worsens, or the symptoms increase?

He asks whether you mean for example during menstruation?

For example...

He says that there is no duration for prevention of disease. You must constantly treat it. Yes, it can get worse sometimes.

And when do you think leprosy is worse than normal, so to say?

He's not saying about the symptoms of leprosy now, but about the consequences. In marriage it can create problems. People don't look you know, people don't do marriage.

Ah ok. Thanks. And if I may ask, with whom do you associate leprosy? You mentioned already the bloodflow, and the living bad, so I can also imagine that elderly, who have got worse circulation are more easily affected?

It happens after 30 years of age. But it is upon the Gods he says. Who gets leprosy.

I asked you, whether you knew someone with leprosy, you said no, but since you are a HCW, you are a health professional, you know about leprosy. Do you know whether there are any leprosy patients here in this clinic, on treatment?

Yes, he is saying two patients were, but now only one that he is aware of.

Are you yourself involved in diagnosing or treating the leprosy patients?

He says, that when the patient came, he said to that patient, he said to a nurse, that her age was too old, so she could not be treated.

She was too old to be treated?

65 he says. Or even older.

Ok. Can you maybe tell me about the views of the doctors and nurses in general regarding leprosy patients?

Only the sir does the treatment. [The sir being the head of the hospital clinic]. The nurses and doctors treat leprosy patients normally. They are professionals. They do.

Ok. Thank you. So are leprosy patients not seen as inferior, or lower people, with less dignity? In comparison to other patients?

He is saying that in his early days it happened, but now that does not happen he says. He doesn't like it when that happens. Now, it is better.

All people are equal in the eyes of the doctor?

Yes. Yes.

Do... Are doctors willing to examine a leprosy patient?

Yes they do.

And do you touch a leprosy patient when you examine him?

Yes.

Ok. And what kind of problem do you think people with leprosy face in their lives, outside of the hospital. Just in their regular life.

He's saying that the people in the community's society they think that: avoidance, they do not touch, they do not look. They are not equal for society. Not equal... No.

Are there any other problems for people with leprosy? You mentioned problems in marriage already, but are more problems apparent?

He's saying that leprosy is also a problem for people living bad. So the children of someone who has got leprosy, because people are older than 30 with leprosy, so they already have children, have problems. Peoples think they are affected too. Because they grow up with parents that lived bad lives. So children will not get better.

Ah, ok. So the family is affected as well if someone has leprosy?

Yes, because the family is in house with someone who has sins.

Ok. How do you yourself personally feel about the different treatment people with leprosy get in the community?

He thinks it is wrong. You have to treat all equal. He's saying that what the thinking is set up in mind, that is what society does. But they have no knowledge, thus they do.

What do you think can change the mindset of the people?

He's saying that, you know, a place in society is there for people with leprosy. Protected they are there.

Like an ashram?

Correct. It is good society work. There are 50 bed for leprosy patients. They live there, they stay there and is good. This is simple for society, they don't have contact with people there. So it is easy. This makes that they don't know about leprosy. Now, people are slowly changing their thinking. Slowly, slowly people see more. Now they change their thinking.

How do you think we can change the thinking of the people more, or a bit faster?

He's saying he don't know about that all, but he knows the thinking is changing, but slowly slowly.

Ok. Then I'd like to proceed to my final questions, which are about the curability of leprosy...

Yes, yes. Treatment. Leprosy can be treated. Medicinal oils and ___?___ seeds. Leprosy patients must be cleaned.

But you also told me about the woman of 65, but she didn't receive treatment because she was old. Can you explain me that a little bit?

He did that once, but he did what he studied with ayurvedics. It was written that an older age woman, was not curable.

Ah, ok. Like that. Do you think ayurvedic way is the only way to treat leprosy, or are there also other ways to treat leprosy?

You can also treat with allopathic, or homeopathic medicine. Also yunani is used.

I'm sorry, I don't know what yunani medicine is. Can you explain this?

Yunani is ehmm... It is... It is used by Hakims [Muslim physician] and it is used by people in the Muslim caste. In Hindu, you can say it is ayurvedic.

Do you think non-ayurvedic medicine can be used for treating leprosy? I don't know how to exactly phrase it, but I mean Western medicine, such as pills and injections, from Bayer or GSK?

Yes, it can be treated, but not for a long time you can use them.

Ok. Thank you, do you feel that you can also combine these non-ayurvedics and ayurvedics?

No, you cannot do that. You know, allopathics, you can

I'm sorry, allopathics?

English medicine, western medicine. That the doctor writes, like antibiotics you know.

Oooh, that was the term I was searching for.

But you can give these in combination with ayurvedics. But, there must be time between it, between both medicines.

You can't give them at the same time?

No.

So, if you give allopathics first, and after a time span of a month you give ayurvedics, is that possible?

He says, you can give both medicine, but with a difference of 6 hours time.

Ok...

Local application of the ayurvedic oils or pastes, but not of allopathics. You have to eat allopathics. You have to eat the allopathic medicine but with 6 hour difference. Else, paste will come off the body, but also the allopathic medicine.

So, if I'm correct, you can combine the both kind of medicines, as long as you take the timeframe into account?

Yes. He says. But the better thing is taking either ayurvedics or allopathics. Not both.

Can you explain why it is better to take only one kind?

He's saying that every patient has a different complication in his body, so why it reacts sometimes to the medicine? Doctors don't know always. So then it is hard to say if it is the ayurvedic medicine or the allopathic medicine. Then you don't know.

So, due to side effects it is better to take only one kind.

Yes, yes.

Ok. Thank you so much for your time, I've asked you a lot of questions about how you thought on leprosy. Do you have questions for me, about the work, or anything [recording stops.]

Noteworthy: despite the participant stating that he treats leprosy patients equal to other patients, he did show me 'special equipment' for diagnosing leprosy patients, such as very thick gloves (gardening gloves), and special scissors, tweezers etc, that he only uses for leprosy patients.

9th May, 2017

Interview 9: Ramnagar 

“Khaleem” (Interview in Hindi)

35 y.o., m., Rural Medical Officer

Received no formal leprosy training

Muslim, higher education

Has no close relationship with anyone who’s diagnosed with leprosy, but has seen people with the disease.

File 11

First of all, thank you very much for cooperating with me during this interviews. Can you tell me what you know about the disease leprosy?

He’s saying that, it is like disease which damages your hand, body and bones also. Which is inside your tissue, you know. About immunity that declines, it harms the body from inside and the bones and skin are also damaged. Blood pressure is not important he says. He doesn’t think blood pressure is causing leprosy, like his colleague.

Could you tell me what you think are the symptoms of the disease?

Yes. I know it starts with white patches, that if you tickle you don’t feel at them. Also, if you use a needle, you don’t feel it. Black hair turns white. Nails fall, you get wounds on hand and feet. Sometimes the nose and eyes hurt.

Ok. You know a lot of symptoms. And what do you think causes the disease?

He says that it is due to insects, that live in polluted areas. The insects makes infection you know. If there is any pollution or dirtiness you can see it on the side of road, there is dirt. Insects will go on this. But, there is also genetics. If my grandfather is having, it is not necessary that my father will have leprosy, but it can happen to me also.

So, it might skip a generation?

Yes, it does not go from father to child always, but sometimes a son is not sick, but a grandchild is.

Ok. Thanks. So, you think leprosy is caused by a combination of genetics and insects?

Yes.

Ok. And specifically, what is in the unclean environment that causes infection via insects?

You know, he is saying, something might happen. You get into an accident and you have wounds. So through skin the insects place the infection inside the body. There are bacteria that the insects bring into your body. Through skin. It goes through skin he’s saying.

Ah, like that! And can you tell me how... Or do you think leprosy can go from one person to another?

No. Leprosy is a non-communicable disease. It is genetic.

Could you maybe explain this a little bit further? Because, I don’t understand how genetics are involved, and insects at the same time?

It can be both. You get leprosy via genetics. Or via your skin because insects take bacteria from the polluted ground. Sometime, you get nailfalling from leprosy. Then, you go to the doctor and get treatment. But sometimes, the instruments are used. If he uses this again, leprosy also happens through that.

So, there are three ways of getting leprosy: genetics, insects and also via used instruments?

Yes. So if I treat with medicine and instruments, like needle or something. If it is not clean I give diseases. So, I use special instruments for leprosy patients.

Ok. But now I wonder, you say leprosy is non-communicable, but you describe two communicable ways, insects and the instruments.

Yes. But these things need to bring disease to someone. It is not that a leprosy patients gives the disease direct to someone.

Ah. Ok. Well thank you for the explanations, it clears it up! I had some trouble wrapping my head around it, but now it's clear. But, for how long do you think leprosy lasts?

He's saying that the person suffering from leprosy, by his knowledge, he thinks that it is for a lifetime. But only by his knowledge, this is what he heard and read.

Ok. And with what kind of people do you associate leprosy?

He's saying that it doesn't matter whether they are rich, poor, child, kids, old. It can happen to anyone. No difference in that.

And what do you think determines whether someone gets leprosy?

It all depends on immunity he says. If someone is healthy and strong, leprosy will not happen. But if a person is hungry, and does not eat the right foods, no proteins, vitamins, then he will get sick. But, poor people cannot eat the right foods. So we must look carefully, extra extra carefully to them.

Ok. So it's mainly about weak immunity? Being in a healthy state?

Yes. Then you're strong. You are right he says.

Well, I just heard that there were 2 leprosy patients in this clinic currently, but much more in the past. Are you yourself sometimes involved in working with leprosy patients?

He's saying: Yes, there were a lot in earlier days. I work with leprosy patients.

And in what way? Do you diagnose, or treat and support?

I diagnose. Te time period I take for the patients is different from the other patients. I give them special time and special treatment he's saying.

What kind of special treatment?

I take extra care of them. I make sure to clean my instruments extra carefully. I try to clean their wounds and explain to them how they must clean their wounds.

Do your colleagues behave differently towards leprosy patients than you do?

Some colleagues have fear. They do not want to touch, or help cleaning wounds. They are scared of the patients. I told them, leprosy is not communicable, so we can easily help them. I always help the leprosy patients. Now there are only 2, but I help them always. I give cream, that makes the wounds

where their nails were falling better. I talk to them. Some colleagues don't. I only use special instruments, that are extra clean. I use my gloves only one time. I keep telling others, it is not dangerous to help.

But the others do not believe you?

No, they don't believe me. I tell, tell, tell, that they must help. But they do not help.

And why is this?

Because they are afraid of leprosy. The person who has knowledge, will not be scared. The person not having the knowledge, he or she is scared always. Either I am doctor or not.

Do you think people with leprosy face problems?

Yes.

Could you elaborate? What kind of problems?

He's saying about, that firstly he has seen that the person suffering from leprosy he or she gets demotivated by themselves. What are they having a ridiculous disease? What did they do wrong? This is the first demotivation. Second after that, people of the society also avoid them. Do not give them works or something like that. Do not marry. They will suffer all problems, also their family members.

Do you think that this demotivation ensures that people do not go to the hospital with their disease? That they feel that they did bad, and keep their leprosy hidden?

He's saying yes, you are right. People feel ashamed, mainly in earlier days. Not now anymore. Now, people go to a hospital which is not in their village, but go far. So they go to hospital, but not their own.

Thus people feel ashamed about their disease... Ok...

Yes... They don't want to go to the hospital closest, they go far away. We had a patient in early days, that came from Bihar [*NOTE: is a different state than Uttar Pradesh*]. He did not want to go to his own hospital. He did not want his symptoms to show to his own doctor, but he came here.

Why did he not want to show the symptoms to his own doctor?

He was scared that in his village they would know he has leprosy. He was early case, with only patches.

If in his village they would know he had leprosy then... What would happen then?

I said, people do avoidance, or will not give work or buy from the shop. They might not visit temples or holy festivals. Also, for family it is bad he says. People are scared.

I believe, if I hear you correctly, that you feel really strongly about people, both community and colleagues being scared of people with leprosy?

Yes. But it is not necessary. Leprosy is not scary.

All because it cannot go from one person to another directly?

Yes.

Ok. Do you think a family of a leprosy patients is concerned about telling others about the disease of the leprosy patient?

He's saying that they are scared, to able to tell society. They have problems. They have worried.

So, they also rather keep it a secret, just like the patient himself?

Yes, I think.

Ok. Thanks. Now the last set of questions. Do you feel that leprosy is treatable?

Yes, it can be treated.

And how, could you explain?

He's saying that he prefers eating allopathic medicine. It is easier and it can help. It can be treated for the leprosy with medicine, such as antibiotics. In earlier days, ancient times, it was all from the nature, medical herbs. That time, the peoples were able to arrange that. Now it is not easy to arrange the leaves. People do not have too much time for that. I don't have too much time to make ayurvedic medicine also.

Aha. Ok.

So they are taking antibiotics like that, but the formulas are the same as ayurvedic. But is is from the scientific method, and not the natural method. So, it is easier to take allopathic medicine. But, he's saying, that sometimes when peoples really want ayurvedic medicine, he gives them some leaves and oil that do not work. And also gives them allopathic medicine. So, they think it is the ayurvedic medicine that work.

You do that with other diseases? Not only leprosy?

Yes, also with other diseases like rashes or allergies.

Ah. Ok... now my last question. For how long do you think leprosy should be treated, either with ayurvedic medicine or allopathics?

He's saying that it depends on the person. How much the disease is increasing or not.

Like, if the leprosy is in an advanced stage?

Yeah, you know. He's saying that leprosy must be treated for the lifetime, by a life-long medicine regime, such as antibiotics. Sometimes, he gives extra oil, to a patient.

Extra oil?

Yeah, he says that some people feel better if they also get oil.

But not only leprosy patients you mean?

He says that he sometimes gives oil to all his patients. Then they think that they use ayurvedic medicine.

Aha. Well thank you so much for your time and answering our questions ...

Noteworthy: the interviewee brings in a patients from his clinic to show us. He says that this patient has leprosy, however, we can see that this is not the case, but that it is vitiligo.

15th May, 2017

Interview 10: Ax Hospital

“Mobasshir” (Interview in Hindi, )

30 y.o., m., Rural Medical Officer

Received no formal leprosy training

Muslim, higher education

Has a close relationship with someone who’s been diagnosed with leprosy.

File 12

First of all, thank you for your participation. Could you maybe tell me about *kushta rog*, or leprosy?

He’s saying that tuberculosis is also in leprosy.

Do you mean a tuberculoid leprosy case?

Yes, he says that is what he means.

Ah ok. Do you know anything else about leprosy?

He says that he is confused by the name. We call it *kushta rog*, but he calls it *djazam*, which is Urdu for leprosy.

Could you tell me what you think causes *djazam*?

He is saying that he has no idea about that.

No worries, that is fine. Could you maybe tell me what kind of symptoms you think of when thinking about leprosy or *djazam*, since you told us that you know someone in your village back home with the disease?

Nail falling, fingers get lost. He is saying those things. Stumpy feet also.

Any other symptoms?

No, he doesn’t know.

Do you know how long leprosy can last in a patient?

He’s saying that is for a lifetime.

Thank you. With what kind of people do you associate leprosy?

He has saw, he has saw leprosy mostly in children. Yes, most cases were children he says.

Mostly in children, you say. Have you seen some adult cases too?

Yes, he says, but now he does not treat them himself.

Ah, ok. So, you told us you saw some patients with leprosy, but are you aware of any leprosy patients that are being treated here in this health care facility?

No, here are no leprosy patients.

Have you ever, maybe earlier on in your career, or during your residency, treated any leprosy patients?

No, not myself. I've seen them at other doctors he says.

Ok. Can you maybe tell me if these doctors, that treated those leprosy patients, do they behave towards them as they behave towards other patients?

He says, that some doctor back in his village once told him, that leprosy patients must be treated separately. They cannot sit and wait with other patients.

Could you tell me why they did not want the patients affected by leprosy to sit with the others?

Because, he says, because he was worried that the other patients might get leprosy too.

Ok. Do you think this is true too?

This doctor was his teacher he is saying. So yes, he cannot say it is not true.

I'm just looking for your personal opinion, on whether you think it is correct that sitting together with a person who has got leprosy, will result in someone else also getting leprosy?

He says that he doesn't know. Sitting next to someone will probably not give leprosy, but he does not know more.

Ok. Were there any other differences between how your colleagues behaved towards leprosy patients and other patients?

He's saying that the doctors sometimes avoid leprosy patients. Sometimes, they are referred to the government hospital. Then, the doctors there have to take care of leprosy patients, and not private hospitals, like here in Ax hospital.

So, they refer to a government hospital, so they don't have to deal with leprosy patients themselves..? Aha, ok. Could it also be that maybe doctors refer to a government hospital, because the treatment patients get there are for free, whereas they need to pay in a private clinic?

He's saying not. Because if doctors in private hospitals really want to, they can provide care for free. Especially for the extreme poor.

Just out of curiosity, but do you yourself sometimes provide free care here?

Sometimes, Ax hospital staff goes to clinics in villages. There, we give care for free he says.

Ok. That ...

He says that that is really nice to do. People are happy when they come. They are really sick, but can't pay for medical treatment. People are always nice.

That is great to hear. I can imagine it is really fulfilling to do that kind of work. If you're okay with it, I'd like to come back once more to the behavior of your colleagues towards leprosy patients. Can you think of why leprosy patients are sent to a government hospital? Why do private doctors do not want to deal with leprosy patients?

Maybe, he says, maybe it is because they are scared. Like him, he doesn't know how leprosy comes, where it comes from, what causes it. How it goes between persons. So, doctors might be afraid to treat.

So, fear is a driver for referral?

Yes, he agrees. They don't want to touch maybe.

Ok. Thank you. These were mostly questions about doctors and leprosy patients, but I'd also like to ask you about leprosy patients themselves, what kind of experiences they have. So, what I wanted to ask you, is what do you think are the problems that leprosy patients encounter?

Firstly, the people hate to that person. He gets avoided by them, from society. He gets less respect, also his family gets less respect.

Ah, ok. And in what ways can you see that he or she gets less respect?

Sometimes, in earlier days people were not allowed to live in my village when they were sick.

Also leprosy patients?

Yes. But now, not it is, not anymore, nothing like that anymore. Society don't like to –static noise— [interact?] with patients. They leave them. They don't want the patient in groups. But now, slowly, it is better. Especially, if patients get medicine. People are more nice.

Do you think the family of a leprosy patient also has problems?

Yes, definitely. Maximum.

Could you tell me what kind of problems?

They can't go with the leprosy patient anywhere. In my village, the patient was often kept inside the house.

Ah, ok. Why was that, was the family ashamed?

Yes.

Can you think of any other problems a patient may encounter? For example in marriage, or jobs.

Yes, problems in marriage. And they cannot keep a job. Also, society does not want to eat with a patient he says.

Is this only in rural areas, or also in the somewhat bigger places, like Chandauli?

Mostly in villages.

Hmmhmm, ehmm. Do you think people treat a leprosy patient differently, because of how he looks?

Yes, it happens. When you see disease, it is scaring. If you don't see disease, you don't know. So no scaring, he says.

So you think there is fear involved?

Yes, most definitely they have fear. They have fear they will also get disease. You know this.

How do you personally feel about the different behavior towards leprosy patients?

You know, the things done by society he says. They shouldn't be done. It is not good. He believes, that if someone has leprosy, or any other disease, for example diabetes, they are still human beings. I need to give help he says. Society also makes sure that they do not get treated. But people in the village should help each other and give each other medicine.

What do you mean by that, by not getting treated?

Also for the doctor patients hide their disease, he says. Not only in leprosy, also with other diseases for example.

Which other diseases?

You know. Scabies or ulcers or wounds he says.

You said you think people are always human beings and need help. But people in the village, for example your village, do not think like that? They have a different mindset?

Yes. I know that some people in my village, they think that disease is due to karma. But I know this is not always true. Some people just get sick because their body does not work right.

Some people, not all people?

Some things, he says, some things he cannot explain. He cannot use his knowledge to say what causes the disease. So, then, it might be that not something in the body gives disease, but something else you know?

What do you mean with something else, sir?

He says, that he read that the mind of a person can be stronger than the body. The mind can heal the body, so can also make it sick.

Ah, ok. A 'mind of matter' issue you mean. Thank you. A few last questions. Do you think leprosy can be treated?

He's saying that, he don't think like that. The patient he saw in his village, his disease is not prevented. So, it can be happen only that they do not take the proper medicine or that he does not get right treatment.


But you yourself, sir, do you think there is a correct treatment for leprosy? And if so, what is it?

Yes, it can be. But I don't know what the treatment is, he says.

Ok. That is no issue. Lastly, you stated that leprosy was a disease for a lifetime you thought? Should you also take disease for a lifetime if you have leprosy?

He says he has no idea about this treatment, he does not know the answer to this question.

Ok. That is fine, no problem. I just want to thank you very much for your patience and time...

15th May, 2017 

Interview 11: Ax Hospital

“Rishma” (Interview mostly in English, partly in Hindi)

27 y.o., f., junior doctor

Received no formal leprosy training

Muslim, higher education

Has no close relationship with anyone who’s diagnosed with leprosy, but has seen people with the disease.

File 13

Rishma, thank you so much for contributing to this research by participating in this interview. We really appreciate it. I’d like to ask you first, what can you tell me about the disease leprosy?

She is saying that you will mostly see it in the places of rural areas, it can be happening due to a lack of vitamins and also due to additional causes. I believe there is no bias in gender, so I know it has got no hormonal cause. I only learned about leprosy superficially during my training, I know notice how little I know about it.

Ha, ok. Well, I’m not testing or quizzing you. It’s just to see what you think of leprosy and of people affected by leprosy, remember? So, just answer honestly if you don’t know the answer, or if you are doubting. So, do you know any symptom of leprosy?

The fingers dissolve in the end, so do the nails. Like wounds on the hands, you know?

Do you know any other symptoms?

Skin patches occur also, if I’m right.

Thanks. How long do you think leprosy lasts in a patient?

I believe it can last the rest of your life, but if you are early with treatment, you can prevent many complications, such as the dissolving nails and fingers. Also toes can become numb, right?

Yeah, feet are also affected by leprosy sometimes. But thanks for these answers. With whom do you associate leprosy?

It can happen to anyone. I think it happens more often in poor people, since these are uneducated and maybe don’t have the medical facilities to treat it correctly. Therefore, they have more extreme forms of leprosy. But... Yeah... Poor people lack vitamins more than rich, so that is also of importance.

Right, and do you think age matters?

No, age doesn’t matter. I believe children and parents and grandparents can get leprosy.

Ehmm... Ok. Do you know how leprosy is transmitted?

Honestly, I don’t even know whether leprosy is an infectious disease and can be transmitted, whether it is hereditary or differently ___??___ [acquired?]. Do you know how it goes?

Yeah, leprosy is an infectious disease, it is caused by a mycobacterium, which is now thought to spread via droplets that enter one’s body via mucosae in the airways. But, I’m happy that you are answering frankly that you didn’t know how it is transmitted. Did you even treat a leprosy patient during your residencies?

No never.

Were you ever involved in diagnosing leprosy? Or with a leprosy patient at all?

No, never.

Ok. Then we'll move on to the other set of questions. What kind of problems do you think people with leprosy face?

I think... I think... that people will dislike that person who is suffering from leprosy. People don't like to be with them, and will avoid them.

Do you think leprosy patients are scared to go to the hospital?

I hope not. But I think leprosy patients are scared about the peoples in the hospital, how they will treat them. They will notice their patches, and mind find them repulsive.

So, you think the patients are ashamed to come, as they might feel uncomfortable with for example staring?

Yeah...

Ok, but you said 'peoples in the hospital'. Do you mean patients, or hospital staff?

I actually think both. Patients, or visitors don't know about disease. That they are looking at leprosy patients is normal. Hospital staff should know about leprosy, but doesn't. I don't know. I would also stare maybe, if I see someone with large patches, or with disfigurement. I would try not to, but that is because I'm aware of what I'm doing. Some other staff might not.

Ok. So we established shame to be a barrier to visit the hospital, right?

Right. Yes. They are ashamed of their disease.

Do you think that people with leprosy also have problems in their personal life?

Yeah, I don't think a person affected by leprosy is a great candidate to marry. And, if you have severe leprosy, with disfigurements, a job is difficult. I don't know whether leprosy influence one's ___??___ [Hindi word for fertility], but if men think it does, this makes a woman less wanted.

Ah, that is... yeah, that could affect indeed if a woman gets easily married. But do you also think that hospital staff treats a leprosy patient differently, or behave differently towards a leprosy patient, than towards patients with other diseases, infectious or not?

Yes, I do think so. Like, with the staring maybe.

Ok, also other things?

Hindi: They don't like to go to that person. Other patient gets properly treated, but leprosy patient is being disliked to be treated.

Ok, why is that?

She is saying that they are having a fear, that for example due to touching them, they will also get that. They fear. Leprosy looks scary.

Hmm, ok. How do you personally yourself feel about this different behavior?

Mainly, private doctors send leprosy patient to government hospitals also. If this is the best way for the patient to get correct treatment, I think this is correct.

But you also said that doctors do not really like to diagnose and treat leprosy patients.

Yes, not in private clinics.

Do you think this is also the case in government hospitals? I can imagine that those doctors feel the same?

Yes.

Ah, ok. Do you think it is fair that leprosy patients get this treatment?

I want everybody to be treated equal. Everyone is the same.

Ok. Good to hear. Would you yourself also be a bit scared by a leprosy patient if I may ask?

I think I would get a little bit of fear, but I would treat the patient anyway.

Would you know a way of reducing the fear that is present in health care workers?

No. Not really.

How would you feel about leprosy training, do you think this reduces fear?

I think that the more knowledge on the disease, the better. So, if you increase doctor's understanding of the disease, they will treat a leprosy patient better. If they know what they are doing, they are also more confident to treat someone, and more confident in how to handle someone.

Ok, thank you for that. Just some last questions now... Do you think you can treat or cure leprosy?

I think it can be treated, I'm not completely sure whether you can cure it. But, proper treatment can stop the developing of disease. But proper treatment cannot be done.

Can you explain that to me?

You can do treatment, but it is not totally curable.

Ok, why do you think it is not totally curable?

I think a little bit is left, if you use English or allopathic medicine, but some things are left in the body. Some particles.

A little bit of the disease will be left in the body?

Yeah, and next time it will go again, and when the body is weak, it will be present again.

What kind of particles do you mean, that are left?

Not really particles, but maybe just disease parts.

Ok... I think we are done actually, is there anything you would like to ask me, or Aakash?

