

District: Pamekasan

Participant type: close contact

Contact 1

Interviewer (P)

Juhawi PKM Talang (J)

- P : Assalamualaikum warahmatullahi wabarakatu
- CC-PAM-B1 : Waalaikumsalam warahmatullahi wabarakatu
- P : Good afternoon, Sir. I am sorry to be taking your time. Allow me to introduce myself. My name is Lingga, I am an officer from NLR. I am here to conduct interview with the society in relation to drug distribution to prevent leprosy, which has just commenced in your area. Are you willing to provide me with your opinion on this? This interview will take about 30 minutes. Are you okay with that?
- CC-PAM-B1 : Yes
- P : Okay. What is your relation to the patient? Who is he to you?
- CC-PAM-B1 : Father
- P : Oh, your father. What is your name, Sir?
- CC-PAM-B1 : XX
- P : Mr.. Let me ask you the interview questions now, since you seem to be in a rush. Can you tell me about leprosy?
- CC-PAM-B1 : Leprosy is an infectious disease which at the time is seen as the epitome of affliction in the community. So it is highly feared, and people with leprosy feel as if they are shunned from society for the time being.
- P : What is the cause?
- CC-PAM-B1 : To my knowledge, women in their menstrual cycle are not permitted to have sexual relations in any religion. So the majority of the community here believe that to be the cause. Bacteria is the cause, and it is believed that (babies) born carrying contaminated bacteria (end up having leprosy)
- P : All right. You mentioned earlier a number of causes. Do you know the symptoms?
- CC-PAM-B1 : The symptoms are usually excessive itching and inflammation of the skin. Other than that, I don't know. But what I know is that there is a bit of itching and inflammation of the skin, that is all.
- P : Okay. Let us go to the second question: from where or from whom did you receive information regarding leprosy?

CC-PAM-B1 : Information on leprosy is something I have had for a long time, so the information can be from the media to launch right to the society.

P : What about yourself, where did you get your own information?

CC-PAM-B1 : Information that I know I got from the community. So I can immediately discern such symptoms as being leprosy. Sometimes people have itch spots that persists...

P : Has there been any education on leprosy in your village, Sir?

CC-PAM-B1 : I would say there has been, but it is a rare occasion. At the regency level, there probably are more, but in the district level we rarely have any.

P : Are there any representatives or cadres from the Health Center or whatever to provide education on leprosy? Perhaps you've heard about such initiatives or perhaps you were personally present at one?

CC-PAM-B1 : Not particularly, but I have heard of irregular education on leprosy. Specific initiative to eradicate or eliminate leprosy at the district level, I don't think I've heard any.

P : Never or rarely, Sir?

CC-PAM-B1 : Rarely. There has never been any particular initiative that invites the... (society) but there are irregularly initiatives of education that I've heard of

P : Alright. When did you get the information on leprosy, from when?

CC-PAM-B1 : I got the information for a long time now, even before I got married. But in terms of education, that is rare. Initiative for prevention is even more rare at my village.

P : You mentioned that you had your information from the society. I've heard from social media. What was informed to you that you can give input to. What did they inform you?

CC-PAM-B1 : What I can inform there is, ofcourse, initial symptoms, the stages of leprosy. Those are the things usually given there. So I understand and know what the symptoms are like, such as itching and all.

P : Alright. Let me go on to question number three: can you tell me about the perception or opinion of your community regarding leprosy patients or people with leprosy?

CC-PAM-B1 : For the time being, the opinion and perception of the community towards people with leprosy is malevolent. In other words, it is terrifying the society. So terrifying so that the patients are ostracised from society. Perhaps the patients then feel inferior and all that.

P : Allow me to explore deeper here. Mr. Bahrud here stated that he has been diagnosed with MH. Let's just say it is that leprosy thing. Are there friends of Bahrud or his relatives or his neighbors that shun him?

CC-PAM-B1 : Up to this point, everything is just normal. Perceptions of people outside is that it is not a problem. Same goes with close friends: it is not a problem

P : Okay, do the people in your community treat leprosy patient differently to other people?

CC-PAM-B1 : In my community, I don't think there is any difference at all. Every morning we see one another and we (do this), but perhaps in other communities are different. We have no problem in our community.

P : Alright. Is there any difference if a person has visible leprosy signs or not?

CC-PAM-B1 : There is

P : What about those with visible signs, what are they like?

CC-PAM-B1 : Those with visible signs usually have reddish (spots). Sometimes they become open sore and persists, not healing. And then there is sign that the hand is like this. There is reddish spot on the ear, on the cheek sometimes. That would be acute case by then.

P : Yes, so by the signs of the visible and invisible, leprosy can be diagnosed, is that so? Next question: can leprosy affect just anyone?

CC-PAM-B1 : Yes, it can

P : It can. How so, Sir?

CC-PAM-B1 : Because it is bacterial and everyone is vulnerable to it. However, incubation period and infection time is rather long term, so it is not one or two days or a week. It takes longer period. Infection can affect husband and wife through touch.

P : You are quite knowledgeable about this. You have been answering my questions without hesitation. Would you be curious if you knew someone has leprosy?

P : Let me clarify that: would you like to know more what leprosy is like, judging by the visible signs?

CC-PAM-B1 : Yes.

P : Why? Why are you inquisitive about it?

CC-PAM-B1 : I want to know the stages of leprosy, whether the leprosy is treated, and whether it is visible

P : I see. Next. How do you feel if I tell you that there is a drug available to prevent leprosy?

CC-PAM-B1 : That is very good. And highly expected both now and in the years to come. I hope it will not be delayed further if there is such a thing as preventive drug for leprosy

P : Would you take the drug?

CC-PAM-B1 : Yes, definitely

P : Definitely. Why so, Sir?

CC-PAM-B1 : For protection and for my own health. So I would be very grateful for any handling and treatment I will be given

P : Okay, so your opinion (about this) is similar to that of polio vaccination, is that so?

CC-PAM-B1 Yes

P For protection. Okay, Sir, now the last question. It might be nice to have a few more questions because we have such flowing interaction. Okay, last question: Would you like to receive further information about leprosy?

CC-PAM-B1 Yes.

P Yes. Okay, is there anything else you would like to tell me as an officer handling leprosy or monitoring leprosy cases?

CC-PAM-B1 I would like to suggest that there should be vaccination of some sort. Up to now there has only been polio vaccination, meanwhile leprosy vaccination is crucial and needed. Not just now, but should have been given since a while ago so that leprosy patients do not feel alienated and they can gain self confidence, mingling with the community. Up to now we have only been administered polio vaccination, nothing yet for leprosy. With this program, I would suggest that it is implemented permanently

P All right, so you are very enthusiastic (about this program), aren't you?

CC-PAM-B1 I am very keen on it. I would like to see there is no longer discrimination or alienation. Now is no longer the time...

P Now is no longer the dark ages, is that so? So now we should open our eyes wide to see in broad view how (leprosy) is treated. We are not strangers to the such and such treatment (for leprosy). Okay, thank you so much, Sir. It is a pleasure to interview you. I am very happy with your answers. Thank you for your time. Sorry for interfering with your activities. Please carry on. Thank you so much.

CC-PAM-B1 Thank you.

P Assalamualaikum warahmatullahi wabarakatu

CC-PAM-B1 Waalaikumsalam warahmatullahi wabarakatu

Contact 2

Interviewer (P)

P : Assalamualaikum warahmatullahi wabarakatu

CC-PAM- : Waalaikumsalam warahmatullahi wabarakatu

B2

P : Thank you for your time, Ma'am. Please allow me to introduce myself. My name is Lingga. I am an officer from NLR in East java. I am here on interviewing mission with

the society in relation to distribution of preventive drug for leprosy that has just started in your area. Would you be willing to provide your opinion on this program? The interview will take about 30 minutes. Would you be willing to be interviewed?

CC-PAM- : Yes.

B2

P : Alright. May I have your name, please?

CC-PAM- : My name is XXX

B2

P : Siti Aisyah. What is your relation to [this man]

CC-PAM- : I am one of his in-laws.

B2

P : An in-law. Okay, let's get into the topic. Can you tell me about leprosy?

CC-PAM- : Leprosy is a type of skin condition, if I'm not mistaken.

B2

P : What do you think causes it?

CC-PAM- : The cause is first of all dirty environment, and second is bacteria, if I'm not mistaken.

B2

P : What are its symptoms?

CC-PAM- : The skin turns white, kind of like skin fungus. And it itches.

B2

P : Are there more?

CC-PAM- : That is all I know.

B2

P : Alright. Let me carry on to the second question: from where or whom did you get information about leprosy?

CC-PAM- : Leprosy....

B2

P : Let me repeat the question: can you tell... I'm sorry.... From where and whom did you get the information about leprosy?

CC-PAM- : Leprosy, to my knowledge, when I go to the Health Center or the hospital, I would read the posters or announcement or pamphlet. It would describe leprosy itself.

B2

P : All right.

CC-PAM- : And second, I got it from this training at the Ladies' Meeting, prayer meeting. The
B2 Ustazah herself informed us that we must keep a healthy life. And she also informed us about leprosy

P : What was it about leprosy that was informed there?

CC-PAM- : At the prayer meeting...about the symptoms and treatment of leprosy.
B2

P : Okay. Can you tell me the perspective or perception of your community regarding leprosy patients?

CC-PAM- : In general, leprosy patients are alienated. Why? Because it looks horrifying,
B2 disgusting. Particularly to the people in their own neighborhood.

P : Oh I see. So there is fear of contagion?

CC-PAM- : Yes, definitely. The Madurese people would say it is "kuddu", it is a disease that is
B2 more severe and more contagious than all other diseases. But in fact, it is treatable. If there is medication, I think.

P : I see. Do the people in your community treat leprosy patients differently than they do other people?

CC-PAM- : Yes, definitely. By the looks of it, the disease is horrifying. So it is definite that this
B2 disease is different from other diseases. Different from rash, or cough, or whatever. So because of its horrid nature, the treatment (towards the patients) is different.

P : How do you feel about this? From your heart, seeing that these leprosy patients are alienated. How are they alienated? How do you feel about this?

CC-PAM- : I feel sorry for them. One, because they are alienated from their community. Two,
B2 because rarely ever would anyone talk to them or involve them or allow them to raise their own children. But what to do? As a community, if someone has leprosy, we would fear for our own health, fear of infection. It is horrifying. So it is highly possible that the neighbors would stay away from the leprosy patient.

P : I see. Okay. Is there any difference between someone who shows visible signs of leprosy and someone who does not?

CC-PAM- : Yes, there is. From what I have witnessed, some of them have severed digits, and
B2 some have open sores, they have burns when they go out in the sun. I feel bad for them.

P : They have burns all over?

CC-PAM- : Yes
B2

P : All right. Do you think anyone can contract leprosy?

CC-PAM- : No. In my opinion, the leprosy patients do not have many people who have contact
B2 with them.

P : Why is that so, Ma'am?

CC-PAM- : Those who come in contact with the patients are usually afraid of being infected.
B2 That's number one. Number two, looking at them is a horrid picture. They have open sores that look disgusting. Don't even talk about hanging around with them. And if they go out in the open air, they might catch contamination.

P : Okay, I see. Let me go on to my next question: would you like to know if someone has leprosy?

CC-PAM- : No. A person with leprosy, they have skin that will turn red and burn when they go
B2 out in the sun. That's the first. Second... I don't know what else. That is all I know. Perhaps the health worker can explain in details.

P : All right, let me go on to question number seven: How would you feel if there is a medication available to prevent leprosy?

CC-PAM- : Thank God, then. Perhaps there is some available for the leprosy patients. They
B2 would be happy.

P : Would you take the medication?

CC-PAM- : No. I am not ill. Let those who have (leprosy) take the medication. Why would I take
B2 it? So, no.

P : What I mean is, if you contract (leprosy), would you be willing to take the medication?

CC-PAM- : If there is suggestion to take the medication, then maybe. I have to, especially if
B2 there is a treatment program for a certain number of months taking the medication. But if I don't have it, why would I take it. No, I won't.

P : Okay, last question, question number eight. Would you like to receive more information about leprosy, or is there something you would like to tell us?

CC-PAM- : Hmm. About information, I think this is crucial to those that do not have it. They
B2 need to know what leprosy is. So it would be nice if this is informed to people who do not have it, and even more so to those who already have leprosy.

P : Thank you for your time, Ibu Siti Aisyah. I am satisfied with the answers you gave me. There is so much that you know already. I am thankful for your insight and input, and also for your time. Sorry to take up time from your busy day. Thank you. Assalamualaikum warahmatullahi wabarakatu

CC-PAM- : Waalaikumsalam warahmatullahi wabarakatu
B2

Contact 3

Interviewer (P)

P : Assalamualaikum Ma'am. My name is Lingga, I am an officer from NLR in East Java. I am here to interview you about leprosy. May I have your name, please?

CC-PAM- : Ibu XXX
B3

P : Ibu, are you a relative of Mr. XXX?

CC-PAM- : Yes
B3

P : How are you related?

CC-PAM- : I am his aunt.
B3

P : How old are you?

CC-PAM- : 50
B3

P : 50 years old. And what is your most recent education?

CC-PAM- : High school
B3

P : Occupation?

CC-PAM- : Housewife
B3

P : Marital status?

CC-PAM- : Married
B3

P : Religion?

CC-PAM- : Islam
B3

P : All right. Let me ask the interview questions. Can you tell me about leprosy? What is leprosy in your opinion?

CC-PAM- : White spots.
B3

P : Next, let me repeat the question: Can you tell me about leprosy?

CC-PAM- : Leprosy is a (skin) condition with white spotting. Usually, if untreated, can lead to
B3 disability/disfigurement

P : Okay. What are the symptoms?

CC-PAM- : The symptoms is caused by friction
B3

P : The symptoms? Let me repeat that: What are the symptoms of leprosy?

CC-PAM- : White spots.
B3

P : And then?

CC-PAM- : Numbness
B3

P : And then?

CC-PAM- : I don't know.
B3

P : Okay. From where or from whom did you receive information about leprosy?

CC-PAM- : From village training
B3

P : And?

CC-PAM- : And from the Health Center
B3

P : Okay, so from the village training. When was that, Ma'am?

CC-PAM- : It's been awhile, maybe more than a year
B3

P : What was the information given?

CC-PAM- : Whether or not leprosy is contagious
B3

P : Can you tell me about the perspective or perception of your community about
leprosy patients?

CC-PAM- : People usually stay away from leprosy
B3

P : Okay. Can you tell me if leprosy patients are treated differently from people in general? I mean, let me repeat that, do people in the community treat leprosy patient differently than other people?

CC-PAM- : No

B3

P : How do you feel about this?

CC-PAM- : Just okay.

B3

P : Is there difference if someone shows visible signs of leprosy and if they don't?

CC-PAM- : Yes.

B3

P : What is that?

CC-PAM- : The white spots.

B3

P : And?

CC-PAM- : I don't know.

B3

P : Can anyone contract leprosy?

CC-PAM- : Yes.

B3

P : How so?

CC-PAM- : It is contagious

B3

P : Because it is contagious. Do you want to know if someone has leprosy?

CC-PAM- : Yes.

B3

P : Why?

CC-PAM- : So that I know and that I can protect myself

B3

P : How would you feel if there is medication to prevent from contracting leprosy?

CC-PAM- : I am willing to take it.

B3

P : How do you feel (about it)?

CC-PAM- : I am willing to take it

B3

P : Let me repeat: How would you feel if there is medication to prevent from contracting leprosy?

P : Let me repeat: How would you feel if there is medication to prevent from contracting leprosy?

CC-PAM- : I would be very happy and I would gladly take it.

B3

P : Would you take the medication?

CC-PAM- : yes, I would.

B3

P : Why?

CC-PAM- : So I would get better.

B3

P : Would you like to receive more information about leprosy?

CC-PAM- : Yes.

B3

P : Or is there something else you would like to tell us?

CC-PAM- : No.

B3

P : Okay. Thank you, Ma'am. It was a pleasure speaking with you. Thank you for your time. I hope that through this interview, you would be more informed of what leprosy is, its symptoms, how it is passed, and how it is handled. Thank you, Ma'am. Good afternoon. Assalamualaikum warahmatullahi wabarakatu

CC-PAM- : Waalaikumsalam warahmatullahi wabarakatu

B3

Contact 4

Assalamualaikum wr wb. Allow me to introduce myself first. My name is Interviewer, I am with NLR Indonesia, and currently I am conducting interviews with members of the society in relation to distribution of preventative drug for the condition that your relative is suffering from. This interview will last approximately 30 minutes.

Interviewer : Are you willing to be interviewed, Ma'am?

CC-Pam-B4 : Yes, Ma'am.

Interviewer : What is the nature of your relationship with him/her?

CC-Pam-B4 : I am her aunt

Interviewer : Can you tell me what disease is she suffering from?

CC-Pam-B4 : Yes, Ma'am

Interviewer : Do you know what causes the disease?

CC-Pam-B4 : It is itching.

Interviewer : What are the earlier symptoms that she experienced?

CC-Pam-B4 : Pale and redish patches on her skin

Interviewer : From whom you know about this disease?

CC-Pam-B4 : From Mrs. Aini

Interviewer : Who is Mrs. Aini?

CC-Pam-B4 : She is from Puskesmas

Interviewer : Which Puskesmas, Ma'am?

CC-Pam-B4 : Puskesmas at the north side, Panguane

Interviewer : When did Mrs.Aini tell you about this disease?

CC-Pam-B4 : It was about 3 months ago

Interviewer : Do you know what people think about the disease?

CC-Pam-B4 : They said that this disease is inherited

Interviewer : What Mrs. Aini told you?

CC-Pam-B4 : She said that this is a skin disease

Interviewer : How your neighbor behave towards you about this disease?

CC-Pam-B4 : They think this is just a usual skin disease.

Interviewer : So they think that this is just a common disease in the community?

CC-Pam-B4 : Yes, Ma'am

Interviewer : How your neighbor react to you?

CC-Pam-B4 : They are fine.

Interviewer : Do you think that everyone can suffer from this disease?

CC-Pam-B4 : Yes

Interviewer : Do you want to know if someone else also suffers from this disease?
CC-Pam-B4 : Yes, Ma'am
Interviewer : Why?
CC-Pam-B4 : So that we can prevent from getting the disease
Interviewer : If someday there is a drug that can prevent the disease, what do you think?
CC-Pam-B4 : That is good Ma'am
Interviewer : Would you take it?
CC-Pam-B4 : yes Ma'am
Interviewer : Do you have any suggestion to me or Mrs. Aini?
CC-Pam-B4 : Yes, please distribute the preventing drug as soon as possible
Interviewer : Thank you Ma'am
CC-Pam-B4 : You are welcome

Contact 5

Assalamualaikum wr wb. Allow me to introduce myself first. My name is Ira, I am with NLR Indonesia, and currently I am conducting interviews with members of the society in relation to distribution of preventative drug for the condition that you are suffering from. This interview will last approximately 30 minutes.

Interviewer : Are you willing to be interviewed, Ma'am?
CC-Pam-B5 : Yes, Ma'am.
Interviewer : What is the nature of your relationship with him/her?
CC-Pam-B5 : Nephew
Interviewer : Ma'am, would you please tell me what disease that he is suffering from?
CC-Pam-B5 : It is a ringworm.
Interviewer : What caused it Ma'am?
CC-Pam-B5 : It is itchy
Interviewer : What was the earlier symptom of this disease?
CC-Pam-B5 : It was redish
Interviewer : Ma'am, from whom you know about this disease?
CC-Pam-B5 : From Mrs.....
Interviewer : Mrs who?
CC-Pam-B5 : Mrs. Aini
Interviewer : When was that?

CC-Pam-B5 : Three months ago

Interviewer : What did she tell you?

CC-Pam-B5 : That it is a skin disease

Interviewer : Do you know what people think about this disease?

CC-Pam-B5 : They do not know.

Interviewer : Now that people know what he is suffering from, how do they react to your nephew?

CC-Pam-B5 : Just usual.

Interviewer : Do you think this disease could affect all people?

CC-Pam-B5 : Sorry

Interviewer : Why did you say sorry?

CC-Pam-B5 : People could get prevented by taking medication

Interviewer : Do you want to know if someone has leprosy?

CC-Pam-B5 : Yes, Ma'am

Interviewer : Why do you want to know?

CC-Pam-B5 : To be cured

Interviewer : How do you feel if later there is a drug that could prevent us from leprosy?

CC-Pam-B5 : Yes there will be probably.

Interviewer : Do you want to take it?

CC-Pam-B5 : Yes, I would like to.

Interviewer : Do you have anything more to say to me or do you have message to bu Aini?

CC-Pam-B5 : No, Ma'am.

Interviewer : Thank you, Ma'am.

CC-Pam-B5 : Yes

Contact 6

Assalamualaikum wr wb. Allow me to introduce myself first. My name is Interviewer, I am with NLR Indonesia, and currently I am conducting interviews with members of the society in relation to distribution of preventative drug for the condition that your relative is suffering from. This interview will last approximately 30 minutes.

Interviewer : Are you willing to be interviewed?

CC-Pam-B6 : Yes, Ma'am

Interviewer : What is the nature of your relationship with him/her?
CC-Pam-B6 : He is my husband
Interviewer : Could you please tell me about his disease?
CC-Pam-B6 : Yes, Ma'am
Interviewer : What is the disease that he is suffering from?
CC-Pam-B6 : it might be because of heat. He owns a motorbike repair shop.
Interviewer : What were the first symptoms that he experienced?
CC-Pam-B6 : Swelling and bruises on his skin
Interviewer : From whom you know about this disease?
CC-Pam-B6 : From Mr. XXX
Interviewer : who is he?
CC-Pam-B6 : He is the health worker from Puskesmas
Interviewer : Do you know what people think about this disease?
CC-Pam-B6 : they said that this is an inherited disease
Interviewer : Do you see any differences on neighbor's behavior towards you now?
CC-Pam-B6 : No Ma'am, they are fine
Interviewer : How do you feel after you know that your husband has this disease?
CC-Pam-B6 : This disease is from God Ma'am, I am fine
Interviewer : Do you see any differences if someone with clear leprosy lesion and someone with not clear leprosy symptoms?
CC-Pam-B6 : My husband's symptoms are very clear Bu
Interviewer : Do you think that everyone can suffer from this disease?
CC-Pam-B6 : Yes
Interviewer : Do you want to know if someone also suffers from this disease?
CC-Pam-B6 : No Ma'am, I hope it is only my husband suffers from this disease
Interviewer : What do you think if someday there is a drug that can prevent from this disease?
CC-Pam-B6 : That would be good Bu because I want to be healthy

Interviewer: Lingga (first three), Ira (last three)

District: Pamekasan

Participant type: health care worker

Health Worker 1

Interviewer (P)

P : Assalamualaikum warahmatullahi wabarakatu

HCW-PAM- : Waalaikumsalam warahmatullahi wabarakatu
B1

P : Please allow me to introduce myself. My name is Lingga. I am from NLR in East Java office. I am conducting interviews with society in relation to drug administering to prevent leprosy, which will begin soon in your area. Will you be willing to provide your opinion in this interview? The interview will last approximately 30 minutes.

HCW-PAM- : Yes, I am.
B1

P : Very well. May I have your name, please?

HCW-PAM- : XXX
B1

P : Okay. How do you I address you?

HCW-PAM- : XXX.
B1

P : All right. Ibu, it is. Ibu, what is your occupation and position?

HCW-PAM- : I am managing the leprosy program in XXX Health Center.
B1

P : And your occupation?

HCW-PAM- : Village midwife.
B1

P : What is your main duty?

HCW-PAM- : Program manager.
B1

P : For leprosy?

HCW-PAM- : Yes.
B1

P : Have you received formal training for leprosy?

HCW-PAM- : Yes.
B1

P : How many years have you worked as health worker?

HCW-PAM- : Now it is 18 years
B1

P : How long have you worked in the leprosy program?

HCW-PAM- : 10 years.
B1

P : All right, I will now begin the interview questions. Please let me know if it is not clear, and I will repeat the question.

HCW-PAM- : Yes.
B1

P : Can you tell me about leprosy?

HCW-PAM- : Leprosy is a skin disease, marked by white or reddish spots, which are numb in senses, followed by stiffening of the peripheral nerves and followed by nervous dysfunction.
B1

P : What is the cause?

HCW-PAM- : The cause is microbacterium lephera
B1

P : And what are the symptoms?

HCW-PAM- : The symptoms are white or reddish spots that are numb in senses, then followed by stiffening of the peripheral nerves and also disability of the peripheral nerves
B1

P : Is that all?

HCW-PAM- : Also positive when tested for BTA
B1

P : When did you first hear about leprosy?

HCW-PAM- : I heard about it when I studied at the nurse academy
B1

P : From where or whom did you receive information on leprosy?

HCW-PAM- : I got the information from my teacher, when I was studying at the nurse academy
B1

P : What did they tell you?

HCW-PAM- : They told me that leprosy is an infectious disease.
B1

P : Do you know of anyone with leprosy in your vicinity or in the area where you work?

HCW-PAM- : Before I managed this program, no. I had not seen any (prior to that). After I managed the program, I was able to see in person and handle the cases directly.
B1

P : Okay. Are there currently any patients undergoing medication in your Health Center?

HCW-PAM- : Excuse me?
B1

P : Let me repeat that: Are there currently any patients undergoing medication in your Health Center?

HCW-PAM- : Yes. Many.
B1

P : How many approximately?

HCW-PAM- : There are maybe 12 every year.
B1

P : Are you directly involved in diagnosing and treatment of leprosy?

HCW-PAM- : Yes.
B1

P : If yes, in what way?

HCW-PAM- : The handling. We need to determine the coordination first. If there is white or reddish spots that are numb, and layering of the peripheral nerves with nervous dysfunction, which nerves are dysfunctioning?
B1

P : Can you tell me the perspective or perception of health workers on the leprosy patients?

HCW-PAM- : My perception... I actually feel like this is a moral calling. I feel sorry for them.
B1
Some of them had to hide their condition. In my experience, they hide it and they are not allowed to access treatment. They hide it and they end up being disfigured. I work across sectors to visit them, but they insist on hiding their condition. Some of them had their wedding canceled because of their condition. I feel sorry for them. They should have been given treatment to avoid disfigurement.

P : Are there any health workers that treat leprosy patients differently than other patients?

P : Let me repeat that: Are there health workers who treat leprosy patients in a different way than other patients?

HCW-PAM- : No. We treat leprosy patients the same way we treat other patients. But there is separate room, as per standard operational procedure. There is a separate room for leprosy.
B1

P : How do you feel about this? About what you answered just now?

P : Let me repeat that: How do you feel about this?

HCW-PAM- : In my opinion, leprosy patients should not be separated from other patients.
B1 Why? Afraid they would feel inferior? They would ask why they are separated from other patients. They would feel alienated. But I don't know what to do. That is the SOP in my Health Center. TB and leprosy have separate units.

P : Okay. Is there any difference if a person has visible signs and if they don't?

P : Let me repeat that: Is there any difference if a person has visible signs of leprosy and if they don't?

HCW-PAM- : There is no difference
B1

P : Have you heard of the PEP intervention, in which leprosy patients' contacts are prevented from contracting leprosy?

HCW-PAM- : I've heard of PEP.
B1

P : Do you know about it and how it is implemented?

HCW-PAM- : Implemented...
B1

P : Let me repeat that: Do you know about it and how it is implemented?

HCW-PAM- : I don't know.
B1

P : What is your opinion about this intervention?

HCW-PAM- : I don't know about it yet for the time being, so I don't understand what PEP implementation is going to be like.
B1

P : Is there anything you would like to tell us? Your message to us?

HCW-PAM- : I would like this activity to continue and improve. I also would like this program to go into the field with me. That's all. I just hope this program is sustained.
B1

P : Okay. Thank you, Ibu Dewi. Thank you for your time. That is all for my interview. Thank you. Assalamualaikum warahmatullahi wabarakatu

HCW-PAM- : Waalaikumsalam warahmatullahi wabarakatu
B1

Health Worker 2

Interviewer (P)

P : Assalamualaikum warahmatullahi wabarakatu

HCW- : Waalaikumsalam warahmatullahi wabarakatu

PAM-

B2

P : Allow me to introduce myself. My name is Lingga. I am from NLR. My purpose here is to conduct interviews with the society in relation to distribution of preventive drug against leprosy that is to be implemented soon in your area. Are you willing to give your opinion about about it in this interview? This will take about 30 minutes. Are you willing to do so?

HCW- : Of course, of course.

PAM-

B2

P : Can you tell me your name?

HCW- : My name is XXX

PAM-

B2

P : How old are you, Sir?

HCW- : 35 years

PAM-

B2

P : Address?

HCW- : XXX

PAM-

B2

P : Alright. Your occupation or position?

HCW- : Civil worker at XXX Health Center, in XXX

PAM-

B2

P : As what?

HCW- : Nurse.

PAM-

B2

P : What is your main duty?

HCW- : I am in charge of the Emergency unit. I am also responsible of the leprosy program,
PAM- as well as the health clinic in Larangan Salampar, a subdistrict of the Health Center.

B2

P : Very well. Did you receive any formal training for leprosy?

HCW- : I did one time. It was a coincidence, the training was in Batu, Malang, and it was a 5-
PAM- day training.

B2

P : Okay. How many years have you worked as health worker?

HCW- : In XXX alone, about 9 years. In total, my career in health care is about 15 years.

PAM-

B2

P : How many years have you been working in the leprosy program?\

HCW- : Starting in 2010 until now, so that is about 9 years.

PAM-

B2

P : Let me start the interview questions now. First question: can you tell me about
leprosy?

HCW- : Leprosy is a disease caused by mycobacteri leprae, a type of bacteria. The typical
PAM- symptoms include white spots or reddish spots, usually numb or hypoanasthetic.

B2

P : What could be the cause?

HCW- : Like I said earlier, it was caused by mycobacterium leprae

PAM-

B2

P : And the symptoms?

HCW- : Usually white or reddish spots that do not cause itching, does not produce sweat,
PAM- and numb in senses. Those are the symptoms.

B2

P : When was the first time you heard about leprosy?

HCW- : Since I started being in charge of the program

PAM-
B2

P : Where did you receive... I mean, where and from whom did you receive the information about leprosy?

HCW- : From the previous person in charge of the program. Plus from literature or books,
PAM- and also I had a 5-day training.

B2

P : Very well. What was it that they informed you about?

HCW- : The point is to sever the chain of leprosy infection. This is in line with the government
PAM- program through PELITA in Pamekasan area: to eliminate leprosy. That means for us
B2 as health workers to make early discovery or tracing in order that Pamekasan be free
of leprosy

P : Do you know of anyone in your vicinity with leprosy?

HCW- : In 2017 we've had about 11 new leprosy patients. In 2018 we have about 9... 8 or 9
PAM- new patients.

B2

P : Is there any leprosy patient currently undergoing medication in your Health Center?

HCW- : Yes, there are.

PAM-
B2

P : Are you directly involved in diagnosing and treatment of leprosy?

HCW- : As for diagnosing, because there is a doctor working at the Health center, we are
PAM- collaborating with the Health Center doctor for drug monitoring. As for POD
B2 monitoring, that falls under the responsibility of the program manager.

P : So in general, you are directly involved?

HCW- : Directly involved, because every 3 months... 2 or 3 months, we direct our focus to
PAM- the contacts. This means, people who are directly in contact with the patient. We
B2 want to know whether or not any members of their family are positively diagnosed
with leprosy. We also want to monitor the regular administering of drugs.

P : Can you tell me about the perspective or perception of the health workers regarding
leprosy patients?

HCW- : Leprosy in Bandaran Health Center area is a very sensitive issue, so much so that the
PAM- term "leprosy" uses a (euphemistic) term to respect the client or patient's privacy.
B2 We always use the MH language to show our respect to them. This is related to the
risk of rejection or alienation from the society if we use the term "leprosy".

P : Do health worker treat leprosy patients differently from other patients, in terms of
behavior towards them?

HCW- : No, we treat them the same. We don't discriminate based on economic status, age,
PAM- group and standing. Everyone is the same. Except maybe for patients with ulcers or
B2 additional wounds, then they receive higher priority because of the presence of
wounds. Not that we don't pay attention to the spotting, but the ulcers demands
priority, so that requires difference in treatment. So difference in treatment between
patient A and B is based on whether there are ulcers or not.

P : How do you feel about it?

HCW- : I am satisfied, and I feel a sense of accomplishment when a patient makes full
PAM- recovery with zero disfigurement. Secondly, I look at it as an act of faith to help other
B2 people.

P : Is there any difference if a person displays visible signs of leprosy and if he doesn't?
Is there any difference?

HCW- : Usually they emit a typical body odor. But for definite result we need to conduct an
PAM- examination, like what I mentioned: seen through light, touched, and scrutinized.
B2 This is to ensure that a person is positively diagnosed with it. Then this must be
followed up by doctor consultation.

P : Have you heard of PEP intervention, in which patients' contacts are prevented from
leprosy infection?

HCW- : Yes I have. But maybe that is only in Pamekasan Regency. It is not here yet. And so
PAM- that is why we suggest that our health workers conduct examination on contacts
B2 every 2 or 3 months in order to sever the chain of infection, particularly in the vicinity
of the patient or the contact.

P : What is your opinion of this new intervention?

HCW- : It is more... more... It is better and more progressive, in my opinion. So this activity
PAM- or intervention brings more benefit, particularly in severing the chain of infection and
B2 prevention of contracting the disease. As such, perhaps PELITA will be successful,
particularly in Pamekasan

P : Amen to that. Is there anything else that you'd like to tell us?

HCW- : Intervention such as this, please don't let it be a one-off endeavor. Perhaps you can
PAM- design it to be structural type of activity, meaning periodically. People such as Mr.
B2 XXX said to me once that East Java is predicted to be leprosy-free by 2019. I hope we
will achieve that. I also hope that at least every 3 months or trimesterially,
intervention like this will be conducted.

P : Okay. Thank you, Sir. I am satisfied with your answers. Thank you for your time and
thank you for the interview. I hope I did not take too much of your time.
Assalamualaikum warahmatullahi wabarakatu

HCW- : You are welcome. Waalaikumsalam warahmatullahi wabarakatu

PAM-
B2

Health Worker 3

Interviewer (P)

P : Assalamualaikum. My name is Lingga and I am from NLR. Do you know what NLR
is?

HCW- : Yes, I do.

PAM-
B3

P : NLR's (mission) in general is to find and to suppress the number of leprosy cases. In
this interview, I would like to discover your knowledge on leprosy and to find the
presence of stigma. Is stigmatic perception still high or is it low here, both in
community and in personal opinion. I did say that my name is Lingga from NLR. Can
you tell me your name?

HCW- : My name is XXX
PAM-
B3
P : Okay. Your age?
HCW- : 27 years.
PAM-
B3
P : Address?
HCW- : XXX
PAM-
B3
P : Do you work here?
HCW- : Yes.
PAM-
B3
P : As what?
HCW- : Nurse
PAM-
B3
P : Okay. Have you had any training?
HCW- : Not yet.
PAM-
B3
P : Is there any plan to enroll in training?
HCW- : If the opportunity comes, yes.
PAM-
B3
P : What is your recent education?
HCW- : D3 Nursing
PAM-
B3
P : Religion?

HCW- : Islam

PAM-
B3

P : Marital status?

HCW- : Married.

PAM-
B3

P : Married. Where did you say your address was?

HCW- : Desa buke kecamatan taranakan kabupaten pamekasan

PAM-
B3

P : Okay. Let us now begin the interview. What is your relation to the patient?

HCW- : No relation.

PAM-
B3

P : No relation. Okay. Can you tell me about leprosy?

HCW- : Leprosy is characterized by a white spotting that does not itch. It does not respond
PAM- to cotton swab receptivity test. There are two types of leprosy: dry and wet

B3

P : What is the cause?

HCW- : Leprosy can be a hereditary condition.

PAM-
B3

P : And then?

HCW- : I forgot.

PAM-
B3

P : So that is the general idea. What are its symptoms?

HCW- : The symptoms include white spots throughout the body. That is all I know. The
PAM- fingers become stiff. That's all.

B3

P : When was the first time you heard about leprosy?

HCW- : 2012, I first encountered a leprosy patient. In a more general knowledge, I heard
PAM- about leprosy when I was in 5th grade.

B3

P : From where or whome did you get the information about leprosy?

HCW- : When I was in 5th grade, from my parents. Then when I started working, I had an
PAM- emotional bonding with the program coordinator, so I knew somewhat about
B3 leprosy patients.

P : What did they say about leprosy?

HCW- : Leprosy is treatable.

PAM-

B3

P : Do you know of anyone with leprosy in your vicinity?

HCW- : You can't tell from a distance. If a patient comes in with complaints of white spots,
PAM- we will examine that if there is any reaction to cotton swab receptivity test. If there
B3 isn't any, then we can diagnose it as leprosy.

P : Are there any leprosy patients currently under treatment at your Health Center?

HCW- : Yes.

PAM-

B3

P : If yes, then what is the treatment method?

HCW- : Regular medication, regular check up, that is all. And house visit.

PAM-

B3

P : Can you tell me about the perception or opinion of health workers regarding
leprosy patients?

P : Let me repeat that: can you tell me about the perception or opinion of health
workers regarding leprosy patients?

HCW- : Perception of health workers...there is no negative perception of leprosy on the
PAM- part of the health worker. There is just affirmation to the patients that leprosy can
B3 be treated, that's all.

P : You are not afraid you might be infected?

HCW- : No.

PAM-

B3

P : Okay. Do health workers treat leprosy patients differently compared to other patients?

HCW- : No. Health workers working for leprosy cases have house visit schedules. We
PAM- provide the education there on how to treat leprosy patients with open sore, or
B3 without sore, on how to take regular medication. That's all. There is no
discrimination between leprosy patients and regular patients.

P : How do you feel about it?

HCW- : About leprosy?

PAM-
B3

P : Yes.

HCW- : I am moved by the wish to heal them. In the general public, most leprosy patients
PAM- are alienated.

B3

P : Yes. That's it?

HCW- : Yes.

PAM-
B3

P : Is there any difference if a person has visible leprosy signs and if not?

HCW- : Usually the skin bears reddish marks, and there are numerous white spots
PAM- throughout his body. That's all I know.

B3

P : Have you heard of PEP intervention, wherein leprosy patients' contacts are
prevented from contracting leprosy?

HCW- : No I haven't

PAM-
B3

P : Do you know about it and how it is administered?

HCW- : No I don't know.

PAM-
B3

P : What do you think of this new intervention?

HCW- : In my opinion, the intervention you just mentioned, the PEP, is very good.
PAM- Whenever we come into direct contact with leprosy patient, at least we are
B3 protected against the patient.

P : Is there anything else you would like to tell us?

HCW- : Maybe there is. Most patients complain about taking too many drugs. Second...

PAM- That is all.

B3

P : Thank you, Mr.. Your answers are very definitive and broad. Thank you for your
time for me. That is all the interview from me. Assalamualaikum warahmatullahi
wabarakatu

HCW- : Waalaikumsalam

PAM-

B3

HCW 4 (Officer 1)

First of all, I would like to introduce myself. My name is Ira. I am with NLR Indonesia, working in Proppo district. I am currently conducting interviews with members of society in relation to distribution of preventative drug for leprosy that has just commenced in your area. This interview will last approximately 30 minutes

Interviewer : Are you willing to be interviewed?

HCW-Pam-B4 : Yes, I am.

Interviewer : What is your position currently?

HCW-Pam-B4 : Nurse

Interviewer : What is your main duty currently?

HCW-Pam-B4 : I oversee the leprosy program.

Interviewer : Have you received formal training for leprosy?

HCW-Pam-B4 : Yes, I have.

Interviewer : How many years have you been working as health provider?

HCW-Pam-B4 : About 30 years now.

Interviewer : How many years have you been working in leprosy program?

HCW-Pam-B4 : About 18 years

Interviewer : Can you tell me about leprosy?

HCW-Pam-B4 : Leprosy is an infectious disease, but it is difficult to be infected from this condition.

Interviewer : What is the cause for leprosy?

HCW-Pam-B4 : Leprosy is caused by bacteria called mycobacterium lepra

Interviewer : What are the symptoms most reported by patients?

HCW-Pam-B4 : Patients usually report spots that resemble fungal infection. I don't think patients report complaints to us. When we don't have early detection, then patients come in with complaints such as loss of senses or tingling sensation in their pinky finger. That is usually when they report to the Health Center. Sometimes their digits are swollen or their spots have turned reddish and they are uncomfortable. By then, when they actually have complaints, they report to the health workers.

Interviewer : When did you first hear about leprosy?

HCW-Pam-B4 : I knew about leprosy a long time ago, since I was in school. But even as a junior high schooler I did not understand much about leprosy. But I did hear about it since that time.

Interviewer : From your school teacher?

HCW-Pam-B4 : Yes, from my school teacher. It was just something I heard about.

Interviewer : So it was not a comprehensive or significant information about leprosy?

HCW-Pam-B4 : No. When I became a health worker, then I received training on leprosy. That was 1969. I received formal training then. Before that, it was just general information about leprosy.

Interviewer : Did you know anyone who had leprosy in your vicinity?

HCW-Pam-B4 : Yes, I did.

Interviewer : Are there currently any leprosy patient undergoing medication in your Health Center?

HCW-Pam-B4 : Yes, there are. The Health Center is where they get their medication from.

Interviewer : How many are there, do you know?

HCW-Pam-B4 : Do you mean this year or last year or several years ago?

Interviewer : What about this year?

HCW-Pam-B4 : For this year, 2018, there are 6 patients. Last year we had 13. So we are experiencing a decline this year compared to last year. Hopefully soon there will be none.

Interviewer : Hopefully, Sir. Are you directly involved in diagnosing and treatment of leprosy?

HCW-Pam-B4 : Yes, I am directly involved in diagnosing and treating as well.

Interviewer : How do you diagnose?

HCW-Pam-B4 : Diagnosing is according to procedure, using cardinal sign method: seeing, observing, touching. Palpating is a procedure of its own.

Interviewer : What about treatment for leprosy?

HCW-Pam-B4 : Treatment for leprosy is administered only after it is diagnosed whether it is type MB or PP. PP requires treatment of 6 months only, while MB requires 12 months.

Interviewer : Can you tell me about the perceptions of other officers regarding leprosy patients?

HCW-Pam-B4 : As for other health workers, some of them still hold on to the stigma, even if they are health workers, and even after we educated them on the facts of leprosy. I thought because they are working as health workers, they would understand. But apparently one or two still hang on to the stigma. I understand this, because the stigma revolving around leprosy is hard to get over. Even the health workers have some of the stigma remaining, much less the general population.

Interviewer : What about the health workers, are there difference in treatment for leprosy patients compared to others?

HCW-Pam-B4 : No, there isn't There can never be discrimination in terms of diagnosis, even though it is leprosy and disability, our treatment toward patients should remain the same, there should not be any fear.

Interviewer : Okay, about the treatment now. Are other officers willing to touch leprosy patients as much as other patients?

HCW-Pam-B4 : Just like what I said earlier, health workers handling leprosy patients thankfully are no longer shrouded by stigma. Other people, not health workers but still working in health, some of them still have that stigma. Some of them are afraid of leprosy patients and are afraid to touch or even see. Some of them see the patients coming, and they run to avoid meeting them.

Interviewer : Okay. Regarding your emotions. How does it affect you when you observe some health workers' behavior towards leprosy patients?

HCW-Pam-B4 : Well now I feel just normal, because I know how leprosy is transferred. We just have to maintain personal health to keep from being infected. But infection is actually very hard. I think, personally, with knowledge, we can keep away (from infection).

Interviewer : Have you ever heard of Pep Intervention? It is where there is limited contact with leprosy patient to avoid infection

HCW-Pam-B4 : I have only heard about Pep. I know only the term: Post Expose Profilaxis, is that it?

Interviewer : Yes, do you know about it and how it is administered?

HCW-Pam-B4 : I don't really understand it myself. I just know what it stands for. Technical application or whatnot, I don't know much about yet

Interviewer : What is your personal opinion about this intervention?

HCW-Pam-B4 : This intervention seems better, because it is an innovation. So it provides more to the knowledge.

Interviewer : Perhaps you have suggestions or ideas you'd like to give NLR?

HCW-Pam-B4 : Perhaps for the interviewer. This is just an additional suggestion. Perhaps when you finish interviewing, you can spare some time for information session, explaining about leprosy. Just that.

Interviewer : So you mean directly going to the field for information sharing

HCW-Pam-B4 : That's right

Interviewer : Okay. Thank you, Sir.

HCW 5 (Officer 2)

First of all, I would like to introduce myself. My name is Ira. I am with NLR Indonesia. I am currently conducting interviews with members of society as well as health workers in relation to distribution of preventative drug for leprosy that has just commenced in your area. This interview will last approximately 30 minutes

Interviewer : Are you willing (to be interviewed)?

HCW-Pam-B5 : Yes, I am

Interviewer : What is your work or position currently?

HCW-Pam-B5 : I am responsible for the leprosy program

Interviewer : What is your main responsibility currently?

HCW-Pam-B5 : Tracking, diagnosing and treating patients

Interviewer : Have you received formal training on leprosy?

HCW-Pam-B5 : Yes, I have

Interviewer : How many years have you worked as health worker?

HCW-Pam-B5 : About 8 years

Interviewer : How many years have you worked for leprosy program?

HCW-Pam-B5 : About 2 years

Interviewer : Can you tell me about leprosy?

HCW-Pam-B5 : Yes. It is a skin disease cause by mycobacterium leprae that affects peripheral nervous system. It is an infectious disease, although it is very hard to infect. The symptoms include reddish or white spots, and can be numb in senses

Interviewer : When did you first hear about leprosy?

HCW-Pam-B5 : The first time I heard about leprosy was in college, pretty much like what I told you earlier.

Interviewer : Do you know of anyone with leprosy around you here?

HCW-Pam-B5 : yes

Interviewer : Are there leprosy patients undergoing treatment at your Health Center?

HCW-Pam-B5 : Yes, about 6 patients now

Interviewer : Are you directly involved in diagnosing and treating leprosy, Ma'am?

HCW-Pam-B5 : Yes, diagnosis through cardinal sign and treatment through two methods: PB is treated for 6 months and MB is treated for 12 months.

Interviewer : Can you tell me about the perspective of other officers regarding leprosy patients?

HCW-Pam-B5 : Stigma is actually persisting, but not as bad as it used to. Now, there is still that fear of being infected felt by other health workers.

Interviewer : In daily life, do health workers treat leprosy patients differently compared to other patients?

HCW-Pam-B5 : Actually, no, because other health workers are knowledgeable about leprosy

Interviewer : Next question. Have you heard of PeP Intervention, where contact is made with leprosy patient to prevent leprosy bouts?

HCW-Pam-B5 : Yes, it is an innovative way to contain leprosy infection by means of administering prophylaxis

Interviewer : What is your opinion about this new intervention?

HCW-Pam-B5 : Highly agree and it should be applied soon

Interviewer : Perhaps you have any suggestion or ideas you might want to give NLR?

HCW-Pam-B5 : We experience difficulty in transportation due to natural circumstances. Perhaps NLR can provide solution to this

Interviewer : Is that all?

HCW-Pam-B5 : Yes, I think that is all

Interviewer : Thank you, Ma'am

HCW 6 (Officer 3)

First question

Interviewer : What is your work or position currently?

HCW-Pam-B6 : I am responsible for the leprosy program

Interviewer : What is the main responsibility?

HCW-Pam-B6 : Tracking, seeking, and treatment

Interviewer : Have you received formal training on leprosy?

HCW-Pam-B6 : Yes, I have.

Interviewer : How many years have you worked as health worker?

HCW-Pam-B6 : Here, for 8 years

Interviewer : How many years have you been working for leprosy program?

HCW-Pam-B6 : About 4 years

Interviewer : Can you tell me about leprosy?

HCW-Pam-B6 : Leprosy is a disease caused by bacteria called mycobacterium lepra, which affects peripheral nervous system, and not central nervous system

Interviewer : What are the symptoms most reported by patients when they first come in for treatment?

HCW-Pam-B6 : Usually the presence of spots. Sometimes the spots are almost numb or completely numb. Previously we even had patients who came with disabilities. But thankfully nowadays we don't have anymore.

Interviewer : When did you first hear about leprosy?

HCW-Pam-B6 : When I was in college

Interviewer : Where did you study?

HCW-Pam-B6 : In William Booth Nurse Academy in Surabaya

Interviewer : So can you tell me a little what your professor relayed to you?

HCW-Pam-B6 : It was that this is a disease affecting the nervous system which began its infection through skin contact that is direct and prolonged. The symptoms include spotting, both partially numb or completely numb, loss of senses and diminishing nervous functions.

Interviewer : Do you know of anyone who suffers from leprosy around here?

HCW-Pam-B6 : Yes.

Interviewer : Are there any leprosy patients undergoing treatment at your Health Center?

HCW-Pam-B6 : Yes, many.

Interviewer : How many?

HCW-Pam-B6 : Last year we had about 13. Now about 9 remaining.

Interviewer : So the number goes down. Are you directly involved in diagnosing and treating leprosy?

HCW-Pam-B6 : Yes, for the patients here.

Interviewer : How do you diagnose leprosy?

HCW-Pam-B6 : In diagnosing leprosy, we know of a method called cardinal sign. There are three particular signs to it. The first is spotting, both partially and completely numb. Then there is a decline in nervous function, then positive result for BTA testing. If one of the signs prove to be positive, then it is positive (for leprosy)

Interviewer : How do you treat leprosy?

HCW-Pam-B6 : itukan dibedakan kusta ada dua pb sama mb kalo pb 6 bulan kalo mb kan 12 bulan

Interviewer : dapatkan anda memberi tahu saya tentang pandangan atau persepsi Officer yang lain mengenai pasien kusta?

HCW-Pam-B6 : I cannot lie that negative stigma is still largely persistent. But I cannot be sure if the negative stigma is still looming as bad as it used to be. I think it is better now, at least

within health worker circles. Health workers now understand that leprosy, when treated properly, is not transferable.

Interviewer : Is there different health worker assigned for leprosy to separate from other patients?

HCW-Pam-B6 : No, there is no separation

Interviewer : So they touch both leprosy patients and regular patients?

HCW-Pam-B6 : There is no separation

Interviewer : Have you heard of Pep Intervention, in which contact with leprosy patient is made to avoid leprosy bouts?

HCW-Pam-B6 : Yes, I have

Interviewer : What do you know about this intervention?

HCW-Pam-B6 : Treatment by means of profilaxic dispensed to contacts around the patient in order to stop infection

Interviewer : How did you know about this intervention, Sir?

HCW-Pam-B6 : From meetings at the Health Department

Interviewer : What do you think about Pep Intervention?

HCW-Pam-B6 : As long as it is good, the sooner it is applied, the better. Just so happens that here in Pegantenan we don't have it yet. It is applied in Sampan and Sumenep so far.

Interviewer : Perhaps you have a suggestion or ideas you might give NLR?

HCW-Pam-B6 : Each district is unique, each with its own perception. So my suggestion is that socialization of program is intensified so that more of the community is informed. That way, leprosy can be handled better.

Interviewer : Thank you, Sir.

HCW-Pam-B6 : You're welcome.

District: Pamekasan

Participant type: index patient

IC1

Interviewer (I)

Interviewer : Assalamualikum Mr. IP-Pam-B1, my name is Lingga from NLR Indonesia. My presence here is meant to suppress the number of leprosy cases. I would like to interview you regarding your health during treatment. Do you agree (to the interview)?

IP-Pam-B1 : Yes

Interviewer : Okay. First question: how many people members of your family are living with you at home?

IP-Pam-B1 : Four

Interviewer : Who are they?

IP-Pam-B1 : My wife, my father-in-law and my mother-in-law

Interviewer : And yourself?

IP-Pam-B1 : Yes

Interviewer : How long have you been on medication?

IP-Pam-B1 : 6 months

Interviewer : Okay, six months. Where did you go the first time to get your treatment?

IP-Pam-B1 : Health Center (inaudible)

Interviewer : Let's move on to more serious questions, shall we?

IP-Pam-B1 : Yes.

Interviewer : Can you tell me about your condition? penyakit anda?

IP-Pam-B1 : Yes

Interviewer : What condition do you have?

IP-Pam-B1 : Leprosy

Interviewer : When did it first appear?

IP-Pam-B1 : In 2016

Interviewer : 2016, was it at the same time you began treatment or was it before treatment?

IP-Pam-B1 : Before treatment

Interviewer : Sorry?

IP-Pam-B1 : Before treatment I had found the symptoms

Interviewer : From the time you discovered the symptoms to the time you had yourself examined here, how long was that?

IP-Pam-B1 : A year

Interviewer : There was a year before you got yourself examined?

IP-Pam-B1 : Yes

Interviewer : Okay. Has there been any training or health education about leprosy in your area?

IP-Pam-B1 : No.

Interviewer : No training. Okay, can you tell me what causes your condition?

IP-Pam-B1 : Hmmmm low immune system, not enough rest, poor hygiene.

Interviewer : All right. How did you feel when you heard the diagnosis for leprosy?

IP-Pam-B1 : Hmm I was anxious. I was afraid I won't be able to recover like other conditions would such as diabetes, high blood pressure and cholesterol

Interviewer : Can you tell me the reason for your anxiety?

IP-Pam-B1 : I was afraid. First, I was afraid I won't get better. Second, I was afraid my family would shun me. Third, I heard that leprosy can cause death.

Interviewer : Okay. Did you know anyone with leprosy before this?

IP-Pam-B1 : Yes

Interviewer : How did the society treat the person?

IP-Pam-B1 : People usually avoided him, they would not be friendly with him. Hmm he was made fun of

Interviewer : How did you feel about this?

IP-Pam-B1 : If it was just made fun of, for me that's okay. I have leprosy, so I get used to it.

Interviewer : Okay. Prior to your diagnosis, what was your opinion on leprosy?

IP-Pam-B1 : Prior to my diagnosis, I thought leprosy was just another illness, like fever... what is that... I just knew that leprosy affects a person's comfort, and that it can cause people to stay away, including neighbors and family

Interviewer : What do Madurese call leprosy?

IP-Pam-B1 : Hmm Madurese call leprosy 'jeseen', and the cure is a type of water called 'air tupa'. Some also say Minyak Teguh can cure it.

Interviewer : In your opinion, can your friend who has leprosy pass the leprosy to you?

IP-Pam-B1 : My opinion, leprosy... I didn't know that it was leprosy. I thought it was just another condition, but his hand was dismembered, like it was amputated. I thought that the cure is just that 'tupa water'.

Interviewer : Okay

IP-Pam-B1 : I felt sorry for him. He refused treatment, he said it was just any other condition. Leprosy can actually ruin physically. A person with leprosy should take medication regularly.

Interviewer : Have you informed your family that you have leprosy?

IP-Pam-B1 : Yes, I have.

Interviewer : What is their reaction when they found out you have leprosy?

IP-Pam-B1 : They were anxious. There is fear because in the village we have never heard of leprosy. We thought it was a new illness. I was afraid that it would be deadly

Interviewer : What is your role in your household?

IP-Pam-B1 : Head of the household

Interviewer : Do you have troubles performing your role because of your condition?

IP-Pam-B1 : Yes, during medication. Nowadays, thankfully I am back to normal activities like
it was before

Interviewer : Have you told your friends that you were diagnosed with leprosy?

IP-Pam-B1 : No.

Interviewer : Can you tell me what their reactions might be?

IP-Pam-B1 : If I told them, perhaps they would stay away from me because of my leprosy. Leprosy is said to be contagious. They won't want to be friends or cornered

Interviewer : And how did you feel after you told them?

IP-Pam-B1 : I was anxious they would leave. I was afraid no one wanted to be friends with me

Interviewer : Did you expect such reaction?

IP-Pam-B1 : No

Interviewer : Can you tell me your friends' reaction toward leprosy prior to telling them of your diagnosis?

IP-Pam-B1 : hmmm what is my reaction? I don't have any reaction. I was just anxious. I was afraid of the fact I had leprosy, just that.

Interviewer : Do you speak to them openly about your condition?

IP-Pam-B1 : No

Interviewer : Have you informed your neighbors that you were diagnosed with leprosy?

IP-Pam-B1 : No

Interviewer : What was their reaction?

IP-Pam-B1 : They didn't have any. I told them it was just a regular rash

Interviewer : Did you expect that reaction?

IP-Pam-B1 : No

Interviewer : Can you tell me your neighbors' opinion about leprosy before you told them you are diagnosed with leprosy?

IP-Pam-B1 : My neighbors' opinion, they are afraid of leprosy contagion. Leprosy will continually eat up a person alive. So I told my neighbors that I had a regular skin condition. Kind of like skin cancer. I didn't tell them anything. They don't know I have leprosy

Interviewer : Do you still talk openly to them about your condition?

IP-Pam-B1 : No

Interviewer : Is there anything else you would like to tell us?

IP-Pam-B1 : Yes. My message to people with leprosy is that they should receive regular treatment and that they should maintain health. That is all my message.

Interviewer : And for me?

IP-Pam-B1 : My message for the health worker is that education should be given to the remote villages, because in the remote villages there are people with leprosy, but it is too late for them for treatment. Please support the villagers here to improve their condition. Also, they should be monitored, although maybe be twice a month is impossible to do. That is all from me, please support this cause because leprosy is an unbearable disease.

Assalamualaikum warahmatullahi wabarakatu

Interviewer : waalaikum salam warahhmatullahi wabarakatu

Interviewer (P)

P : Assalamualaikum Mr., My name is Lingga from NLR East Java chapter. I am here to interview you, to discover the extent of your knowledge about your condition. Are you willing to be interviewed?

IP-PAM- : Yes.

B2

P : If so, will you please sign this informed consent first?
Okay, Sir, how old are you?

IP-PAM- : 40

B2

P : Your address, please?

IP-PAM- : XXX

B2

P : Occupation?

IP-PAM- : Entrepreneur

B2

P : Most recent education?

IP-PAM- : High School

B2

P : Religion?

IP-PAM- : Islam

B2

P : Marital status?

IP-PAM- : Widower

B2

P : How many months have you been in medication?

IP-PAM- : 1 year

B2

P : Okay, thank you Mr.XXX. Let us move to the first question. How many family members are there in your family?

IP-PAM- : Five

B2

P : Five. Where did you go the first time to get treatment for your condition?

IP-PAM- : The Health Center

B2

P : You went straight to the Health Center. Can you tell me about your condition?

IP-PAM- : Yes

B2

P : When did it first appear?

IP-PAM- : I don't know, but the health worker gave me that

B2

P : What condition do you have?

IP-PAM- : Leprosy

B2

P : Can you tell me what caused your condition?

IP-PAM- : Yes

B2

P : What is the cause?

IP-PAM- : I don't know

B2

P : How did you feel when you were diagnosed with leprosy?

IP-PAM- : At first it was pain in the knee. I went for a check up at the Health Center, and there I
B2 found out it was the symptom for leprosy

P : How did you feel when you found out you have leprosy?

IP-PAM- : I was scared

B2

P : Can you tell me why you were scared?

IP-PAM- : I was afraid of disfigurement. It would be embarrassing

B2

P : Did you know anyone with leprosy prior to this?

IP-PAM- : Yes

B2

P : How did the society behave toward that person?

IP-PAM- : Unusual

B2

P : How did you feel about that?

IP-PAM- : Just worried

B2

P : Before you were diagnosed, what was your opinion about leprosy?

IP-PAM- : I thought that required treatment

B2

P : Before you were diagnosed with leprosy, what was your opinion about leprosy?

IP-PAM- : Unclear

B2

P : Okay, let me repeat the question. Before you were diagnosed with leprosy, what was your opinion about leprosy?

IP-PAM- : I was worried about it. I was worried I would be disfigured

B2

P : Did you tell your family that you have leprosy?

IP-PAM- : Yes

B2

P : Can you tell me what their reaction was knowing you have leprosy?

IP-PAM- : They were slightly worried. But they told me to get treatment

B2

P : What is your role in your household?

IP-PAM- : Child

B2

P : Do you have difficulties carrying out your role because of your condition?

IP-PAM- : No

B2

P : Have you told your friends that you have been diagnosed with leprosy?

IP-PAM- : No

B2

P : Can you tell me what your friends' reactions were when you told them this?

IP-PAM- : No. I didn't tell them

B2

P : And how did you feel when you told them?

IP-PAM- : Embarrassed

B2

P : Did you expect that reaction?

IP-PAM- : No

B2

P : Can you tell me your friends' opinion of leprosy before you told them you were diagnosed with leprosy?

P : Okay, let me repeat the question: Can you tell me your friends' opinion of leprosy before you told them you were diagnosed with leprosy?

IP-PAM- : No, no response

B2

P : Do you still talk openly about your condition to them?

IP-PAM- : no

B2

P : Have you told your neighbors that you are diagnosed with leprosy?

IP-PAM- : No

B2

P : What was their reaction?

IP-PAM- : Reaction... no disfigurement

B2

P : Their reaction?

IP-PAM- : Nothing

B2

P : Did you expect such reaction?

IP-PAM- : No

B2

P : Have you told... let me repeat the question... Can you tell me what your neighbors' opinion is about leprosy prior to your informing them that you are diagnosed with leprosy?

IP-PAM- : No. No reaction

B2

P : Do you speak openly with them about your condition?

IP-PAM- : No

B2

P : Is there anything else you would like to tell us?

IP-PAM- : Yes

B2

P : What is it?

IP-PAM- : I hope to get better soon

B2

P : Let me repeat the question: Is there anything else you would like to tell us?

IP-PAM- : Yes, there is

B2

P : What is it, Sir?

IP-PAM- : Regular monitoring, once every few months, so that nothing happens. So it is

B2 satisfactory

P : Is that all?

IP-PAM- : Yes, that is all.

B2

P : Okay. Thank you, Mr., for your time for this interview. I hope you will be better. No need to be pessimistic, just keep optimism high. Leprosy is not as bad as people out there think. Thank you, Sir. Assalamualaikum

IP-PAM- : Waalaikum salam

B2

IC 3

Interviewer (P)

P	:	Assalamualaikum Sir.
IP-PAM-B3	:	Walaikum salam
P	:	My name is Lingga. I am an officer from NLR in East Java. I am here to conduct an interview with the society in relation to drug administration to prevent leprosy, which will be implemented soon in your area. Would you be willing to be interviewed? This interview will take approximately 30 minutes.
IP-PAM-B3	:	Yes
P	:	You are willing?
IP-PAM-B3	:	I am.
P	:	Alright. What is your name?
IP-PAM-B3	:	I am XXX
P	:	What can I call you?
IP-PAM-B3	:	XXX
P	:	Yes, XXX. How old are you?
IP-PAM-B3	:	23
P	:	What is your address?
IP-PAM-B3	:	XXX
P	:	And your most recent education?
IP-PAM-B3	:	High school
P	:	Are you married?
IP-PAM-B3	:	Not yet.
P	:	Your religion, Sir?

IP-PAM-B3	:	Islam
P	:	How long have you received treatment for leprosy?
IP-PAM-B3	:	9 years... I mean, 9 months.
P	:	9 months. How many people are there in your family?
IP-PAM-B3	:	Four
P	:	Who are they?
IP-PAM-B3	:	My younger sibling, my mother and father. My younger sibling is in the Pondok (Pesantren – red)
P	:	And then yourself
IP-PAM-B3	:	Yes
P	:	Okay. Where did you go for treatment the first time for your condition?
IP-PAM-B3	:	I went straight to the Health Center
P	:	Alright. Let me go straight into the next interview topic now. Are you ready?
IP-PAM-B3	:	Yes
P	:	Don't be too tense, please, Sir. Can you tell me about your condition?
IP-PAM-B3	:	Ready.
P	:	What is your condition?
IP-PAM-B3	:	Leprosy
P	:	When did the condition first appear?
IP-PAM-B3	:	Quite some time now.
P	:	How many months has it been?
IP-PAM-B3	:	Half a year
P	:	Half a year, so about six months or so maybe?

IP-PAM-B3	:	Yes, more.
P	:	How long have you had your treatment?
IP-PAM-B3	:	It's been 9 months.
P	:	Okay 9 months. Next question: can you tell me what caused your condition?
IP-PAM-B3	:	I heard that if someone as a child bathes in the river, the bacteria would stick to the skin
P	:	So the cause is environment that is...
IP-PAM-B3	:	Environment that is not clean.
P	:	Okay, so I can conclude as such. How did you feel when you were diagnosed with leprosy?
IP-PAM-B3	:	I was shocked.
P	:	Can you tell me why you were shocked? What is the situation behind it that got you shocked? What is in the picture?
IP-PAM-B3	:	It was so sudden. I was shocked.
P	:	So did the shock come from fear?
IP-PAM-B3	:	Fear.
P	:	So the fear... what came into your mind at the time?
IP-PAM-B3	:	I was afraid of the neighbors. I was afraid they would shun me.
P	:	Just that?
IP-PAM-B3	:	Just that.
P	:	Did you know anyone with leprosy before?
IP-PAM-B3	:	I have one friend. But he made full recovery now.
P	:	Alhamdulillah. How did the society behave towards that person?
IP-PAM-B3	:	Just normally.

P	:	Despite knowing that he had leprosy?
IP-PAM-B3	:	They knew, but I think it wasn't like that. When he went to the Health Center, he found out it was leprosy.
P	:	How did you feel about that?
IP-PAM-B3	:	I was afraid
P	:	Prior to being diagnosed, what was your opinion of leprosy?
IP-PAM-B3	:	I was afraid. I was afraid I would lose my digits, I would have open sores on my legs
P	:	Just that?
IP-PAM-B3	:	Yes.
P	:	Alright let me go to the next question. Have you told your family that you have been diagnosed with leprosy?
IP-PAM-B3	:	Yes, I told them.
P	:	Can you tell me how they reacted?
IP-PAM-B3	:	They were also afraid, my parents. They were afraid it would transfer to my younger sibling.
P	:	What is your role in the family?
IP-PAM-B3	:	I am the son.
P	:	Alright, can you tell me how they reacted... Oh I am sorry. Let me ask you the question again: do you have any difficulties performing your duties due to leprosy?
IP-PAM-B3	:	No difficulties at all.
P	:	Have you told your friends that you have leprosy?
IP-PAM-B3	:	No, no. I did not tell them. They won't hang out with me anymore if I did.
P	:	And how did you feel after telling them?
IP-PAM-B3	:	I was sad, afraid they would pull away.
P	:	Did you expect that reaction?

P-PAM-B3	:	Well... no.
P	:	Can you tell me about your friends' opinion towards you before you told them you have been diagnosed with leprosy?
IP-PAM-B3	:	It is just a regular condition that is treatable
P	:	Do you talk openly to them about your condition?
IP-PAM-B3	:	No, of course, because I worry they might avoid me.
P	:	Okay, the next question: have you told your neighbors that you have been diagnosed with leprosy?
IP-PAM-B3	:	Of course not, I didn't tell them.
P	:	Did you expect that reaction if your neighbors knew you have leprosy?
IP-PAM-B3	:	No, of course not. I opt for secrecy. I hope they don't react in any way.
P	:	Do you talk openly with them about your condition?
IP-PAM-B3	:	Of course not.
P	:	Is there any other thing you would like to tell us?
IP-PAM-B3	:	No.
P	:	Okay. Thank you for your time in this interview. We hope that you will be better, you will stay positive, and you will keep learning new knowledge about your condition. Whether you have a positive or negative outlook will depend on your own outlook. We hope you motivate yourself to keep yourself in the up and not easily depressed. Stay in the up. Thank you, Sir, for your time. Assalamualaikum warahmatullahi wabarakatu
IP-PAM-B3	:	Walaikumsalam warahmatullahi wabarakatu

Index 4 (1 Ira)

First of all, I would like to introduce myself. My name is Ira. I am currently conducting interviews with members of society in relation to distribution of preventative drug for the condition that you are suffering from. This interview will last approximately 30 minutes.

Interviewer : Are you willing to be interviewed?

IP-Pam-B4 : Yes, I am.

Interviewer : How many people are there living in your home currently?

IP-Pam-B4 : 3 people

Interviewer : Where did you go for treatment when you first noticed the illness?

IP-Pam-B4 : I went to the Health Center at Proko

Interviewer : Can you tell me about your illness?

IP-Pam-B4 : Yes.

Interviewer : When did it first appear? When did the first signs appear?

IP-Pam-B4 : Several months ago, approximately. About a year ago.

Interviewer : You went for treatment last year, then? Can you tell me what caused your illness?

IP-Pam-B4 : I don't know.

Interviewer: How did you feel when you were diagnosed with this illness?

IP-Pam-B4 : I took it just okay. I see it as life's trials.

Interviewer : Prior to being ill, did you know anyone or did you have any friends with this illness?

IP-Pam-B4 : No.

Interviewer : Did you tell your family about your illness?

IP-Pam-B4 : I have.

Interviewer : How did your family react upon hearing that you have this illness?

IP-Pam-B4 : Their reaction was just calm. For them, what was important was that I stay healthy.

Interviewer : In your daily living, what do you do at home?

IP-Pam-B4 : I am a farmer.

Interviewer : In your work as a farmer, do you find any difficulties?

IP-Pam-B4 : Thankfully, no.

Interviewer : With your illness, has there been any difficulties at all?

IP-Pam-B4 : No.

Interviewer : Have you informed your other friends that you have this illness?

IP-Pam-B4 : I have.

Interviewer : What was their reaction?

IP-Pam-B4 : They were cool about it. Infact, they supported me so that I get myself treated and to be healed.

Interviewer : How did you feel when you informed people about your illness?

IP-Pam-B4 : I felt relieved, because there was nothing to hide anymore.

Interviewer : Did your friends, upon realizing of your illness, react in the same manner as you hoped?

IP-Pam-B4 : Yes.

Interviewer : Before you told anyone this, you and your friends must have known that leprosy exists in Indonesia. Prior to telling your friends, how did they feel about leprosy?

IP-Pam-B4 : Just like my friends, just like myself, free from leprosy.

Interviewer : So that means you have been communicating openly with your friends?

IP-Pam-B4 : Yes.

Interviewer : Regarding neighbors, have you notified your neighbors about it?

IP-Pam-B4 : I have.

Interviewer : What were their reactions?

IP-Pam-B4 : They reacted differently. Some of them were surprised, some of them became embarrassed. They just reacted differently, because people are just different.

Interviewer : Your neighbor who became embarrassed, how was it that they become embarrassed with your condition?

IP-Pam-B4 : Well, they thought it was a genetic condition.

Interviewer : Did they think this was contagious?

IP-Pam-B4 : Yes.

Interviewer : Perhaps you have any suggestion for me, or for the government, or for global leprosy organization?

IP-Pam-B4 : Yes, I have.

Interviewer : What is your suggestion?

IP-Pam-B4 : My suggestion is this: let us eliminate leprosy from the world by regular medication, regular visit to health centers, and early detection if any spot symptoms are found.

Interviewer : Perhaps you have any suggestions for those who have not contracted leprosy?

IP-Pam-B4 : For those yet to be diagnosed, make sure you know the symptoms.

Interviewer : Okay. Thank you, Sir

Index 5 (2 Ira)

First of all, I would like to introduce myself. My name is Ira. I am currently conducting interviews with members of society in relation to distribution of preventative drug for the condition that you are suffering from. This interview will last approximately 30 minutes.

Interviewer : Are you willing to be interviewed?

IP-Pam-B5 : I am.

Interviewer : How many people are living in your house currently?

IP-Pam-B5 : 3 people

Interviewer : Where did you go when you first realized you did not feel well?

IP-Pam-B5 : Sorry, Ma'am. I only applied ointment on it. I bought some ointment and put it on me.

Interviewer : So you first bought some (over the counter) ointment. When it did not improve, where did you go for treatment?

IP-Pam-B5 : Health Center in Panaguan

Interviewer : Can you tell me about your illness?

IP-Pam-B5 : Yes, I can.

Interviewer : When did the symptoms first appear?

IP-Pam-B5 : Four months already

Interviewer : In your opinion, what is the cause of your condition?

IP-Pam-B5 : yes I know. It looks like patches.

Interviewer: What is the color of the patches?

IP-Pam-B5 : It is reddish.

Interviewer : How did you feel after you know that you are suffering from this disease?

IP-Pam-B5 : I was fine. I thought it was just ringworm.

Interviewer : Did you tell your friends that you were suffering from this disease?

IP-Pam-B5 : Only my brother and my mother.

Interviewer: Sorry?

IP-Pam-B5 : Yes only my brother.

Interviewer : How did people react to your brother?

IP-Pam-B5 : Just fine. Most people think this is just ringworm. Not something dangerous.

Interviewer : After you know what disease you are suffering from now, how do you feel?

IP-Pam-B5 : Yeah, I am just confused since it does not heal. I have been given many medication (Kalpanaxal, tablet) but it is still there.

Interviewer : Have you told your neighbor about this disease?

IP-Pam-B5 : No

Index 6 (3 Ira)

First of all, I would like to introduce myself. My name is Ira. I am currently conducting interviews with members of society in relation to distribution of preventative drug for the condition that you are suffering from. This interview will last approximately 30 minutes.

Interviewer : Are you willing to be interviewed?

IP-Pam-B6 : Yes, I am.

Interviewer : How many people living in the same house with you?

IP-Pam-B6 : Three

Interviewer : Where did you go when you found that you have the symptoms of this disease?

IP-Pam-B6: To the XXX health center.

Interviewer : Can you tell me about your disease?

Salman : yes, I can.

Interviewer : When did it first appear? How many months ago?

IP-Pam-B6 : It is about 9 months

Interviewer : What do you think the cause of your disease?

IP-Pam-B6 : I do not know, Ma'am

Interviewer : How did you feel when Mrs. XXX (health worker) tell you that you have this disease?

IP-Pam-B6 : I was fine, because she told me that it is a kind of ringworm.

Interviewer : Did you notice any of your friends having this disease also?

IP-Pam-B6 : No, Ma'am.

Interviewer : Have you told your family that you have this disease?

IP-Pam-B6 : Yes, Ma'am.

Interviewer : How did they react?

IP-Pam-B6 : they were fine.

Interviewer : What do you do at home ?

IP-Pam-B6 : Nothing, just regular activity.

Interviewer : Do you help your parents?

IP-Pam-B6 : No, Ma'am.

Interviewer : Did you tell any of your friends about your condition?

IP-Pam-B6 : No, not yet.

Interviewer : Why ?

IP-Pam-B6 : I am embarrassed.

Interviewer : Why do you feel that way?

IP-Pam-B6 : I do not know Ma'am, I am just embarrassed.

Interviewer : How do you think people think about this disease?

IP-Pam-B6 : It is just ringworm Ma'am.

Interviewer : Any of your neighbors already know about this?

IP-Pam-B6 : No, not yet Ma'am.

Interviewer : Do you have any suggestion for me or to Mrs. XXX?

IP-Pam-B6 : No Ma'am. Thank you.

Interviewer : You're welcome.

TRANSCRIPT OF QUALITATIVE INTERVIEW WITH SOCIETY

LEPROSY PERCEPTION STUDY IN PAMEKASAN

CM-Pam17-B1

INTERVIEW DETAILS

Interviewer : Ari
Observer : Kiki
Code : CM-01-MA
Date : June 13, 2017
Location : Informant's home in Kowel, Pamekasan
Time : 10.00 – 10.22

DEMOGRAPHIC DATA

Name : XXX
Age : 62 years
Gender : Male
Occupation : Religious leader (ustadz) / farmer

REASON FOR CHOOSING INFORMANT

...

PROLOGUE

Prior to conducting interview, the interviewer reads the consent created for society interview. The reading of the consent followed by signature of agreement to be interview subject takes place

approximately 1"55'. The interview is conducted at the home of the informant, wherein the ambience is rather not conducive due to pet noises.

DESCRIPTION

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT

P : How old are you, Sir?
I : 62
P : What would you say your daily occupation is?
I : None, I do not work. I do not have any job. Farming, probably. Farming.
P : How many people are there in your family, Sir?
I : All of them?
P : Living in your house.
I : Oo in one house, only three of us.
P : What was your most recent education? Schooling?
I : Primary school
P : In your opinion, what is leprosy to your knowledge?
I : It is a disease...as the villagers refer it, bad flesh. It is called bad flesh.
P : What causes it, to your knowledge?
I : Well, some people work together and then they get infected.
P : So it is infectious?
I : Yes, infectious. From work, you can infect one another.
P : Contact?
I : Yes, contact. What you touch can... you know... it may pass through your sweat maybe.
P : Is there any other cause? Aside from sweat and contact?
I : Not to my knowledge. People say that if you often have contact with someone with leprosy, you often share bathing (equipment), often have contact, share soap (bar), that's how you get it.
P : So the cause is close contact?
I : Yes, close contact.
P : Using the same equipment also?
I : Yes, yes.

P : To your knowledge, what are the symptoms of leprosy? What appears in the body?

I : It looks like fungal breakout, fungal breakout that appears white and itchy, but there is a loss of sense there.

P : Loss of sense?

I : And then it spreads. There is a neighbor around here that has it. But the person is afraid, embarrassed. His face is changed now.

P : Changed how?

I : It turned reddish and black, red splotches.

P : In your opinion, is this condition treatable?

I : Some people receive treatment and they fully recover. But some other people are too embarrassed to get treatment.

P : So many people are still embarrassed (by their condition)?

I : Yes, they are still embarrassed.

P : Do you know why they are embarrassed and not wanting to get treatment?

I : Yes, yes, that is probably because they have to go out in public while their faces are already turning different.

P : So they are embarrassed because they now look different?

I : Yes, they are embarrassed because of that. They look in the mirror and see that their faces are different and they don't want to see their friends and neighbors anymore. They become embarrassed, and then they don't feel like working. All because of their faces that change.

P : But some people made recovery?

I : Yes, some people recover. Some of their relatives are treated and recovered.

P : Religion wise, what causes leprosy? From the mythical explanation, not from medical.

I : Some say it is hereditary. It is passed down from the older (generation)

P : Do you agree that leprosy is a genetic disease?

I : Yes, if the older generation has it the children will surely have it.

O : Up to how many generations?

I : Up to 10, we have (a family) whose child passed away because of leprosy.

P : This means many people still believe that leprosy is genetically passed down?

I : Yes. But if they receive proper medication, even though the condition persists for seven generations, it is treatable and they will recover. We have a man here by name of Jamal, to the neighbors' knowledge he has made full recovery after receiving treatment. They say that he has to continue taking medication everyday.

P : So you know that some of your neighbors have this condition?

I : Yes, I know. If I go to their houses, talking about it, I'm a little...I don't know...awkward. They are afraid of being advised to get medication, and I'm afraid they will reject me. It is as if they are afraid of being exposed and embarrassed.

P : Oh, you mean you have given that suggestion (to seek medication)?

I : Well, no. I want to. I want them to get better so they would not be like this (*-bending his fingers*). But they are not easy to talk to.

P : And how does the society treat people with leprosy? Do they treat them differently?

I : No, the majority already understand the situation. Even the Prophet (Mohammad) was said to share meals with them. So because of this the society does not... they don't bicker about it. They just behave as normally.

P : Do they avoid anything?

I : They avoid marriage with them. That's what they will avoid at all cost.

P : Because they are afraid of being infected?

I : Yes, they are afraid of being infected.

O : And so for people with leprosy, can they marry at all?

I : They can if they want. But as for who can accept (their condition), that's not possible because all their neighbors already believe it is not possible.

P : They don't "sell" very well?

I : They don't "sell" very well.

P : Are there any who marry (in the society)?

I : Die?

P & O : Marry.

I : Oh, marry. Yes there is one who got married. But she married someone who is not from around here, so I don't know. It is Yadi's sister, perhaps you (*pointing to the leprosy spokesperson*) know. The girl is beautiful. But (leprosy) is hereditary, and she married someone who is not from here. There was no possibility for her to marry someone local because the neighbors know her condition.

O : So you mean that the locals who know her condition do not wish (to marry her)?

I : Yes. She worked in Surabaya, and met with a man from Bangkalan, then they got married.

P : So the society here does not avoid but when it comes to marriage they will avoid.

I : Yes, that is right. They will not marry (a person with leprosy). Including them in social functions is still possible.

P : In your opinion, how do you see people with leprosy?

I : In my opinion, if I have a genetic condition like that I would want to find the first person. Person zero. I would ask my neighbors or anyone who knows.

P : So you don't want (to marry) a person with leprosy either?

I : No, I don't. If it is a genetic condition, I don't. It is not possible.

P : When it comes to social gathering, how far will you allow?

I : For social gathering it is okay.

O : Would you eat together with them?

I : I have never done that.

P : How about shaking hands?

I : Shaking hands is still all right. I don't mind. I also go to their events if I am invited.

O : So if they have a party and you are invited, would you come?

I : Sure. I even shake hands with everyone.

P : If a family with leprosy have an event, such as circumcision or wedding, would you eat the food served in the function?

I : Sure. But it is a known situation. They usually don't... Perhaps everyone has been notified of the situation. Sometimes people gather and when they know about the situation, they move away. That's hurtful, actually, to their feelings.

P : Oo...Are there still people who do that?

I : Yes, definitely. Some people still do that. For example, at a wedding some people come and then they leave. That's hurtful. I won't do that, I would stay. Some people still avoid, though.

P : So some people still avoid them?

I : Yes, some people still do.

P : But you don't?

I : No, I don't. It is just a social gathering. I draw the line at producing heirs that have the condition.

P : But for socializing, gathering with neighbors, it is not a problem?

I : That is correct.

P : Would you like to be notified if anyone in your society has leprosy?

I : I think that's possible. If you take them here, or if you take me to their house, I still can take it. I can take you to their house, Some people would not, though. They think lepers are disgusting.

P : Are there still many people who think that? That lepers are disgusting?

I : Yes, there are.

P : Are there still many (who think that)?

I : Yes, there are. They would avoid anyone who has leprosy.

P : Which is more, people who avoid or people who are neutral such as yourself?\

I : To my knowledge, I think many people are avoiding. I see people who are friends, but when one of them experience a change in the face, the friends became distant. I see people like this turning solitary because their friends refuse to come around anymore.

P : So, many people distance themselves here? Why is that?

I : They might think it is disgusting or whatever, I don't know. I cannot guess how they feel about it.

P : Have you ever criticize them for this behavior?

I : Not yet.

P : I mean, have you ever reminded these people not to ostracize or avoid these people?

I : One man caused his workmates to quit. He works at the ironsmith. A new worker came and quit immediately.

P : Because of this one man with leprosy?

I : Yes. He was afraid because working there means seeing this man everyday, sharing tools with him, such as the pincers and all that.

P : But the man with leprosy is still working?

I : Yes, he is.

P : I mean, the man with leprosy is still working well?

I : Yes. The employer thinks he is doing a very good work so he gets to keep the job.

P : How bad is the leprosy?

I : His face changed. Another person is already beginning to show this (*showing distended fingers*), his fingers already like this. But he recovered, the man whose fingers are like this (*distended fingers*), He is still in therapy for his fingers. His body if fully recovered, he even gained weight already.

P : Are there myths about leprosy? Myths such as from the traditional society, like from ancient times?

I : Yes, partially. I heard about a lady who had leprosy. There is a belief that leprosy is genetic. One person with leprosy was treated but died. He didn't finish the medication. It was already acute.

P : Last question, Sir. In your opinion, how does the society treat persons with leprosy?

I : What do you mean?

P : How should the society treat persons with leprosy?

I : This is my opinion. One of my neighbors claim he wants to get better, unlike now. He wants to be like he was before, but he was too embarrassed to consult with experts. God willing, if he is contacted in person, he will go and be willing to receive help.

P : Thank you so much, Sir.

I : You are welcome.

Interview ends after duration of 22"12', at the end of interview the interviewee is presented with a souvenir, and a photo is taken as evidence of interview.

**TRANSCRIPT OF QUALITATIVE INTERVIEW WITH SOCIETY
LEPROSY PERCEPTION STUDY IN PAMEKASAN**

CM-Pam-B2

INTERVIEW DETAILS

Interviewer : Ari
Observer : Kiki
Code : CM-05-FE
Date : June 17, 2017
Location : Informant's house in Bulangaji, Pamekasan
Time : 10.05 – 10.18

DEMOGRAPHIC DATA

Name : XXX
Age : 45 years
Gender : Female
Occupation : Homemaker

PROLOGUE

Prior to interview, the interviewer reads the consent for family members. Reading of the explanation followed by signature of agreement as research subject takes place approximately 1"09'. Interview is conducted at the home of the informant under conducive circumstances.

DESCRIPTION

P : Interviewer
O : Observer
I : Informant
..... : Question as per interview module

INTERVIEW TRANSCRIPT

P : What is your name, Ma'am?
I : XXX
P : How old are you?
I : I am 40
P : Occupation?
I : Homemaker

P : To your knowledge, what is leprosy?

I : In my opinion, as is the opinion of the society here, leprosy is a very strange illness. I think it is communicable, and that is why it is bound for exclusion. But I don't know the medical definition. As for people, I think people are afraid to go anywhere near (a person with leprosy).

P : To your knowledge, what causes leprosy?

I : It might have been genetic. But I don't know the real cause. For us in this community, it is hereditary.

P : Is there any other cause besides genetic?

I : Perhaps eating the wrong food, or from infection.

P : What are the symptoms, to your knowledge?

I : Reddish

P : Is it treatable?

I : It is not treatable. I don't think so. I don't know, though, with modern medication.

P : So people in this community think it is not treatable?

I : Yes. There is no medication for that.

P : Umm.. can you specify what the people in this society or community see about people with leprosy? I mean, what it is or how they are avoided?

I : Some people experience skin abnormalities, and it is scaring us so that we don't come near.

P : Scared, and..?

I : We are afraid of being infected.

P : Do you openly keep away from people who have leprosy?

I : No, we do it subtly. It is not nice to say openly to them, pointing out their illness. We don't say to them that we don't want to get near them because of their skin condition. That's not possible.

P : So you try to keep them in good spirit?

I : Yes, yes.

O : So you don't exclude them too much?

I : Yes.

P : Aside from avoidance, will anyone marry someone knowing that the person has leprosy? Or if there is leprosy in the partner's family?

I : No. Except if it is someone who is not from here who doesn't know the situation.

O : New (people)?

I : Yes. Locals who know the situation will not go (into marriage).

P : So the majority of the community here still sees it that way?

I : Yes. It is indeed a horrifying illness.

O : If the society sees this as an incurable illness, what will happen if someone recovers?

I : No, nothing.

O : Is there treatment, perhaps traditional medication or something?

I : I don't think there is any traditional medication for this situation. And anyway there is medicine. Modern medicine already sees leprosy as illness.

O : So you mean to give in?

I : Yes.

P : But supposing that there is medication for leprosy, will it change the view of the society or community in this area, in your opinion?

I : God willing, yes. Provided that we can bring the word out to the lay community.

P : Are there any myths or beliefs in relation to leprosy that the society still believes in?

I : Yes, there is. Just recently someone passed away, and it is believed that leprosy caused his death. Even his family, and even his own mother, refused to touch the corpse for fear of infection. While actually, it is not communicable; it is passed down genetically. That is how you get infected. That is horrible: not even his own mother would touch the body.

P : In your personal opinion, how do you see a person with leprosy?

I : Just the same. For the time being I don't see any evidence of a person with leprosy recovering from it. So I still see it the same way. But personally... there is actually one of my neighbors who is said to have leprosy. For me personally, before it is made public, I can still hang out with them, eat together with them, visit each other's houses, as long as I don't touch their spittle. Just brushing or touching hands is not likely to transmit the illness to me.

(leprosy spokesperson intervened by telling about index case who often made visits to XXX house)

I : The other day, she...she came with homemade chips. She gave some to the neighbors, but I think the neighbors didn't want to accept.

P : The other neighbors did not eat the cassava chips?

I : Yes, they did not want to accept her homemade goods. I have no problem with it because it was processed, it was fried. There is no chance for infection there.

(leprosy spokesperson once again intervened by telling the interviewee about the treatment the index case has been in for 6 months)

P : So now leprosy can be treated?

I : Yes, there are medication effort.

P : So you know someone with leprosy?

I : Yes.

P : And you don't treat him or her differently?

I : No, no. I learned this from training from the Health Department, that we should not ostracize people with leprosy. Infection is through saliva, so touching will not cause infection.

P : And so, in your opinion, why does the society still ostracize persons with leprosy?

I : That's because of their understanding, and that's difficult.

P : Not enough (knowledge)?

I : Yes, because of that, because it is not treatable.

P : So perhaps there needs to be someone who is fully treated first to make it happen?

I : Yes, and maybe that will change how people perceive it.

P : Nowadays there is medication available for leprosy. Let's say you see one of your neighbors having the signs of leprosy, will you advise him or her to go for treatment?

I : Yes, I might.

O : Regarding symptoms, what are other symptoms aside from reddish skin?

I : The body shrinks.

O : What is the worst symptom of leprosy that you have witnessed?

I : To my knowledge, the (skin) of the body turns blackish color.

P : Have you ever seen anyone with severed finger?

I : Yes, I have.

P : Do you think someone with that stage will be further stigmatized or discriminated?

I : Yes. The further the stage, the less people are willing to go any closer.

P : So it becomes more openly?

I : Yes, it is obvious, and people will be less subtle in their attempt to avoid.

P : Why do you have a different treatment toward people with leprosy compared to the society?

I : Well, I don't want to be infected, so it is better to avoid then.

P : But you don't avoid them as much as the other people in society. Why is that? Why are you more tolerant?

I : Umm... I think it is the human side. I mean, who would want to have an illness like that? I don't think anyone would. It is probably something that is in their fate.

P : All right. Thank you for sharing, Ma'am.

I : Yes, you are welcome.

Interview ends after duration of 13"12', at the end of interview, the interviewee is presented with a souvenir, and a photograph is taken for evidence of interview.

TRANSCRIPT OF QUALITATIVE INTERVIEW WITH LEPROSY CADRE

LEPROSY PERCEPTION STUDY IN PAMEKASAN

HCW-Pam17-B1

INTERVIEW DETAILS

Interviewer : Ari
Observer : Kiki
Code : HW-01-FE
Date : May 13, 2017
Location : Informant's house in Koel Jaya
Time : 12.12 – 12.23

DEMOGRAPHIC DATA

Name : XXX
Age : 51 years
Gender : Female
Occupation : Homemaker

Have received training on leprosy

PROLOGUE

Prior to the interview, the interviewer reads the consent for agreement presented to the family members. Reading of the consent and signing the agreement as research subject takes place in approximately 1"13' duration. The interview is conducted at the home of the informant, located in Koel, in a conducive setting credited to the relatively quiet situation of the house.

DESCRIPTION

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT

P : What is your name?
I : XXX
P : How old are you?
I : I am now 51
P : What is your occupation?

I : Homemaker

P : Umm... have you ever received any training on leprosy?

I : I have, once, but I think I forgot what it was.

O : How many times of training did you receive?

I : It wasn't a training. It was... I think it was a sort of cadre meeting. Something like that.

O : Did you often go to such meetings?

I : Yes, I did. I have been a cadre for something like 25 years now.

(intervened by the informant's grandchild, who distracted her attention)

P : Please tell me about leprosy, to your knowledge.

I : Leprosy is... you can say it is infectious, if you hang around a person with leprosy for about two years. And then... I forgot...

P : That's okay, Ma'am, just what you can remember. What about the cause? Or symptoms?

I : Itchy. Yes, itchy. And then loss of sense. What else... itchy and loss of sense... It looks like skin fungi. And loss of sense, I mean like white patches... what else...

P : Do you know anyone around you who is affected by leprosy?

I : No, I mean I used to. Many have passed away now.

P : Are there any of them who went for medication from the Health Center?

I : I don't think so. Not all of them (have the access). People in this area mostly are medicated, though.

P : Those who are not treated, do you know why they are not treated?

I : They don't want to. Just that. I did suggest it to them, subtly. I told them to go and get a shot to keep themselves healthy. I didn't say openly for what, I don't want to offend them. Usually if it is for maintaining health, people are more keen to get a shot. I said: "*bedhe suntik kesehatan*" (*go for the health injection*).

O : In your opinion, how do you see people with leprosy?

P : Well, if they are at the later stage of leprosy, it may be gross. May be it is scary to see people who are severed or disabled. They also turn reddish if they are exposed to heat.

I : So even though you have received training that leprosy is transmitted through this, and the medication is by that, you still have that fear?

P : I am just cautious.

O : Are you more cautious to the person, or the illness?

I : Illness. When I meet someone with leprosy, I tend to be aware of my distance.

O : But have you ever have close contact or direct touch?

I : Before I knew (that someone has leprosy) I was behaving normally, shaking hands and all. I didn't understand, so it was okay. But after I knew about leprosy, I still think it is okay (to have close contact) but I wash my hands afterwards. I don't stop from shaking hands with them, because it is not polite. Sometimes I report to the Health Center.

O : Do you have any experience you can share with us?

I : I don't think so...

P : Maybe someone got angry when you tell them they have leprosy?

I : No, I never tell anyone directly that they have leprosy. I only tell them to go to the Health Center, and when they ask why I only say because they can get themselves checked up. I don't say to them directly that they have leprosy.

O : But supposing you do, what do you think the response will be?

I : They will be angry. No doubt. The cadre is always at the brunt. Let's say for vaccination. After a child is vaccinated, she or he might have a slight fever. The cadre is always blamed for that. Some other people have lumps on their body. They got mad at me that time, but I said to them it may be symptom for another illness. People who are educated will not respond (negatively), but those who are not educated, they don't understand. But now there are more who are knowledgeable.

P : All right. Thank you so much, Ma'am.

Interview ends at duration of 11'05', at the end of the interview, the informant is presented with a souvenir. A photograph is taken as evidence of interview.

TRANSCRIPT OF QUALITATIVE INTERVIEW WITH LEPROSY CADRE

LEPROSY PERCEPTION STUDY IN PAMEKASAN

HCW-Pam17-B2

INTERVIEW DETAILS

Interviewer : Ari
Observer : Kiki
Code : HW-02-FE
Date : May 15, 2017
Location : Informant's house in Ragang, Tlanakan
Time : 12.47 – 12.56

DEMOGRAPHIC DATA

Name : XXX
Age : 39 years
Gender : Female
Occupation : Teacher/homemaker

Has not received training on leprosy

PROLOGUE

Prior to the interview, the interviewer reads the consent for agreement presented to the family members. Reading of the consent and signing of the agreement as research subject takes place approximately 1"05'. Interview is conducted at the home of the informant, located in Ragang, interview is considered ineffective due to the inconducive setting of the informant's home, wherein the recording captured the noise of children playing, chatter from other conversation, and vehicles passing.

DESCRIPTION

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT

P : What is your name?
I : XX
P : How old are you?
I : 39
O : Your occupation is teaching?
I : Yes, homemaker and teacher
P : Have you ever received any training on leprosy?
I : Not exactly training. Just the counsel.
P : What can you tell about leprosy, to your knowledge?
I : To my knowledge, leprosy is an illness that... here it is said that it is a curse. A person with leprosy shows patches that are senseless. If you do something to it, like pinching or whatever, the person won't feel it. It is whitish, like the skin fungi.
P : Do you know anyone with leprosy near you?
I : Well, there is one suspect who is showing the signs.
P : Is he or she under treatment?
I : Yes, under treatment. There is someone from the Health Center who is tasked to seek anyone with leprosy. Another is tasked to seek anyone with mental illness. And the Cadre from the Posyandu is tasked to report any cases of illness.
P : So far, how many people have you referred or suspected for leprosy?

I : We have many cases of leprosy here, but only one person goes in for treatment. The other are... well... you know, it is not polite to say to people's face that they have leprosy. I could only report it to the Health Center, and the Health Center would ask them if they have this or that illness. The patient doesn't know and usually too embarrassed to go in for treatment. Some are willing, though.

O : So you only refer them to the Health Center if you see the leprosy symptoms?

I : Yes. If I had told them myself (they have leprosy) it might cause them discomfort and they might not understand. If someone from the Health Center talks to them, it becomes a medical counsel that they have symptoms of leprosy. If it looks like skin fungi, then I refer them to the leprosy taskforce. And there is also Ibu Sofi (from Health Center) tasked with cases of mental illness. The other day I referred someone for leprosy and the Health officer came. But the patient stopped the treatment so he didn't recover.

P : What is your personal opinion about people with leprosy?

I : For me personally, I understand from the information I got from the Health Center that leprosy is treatable. If a person with leprosy goes for treatment, then it will not be infectious. Infection is through skin contact, from sweat. The problem is that we live in a less-educated community. It is difficult in this kind of village setting to provide education.

O : So that would be the challenge, that the community is not educated?

I : Yes, the community is the problem. Let's take the Women and Children Health Center case. Some people still refuse vaccination, even after the explanation and evidence that not vaccinating will cause longer term of illness. Still, people would not believe if they don't experience it themselves.

P : To your knowledge, do you see that leprosy treatment at the Health Center is different?

I : Leprosy has its own ward, mental illness has its own ward too.

P : I mean, for treatment of leprosy, is there any discrimination? For example, the ward is placed separately or hidden from public?

I : No, it is just the same. Consideration of the patient's feelings. If there was discrimination, then patients will stop going in for treatment.

P : If there comes the need to touch a leprosy patient, will you do it?

I : Touch? That depends, if it is earlier stage of leprosy, I'm still okay with it. But if it is later stage...well, I have to take care of myself, don't I? If it is not touching, I'm still okay. I have to take care of myself, too.

P : Earlier you told us that leprosy is a curse. What do you mean by that?

I : I don't know about that. I am a Javanese (*Central Java*). We don't have this case in (Central) Java, I only knew about leprosy here. People here say that leprosy is hereditary, and they call

it *daging jubek* (bad flesh). I did not know what *daging jubek* is. All I knew was leprosy. I am here because of my husband. So I am quite foreign to local terms like that. People here don't understand the term leprosy, they only understand the term *daging jubek*. So in the next seven generation, a person is doomed with that.

O : Oh, you mean curse as in an illness that will continue for seven generation?

I : Yes, that's what they say. For me, personally, we have nothing like that belief in (Central) Java, so I have no knowledge about it. I only found out here.

P : So you don't believe that leprosy is hereditary?

I : No. I believe that there is treatment for all illness, unless it is an illness that we created. You know what I mean.

O : Perhaps you can share with us your experience as a cadre for leprosy? The challenges or something like that?

I : Well, no, I mean, I have never directly handle any case. I only report them. I only have to report that there is a case that looks like leprosy. I report so that the people are not infected, to protect the children and the community in general. So that it does not become an outbreak. That's all my intention, so that we all have good health.

O : How do you do it? Do you secretly spy around?

I : No. Here, change is obvious. Usually the person changes. Sometimes a skin wound, sometimes change of skin color, then missing (xx). We can't judge them, we can only see the physical changes.

P : All right then. Thank you for your time.

I : Yes, you are welcome.

Interview ends at the duration of 09"53', at the end of interview, the informant is presented with a souvenir.

**TRANSCRIPT OF QUALITATIVE INTERVIEW WITH LEPROSY CADRE
LEPROSY PERCEPTION STUDY IN PAMEKASAN**

HCW-Pam17-B3

INTERVIEW DETAIL

Interviewer : Ari
Observer : Kiki
Code : HW-03-FE
Date : 16 Mei 2017
Location : Pergi Women and Children's Health Center
Time : 12.05 – 12.17

DEMOGRAPHIC DATA

Name : XX
Age : 35 years
Gender : Male
Occupation : Farmer

Have received training on leprosy

PROLOGUE

Prior to the interview, the interviewer reads the consent for agreement presented to the family members. Reading of the consent followed by signing of agreement as research subject takes place approximately 1"31'. Interview is conducted at the Pregi Women and Children Health Center, in a conducive manner.

DESCRIPTION

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT

P : What is your name?
I : XXX
P : Age?
I : 35
P : Occupation?
I : Farmer
P : Have you ever received any training on leprosy?
I : Yes, I have.
P : Where?
I : At the Health Center.
O : How many times?
I : If I'm not mistaken, just one.
P : To your knowledge, what is leprosy?
I : It is when there are reddish patch, with no hair, and senseless.
P : What is the cause?
I : It is bacteria

O : What are the symptoms?

I : Loss of sense, swelling in the ears and nose, and then there might be loss of fingers one by one. When it gets worse, you will lose fingers and have wounds all over.

P : So you know someone with leprosy?

I : Yes, but they don't live here. They live over there at the end (of the village) and in the mountain. They don't live here.

P : Have you ever made referrals?

I : Yes, I made referral for the people living in the mountain.

P : How do you spot a leprosy patient?

I : Well, you hold it up to light, and you can immediately see (*demonstrating with his own hand how to diagnose skin*), if you don't sense it, then it is definitely leprosy.

P : What happens if you hold it up to light?

I : It turns reddish color.

P : And then you make the referral to the Health Center?

I : Yes. There are two kinds of leprosy, there is the wet kind and dry kind. The wet kind is more malignant, it can be infectious quite fast. Treatment is also different. Whereas the dry kind is six months, the wet kind might take longer, a year or even more.

P : How many people have you referred?

I : Not too many. Maybe four or five. Not many in this area, but many from that area in Bajur, near the Sumenep border. Mostly from Sumenep.

P : How do you personally see persons with leprosy?

I : Hmm. It is a rare illness. The lay people say that it is a hereditary illness, but from the viewpoint of medicine, it is not. But it is transmittable, so seeing it still makes me scared. I don't think it is hereditary, though, although it makes sense because if you swap clothes, have close contact, etc, you will probably be infected even after 5 years. It does make sense if you say it is hereditary. Even if you are not from the same family, but if you live under the same roof, you will be infected

P : Most people in the society are still afraid?

I : Yes, definitely, they are still in fear

O : But does the society take their distance?

I : Yes, if they found out. Why won't they be scared? However if they don't know, they won't be called hereditary condition. Normally, lay people see it as hereditary so they won't call it infectious, and therefore they don't fear it. If one is not related to anyone with leprosy, he won't be infected, and the society behave normally towards him

O : So no one avoids him?

I : Yes. That would be how lay people in the society behave

P : What if a person has leprosy at later stage, with numerous wounds?

I : No one here has that. There is one over there near the border. He was ostracised, his family built him a house where he lives separated from them. He is in a very bad condition, his body full of sores and his digits are missing

P : To your knowledge, is the leprosy treatment at the Health Center different? Discriminated or separated, perhaps?

I : Just normally, but usually the lay people do not believe because they are not educated enough. They would call it the devil's disease. They would say the patient is hexed. All of this is because they are not educated enough. But if they are educated, they won't think that way

O : So that means many people still believe that leprosy is a curse?

I : Yes, some people still believe it as the devil's disease or curse. But if they are educated, even just a little, they won't think that way

O : So if they still believe (that leprosy is a curse), what is the cure then?

I : They go to the shaman. If they go to a shaman, then treatment is whatever the shaman gives them. Lay people, you know. But nowadays many people know about leprosy. Only people who live in the interiors still believe that way. The others believe in modern medicine.

P : If there is necessity to have direct physical contact with a patient, would you do it?

I : You mean if the patient does not mind? If I already knew the patient's background, then it is down to feelings. I would feel sorry for him. But if I had to (have contact with a patient) then it is okay, I would prefer it than being slandered. Afterwards, I would wash my hands or something

P : Are there interesting experience while being a leprosy cadre?

I : My hardest experience is making people in the interiors to believe. That would be the hardest challenge. They still believe in magical stuff, so they need to be educated. But even after being educated, they would still go to shamans. And as a result, nothing happened, their condition continue to persist. When they resort to modern medicine, then they begin to show progress, and they slowly believe it

O : Do you know what they are given if they go to the shaman?

I : Well, incense, oil, herbs, water, things like that. I don't know much about this, Miss

O : How long have you been a leprosy cadre?

I : It's been a while, a little over 5 years

P : How did you first became a leprosy cadre?

I : At first it was because I live next door to the Health Center. A friend of mine was already a leprosy cadre, so I tagged along. And then I became interested and I liked doing it

P : Thank you for your time for this interview

I : You are welcome

Interview ends at 12"23', at the end of interview the informant is presented with a souvenir and photograph is taken as proof of interview.

**TRANSCRIPT OF QUALITATIVE INTERVIEW WITH LEPROSY CADRE
LEPROSY PERCEPTION STUDY IN PAMEKASAN**

HCW-Pam17-B4

INTERVIEW DETAIL

Interviewer : Ari
Observer : Kiki
Code : HW-04-MA
Date : June 20, 2017
Location : Informant's house in Montor, Teja Barat
Time : 09.20 – 09.39

DEMOGRAPHIC DATA

Name : XXX
Age : 50 years
Gender : Male
Occupation : Goat breeder
Has received training on leprosy.

PROLOGUE

Prior to interview, the interviewer reads the consent for agreement directed to family members. Reading of consent and signing of agreement as research subject, takes place approximately 1"20'. Interview is conducted at the house of the informant and in conducive manner.

DESCRIPTION

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT

P : What is your name, Sir?
I : XXX
P : Your age?
I : I am 50

P : Your occupation?

I : My occupation is selling goat, slaughtering

P : Have you received training on leprosy?

I : Leprosy? Yes.

P : How many times?

I : Twice

O : Where is that, Sir?

I : First time was at the Health Center, and then the second one was at the home of a villager, where a health officer was brought in from the Health Center. It was at the home of a villager, and I came to the meeting.

P : What year was that, Sir?

I : Recently. This year it was about two months ago

(the interview was intervened as the informant received a phone call from the village chief or "klebun", for about 2''10')

P : Can you tell me about leprosy?

I : About leprosy... leprosy for me is the most dangerous illness. When it comes to marriage, one would be questioned all about their family background, especially here. I see it as the most dangerous because, aside from infectious factor, for example, it would ruin how one looks.

P : So it would affect physically.

I : Yes, it would not be good physically. Then treatment and anticipation take a long time. And also, once a person is affected with leprosy, his self-esteem is deeply affected, and he will feel strange. He will lose (self-esteem)

P : What is the cause of leprosy?

I : The cause, to my knowledge, is contact. Not hereditary.

P : But many from the community here still believe it is hereditary?

I : No, they are starting to understand that this is a transmittable illness, not passed down

P : Umm... can you describe the symptoms?

I : The early symptoms, the way I see it in a friend of mine who has leprosy, at a passing glance you can see missing this part (*pointing to the tendon between the thumb and forefinger*). I have always suspected this friend, because he was missing that part. After seeing him for awhile attending school, this part is slowly disappearing (*pointing to the eyebrows*), and this

part is widening (*pointing to both cheeks*), this becomes slightly blunted (*pointing to the nose*), and this becomes wider (*pointing to both earlobes*)

(*leprosy spokesperson intervened by explaining the symptoms of leprosy patient*)

I : At later stage, when it has set, the joints become twisted. Sometimes you lose your digits.
Hahahah

P : And do you know anyone with leprosy in this area?

I : Passed away now.

P : So you do know, but the person has passed away?

I : Yes, the person has passed away. My friend that I mentioned earlier is still in school, and he is still alive. The other person that is from around here has passed away now, and another one I know is declared clean of bacteria by medical professionals.

P : Clean?

I : Yes, because he was treated routinely. But he has moved from here now.

P : What about yourself, have you ever referred a leprosy patient?

I : I don't make referrals. I only deliver information that leprosy requires routine medication.

P : Have you ever taken a patient to the Health Center?

I : Yes, I have taken them to Health Center.

P : How many?

I : From this hamlet, only two people. One has passed away due to old age, and the other is still young. The young one is now declared clean from bacteria

P : So not very many from around here?

I : No, just that one. The older one passed away a long time ago. The young one, however, has relocated.

P : Can you spot someone with leprosy? Can you discern the symptoms?

I : At this time, yes, I can see that it looks like skin fungi, but shaped differently. Skin fungi looks different. When I see skin patches, I would be suspicious. Just so happens that I have a friend that I see everyday at the marketplace. Whenever he is sweaty, he would take off his shirt. I said to him, "This is different. This is not regular skin fungi, this is different." And then I gave him some information that he should get treatment because what he had was not regular patch. "Why is that?" he asked me. I told him that he has a suspicious skin patch, unlike regular skin fungi. And this part (*pointing to the elbow*) was beginning to get pointy.

O : Pointy?

I : The elbows are starting to be more pronounced. This (*pointing to the cheeks*) is starting to seem more puffy.

P : Did your friend go for medication?

I : One

P : Did your friend go for medication?

I : I don't know. It was a friend of mine at the marketplace.

P : Oo.. you didn't tell him to go get treatment?

I : I did give him suggestion

O : But you don't know whether or not he went for treatment

I : I don't know. He is not from around here. He is just someone I often run into at the market

O : What else?

I : That's all. I became suspicious when this (*pointing to elbows*) became more pointy. That is one of the symptoms. And these (*pointing to earlobes*) widened, joints in the hands became twisted. And also there were patches which are different than regular skin fungi. Generally it looks different to patches caused by fungi. It is thicker.

P : Thicker?

I : Yes.

P : Can you tell me what your perspective is about leprosy patients? Do you understand them?

I : If they are exposed to heat, (the skin) turns reddish, if they are exposed to light for a bit of time their (skin) turn reddish.

O : How do you view leprosy patients?

I : I just wish that none of my descendants have it. I don't know what it is like out there, but here people are asked about their family history, whether anyone from the family has leprosy or not.

P : What if there is (history of leprosy in the family)?

I : If there is... well people from the same family tend to get together and have close contact everyday. This is what one must look out for; it is not a genetic illness. It is a contagious illness. If there is a leprosy patient in a family, the family will have close contact: eat together, drink together, switch clothing. That is what one must look out for. Someone in the family would surely catch it because (the house) is not sterile. It is not possible (to have a sterile house)

P : Oo...so it is not hereditary but more likely because of close contact?

I : Yes it is not hereditary

P : So there is fear of contagion

I : It is like tuberculosis, it is dangerous because it is fast, the infection factor is fast and that is dangerous. In the case of tuberculosis, if one of the family has it then the whole family must be under suspicion. At least they should use protective mask. In the case of leprosy, mask is of no use, but (the house) must be sterilised.

P : How does leprosy pass?

I : Infection takes some time, compared to TBC. Leprosy infection is at most six years, give or take

P : What is the medium of infection?

I : Direct touch, sweat, towels, things like that

P : But over a long period?

I : Yes

P : To your knowledge, is treatment for leprosy patient discriminated from the general patients?

I : I have not been there. I only make the referral to people I think should get treatment. I have not taken anyone there myself, I only suggest for them to get medication once I spot the symptoms. I asked the man and found out he didn't have anyone in his family history who has leprosy, so this is an anomaly. That was when I was working in Malaysia. The man lived with three other people: one a Batak, another from Manado and one other from Sampang. They lived under one roof. One of them must have had (leprosy) and the others feel bad because they were all friends, so they stayed under one roof. They had close contact every day and got used to it. And so this man got infected.

O : But what is your personal view of leprosy patient? Do you feel sorry for them or anything?

I : Of course I feel sorry for them. They lose their confidence. They feel ostracised

O : They pull themselves away?

I : Yes, they become avoidant.

P : The people in this society, do they distance themselves (from the person with leprosy) or do they behave normally?

I : They just maintain their distance

P : They don't openly distance themselves?

I : No, no. The person's feelings are considered too

P : To what extent do people maintain their distance? What if they receive something (from a person with leprosy)?

I : Well, here is the thing. Everyone has feelings. If in a gathering, and a person with leprosy happens to approach, and then the group disperses, that is not polite. So each person seeks to find their own strategy. They don't just walk out and avoid the person with leprosy.

Leprosy is not anyone's willing – it is just their bad luck. I feel sorry for people whose spouses are affected with leprosy. They can't distance themselves.

O : Are there any local belief about the cause of leprosy? Like, belief passed down from previous generations?

I : From the previous generations? Yes, there is, that it is hereditary. Now it is waning, and now people know that it is infectious. There are people who died, presumably because of leprosy, based on the symptoms. It looks different, even before any other sure symptoms begin to show. Once the symptoms is there, if they are exposed to heat the skin turns reddish. That is if the person is carrying the illness, that is different.

P : Supposing you have to have direct contact in order to check a person with leprosy

I : I do that often

P : You do not mind?

I : I don't mind. But if I shook hands (with a person with leprosy) and there would be eating afterwards, I have to wash my hands first. If the person wants to shake hands, I don't mind. I don't shake his hand, that would be offensive. But I have to be aware that the other person carries bacteria with him, so I have to wash my hands. I can pretend I need to use the toilet. It is not polite to refuse luck. For example, if I declare that my hands are dirty (after shaking hands with a person with leprosy) and I refuse food, saying I am still fasting or something. That's rude.

O : Perhaps you can tell us a personal story being leprosy cadre, perhaps you have a unique story?

I : That was the only one. The person is not here anymore, he has relocated. But then again, he routinely has treatment. I did give him the suggestion that he has a condition. I asked him if there are anyone from his family that has the condition, and he said no. The symptoms began to appear after he returned from Malaysia. I asked him how he felt, once he knew he had it. He said he felt alone, that his condition made his friends afraid of him, afraid of offending him. But he said that he was thankful so far no one had offended his feelings. He is like you, he refers to me as an uncle. He said that he understood, even before I suggested anything to him. After Malaysia, he stayed at his grandmother's house in Bangkalan. From there he was supposed to be treated at the hospital, not quarantined. He had to have his regular treatment.

O : His family was also supportive?

I : Yes. My wife is most scared that my children are like this with the neighbors.

P : Thank you so much for this interview, Sir.

I : Yes, you are welcome

Interview ends at recorded duration 19"49', at the end of the interview, the informant was presented with a souvenir, and a photograph was taken as proof of interview.

**INTERVIEW TRANSCRIPT FOR LEPROSY CADRE
LEPROSY PERCEPTION STUDY IN PAMEKASAN**

HCW-Pam17-B5

INTERVIEW DETAILS

Interviewer : Ari
Observer : Kiki
Code : HW-06-MA
Date : June 20, 2017
Location : Informant house in Sakathuk, Kador
Time : 12.30 – 12.46

DEMOGRAPHIC DATA

Name : XXX
Age : 41 years
Gender : Male
Occupation : Farming/ustadz/'klebun'
Has received training on leprosy.

PROLOGUE

Prior to interview, the interviewer reads the consent directed to family members. Reading of the consent, followed by signing of the consent as research subject, took place approximately 1"13'. Interview was conducted at the home of the informant in conducive manner.

DESCRIPTION

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT

P : What is your name, Sir?
I : XXX
P : How old are you?
I : Umm...41
P : What is your occupation, Sir?
I : Farmer

P : Have you received training on leprosy, Sir?

I : Yes, yes. Often, as a matter of fact.

O : How many times, Sir?

I : Umm... three

O : What year did you start receiving training?

I : The first one was in 2013

O : Were you chosen to be cadre?

I : Yes, I was chosen by the Hajj.

O : Why did you agree to be a cadre?

I : Because, firstly, I was a village official. I was the chief of the hamlet. After a study was conducted here, it appeared that there were many cases in this hamlet, myself included. For example, I had numerous red spots, and I was referred to Kadur Health Center. And afterwards, it was found that there were many who had leprosy, while many did not have.

P : In your opinion, what is leprosy?

I : In my opinion... well, in the words of Madurese language, it is called "*daging jubek*". *Daging jubek* happened when a pregnant woman is... umm well let's just say what married couples do. That's how people in the village see it. Medically, I don't know. That's what leprosy looks like.

P : What does it look like? What are the symptoms?

I : Sometimes it is reddish, sometimes whitish spots in the body.

P : What does it look like when it gets bad?

I : If it gets bad, sometimes the hands look like this (*showing crippled, twisted fingers*), and then the earlobes widen, the nose shrinks, and then the lips... it is unbearable to see.

P : That is when it worsens?

I : Yes, when it worsens, when it gets to later stage. If it is detected quickly, it won't get to that stage. Here we have three (cases), we have found three positive cases already.

P : Was the medication quick or slow?

I : It was quick, Sir. Thankfully it is quickly handled so that it didn't get worse. Once the symptoms I mentioned are present, I immediately report to this man, as a health officer in Kadur Health Center.

P : It was immediately processed?

I : Yes, immediately. If not taken in person, then via phone call.

P : Do you sometimes bring patients to the Health Center?

I : Yes, yes. So I make suggestion, as I am the ustadz, the religious teacher. I suggest that they be taken to the Health Center.

P : But do many people from this community still believe that *daging jubek* is caused by intercourse?

I : They used to. Prior to (knowing about this illness) they used to believe like that. But now many people see it as an illness. I educated them by showing them pictures. I have disgusting illustration.

P : So that means the perception of the community has changed in regard to leprosy?

I : Yes, now they know that it is an illness

P : Is it because there is much effort put into sensitization?

I : Yes, aside from suggestions from me. I patrol not only here, but also in surrounding areas. If I see a case, I refer them to Kadur Health Center.

O : What is the usual response of people you make reference for? Are they receptive or are they not?

I : They are receptive, thankfully.

P : Because sometimes people do not want to get treatment

I : Everyone here wants (to be treated). I ask for their number. If in 2-3 days they still haven't reported to the Health Center, then I call them. I feel sorry for them, Sir. When I see that their condition is similar to what I see in illustration, that is tremendous

P : Do you personally feel sorry for them?

I : Yes, I feel sorry for them. We are all the same. Beautiful for a woman, handsome for a man. But what can we do? Thankfully, in my young son's case, it was immediately treated. He took 18 doses of medication. Now he is back to his handsome self. I used to not know anything about this illness

P : So you also used to believe the myth of *daging jubek*?

I : I did not know what this illness was. After diagnosis, I went to the Kadur Health Center, and then found out it was leprosy

P : Nowadays, are there still people who believe in *daging jubek* illness?

I : No, no more. Nowadays everyone refer to leprosy as an illness. As a matter of fact, I have numerously organized training here, so that we all comprehend this

P : All the villagers were invited to attend?

I : Yes, all the villagers. Well, at least representatives. For example, 2 from that area, like that. I feel sorry for those with leprosy

P : To your knowledge, is there any difference of service for leprosy patients?

I : No, just the same. For example, if A has leprosy and B has another illness, they both are treated the same. They both receive equal service.

P : Do you mind if you need to have direct contact with an index case?

I : What do you mean?

O : If you need to have direct contact, like for example shaking hands or touching them?

I : If it is a severe case, I would be cringing too

P : Ooo so if it is just a spot, it is still okay?

I : Yes, it doesn't bother me

P : But cases where there are wounds?

I : I would be a little scared

P : In your opinion, is leprosy contagious?

I : It is contagious, perhaps if it is not medicated. But if medicated, then it is not

P : How is it transmitted?

I : It is transmitted through... soap bars, and close contact

O : But on the average, if a person has leprosy, would the whole family be infected?

I : No, just one. Here, if there are 3 or 2 people with leprosy, at most only 1 is infected, but not the others. I don't know, though, because leprosy is not a recent illness. It is an old illness. This particular index case refuses to get treatment. I pray to God that he will want to be treated.

O : Is there something that you want to tell relating to your experience as a cadre? Perhaps there is something interesting that happened or some difficulties?

I : My experience is that I am proud after treatment is available in Kadur. I am proud. If there is no treatment available in Kadur... I don't know who to ask. In the villages, there are many who are beginning to show this (*showing fingers that are already twisted*), some are worse than others. Thankfully, after treatment is available in Kadur, those who were ugly now became handsome and pretty again after being treated

P : So it has been helpful?

I : Yes, very very much

O : How was treatment in the olden days, Sir? What happened before there was treatment?

I : They were left alone, what else to do? People at the Health Center did not know what to do about it, either. They did not know what pills or what medication to administer to the patients. There was one case in Sumber Jati, where you had been just now. If that case had been treated earlier, it should not have been like that. That was my uncle there. I told him to show himself to the Hajj and to the Health Center.

O : So leprosy patients were left alone? Perhaps there were herbal medicine or shaman doctors?

I : Yes, shaman doctor. Yes, a lay person only consulted the shaman doctor

O : Usually what were administered to them?

I : Many things. Sometimes it is a mixture of water and sugar for drinking. Shamans usually provide conditions. Only God knows, Sir

O : But that means nowadays no one goes to shamans anymore?

I : No more. Nowadays people go to the doctor because it has been... umm..

P : Proven?

I : Yes, there is evidence of cure

P : Umm in the old days people would still believe that leprosy is hereditary. What about now?

I : Nowadays the word hereditary is no longer heard. In the old days there were no treatment available. People did use to believe. Thankfully, there is treatment now, because there are several of my villagers who are affected (by leprosy)

P : All right, Sir, thank you for your time and sorry for bothering you

I : Yes

Interview ends at duration of 16"52', at the end of interview, the informant is presented with a souvenir and a photograph is taken as proof of interview.

TRANSCRIPT OF QUALITATIVE INTERVIEW FOR INDEX CASE LEPROSY PERCEPTION STUDY IN PAMEKASAN

INTERVIEW DETAILS

Interviewer : Ari
Observer : Kiki
Code : IC-01-FE
Date : June 20, 2017
Location : Informant's house in Laden hamlet, Teja
Time : 08.50 – 09.07

IP-Pam17-B1

DEMOGRAPHIC DATA

Name : XXX
Age : 48 years
Gender : Female
Education : High school
Occupation : Homemaker / merchant at marketplace
Duration of illness : Less than 1 year
Leprosy type : Dry
of Family Members : 2 people

PROLOGUE

Prior to interview, the interviewer reads the consent directed to family members. Reading of consent, followed by signing of consent as research subject, which took place approximately 1"22'. Interview is conducted at the home of the informant in Teja, in conducive manner.

DESCRIPTION:

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT:

P : What is your name, Ma'am?
I : XXX
P : How old are you?
I : 48
P : What is your occupation?
I : I do not have any. I am a homemaker
P : How many family members live in your house?
I : Just the two of us, myself and my child
P : What is the most recent level of education?
I : High school

(Leprosy spokesperson intervened the observer who wrote the informant address wrong)

P : How long have you had leprosy?
I : It first appeared in September 2016
P : What symptom or pains did you experience when you first found leprosy?
I : No pain. It was just reddish spots. First in my cheek here
P : What else aside from reddish spot?
I : Reddish spot here (*pointing to arm*), here (*pointing to back*), and here (*pointing to leg*). Nothing else.
P : When you first found it, did you go straight away to the Health Center or anything?
I : I went straight away to the Health Center
O : Did you try any other alternative treatment?
I : No. I went to the Health Center because it was close by
P : Why did you go to the Health Center?

I : No, I went to the Health Center first. Then I began to see swelling, so I went to the dermatologist. The doctor asked me if I knew what condition I was having, and I told him I knew

P : So you went to the doctor after you went to the Health Center, and after knowing the condition, because you experienced swelling?

I : That is right

P : Did you know what caused your condition?

I : I did not know

P : You did not know

I : Yes. I just went in for consultation at the hospital, then I went to the ER, where they told me to have it checked at the Health Center. So I did. I went for numerous check up. Before that, for a whole month I was swollen, and I could not walk at all for seven days

(intervention in the interview where the informant had to quiet her child)

P : How did you feel when you were first diagnosed with leprosy?

I : It grew and grew, and I met someone at the ER who told me to have it checked at the Health Center.

P : So you went to have it checked?

I : Yes, I did. Before that, I did not know I should

O : How did you feel when you were first diagnosed with leprosy?

P : When you went for check up and you were told that you had leprosy, how did you feel?

I : I did not feel anything back then

O : Oo, you did not?

I : After I found out, I felt... how did I have this? What caused it?

P : Were you worried or anything?

I : I was worried. I worried that I would die soon hehehe. No one in my community has this illness. In the olden days, I was told that leprosy is hereditary, but now why was I the only one who had it?

P : No one in your family has it?

I : No one

P : So that means you do not know anyone who has leprosy before?

I : No. I just knew about leprosy when I went to the Health Center. Even though the Health Center was close by, I never went to the Health Center

O : Do you believe that leprosy is hereditary?

I : That is what old people would say. But when I was told this, I knew that none of my siblings have it. Only me

O : So you do not believe it?

I : Believe but not believe. Because if they say it runs in the family, I am the only one who had leprosy. But eventually I believe too. I saw the banner placed in front of the health center, and I understood I have leprosy. What is usually the cause of leprosy?

P : We will explain shortly, but now let us continue with the interview. To your knowledge, aside from hereditary as the cause of leprosy, what else can cause it? What do people in the past believe about leprosy? Can you explain?

I : I have never heard anything about it. All I know is that diabetes and leprosy are passed down genetically

O : Perhaps there is supernatural factor?

I : When I knew I had it, my sister in law advised me not to consume MSG too much. I don't consume it anymore, it has been reduced greatly

O : Do you have any special diet after you were diagnosed with leprosy?

I : No. I did not, no abstinence, I eat everything. I checked with the doctor and there was no abstinence. I always ask this when I go to the doctor, whether or not I should abstain from any food. Apparently, I did not have to abstain from anything, so I eat just about anything

P : Does your family know of your condition?

I : Everyone knows

P : What is their reaction?

I : They told me to get myself treated as soon as possible, not to let it fester, go for treatment quickly. I was also told to not skip any medication

O : Do you feel better after informing your family?

I : Yes. They were just shocked that I had leprosy. I did not feel better, though, because I was still wary

P : While you had leprosy, did it ever get in the way of your activities?

I : Yes, it did at one point. Because of my leg

P : Were there reactions then?

I : Yes, it was swollen

P : What did it keep you from doing?

I : I could not walk. My legs were swollen both the upper and lower parts

O : But afterwards, it was okay?

I : It was okay afterwards

P : Just that one time?

I : Yes, it was swollen for a week

P : Did your neighbors know about it?

I : They knew I was ill, but they did not know what illness

O : Would you tell your neighbors?

I : No. I don't socialize very much with them anyway. In this community people do not socialize too often. They only stay at home

P : If you did tell your neighbors, what do you think would be their reaction?

I : I don't know. At most I go out to the marketplace, when I was healthy, very early in the morning and come back at 12 midday, then I take a rest. I don't have time (to socialize with the neighbors)

P : Do you also work at the marketplace?

I : Yes. I was a merchant

P : Did you stop trading because of this illness, or is there any other reason?

I : I still have my pains and shivers! My legs are still shaky. But if I were healthy, I would go to the marketplace

P : So when you first realised the illness, did you still trade at the market?

I : Yes, I did. Even when my leg was swollen, although at that time it was not painful

P : How did your friends at the marketplace react?

I : They only asked, "What are you suffering from?". I told them I had skin infection, or was it skin glands, or whatever. I could not tell them the truth, it was embarrassing. People at the marketplace are mostly people who live in villages. They only told me to go see the ustadz or shaman

P : Oh, so that what the other merchants said?

I : Yes, because I had swollen leg. Also, (the skin) turned black. People at the marketplace did not understand, of course

P : They told you to go to the shaman?

I : Yes, and also to the kyai. They gave me the direction to the place

P : But you did not go?

I : No, I did not go. I already knew what my condition was, so I did not have to seek alternative treatment from the shaman. What would I be looking for then?

P : You believed in (modern) medicine then?

I : Of course. The doctor knows more

P : But people in villages in Pamekasan still believe in shaman, don't they?

I : Mostly, yes. I have someone who always shops at my stall, who also has leprosy. Her face turned black. So one time she was shopping, and I told her that her condition can be infectious. But that was all I said.

O : So did she get her treatment at the kyai?

I : No, she also went to the Health Center

O : Oh, but the belief is that it is infectious?

I : Yes, that is why I told her to go to the Health Center. She has now recovered, totally. Her facial skin used to be dark!

O : So that means the people in your community believe that it is a hereditary illness?

I : Yes, the neighbors do. But my neighbors were never suspicious

O : What about the friends at the marketplace?

I : No, they were never suspicious. They only wondered why I still haven't recovered. I don't socialize much with people at the marketplace, either. I usually would be busy serving the customers. At most just sit around together and tell stories

O : Do you think it is infectious?

I : Yes, I heard it is infectious

O : Do you believe so?

I : I don't know. But it is infectious, isn't it? But I have been careful with my child, we use different cups for drinking. I hope I don't infect my family

P : Aside from your using different cups from your child, what else other different behavior did you make when you found out about this condition?

I : Towards my child?

P : In your daily life, is there any change that you made?

I : My child's behavior, you mean?

P : Yourself, your own behavior

I : Oh. No, everything is as usual. We only have separated utensils for eating and drinking

P : Such as plates and glasses?

I : Yes. But we eat the same food

O : What about your behavior in bathing or changing clothes, are there changes? Like for example you bathe or change clothes more often?

I : Myself? I do the usual habit, I took three baths a day. Nowadays I take two baths. It is cold, in the early morning it is too cold

O : Perhaps there is something you would like to say to people out there with leprosy, but refuse to get treatment. Is there something you would like to say to them?

I : People with leprosy? Well, if I see someone with similar condition as myself, I would tell him or her to go to the Health Center so that they would recover soon

P : Have you ever done that?

I : No, I have never done that yet

P : So you would do that if you meet someone (with leprosy)?

I : Yes. I feel sorry for them. I don't want them to be like me. I would tell them

O : All right Ma'am. Thank you so much for your time in this interview

I : You are welcome, Miss, Sir

Interview ends at 17''47', at the end of interview the informant is presented with a gift and a photograph is taken together with interviewers.

**TRANSCRIPT OF QUALITATIVE INTERVIEW FOR INDEX CASE
LEPROSY PERCEPTION STUDY IN PAMEKASAN**

INTERVIEW DETAILS

Interviewer : Ari
Observer : Kiki
Code : IC-02-MA
Date : June16, 2017
Location : Informant's house in Pregi
Time : 10.45 – 11.01

DEMOGRAPHIC DATA

Name : XXX
Age : 18 years
Gender : Male
Education : High school
Occupation : Madrasa student
Duration of condition : More than 1 year
Leprosy type : Dry
of family members : 9 people

DESCRIPTION:

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT

P : What is your name?

I : XXX

P : How old are you?

I : 18 years

P : And your occupation?

I : I am still a student at the Madrasa

P : How many people live in your house?

I : Umm... 9 people in our house

P : How long have you had this condition? When did it start?

I : Umm... around... starting 10th grade. Which is recent.

O : Has it been a year?

I : Yes, a little over one year now

P : When you first found the symptoms, where did you go to get treatment?

I : I went to the Health Center

P : The first time? Before you went to the Health Center, where did you go?

I : Before I went to the Health Center, my uncle told me that I have this condition, and he told me to go to the Health Center

P : Before you realized your condition, did you have it treated?

I : No. I only had pain in my leg

P : When you found the spots, did you apply Kalpanax (*brand of cream used to treat skin fungi)?

I : No

P : Oh, so you found the spots and you left it like that? You did not do anything to it?

I : Yes

P : In your opinion, what is the primary cause of this condition?

I : I don't really know. When I found out, I was still living at home

(intervention from the leprosy spokesperson, in which the spokesperson explained the question in the local Madurese language so that the informant understands the question better)

I : Before I found out this reaction, I went on a tour to Sumenep with a group of my friends from the Madrasa. And then I came home. I went to bed, and immediately I felt the reaction

P : Where did you go on a tour?

I : To another Madrasa in Sumenep. After I came home, I went to bed, and I felt the reaction. My father said my face turned red, and then my leg was in so much pain

P : What about the other friends from the Madrasa, did anyone experience similar pain? Did anyone fall ill?

I : Yes, some of them did. My roommate for one. He told me that he also experience this pain. He went into treatment. Usually when I returned (to the Madrasa) he would be bringing these pills, because he knew that I have this condition as well

P : And when you were first diagnosed with this condition, how did it make you feel?

I : I was disappointed, because I wanted this particular assignment. I am now a senior at school, so with this condition I had to drop all programs. I had to take a break for recovery. I had to take total rest

(leprosy spokesperson intervened to explain the treatment Khomaini undergoes)

I : I already obtained a doctor's permit. I am supposed to go for a test. I am in my senior year at school. But the doctor would not let me

P : And what about your friend who also experienced this condition?

I : Yes, he is from Karang Penang, Sampang

P : Did his condition worsen?

I : It was bad. His face turned black, while the rest of his body remained fair. Only his face turned dark color

P : Did your other friends keep their distance?

I : No. None of the friends in my group knew about this condition. I did not tell them, so they did not keep their distance because they did not know it

O : Why did you not tell them?

I : I was afraid they would leave. Also, I was afraid I would infect them because then I would be affected too

P : Before you had this condition, have you ever heard about it?

I : No, before I have leprosy, I don't know anything about it. I once came home from the Madrasa, I went straight to the kitchen and got me a bit of fire and put it here (*pointing to right arm*) but I didn't feel the heat burning

P : Does your family know?

I : My family knows

P : And how did they react?

I : They were also disapoointed, because I am the only one with a duty

P : So you never spoke of this openly with your friends regarding your condition?

I : Yes, never openly. I have become a hermit. My friends are at the Madrasa, while I am here alone

O : What did your friends think you have?

I : They only knew that I was not well. But they don't know what I have

P : Are there anyone in your neighborhood who has the same condition as yourself?

I : I don't know

P : Do your neighbors know you have this condition?

I : They know. They even paid me a visit because I was not well. So they know

P : Did they treat you differently?

I : Not really, just the usual even though they knew. They behaved normally

O : So it made you feel relieved?

I : Yes, of course. I was relieved they did not ostracize me

(leprosy spokesperson again intervened the interview to explain the condition of the informant during treatment)

P : Do your friends hang around at your home like usual? Or don't they?

I : Yes they do, but it was me who pulled back

P : Why?

I : I was afraid

P : Embarrassed or afraid?

I : I was afraid of infecting other people. I was 'sentenced' with this

P : Is there something you would like to tell about your condition? Is there any message you'd like to pass to those who refuse to get themselves treated?

I : Yes. I'd like to say that if anyone has this condition, don't be disappointed or afraid because everything is God-given. Be patient because the future is still bright. Let bygones be bygones. Today belongs to us, and the future is still bright. We still have options, and because of that if you feel any reactions such as loss of sense, pain in the legs, go see a doctor immediately. Those were the sensations I felt from this disease

P : Suppose you go back to the Madrasa, and you see a mate with similar symptoms like you had, would you suggest him to go see a doctor?

I : Not only suggest, I would also help him. I already experienced how excruciating this illness was

O : Are there tips you would like to share? Like, tips for daily living, diet, or anything that you can share with us?

I : Oh, like habit? Everyday you would feel a loss of appetite, food does not taste good, but still has to be eaten. Do not leave prayer, no matter how bad the illness get. Hygiene must be given extra attention. The worse time of the illness is the reaction after medication. You might find it hard to even stand up

Interview ends at 15''22', at the end of interview, the informant is presented with a souvenir gift and a photograph is taken together

QUALITATIVE INTERVIEW TRANSCRIPT FOR INDEX CASE

LEPROSY PERCEPTION STUDY IN PAMEKASAN

IP-Pam17-B3

INTERVIEW DETAILS

Interviewer : Ari
Observer : Kiki
Code : IC-05-MA
Date : May 17, 2017
Location : Informant's house in Pegantenan
Time : 11.45 – 12.01

DEMOGRAPHIC DATA

Name : XXX
Age : 42 years
Gender : Male
Education : Primary
Occupation : Farming
Duration of condition : More than 1 year
Leprosy type : Dry
of family members : 10 people

PROLOGUE

Prior to interview, the interviewer reads the consent directed to family members. Reading of consent as research subject and followed by signing of the consent took place approximately 1''31'. The interview was conducted at the home of the informant located in Pegantenan, and in conducive manner on account of quiet setting at the home of the informant.

DESCRIPTION

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT

P : I will be recording this. What is your name, Sir?

I : XXX

P : How old are you, Sir?

I : 42 years

P : Occupation?

I : Farmer

P : How many people are living in your house?

I : 10

P : What is your most recent education? Your schooling?

I : The usual, primary school

P : How long have you had this condition?

I : A little over 1 year

P : How did it begin? What was the symptom?

I : First it looked like skin fungi, whitish spots. I treated it, but after I treated it, it turned reddish

P : So the first time it looked like skin fungi, and did you go for the treatment at the Health Center, or were there alternatives?

I : Health Center, immediately

(leprosy spokesperson intervened by telling of the informant's work experience in Malaysia)

P : Oh, you have worked in Malaysia before?

I : Yes. It wasn't treated when I was in Malaysia. No one dared to treat it. I was told to return here

P : After you returned from Malaysia, did you go straight to the Health Center? Did you try to treat it elsewhere?

I : It was not good going to the shaman. It did not bring any result. He only gave me herbal drink

O : Herbal drink like what?

I : Powder. Powder, and mixed with water. It did not do anything

P : Did anyone suggest you to go to the Health Center?

I : I went by myself

P : Do you know what caused it?

I : In Malaysia, I drank Halwadi, an herbal drink. I did not get sick

(leprosy spokesperson explained the intent of the question, but apparently the informant failed to understand. The question was explained several times, both in Bahasa Indonesia and Madurese, assisted by the spokesperson, but the informant still failed to understand the question)

P : When you first were diagnosed with leprosy, how did you feel? Worried or scared?

I : I was afraid. I was afraid to die

O : In your opinion, is your condition scary or is it just okay?

I : It is just okay

P : Have you ever feared it would worsen?

I : Yes, I was afraid so

P : Have you ever known anyone who has similar condition as you?

I : No. I only saw pictures. I don't know anyone here (with leprosy)

P : What about in Malaysia?

I : No one

P : What is the behavior or attitude of the community about this condition?

I : I have never paid any attention

P : Before you had this condition, have you ever had any information about it?

I : I have never heard about it. This is something I just found out when I developed the symptoms

P : What is your daily role at home? Are you the head of the family?

I : No

P : But you work? I mean, everyday aside from farming, what other work do you have?

I : Nothing

P : When you are ill such as you are now, does it bother your activities?

O : Maybe you cannot work or something?

I : I can still work, it doesn't bother me. Just the usual, thankfully

O : Normal then

P : Do your friends know about your condition?

I : Yes, they know

P : You are honest (with them)?

I : Yes, honest

P : And how did they react?

I : They were afraid. They were afraid of coming near me

P : Including your friends?

I : Yes, they were afraid. They were afraid of being infected. Everyone was afraid

P : How did you feel when all your friends found out?

I : I was ashamed

P : Did you wish your friends were not afraid? Do you wish you could go back to hanging out with them like you used to?

I : Yes, probably if I get treated then they won't be afraid anymore

P : Compared to the beginning, is it now better or not?

I : Yes, I am better

P : How bad was it? How bad was your condition?

I : I had pictures, but I lost them. I was shapeless, my skin was reddish all over my body. I did not have this crevices. I had a video about it, but I lost it. My whole body was red and all the crevices were covered. All red, and even my ears were both red. Now (I am better) thankfully

P : So now you are mostly treated, and unlike your condition previously?

I : Yes, I have been treated. Thankfully all the crevices are back

P : You knew that having this condition you would be avoided by your friends. Why did you still tell your friends?

I : With my friends? I told them the truth

O : And then they avoided you. Why did you tell them?

P : Yes, why did you not cover up or anything? Or tell them you have other condition?

I : I don't know. People say I have this condition, so I just followed along. I don't know. People did not know about my condition from me. Perhaps someone told them

P : But are there still people who behave normally with you? I mean, still treat you normally like they used to?

I : I told them this: if treated, this will not be infectious. That was what I told them

P : Then your friends were not afraid?

I : Yes, they were not afraid. I told them I had treatment. If it was not treated, then it would be infectious, I told them

P : Are people still afraid of you now?

I : No one. No one is afraid of me. If I wasn't treated, then no one would come in here. They would only look from afar. I would not dare to come near anyone, either, I would be sorry for them (if I infected them)

O : In your opinion, how can this be infectious?

I : I don't know. Maybe if a soap bar is shared, maybe

P : So your friends kept their distance from you for fear of infection?

I : Yes

O : But your family knows all about it?

I : They do

O : What was their reaction when you first told them?

I : Nothing. They were not sad, not worried or anything

O : But that means your neighbors also know?

I : Neighbors? No, I did not tell them. That is too embarrassing

P : Oh, your neighbors did not know?

I : They don't know

P : Why were you more embarrassed telling the neighbors rather than your friends?

I : My friends hang out with me on a daily basis. Neighbors... well, they are just that. We don't hang out.

P : In your opinion, what is your condition like? Is there a belief about it?

I : I don't know

O : Like, for example, based on local belief, what causes it?

I : I don't know any tales, I don't know

O : Perhaps you have an experience you can share, or perhaps you can tell us what sad things happened during your struggle?

I : Nowadays I am not sad anymore. I see this as trial from God. But back then, I remember I felt like dead

P : At that time it was very bad?

I : Yes, it was very bad. I remember the death feeling

P : If you know any of your neighbors having this condition, would you suggest him to go to the Health Center to get treated?

I : Yes, if there is any

P : So you do not mind suggesting or reminding?

I : If there is any that I know, I will tell them

O : Perhaps you have any messages for people out there with similar conditions as you, who are too embarrassed to get treatment?

P : There are people who are too embarrassed to get treatment. How to beat the embarrassment so they would be in good spirits?

I : Nothing

P : Thank you so much for this interview

I : Yes

Interview ends at 15''22', at the end of the interview the informant is presented with a souvenir as token.

QUALITATIVE INTERVIEW TRANSCRIPT FOR FAMILY MEMBERS

LEPROSY PERCEPTION STUDY IN PAMEKASAN

CC-Pam17-B1

INTERVIEW DETAILS

Interviewer : Ari
Observer : Kiki
Code : NK-01-MA
Date : May 13, 2017
Location : Informant's house in Balubajung
Time : 11.51 – 12.03

DEMOGRAPHIC DATA

Name : XXX
Age : 50 years
Gender : Male
Occupation : Farmer
of family members : 7 people

PROLOGUE

Prior to conducting interview, the interviewer reads the consent directed to family members. Reading of the consent, followed by signing of the consent as research subject, takes place approximately 1''36'. Interview is conducted at the home of the informant, located in Balubajung, in conducive manner due to relatively quiet setting of the recording. Some interfering sounds include animal sounds of the informant's pets, such as birds and chickens.

DESCRIPTION

P : Interviewer
O : Observer
I : Informant
..... : Questions as per interview module

INTERVIEW TRANSCRIPT

P : What is your name, Sir? Your full name?
I : XX
P : How old are you?
I : 50 years

P : What is your occupation?
I : Farmer
P : How many family members are living in this house?
I : In my house? Seven
P : Most recent education?
I : School? Primary

(at this point, the interviewers asked the son of the informant, who himself is an index case. However, due to difficulty of communication the interviewers decided to direct the interview to Mr Abidi as family members)

P : What was the symptom of the condition?

I : At first it was itchy and there were patches
P : How long did you son have this condition? Starting from when?
I : In junior high school, I guess? In first year of high school
P : Where were the patches started to show? In which part of the body?
I : In the chest, hands, in the back
P : Was it itchy?
I : It wasn't itchy
P : Did you know what caused the patches?
I : I did not know

P : Did he get the treatment after finding the patches, or was there wait time?

I : No, we immediately sought treatment. At first to the Health Center
O : Did you try any other alternative treatment?
P : No, Miss, we went straight to the Health Center
I : What did the Health Center say about this condition?
P : We were told it was leprosy
O : And how did you feel when you found out it was leprosy?
I : I was worried. I was worried it would get worse
P : In this community, is there any other person with leprosy aside from your son?
I : I don't know
P : And prior to having leprosy, have you heard about leprosy before?
I : I have heard about leprosy. I heard some people made immediate recovery, meanwhile my son has leprosy

P : To your knowledge, what is leprosy like? What you heard about it?

I : Well, what I heard from people, because someone in my neighborhood has leprosy and his... (*pointing to fingers*) came of over time, he lost his fingers over time

P : Umm... how does the society view persons with leprosy, to your knowledge?

I : To my knowledge, leprosy is feared. It is considered disgusting

O : Disgusting because it can cause loss of fingers?

I : Yes. And also leprosy causes the whole seven generations of the patient to receive negative stigma

P : Your nextdoor neighbors, do they know that your son has leprosy?

I : Our friends know, but not our neighbors

P : How do your friends react?

I : We are still close, nothing changed. Perhaps because it did not get worse, because it was quickly treated

O : Does it interfere with daily activities? Does it make it hard?

I : No, just the usual

P : Does your family know?

I : My family knows, but not friends

P : What was the reaction of your son's friends when they knew he had leprosy?

I : No reaction, because his friends had never heard of this illness

P : So the society still believes that leprosy is a hereditary condition?

I : Yes, hereditary

P : Is there any other local beliefs? Like perhaps myths that you have heard of?

I : No, people only knew leprosy, that is all. No other beliefs found here. But I've heard that curses might be passed down to children. If the parents die, the children might "contract" the curse. Some hexes are like that

P : What about your own opinion, what causes leprosy?

I : No, I just heard that leprosy can be passed down through seven generations, perhaps because of the bloodline

P : There is a word in Madurese for leprosy, what is that?

I : Oh, people in Madura calls it *daging jubek*

Interview ends at 12''33', at the end of the interview, the informant is presented with a souvenir