

District: Pasuruan

Participant type: close contact

1. CONTACT:

Interviewer : What is your relation with him, Sir? Your familial relation, is he your son?

CC-Pas-B1 : I am the father

Interviewer : So you are the parent. Sir, do you know of his condition? What are the symptoms, and what are the causes?

CC-Pas-B1 : I don't know.

Interviewer : You don't know. Do the people in the society look at people with skin condition or allergy? What is the society like here?

CC-Pas-B1 : They behave normally.

Interviewer : They behave normally

CC-Pas-B1 : They behave normally. They don't exclude

Interviewer : They don't avoid?

CC-Pas-B1 : Yes

Interviewer : What do you mean by behaving normally, does it mean they are still socializing or something?

Informant : Yes, they still socialize like normally. They don't single us out

Interviewer : What about gossiping?

CC-Pas-B1 : They do. Almost 4 or 5 years now. I am originally from Sidoarjo... (unclear)

Interviewer : In your opinion, is this skin condition possible for anyone to have? Do people have the possibility to experience this skin condition?

CC-Pas-B1 : Perhaps it is possible

Interviewer : What is perhaps the cause?

CC-Pas-B1 : It can be from the person himself

Interviewer : What do you mean from the person himself?

CC-Pas-B1 : From his behavior, from his social circle, or perhaps it is genetic

Interviewer : From his behavior, what kind of behavior do you think can cause skin condition? Perhaps his lifestyle or diet?

CC-Pas-B1 : Diet or lifestyle, maybe

Interviewer : Okay. So if it is from diet, what food can cause this condition?

CC-Pas-B1 : I don't know much about that...

Interviewer : Okay. If someone around here has this skin condition, would you like to know about it? I mean, knowing that there is someone that has a condition. Or perhaps you are okay with not knowing because it does not make any difference? What do you think?

CC-Pas-B1 : I knew of a case one time. But the kid was kept at home by his relatives

Interviewer : So do you think it is not good?

CC-Pas-B1 : Yes, that was not good.

Interviewer : How should it be?

CC-Pas-B1 : They were embarrassed. They did not try to seek treatment

Interviewer : Okay. So do you agree with such behavior?

CC-Pas-B1 : I disagree.

Interviewer : How should the child be treated, in your opinion?

CC-Pas-B1 : Humanly treatment...

Interviewer : From the Health Department or PKM, if they provide a medication plan that can prevent skin condition, will you be willing to take it?

CC-Pas-B1 : Yes, I am

Interviewer : Why are you willing?

CC-Pas-B1 : So that I won't...I don't know... (*embarrassedly*)

Interviewer : It's okay, you can use Javanese.

CC-Pas-B1 : So that I don't...

Interviewer : Oh, you mean so that you don't get infected as well?

Interviewer : Would you like to receive information about leprosy from health workers or other sources?

CC-Pas-B1 : Yes, if there is any information

Interviewer : But you haven't had any information this far?

CC-Pas-B1 : Yes

Interviewer : How do the health workers socialize this here in the ladies community, cadres, and others?

CC-Pas-B1 : The health issues in this area is around hygiene such as sewerage, toilet, waste water from washing

Interviewer : Oh, I see. Would you like to give any comment to us? Suggestions or complaints?

CC-Pas-B1 : My suggestion is that information regarding health should be socialized in the community.

Interviewer : Thank you, Sir.

2.

CONTACT:

Interviewer : Ma'am, earlier you said that your husband has skin condition that is similar to spotting. What do you know about his skin condition?

CC-Pas-B2 : What do you mean?

Interviewer : What do you know about it, such as symptoms, ways of transfer, treatment?

CC-Pas-B2 : Treatment is at the Health Center

Interviewer : Oh, so based on your knowledge, treatment is at the Health Center. What about the symptoms? What do you know about the symptoms?

CC-Pas-B2 : I don't know

Interviewer : You don't know. Do you know what the cause is?

CC-Pas-B2 : I don't know

Interviewer : Prior to this, have you ever received any information about the skin condition your husband has from the Health Center?

CC-Pas-B2 : I did once received information from the Health Center when I picked up prescription

Interviewer : When you pick up prescription, did you experience any issues?

CC-Pas-B2 : Nothing, just pick up. All good.

Interviewer : What about him? What is the community's perception towards someone with skin condition?

CC-Pas-B2 : There isn't any. Just as long as we keep him

Interviewer : What do you mean by keeping him?

CC-Pas-B2 : Keep the patient at home. No need to go out. But the community here is alright, because he is not severely ill.

Interviewer : So no problems?

CC-Pas-B2 : Yes. Just okay, because he is not severely ill.

Interviewer : Do neighbors still come to visit your home?

CC-Pas-B2 : They still do.

Interviewer : What about yourself? Is it okay to socialize with someone with skin condition?

CC-Pas-B2 : They should not be ostracized

Interviewer : There are some skin condition that are severe, and there are ones that mild. In your opinion, if someone has severe skin condition that makes them seem disabled, what would the society think of them?

CC-Pas-B2 : Well, no one would... (unclear)

Interviewer : And do you think this skin condition can happen to anyone?

CC-Pas-B2 : No

Interviewer : Why can't just anyone have this skin condition?

CC-Pas-B2 : I don't know

Interviewer : Okay. If the Health Department or PKM provides medication to prevent skin condition, would you be willing to take it?

CC-Pas-B2 : What?

Interviewer : Would you be willing to take medication if it is provided by PKM to prevent skin condition?

CC-Pas-B2 : Yes

Interviewer : You would. For what reason?

CC-Pas-B2 : I don't want to be infected. It's a precaution

Interviewer : What other information do you know regarding skin condition aside from treatment?
What do you know?

CC-Pas-B2 : Before my husband got sick?

Interviewer : Either before or after

CC-Pas-B2 : I don't know... it's

Interviewer : What do you mean?

CC-Pas-B2 : He was just affected, that's all.

Interviewer : Okay

Interviewer : If someone in this community has skin condition other than your husband, would you be curious? As to who it is, where he lives, et cetera?

CC-Pas-B2 : Yes, I would

Interviewer : Why?

CC-Pas-B2 : Just curious. I would want to know what that person is ill from, how severe it is

Interviewer : So you would try to find out whether there are other patients in your area. What benefit would it provide you?

CC-Pas-B2 : Anticipation, I guess

Interviewer : Okay. Thank you.

3. CONTACT:

Interviewer : Sir, my name is Ririn. I am interviewing you as a follow up to the multiple choice survey I gave earlier. This interview will last approximately 30 minutes. It is about health.

Interviewer : What is your relation, Sir, to Ibu XXX? Are you a relative, family, like that.

CC-Pas-B3 : We are neighbors.

Interviewer : Oh. Does Ibu XXX visit your home often?

CC-Pas-B3 : Yes, often

Interviewer : When does she usually visit?

CC-Pas-B3 : Usually in the daytime

Interviewer : Oh, I see. Do you know about leprosy?

CC-Pas-B3 : Yes, I know.

Interviewer : You know.

What about skin condition?

CC-Pas-B3 : Skin condition is like what Ibu XXX has

Interviewer : Okay. What do you think causes Ibu's skin condition?

CC-Pas-B3 : Perhaps she has bad diet, bad hygiene, and perhaps too much seafood as well.

Interviewer : Oh, I see. So in your opinion, that is because she eats seafood?

CC-Pas-B3 : Yes.

Interviewer : What do you think are the symptoms to the skin condition?

CC-Pas-B3 : Appearance of spots

Interviewer : What kind of spots, to your knowledge?

CC-Pas-B3 : Reddish spots

Interviewer : Oh, I see. You said earlier that the cause may be from eating fish, food that are not hygienic... where did you get the information from?

CC-Pas-B3 : Actually I didn't get any information, but when I came over to visit Ibu XXX, she and her children told me that.

Interviewer : What did her children say? That it was caused by eating fish?

CC-Pas-B3 : Yes, something like that

Interviewer : So you got the information from Ibu's children. Are there any others?

CC-Pas-B3 : That is all.

Interviewer : What is the society's opinion of leprosy?

CC-Pas-B3 : You mean skin condition?

Interviewer : Yes, Sir. What I meant was the skin condition. What is the society's opinion of the skin condition?

CC-Pas-B3 : Skin condition is normal condition

Interviewer : Do the people avoid the person or treat her differently?

CC-Pas-B3 : It depends on the person. Some people tend to avoid.

Interviewer : Why did they avoid?

CC-Pas-B3 : Perhaps the patient has severe condition or people are afraid of getting infected

Interviewer : What about you personally? If someone has skin condition, would you avoid the person?

CC-Pas-B3 : No

Interviewer : What if you know that the condition may be contagious, would you avoid the person?

CC-Pas-B3 : No.

Interviewer : Oh, so you would behave normally?

CC-Pas-B3 : Yes, just normally

Interviewer : Does the society know whether a skin condition is infectious or not?

CC-Pas-B3 : I don't know

Interviewer : What does the society know about a certain skin condition?

CC-Pas-B3 : What do you mean?

Interviewer : What is the perception of the society or the village here? What do they make of the skin condition, do they take it well or do they treat the person differently?

CC-Pas-B3 : That depends on the person. Some people are okay with it, some avoid it.

Interviewer : Those who avoid, why do they avoid?

CC-Pas-B3 : Perhaps they are afraid it might be infectious. If the condition is severe, it might be gross

Interviewer : What do you mean by severe?

CC-Pas-B3 : The spots

Interviewer : Oh, right. So people with such skin condition here might be ostracised, is that so?

CC-Pas-B3 : Yes, it is possible

Interviewer : Because people are afraid

CC-Pas-B3 : Yes, people are afraid of infection

Interviewer : Okay, Sir.

Do people with skin condition experience difference in treatment from the community? For example, those with mild condition are treated just the same but those with more severe condition would scare people away. Is there difference?

CC-Pas-B3 : Yes.

Interviewer : What is the difference? Is there difference (of treatment) between those with severe spots and those with mild spots?

CC-Pas-B3 : As I said earlier, people are afraid of contagion, so they keep away

Interviewer : In your opinion, can skin condition like XXX experiences be experienced by just about anyone?

CC-Pas-B3 : No, only certain people

Interviewer : Certain people, what do you mean?

CC-Pas-B3 : Unhygienic handling

Interviewer : So in your opinion it is not an illness that can affect just anyone, but only those who do not keep hygienic diet. If not, then it won't affect them?

CC-Pas-B3 : Yes, that's right

Interviewer : So in your opinion this condition is caused by wrong diet?

CC-Pas-B3 : Yes

Interviewer : Have you ever eaten fish?

CC-Pas-B3 : No. I don't want to have skin condition like Ibu XXX.

Interviewer : If someone has skin condition, would you be curious about it?

CC-Pas-B3 : Yes, I would. Who knows it might be contagious. If it was contagious, then I would keep my distance. Otherwise, it's fine

Interviewer : So you would be curious because of that?

CC-Pas-B3 : Yes, because I am afraid of infection

Interviewer : Okay. Sir, if there is a medication that can prevent skin condition outbreak, would you be willing to take it?

CC-Pas-B3 : yo gelem mba,

Interviewer : karena apa mboten

CC-Pas-B3 : So that I would avoid skin condition

Interviewer : So you are willing to take it?

CC-Pas-B3 : Is there such a medication?

Interviewer : Supposing there is, will you take it?

CC-Pas-B3 : Yes. It is free, isn't it?

Interviewer : Would you like to receive further information regarding skin condition?

CC-Pas-B3 : I would like to, but there hasn't been any coaching here, so we don't know anything (about it)

Interviewer : Don't you have local cadres working here? Or Community Ladies' Meeting or health workers here who provide learning?

CC-Pas-B3 : I don't know. It has been quiet so far

Interviewer : Where did you get your health-related information, Sir?

CC-Pas-B3 : Usually from the Health Center

Interviewer : I see. Is there something you would like to tell us, as we are from an institution working for skin-related condition? Would you like to provide any criticisms or suggestions?

CC-Pas-B3 : No, Ma'am.

Interviewer : Thank you very much for your time. Sorry for your troubles

CC-Pas-B3 : That is okay.

Interviewer: Ririn

District: Pasuruan

Participant type: health care worker

Officer 1 (Health Worker)

So this interview will last approximately 30 minutes

Interviewer : First of all, what is your job or position at the Health Center?

HCW-Pas-B1 : At the Health Center I am doubling my duty at health clinic; I am helping with treatment but at the same time I am also responsible for the leprosy program

Interviewer : What is the main task for P2 leprosy?

HCW-Pas-B1 : First, on the job task refers to at minimum a cooperation across programs and across sectors, so that anytime we are asked to investigate symptoms at community level by the district head or village chief, we are able to perform such requests.

Interviewer : What about the other duty related to recording and reporting?

HCW-Pas-B1 : Aside from recording and reporting, our task as leprosy worker is to determine diagnosis and clarification whether a certain symptom is related to PP or MP

Interviewer : So you have received formal training prior to this, haven't you, Sir?

HCW-Pas-B1 : Yes, I have. I had my training in Bendul, Surabaya.

Interviewer : When was that, Sir? Date and year.

HCW-Pas-B1 : I can't remember the date, but the year was 1995 or 1997

Interviewer : So that was 23 years ago

HCW-Pas-B1 : Yes, more or less so

Interviewer : How many years have you worked as Health Center worker, Sir?

Infoman : I started working at Health Center in 1986

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

HCW-Pas-B1 : I started working as leprosy worker in 1989, so that means 29 years now

Interviewer : Can you tell me a little bit about leprosy: the cause, the symptom, and definition of leprosy?

HCW-Pas-B1 : Leprosy is recognized through cardinal sign. For lay community, the cardinal sign is usually called "PB" or paucibacillary; it is white spots on the skin that does not recognize senses. If the symptom is reddish spots and there are more than 5 spots negative BTA, plus loss of nerve function, which is usually found in the village, then we can come to clarification for leprosy. There are two types: paucibacillary and multibacillary.

Interviewer : That is the classification for the leprosy type. What is the cause of leprosy, in your opinion?

HCW-Pas-B1 : The cause in most recurring cases is that there are leprosy type mb patients who hide the fact that he/she has leprosy, and there is hardly any opportunity to ask questions much less for treatment, then further he/she infects other people. So the main cause of leprosy type mb is untreated patients

Interviewer : Oh so they then infect other people?

HCW-Pas-B1 : Yes, they infect their immediate family foremostly, then later their community, or at least their social contacts.

Interviewer : When did you first heard about leprosy, Sir?

HCW-Pas-B1 : When I first joined the Health Department. I heard it from my friends or my senior who is now retired. That was the first time I heard about leprosy, prior to that I have never heard anything about it. In my area of origin I have never heard leprosy. We knew what it was but we used other terms to define it. In my area of origin, we only say "you have spots" or "that's bad flesh" or "that's genetic illness". That's all. "Kusta" is the term in Bahasa. We knew what it was previously, but we didn't know "kusta" was the name for the condition.

Interviewer : What was the information your friend gave, the one that is retired now?

HCW-Pas-B1 : I first came here in 1987 because I was replacing my senior, a health worker who was going into retirement. I was already working as a health worker, then the head of the Health Center told me that one of the health workers was going into retirement, and that was I was nominated to succeed him as coordinator of the program. That was in 1987. In 1989 the man finally retired, then I took over the job as program coordinator. It was then that I was given information, books, and all, and that was when I learned about it.

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

HCW-Pas-B1 : At the time, yes. I was living in Badong hamlet, RT 02 RW 03. In that area I knew (of someone with leprosy). The health worker at the time told me that leprosy was high in my village. I found out that the condition in which the digits might fall off is called leprosy.

Interviewer : Oh so you knew?

HCW-Pas-B1 : Yes, I knew.

Interviewer : There are a number of leprosy patients at the Health Center. How many in total, do you know?

HCW-Pas-B1 : I would like to provide real numbers here. In January 2018 to today, November, there are a total of 9 leprosy patients: 0 PB and all MB. That was the latest information of the case in 2018. All are MB patients; there are no school-age children or under the age of 10.

Interviewer : So there are no child patients between the age of 10 to 15?

HCW-Pas-B1 : No, there isn't.

Interviewer : Are you directly involved in diagnosis and treatment of leprosy?

HCW-Pas-B1 : As a worker, I am clearly involved directly in diagnosis and MDT, even down to contacting the patients. I am directly involved.

Interviewer : How is the diagnosis and treatment for leprosy conducted?

HCW-Pas-B1 : For diagnosis, we determine the cardinal sign. Cardinal sign seeks for main symptoms, whether it is PB or MB. Then we diagnose and discern the classification of the leprosy patient. But if I were to be doubtful, then I would monitor the patient for 3 months, during which time the patient is called a suspect. If I were still in doubts and if the patient is also doubtful, then I just have to refer the patient to the hospital for lab check. If the lab check proves to be positive, then the patient needs to go back to the Health Center. Why do I need to refer and not jump into diagnosis? The reason is that once a patient did not continue medication for a year and his condition worsened, then he became very angry because the leprosy persisted and even worsened, to the point of his skin turning black, and then put the blame on us as health worker. (Hospital statement) would be our safety net. We would be able to provide a reason that prior to our diagnosis whether the patient is PB or MB, the patient would have received hospital statement that he is positive for leprosy. That is my secret weapon. Why do I need this? It is because I have been a hospital worker for decades. I had my share of threats from patient families who did not take it kindly that their family member is diagnosed with leprosy.

Interviewer : The patient's family?

HCW-Pas-B1 : The patient's family. Why? Because they had a family member diagnosed with leprosy, and they did not take that kindly

Interviewer : Oh, so the diagnosis is made at the hospital for clarity?

HCW-Pas-B1 : Yes, for clarity. I knew for sure that it was AB type, but for this kind of patient, I had my own tricks.

Interviewer : Once the patient is referred and returned, do they have medication then?

HCW-Pas-B1 : In terms of medication, they are given option whether it is at the hospital or at the Health Center. If they choose the Health Center because it is close by, then I administer MDT to the patient.

Interviewer : Is MDT different for PB and MB patient?

HCW-Pas-B1 : PB and MB receive different treatment. Paucibacillary requires from 6 monthss to 9 months. If RFT goes well, without any defaults, then 6 months but with defaults then 9 months. MB requires a year or 12 months up to 16 months if there are defaults. RFT without default can be completed in 12 months or 2 semesters, and if there are defaults during RFT then 16-18 months.

Interviewer : That is comprehensive answer. What is your view or perception toward leprosy patients, Sir? You are a health worker, so what is the perception of a health worker toward leprosy patients?

HCW-Pas-B1 : For me as a health worker, there is not difference if a person was a former patient, or a former beauty queen or a celebrity or an athlete. As a health worker, what matters is that a patient completes his medication in full and orderly and that the disease does not create any disabilities, and so to achieve that a health worker does not discriminate. For example, if I were asked as a health worker to treat a street vendor, of course I would take the patient if I knew the patient had good medication record.

Interviewer : So treatment towards leprosy patient and other patient is not different? Would you refrain from touching a leprosy patient, while no problem touching other patient? Is there difference or do you see it the same as other illness?

HCW-Pas-B1 : As a health worker, to me there is no difference whether it is leprosy, upper respiratory infection, itches, hypertension, and others. There is no difference. I tend to them all well and in the same scrutinized manner. So no difference at all.

Interviewer : Have you heard of PEP intervention?

HCW-Pas-B1 : PEP is still news to me

Interviewer : PEP is an intervention in which contact with patient are prevented from turning into leprosy infection

HCW-Pas-B1 : For prevention, we as health worker didn't know PEP yet. Is it a type of food? A type of equipment? We haven't heard of PEP before. Prior to knowing PEP we approach the patient's social contact. Upon diagnosis, the patient is indeed told that leprosy can infect the whole house if not treated. But we did not mention anything about PEP at that point. But the concept of leprosy being infectious is given by the health worker. So the point of focus lies on the household where the patient lives, and the immediate neighbors up to 20 houses from the patient's residence. This concept is given so that it would be easier to control contact between patient and his neighbors.

Interviewer : PEP is one of the programs of NLR. In PEP, all the immediate contacts of the patient are given single-dosage rifampicin, which function as barrier from infection due to day-to-day contact with the patient. In India there has been several research underway, but Indonesia is relatively new to PEP. In your opinion, if this single-dose rifampicin intervention is administered to patient's contact, what is the effect?

HCW-Pas-B1 : For me that is both positive and negative. From the positive side, the patient's family realizes that their family member is down with the condition. Although it is treatable, but rather than risking infection, medication is preferred. That is the positive side. The negative side, up to now there are just so many (people to administer to). It is almost

impossible. A family of five, with one patient, meaning all five are infected. So five people, one focus. That is impossible, and so that is the negative side.

Interviewer : In your opinion, is this program beneficial? From the viewpoint of a health worker

HCW-Pas-B1 : As a health worker, especially as first officer, I tend to agree. I agree on the basis of how we can prevent infection among patient's immediate contact and social contact. For me this is positive and I agree with this. Perhaps not 100% because from my experience on the field I realize that it is not that easy to implement. There are transportation costs to consider, and people may not understand what we are trying to do. For example, we used to have family planning program. This was back in the time the Health Center first opened. I forgot the year. I just remember that I was involved on the field, in district 3-I. It was to promote distribution of free birth control pills so that people can regulate pregnancy, so they can raise their children better. We tried to promote use of the birth control pills. The concept was not yet grasped fully, to the point that the pills were given to cats. The community did not understand the concept yet at the time. Gradually, people began to understand that if they have many children they cannot have financial stability, they cannot provide good education for their children, they cannot even provide decent food for their family. Nowadays the program is running well, but back then it was so difficult. Now people are willing to pay for it, Rp 10,000 or Rp 20,000. But back then no one would take it. In order for a project to be successful, time is needed.

Interviewer : So in your opinion, PEP intervention is good, but its application on the field would meet with obstacles?

HCW-Pas-B1 : The obstacles is that it has to be on-point with target. Let's say (the target) is educators for leprosy, at the minimum the target is on point. So we don't invite every single person but resulting in no understanding. And even if there are families, if they are not the focus, they won't understand anything. Later when the focus shifts to family and neighbors, they can be given examples. For example, if you tell Pak XXX, in order that patients' family and neighbors are not (infected), they should be invited (to the training). For me as a health worker, PEP is effective when it is on point with the target. So if there is a meeting, it should be specified what the focus is: the patient, neighbors and family.

Interviewer : Last question, Sir. Is there anything you would like to tell NLR, any critic or suggestion?

HCW-Pas-B1 : In my opinion as a health worker, my suggestion is that if NLR launches PEP, please publish books that are on point to the target, which is the health workers. This means the information will be given to health workers, namely midwives, nurses, doctors. First reason being that the book should be distributed across sectors, and second reason is that because this is a project so it requires a lot of things. As you know yourself, leprosy patients are like it or not usually those who are poor financially. And so patients who are positive with leprosy have very limited movement. Please budget some funds from the project. It is clear that financially and socially there are limitations, like everything is compartmentalized

Interviewer : Thank you, Sir, for your time.

Health Worker 2

Allow me to introduce myself. My name is Ririn. I will be conducting an interview on information regarding leprosy. Are you willing to be interviewed? The interview will last approximately 30 minutes.

Interviewer : What is your position at the Health Center, Sir?

HCW-Pas-B2 : I handle the leprosy program

Interviewer : In your opinion, what is the main task of someone who handles the leprosy program?

HCW-Pas-B2 : The first duty is to identify patients of leprosy, both at the polyclinic and at the ER, or at other units such as KIA (Mother and Child Community) and BPJS. If there is any clinical symptom resembling leprosy, we are to proactively identify the outbreak.

Interviewer : So the patients may be from various programs such as from KIA-MTBS?

HCW-Pas-B2 : It can also be from the village midwife, so it is a cross-sectoral program

Interviewer : And then it would be reported to you. So what is the mechanism of reporting, Sir?

HCW-Pas-B2 : So the village midwife, should they find any cases of leprosy, may refer the patient to the Health Center, to the polyclinic, so as to be reported as new case. It can also be from doctor's clinic, because sometimes patients do not go straight to the Health Clinic and instead they go to dermatologist. Doctors know where to refer, because this is a program.

Interviewer : What about duties pertaining recording and reporting?

HCW-Pas-B2 : That is also our duty, to record and report. We continue to record and report, and tracing by means of visit to contacts.

Interviewer : So there is also tracing the contact?

HCW-Pas-B2 : Yes. If you ask about tracing, that would be related to administering the PEP, because that would mean the family of the contact would be administered profilaxis. We can discuss the logics later so that we can find out how many family members need to be administered profilaxis. That would make it easier for you in the project. This project, the administering of Rifampicin, is very good.

Interviewer : Have you received formal training from the Health Department such as OJT?

HCW-Pas-B2 : The most recent one is in Surabaya

Interviewer : When and where in Surabaya was it?

HCW-Pas-B2 : In XXX, Surabaya

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

HCW-Pas-B2 : Over 20 years

Interviewer : What about heading the leprosy project?

HCW-Pas-B2 : Only a year now

Interviewer : What do you think are the causes of leprosy? And what are the symptoms? Can you tell me what you know about leprosy?

HCW-Pas-B2 : So leprosy is a disease that is caused by bacterial infection. Clinically, (the symptoms) include spots that may bleed and can be sensed. That stage should be followed-up by examining through BTA diagnosis. Then we also conduct recording and reporting and tracing of the contact's family. That is very important. Without it, without the

recording and reporting process, it is impossible to find out the total of contacts that need to be given profilaxis.

Interviewer : When did you first heard about leprosy?

HCW-Pas-B2 : When I was first given the responsibility for the leprosy program. But prior to that, I've heard about it in college, but only the knowledge base. I did not have the details and experience comprehensively (at that time)

Interviewer : So the majority of the information you had about leprosy was from your experience as the head of the leprosy program?

HCW-Pas-B2 : Before that I have received (information) clinically on the treatment and medication, but only up to certain levels. I had not seen it comprehensively.

Interviewer : Did you receive the leprosy book, the one that is orange-colored? Do you often or do you like to read it?

HCW-Pas-B2 : I hope that I will like reading it. We can provide constructive criticism to the sources, just like what I did the other day. I only knew the yellow book. Even a friend of mine asked me how is it that I come up with those questions. I told them to read the book and I told them the its weaknesses regarding the treatment. I told them that some bacteria have static features. The possibilities of an infection and also the sources also describe that this is a trial stage, so why not this particular static bacteria? Incidal is still under trial. Perhaps WHO is going to conduct 100 other trials. When the result is discovered, perhaps under one year, or maybe 6 months, there will be cure found, just like TB.

Interviewer : So from the training you received information on leprosy from sources? What information did you get other than symptoms?

HCW-Pas-B2 : Apart from the symptoms, there is also information regarding society's stigma, particularly than in culture's point of view there is bound to be a variety of perception. Perhaps in the Madurese context, we have to approach this gently so they would not run away. In the Madurese context we should not mention the word leprosy; instead we refer to it as skin condition that is treatable. This is so that the patients do not evade treatment. If we do (say that it is leprosy) then patients definitely will not come back. It is a sociocultural issue.

Interviewer : Do you know anyone in your vicinity that has leprosy?

HCW-Pas-B2 : The other day I heard of a patient in a madani clinic. At first the patient was reluctant to go to the Health Center. Because of his/her reluctance, he/she ended up bouncing from one specialist to another, then bouncing back to the Health Center to see the Program Coordinator.

Interviewer : Do you know why he/she is reluctant to go to the Health Center? Is it because the patient lives far away from the Health Center or because of limited access?

HCW-Pas-B2 : The patient that (.....) there are several possibilities. Perhaps the first reason is that the patient is feeling inferior. Second, the patient might not understand why he/she is experiencing skin condition like so, such as losing senses and spotting, and not reacting

to regular skin ointment. The most important issue at hand is we must be wise in educating the patient so that patient understands leprosy as early as possible.

Interviewer : At Purwasari Health Center, are there any patients currently undergoing treatment?

HCW-Pas-B2 : The most recent we have one, Mbak Kasugi, who is yet to be RFT. The others have completed RFT

Interviewer : How many are yet to complete RFT, Sir?

HCW-Pas-B2 : Thankfully, just one.

Interviewer : How many have completed RFT?

HCW-Pas-B2 : Three have completed RFT

Interviewer : Are you directly involved in diagnosing and treating leprosy cases in this Health Center?

HCW-Pas-B2 : It depends where the patient is from. If the patient is from dr. XXX, then my job description would be relieved. We simply continue the treatment. But if a new patient comes in at the polyclinic, then we need to see the clinical condition and lab result, before we can determine the diagnosis. So in terms of patient, there is a variety (of involvement) because they might be coming from the clinic, or from dr. XXX, so that depends on where they are coming in from.

Interviewer : In terms of treatment, are you directly involved in it? Like, for example administering the MDT medication? How do you provide medication to patients who come here?

HCW-Pas-B2 : So once the patient receives a prescription, the patient goes straight to the infirmary, and I also ask them to come back here. So the first consumption of medicine must be in the presence of the program coordinator. The next medication, about 20 days, the patient can do it independently at home. So their presence in the clinic here is designed so that they receive instruction on how to take the medication. The medicine is numbered and dated.

Interviewer : Patients are given medication for one month (supply)... Patients with PB are treated for 6 months, is that correct, Sir? What if, for the patient given medicine for one month supply, then he/she does not come to pick up his/her prescription?

HCW-Pas-B2 : We conduct investigation immediately to find out why they don't continue their medication

Interviewer : What are the views or perception of the health workers on leprosy patients? Are they different from other patients?

HCW-Pas-B2 : I think it differs. Some patients are diagnosed while they are still school-aged, and so they develop a little inferiority complex. But the older patients, so as to avoid this, we need to educate correctly and in general they are able to (.....)

Interviewer : What is your own personal view of leprosy patients?

HCW-Pas-B2 : I think leprosy can be cured as long as the patient is willing to undergo regular medication, willing to look after themselves, willing to watch their nutrition, and willing to regulate rest. With all this in place, it can be treated.

Interviewer : So you think it is just normal. No stigma, whatsoever, Sir?

HCW-Pas-B2 : I think stigma can be reshaped, because the agents are the health workers. They are the ones who are able to reshape and change stigma. If we let stigma roam, we will never see the end of it. So we slowly educate through knowledge, cognitive, and psychomotor domains, so that the patient is able to take care of himself at home after they are equipped with the education here.

Interviewer : In treating the leprosy patients, or in behaving toward leprosy patients, in comparison to other patients, are there health workers here who refuse to touch leprosy patients or to conduct examination? Especially patients who are showing symptoms of advanced leprosy.

HCW-Pas-B2 : I think we don't have such stigma here, particularly those who have been trained and educated. In each training session, I share with the group, because I do not work here in individual (sector) but across sectors and across programs. So everyone needs to understand this and pass the information from the program coordinator. If not, then, for example, the village midwife will not be able to identify leprosy patient properly. So this is important to pass to them. And then across sectors, in particular the TB program because leprosy patients are also potential for TB patients. As to how the technicalities go for combination between TB and leprosy programs, that for me would be cross-program issue, aiming for optimum cooperation between the two programs.

Interviewer : So if I may conclude, there is no difference in treatment or behavior towards leprosy patient in comparison to other patients. Have you heard of PEP, Sir? Where those in contact with the leprosy patient are prevented from infection. Have you heard of the term PEP, Sir?

HCW-Pas-B2 : Yes, I have. PEP is the NLR change project in which single-dosage Rimfamycin is given. Rimfamycin is bactericidal drug, so those in contact with the patient or the patient's family are administered profilaxis. In our opinion this is a very effective project. But if possible, it should be realised as soon as possible. Meaning, no further delay.

Interviewer : Where did you get the information regarding PEP? Is it from training?

Informasi : Yes, I got that from training the other day.

Interviewer : So your opinion about this intervention is that it is effective in cutting the link of leprosy infection, is that so, Sir?

HCW-Pas-B2 : Yes, by God's blessing it is effective.

Interviewer : Is there any suggestions or critic for NLR or any suggestion for the PEP program? Is there anything you would like to tell us?

HCW-Pas-B2 : Yes. PEPE is a good project, but it should be implemented soon. Second, prior to implementation of PEP, it should be socialized to first, program coordinator; second, across sectors; third, across program; and next, policy makers. This is important, so that it can be comprehensively understood.

Interviewer : So in your opinion this program should be implemented soon because of its urgent nature?

HCW-Pas-B2 : Yes, it is very important, because this is the outcome from PEP studies conducted by NGOs. If it can be implemented as soon as possible and in the proper manner, it would be very good. If it can be today, why wait tomorrow?

Interviewer : Thank you, Sir, for this interview.

HCW-Pas-B2 : You are welcome.

Health Worker 3

This interview will last at most 30 minutes

Interviewer : What is your job and position at the Health Center, Ma'am?

HCW-Pas-B3 : I work as nurse, and I have daily duties at the BPP

Interviewer : Nurse and BPP duty everyday. What are your main duties here?

HCW-Pas-B3 : At the Health Clinic here, my main duty is tending to patients. I take their blood pressure, interviewing patients... anamnesa.

Interviewer : Are you also involved in diagnosis?

HCW-Pas-B3 : Yes, all of that. Doctors rarely come here. If any special cases surfaces, I consult the doctor. If there is an emergency, I don't take matters into my own hands but I refer the patients to the ER. I only take care of mild cases, but if it is not something I can handle, I would refer the case.

Interviewer : So this means you and Pak XXX are present everyday at the Clinic?

HCW-Pas-B3 : Yes. Later in the daytime we make our rounds.

Interviewer : You take your attendance in the afternoon?

HCW-Pas-B3 : Yes, at 2.

Interviewer : Have you received any formal training in leprosy?

HCW-Pas-B3 : No I haven't. I have the knowledge only. Pak XXX is here everyday, and I see him later in the day. After (the patients) are treated, they are given vitamin. If they still need further medication, I hand them over to Pak XX.

Interviewer : Oh so you provide initial treatment, and then further medication with Pak XXX. How many years have you worked as health worker?

HCW-Pas-B3 : My appointment letter states that I began in 1988. So that's about 30 years now

Interviewer : That's quite long. Have you ever been responsible for a program here?

HCW-Pas-B3 : The Upper Respiratory Infection Program

Interviewer : How many years were your responsible for this program?

HCW-Pas-B3 : I have been responsible for it as long as I was here up to now

Interviewer : In your opinion, what causes leprosy, and what are the symptoms?

HCW-Pas-B3 : Reddish spots, whitish spots, loss of senses, lack of itching, and does not respond to regular skin mediation.

Interviewer : When did you first hear about leprosy and from where?

HCW-Pas-B3 : From Mr. XXX

Interviewer : Because you work together daily with Mr. XXX? Oh so Mr XXX provides the information that you have.

HCW-Pas-B3 : That was the symptoms, and then this...

Interviewer : Do you know anyone in the vicinity who has leprosy?

HCW-Pas-B3 : On a daily basis, you can spot the symptoms already. Each patient from outside the region have this strange skin condition. I notify Pak XXX and then we would travel out to that region

Interviewer : So your job here is administering patients, diagnosis, and then referring them to Pak XXX?

HCW-Pas-B3 : That's right.

Interviewer : Do you know how many patients are getting treatment here?

HCW-Pas-B3 : In terms of medication, as Pak XX said earlier, at most nine patients. But we see increase every month, not decrease. So we find new cases. We can't say we have eliminated leprosy yet.

Interviewer : Are you directly involved in diagnosis and treatment?

HCW-Pas-B3 : Diagnosis is the doctor's job. Myself and Pak XXX, we are helping with treatment. Pak XXX administers medication, I help with checking up. I help with female patients and Pak XXX examines male patients. For female patients, there is a limitation, in which I would step in. Male patients, Pak XXX does the examining himself.

Interviewer : Oh so there is differentiation?

HCW-Pas-B3 : Yes. Female patients don't appreciate a male health worker performing examination on them

Interviewer : Do you know what treatment is given for leprosy? For example, what type of tablets are given, how many months medication is taken?

HCW-Pas-B3 : There is medication for 6 months, and there is one for 9 months, and then there is one that lasts for a year. Red (pills), and yellow or green pills.

Interviewer : In your opinion as a health worker, what are leprosy patients like?

HCW-Pas-B3 : There is no difference. They are just the same as other patients.

Interviewer : Your job is administering to the patients. Do you treat leprosy patients differently than other patients? For example, you refrain from touching them?

HCW-Pas-B3 : No, they are just the same. I take their blood pressure, I perform anamnesa, I record their weight. Everyday, the same room.

Interviewer : So the same treatment

HCW-Pas-B3 : Yes.

Interviewer : What about leprosy patients at later stage, compared to those who are in the early stage? Do you treat them differently?

HCW-Pas-B3 : Of course

Interviewer : How do you treat them differently?

HCW-Pas-B3 : They have different rooms for examinations. Actually, treatment for gangrene is in a special room, usually at the ER. About those in the later stage, thankfully we have not any.

Interviewer : But so far the treatment is just the same?

HCW-Pas-B3 : Yes, we haven't had any that are in the later stages. Usually the patients that come here are those with 'dry' lesions. I haven't yet come across any with oozing wounds.

Interviewer : So those who come here are still regarded as normal-looking? What about diabetic patients with open sores? Have you heard about PEP intervention?

HCW-Pas-B3 : I don't know that. I heard that from you, actually. What is PEP?

Interviewer : PEP stands for post exposure profilaxis

HCW-Pas-B3 : Write it down, please.

Interviewer : Yes, Ma'am. So you have not heard yet about PEP?

HCW-Pas-B3 : No, what is it?

Interviewer : So leprosy patients often come in contact with people. This is just preliminary plan, but the plan is that they are administered Rifampicin to prevent infection of leprosy.

HCW-Pas-B3 : So you mean the health worker is given medication?

Interviewer : Medication given to the patient's immediate contact, their family, so that they are prevented from leprosy infection. What do you think of this program plan?

HCW-Pas-B3 : For prevention?

Interviewer : Yes. Do you think this program might be beneficial? What do you think?

HCW-Pas-B3 : Yes, that is beneficial for the family so they are prevented from leprosy infection

Interviewer : Do you as health worker think this program is beneficial?

HCW-Pas-B3 : Yes, it is much needed and beneficial

Interviewer : Any suggestions to NLR from you?

HCW-Pas-B3 : Handling patients requires patience. You need to be understanding. "You have this condition, and this is the treatment" You can't tell them they have leprosy, or they might hit you.

Interviewer : They are pretty extreme here, Ma'am?

HCW-Pas-B3 : Yes. These are Madurese ethnicity.

Interviewer : So if you are a leprosy patient, we should not tell them straightforward?

HCW-Pas-B3 : No. Leprosy should be referred to as skin condition, and the treatment should be for this many months, the medicine must be taken regularly, it shouldn't be halted mid-treatment.

Interviewer : So, the society here indirectly realizes that leprosy is an embarrassing illness, is that so?

HCW-Pas-B3 : Yes, some of them think that way

Interviewer : How do you say leprosy to them then?

HCW-Pas-B3 : You don't. You tell them to go to their family, and it might be embarrassing. You tell them not to handle certain things. You tell them to pick up their pills at the Health Center. That's what I sometimes do.

Interviewer : So the stigma still persists. All right, Ma'am. Thank you very much.

Interviewer: Ririn

District: Pasuruan

Participant type: index patient

IC 1

Good afternoon. I will conduct an interview with you regarding your condition

Interviewer : How many members of your family are living with you at home?

IP-Pas-B1 : Now there are 3, and with a nephew(/niece) so that makes 4. Originally we had 8

Interviewer : Oh so previously you had 8 people living with you at home?

IP-Pas-B1 : 6 children, 2 of the parents

Interviewer : But they are rarely home?

IP-Pas-B1 : The youngest is already working

Interviewer : Where did you first go for treatment? First treatment for your condition?

IP-Pas-B1 : A friend of mine is a nurse. S/he told me to go to the Health Center, but I didn't respond to it because it was an ordinary symptom

Interviewer : Okay

IP-Pas-B1 : But when I went to "kutamol", the reaction was "Why is it like this?"

Interviewer : So you first went to the Health Center

IP-Pas-B1 : Yes

Interviewer : So what do you know about your condition?

IP-Pas-B1 : Hm... I know that it is a skin condition that might lead to disabilities... disability in the limbs, loss of senses. That's all I know.

Interviewer : When did the symptoms first appear?

IP-Pas-B1 : On the face

Interviewer : How many months ago was that?

IP-Pas-B1 : A year ago

Interviewer : So when the first symptom appeared, you did not go to the Health Center?

IP-Pas-B1 : No. It was an ordinary symptom, unlike it is now. The blackened skin is the effect of hepatitis

Interviewer : Actually it is good if it turns black

IP-Pas-B1 : It didn't use to be black like this. My skin is beige-colored

Interviewer : If it didn't turn black, it means the medication is not working

IP-Pas-B1 : That's true

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

IP-Pas-B1 : I don't know

Penyebab : You don't know. Didn't anyone informed you? You said earlier you tried to find information off the internet. Did Pak XXX tell you anything?

IP-Pas-B1 : Pak XXX said that infection can be through lifestyle

Interviewer : What do you mean lifestyle?

IP-Pas-B1 : If living condition is too dirty and not keeping good hygiene

Interviewer : How did you feel after you were diagnosed by Pak XXX and he told you that you have leprosy? How did it make you feel?

IP-Pas-B1 : It was okay. I take that as my fate.

Interviewer : So for you it was okay because it is how the Higher Powers had prescribed your fate. And do you know of anyone with leprosy before this?

IP-Pas-B1 : No. Pak XXX said that most leprosy patients feel inferior when they come across other people

Interviewer : But you did not feel inferior?

IP-Pas-B1 : No. I feel just fine. None of my friends make fun of me

Interviewer : Did you tell your family about your condition?

IP-Pas-B1 : No.

Interviewer : So up to now the family...?

IP-Pas-B1 : They know now. Since I started treatment, they know about my condition

Interviewer : And how did your family react?

IP-Pas-B1 : They told me to take the medication in full, that's all. We tried other alternatives but, I don't know. Including the woodpecker treatment, because we got one.

Interviewer : Woodpecker for what?

IP-Pas-B1 : Dad, what is the woodpecker for?

Bapak : To rub the feathers onto the skin

Interviewer : Oh, I see.

IP-Pas-B1 : Red woodpecker. But I haven't responded to that

Ibu : Just medication?

Interviewer : Oh, just medication. You work as a freelance driver, is there any difference before and after you were diagnosed with the condition?

IP-Pas-B1 : I get physically weaker

Interviewer : So you find it a little harder to carry out the activities you are used to doing?

IP-Pas-B1 : Before, I could drive for the whole day. Nowadays I drive for a bit and my leg gets tired. 3-4 hours and my legs give in. But sometimes when I feel fit, I don't feel that. When I am not fit, I get tired easily.

Interviewer : So that means there is a difference, right?

IP-Pas-B1 : Yes, there is difference

Interviewer : Do you feel it becomes a hindrance now that you have this condition and you feel physical weaknesses?

IP-Pas-B1 : Yes, it feels like a hindrance

Interviewer : Do your friends know that you are sick?

IP-Pas-B1 : No. They know I have skin condition, but they don't know the name of the condition

Interviewer : So they know that you have skin condition. And how did they react?

IP-Pas-B1 : They told me to find medication. I told them I have been treated at the Health Center for a year

Interviewer : So your friends behave normally? Did they advise you to find treatment here and there?

IP-Pas-B1 : Yes

Interviewer : How did you feel after informing them?

IP-Pas-B1 : I felt just normal

Interviewer : Yes. How did you expect your friends to react? Just normal reaction or what?

IP-Pas-B1 : My friends responded just normally, trying to keep maintain feelings. And when the condition worsened, they also responded normally, they did not inquire any deeper

Interviewer : Do your friends know about leprosy?

IP-Pas-B1 : They don't

Interviewer : So you just told them that this is a skin condition, but not leprosy, is that so?

IP-Pas-B1 : Yes

Interviewer : Do your neighbors know that you are ill?

IP-Pas-B1 : They know. My skin turned black, from arms and on, from light color skin then turned black

Interviewer : But it will turn back to light later

IP-Pas-B1 : I hope so

Interviewer : It will come back. But if your neighbors ask you, "what condition do you have?" what will you answer?

IP-Pas-B1 : Oh, but mostly (the skin) changes

Interviewer : And what did you answer?

IP-Pas-B1 : They asked, "Do you have allergic reaction?" I said yes

Interviewer : And when you told them you have allergic reaction, how was it?

IP-Pas-B1 : They kept quiet. They did not know anything about leprosy

Interviewer : Do you have any suggestions for the Health Center, or for me personally as a representative from leprosy center in Surabaya? Are there suggestions or criticism?

IP-Pas-B1 : To be honest, when I go to the Health Center I can't find Pak XXX or other officers. I understand Pak XXX is a busy man. He is usually on field duty on Fridays and Saturdays. On Fridays and Saturdays I work at 7 o'clock. I got the car prepared, at 8 I come around and he isn't there. At 7 I come, he isn't there either

Interviewer : So most of the time you don't get to see him?

IP-Pas-B1 : Yes, I don't get to see him. One time, the medicine was late

Interviewer : So you came but you did not get to see him

IP-Pas-B1 : Yes, I go there usually 3 days or 4 days.

Ira : But the medicine is disbursed monthly?

IP-Pas-B1 : Yes. Once my medicine was late for a week and a day or two

Interviewer : When you speak to your friends, do you speak frankly or do you keep some secrets?

IP-Pas-B1 : When it comes to my condition, I don't really discuss it with them. I just tell them it is a skin condition. We never talk about it in depth. I just say it is allergic reaction

Interviewer : Thank you, Sir

IC 2

- Interviewer : How many family members do you have at your home, Sir?
- IP-Pas-B2 : Family members plus my in-laws or just my nuclear family?
- Interviewer : People living here in your house, how many are there?
- IP-Pas-B2 : Four... five with my younger sibling. Seven, if you count my in-laws. My in-laws and my mother are now with my children, but sometimes they live here.
- Interviewer : So which is more often, five or six people living in this house?
- IP-Pas-B2 : Seven. All is seven. If you count my nephew, there are eight, but he doesn't stay here all the time, sometimes he comes and sometimes he goes.
- Interviewer : So it is more often that there are seven people living here?
- IP-Pas-B2 : Yes.
- Interviewer : Where did you go the first time when you found your spots?
- IP-Pas-B2 : I went to the dermatologist in Pandaan. Then I was advised to go to the Health Center
- Interviewer : Was it at a hospital in Pandaan?
- IP-Pas-B2 : No, it was the specialist's private clinic
- Interviewer : And then after that you were advised to go to the Health Center
- IP-Pas-B2 : Yes, the Health Center
- Interviewer : What do you know about your condition?
- IP-Pas-B2 : Which one?
- Interviewer : The one where you found spots and then they became itchy. What do you know about your condition? For example, what is it called and what caused it?
- IP-Pas-B2 : Yes. Pak XXX told me that it could have been when a person has fever and in low immune condition, he is affected by the virus. When in low immune condition.
- Interviewer : When did you first noticed of your condition? As far as you can remember?
- IP-Pas-B2 : April or May... If my memory serves me it was May or June, then in July the doctor prescribed me something. He was worried I had allergic reaction to chicken. So I did not eat any, then I went to see the dermatologist, who later told me to have my treatment at the Health Center
- Interviewer : So that means five or six months ago that you found out you have this condition?
- IP-Pas-B2 : I started seeing Pak XXX around September
- Interviewer : So it is almost a year?

IP-Pas-B2 : Yes, I started treatment in September, then I started experiencing heartburn problem in October

Interviewer : After taking the medication?

IP-Pas-B2 : Yes, it was all okay, but Maryono got my medication coming late one time. I was getting my treatment at the hospital, and no one put in my request for the medicine. I called Pak XXX, but he was in Malang at the time. He said, "you can combine this medication with that medication". Then I put in my medicine request. So that meant that I discontinued medication for two months.

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

IP-Pas-B2 : What I know is that a virus is the cause of this condition. Pak XXX said that I was in low immunity condition when I caught it

Interviewer : Were you a vendor previously?

IP-Pas-B2 : I sold bananas. If I don't go to work in the afternoon, I would spend my morning selling bananas.

Interviewer : What was your reaction when Pak XXX or the hospital in Pandaan first informed you of your condition? When you were told you had this condition, how did you react? Were you sad?

IP-Pas-B2 : I was not. I made a phone call when I was in Pandaan for my digestion problem, I told them of my condition. Then I went to the Health Center to meet Pak XXX. At that time I was already experiencing loss of senses on my reddish spots, but there weren't many. I was prescribed a medication, and pretnisen, then it got better. The redness was gone.

Interviewer : But were you sad, or experiencing discomfort?

IP-Pas-B2 : Yes, I said to myself how did I get to have this condition? I don't have any history of this

Interviewer : Did any of your family ever have leprosy like you do?

IP-Pas-B2 : No

Interviewer : So you don't know anyone with leprosy prior to yourself having leprosy. What about other skin conditions such as fungal infection or allergic spots?

IP-Pas-B2 : I can see people who have that at the marketplace. People with fungal infection, you can see it clearly on their arms

Interviewer : So you have seen fungal infection when you were at the marketplace

IP-Pas-B2 : Yes. Pak XXX said that such things can infect you when your immune system is down. Like this virus, which affected me, as Pak XXX said

Interviewer : In the society around you, are there people with skin condition such as allergy? And how did people react to it?

IP-Pas-B2 : No

Interviewer : No reaction at all?

IP-Pas-B2 : No

Interviewer : Do your neighbors here know that you have this condition? Did they ask what you are ill from?

IP-Pas-B2 : Common illness, no.

Interviewer : Did you tell your family that you have this condition? Did you tell the people living in your house? Did you tell your wife?

IP-Pas-B2 : Yes, my wife knows. When I went to Pak XXX, my wife came along

Interviewer : How did your wife react?

IP-Pas-B2 : She was sad. She was sad, and then she phoned our family, telling them that if I take my medication then it will be safe. I was okay, and they should not be worried.

Interviewer : You were working up to then. In your opinion, did your condition interfere with your work?

IP-Pas-B2 : When I first got ill, I went to the hospital a lot, so I did not work.

Interviewer : So you took leave from work when you were ill?

IP-Pas-B2 : Yes, I took my leave. Sometimes I use hand sanitizer first when my children are about to leave for school. They would shake my hand before leaving, and I am afraid of transferring virus. Also, the soap bars in my bathroom are rinsed with bleach so that the virus does not transfer

Interviewer : What about the people you know at the marketplace or at work, did they ask you about your condition?

IP-Pas-B2 : They did not. Since I stopped going to the marketplace, they just knew that I was sick, that's all

Interviewer : So they only knew that you were sick, but not what the illness was?

IP-Pas-B2 : Yes. I told them I had digestive problem. Liver problem. I do have liver problem, and I have the coughs

Interviewer : You did not tell your friends the details of your condition?

IP-Pas-B2 : No

Interviewer : What was the reaction your friends make when they knew you were ill?

IP-Pas-B2 : I had my old school friends come here when I had nerve dysfunction. I could not walk at that time. It was the holiday season, and many of my friends came to visit me at home

Interviewer : What was their reaction about your condition?

IP-Pas-B2 : First I said it was the digestive problem, then I said liver problem and finally I had nerve dysfunction

Interviewer : But your friends reacted just normally?

IP-Pas-B2 : Yes, they reacted normally. It was okay. Oh yeah, they did comment that my skin got darker because of the medication

Interviewer : It's okay, Sir, it will turn back to normal color later. Infact, if it did not turn darker, then you would be questioned whether or not you took your medication. The fact that it did turn black showed that you did. The color will return. What was the reaction that you expected from your friends? How do you want them to behave in relation to your condition?

IP-Pas-B2 : It's okay that I had this condition

Interviewer : And how did your friends behave?

IP-Pas-B2 : They were okay. We shared meals together and they wished me to get better

Interviewer : Did your neighbors know about your condition?

IP-Pas-B2 : They know that I have regular illness

Interviewer : Did you keep the information from them intentionally?

IP-Pas-B2 : No.

Interviewer : Your neighbors know that you have regular illness. But what if they found out that you have a special condition such as now. What would their reaction be?

IP-Pas-B2 : They would react normally. Infact, one of my neighbors know Pak XXX. A relative of Pak XXX, actually. He knew, but he did not spread the word around. He knew, and sometimes I even ask him to pick up my medication

Interviewer : So your neighbors are still okay. But if they knew about the actual condition that you have leprosy, do you think they would still be okay with it or not?

IP-Pas-B2 : Yes, they would behave normally.

Interviewer : But you are just not being frank with them?

IP-Pas-B2 : No

Interviewer : Do you have any complaints or suggestions to make to the health department?

IP-Pas-B2 : Treat immediately so that patients get better quickly

Interviewer : Do you think the medication is effective?

IP-Pas-B2 : The prescription from Pak XXX is very effective. Just don't delay. Right now I have only this much medicine left. I need to replenish my supply

Interviewer : So your suggestion is to seek medication?

IP-Pas-B2 : Yes. Seek medication, don't be late

IC 3

Index case : Pasuruan

IP-Pas-B3: Ma'am, I would like to ask you several questions about your 'allergy'. You said that your skin is having an allergy. May I?

IP-Pas-B3: Yes, Ma'am

P: How many people living in the same house with you, Ma'am?

IP-Pas-B3: Here they are (showing a photograph)

P: There are 6 of them?

IP-Pas-B3: Yes, there are 6 persons

P: When you get your allergy for the first time, where did you go for medication?

IP-Pas-B3: To Puskesmas

P: Was it Puskesmas Sukorejo?

IP-Pas-B3: Yes

P: When was it first appeared?

IP-PAS-B3: About a year ago. Yes, a year ago.

P: What do you think have caused your allergy?

IP-PAS-B3: I do not know Miss. Maybe it is because 'jamu' (traditional drink). I drank jamu at around 8 pm and then at 9 pm I found that my skin got irritated and inflamed. Just like this (pointing to her skin lesion).

P: Oh so you think this is because of allergy to jamu?

IP-PAS-B3: Yes I think so. This is not because of food. I have never eaten sea food. I just eat tofu and 'tempe', potatoes, MSG. I am afraid to eat seafood because I am afraid of allergy. I remember when it got worst I went to Pak XXX (health worker). If you saw me that time I am sure you would feel disgusted.

P: According to pak XXX, what was the cause of your allergy?

IP-PAS-B3: I forgot what he said. But I think my allergy is because of that 'jamu'.

P: How did you feel after you get that allergy?

IP-PAS-B3: I felt itchy and swollen because of that jamu. What I know was I got allergy because of that jamu.

P: How was your feeling? Did you feel sad, upset, fine, or how was it?

IP-PAS-B3: Yes I was sad. I went to Puskesmas the next morning.

P: Why do you feel sad?

IP-PAS-B3: Because of this disease, it was so uncomfortable. It has been better this year but it was very severe last year. There is still scars because of that disease. It (the allergy) spread all over my skin. My skin became reddish. When I visited Pak XXX, it was very severe. Even there was ulcerations. But it was not diabetes. My blood pressure was high. 170.

P: Have you ever known someone with this kind of allergy?

IP-PAS-B3: No, I have never. I think it is only me suffers from this in this area.

P: If someone around here got allergy just like what you have got, how do you think people will treat him/her?

IP-PAS-B3: What do you mean?

P: I mean, whether this person will be taken care of, neglected, or what?

IP-PAS-B3: Yeah I think people will take care if someone is sick. When I was ill, my neighbors visited me.

P: How do you feel when you got visited by your neighbors?

IP-PAS-B3: Of course I was happy. It means that people still like me. There were many of them visited me.

P: How about your family? How did they react?

IP-PAS-B3: I was taken to dermatologist by my son once. But the doctor said it was not that skin disease.

P: So what did the doctor tell you?

IP-PAS-B3: he said it was allergy. I was referred to Sumberglagah (Hospital; known to be a leprosy hospital previously)

P: Oh that one in Mojokerto?

IP-PAS-B3: Yes, I was taken there. My son was confused and he was afraid if I have a skin disease. He said "Let us go to hospital Mother, I am afraid you have a skin disease". The drug that was given in Sumberglagah was similar to the drug that was given by Pak XXX. But it was only shown to me. They (Sumberglagah hospital) only gave me ointment for my skin.

P: So you have told your family that you got this disease?

IP-PAS-B3: Yes, I have. I visited the Puskesmas by myself at the beginning.

P: Did you then tell your family?

IP-PAS-B3: Yes

P: How did your family react?

IP-PAS-B3: My son took me to Sumberlagah once. But now only to Puskesmas to take the drug. To pak XXX.

P: What do you do at home? Do you help your daughter cooking, cleaning the house, or what?

IP-PAS-B3: No, I am not allowed to.

P: Oh so you do not do anything?

IP-PAS-B3: Yes, Miss.

P: Have you ever faced difficulty in doing your daily activity? I heard that you used to sell things at the market.

IP-PAS-B3: I cannot do that now because I am still ill. My kids told me to stop.

P: Have you ever told your friends about this 'allergy'?

IP-PAS-B3: Which friends? My friends at the market?

P: Yes, Ma'am.

IP-PAS-B3: No, they do not know. I did not tell them.

P: How about your neighbors? Did you tell them?

IP-PAS-B3: I answer only if they asked. They usually asked, "What are you suffering from?" So I just told them I got an allergy.

P: So how was then their reaction about your allergy?

IP-PAS-B3: They were fine. They remind me not to drink 'jamu' that has caused the allergy.

P: Are you happy with your neighbors' reaction? What do you expect from them?

IP-PAS-B3: I was happy. Of course we feel happy if our neighbors put attention to us.

P: If someone from your surrounding got similar disease or another skin disease, how was the reaction of your neighbors?

IP-PAS-B3: They are fine, no one around here has similar disease. Only me. Yesterday I heard one of my neighbors got surgery. My son usually only gets "urticarial". He cannot eat egg. I ate chicken during Idul Fitri, then my allergy started again. So now I only ate tofu and potato.

P: So your neighbors were fine even though there is someone suffering from this disease?

IP-PAS-B3: Yes they were fine.

P: If you talk about your condition to your neighbors, did you tend to speak openly or you tried to hide anything?

IP-PAS-B3: No I did not speak openly about my disease. I just told them I got allergy. That is all. I have never explained too much. There is no point to do it. If doctor said it was only allergy, then it is. I have never explained anything to my neighbors.

IC

Interviewer : Sir, my name is Junita. I am from the District Health Agency working together with NLR. I would like to ask some questions regarding the medicine that is given to you for your condition.

IP-Pas-B4 : Particularly MDT?

Interviewer : No, I am just going to ask things like, how many people live in this house?

IP-Pas-B4 : Five

Interviewer : Five people. The first time you got sick, where did you go to have it examined?

IP-Pas-B4 : At <location>, when I was little

Interviewer : Can you please tell me about your condition, about leprosy?

IP-Pas-B4 : At first I got swollen and I lost senses. It was all sorts of wrong. Usually, even with swelling, I would be fit for work, but at that time I could only work for three days in a week. I only came in for three days. People asked me what's wrong, and I said I felt cramps. I worked with motorbike spareparts, and I couldn't work. When it felt a bit better, I found it hard to work.

Interviewer : Your whole body?

IP-Pas-B4 : No, just my legs.

Interviewer : When did this start? At what age, were you very young?

IP-Pas-B4 : If I'm not mistaken, starting when I was 6 years old. But I didn't take the MDT.

Interviewer : Do you know what causes your leprosy?

IP-Pas-B4 : Bacterial infection.

Interviewer : The first time you went for a check up was at the Health Center, correct? And then when you found out you had leprosy, how did you feel?

IP-Pas-B4 : I didn't go to the Health Center at that time, but (...inaudible) legs. My mother said I have leprosy and that I should go straight to the hospital.

Interviewer : When you realized you were ill, did you know anything about leprosy?

IP-Pas-B4 : No.

Interviewer : What is leprosy?

IP-Pas-B4 : In the past there were 2 people with leprosy

Interviewer : What does your community think of leprosy? Would they cover up the fact they are sick?

IP-Pas-B4 : No

Interviewer : So this means your family knows? Everyone, your relatives and your friends know that you have leprosy?

IP-Pas-B4 : Yes, they know

Interviewer : What did your friends think when they knew you had leprosy? What did they say?

IP-Pas-B4 : Sometimes they would say skin condition

Interviewer : Don't you...?

IP-Pas-B4 : No.

Interviewer : So everyone knows about leprosy?

IP-Pas-B4 : Yes.

Interviewer : If one of your neighbors don't know about leprosy, what would they say or think about leprosy?

IP-Pas-B4 : They look at it as a common illness

Interviewer : Common illness. So nobody sees you as different? As someone who had leprosy, what message would you give them?

IP-Pas-B4 : For those (who have leprosy), don't lose hope and get treatment (inaudible)

Interviewer : Is that all?

IP-Pas-B4 : Yes.

IC 2

Interviewer : Sir, I would like to ask questions to you about leprosy, and about medication for leprosy

IP-Pas-B5 : Yes, Ma'am

Interviewer : If I ask you what you feel about your illness, what would you say, Sir?

IP-Pas-B5 : I am angry, actually.

Interviewer : When did this condition begin?

IP-Pas-B5 : When I had my first xx

Interviewer : What year was that?

IP-Pas-B5 : I can't be sure.

Interviewer : You don't remember?

IP-Pas-B5 : I don't remember.

Interviewer : Do you know what is the cause of your leprosy condition?

IP-Pas-B5 : I don't know

Interviewer : You don't know at all?

IP-Pas-B5 : Yes.

Interviewer : When you had your examination with Mrs. Linda about leprosy, how did you feel about it?

IP-Pas-B5 : I don't feel anything.

Interviewer : You don't feel anything. You don't feel strange about it?

IP-Pas-B5 : No.

Interviewer : Did you know previously what leprosy is?

IP-Pas-B5 : No, I don't

Interviewer : Did your neighbors know that you have leprosy?

IP-Pas-B5 : No.

Interviewer : No one asked you about it?

IP-Pas-B5 : Yes.

Interviewer : Your friends, do they ask you anything?

IP-Pas-B5 : Nothing. They are just okay with it.

Interviewer : Did you tell them anything?

IP-Pas-B5 : No.

Interviewer : Did your friends talk about leprosy?

IP-Pas-B5 : No

Interviewer : If someone has the same condition as you, what would you do?

IP-Pas-B5 : I would ask about it

Interviewer : You would ask.

IP-Pas-B5 : I would ask what condition they have, and if their infection is worsening

Interviewer : That's all?

IP-Pas-B5 : Yes.

IC 3

Sir, I am from the District Health Agency. I would like to ask some questions about leprosy.

Interviewer : How many people are living in one house?

IP-Pas-B6 : Four

Interviewer : Where did you have yourself examined the first time?

IP-Pas-B6 : At the Health Center

Interviewer : At the Health Center in Lekok? What did they tell you about your condition?

IP-Pas-B6 : It was leprosy

Interviewer : Can you tell me about your condition, starting from the time you first got ill?

IP-Pas-B6 : It was a burning sensation

Interviewer : What else?

IP-Pas-B6 : Nothing. And then I started to lose digits

Interviewer : Lose digits?

IP-Pas-B6 : Yes

Interviewer : When did that start?

IP-Pas-B6 : I don't remember

Interviewer : How much medicine did you take?

IP-Pas-B6 : I don't remember

Interviewer : When you were informed that you had leprosy, how did you feel?

IP-Pas-B6 : I was sad

Interviewer : Why were you sad?

IP-Pas-B6 : I was sad (...) that person

Interviewer : Before that, did you know know about leprosy?

IP-Pas-B6 : I did

Interviewer : What do other people do to leprosy patients?

IP-Pas-B6 : I feel sorry, Ma'am

Interviewer : Do people alienate leprosy patients? Or do they behave just normally?

IP-Pas-B6 : People behave normally. This condition is God-given. Illness is also God-given

Interviewer : Do your neighbors know you have leprosy?

IP-Pas-B6 : They don't know. I am new here

Interviewer : Do people at work know you have leprosy?

IP-Pas-B6 : They don't know

Interviewer : They don't know. So if your neighbors find out you have leprosy, what would happen?

IP-Pas-B6 : I would be embarrassed

Interviewer : Just embarrassed? But anyway, you have made full recovery.

IP-Pas-B6 : Yes, but still it is embarrassing

CONTACT:

- Interviewer : Miss, I would like to interview you about leprosy. We have a new program to prevent leprosy infection. It hasn't started yet, but soon.
- Interviewer : Can you tell me what leprosy is?
- CC-Pas-B4 : I've seen it in Google. Leprosy is a skin disease, it looks like skin fungus, but it can damage the nerves up to the extent of disability.
- Interviewer : So you found out by yourself?
- CC-Pas-B4 : Yes, I found the information myself.
- Interviewer : From Google. Did you get any other information from anywhere else?
- CC-Pas-B4 : That's all.
- Interviewer : How do people in this community see leprosy?
- CC-Pas-B4 : We don't have leprosy case here just yet, so it is a rare thing. Unusual.
- Interviewer : Unusual. So people here do not have any opinion about it?
- CC-Pas-B4 : That's right. We don't.
- Interviewer : Supposing someone here has leprosy and then it got bad to the point of disability or disfigurement, because that's what leprosy usually comes to. How would that be?
- CC-Pas-B4 : I would be scared, because of the disfigurement/disability
- Interviewer : Would leprosy cause embarrassment here?
- CC-Pas-B4 : I guess by and by it will cause embarrassment if the patient becomes disfigured/disabled because they would lose (bodily) functions
- Interviewer : So there has not been any case of leprosy here?
- CC-Pas-B4 : Yes, never. I've heard of stroke, but that's all
- Interviewer : Oh. In your opinion, is leprosy a genetic condition, or can it infect just about anyone?
- CC-Pas-B4 : No. According to what I read, it is not genetic
- Interviewer : According to what you read, what causes it?
- CC-Pas-B4 : Temperature. Yes, I read that temperature or climate is the cause
- Interviewer : Do you know the signs of leprosy?
- CC-Pas-B4 : I heard that numbness is the symptom
- Interviewer : Miss, if there is a drug available for leprosy, would you take it?
- CC-Pas-B4 : Is there side effect?
- Interviewer : Would you take it?
- CC-Pas-B4 : I would, but I want to know what the side effects are. I know that leprosy can cause the skin to turn black.

Interviewer : Yes, there are several side effects. After the medication program for those who are infected, the skin color would return

CONTACT:

Interviewer : Mam, I would like to ask questions about leprosy, such as medication, prevention. If there is a drug to prevent leprosy, do you think you would take it?

CC-Pas-B5 : Of course I would

Interviewer : To prevent you from getting sick

CC-Pas-B5 : Yes, to prevent from sickness

Interviewer : Can you tell me about leprosy?

CC-Pas-B5 : I don't know

Interviewer : That condition that is the same as Pak Akib over there

CC-Pas-B5 : I have that condition that Pak Akib has. I was going to say that.

Interviewer : From whom did you hear about leprosy?

CC-Pas-B5 : From Ibu

Interviewer : Which ibu?

CC-Pas-B5 : Ibu Linda

Interviewer : Ibu linda. Where does Ibu Linda work?

CC-Pas-B5 : Health Center

Interviewer : Oh at Health Center. What does the community think about leprosy?

CC-Pas-B5 : I don't know

Interviewer : Supposing someone has leprosy and stays at home, how would they keep their condition secret?

CC-Pas-B5 : Yes, I keep it a secret

Interviewer : Do people keep away from you or just normally?

CC-Pas-B5 : Just normally. If anyone asks me what condition I have, I answer that it is just normal infection

Interviewer : Do you think anyone could have leprosy?

CC-Pas-B5 : No.

Interviewer : Who can have leprosy?

CC-Pas-B5 : I think my neighbors have it

Interviewer : If, for example, a member of your family has leprosy, what would you do?

CC-Pas-B5 : Just surrender to God, I cannot do anything

Health Worker

Miss, my name is Nita. I am conducting interviews related to distribution of drugs and prevention of leprosy

Interviewer : What is your position here?

HCW-Pas-B4 : Nurse

Interviewer : Where is your main duty?

HCW-Pas-B4 : Polyclinic

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

HCW-Pas-B4 : Since 2014

Interviewer : Can you tell me what leprosy is?

HCW-Pas-B4 : Skin disease that affects peripheral nerves, is that it?

Interviewer : What is the cause and the symptoms of leprosy?

HCW-Pas-B4 : The cause is white and reddish spots

Interviewer : Please don't be afraid, I am not mean.

HCW-Pas-B4 : I am not

Interviewer : Supposing that a patient here asks you about leprosy, what would you say? Have they ever asked or said anything?

HCW-Pas-B4 : No, because I handle children.

Interviewer : That's true. Normally lay people would not know (about leprosy). If you met someone who has leprosy, would you tell them about it right away? For example, if someone comes to your house for an examination, and he/she shows signs of leprosy, would you tell them that they have leprosy?

HCW-Pas-B4 : I would suggest going to the Health Center. I cannot decide, I don't know.

Interviewer : Can you give me an estimate what the society here, particularly the health workers, about leprosy?

HCW-Pas-B4 : Usually, they are brushed off

Interviewer : Oh so prayers are said. Here you have in-patient ward, right? Let's say there is a patient that has leprosy. Does the patient receive different treatment?

HCW-Pas-B4 : Yes.

Interviewer : Different how?

HCW-Pas-B4 : The Health Workers usually pass them around.>

Interviewer : Do you know about PEP intervention?

HCW-Pas-B4 : No

Interviewer : Let me provide an explanation about PEP, that PEP is an intervention to prevent transmit of leprosy, like profilaxis for leprosy prevention. The previous method is through single-dose rifampicin. This method is combination of rifampicin and amoxi or something. What do you think of this new intervention?

HCW-Pas-B4 : I think this is very good for future progress

Interviewer : Is that all?

HCW-Pas-B4 : Okay. Let me finish this.

Health Worker

Good morning, Miss. My name is Nita. I would like to conduct an interview with the community in regard to distribution of a drug to prevent leprosy. This program is just about to begin.

Interviewer : Would you be willing to provide your opinion? What is your occupation and position and the Health Center?

HCW-Pas-B5 : Yes. I am the midwife here.

Interviewer : What is your main duty?

HCW-Pas-B5 : Village midwife

Interviewer : How many years have you worked as village midwife here?

HCW-Pas-B5 : 8 years

Interviewer : Can you provide me a description about leprosy? What do you know about leprosy?

HCW-Pas-B5 : The description I know about leprosy is that it produces white spots, and when touched it is numb. That's all I know.

Interviewer : Do you know the cause?

HCW-Pas-B5 : Germs, as far as I know

Interviewer : When did you first hear about leprosy?

HCW-Pas-B5 : I heard about leprosy back in college

Interviewer : Did you find the information yourself or from books?

HCW-Pas-B5 : I read, and I got information from my friends

Interviewer : Are there any leprosy patients around you?

HCW-Pas-B5 : Yes. Many

Interviewer : How many leprosy patients do you know here in Lekok Health Center?

HCW-Pas-B5 : I don't know

Interviewer : Are there any leprosy patients who go to your clinic for examination?

HCW-Pas-B5 : Yes, there are. I urge them and refer them to go to Lekok Health Center.

Interviewer : What is the perception of the health workers about leprosy at the Lekok Health Center? What is leprosy in the eyes of health workers?

HCW-Pas-B5 : For the Health Workers, it's just the same (as other conditions)

Interviewer : Aren't they afraid of infection?

HCW-Pas-B5 : No.

Interviewer : If there is a patient here who is found to have leprosy, would there be a difference of treatment compared to treatment of other patients?

HCW-Pas-B5 : No. They are all treated the same.

Interviewer : Have you ever heard of PEP plus-plus Intervention?

HCW-Pas-B5 : No. I don't know that

Interviewer : PEP plus-plus is directed to people who have direct contact with leprosy patients. Infection can be prevented by administering prophylaxis, and that is the common way, through rifampicin single dose. In this intervention, rifampicin is combined with other drugs. What do you think of this intervention?

HCW-Pas-B5 : I don't know what to think of it.

Interviewer : Would that be a better intervention, or would the usual method be useful enough?

HCW-Pas-B5 : But this intervention can guarantee recovery, right?

Interviewer : Leprosy is treatable, basically

HCW-Pas-B5 : I mean, this treatment will expedite healing?

Interviewer : Yes, this will promote healing faster

HCW-Pas-B5 : Then my opinion is that I agree with it

Interviewer : I see. Thank you, Miss.

Health Worker

Sir, my name is Nita. I am here to interview you pertaining leprosy. Your answer should be your own, you do not need to be influenced by other's opinion. I would like to ask you about the plan to administer a new drug to prevent leprosy.

Interviewer : Would you like to be involved in passing the message to the public that this drug can prevent leprosy? So that people who do not wish to be infected with leprosy would be willing to take this drug as well.

HCW-Pas-B6 : For socialization? Yes, I would

Interviewer : Yes. Now, can you please tell me what leprosy is?

HCW-Pas-B6 : Leprosy is a communicable disease caused by mycobacterium leprae which affects peripheral nerves

Interviewer : What are the symptoms of leprosy?

HCW-Pas-B6 : The symptoms of leprosy include white or reddish spots on the skin that is numb in senses. Umm damage to the peripheral nerve can affect a single nerve or more

Interviewer : Where did you first hear about leprosy, Sir? I mean, from whom?

HCW-Pas-B6 : I knew about leprosy for a very long time, even since before I became a health worker. I've known leprosy since before I work in health industry.

Interviewer : If someone asks you what leprosy is, how would you describe it?

HCW-Pas-B6 : Same. I would describe by comparing it to other infections such as lung infection, because the bacteria (in leprosy) is similar to lung infection, just the method of infection is different.

Interviewer : In a single area, for example, if a leprosy patient lives there, would the surrounding community know that the person has leprosy?

HCW-Pas-B6 : People in Tebas area would know if one of them has leprosy. But (here) usually people don't know if someone has PB-type leprosy. If it is the "wet" type of leprosy, then people would know.

Interviewer : Do you know precisely how many leprosy patients are in this Health Center?

HCW-Pas-B6 : Know precisely?

Interviewer : For this year?

HCW-Pas-B6 : The precise number that I have in my list is only 3 patients

Interviewer : Those who get their treatment here?

HCW-Pas-B6 : Yes.

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

HCW-Pas-B6 : Yes.

Interviewer ; Directly involved?

HCW-Pas-B6 : Yes, directly involvd

Interviewer : What is the perception of the health worker here about leprosy patients?

HCW-Pas-B6 : In general they know leprosy

Interviewer : What about their perception?

HCW-Pas-B6 : Their perception... they do still have the stigma. So some of them are afraid.

Interviewer : If there is an in-patient here who is a leprosy patient, would the health worker treat them differently compared to other patients?

HCW-Pas-B6 : Because we don't have isolation rom here, so we cannot treat leprosy patients. We used to have, just for reaction. We treated the patient for three days. We installed the patient at the treatment ward.

Interviewer : I explained to you earlier about PEP intervention. PEP is Post Exposure Profilaksis. What do you think about this intervention?

HCW-Pas-B6 : I think this is for early detection and medication

Interviewer : Yes.

HCW-Pas-B6 : Perhaps it is better like that, particularly for areas that are endemic

Interviewer : Thank you, Sir.

April/May 2017

<i>Male contact 1 – age: 40</i>	50
Notes:	50
Transcript	50
<i>Female contact – age:</i>	54
Notes:	54
Transcript:	54
<i>Female contact 3 – age: 60</i>	60
Notes	60
Transcript	61
<i>Female contact 4 – age: 70</i>	67
Notes	67
Transcript	68
<i>Male contact 5 – age: 37</i>	73
Notes:	73
Transcript	73
<i>Male contact – age: 74</i>	78
Notes:	78
Transcript	78

Ages:

Contact 1: 40 → [CC-Pas7-B7](#)

Contact 2: 45 → CC-Pas7-B8

Contact 3: 57 → CC-Pas7-B9

Contact 4: 70 → CC-Pas7-B10

Contact 5: 37 → CC-Pas7-B11

Contact 6: 74 → CC-Pas7-B12

Male contact 1 – age: 40 CC-Pas7-B7

Notes:

Symptoms started in the (kuiten), then the arms. He is the father of the index case. His son is diagnosed with leprosy 5 years ago.

He think it can be cured, but also have come-backs. After finding out about the symptoms they went straight to puskesmas. He is in treatment for 5 years but still has reactions.

The cause is black magic, someone charmed his child. They were immediately open about it and not shy, the son is 21.

Since 5 years the son is not working, before he worked in construction
Because of leprosy he cannot work anymore.

They don't experience discrimination. No worries about exclusion. Friends are accepting.

Marriage probably won't happen because ashamed.

When his son has reactions he will not go to religious events.

He thinks you should keep get medicine and seek treatment right a way. All parents want their child to be healthy and that is possible with treatment adherence

Transcript

Translator: [talks indonesian] paks [name participant]

T: we are talking with Mr [name participant] and he is 40 years old.

#00:00:22.58#[T+P Talk]#00:01:02.55#

T: it started with tremor, when I asked what is leprosy. He says: it is tremor or.. [health worker starts talking]

I: You asked the first question?

T: Yes

#00:01:34.29# [T+P Talk] [Health workers talks also] #00:02:22.32#

T: He don't know the cause of leprosy, he only knows that yes suddenly there became white spots all over the body. He still doesn't know what the cause of leprosy is.

I: Okay

#00:02:45.82# [T+P+Health worker Talk] #00:03:32.91#

T: there is a red patches and white patches. It is like what the health worker says. [points to red skin] and then the patches become swollen en usually after that the patient dropped on the floor. Patient cannot move, cannot do activities, become very ill, cannot start there day.

I: where did the skin patches start? [silence] legs/ or arms?

#00:04:02.44#[T+P Talk]#00:04:36.77# [health worker participant and translator all talk at the same time]

T: at the leg [points to chives], and the arms, and back.

I: What is the relation? How do he know the leprosy patient, is it family or?

T: the leprosy patient is his son [I: Son?] yes

#00:05:20.03#[T+P+Health worker Talk]#00:05:35.75#

T: yes leprosy can be cured and then maybe sometime it would come back, but yes it can be cured. [I: and how?] with medicine

I: when was the first time that they were seeking help? Did they go to Puskesmas first, or what did they do?

#00:05:57.27#[T+P Talk]#00:06:13.98#

T: Went to Puskesmas [I: straight?]

T: Yes go straight to Puskesmas.

[silence]

I: and how long ago was the diagnosis?

[T+P+Health worker Talk]

T: it is now 5 years ago, but his son still get reaction sometimes.

I: okay..

[T+P+Health worker Talk for like 1 minute]

T: some people say that it is black magic

I: as the cause?

T: yes black magic, it is like charms and curses

I: how is that for the family? Has it have big impact on their family?

[T+P talk]

T: they are not making a big deal out of what people say they just ...[T+P Talk]

T: because they themselves don't believe that leprosy comes from this, so they don't make a big deal of what people are saying.

[T+P talk] [Health worker asks things in between] T: do you want to interview 1 contact?

I: well we could do two

[T+ health worker talk]

#00:10:01.67# T: yeah but this is not the common view, just there is little part of little percentage of people that say leprosy is caused from black magic, but most people just think it is a common disease

[I: okay]

[T+P Talk]

I: what did you ask here? [silence]

I: Maybe you can ask? Would they hide their son has leprosy?

T: No..

[T+P talk]

T: no they are not hiding, and the son also don't feel ashamed.

I: how old is the son?

T: 21 now

I: what is he doing? Going to school or working?

[T+P+Health worker Talk]

T: since 5 years he is diagnosed with leprosy he is not working anymore. But before that he was a worker in construction or something like freelance worker.

I: because of leprosy he cannot work anymore?

[T asks P] T: Yes, that is why.

[T asks P question, Health worker talks to]

T: they community treat normally with their son, there is no discrimination or...

[P talks]

T: he has no worries for his son gonna be discriminated because he has a lot of friends that accept him

I: okay, and how, would they think he can work again in the future or marry someone, or something like that. How do they feel towards that, towards the future?

[T+P talk]

T: Yes, but for work he really wants that he can get working again. But marriage, there is still no.. he doesn't think not yet.

I: why?

[T asks P] T: because he still have reaction sometimes, maybe he would feel afraid of himself, so self-stigma. Worrying about himself

I: so worrying about himself, how he looks?

T: yes and maybe worrying about his wife cannot accept him or so.

I: so there is still little stigma, self-stigma?

T: yes with marriage.

I: how about with other cultural events or religious events?

[T asks P]

T: if there is no reaction, he will come, if he is like 'normal', but when he still in reaction, of course he cannot go?

I: why?

T: it is painful, and cannot stand up?

I: what would he advice to other families? Many families are afraid to seek health care... [T: because it looks ugly?] Well, what would he say about that?

[T+P+health care worker talk]

T: just keep get medicine, because a lot of parents want their child don't want to become their child to become healthy again. And that is only [I: possible with treatment?] yes yes.

[P+health worker talk]

T: is this okay? Can we stop?

I: can you ask him if he has questions for us?

[T+P+health worker talk]

[health worker asks about interviewer]

I: does he has questions for us?

T: no

[End interview]

Female contact – age: CC-Pas7-B8

Notes:

Points to legs and arms when talking about symptoms

2 months ago she recognised white spots at her neighbour's skin. They were not itchy but got bigger over time.

Neighbour can do anything still, and is not discriminated.

Another neighbour she knows with leprosy is discriminated because of disability. Shows picture while telling us, he is much worse.

Example male index case (Bapak Suki): there are 4 daughters in the community of index case.

- 10 years ago it started with skin patches and he didn't want to go to puskesmas

- 2 were already married and got divorce because of leprosy, which is not something that happens soon

- no one wants to take him to puskesmas now

- daughters have quite normal life now

[laughing while telling us] of course he is treated different because he is not normal, he is not human, afraid of him. The neighbour that is just diagnosed is normal still.

She believes he is an Islamic teacher and don't wanted to get modern medicine because it is fate from God. He leaves it to God.

cause is hereditary

Transcript:

I: so who is this?

T: this person is a neighbor

I: neighbor?

T: Yes neighbor

I: who is the leprosy patient?

T: is a female patient that is 25 years old.

I: okay..

I: when did she know her neighbor has leprosy?

[T+P talk]

T: it is about two. Months ago, and first it seems not too bad. Red spots on the skin [I: red spots?]

and it did not itch or anything, but it get more over time, it get spread.

I: they get bigger?

[T asks P]

T: Yes they get bigger

[T+P talk]

T: and in the back, and on her legs.

I: itchy?

T: no it not itch.

I: what is her reaction on leprosy?

[T+P talk]

T: She says that she is a kind of health worker, she is a volunteer. She gets used with people with leprosy. [I: she is a health worker?] not a health worker like 'cutter'? Like a community member that got the information an socialization already and now volunteering in her neighborhood. When she saw the white spots on her neighbor she was curious and asks to the daughter of the patient about it, and checking it. And straight go to Puskesmas to get treatment. [I: so she initiated that she gets treatment?] yes she initiated

I: and now is the patient on treatment?

[T asks P]

T: yes

I: and how is it going now with the patient? Improving the skin patches?

[T asks P]

T: yes it is getting improved with the salt, and to clean it.

I: because she is a volunteer in her neighborhood, what is the general opinion of her neighbors on leprosy and on the patient?

[T+P talk quite long for 3 minutes]

T: they call it 'daging elek' or 'gatal-gatal'. So it is interesting, I also found this in Sumenep, that for this Ibu, Ibu [name participant], she doesn't tell to the patient that the patient got leprosy. Because she don't want people to know, or the neighborhood to know, or question herself for feel like ashamed or feel like angry, or feel angry. She just feel like the people get usual excema that itches. Even though it is not even itchy, and then just ask for the patient to go to the Puskesmas, to get checked to get medicine. [I: And the patient does not know it is leprosy?] No, but now after medicine she will reveal it. You. Have got leprosy.

I: why would she do that?

T: it is more important they get treatment, then the label. With this bus, she told first that it is usual excema. But she don't want to go, because it is usual disease, no need to go to Puskesmas. So maybe if it is usual disease people don't think it is worth it to go to Puskesmas, but finally after the Ibu tell the truth, tell it is contagious or your family can get this disease to then the patient will come to Puskesmas.

I: so the previous question they tell a lot, what did she say? She said she would not tell her neighbor or patient first? Why, because of shame or?

T: Yes, because a lot of people think that this is a hereditary disease, and a shameful disease. So people that get leprosy can come a minority in society.

I: so she wants to stimulate that it is treatable, she would just seek help and then it will be okay, so that it will not be spread?

T: yes that's what she wants?

I: that is her aim?

[T asks P]

T: Yes

I: Okay and what do people think when they hear about leprosy? Because they think it is hereditary?

T: yes...

I: what else?

[T+P talk, T asks about the myths]

[silence]

I: what did she say?

T: wait.

[T+P talk]

I: she says people think it is from about breaking a vow? [I: a promise?] yes breaking a promise, in a marriage or like saying 'I'm not stealing' but actually you are so the promise, but you still breaking the promise.

I: so immoral conduct?

T: Yes, immoral conduct.

I: how do people treat her neighbor now? Do they treat her differently?

[T+P talk]

T: treat normally

[P talks]

T: normally because the patient is not in far stage. Does not have obvious reaction, it is just some small skin patches, it is not too visible. So they still act. Normally and treat her normally

I: but does the community know?

T: yes the community already know that she has leprosy

I: okay so she is treated also the same? She can still work or?

[T+P talk]

T: yes she can do normal activity, because still it is PP or MP, it still not too severe, not disabled to do activity.

I: is her family now also treated?

[P+T talk]

T: no not yet, it is next week.

I: what does Ibu [name participant] think, how does she.. what .. how to prevent leprosy in the future? Also with other neighbors?

[T asks P]

T: keep good hygiene, but also little bit avoid the patient. [during this the participant giggles] we usually talk like this [points to our normal distance of sitting]. But with leprosy patient, after I know you are patient, I can only talk with you like this [moves chair a little bit backwards] [participant is giggling/laughing]

I: why?

T: yes because it is contagious still, not too close.

I: how is it contagious? Or how?

[T asks P] T: it form spit form the mouth, [P talks] so you should give self-hygiene and neighborhood should also have good sanitation.

I: she feels that the neighbor, besides keeping hygiene, the neighbor can do anything? Religious events? Having children, marriage? Work? Is she still able to do anything? Or should she stay inside?

T: the patient?

I: Yes according to her opinion, can the patient still do anything he or she wants?

T: Ooh okay, yes yes..

[T asks P]

T: well this person is already married, and now she is pregnant. So yes she is having children. [T+P talk].

T: desa balonganjar is the endemic village with leprosy.

[T+P talk]

T: there was also another neighbor, and he is much worse an she got stigma. He was discriminated, because yes.. you know.. visible disability. And visible reaction.

I: and what? Can she tell us some examples where the discrimination shows?

[T asks P]

T: this Bapak has four daughters, two of them were married, two of them not. And the two married daughter are divorce by their husband because they got leprosy. [I: because the father has leprosy?] No, because they were also infected, and when the husband found out, they would leave the women.

I: and how is that in daily life?

T: when Ibu [name participant] wants to take them to Puskesmas, there was no one that want to take them with motorcycle or car, because yes, there is a chance that it is contagious?

I: what else? Is that all she said?

T: yes?

I: how does she personally feel towards her female neighbor and to the Bapak?

T: different treatment or what?

I: aya, how she herself feels towards them. If it is different?

[T asks P] [Health worker and P laugh]

I: what do they say?

T: she would treat them totally different. Because the neighbor just normal, and the other one is mostly not human. He is not human, because she is afraid of contagious, [I: afraid of him?] yes she is afraid of him.

[T asks P something]

T: But the person that live in the same household she would treat normally. So the 4 daughter, they would be treated same, they would get a normal life. Get work and socialize normally.

I: how does she think that the Bapak got leprosy? What is the cause for his leprosy?

[T asks P]

T: first it started more than 10 years ago. The Bapak don't want to go to Puskesmas? Then it became worse.. and then ya... [P says something] He, the Bapak was islamic teacher [I: oh okay!] he was like religious teacher in islam, he just don't want to get modern medicine, he just want to surrender it God, to Allah. So he don't want to get modern medicine. And then a few days ago, the health worker received a threat from the Bapak, if I take your medicine and I die, I will get you in the after world, in after life. Something like that..

I: and what do they think how it is also caused? Does he think it's from he Gods?

[T asks P]

T: she still thinks it is hereditary. The health care volunteer thinks this is hereditary [she laughs]

I: and therefore they divorced the daughters right?

[Health worker + P + T talk]

T: they think the cause for the Bapak, they suspect he have black magic and then he got promise, vow, from a [unknown word].. like religious chief. So the chief of islamic boarding school, promised to him. No I don't do black magic. But after the promise he got leprosy. So they think that the Bapak actually performs black magic: they call it Santek, this is black magic. Magic to harm other people. [I: so he is punished?] yes because he is breaking his promise.

I: okay.. [silence] Can you ask her if I can make a picture with her?

T: Yes you can, she would like that

[T+P talk]

T: she has to go now..

I: okay

[End interview]

Female contact 3 – age: 60 CC-Pas7-B9

Notes

She is the wife of the index case. Already quite old - already retired. First her husband had stroke symptoms. Then followed by itchiness and red skin all over the body. Become uncontrollable.

Now in treatment and gets better, sometimes it comes back. He drinks jamu —> gave hardly any effect.

So in January 2017 was diagnosed with leprosy and since this month receives treatment. It is now reducing but still itchy.

“What else can we do?” It is God's fate and they should receive it and try to get medicine.

She thinks that there is a difference in cause when talking about *lepra* or *musta*. *Lepra* is with deformities and worse symptoms. *Kusta* is only the itchiness. Cause is from fatty food like meat.

Itchy and stroke symptoms is part of it.

Neighbourhood doesn't ask about it, And we don't tell. Because it is just *kusta*.

They feel it is not *lepra*, fear leprosy and think it is contagious. Neighbourhood does and so does this *ibu*. Wouldn't want to know if someone has leprosy.

Lepra patients get different treatment. They are excluded. When people are not sick enough to go to the hospital, it is still okay. But when condition gets worse and you need treatment people would exclude *lepra* patient.

When there is a gathering in *desa* *lepra* patient is invited, however someone other from the family would come instead of the *lepra* patient. *Lepra* patients don't want to join. Family members are not excluded.

Her husband has *kusta* and not *lepra* so it is not that bad and maybe that is why their family is not experiencing any exclusion. *Kusta* is accepted

If you don't get routinely treatment it can become worse and can become *lepra*.

A person with leprosy is different, they fear that it is contagious and the person itself is just 'different'

Doesn't fear condition of her husband. She trust the medicine and that it prevents from getting worse.

Transcript

[many family members are gathered in the living room, also a health worker is present, and a researcher from the research team (T2) which helps to translate/explain. Translator (T1) tries to translate in the meanwhile which is sometimes hard to hear. Overall it is a very crowded setting]

I: can she tell me a little bit about herself and her family?

T1: She doesn't know her age.. So she is now getting her ID-card. [name participant]. is the name.

[rumour]

T2: she thinks she is 60 years old

[researcher and translator and participant talk]

[index case is also present, walks in]

I: [understands some Indonesian words] She is a seller of daily needs, and?

T2: yes

[silence]

I: what is leprosy, can she tell me about the disease leprosy?

[T +P talk, T translates in the meanwhile]

T1: First she saw stroke symptoms, and then that heal.. or get better. And then it got to itchy and reddish over the skin.

I: and what did they do when they found out about it?

[T2 asks P]

T1: Okay they try to go to Puskesmas but, itch is not like.. it still itch, it is not getting better..

I: okay and then?

[T1 asks P]

T2: Get better for a while. And then it come back. They also drink '*jamu*' [T1 and T2 discuss] but it did not gave any effect.

I: did they already know it was leprosy then?

[T1+T2+P talk] [P cannot hear so well, so sometimes they have to ask twice] [People walk in and out]

T1: Yes they know, even though the Ibu. [T1 and P talk]

I: can you ask it one more time?

[many people talk, including health working]

T1: the first diagnosis was in January [I: last January?] yes. And after that the Bapak didn't take the medicine. So he started again this month.

I: with the treatment?

T1: yes

I: and how is it going now?

[T1+P+index case talk]

T1: there is still itchiness but it is reduced it is better than the follow... previous month.

I: how did she feel when she found out her husband had leprosy?

[T1 asks P, T2 repeats question]

T1: It is just like, 'what else can we do?' They think it is a fate. It is God fate. So they if they want it or not, they just have to receive it and try to seek medicine.

I: what does she thinks is the cause?

[T1 asks P]

T1: they think there is a difference between 'kusta' and 'lepra'. Kusta is like the worse one, with deformities. And kusta is like the itch and reddish skin and skin patches. They think 'lepra' is the worst symptom.

I: so they know that is like the worst symptom but they see it as the same disease?

T1: no it is a different disease.

I: and what do they think is the cause?

[T2 and T1 discuss, in the meanwhile of previous translation T2 already tried to ask it so he knows the answer now]

T1: So the index case think it is from food, from eating fatty food, like mie, or meat.

[T2 laughs]

I: And does the community and neighbors know about that he has leprosy?

[T1+T2+P]

T1: No they just know it is itchiness and stroke symptoms.

I: So they don't want to tell it?

T2: what?

I: They want to keep it that way, they don't want to tell it?

T1: oh okay wait

[T1 asks P]

T1: the neighbor don't ask about it, so the Ibu will not tell it anyway. They just say itchiness.

I: and how does the community look, have views towards lepra?

[T1 ask P] [T1 and T2 discuss]

T1: The community here is like afraid if there is someone with leprosy, they think it is contagious.

I: and how does she feel about it personally? How does she see it herself?

T1: what, you mean like?

I: yes like with this view. How does she feel about that?

[T1 asks P]

T1: she feels the same.

I: same?

T1: yes

I: would she like to know if someone has leprosy or not?

[T1+P talk]

T1: It is better they know

I: are people with leprosy treated differently?

[T1+T2+P talk]

T1: yes it's treated differently, they exclude because it is contagious.

I: and at what events do you see it is different?

[silence]

I: how are they excluded?

[T1 asks P, T2 helps say it louder, takes a while]

T1: So it also happens for other disease. If the people get sick enough so they go to the hospital, then they do it. But if they are sick, but not too worse, they will not come to the hospital, then it is okay.

I: So then the exclusion is less? [T1: yes] If it is not too bad? [T1: yes] Okay but how are they excluded, can she give me an example of how?

[T1+T2+P talk, laugh a few time]

T1: The example is maybe when there is someone holding a gathering in the house, the patient's family will still be invited, but surely not the patient himself, but a member of the family. So maybe the son is then invited.

I: why is that?

T1: because they knowing it is contagious so they don't want to.. they are afraid maybe himself can be contagious to us.

I: is invitatie from the patient? Or from the?

T1: yes from the patient, they still invite it, by the community. But the one who come is often the son.

I: and the family treated different? Family of the patient?

[T1+T2+P talk]

T1: There is still.. they just don't exclude the family. [silence]

I: that's it?

T1: but maybe when her husband get worse symptoms, maybe it changes.

I: they say there is difference between kusta and lepra, is there also difference in treatment?

[T1 ask P]

T1: it is treated different. Lepra is total exclude. [P talks]

I: is there also a different cause of the two?

[T1 + P talk]

T1: When kusta is not get treatment, then it.. [P talks] when it is not get treatment continually it will get worse.

I: so kusta becomes lepra? [T1: yes]

[silence]

I: what is the general attitude towards a person having kusta or lepra?

[T1+T2+P+health worker talk]

T1: it is treated differently, they think it is different in society. Because they are afraid of contagious.

I: And now we are talking about lepra?

T2: Yes

I: So the person with lepra is seen different?

T2: Yes

I: is she afraid that the Bapak also may develop leprosy? Or she just mentions it?

[T1+P talk]

T1: is not afraid, because of the medicine?

I: does she think it can be cured?

T1: yes

I: uhm, does she know other patients with lepra?

T1: yes seeing them on the market, not personally

I: how does she feel about them?

T1: she is afraid

I: afraid?

T1: yes

I: uhm? Yes, I think I know some.. Do you know anything interesting from the things she mentioned I can ask?

[T1 starts talking] [T1 + T2 discuss]

I: can you maybe asks if there are any myths are present in the community?

[T2 asks P]

T2: There is no myth here, just hereditary

I: but he has early treatment, so not so much to ask?

T2: yes life is not so different for them

[End interview]

Female contact 4 – age: 70 CC-Pas7-B10

Notes

Ibu of this household got leprosy and was treated. Now her son and daughter got leprosy too (skin patches). She only has stiffness in the fingers. Leprosy patient is 29 and interview is with her mother (70). Leprosy patient herself is also joining the interview and so is her brother-in-law.

She didn't know about leprosy at first. But what happened to her daughter is that skin patches arises. Then it was itchy and then it seemed like excema. She doesn't know the cause.

What she does know is that the husband of her daughter (the index case) comes from a high-endemic family. So in his family many people affected by leprosy and in his desa he's from. (desa balong-nguling).

Symptoms stayed for three months they went to puskesmas.

Myth- there is the belief that leprosy is sent by bad people through witchcraft and then medicine would not work. You have to go to the shaman for a ritual. - 'brother in law' of interviewee

Ibu doesn't believe in the ritual, because she saw her daughter be cured with medicine. But also going to puskesmas was free and going to shaman costs money. So their reason then was that they could not afford shaman. Now they don't believe it works that way..

Fear in the community exists that it is contagious. and would keep distance while her daughter was in treatment.

But then after treatment skin patches reduces. Now her children are treated in early stage and don't experience exclusion at all at school. Still play with other children. Son started treatment in January and daughter in april and both improving now. They hardly have any visible symptoms.

Neighbours knew about the situation, but still come to their house. And in community gatherings food meetings they are still invited. Her daughter is still working (collecting waste) When she was in treatment the community acted differently. They were disgusted with it.

But now her daughter is living proof it can be healed. So now no longer would take distance. Community feels empathy at first. Some are okay with it and some people are discriminative. But now she is cured her neighbours treat her normal

During treatment she noticed exclusion because she feels that in a small crowd people keep distance, talk about her and back off naturally with her appearance. Wouldn't make contact.

Nowadays: when she gives food as family the community would not accept it. but she is sure future of children is okay and healthy.

She knows that many patient hide - because they are ashamed with themselves. And are ashamed when people know. Daughter also felt ashamed.

Biggest cause for this shame according to daughter is that people ask difficult questions about the disease. It is seen as a 'bad disease' Because it may be contagious and family can get it.

Treatment is important and can heal patients if it happens routinely and continually.

Transcript

[the interview was held in the household of three leprosy patients, a mother (M) with a son (S) and daughter (D). We interviewed the grandmother (P), who was also living there. Although, many answers were given similarly when the Participant and M, de index case talked. It was sometimes difficult to distinguish who gave the answer exactly. M that was first infected, but treated, is now considered ex-index case. M is also there and talks along while giving the answers. The story line of this interview is so to say from two perspectives: contact and index case.

There was one interviewer (I) and one translator (T1) and another researcher from the research team (T2) that helped making notes and translation. Also a health worker was present.

During the interview the recording gave an error so it couldn't record everything. Straight after the interview the translators and interviewer talked about the answers given, discussed field notes and try to replicate some of the answers and field notes from I and T2 were taken into account closely. The data of this interview should be used carefully and with consideration of potential researcher bias]

T: First the Ibu in this house was infected, and then his daughter and two of her daughter are also infected now and one son as well.

I: How long ago was that? Since when?

T: the Ibu has already done the treatment a few years ago but the son and daughter are now still in treatment.

I: T2, Can you also write along? Since you're here? So I can look at it later

T2: Okay yes, hahaha

I: who are we interviewing now, the sir or the mother?

[health worker and ex index case talk]

T1: wait..

T1: Ibu [name participant] [a lot of laughter]

I: what is going on?

T1: They don't know their age, so they are looking for their ID.

T2: Many people in here don't know their age.

I: Haha okay

[in the back a child is crying]

T2: still cry, haha

[stopped]

I: okay this is simulation of the recording because it failed during the interview.

I: we were at the house of. Ibu [name index case]. And Ibu [name participant]?

T1: yes

I: Ibu [name index case] was affected by leprosy but already treated, but ibu [name participant] is her mother and she was the one we interviewed, but also her grandchildren, her son and daughter?

T1: Her son and daughter were now also infected by leprosy.

I: name of the son is? [T2/T1: Farku] and Manis is the daughter [T1/T2: yes]

I: many people in the community belief, according to the brother in law, that leprosy was send by bad people through which craft and black magic [T1/T2: yes] and don't belief in medical treatment but you have to go to the Sha'man for a ritual to be cured, [T1/T2: yes] however, this Ibu went to the?

T1: this Ibu went to the Puskesmas because the reason is first, because Puskesmas is free [T2: yes free, it's free] when you go to seek the treatment by Puskesmas, but you should pay to the Sha'man [T2: yes]

I: the symptoms?

T1: the symptoms of the Ibu is uhh [I: stiffness in fingers?] first of all she feels cold, and then heat. High temperature. [I: feverish?] until like everyone is like getting that symptom. They say that everyone that has high temperature, forgetting all the people around him.. [I: so hallucinations] [T2: yes hallucinations] hallucinations, yes, [I: so really high fever] After then they get white skin patches and little itchy and the hands become stiff [T2: yes] and so on.

I: and after three months in didn't get away?

T1: yes so she decided to go to the Puskesmas.

I: She doesn't know lepra or leprosy, but she knows kusta?

T2: yes kusta, or deging elek.

T1: bad flesh

I: she does not believe it is hereditary?

T1: she says she does not believe it, but then the brother-in-law says that the problem is that when Ibu [name index case] married her husband. And her husband all of the family is affected by leprosy, and they think that is how they got infected now.

I: So although she herself does not believe it is hereditary, there still a suggesting thought. Because she married her husband from which many family members have leprosy, she got it to?

T1: yes

T2: yes

I: uhh and her husband comes from Balong,

T2: Balong is from Nguling and lot of people there are infected by leprosy. There is a myth [T2: yes yes] that even though the balong president selling chicken then no one will buy it. Living chicken.

I: So the baling people are refused? Because they have leprosy?

T1: yes

T2: yes

T1: and then the Ibu [name participant] say that there is no clearly excluded in this community, but Ibu [name index case] was still in treatment and in disease, just.. there is this, there are, there is just Ibu [name index case] that got excluded, but not the other family members. Because the other family members still have a good relationship with the community. Just when Ibu [name index case] is close, they just keep a distance?

I: you said that she felt it when walking in a crowd, she felt that people would back up?

T1: yes people would back up, but not now, now when she is treated, now people of the community treat Ibu [name index case] as normal people because they know she is already cured. [T2: cured]

I: and during treatment she felt exclusion and because there was fear in the community?

T1: yes, during treatment. There is fear of community, but she feels ashamed when people ask about her and her disease and asking [T2: yes yes] 'why do you come here when you got this disease?' Like that

I: she felt ashamed?

T1: Yes she felt ashamed.

I: And now she is no longer ashamed?

T1: Yes [T2: yes] now no longer, because all the neighbor know about the disease they know. And know: when she was cured there was no more shame and no more exclusion. So no more shame and no more exclusion.

I: uh uh, and the common view of the community?

T1: of the community, afraid of contagious disease. Yes, keep a real distance, but still keep in mind the feeling of the patient as well. So, when there is gathering, the patient will still be invited but maybe she is not come because she is afraid of herself.

I: and is it now different? Now she is cured?

T1: no it is healed, but she will don't want, like if it is helping with the food, she still don't want. But like usual gathering she will come

I: My notes say, if there is a wedding, and they prepare food, she will not come, although she is invited?

T1: yes still invited, yes not come

I: Do people visit their house?

T1: Yes, normally they do.

T2: since.. sin. [says something in Indonesian]

T1: so at first when she got the disease and get reaction and high fever, the neighborhood is come to see her too as usual. But the people still come to her house.

I: she also still works?

T1: yes [T2: yes]she is collecting waste in siduarjo

I: When she was still in treatment people felt as a disgust, also, but now no longer after she was healed. [T1: yes that was what she said] And also my notes say, community's view: some feel empathy, some are okay, some excluded

T1: yes some feel empathy so they come to her house to bring food or just see how her progress was. And some people just say; they don't and say it is just okay. Just okay. And some ibu's say I don't want to come to close.

I: and what if they give food as a family? Will people accept it?

T1: when Ibu [name index case] was still in disease they don't accept the food, but now they would want it.

I: she is sure about the future of her child?

T1: yes she is sure about the future of her grandchild, because her daughter can be cured, so she believe that her children can be cured as well.

I: and what did she say about the patient that do hide? Their family is not hiding? What did she say about those patients?

My note says: they feel ashamed of themselves, because they have leprosy?

T2: yes yes she feeling ...

T1: yes, she feels ashamed with herself because her family got that disease.

I: So the stigma is?

T1: so the stigma is people with leprosy is different [T2: yes] and it is contagious, so they treat different and we exclude it with the community, so yeah it is disgusting.

I: and also, leprosy is a bad disease?

T1: Yes she said leprosy is a bad disease, [T1: yes disease] because it can be contagious and it affects the family, [T1: yes family can be infected

I: and then what she said in the end? I wrote down: treatment is important, it can heal me if routinely and continually repeated. [T2: yes] [T1: yes she feels that]

I: anything else? Oh yes, the children are not treated differently? As far as she knows? Not exclude in playing and also not in school?

T1: the children are not treat different in school, all, most of the friend know the status but yeah they play normally, there is no exclusion. But the grandson go to friends house, and it is okay, there is no rejection from the parents.

I: symptoms are hardly visible right?

T1: yes they don't see

I: Grandson started treatment in January and the granddaughter in April. [T1/T2: yes]

I: and the neighbors?

T2: yes they know

T1: the neighbors, all the neighbors know.

I: why she didn't hide it?

T1: because from the very first time, the neighbor already know that Ibu [name index case] is infected [T2: yes] and all the neighbors, close friends, feeling empathy they go to her house and see the progress, and see how its.. and see the condition. From then, Ibu [name index case] feels like she is being cared for by her neighbors, so become open en just tell the neighborhood and also tell that she gets treatment and now it is already better, it already cured.

I: What did the mother say?

T1: neighbourhood does not know much about the disease, even though her daughter get the disease, she doesn't know either. But the people around her in the neighborhood is not exclude all the members of family, just Ibu [name index case] in treatment.

I: what was the cause?

T1: she didn't know, when we talk about the cause, and then the myth with leprosy: she doesn't live with black magic. But the brother in law say that they say that because there is Ibu there, so they don't want.. they feel hesitate to discuss about the myth.

I: because?

T1: because there was someone there from the Puskesmas. So they didn't really answer. So maybe it is the brother-in-law's opinion. We are not sure.

T2: yes they stopped talking.

[End interview]

Male contact 5 – age: 37 CC-Pas7-B11

Notes:

This is the son of the index case. He is a food seller (37).

His father started to get wounds at his nails and the wounds would spread over the feet and get worse. In 2005 he would just take care of it as it were usual wounds. But it didn't improve So he go to puskesmas and then got diagnose with leprosy.

Normal wounds happen so often because sometimes you neglect them, you work hard and have not so high economic status he says.

Thought it was usual wounds but after treatment they finally improved. He doesn't believe it is contagious because he experienced it himself. He touched infectious wounds even. but nothing happened.

He doesn't know about symptoms from other patients but know more people with leprosy.

There is this myth about overdosis. If you have an overdosis of pills that they use for gaining weight. You can get leprosy.

Also there is this belief of black magic: He doesn't believe it himself because his father became better after treatment. So, there nothing 'supernatural' about it.

They treat his father normal, no exclusion. Still invited to ceremony event but only when the wounds are clean. This is a requirement form hygiene perspective. Sometimes there is gossip because it smells not good. And then they fear its contagious they can get the smell too.

People think little less of the person because it has leprosy. This happens also with other diseases like diabetes. Disease with wounds in general cause this verbal stigma. People consider you less because you are not healthy.

cure is important, and be hygiene. But it is a lifestyle to live healthy and then it will be okay. He himself does not experience any different treatment.

Transcript

I: can you ask him his name, what he does and how old he is?

[T+P talk]

T: this is [Name] and he is a mersyon?

I: mersyon?

T: like a food seller

I: and how old is he?

T: 37

I: what is the relationship between the index case.

T: It is his son.

I: can you ask me about leprosy, what it is and how you can get it?

[T+P talk]

I: First, his father is like, gets wounds from the nails on and then after that the wounds are get wider and get like.. [I: spread] yes like spread over the hand.

[P says something]

T: it happens on 2005

I: and what, how long did it take for them to find help?

[T+P talk]

T: first they carried out like it is an usual wound, treatment of infection. Because it for several times didn't get healed or get better. They seek the help of the local health care worker, and from there they get diagnosed that it is leprosy.

I: did they get medical treatment, or other?

T: yes they went straight to medical help, but treat it first as usual wounds, not thinking about leprosy first.

I: and then his father got treatment, or what happened next?

[T+P talk]

T: Yes they get treatment

I: okay and how... [P adds something]

T: they send the father to go to leprosy hospital in Mojokerto

I: and did it improve?

T: yes it improved after that

I: Okay... does he think leprosy is contagious?

[T+P talk]

T: No he think it is not contagious because he lives in the same house..

I: and what is according to him the cause?

T: it is because of the infection of wounds, they think that is the cause.

[P talks]

T: because they come from the lower economic level, so the wounds can get neglected and he didn't care about that. So after that it get spread over the body.

I: So, at first it was just regular wounds and ..

T: yes normal wounds, so he wouldn't get special treatment and so on

I: does he know more leprosy patients?

[T+P talk]

T: yes he know a few more

I: did it start in the same way?

[T+P talk]

T: he doesn't know the cause, but it is different, it didn't come from the wounds.

I: did he know about leprosy before his father got it?

[T+P talk]

T: No he doesn't know about leprosy, but after his father get infected he just know it from the healthcare worker.

I: okay, can he tell me about the views in your community of leprosy?

[T+P talk]

T: It is like the cause, it is the cause. Overdosis of certain medicine. There is a pill for getting fat. [I: diet pills?] no pills for gain weight, not loose it. Some people think that the cause is also from the overdose of that pill.

I: okay

[T asks P something again]

T: The other people belief that it is from black magic, too

I: does he belief that too?

[T+P talk]

T: no he doesn't, because he don't believe it.. because he has prove that his father get treatment and it is healed, so it is not because of the other super natural.

I: is that view that he has the general view in this community or his neighbors?

[T+P talk]

T: not so much, there are still people that have supernatural disease.

I: okay, not so much? [T: yes] Euhm, what does the community think about the person having leprosy?

[T+P talk]

T: There is no exclusion here, it is normal...

[T+P talk]

T: It is still invited to the ceremony's even. But he said: the wound should be clean first before they go out.. just for [I: hygiene?] yes hygiene.

I: we are now talking about treatment, but the person itself, how do people see that person?

[silence, T doesn't understand question] Like we now talking about that the person is not treated differently, not excluded, still invited. But how about uhh, what do people think about people having leprosy? Is there gossip, do they see the person itself as less or?

T: oh yah

[T+P talk]

T: there are some people that are gossiping, and think less about persons with leprosy

I: how, why does that happen?

[P answers]

T: he said maybe it is from the smells

I: how does it smell?

[p talks]

T: he says it does not smell good

I: and only because of smell or?

[T+P talk]

T: they are also afraid that it is contagious, or infectious

[P says something]

[wife of participant comes in and brings tea]

I: is this also how they would treat other diseases, or is it specifically for this disease?

[T+P talk]

T: yes it also happened on the other disease, like diabetes, disease that have wounds on the skin or different appearance.

I: okay yes, is there a difference in how his family was regarded, after the father was diagnosed with leprosy?

T: how the community treat their family?

I: yes?

[T+P talk]

T: There is no different, it is just normal for the family members.

I: okay... anything else he would like to share with his experience with leprosy?

[T+P talk, health worker also, takes a while]

[wife of participant is saying something] I: what is she saying?

T: she wants her father in law, like.. cure..

I: she wants the father in law to be cured?

T: yes

I: do they think that is possible? I just want to be sure?

[T asks wife of P, P responds himself]

T: yes it can be cured but it should be balanced with a good diet, but not only infect, but also diabetes can.. can .. euehm, diabetes can also be attacked when keep diet [I: healthy live style?]

I: anything else?

T: no

End interview

Male contact – age: 74 CC-Pas7-B12

Notes:

He is the father of an index case (74). This index case is very known in his desa. Everyone knows him and knows he has leprosy. From interview with community member we found out this index case does not hide.

Started with infections in the fingers. But interviewee (father index case) says it is an allergy. Like normal allergy. his hands got wounds.

But he has lost fingers, but that is because of an accident with a chain. Not because of infection or anything. He does not have leprosy. If it would be leprosy it would heal his heart and he would be angry.

Father of index case tells us it is a rumour his son has leprosy. It is just an allergy after eating fish. Leprosy patients are excluded, and his son is not. his son has friends and can still work.

Leprosy patient have rotten skin and skin between thumb and index finger is gone. His son doesn't have that. It's just allergy. He can still eat with people. so that is proof he has no leprosy..

Skin allergy with swollen and small spots after eating seafood. Smell of kust is also different. It is the smell of blood. And neighbour would not get too close. So his son doesn't have it.

The rumour started because the health worker diagnosed him wrongly with leprosy. He started treatment but then he stopped so it didn't work.

[asked health worker from puskesmas, and he told us that this index case was not adapting well to the treatment and then refused further treatment]

Leprosy is a bad thing and for and people. Deformities and disgusting. But the early symptoms are okay.

You can get it from stepping on leprosy patient graveyard. Also on the graveyard the grass will not grow, because the soil is too 'hot'.

This does not happen to his son. Because he is still a social person. People with leprosy would stay inside and community would keep distance. They would not visit the patient because they are afraid. Shaking a hand is already disgusting. Everywhere where the leprosy patient would sit, if he walks away community would mop the floor.

He shows the medicine his son is taking, it is just medicine against itchiness. Symptoms did not improve with puskesmas treatment.

If the neighbourhood talk about his son like it is leprosy it 'hurt his heart'. He is offended and is angry. Having a social life as a lepre is hard. but my son has many friends. The issue is just a rumour and gossip and negative thinking. But only Allah can judge.

He beliefs lepra can be healed but the medicine didn't work with his son, so it is not leprosy. If it would be real, it would've worked. And also with leprosy you can see it. and my son looks great.

Transcript

[This interview was very chaotic. There were again one interviewer (I) and translator (T1), also an additional person from the research team joined and was taking field notes (T2). This person was the

father of the index case (P) and was very old. He couldn't hear very well, so T2 helped by sitting close to his ears to repeat questions. As a result P, T2, and T1 talk at the same time a lot, which made it very hard for the interviewer to follow the conversation, right after the interview follow up questions to T1 and T2 were asked to clarify the story of P at the basis of the field notes]

T2: [Name participant]

I: and his age?

T2: 74

[T2 + P Talk while T1 translates] T1: he went to junior high school, he is already on pension

I: can he tell me something about leprosy?

[T2 + T1 try to talk to P]

[while T2 and P talk] T1: he said like.. first of all, the hand of his son is getting wounded by like a.. like.. catrol and chain. Like an infection then started.... And it's, wait wait.

[P tells something]

T1: so this sir doesn't believe that his son get infected with leprosy, [P starts talking again] so when his son gets diagnosed with leprosy he gets angry. And then he is sure that his son get an allergic reaction, is this okay? Can we continue?

I: Yes but I would like to know what he is telling

T1: okay he doesn't believe it, because all of his ancestor never get a leprosy story, no one has leprosy. so he doesn't believe it.

I: what words did he use to express his anger? What did he say literally?

T1: He says, it makes me angry.

I: started with fingers and then?

T1: yes then he get allergy to a fish.

[P starts telling and talking with T1 and T2]

T1: sometimes it is swollen and sometimes it is not, because it's not treated.

I: not treated?

[T1 + T2 + P talk]

T1: he did not get the test with leprosy test, just a seeing test, visual test. So..

[T1 confirms something with P, T2 tries to explain something]

T1: it was ever .. [P starts raising voice] his son sometimes started with treatment, because they think it was not getting better so they stopped the treatment. So it was not really showing a better result.

[P is continuing talking and T1 and T2 engage in conversation again]

T1: leprosy is hereditary,

[T1 + T2 + P talk]

T1: so the leprosy start with itchiness, and scratch, becomes wounds so it get worse.

I: that is leprosy, and not what is son has?

T1: yes that is what he says

[T2 + P talk]

I: what has the son then?

T2/T1: allergy

I: and how did it come?

[T2 + T1 discuss]

I: what?

T2: skin ... allergy

T1: he has an skin allergy from eating seafood, certain fish... [P adds something] it is like small swollen.. infection.

[P keeps talking]

T1: so it starts with skin infection

I: what does he feel about leprosy then, his son does not have it, but how does he feel?

[T1 + T2 + P talk]

T1: it is different, it is not good, it is something different. And the neighbor.. they don't want to get too close, and it is like blood on the skin..

[T1 + T2 + P talk]

T1: so over there there is someone with leprosy, it is like 300 meter from here, and then [P talks during with T2] and there it is like hereditary, but not like all of the family members get it, but maybe only 5 of her children only 1 is infected with leprosy.

[T2+P talk]

T1: It is hereditary it is not a curse...

[T1 + T2 + P talk]

I: is it a bad thing to have leprosy? A bad thing?

[T1 asks question, T2 repeats question, P answers]

T2: oh sometimes..

[T1 asks P something]

[T1 + T2 + P talk]

T1: it is disgusting, they have deformities, and like is disgusting. But it is just like early symptoms it is not.

[T2 + P talk] [T1 + T2 + P talk]

T1: also there is a myth that the graveyard of leprosy patient, the grass will not grow because the soil is too hot. And there is no people that want to come to the people with leprosy but not with his son,

because his son have good socialization with his friends. So he think that his son if.. if his son is really infected by leprosy his friend is not, will not want to get close with him.

[T1 + T2 + P talk]

T1: people who have leprosy are like ashamed with himself, [T2: and deformities] and also other people in the community, the community will keep distance.

[P talks with T2] [P takes some pills out of the drawer]

T1: and there is like a solution for the itchininess patients, medicine..

[T1 + T2 + P talk]

T1: so his son takes medicine for the itchininess of allergy, just regular medicine.

[P talks]

T2: anything, anything?

[P talks]

I: his son was in treatment, was diagnosed and then no longer? What happened? Or I don't?

T1: well eeuh it is not tested, just like visible symptoms, then the health care worker say it is leprosy, but it if he ever got treatment it only was after.. [I: symptoms didn't change?] yes they think it is not leprosy they stopped treatment and go straight to Puskesmas when it begins to become itchy, and the Puskesmas just give the powder and salve to put on the skin to cure... the skin.

[T1 + T2 discuss]

T1: and then?

I: and people in the community will be treated differently?

T1: yes it will get exclusion

[P starts talking again]

I: would he have someone with leprosy have him visit.

T1: no he wouldn't, the problem..

[P talks] [T1 and T2 ask a question again]

T1: he is afraid, afraid

I: why?

[P talks]

T1: afraid when someone want to shake a hand it is disgusting

I: Does his son have leprosy or not?

T1: no the health worker said so

[P in the meanwhile talks with T2]

I: you asked?

T1: yes, and then he said he did not get the treatment well, he stopped.

I: okay?

[T2 and T1 discuss]

T1: So, if there is a leprosy patient that sit outside, like just gathering around, after that the community will like clean the floor with water. [P talks]

[T1 + T2 + P talk]

T1: if the neighbour think that his son is get leprosy, it will hurt his heart.

[P talks]

I: you just have to tell me more later, it is interesting but it is going so fast

T1: yes will do that

[P tells some more]

T1: he now says if it is really leprosy then it would be hard for his son to socialize. But my son have a lot of friends...[P talks] there is an issue with the health worker when he spread to the community a negative thinking. The only one that can judge is allah in this case.

I: so there is a rumor that his son has leprosy?

T1: yes he thinks so, it is just a rumor.

I: he is happy his son has no leprosy?

[T2 asks question, P answers, while T1 translates]

T1: yes he is happy, if he really gets leprosy he is willing to get the medicine wherever it is. [I:but it is not?] but it's not

[P talks]

T1: if we live now, leprosy can be healed. Already there is medicine.

[T1 + T2 + P talk]

T1: there is no other information, is there enough?

I: in a few minutes you have to tell me some more again, because I missed half of the conversation.

Because T2 was just talking with him.

[P talks]

I: what is he saying?

T1: but if it is like real leprosy whether it is from a little bit far distance, it can already be seen, and you can see it obviously.

[T1 + T2 discuss]

[pause in recording]

I: can you tell me again what the sir said

T2: in English?

I: yes try, just everything you know. He started telling about his son.

T2: yes.. [talks indonesian]

T1: the Bapak says that his son doesn't have leprosy, he thinks that it is just some allergy from seafood [T2: yes allergy yes]

I: and his fingers?

[T2 talks indonesian]

T1: his fingers is like [T2: his fingers is not like, like this]

I: so the flesh between his thumb and index finger is still present but his finger tops are missing?

T1: yes his fingers are missing because of an accident with a chain [T2: yes [speaks indonesian]] yes with a chain.

[T2 starts telling in Indonesian]

T1: He feels happy because his son still has friends, and can gather with his friends. And the community [T2: yes the community is still..] still like receive him, accept him.

[T2 talks indonesian]

T1: but with the real leprosy.

T2: yes with real leprosy.. [speaks indonesian]

T1: and usually they are being excluded from community..

[T2 talks indonesian]

T1: and the place that they sit down is being cleaned with warm water, with real leprosy patient, but it is not happening with his son.

I: and why is it not real leprosy?

T1: because in his family there is no leprosy story [T2: yes yes]

I: and what do they think about leprosy?

T1: he thinks leprosy is a bad think and someone who caught leprosy, who is infected by leprosy will be excluded [T2: yes] and they have a different smell, smell is not good [T2: yes] and it will make people feel disgust, and then like the wounds the deformities [T2: yes wounds..], it make people disgusted and make distinct with the community. [T2 says something in indonesian] but with his son it is not like that.

I: how does it come that people think he has leprosy according to him?

T1: it is like the wounds, the deformities and the itchiness and the different flesh and different skin and like the swollen and reddish face and chicken pox like all over your body.

I: how.. but he said his son affected by leprosy is a rumor? How?

T1: yes because the health worker come to see his son and without a blood test the health worker diagnosed that his son is infected with leprosy. And then he think it is rumor because he thinks that his son does not get infected so he believed that when the health worker says it, that the health worker told the entire community. So all of the community believe that he is infected by leprosy.

I: how does that make him feel?

T1: he doesn't like that [T2: angry] he is very angry he asked.. he like.. he dare some people to proof if his son really is infected by leprosy.

I: okay, and how about any myths or?

[T2 talks indonesian]

T1: the graveyard of leprosy is very hot and the grass will not grow up in upper side of the graveyard..

[T2 tells something] and he believe that leprosy is hereditary [T2: yes] and in the 7 generation one of them.. one of them can get infected by leprosy. And by that. But in his family there is no one of his ancestor or his offspring is infected by leprosy. He was very proud of that. So he thinks that leprosy will not get into his family because it is only infected by inherditary.

[End interview]

April/May 2017

<i>Male community member 1 – age:</i>	86
Notes:	86
Transcript	86
<i>Female community member 2 – age: 62</i>	90
Notes:	90
Transcript	91
<i>Male community member 3 – age:</i>	96
Notes:	96
Transcript	97
<i>Female community member 4:</i>	102
Notes:	102
Transcript	103
<i>Male community member 5 – age:</i>	107
Notes:	107
Transcript	108
<i>Female community member 6 – age:</i>	112
Notes:	112
Transcript	114

Ages:

Community member 1: 39 CM-Pas-7-B1

Community member 2: 60 CM-Pas-7-B2

Community member 3: 65 CM-Pas-7-B3

Community member 4: 42 CM-Pas-7-B4

Community member 5: 59 CM-Pas-7-B5

Community member 6: 44 CM-Pas-7-B6

Male community member 1 – age: CM-Pas-7-B1

Notes:

Had 2 friends that were walking on sanctuary land “hot soil” at the cemetery.

There is one with disability. He got it from walking on hot soil in cemetery

There is one who got it hereditary. No disability

And other neighbour is very old when he got it and he got it after working in Pasuruan on a household with leprosy then got infected.

His attitude: He feels sorry for the people and empathy because he thinks leprosy persons have no social life. Because they have self-stigma. He gives food to patient, because ‘what else can you do?’

He does not think its not always hereditary, you have to have same blood type. Some have sweet skin some have bitter skin, and some have sweet flesh.

Leprosy is not contagious. He is sure because he spend many time with his friend and do everything together and he is still healthy. 1 of the 2 is treated and the other is not.

He is not treated because he is ashamed and because of financial reasons.

He beliefs about the myth about period-sex, having sex with a women while she is on her period. His teacher told him and he read it in some book as well.

#00:00:08.51#

Transcript

I: Can you tell me about your friends and who they are and how they got leprosy?

T+P praten#00:01:11.74#

T: He said that he knows the patient from young age. And when they in junior high school they were playing on the graveyard, cemetery, and they stepped on hot.. like hot.. (I: soil) Here hot means not hot literally, but it is not really like hot literally hot, but it is like ...#00:01:35.86#

[T+P talk]#00:01:54.64#

T: step on hot land.. [I: hot land?] yes hot piece of land.. [I: is that positive or negative? or what is it? It seems very, not so well] It is in a graveyard so yeah it is not really, it is like contagious [I: that is how he knows that?] yes. #00:02:14.88#

[T asks questions]

[P says something]#00:02:21.70#

T: Oooohh [nods] graveyard is people with people with leprosy, so they get infected #00:02:21.83#

I: and he believes that he gets infected by stepping on that land?

[T asks P]

T: Yes they believe that #00:02:36.01#

I: And hey didn't do it? He didn't step on it?

[T asks P, they talk]

T: The one that stepped on it is the one that untreatable. But the other friend got it from hereditary

P: says something

T: the patient that lives behind is house he's affected when he was old, when already having grand children.

I: what would that mean for his family?

[T+P talk] #00:03:53.98#

#00:03:59.25# T: he was infected after working in the pasuruan harbour.

I: How does he think he got it

T: He doesn't know after work he just got infected.

I: how does he feel towards the persons that he knows with leprosy?

[T asks T+P talk] #00:04:38.53#

T: he feels sorry, he feels empathy and would often bring food to their home

I: why does he feel sorry?

[T+P talk]

T: because he think that the people with leprosy cannot socialise as well as a the normal being

I: In his community persons are rejected a lot?

[T+P talk]

T: *#00:05:17.23#* people are not necessarily rejected but have self-stigma, decide themselves to stay inside. They are ashamed with him/herself

I: what does he think that is the general view on leprosy?

T: His general view is that he feels ashamed with himself so keep distance with the other people, cannot get to close. But the community around here actually don't have trouble with people with leprosy.

I: are the people he knows treat differently?

#00:06:16.23# [T+P talk]

T: one of them selling pulsa, one selling fish [I: food?] selling fish, raw fish.

I: does he experience any discrimination towards people, with regard to gossiping or something towards person with leprosy?

#00:06:52.98# [T+P talk] #00:07:02.15#

T: they feel empathy, but patient does self stigma himself

I: has he any idea what you could do about it, for example he gives food, what else could community maybe do?

#00:07:28.66# [T+P talk] #00:08:04.11#

T: although the patient is hiding themselves, or the family hides him. The people here still come to the patient's house and say like, I want to meet with the patient.

I: what can you do about leprosy? medicine or what?

T: this bapak said leprosy is not contagious as long as you have the same blood, but it is okay if you have contact if you eat from the same plate or same towel or bathroom it's okay. he already say that

I: Okay, why would the family hide the person?

#00:09:09.93# [T+P talk] #00:09:30.95#

T: the bapak said that the family like him, but the .. he says the self-stigma. [interrupt each other] so the people with leprosy ask themselves have this different room and separate living facilities. [participants and family of participants talk]

#00:09:59.75# I: why do they feel ashamed? because of deformities?

T: Yes, ya, #00:10:10.91#

[T ask questions]#00:10:14.55#

T: Yes they feel so#00:10:17.89#

I: How does he feel about.. how is the community perception, or his perception towards the family of the patient? Does the family of the patient have problems because they have a family member with leprosy?#00:10:34.07#

[T ask questions] #00:10:41.55# [T+P talk] #00:10:56.96#

T: No they are treated normally, the family members of leprosy patient, because this person they believe didn't get it from hereditary so it's okay, and then the one of whom they think it has hereditary leprosy thinks it's okay too, because have different blood than us. You know like the concept of same blood? [I : yes] [P talks] T: They say they have sweet skin and heated skin same like sweat/same blood. Not same blood actually. They call it sweet 'skin' or sweet 'blood' or sweet 'flesh' but it actually the same concept. #00:12:23.11#

I: According the interview just now, do you have some interesting questions to ask him? About the topic that leprosy is not contagious?#00:12:42.03#

[T asks questions]#00:13:03.05#

T: he is sure that leprosy is not contagious because two leprosy patients are his friends, they spend a lot of time together and eat together and now he is still healthy and is not getting infected and eating together. #00:13:26.24#

I: are the people treated?#00:13:30.56#

[T+P talk]#00:13:36.63#

T: Yes one is not treated, but the other one is on treatment. #00:14:02.34#

I: why is the one not on treatment not treated? #00:14:02.34#

[T aks question]#00:14:10.53#

T: financial reason. #00:14:19.92#

I: you just told them its free right?#00:14:26.27#

T: Yes.#00:14:27.60#

[stilte, participanten praten met familie]#00:14:37.15#

I: they think it's mainly hereditary, but do they believe in other causes or myths? #00:14:57.70#

[T+P talk] #00:15:16.76#

T: no they think it is just hereditary.#00:15:57.82#

I: where do they know this information from?#00:15:57.82#

[T+P talk]

T: from my teacher, and just found it in some book, read it in some book. #00:16:15.04#

End interview

Female community member 2 – age: 62 CM-Pas-7-B2

Notes:

Quant 5A-03-MA

she says it is mostly in costal area, don't know exactly how leprosy looks like, but just got it from media.

many people will discriminate. As long as it is not contagious it is okay to be together.

She feels it is hereditary, and no one is allowed to marry someone with the disease or with deformities.

As symptoms she thinks it is stiffness of the hand and then deformities start. Also the skin gets darker

If the patient would accept advice from her she would give advice to go the puskesmas.

She feels that Bangil is a more modern environment and people are aware of health issues here. So would understand to seek health care as soon as possible. And that is also what I should do.

"It is difficult to work as leprosy patient when the disease is in a further stage, because then there is already disability. But if you can work it is totally okay."

She feels empathy with a leprosy patient because they are discriminated. She feels people should be empowered, get courage to get better and treatment. without treatment it would kill you.

'We are all God's same creation'

Because of low human resources in education knowledge is very low an people don't do anything, don't seek treatment.

Tells a long story about schools, president, east/west, and administration. Education level is the highest in Pandaan for Jawa Timur, and the schools are the most prestigious schools. (institutional stigma: religious schools)

In the Coastal area the schools are less and this affects the mindset about health-related issues in general. There is a long way to go. Lekok has a lot of religious education but a lack in formal education and the quality is less.

More socialisation is needed especially in remote areas. Would take a long time to make it sustainable and long-term effects and collaboration with desa office, puskesmas and health workers and schools. The people involved should be appropriate for that desa, or from that desa. Because respected persons in the community, community-specific, the person who should give education.

Islamic schools - easy to make contact with community and more people will receive the messages. More credible. So maybe in collaboration with them. Religious education itself should change according to ibu. #00:00:00.00#

Transcript

Before this interview a quantitative questionnaire was conducted.

I: Can you briefly summarize what comments [participant] just made?

T: what is your name?

P: [name]

T: [name], most of leprosy patients are in the coastal area and they don't know exactly how the leprosy patient what it looks like. Never see it in real life just from picture or media. [Name] and mother of participant are okay with leprosy patients as long as it is not contagious or already healed or cured it is okay if there is no restrictions. If they work together, live in the same place or are neighbors. But still consider it is hereditary so they would not allow the daughter to marry a leprosy patient. That is the main point

I: What are the symptoms of leprosy?

T: They just know about the deformities?

I: How do you think that leprosy starts? How would you recognize leprosy in the early beginning?

P: says something in Bahasa Indonesia

I: You can also say it in Bahasa Indonesia, and we will translate for you?

T translates

[P nods yes.]

I: *[Now directed towards translator]* How would [name] think that leprosy starts and what are the early symptoms, how would you recognize it?

#00:02:52.38# T+P talk #00:03:23.86#

T: she is talking about the stiffness in the hands and starting to develop deformities in the skin

[P interrupts] the skin gets darker.

I: what would her advice be for someone? What would be done?

#00:04:05.63#[T+P talk] #00:04:36.58#

T: she can just give advice, whether the patient approve it or not, she would advice to go the nearest health centre and then from the Puskesmas maybe they can give more specific advice.

I: what are the general views of people in her community towards patients? If someone would live here how would people might see that person, what is her idea on that?

#00:05:23.83# [T+P talk]

T: Since this desa is more modern and she thinks that the people here are already aware about how to deal with health issues maybe including leprosy so they would give advice to people with leprosy to go to seek medicine health care and treatment.

I: So that would be the same as she would do?

T: Yes

I: And would people think differently about that person?

#00:07:42.40# [T+P talk] [mother of participant talk too] #00:08:15.41#

T: she think that people wth think less or discriminate the leprosy patient because people here are already aware and already modern with the mindset on how to deal with health.

I: How about with regard to finding a job? Would they suspect that it is difficult if the person would find a new job if leprosy would be an obstacle for getting hired?

#00:08:44.53# [T+P talk] #00:09:25.74#

T: she thinks it will not happen, but if the disease is already in a far stage it make that he or she cannot work properly anymore then maybe it can get in the way. But like in a story of SDS, the patient can still work, then its okay but make sure the person gets medicine so it not contagious.

I: how does she feel about, because leprosy patients are discriminated in other places, how does she feel about that?

#00:10:04.91# [T+P talk] #00:11:13.19#

T: She feels very empathic with the patient because with that treatment they need it, without he or she can't leave home. But if the environment/community is not helping with getting the cure it is not only bad for curing leprosy but also can kill the leprosy patients spirit, to get a better life. What they should do is giving the right solutions and giving the spirit(courage) and motivation to seek health and seek medicine and if all the people remember we all are same human and gods creation she thinks discrimination will no longer happen.

I: Ibu pointed out that but why this is difference maybe with other kecamatan here? She said people should she the poepie as equal because we are all Gods creation but why is this still a difference with here and other kecamatan, what is the cause for that?

#00:12:48.40# [T+P talk] #00:13:42.47#

T: she says there is low Human Resources, like education. So education is less strong, in here there are enough.

I: So it is about education, the right Human Resources to give the right education, something to do with knowledge?

T: yes yes, something with knowledge

#00:14:14.31#[P talks with mother while] [and talks to Translator] [long story] #00:16:11.93# [T talks with P] #00:16:51.36#

T: there is a difference in educational stage, but in this [kecamatan] is the ...[I: highest education level?] ya education level. The school in Pandaan is like the highest.. the most predege.. [I: prestigious?] yea the most prestigious, better education better school here if it compare with Pasuruan in the costal area, like Lekok and Grati and Nguling. [I:okay what else?] of course that affects the Human Resources and education in here and their mindset on health issues. And she thinks that's why they have a different view on leprosy.

[P talks]

T: Lekok is far away with the education level, [I: long way to go] In lekok they think more about their religion and islamic school and religious education, but in the formal education they lack in quality. [I: okay yeah so a lack in proper formal education?] yes

I: is there anything she would like to share about this topic, what is interesting here?

#00:19:05.11# [T+P talk] [P tells] #00:21:19.18#

T: she thinks more socialization is needed, especially in the remote areas. So, maybe she think It will take a long time, not just one or two socialization, but long term and sustainable socialization. And they would need teamwork with the desk office, health workers, or local community that know the culture and know the habit of the community.

I: And how about the schools? Would that be possible?

#00:22:21.28# [T asks the questions]

#00:22:26.50#

T: yes

[P talks further with T] #00:22:55.80#

T: that would be good if there is a good report or relationship with the teacher of the islamic school it will be easier to get in with the islamic school and when one of them speaks it is more easy to receive and believe for the students and they have more, regard him.. [I: more open yes] more credible.

#00:23:30.40# [P talks further] #00:26:09.52#

T: she talks about the importance of, it is not important to this topic but the religious education itself in pasuruan how it works..[I: ohh okay]

I: thank you so much, your advice is very relevant

P: yaaa sama-sama (you're welcome)

Einde interview

Male community member 3 – age: CM-Pas-7-B3

Notes:

In here it is believed that if chinese and javanese marry that is the cause for leprosy. In this neighbourhood.

There was 1st family infected and they moved after marriage.

Then there was a 2nd family that were in treatment
and a 3rd family where 1 person was infected.

1 person died from leprosy

There was 1 family infected first, they quarantined the leprosy patient that died. they burned down the house but still wouldn't live there.

Then a second family infected (transmitted)
and also their back neighbours

He don't know about the cause

Desa chief took care of [Patient 1] that had kusta (first index case there, around 60 years ago), by sending food and put in quarantine and build a house.

The family of [Patient 1] didn't want to do that, so the desa office took responsibility. The houses were burnt after. But still is contagious because there are personal belongings there.

There is a fear of contagious because it was then transmitted to neighbours.

The patient back then was ignored, he wouldn't go out of the house, so people just ignored his presence/existence. Now, self-stigma of [Patient 2] is different. He would go out, buy cigarettes but will not step up the terrace. Also in the warring he would come to eat but gets a special plate and cup. The warring is a family member of [Patient 2] therefore he is accepted.

He has lack in confidence, but his friends are okay with him. Many people see him now as a normal person. He got married but people talk about his offspring and are concerned. It is hereditary and contagious at the same time.

[Patient 2] still does anything and can do anything. His job is renting a box car and brings furniture everywhere. Don't know about visible. But his face is just red.

Medical treatment really works, people saw so in the case of foes himself. This person thinks that with the right treatment leprosy can be healed and that should be used as proof to convince people.

Besides the different plate there is hardly any difference. and he himself is a little ashamed.

It's okay to socialise with [Patient 2] but don't come to close because it can be contagious. He is doubting. Maybe also through water or anything.

In this interview: change of perception over the years. Difference is that foes is not restrained by his family and foes comes from the leprosy family but maybe is not hereditary. people see it can be treated. Acceptance increases.

He believes in the myth of offspring is beautiful and handsome

Transcript

I: so what is now exactly the cause for leprosy?

#00:00:24.18# [T: asks]

T: he don't know [P talks] his mother is [P talks] His mother is the little sister of the head of desa offer at the time and there is one person that is called [Patient 1] and no one take care of [Patient 1] because it has leprosy [P talks] so the desa chief take care and his mother always send him food.
#00:01:32.59# [T+P talk] #00:01:50.28# then the [Patient 1] received quarantine sentence in one house.

I: so he was a leprosy patient?

T: yes, the first index case yes, and his mother is the one always send food to [Patient 1]..

#00:02:12.29# [T+P talk] #00:02:58.73#

T: so the family of [Patient 1] didn't want to care of him, so the desk felt responsible and they make a small house at the [T asks question to P] ...and short after [Patient 1] died, the family burnt his house.

I: they burnt his house?

T: Yeah because it's.. [T asks P] .. because they are afraid that it can be contagious from the clothes and personal belongings.

I: hmm, and how did the community reacted towards the help the desk office gave to [Patient 1]?

T: They just don't care about it, it was aboutt 60 years ago.

I: and how is it now with the index cases here? How is the community treating him?

#00:04:54.92# [T+P talk]#00:05:07.66#

It is because the symptoms are contagious to neighbors, they don't know whether it is from the water or anything. But all of the family of the next house is infected, all members of the second family. The second family have a child that have become infected so if it gets treatment and the right treatment to do. [T interrupts his sentence to ask something to the participant]. Ohh it is behind, so after the next house it was spread to behind the house.

#00:06:31.82# [T+P talk] #00:07:56.99#

T: So the, maybe when the [Patient 1] at the start of that era, patients were quarantined, so they cannot go outside the house. So from the outside there is nothing difference, no special treatment, no discrimination, or what so ever, there is no discrimination because yaaa.. they think it does not exist. But with this new patient [Patient 2], he also have this self-stigma the Bapak said. He had it in the sample when [Patient 2] buy cigarettes here. Here is unwilling to step on the step, terrace, but stays outside. But there is also a story that when [Patient 2] eat at the warung (=small Indonesian place to eat), which is owned by his relative. On the warung he has a special plate, just for him.

#00:09:23.43#[T talks to P]#00:09:48.86#

T: Yes so, he has a lack of confidence in himself but his friends are okay with him and with the self-stigma.

I: How does this Bapak thinks about [the name of an index case in the neighbourhood] himself?

[T asks P] T: just like ordinary people, person. There is no need to discriminate.

I: Or what is the general perception they have on this person? [silence] Uhh, do people talk about him behind his back or?

#00:10:48.66#[T+P talk] #00:11:18.97#

T: lately [the name of an index case in the neighbourhood] got married and then they started about it. They are concerning about how will his offspring will be. [silence]

I: okay.. is here also.. they think it is contagious, but also if it is hereditary?

#00:11:49.33#[T+P talk]#00:12:01.57#

T: yes lot of people think it is hereditary, they've seen already the proof of contagious.

[P interrupts to tell something, T+P talk]

T: Yes, There are still people here that think its hereditary.

I: how.. is he working or?

T: yes he now become furniture sells to drive a car that drives furniture around.

I: does he have disability, or can you see visibly he has leprosy?

[T+P talk] T: the Bapak don't know, whether he is wounded already or not. He just see a reddish in the face, that is all.

I: and what are the beliefs about treatment, what is his belief about treatment?

#00:14:06.70#[T asks P] #00:14:27.90# T: the Bapak think, yes it works, there is treatment possible. Because in the second family there is already member of that family that already healed, so he beliefs in medical medicine, modern medicine.

I: and what can be done to.. because the bapak is telling a lot about there is stigma and people are worried about his children [T: hereditary?], yes does he have any idea what can be done to prevent this?

#00:15:03.62#[T+P talk]#00:16:54.03#

T: He don't have any.. he thinks that with the. Medicine and right medicine kusta can be healed, and maybe that can be proof that can be seen by the community that kusta is not like hereditary and that it is not a permanent disease.

#00:17:24.46#[*T asks P and talk*]*#00:18:14.20#*

I: can I ask another question?

T: Yaa

I: Is the person, Pak [the name of an index case in the neighbourhood] not treated differently by the community, but is that true?

T: Ya, but maybe with the food, that he has a different treatment only for him.

I: with what? The plate?

T: Yes

#00:18:47.34# [*T checks my question with P*] *#00:19:05.60#*

T: there is no other discrimination besides that?|

I: and what do they think about him? Do they like him or not?

[*T+P talk*]

#00:19:40.71# T: it is like the normal, normal other people. Ya sometimes [the name of an index case in the neighbourhood] himself feels ashamed with himself.

I: okay...

I: Uhm, and do you have an idea bout the perception can you ask him if he has some other things to tell about leprosy in general?

#00:20:21.59# [*T+P talk*] *#00:21:32.93#*

T: He just say that it's okay to be socialize with him, but don't come to close, because we still don't know from what leprosy is contagious. So don't look like just .. [*T+P talk*] maybe it is from water, maybe it is from like something else.

[*P talks with T*] *asks about the research and with whom we are conducting it*

#00:23:15.50#T continues with qualitative questionnaire. *Recording put on pause for a while**#00:27:00.49#*

I: Yes, would he like to know if someone is affected by leprosy, if you can't see it would he like to know? [*T asks P*]

T: Yes

I: why?

T: Yes because he is afraid its contagious.

I: And he told a lot of things about the past and now can you explain the biggest change that happened over the years about the perception on leprosy that has changed maybe? If there is a change..

#00:28:08.18# *[T+P talk]* #00:29:32.27#

T: he thinks that the difference big difference is that [the name of an index case in the neighbourhood] is not come from the family with leprosy. Different then with the other families from which it runs in the family.

I: what is the difference? He is not from the family so?

T: [the name of an index case in the neighbourhood] comes from a family that have no record of leprosy before so he think, maybe they think it's not hereditary so it makes him more receiving of accepting towards [the name of an index case in the neighbourhood].

[T asks P to confirm]

T: yes.

Terima kasih Pak (Thank you sir, thank you)

End interview

Female community member 4: CM-Pas-7-B4

Notes:

Sampled via volunteer of puskesmas, lives at the border of desa. So starting point. Not totally random dus. Actually snowball sampling.

“We should change the mindset of leprosy in the community”

A myth in community is that it is hereditary: but she does not really believe it. There is a lot of disgust.

There are no index cases here, and also no socialisation, people are not familiar with it and it is far away and therefore people might not know so much here. There is no one that know one that has socialised with it and never met in real life.

In here socialisation is: education and prevention

Cervix cancer + dengue already happened. There is a volunteer from each desa, that health worker would inform the volunteers (ibu emma is one of those) and then spread it around the community [place to implement knowledge]

She feels that it will develop just like diabetes. More people know about it now and now it is just a common disease.

One case happened and transmitted from family to generations, so now there is a fear associated with it. But through socialisation the case that is there can be used. People get used to it and become more open to receive information about it. ‘community based’

Dengue example: not only to desa office, but also with the help of religious ceremony. because many people go there and attend from the desa. Also can be used are the posiandu - mostly meeting, immunisation moment.

The religious events and information support each other , no obstacle there.

patient view: it is contagious, fear, so socialisation necessary.
She will support a leprosy patient but the society may be not.

[answers seem little bit social desirable]

people feel disgust, followed by empathy. And cause for disgust are deformities. and empathy because they see the life of a leprosy patient and feel empathy because the person is excluded and alone.

Leprosy patients are treated differently, excluded from social life and gatherings as prevention measure. People are also scared. Also patients will hide themselves, they don't want to make others feel uncomfortable.

Patient can be treated in an early stage, so everyone should help and empower the patient. Not exclude or discriminate them.

[Feeling that it were socially desirable answers]

Transcript

I: [Name] was hesitant about the idea whether leprosy is hereditary, could she tell me a little bit more about that?

[T+ P talk]

T: it is like the other disease, like diabetes and hypertension. People think it is hereditary, but also can be from the food factory. They also think it's with leprosy. I: because in the past they thought that diabetes was also hereditary and now they know it's not, so she suspects the same with leprosy?
T: yes yes, like that.

I: Does she know why most people think it is hereditary?

[T+ P talk]

T: because when one case it happened that it was from grandfather to grandchild, maybe their son and daughter, its happened on the scope of one family so that is why people think it hereditary.

I: She also suggested that maybe if here is case in the neighborhood that can socialize people of what leprosy really is, she thinks it would change this idea?

T: yes socialization is like waiting that there is a case happening and willing, yeah, they start socialization.

[T+ P talk]

T: Yes, this Ibu think that the people here are open to new information so there is socialization that say leprosy is not hereditary they shall believe it.

[T+ P talk]

T: So they do it with dengue socialization, was good idea... they do not only go to desa office but this Ibu and other volunteers are like going to some like, religion ceremony in this neighborhood. And then.. share ht information about dengue.. and that is their way to get to... eeuh.. to inform.. much more people in society.

I: Why is especially religious events successful to use?

[T+ P talk]

T: More effective because the people that attend religious public dialogue for religion, we call it 'penajian'? Is much more. More people that attend, than meet in head office or RW office, there are a few people active voluntarily there. So they do also do the socialization on posyandu, I have told you about posyandu on.. euhmm, ohh what desa?

I: can you tell me again?

T: you already write down it, posyandu (community health centre for baby's and infants and pregnant moms, *consultatiebureau in Dutch*) is like the monthly meeting that the Ibu Ibu that get immunization there and vaccin there. To check the health of the baby and maybe someone is pregnant.

I: what has that to do with this?

T: They carry the information that they have maybe with dengue or cervix cancer here. So it makes the volunteer.. they try to spread the information as much as they can do in the where people... in the posyandu

I: what is the influence of religion in these activities? T: what activities? I: of socialization about disease

[T+ P talk]

T It is like supporting each other, there is no religious obstacle, or religion that forbids some information for being shared as long as it help. For example with cervix cancer it was long time ago a taboo to talk or share information about cervix cancer, but now is not.

I: Okay. But my question is not about the obstacle but how it maybe can help.

T: yes they are supporting each other, and helping each other.

I: what do people in this community think of leprosy patients? How do they view leprosy patients?

[T+ P talk]

T: Ibu [name] said that most of the neighbourhood see leprosy is a contagious disease even though it is not. This Ibu know its not. So, yes, we need socialization to change that concept. The fear that it is contagious.

[T+ P talk]

T: If there is.. if she finds.. yes she would support the patient and seek for medicine and try to not avoid it or discriminate it. I: she said that? T: yes she would do that, but maybe that is the same with peer opinion.

I: But how do they see, the action towards the person? Not how they see leprosy, but how do they see the person? Is it considered less the person or how does she feel about that?

T: Avoid it or disgust, but as the time goes they feel sympathy

I: En waar komt.. [herstelt zich] eeu.. And where comes the disgust from?

[T+ P talk]

T: It is because of the deformities?

I: and the sympathy? What makes the change?

T: It is like the, if the people see every day life. And then they see that the people is discriminated, have no friends.. and that is where usually it changes to sympathy.

[T+ P talk]

T: there is no communication between patient other people . [I: what do you mean?] Oh when they see they are alone? So when they see they alone, no friends, no communication also to other people... uhm... I: excluded? T: yes..

I; are people treated differently?

[T+ P talk]

T: Yes. [I: how?]

T: Yes no communication, and like not including them in socially group.

I: is the person discriminated with regard to other events, like during meetings, work or marriage?

[T+ P talk]

T: Yes excluded for social meeting like.. [I: why?] because she said people are scared.

I: Is she scared herself?

[T+ P talk]

T: No she already know how it is, she just feel empathy
[silence]

I: Okay, would she think with leprosy would hide it in this community?

[T+ P talk]

T: Yes she thinks. [I: why?]

[T+ P talk]

T: It is like self stigma, other people may feel disgust, so better hide.

I; but is it true? is it righteous self-stigma? Is it true that others disgust them?

[T+ P talk]

T: Yes that is the case if it, especially if it is worse case. But not with early symptom

I: so is it from two sides? The community feels disgust, and the person is fearing that and therefore the person hides?

[T+ P talk]

T: Yes it is both

I: would she likes to know if someone has leprosy or rather have it disguised?

[T+ P talk]

T: Yes because that person has to have the cure to heal. [I: so she would like to know?] Yes

I: Is that the general view?

[T+ P talk]

T: Maybe, if there is socialization, and people know about this.. maybe..

[P talks]

I: [Could understand the participant] So maybe if there is socialization people will, may accept it?

[T nods yes]

I: so what is the ideal picture of a community with leprosy patients that live in this desa, would they be overt/visible?

[T+ P talk]

T: Yes, it must be helped. It must be helped soon, if there is one people or more people know that is positive with leprosy so the people around him or her should help him or her to help to seek help from Puskesmas or medicine.

[T+ P talk]

T: It cannot be discriminated or excluded for the socialization purposes.

[P talks about the study]

[T answers about study districts]

T: okay?

I: this ideal picture can be reached through socialization or?

[T+ P talk]

[P: nods]

[End interview]

Male community member 5 – age: CM-Pas-7-B5

Notes:

Knows about lepra. Many people die but there is also someone still living with leprosy close to his house.

Step on graveyard and got leprosy. Red face, hand is stiff. Did not take too long he said.

If someone has leprosy and buy something, the persons would separate the money that the patient gives.

There was once a patient expelled from the community. He was from lekkok and moved to his wives' house in Nguling. Had 2 children and then got leprosy. Index case did not want to go to puskesmas regularly, symptoms got worse. Community expelled him because he looks disgust. and deformities.

went back to lemon. He was himself also ashamed for his appearance. But he did not go to puskesmas.

this was 1 year ago, they are very happy that the person is no longer in the community.

having leprosy is a burden, it is heavy disease because the patient will be excluded. People are scared, me too, because it cannot be healed. and it is disgusting.

It can be treated. But some people don't want to be treated. So that patient was expelled.

People with leprosy should feel shame and the example also self-stigma.

Deformities sometimes happen but not on the face. When he face is normal and hands and feet are affected it is okay. That person can still live here.

common view on that person is nothing special, he is just a person. Just you should never have skin contact with the patient. Also the person himself would never initiate contact. And his appearance and face were normal.

Still he is treated differently

- people won't come in skin contact with him

when he buys food it is careful, not to come into contact.

He would stay outside while ordering (warung). Neighbour gives them food as well.

His opinion: very kind, very caring for other people and friendly.

He still chats around with neighbourhood but takes distance himself.

Two kinds of leprosy:

- leprosy was because of graveyard.people with leprosy die, and on friday lucky you cannot step on its grave.

- real leprosy, not from the myth but full face affected leprosy.

He believes that the symptoms emerge after having children. for marriage there is a problem because no one would take the person, or would want to have children with the person

- ends in divorce

- fear of contagious

- hereditary

interviewee is in doubt about hereditary. Maybe sometimes yes.

He does not know a leprosy patient personally and would not have close contact with him.
'No one with leprosy would ever look normal' so you would also know it (answer to the question: would you like to know if someone has leprosy)

If my friend has leprosy I would take a step back, and do it obviously. Just to let him know that we don't want contact. It is disgusting, it is ugly. I would do it with everyone that is ugly.

Transcript

I: we will speak in English, and he will translate me

[all laugh]

I: Can you tell me a little bit about the knowledge with regard to leprosy?

T: It is a very heavy disease comparing to other disease, because it is the patient. The patient will be excluded with the people from the community.

I: What is the main reason that people are excluded?

T: they are scared and cannot be healed, disgusting.. he said disgusting

I: Do they feel that leprosy can be treated?

T: Yes if the people want to, but the person that is expelled does not want to be treated.

[T+ P talk]

I: the patient that was expelled? Why was he not treated?

T: maybe because he himself feel ashamed and yes self-stigma I think. He is ashamed with himself.

[P +P2 talk]

T: they talk about the other patient that just show that had deformities but nothing happened with his face.

[T+ P+P2 talk]

T: This patient in community has a normal face, lives 200 meter from here. Has a normal face. And the hand are only on the deformities and also the feet. And look like slightly normal. They are not expelled or avoided or excluded.

I: The other person died? Still lives here?

T: the person still lives here. Do you want to go there? She asked

I: [laughs] maybe later, after..

What is the view of the community on the leprosy patient? Their opinion?

[T+ P talk]

T: It just.. it's common.. It is not nothing special treatment, because..

[T+ P talk]

T: they treat it commonly but never get to close, never get skin contact so shake hand. But the patient himself maybe like to he.. realize that maybe the people don't want to shake with me. So he never initiates that contact.

I: what is the difference between this patient and the one that got expelled?

T: The appearance in the face.

[T+ P talk]

I: besides making contact other ways that patients are treated differently?

#00:06:18.77#[T+ P talk]#00:07:37.61#

T: If he is buying food or something people would not have skin contact. So when they want to put.. uhh. He would wait outside the warring and say what he wants to eat. And the warring owner would come out to give the order, he would not go inside. But if he is asking for food from his. Neighbor, they also give them something. In warung just, it is like a business and they don't want to scare of other customers.

I: How do they feel about the person that is still living here in the community?

[T+ P talk]#00:08:50.80#

T: he is very kind and very, he cares for other people and he is friendly.

[T+ P talk]

T: So he is chatting around, he is hanging around with the neighborhood and he himself put a little space with the crowd, so not the crowd that go far. But he should realize that maybe I should take distance.

I: so he is around but would take the distance?

T: Yes, so maybe if he would join conversation here, He would sit over there [points to other side of the room]

I: And what do people believe that the cause is for leprosy?

T: His leprosy is because he stepped on the graveyard of a leprosy patient

#00:10:38.77# [T+ P talk] #00:11:11.95#

T: He said that if the people with leprosy would die and would bury, no one can step on the graveyard on Friday Lucky, or people that will step on it will be infected.

I: And the other person that was expelled what was his cause for leprosy?

[T+ P talk]

T: she says it is like the real musts, the real leprosy?

I: what does she mean by that?

T: means.. it means like it is not a mythical cause.

I: What is then the cause?

T: don't know the cause, but say that.. don't know where he gets leprosy but after he lives he for several years he got two children. Then the symptoms emerged, so they don't know where it came from.

[T+ P talk]

I: And what is the consequence of leprosy with regard to marriage, or children..?

[T+ P talk]

T: They know it can be a problem because there is no one here that wants to have a wife or husband that is infected by leprosy. So most of them will divorce and the worse is.. no one would want to have their children, because they are infected

I: is it just because it is contagious? Or also hereditary?

#00:14:33.76# *[T+ P talk]* #00:14:48.18#

T: it is hereditary.

I: okay..

[T+ P talk]

T: he know someone with leprosy, the mother.. but the child is not infected. And it ever happened in this desa when the time when the land is here.. no one wanted to buy the land in this village because many people on that land had leprosy, but now it is not?

I: because of the person with leprosy had children, but the children not so therefor they gets the idea it's maybe not hereditary. They are in doubt?

T: not really in doubt, but they think it is a special case. It is like that. They still believe and agree that it is hereditary as well.

I: do they have a lot of contact with the contact with the index case that lives her?

#00:16:38.02# *[T+ P talk]* #00:16:59.36#

T: for common contact it's just crossing his room. Because their child is married with someone that live there. So near with their home.

I: but no personal contact?

T: No just like neighbor.

I: Would you like to know if someone has leprosy if you cannot see it?

[T+ P talk]

T: They believe that patient with leprosy is always visible. There is no people with leprosy that isn't visible or they can hide it. You see the redness in the face.

[P talks]

T: the Ibu also say that if she had a friend that maybe she would find out have leprosy. They would take step back, take distance, obviously so maybe would make the patient realize that they don't want to get to close to the patient.

I: why would she do that, what is her main reason?

[T+ P talk]

T: Because it is disgusting, it is not for the contagious reason. [participant laughs] for example, you [points at interviewee] you are beautiful, but they look reddish. But if you have deformities P2 would also step back. Would do it with everyone that looks ugly. [P laughs]

I: Do they feel that leprosy patients are allowed to work in the community?

[T+ P talk]

T: yes they are allowed to working, and this person is also still working. He works with sand and selling sand.

[end interview]

Female community member 6 – age: CM-Pas-7-B6

Notes:

Every time when talking about leprosy patient she would lower her voice because it is taboo. but she is comfortable with asking questions.

She thinks it is hereditary. many leprosy patients are living at east side of grave yard.

symptoms are swollen ears itchiness, deformities on fingers. Index cases soaked feet in warm water every morning but made no difference.

Leprosy patient came to her house, she would mop the floor afterwards.

She would not accept food of leprosy patient.

It can be treated in puskesmas, but never healed because it is hereditary. Therefore, never marry and index case because it is hereditary. Bad flesh is the disease.

You can die from it, and disability cannot be prevented because you don't feel that it happens, no pain, so people would neglect it

She would not refuse people, but keeps distance. But not explicitly or obvious. Keep feeling in mind. So therefore not refuse visibly the patient.

She fears contagious because of fishy smell sweat, fishy and oily. She feels disgust but would not show this to the patient.

It is hereditary and attacks hand and finger by shrinking. It can be treated in puskesmas.

we would exclude the person from eating and food. Religious gathering it would still come ut keep distance from crowd

patient themselves would not come too close to others. They know it (index cases) but feel okay in doing so. because it maybe contagious.

Reason for exclusion is disgust, not contagious.

The physical appearance of a person (points at fingers and skin on arms) they have a different skin.

Knows someone, selling tofu waste for cows. The buyer is a leprosy patient not in treatment. She saw the deformities increasing over time. So she thinks treatment is important.

It cannot be cured because it is hereditary and disability just happens. but it is okay because they don't feel pain (illness, disease)

Person is also different. Offspring will get it too, and the person stays different because of leprosy. because you would also see it in the red face. This is the general view.

People would take distance, and people would walk away if a leprosy patient comes. When there is a gathering at the family home people would come but only eat packed food.

In a community event - ibu ibu would come together to cook. The patient with leprosy would not come.

"They work in the field with cows, or as farmers. But as sellers they cannot work with small fingers."

She would rather not have a patient in the house but it is okay to go to the leprosy patient's house as long as you don't drink or eat anything.

She feels sorry for patients because when it gets worse the patient will be expelled from the house to a different smaller house.

distance is made by slight movement. it happens naturally. both parties keep distance because of fear and disgust. The general view is that it is contagious if you have the same sweat. Quite a lot of patients. in here.

They have not live on graveyard or farther away.

she will keep distance to family members as well because it is hereditary. Wedding party in the family. They will help cook for the family of the leprosy patient. Otherwise no one would eat it.

food very important, like significant measure of distinguished.

leprosy patient should have a separate grave but would attend funeral.

She would rather not know if someone has leprosy.

Transcript

[A lot of backnoise from the street.]

I: I think you know what this research is about, leprosy?

[T translates, P nods]

I: Could you maybe tell me what kusta is, what is caused by according to you?

#00:00:35.77# *[T+P talk]* #00:01:03.61#

T: It is kusta, it is hereditary. *[P talks]*

T: It is like shrinking hands and fingers, and as the time goes it will become deformities.

I: and leprosy could be treated?

[T+P talk]

T: yes it can *[T+P talk]*

T: you should go to Puskesmas.

I: Can you tell me about the views in your community about leprosy?

#00:02:21.90# *[T+P talk]* #00:04:14.07#

T: so they make will.. will excluded. Like.. when it is going about food.. *[T confirms with P]*

#00:05:07.12# and then when it comes to religious activities or gathering, they still coming. But leprosy patients will make little space with the others. This woman said that they themselves have the feeling to not be too close with the others.

I: okay and what else?

T: And then they.. no.. I mean. They know that the community would make a space with them and exclude them, but according to Ibu they feel okay with that because they have a disease that maybe can be contagious.

I: What does she think, does she agree upon the common view about keeping distance? [T: what?]
The view of the people is to keep distance, she would do it herself to?

#00:06:25.50# [T+P talk] #00:06:32.46# T: yes she would do it?

I: What is the main reason?

[T+P talk] #00:06:46.24#

T: is is disgusting. It is disgust.

[T+P talk]#00:07:06.13#

T: just disgust, because she says it is not contagious, only hereditary but it is just.. the reasons they exclude the patient is only just disgust.

I: and what is, .. what disgust them? Their appearance or the way they acting?

[T+P talk] T: Yes...

[T+P talk]

T: Yes, because the appearance they have different flesh or different skin

[T+P talk, while P is lowering her voice]

T: she knows one leprosy patient, when Ibu was selling tofu waste for the .. for the cow food. One of the buyers is a patient of leprosy and then she says the deformities like little by little, because he or she come often here, and then at first it was just like until [points to fingers] and then more and more [moves hand down] [refers to shrinking of fingers]

I: was that person in treatment?

#00:09:22.88#[T+P talk] #00:09:33.28#

T: Yes there was one that was treated, but the other is just like neglected, they don't care.

I: and the one with the deformities little by little lost his fingers? Was he treated?

[T+P talk] T: no.

I: Does she think treatment is important?

[T+P talk] T: yes.. *[P talks]* it is important but mostly they don't get treatment *[P talks]*

T: the Ibu said, the reason that they not treat it, they think, because they think it is a hereditary so it cannot be cured or be healed, so yeah it is not pain. They not feeling pain. [Seems translator's interpretation: So that is the difference between illness and disease]

I: What does the Ibu think of the person with leprosy, the patient?

#00:11:34.72# *[T+P talk]* #00:12:11.50#

T: it is different...

[P talks]

T: it is usually, when one member of the family gets disease usually the offspring also... *[T confirms with P]* #00:12:58.48# So they feel like, it is just normal for them, because they don't feel pain or sick.

I: So the Ibu think it is different?

T: yes there is a difference between the two.

I: Does she think there are also non-visible symptoms to leprosy or only the fingers that are deformed?

#00:13:28.01# *[T+P talk]*

T: Just the red finger and feet, and a reddish face. There is no itchiness or coldness. It is just the physical appearance, reddish face and deformities.

I: Do more people think that person affected by leprosy is different, or is it just her opinion? Or like a general opinion in community?

[T asks P]

T: Yes it is different from the rest.

I: In what ways are people with leprosy treated differently? If they are?

#00:15:05.49#*[T+P talk]* #00:16:14.57#

[In the meanwhile she is helping a customer in her little store for daily needs] T: It is just like they make space, and then when the family held some kind of gathering in their home, the people that come there are invited. The people told them to not give food when they in there. Just give food just

like packed. [I: packed food?] Yes a pack of food to bring home. So if the food is pre-packed and bring home the family will not know whether it will be eaten by the people that invited.

I: So the family of the leprosy have to give their guests packed food?

T: Yes besides the packed food the house also give food to eat inside the house during the event. Usually.. With the normal people. But not with leprosy patients

I: and any other ways that leprosy patients are treated differently? *[participant joins again]* T: no just the make space and food.

[T asks P again] #00:18:50.87#

T: So the Ibu says that the other example is, when people when the community have some event, like a wedding party or like that. Usually Ibu Ibu around the neighborhood is helping to cook, but not with the leprosy patient, they are not invited and not asked to help and they themselves don't come to help because maybe the house does not want to be helped by then. They can just work as a farmer or take care of cows in the field. Because if they would sell something then nobody would buy it

I: would she invite leprosy patients into her house? [T: for what?] I don't know, would she let a leprosy patient into her house or not?

[T+P talk] [P shakes head no]

T: no she would rather reject it?

I: why is she afraid or?

T: wait wait, if the Ibu goes to te house or? [I: yes...]

[T+P talk]

T: It is okay to go to the patients house, but no food or drink.

I: Uhm okay.. and how does she feel about that leprosy patients are excluded in somewhat important think? Does she feel sorry [T: what do you mean? For the leprosy patient] yeah?

#00:21:27.88# [T+P talk] #00:22:00.62#

T: it is because sorry, she said that when it is getting worse, the patient will, the family of the patient will make a small house, separate from the main house, to place the patient getting worse?

I: and who is taking care of the patient?

T: the family would take care of him

[P talks]

T: because the y don't wanna be treated so it is confusing when it is getting worse, so only way is to exclude him [I: because they are not treated?] Yes. *#00:23:13.49#*

I: Last time with the interview, uh, she said, I would keep my distance from the leprosy patient, [T: Yes] but not physically? Can you maybe first ask her if that's still.. if that is correct that she said that. And also if that happens in general?

[T+P talk]

T: yes it is not like obviously because ya it is making like.. making slight movement to make a distance. The Ibu says that the patient himself have the feeling he or she must keep a distance and that he or she should not come to close when they gathering around or in a crowd. Like that. [I: she means that it happens kind of naturally that the distance exist] Yes

I: how does she feel about that, is she happy that it works that way? or.. [T: uhmm] like the distance happens naturally, the leprosy patient and people keep distance [T: yes yes, both of them] she thinks that is supposed to be that way?

#00:25:17.95# *[T+P talk]* #00:25:25.71#

T: yes she says like that.

I: and that is important because?

T: She is just afraid and disgust.

[P talks]

T: Oh she is afraid of disgust, and little bit afraid of contagious because if the sweat is the same it can be contagious.

I: Does she maybe know more people with leprosy?

#00:26:24.35# *[T+P talk]* *[P lowers voice again]* #00:26:45.15#

T: there is one inside the graveyard, and behind the graveyard there is also one. But the more they know. But it is not in this desa, but in neighbor desa.

I: oh that is a lot

[P talks]

T: also in the east of the market there are also a lot of patient

[P talks more]

T: so in the east of the market in the Puskesmas there are a lot of patient also and the Ibu says that when it is getting worse, the family would make a small house near the graveyard for the patient. *[P walks away]*

I: why near the graveyard?

T: I don't know.. maybe it is.. because its s little farther from the community. Because the graveyard is mostly separate from the neighborhood.

I: I would like to know.. it is hard to formulate for me in a question but maybe in conversation you can ask her this: I would like to know in marriage ceremonies there is differences, I would like to know about those special events what the difference is between a person with or without leprosy. Because in this interview she highlights some differences, so I would like to know what all the differences are.

T: So you already know about the religious gathering [I: yes] and when the wedding party, but it's.. the other community other that help we don't know about whether the family of the patient is helping a party [I: yes] something like that? And the funeral maybe? Would you like to know [I: yes and where they are buried?] [T nods]

I: after that I would like to know on the effect of family members from the leprosy patient. [T: I should formulate that in a question?] yes or in conversation so you won't have to ask her directly but just respond to what she says.. [T: okay okay]

[P helps customer of local store]

#00:30:50.59# [P comes back and T+P talk] #00:32:18.02#

T: so they also make a distance with the male family member with leprosy even though they look healthy, cause they is afraid of hereditary. The family of the leprosy patient is helping some wedding party the Ibu Ibu would still help to cook the family [T check with P] by going to the market, and getting the supplies.

[T talks with P] #00:34:04.36#

T: so the house and the family of leprosy patient held like wedding party the family itself did not join to cook, help to cook. They would do not have to do anything with the food, but if like that lots of people still don't want to eat the food. [I: but it seems that food is really important in this? Yes

[T+P talk] #00:35:25.67#

T: also when it comes to the funeral, the graveyard is different than the other. It is in the hedge. Or they would still make the distance on the people that already die. [I: still make distance when?] when they die. So the graveyard is separated?

I: will people go to the funeral?

[P noddss]

T: Yes they would still go

I: are there any consequences of family members, also treated differently [T: yes] yes even though they are not infected?

T: Yes I'm sorry the Ibu already said this, even though it's healthy, ,if you are the offspring of the patient with leprosy you would still get stigma and get the exclude treatment.

I: Would she likes to know if someone has leprosy or not? [T: what Ibu thinks]

[T+P talk]

T: No she don't want to know, [I: she would rather not know] no she rather not know..

[T+P talk]

T: Just don't want to know.

[End interview]

April/May 2017

<i>Male community member 1 – age:</i>	86
Notes:	86
Transcript	86
<i>Female community member 2 – age: 62</i>	90
Notes:	90
Transcript	91
<i>Male community member 3 – age:</i>	96
Notes:	96
Transcript	97
<i>Female community member 4:</i>	102
Notes:	102
Transcript	103
<i>Male community member 5 – age:</i>	107
Notes:	107
Transcript	108
<i>Female community member 6 – age:</i>	112
Notes:	112
Transcript	114

Ages:

Community member 1: 39	CM-Pas-7-B1
Community member 2: 60	CM-Pas-7-B2
Community member 3: 65	CM-Pas-7-B3
Community member 4: 42	CM-Pas-7-B4

Community member 5: 59 CM-Pas-7-B5

Community member 6: 44 CM-Pas-7-B6

Male community member 1 – age: CM-Pas-7-B1

Notes:

Had 2 friends that were walking on sanctuary land “hot soil” at the cemetery.

There is one with disability. He got it from walking on hot soil in cemetery

There is one who got it hereditary. No disability

And other neighbour is very old when he got it and he got it after working in Pasuruan on a household with leprosy then got infected.

His attitude: He feels sorry for the people and empathy because he thinks leprosy persons have no social life. Because they have self-stigma. He gives food to patient, because ‘what else can you do?’

He does not think its not always hereditary, you have to have same blood type. Some have sweet skin some have bitter skin, and some have sweet flesh.

Leprosy is not contagious. He is sure because he spend many time with his friend and do everything together and he is still healthy. 1 of the 2 is treated and the other is not.

He is not treated because he is ashamed and because of financial reasons.

He beliefs about the myth about period-sex, having sex with a women while she is on her period. His teacher told him and he read it in some book as well.

#00:00:08.51#

Transcript

I: Can you tell me about your friends and who they are and how they got leprosy?

T+P praten#00:01:11.74#

T: He said that he knows the patient from young age. And when they in junior high school they were playing on the graveyard, cemetery, and they stepped on hot.. like hot.. (I: soil) Here hot means not hot literally, but it is not really like hot literally hot, but it is like ...#00:01:35.86#

[T+P talk]#00:01:54.64#

T: step on hot land.. [I: hot land?] yes hot piece of land.. [I: is that positive or negative? or what is it? It seems very, not so well] It is in a graveyard so yeah it is not really, it is like contagious [I: that is how he knows that?] yes. #00:02:14.88#

[T asks questions]

[P says something]#00:02:21.70#

T: Oooohh [nods] graveyard is people with people with leprosy, so they get infected #00:02:21.83#

I: and he believes that he gets infected by stepping on that land?

[T asks P]

T: Yes they believe that #00:02:36.01#

I: And hey didn't do it? He didn't step on it?

[T asks P, they talk]

T: The one that stepped on it is the one that untreatable. But the other friend got it from hereditary

P: says something

T: the patient that lives behind is house he's affected when he was old, when already having grand children.

I: what would that mean for his family?

[T+P talk] #00:03:53.98#

#00:03:59.25# T: he was infected after working in the pasuruan harbour.

I: How does he think he got it

T: He doesn't know after work he just got infected.

I: how does he feel towards the persons that he knows with leprosy?

[T asks T+P talk] #00:04:38.53#

T: he feels sorry, he feels empathy and would often bring food to their home

I: why does he feel sorry?

[T+P talk]

T: because he think that the people with leprosy cannot socialise as well as a the normal being

I: In his community persons are rejected a lot?

[T+P talk]

T: *#00:05:17.23#* people are not necessarily rejected but have self-stigma, decide themselves to stay inside. They are ashamed with him/herself

I: what does he think that is the general view on leprosy?

T: His general view is that he feels ashamed with himself so keep distance with the other people, cannot get to close. But the community around here actually don't have trouble with people with leprosy.

I: are the people he knows treat differently?

#00:06:16.23# [T+P talk]

T: one of them selling pulsa, one selling fish [I: food?] selling fish, raw fish.

I: does he experience any discrimination towards people, with regard to gossiping or something towards person with leprosy?

#00:06:52.98# [T+P talk] #00:07:02.15#

T: they feel empathy, but patient does self stigma himself

I: has he any idea what you could do about it, for example he gives food, what else could community maybe do?

#00:07:28.66# [T+P talk] #00:08:04.11#

T: although the patient is hiding themselves, or the family hides him. The people here still come to the patient's house and say like, I want to meet with the patient.

I: what can you do about leprosy? medicine or what?

T: this bapak said leprosy is not contagious as long as you have the same blood, but it is okay if you have contact if you eat from the same plate or same towel or bathroom it's okay. he already say that

I: Okay, why would the family hide the person?

#00:09:09.93# [T+P talk] #00:09:30.95#

T: the bapak said that the family like him, but the .. he says the self-stigma. [interrupt each other] so the people with leprosy ask themselves have this different room and separate living facilities. [participants and family of participants talk]

#00:09:59.75# I: why do they feel ashamed? because of deformities?

T: Yes, ya, #00:10:10.91#

[T ask questions]#00:10:14.55#

T: Yes they feel so#00:10:17.89#

I: How does he feel about.. how is the community perception, or his perception towards the family of the patient? Does the family of the patient have problems because they have a family member with leprosy?#00:10:34.07#

[T ask questions] #00:10:41.55# [T+P talk] #00:10:56.96#

T: No they are treated normally, the family members of leprosy patient, because this person they believe didn't get it from hereditary so it's okay, and then the one of whom they think it has hereditary leprosy thinks it's okay too, because have different blood than us. You know like the concept of same blood? [I : yes] [P talks] T: They say they have sweet skin and heated skin same like sweat/same blood. Not same blood actually. They call it sweet 'skin' or sweet 'blood' or sweet 'flesh' but it actually the same concept. #00:12:23.11#

I: According the interview just now, do you have some interesting questions to ask him? About the topic that leprosy is not contagious?#00:12:42.03#

[T asks questions]#00:13:03.05#

T: he is sure that leprosy is not contagious because two leprosy patients are his friends, they spend a lot of time together and eat together and now he is still healthy and is not getting infected and eating together. #00:13:26.24#

I: are the people treated?#00:13:30.56#

[T+P talk]#00:13:36.63#

T: Yes one is not treated, but the other one is on treatment. #00:14:02.34#

I: why is the one not on treatment not treated? #00:14:02.34#

[T aks question]#00:14:10.53#

T: financial reason. #00:14:19.92#

I: you just told them its free right?#00:14:26.27#

T: Yes.#00:14:27.60#

[stilte, participanten praten met familie]#00:14:37.15#

I: they think it's mainly hereditary, but do they believe in other causes or myths? #00:14:57.70#

[T+P talk] #00:15:16.76#

T: no they think it is just hereditary.#00:15:57.82#

I: where do they know this information from?#00:15:57.82#

[T+P talk]

T: from my teacher, and just found it in some book, read it in some book. #00:16:15.04#

End interview

Female community member 2 – age: 62 CM-Pas-7-B2

Notes:

Quant 5A-03-MA

she says it is mostly in costal area, don't know exactly how leprosy looks like, but just got it from media.

many people will discriminate. As long as it is not contagious it is okay to be together.

She feels it is hereditary, and no one is allowed to marry someone with the disease or with deformities.

As symptoms she thinks it is stiffness of the hand and then deformities start. Also the skin gets darker

If the patient would accept advice from her she would give advice to go the puskesmas.

She feels that Bangil is a more modern environment and people are aware of health issues here. So would understand to seek health care as soon as possible. And that is also what I should do.

"It is difficult to work as leprosy patient when the disease is in a further stage, because then there is already disability. But if you can work it is totally okay."

She feels empathy with a leprosy patient because they are discriminated. She feels people should be empowered, get courage to get better and treatment. without treatment it would kill you.

'We are all God's same creation'

Because of low human resources in education knowledge is very low an people don't do anything, don't seek treatment.

Tells a long story about schools, president, east/west, and administration. Education level is the highest in Pandaan for Jawa Timur, and the schools are the most prestigious schools. (institutional stigma: religious schools)

In the Coastal area the schools are less and this affects the mindset about health-related issues in general. There is a long way to go. Lekok has a lot of religious education but a lack in formal education and the quality is less.

More socialisation is needed especially in remote areas. Would take a long time to make it sustainable and long-term effects and collaboration with desa office, puskesmas and health workers and schools. The people involved should be appropriate for that desa, or from that desa. Because respected persons in the community, community-specific, the person who should give education.

Islamic schools - easy to make contact with community and more people will receive the messages. More credible. So maybe in collaboration with them. Religious education itself should change according to ibu. #00:00:00.00#

Transcript

Before this interview a quantitative questionnaire was conducted.

I: Can you briefly summarize what comments [participant] just made?

T: what is your name?

P: [name]

T: [name], most of leprosy patients are in the coastal area and they don't know exactly how the leprosy patient what it looks like. Never see it in real life just from picture or media. [Name] and mother of participant are okay with leprosy patients as long as it is not contagious or already healed or cured it is okay if there is no restrictions. If they work together, live in the same place or are neighbors. But still consider it is hereditary so they would not allow the daughter to marry a leprosy patient. That is the main point

I: What are the symptoms of leprosy?

T: They just know about the deformities?

I: How do you think that leprosy starts? How would you recognize leprosy in the early beginning?

P: says something in Bahasa Indonesia

I: You can also say it in Bahasa Indonesia, and we will translate for you?

T translates

[P nods yes.]

I: *[Now directed towards translator]* How would [name] think that leprosy starts and what are the early symptoms, how would you recognize it?

#00:02:52.38# T+P talk #00:03:23.86#

T: she is talking about the stiffness in the hands and starting to develop deformities in the skin

[P interrupts] the skin gets darker.

I: what would her advice be for someone? What would be done?

#00:04:05.63#[T+P talk] #00:04:36.58#

T: she can just give advice, whether the patient approve it or not, she would advice to go the nearest health centre and then from the Puskesmas maybe they can give more specific advice.

I: what are the general views of people in her community towards patients? If someone would live here how would people might see that person, what is her idea on that?

#00:05:23.83# [T+P talk]

T: Since this desa is more modern and she thinks that the people here are already aware about how to deal with health issues maybe including leprosy so they would give advice to people with leprosy to go to seek medicine health care and treatment.

I: So that would be the same as she would do?

T: Yes

I: And would people think differently about that person?

#00:07:42.40# [T+P talk] [mother of participant talk too] #00:08:15.41#

T: she think that people wth think less or discriminate the leprosy patient because people here are already aware and already modern with the mindset on how to deal with health.

I: How about with regard to finding a job? Would they suspect that it is difficult if the person would find a new job if leprosy would be an obstacle for getting hired?

#00:08:44.53# [T+P talk] #00:09:25.74#

T: she thinks it will not happen, but if the disease is already in a far stage it make that he or she cannot work properly anymore then maybe it can get in the way. But like in a story of SDS, the patient can still work, then its okay but make sure the person gets medicine so it not contagious.

I: how does she feel about, because leprosy patients are discriminated in other places, how does she feel about that?

#00:10:04.91# [T+P talk] #00:11:13.19#

T: She feels very empathic with the patient because with that treatment they need it, without he or she can't leave home. But if the environment/community is not helping with getting the cure it is not only bad for curing leprosy but also can kill the leprosy patients spirit, to get a better life. What they should do is giving the right solutions and giving the spirit(courage) and motivation to seek health and seek medicine and if all the people remember we all are same human and gods creation she thinks discrimination will no longer happen.

I: Ibu pointed out that but why this is difference maybe with other kecamatan here? She said people should she the poepie as equal because we are all Gods creation but why is this still a difference with here and other kecamatan, what is the cause for that?

#00:12:48.40# [T+P talk] #00:13:42.47#

T: she says there is low Human Resources, like education. So education is less strong, in here there are enough.

I: So it is about education, the right Human Resources to give the right education, something to do with knowledge?

T: yes yes, something with knowledge

#00:14:14.31#[P talks with mother while] [and talks to Translator] [long story] #00:16:11.93# [T talks with P] #00:16:51.36#

T: there is a difference in educational stage, but in this [kecamatan] is the ...[I: highest education level?] ya education level. The school in Pandaan is like the highest.. the most predege.. [I: prestigious?] yea the most prestigious, better education better school here if it compare with Pasuruan in the costal area, like Lekok and Grati and Nguling. [I:okay what else?] of course that affects the Human Resources and education in here and their mindset on health issues. And she thinks that's why they have a different view on leprosy.

[P talks]

T: Lekok is far away with the education level, [I: long way to go] In lekok they think more about their religion and islamic school and religious education, but in the formal education they lack in quality. [I: okay yeah so a lack in proper formal education?] yes

I: is there anything she would like to share about this topic, what is interesting here?

#00:19:05.11# [T+P talk] [P tells] #00:21:19.18#

T: she thinks more socialization is needed, especially in the remote areas. So, maybe she think It will take a long time, not just one or two socialization, but long term and sustainable socialization. And they would need teamwork with the desk office, health workers, or local community that know the culture and know the habit of the community.

I: And how about the schools? Would that be possible?

#00:22:21.28# [T asks the questions]

#00:22:26.50#

T: yes

[P talks further with T] #00:22:55.80#

T: that would be good if there is a good report or relationship with the teacher of the islamic school it will be easier to get in with the islamic school and when one of them speaks it is more easy to receive and believe for the students and they have more, regard him.. [I: more open yes] more credible.

#00:23:30.40# [P talks further] #00:26:09.52#

T: she talks about the importance of, it is not important to this topic but the religious education itself in pasuruan how it works..[I: ohh okay]

I: thank you so much, your advice is very relevant

P: yaaa sama-sama (you're welcome)

Einde interview

Male community member 3 – age: CM-Pas-7-B3

Notes:

In here it is believed that if chinese and javanese marry that is the cause for leprosy. In this neighbourhood.

There was 1st family infected and they moved after marriage.

Then there was a 2nd family that were in treatment
and a 3rd family where 1 person was infected.

1 person died from leprosy

There was 1 family infected first, they quarantined the leprosy patient that died. they burned down the house but still wouldn't live there.

Then a second family infected (transmitted)
and also their back neighbours

He don't know about the cause

Desa chief took care of [Patient 1] that had kusta (first index case there, around 60 years ago), by sending food and put in quarantine and build a house.

The family of [Patient 1] didn't want to do that, so the desa office took responsibility. The houses were burnt after. But still is contagious because there are personal belongings there.

There is a fear of contagious because it was then transmitted to neighbours.

The patient back then was ignored, he wouldn't go out of the house, so people just ignored his presence/existence. Now, self-stigma of [Patient 2] is different. He would go out, buy cigarettes but will not step up the terrace. Also in the warring he would come to eat but gets a special plate and cup. The warring is a family member of [Patient 2] therefore he is accepted.

He has lack in confidence, but his friends are okay with him. Many people see him now as a normal person. He got married but people talk about his offspring and are concerned. It is hereditary and contagious at the same time.

[Patient 2] still does anything and can do anything. His job is renting a box car and brings furniture everywhere. Don't know about visible. But his face is just red.

Medical treatment really works, people saw so in the case of foese himself. This person thinks that with the right treatment leprosy can be healed and that should be used as proof to convince people.

Besides the different plate there is hardly any difference. and he himself is a little ashamed.

It's okay to socialise with [Patient 2] but don't come too close because it can be contagious. He is doubting. Maybe also through water or anything.

In this interview: change of perception over the years. Difference is that foese is not restrained by his family and foese comes from the leprosy family but maybe is not hereditary. people see it can be treated. Acceptance increases.

He believes in the myth of offspring is beautiful and handsome

Transcript

I: so what is now exactly the cause for leprosy?

#00:00:24.18# [T: asks]

T: he don't know [P talks] his mother is [P talks] His mother is the little sister of the head of desa offer at the time and there is one person that is called [Patient 1] and no one take care of [Patient 1] because it has leprosy [P talks] so the desa chief take care and his mother always send him food.

#00:01:32.59# [T+P talk] #00:01:50.28# then the [Patient 1] received quarantine sentence in one house.

I: so he was a leprosy patient?

T: yes, the first index case yes, and his mother is the one always send food to [Patient 1]..

#00:02:12.29# [T+P talk] #00:02:58.73#

T: so the family of [Patient 1] didn't want to care of him, so the desk felt responsible and they make a small house at the [T asks question to P] ...and short after [Patient 1] died, the family burnt his house.

I: they burnt his house?

T: Yeah because it's.. [T asks P] .. because they are afraid that it can be contagious from the clothes and personal belongings.

I: hmm, and how did the community reacted towards the help the desk office gave to [Patient 1]?

T: They just don't care about it, it was aboutt 60 years ago.

I: and how is it now with the index cases here? How is the community treating him?

#00:04:54.92# [T+P talk]#00:05:07.66#

It is because the symptoms are contagious to neighbors, they don't know whether it is from the water or anything. But all of the family of the next house is infected, all members of the second family. The second family have a child that have become infected so if it gets treatment and the right treatment to do. [T interrupts his sentence to ask something to the participant]. Ohh it is behind, so after the next house it was spread to behind the house.

#00:06:31.82# [T+P talk] #00:07:56.99#

T: So the, maybe when the [Patient 1] at the start of that era, patients were quarantined, so they cannot go outside the house. So from the outside there is nothing difference, no special treatment, no discrimination, or what so ever, there is no discrimination because yaaa.. they think it does not exist. But with this new patient [Patient 2], he also have this self-stigma the Bapak said. He had it in the sample when [Patient 2] buy cigarettes here. Here is unwilling to step on the step, terrace, but stays outside. But there is also a story that when [Patient 2] eat at the warung (=small Indonesian place to eat), which is owned by his relative. On the warung he has a special plate, just for him.

#00:09:23.43#[T talks to P]#00:09:48.86#

T: Yes so, he has a lack of confidence in himself but his friends are okay with him and with the self-stigma.

I: How does this Bapak thinks about [the name of an index case in the neighbourhood] himself?

[T asks P] T: just like ordinary people, person. There is no need to discriminate.

I: Or what is the general perception they have on this person? [silence] Uhh, do people talk about him behind his back or?

#00:10:48.66#[T+P talk] #00:11:18.97#

T: lately [the name of an index case in the neighbourhood] got married and then they started about it. They are concerning about how will his offspring will be. [silence]

I: okay.. is here also.. they think it is contagious, but also if it is hereditary?

#00:11:49.33#[T+P talk]#00:12:01.57#

T: yes lot of people think it is hereditary, they've seen already the proof of contagious.

[P interrupts to tell something, T+P talk]

T: Yes, There are still people here that think its hereditary.

I: how.. is he working or?

T: yes he now become furniture sells to drive a car that drives furniture around.

I: does he have disability, or can you see visibly he has leprosy?

[T+P talk] T: the Bapak don't know, whether he is wounded already or not. He just see a reddish in the face, that is all.

I: and what are the beliefs about treatment, what is his belief about treatment?

#00:14:06.70#[T asks P] #00:14:27.90# T: the Bapak think, yes it works, there is treatment possible. Because in the second family there is already member of that family that already healed, so he beliefs in medical medicine, modern medicine.

I: and what can be done to.. because the bapak is telling a lot about there is stigma and people are worried about his children [T: hereditary?], yes does he have any idea what can be done to prevent this?

#00:15:03.62#[T+P talk]#00:16:54.03#

T: He don't have any.. he thinks that with the. Medicine and right medicine kusta can be healed, and maybe that can be proof that can be seen by the community that kusta is not like hereditary and that it is not a permanent disease.

#00:17:24.46#[*T asks P and talk*]*#00:18:14.20#*

I: can I ask another question?

T: Yaa

I: Is the person, Pak [the name of an index case in the neighbourhood] not treated differently by the community, but is that true?

T: Ya, but maybe with the food, that he has a different treatment only for him.

I: with what? The plate?

T: Yes

#00:18:47.34# [*T checks my question with P*] *#00:19:05.60#*

T: there is no other discrimination besides that?|

I: and what do they think about him? Do they like him or not?

[*T+P talk*]

#00:19:40.71# T: it is like the normal, normal other people. Ya sometimes [the name of an index case in the neighbourhood] himself feels ashamed with himself.

I: okay...

I: Uhm, and do you have an idea bout the perception can you ask him if he has some other things to tell about leprosy in general?

#00:20:21.59# [*T+P talk*] *#00:21:32.93#*

T: He just say that it's okay to be socialize with him, but don't come to close, because we still don't know from what leprosy is contagious. So don't look like just .. [*T+P talk*] maybe it is from water, maybe it is from like something else.

[*P talks with T*] *asks about the research and with whom we are conducting it*

#00:23:15.50#T continues with qualitative questionnaire. *Recording put on pause for a while**#00:27:00.49#*

I: Yes, would he like to know if someone is affected by leprosy, if you can't see it would he like to know? [*T asks P*]

T: Yes

I: why?

T: Yes because he is afraid its contagious.

I: And he told a lot of things about the past and now can you explain the biggest change that happened over the years about the perception on leprosy that has changed maybe? If there is a change..

#00:28:08.18# *[T+P talk]* #00:29:32.27#

T: he thinks that the difference big difference is that [the name of an index case in the neighbourhood] is not come from the family with leprosy. Different then with the other families from which it runs in the family.

I: what is the difference? He is not from the family so?

T: [the name of an index case in the neighbourhood] comes from a family that have no record of leprosy before so he think, maybe they think it's not hereditary so it makes him more receiving of accepting towards [the name of an index case in the neighbourhood].

[T asks P to confirm]

T: yes.

Terima kasih Pak (Thank you sir, thank you)

End interview

Female community member 4: CM-Pas-7-B4

Notes:

Sampled via volunteer of puskesmas, lives at the border of desa. So starting point. Not totally random dus. Actually snowball sampling.

“We should change the mindset of leprosy in the community”

A myth in community is that it is hereditary: but she does not really believe it. There is a lot of disgust.

There are no index cases here, and also no socialisation, people are not familiar with it and it is far away and therefore people might not know so much here. There is no one that knows one that has socialised with it and never met in real life.

In here socialisation is: education and prevention

Cervix cancer + dengue already happened. There is a volunteer from each desa, that health worker would inform the volunteers (ibu emma is one of those) and then spread it around the community [place to implement knowledge]

She feels that it will develop just like diabetes. More people know about it now and now it is just a common disease.

One case happened and transmitted from family to generations, so now there is a fear associated with it. But through socialisation the case that is there can be used. People get used to it and become more open to receive information about it. ‘community based’

Dengue example: not only to desa office, but also with the help of religious ceremony. because many people go there and attend from the desa. Also can be used are the posiandu - mostly meeting, immunisation moment.

The religious events and information support each other, no obstacle there.

patient view: it is contagious, fear, so socialisation necessary.
She will support a leprosy patient but the society may be not.

[answers seem little bit social desirable]

people feel disgust, followed by empathy. And cause for disgust are deformities. and empathy because they see the life of a leprosy patient and feel empathy because the person is excluded and alone.

Leprosy patients are treated differently, excluded from social life and gatherings as prevention measure. People are also scared. Also patients will hide themselves, they don't want to make others feel uncomfortable.

Patient can be treated in an early stage, so everyone should help and empower the patient. Not exclude or discriminate them.

[Feeling that it were socially desirable answers]

Transcript

I: [Name] was hesitant about the idea whether leprosy is hereditary, could she tell me a little bit more about that?

[T+ P talk]

T: it is like the other disease, like diabetes and hypertension. People think it is hereditary, but also can be from the food factory. They also think it's with leprosy. I: because in the past they thought that diabetes was also hereditary and now they know it's not, so she suspects the same with leprosy?
T: yes yes, like that.

I: Does she know why most people think it is hereditary?

[T+ P talk]

T: because when one case it happened that it was from grandfather to grandchild, maybe their son and daughter, its happened on the scope of one family so that is why people think it hereditary.

I: She also suggested that maybe if here is case in the neighborhood that can socialize people of what leprosy really is, she thinks it would change this idea?

T: yes socialization is like waiting that there is a case happening and willing, yeah, they start socialization.

[T+ P talk]

T: Yes, this Ibu think that the people here are open to new information so there is socialization that say leprosy is not hereditary they shall believe it.

[T+ P talk]

T: So they do it with dengue socialization, was good idea... they do not only go to desa office but this Ibu and other volunteers are like going to some like, religion ceremony in this neighborhood. And then.. share ht information about dengue.. and that is their way to get to... eeuh.. to inform.. much more people in society.

I: Why is especially religious events successful to use?

[T+ P talk]

T: More effective because the people that attend religious public dialogue for religion, we call it 'penajian'? Is much more. More people that attend, than meet in head office or RW office, there are a few people active voluntarily there. So they do also do the socialization on posyandu, I have told you about posyandu on.. euhmm, ohh what desa?

I: can you tell me again?

T: you already write down it, posyandu (community health centre for baby's and infants and pregnant moms, *consultatiebureau in Dutch*) is like the monthly meeting that the Ibu Ibu that get immunization there and vaccin there. To check the health of the baby and maybe someone is pregnant.

I: what has that to do with this?

T: They carry the information that they have maybe with dengue or cervix cancer here. So it makes the volunteer.. they try to spread the information as much as they can do in the where people... in the posyandu

I: what is the influence of religion in these activities? T: what activities? I: of socialization about disease

[T+ P talk]

T It is like supporting each other, there is no religious obstacle, or religion that forbids some information for being shared as long as it help. For example with cervix cancer it was long time ago a taboo to talk or share information about cervix cancer, but now is not.

I: Okay. But my question is not about the obstacle but how it maybe can help.

T: yes they are supporting each other, and helping each other.

I: what do people in this community think of leprosy patients? How do they view leprosy patients?

[T+ P talk]

T: Ibu [name] said that most of the neighbourhood see leprosy is a contagious disease even though it is not. This Ibu know its not. So, yes, we need socialization to change that concept. The fear that it is contagious.

[T+ P talk]

T: If there is.. if she finds.. yes she would support the patient and seek for medicine and try to not avoid it or discriminate it. I: she said that? T: yes she would do that, but maybe that is the same with peer opinion.

I: But how do they see, the action towards the person? Not how they see leprosy, but how do they see the person? Is it considered less the person or how does she feel about that?

T: Avoid it or disgust, but as the time goes they feel sympathy

I: En waar komt.. [herstelt zich] eeu.. And where comes the disgust from?

[T+ P talk]

T: It is because of the deformities?

I: and the sympathy? What makes the change?

T: It is like the, if the people see every day life. And then they see that the people is discriminated, have no friends.. and that is where usually it changes to sympathy.

[T+ P talk]

T: there is no communication between patient other people . [I: what do you mean?] Oh when they see they are alone? So when they see they alone, no friends, no communication also to other people... uhm... I: excluded? T: yes..

I; are people treated differently?

[T+ P talk]

T: Yes. [I: how?]

T: Yes no communication, and like not including them in socially group.

I: is the person discriminated with regard to other events, like during meetings, work or marriage?

[T+ P talk]

T: Yes excluded for social meeting like.. [I: why?] because she said people are scared.

I: Is she scared herself?

[T+ P talk]

T: No she already know how it is, she just feel empathy
[silence]

I: Okay, would she think with leprosy would hide it in this community?

[T+ P talk]

T: Yes she thinks. [I: why?]

[T+ P talk]

T: It is like self stigma, other people may feel disgust, so better hide.

I; but is it true? is it righteous self-stigma? Is it true that others disgust them?

[T+ P talk]

T: Yes that is the case if it, especially if it is worse case. But not with early symptom

I: so is it from two sides? The community feels disgust, and the person is fearing that and therefore the person hides?

[T+ P talk]

T: Yes it is both

I: would she likes to know if someone has leprosy or rather have it disguised?

[T+ P talk]

T: Yes because that person has to have the cure to heal. [I: so she would like to know?] Yes

I: Is that the general view?

[T+ P talk]

T: Maybe, if there is socialization, and people know about this.. maybe..

[P talks]

I: [Could understand the participant] So maybe if there is socialization people will, may accept it?

[T nods yes]

I: so what is the ideal picture of a community with leprosy patients that live in this desa, would they be overt/visible?

[T+ P talk]

T: Yes, it must be helped. It must be helped soon, if there is one people or more people know that is positive with leprosy so the people around him or her should help him or her to help to seek help from Puskesmas or medicine.

[T+ P talk]

T: It cannot be discriminated or excluded for the socialization purposes.

[P talks about the study]

[T answers about study districts]

T: okay?

I: this ideal picture can be reached through socialization or?

[T+ P talk]

[P: nods]

[End interview]

Male community member 5 – age: CM-Pas-7-B5

Notes:

Knows about lepra. Many people die but there is also someone still living with leprosy close to his house.

Step on graveyard and got leprosy. Red face, hand is stiff. Did not take too long he said.

If someone has leprosy and buy something, the persons would separate the money that the patient gives.

There was once a patient expelled from the community. He was from lekkok and moved to his wives' house in Nguling. Had 2 children and then got leprosy. Index case did not want to go to puskesmas regularly, symptoms got worse. Community expelled him because he looks disgust. and deformities.

went back to lemon. He was himself also ashamed for his appearance. But he did not go to puskesmas.

this was 1 year ago, they are very happy that the person is no longer in the community.

having leprosy is a burden, it is heavy disease because the patient will be excluded. People are scared, me too, because it cannot be healed. and it is disgusting.

It can be treated. But some people don't want to be treated. So that patient was expelled.

People with leprosy should feel shame and the example also self-stigma.

Deformities sometimes happen but not on the face. When he face is normal and hands and feet are affected it is okay. That person can still live here.

common view on that person is nothing special, he is just a person. Just you should never have skin contact with the patient. Also the person himself would never initiate contact. And his appearance and face were normal.

Still he is treated differently

- people won't come in skin contact with him

when he buys food it is careful, not to come into contact.

He would stay outside while ordering (warung). Neighbour gives them food as well.

His opinion: very kind, very caring for other people and friendly.

He still chats around with neighbourhood but takes distance himself.

Two kinds of leprosy:

- leprosy was because of graveyard.people with leprosy die, and on friday lucky you cannot step on its grave.

- real leprosy, not from the myth but full face affected leprosy.

He believes that the symptoms emerge after having children. for marriage there is a problem because no one would take the person, or would want to have children with the person

- ends in divorce

- fear of contagious

- hereditary

interviewee is in doubt about hereditary. Maybe sometimes yes.

He does not know a leprosy patient personally and would not have close contact with him.
'No one with leprosy would ever look normal' so you would also know it (answer to the question: would you like to know if someone has leprosy)

If my friend has leprosy I would take a step back, and do it obviously. Just to let him know that we don't want contact. It is disgusting, it is ugly. I would do it with everyone that is ugly.

Transcript

I: we will speak in English, and he will translate me

[all laugh]

I: Can you tell me a little bit about the knowledge with regard to leprosy?

T: It is a very heavy disease comparing to other disease, because it is the patient. The patient will be excluded with the people from the community.

I: What is the main reason that people are excluded?

T: they are scared and cannot be healed, disgusting.. he said disgusting

I: Do they feel that leprosy can be treated?

T: Yes if the people want to, but the person that is expelled does not want to be treated.

[T+ P talk]

I: the patient that was expelled? Why was he not treated?

T: maybe because he himself feel ashamed and yes self-stigma I think. He is ashamed with himself.

[P +P2 talk]

T: they talk about the other patient that just show that had deformities but nothing happened with his face.

[T+ P+P2 talk]

T: This patient in community has a normal face, lives 200 meter from here. Has a normal face. And the hand are only on the deformities and also the feet. And look like slightly normal. They are not expelled or avoided or excluded.

I: The other person died? Still lives here?

T: the person still lives here. Do you want to go there? She asked

I: [laughs] maybe later, after..

What is the view of the community on the leprosy patient? Their opinion?

[T+ P talk]

T: It just.. it's common.. It is not nothing special treatment, because..

[T+ P talk]

T: they treat it commonly but never get to close, never get skin contact so shake hand. But the patient himself maybe like to he.. realize that maybe the people don't want to shake with me. So he never initiates that contact.

I: what is the difference between this patient and the one that got expelled?

T: The appearance in the face.

[T+ P talk]

I: besides making contact other ways that patients are treated differently?

#00:06:18.77#[T+ P talk]#00:07:37.61#

T: If he is buying food or something people would not have skin contact. So when they want to put.. uhh. He would wait outside the warring and say what he wants to eat. And the warring owner would come out to give the order, he would not go inside. But if he is asking for food from his. Neighbor, they also give them something. In warung just, it is like a business and they don't want to scare of other customers.

I: How do they feel about the person that is still living here in the community?

[T+ P talk]#00:08:50.80#

T: he is very kind and very, he cares for other people and he is friendly.

[T+ P talk]

T: So he is chatting around, he is hanging around with the neighborhood and he himself put a little space with the crowd, so not the crowd that go far. But he should realize that maybe I should take distance.

I: so he is around but would take the distance?

T: Yes, so maybe if he would join conversation here, He would sit over there [points to other side of the room]

I: And what do people believe that the cause is for leprosy?

T: His leprosy is because he stepped on the graveyard of a leprosy patient

#00:10:38.77# [T+ P talk] #00:11:11.95#

T: He said that if the people with leprosy would die and would bury, no one can step on the graveyard on Friday Lucky, or people that will step on it will be infected.

I: And the other person that was expelled what was his cause for leprosy?

[T+ P talk]

T: she says it is like the real musts, the real leprosy?

I: what does she mean by that?

T: means.. it means like it is not a mythical cause.

I: What is then the cause?

T: don't know the cause, but say that.. don't know where he gets leprosy but after he lives he for several years he got two children. Then the symptoms emerged, so they don't know where it came from.

[T+ P talk]

I: And what is the consequence of leprosy with regard to marriage, or children..?

[T+ P talk]

T: They know it can be a problem because there is no one here that wants to have a wife or husband that is infected by leprosy. So most of them will divorce and the worse is.. no one would want to have their children, because they are infected

I: is it just because it is contagious? Or also hereditary?

#00:14:33.76# *[T+ P talk]* #00:14:48.18#

T: it is hereditary.

I: okay..

[T+ P talk]

T: he know someone with leprosy, the mother.. but the child is not infected. And it ever happened in this desa when the time when the land is here.. no one wanted to buy the land in this village because many people on that land had leprosy, but now it is not?

I: because of the person with leprosy had children, but the children not so therefor they gets the idea it's maybe not hereditary. They are in doubt?

T: not really in doubt, but they think it is a special case. It is like that. They still believe and agree that it is hereditary as well.

I: do they have a lot of contact with the contact with the index case that lives her?

#00:16:38.02# *[T+ P talk]* #00:16:59.36#

T: for common contact it's just crossing his room. Because their child is married with someone that live there. So near with their home.

I: but no personal contact?

T: No just like neighbor.

I: Would you like to know if someone has leprosy if you cannot see it?

[T+ P talk]

T: They believe that patient with leprosy is always visible. There is no people with leprosy that isn't visible or they can hide it. You see the redness in the face.

[P talks]

T: the Ibu also say that if she had a friend that maybe she would find out have leprosy. They would take step back, take distance, obviously so maybe would make the patient realize that they don't want to get to close to the patient.

I: why would she do that, what is her main reason?

[T+ P talk]

T: Because it is disgusting, it is not for the contagious reason. [participant laughs] for example, you [points at interviewee] you are beautiful, but they look reddish. But if you have deformities P2 would also step back. Would do it with everyone that looks ugly. [P laughs]

I: Do they feel that leprosy patients are allowed to work in the community?

[T+ P talk]

T: yes they are allowed to working, and this person is also still working. He works with sand and selling sand.

[end interview]

Female community member 6 – age: CM-Pas-7-B6

Notes:

Every time when talking about leprosy patient she would lower her voice because it is taboo. but she is comfortable with asking questions.

She thinks it is hereditary. many leprosy patients are living at east side of grave yard.

symptoms are swollen ears itchiness, deformities on fingers. Index cases soaked feet in warm water every morning but made no difference.

Leprosy patient came to her house, she would mop the floor afterwards.

She would not accept food of leprosy patient.

It can be treated in puskesmas, but never healed because it is hereditary. Therefore, never marry and index case because it is hereditary. Bad flesh is the disease.

You can die from it, and disability cannot be prevented because you don't feel that it happens, no pain, so people would neglect it

She would not refuse people, but keeps distance. But not explicitly or obvious. Keep feeling in mind. So therefore not refuse visibly the patient.

She fears contagious because of fishy smell sweat, fishy and oily. She feels disgust but would not show this to the patient.

It is hereditary and attacks hand and finger by shrinking. It can be treated in puskesmas.

we would exclude the person from eating and food. Religious gathering it would still come ut keep distance from crowd

patient themselves would not come too close to others. They know it (index cases) but feel okay in doing so. because it maybe contagious.

Reason for exclusion is disgust, not contagious.

The physical appearance of a person (points at fingers and skin on arms) they have a different skin.

Knows someone, selling tofu waste for cows. The buyer is a leprosy patient not in treatment. She saw the deformities increasing over time. So she thinks treatment is important.

It cannot be cured because it is hereditary and disability just happens. but it's okay because they don't feel pain (illness, disease)

Person is also different. Offspring will get it too, and the person stays different because of leprosy. because you would also see it in the red face. This is the general view.

People would take distance, and people would walk away if a leprosy patient comes. When there is a gathering at the family home people would come but only eat packed food.

In a community event - ibu ibu would come together to cook. The patient with leprosy would not come.

"They work in the field with cows, or as farmers. But as sellers they cannot work with small fingers."

She would rather not have a patient in the house but it is okay to go to the leprosy patient's house as long as you don't drink or eat anything.

She feels sorry for patients because when it gets worse the patient will be expelled from the house to a different smaller house.

distance is made by slight movement. it happens naturally. both parties keep distance because of fear and disgust. The general view is that it is contagious if you have the same sweat. Quite a lot of patients. in here.

They have not live on graveyard or farther away.

she will keep distance to family members as well because it is hereditary. Wedding party in the family. They will help cook for the family of the leprosy patient. Otherwise no one would eat it.

food very important, like significant measure of distinguished.

leprosy patient should have a separate grave but would attend funeral.

She would rather not know if someone has leprosy.

Transcript

[A lot of backnoise from the street.]

I: I think you know what this research is about, leprosy?

[T translates, P nods]

I: Could you maybe tell me what kusta is, what is caused by according to you?

#00:00:35.77# *[T+P talk]* #00:01:03.61#

T: It is kusta, it is hereditary. *[P talks]*

T: It is like shrinking hands and fingers, and as the time goes it will become deformities.

I: and leprosy could be treated?

[T+P talk]

T: yes it can *[T+P talk]*

T: you should go to Puskesmas.

I: Can you tell me about the views in your community about leprosy?

#00:02:21.90# *[T+P talk]* #00:04:14.07#

T: so they make will.. will excluded. Like.. when it is going about food.. *[T confirms with P]*
#00:05:07.12# and then when it comes to religious activities or gathering, they still coming. But leprosy patients will make little space with the others. This woman said that they themselves have the feeling to not be too close with the others.

I: okay and what else?

T: And then they.. no.. I mean. They know that the community would make a space with them and exclude them, but according to Ibu they feel okay with that because they have a disease that maybe can be contagious.

I: What does she think, does she agree upon the common view about keeping distance? [T: what?]
The view of the people is to keep distance, she would do it herself to?

#00:06:25.50# [T+P talk] #00:06:32.46# T: yes she would do it?

I: What is the main reason?

[T+P talk] #00:06:46.24#

T: is is disgusting. It is disgust.

[T+P talk]#00:07:06.13#

T: just disgust, because she says it is not contagious, only hereditary but it is just.. the reasons they exclude the patient is only just disgust.

I: and what is, .. what disgust them? Their appearance or the way they acting?

[T+P talk] T: Yes...

[T+P talk]

T: Yes, because the appearance they have different flesh or different skin

[T+P talk, while P is lowering her voice]

T: she knows one leprosy patient, when Ibu was selling tofu waste for the .. for the cow food. One of the buyers is a patient of leprosy and then she says the deformities like little by little, because he or she come often here, and then at first it was just like until [points to fingers] and then more and more [moves hand down] [refers to shrinking of fingers]

I: was that person in treatment?

#00:09:22.88#[T+P talk] #00:09:33.28#

T: Yes there was one that was treated, but the other is just like neglected, they don't care.

I: and the one with the deformities little by little lost his fingers? Was he treated?

[T+P talk] T: no.

I: Does she think treatment is important?

[T+P talk] T: yes.. *[P talks]* it is important but mostly they don't get treatment *[P talks]*

T: the Ibu said, the reason that they not treat it, they think, because they think it is a hereditary so it cannot be cured or be healed, so yeah it is not pain. They not feeling pain. [Seems translator's interpretation: So that is the difference between illness and disease]

I: What does the Ibu think of the person with leprosy, the patient?

#00:11:34.72# *[T+P talk]* #00:12:11.50#

T: it is different...

[P talks]

T: it is usually, when one member of the family gets disease usually the offspring also... *[T confirms with P]* #00:12:58.48# So they feel like, it is just normal for them, because they don't feel pain or sick.

I: So the Ibu think it is different?

T: yes there is a difference between the two.

I: Does she think there are also non-visible symptoms to leprosy or only the fingers that are deformed?

#00:13:28.01# *[T+P talk]*

T: Just the red finger and feet, and a reddish face. There is no itchiness or coldness. It is just the physical appearance, reddish face and deformities.

I: Do more people think that person affected by leprosy is different, or is it just her opinion? Or like a general opinion in community?

[T asks P]

T: Yes it is different from the rest.

I: In what ways are people with leprosy treated differently? If they are?

#00:15:05.49#*[T+P talk]* #00:16:14.57#

[In the meanwhile she is helping a customer in her little store for daily needs] T: It is just like they make space, and then when the family held some kind of gathering in their home, the people that come there are invited. The people told them to not give food when they in there. Just give food just

like packed. [I: packed food?] Yes a pack of food to bring home. So if the food is pre-packed and bring home the family will not know whether it will be eaten by the people that invited.

I: So the family of the leprosy have to give their guests packed food?

T: Yes besides the packed food the house also give food to eat inside the house during the event. Usually.. With the normal people. But not with leprosy patients

I: and any other ways that leprosy patients are treated differently? *[participant joins again]* T: no just the make space and food.

[T asks P again] #00:18:50.87#

T: So the Ibu says that the other example is, when people when the community have some event, like a wedding party or like that. Usually Ibu Ibu around the neighborhood is helping to cook, but not with the leprosy patient, they are not invited and not asked to help and they themselves don't come to help because maybe the house does not want to be helped by then. They can just work as a farmer or take care of cows in the field. Because if they would sell something then nobody would buy it

I: would she invite leprosy patients into her house? [T: for what?] I don't know, would she let a leprosy patient into her house or not?

[T+P talk] [P shakes head no]

T: no she would rather reject it?

I: why is she afraid or?

T: wait wait, if the Ibu goes to te house or? [I: yes...]

[T+P talk]

T: It is okay to go to the patients house, but no food or drink.

I: Uhm okay.. and how does she feel about that leprosy patients are excluded in somewhat important think? Does she feel sorry [T: what do you mean? For the leprosy patient] yeah?

#00:21:27.88# [T+P talk] #00:22:00.62#

T: it is because sorry, she said that when it is getting worse, the patient will, the family of the patient will make a small house, separate from the main house, to place the patient getting worse?

I: and who is taking care of the patient?

T: the family would take care of him

[P talks]

T: because the y don't wanna be treated so it is confusing when it is getting worse, so only way is to exclude him [I: because they are not treated?] Yes. *#00:23:13.49#*

I: Last time with the interview, uh, she said, I would keep my distance from the leprosy patient, [T: Yes] but not physically? Can you maybe first ask her if that's still.. if that is correct that she said that. And also if that happens in general?

[T+P talk]

T: yes it is not like obviously because ya it is making like.. making slight movement to make a distance. The Ibu says that the patient himself have the feeling he or she must keep a distance and that he or she should not come to close when they gathering around or in a crowd. Like that. [I: she means that it happens kind of naturally that the distance exist] Yes

I: how does she feel about that, is she happy that it works that way? or.. [T: uhmm] like the distance happens naturally, the leprosy patient and people keep distance [T: yes yes, both of them] she thinks that is supposed to be that way?

#00:25:17.95# *[T+P talk]* #00:25:25.71#

T: yes she says like that.

I: and that is important because?

T: She is just afraid and disgust.

[P talks]

T: Oh she is afraid of disgust, and little bit afraid of contagious because if the sweat is the same it can be contagious.

I: Does she maybe know more people with leprosy?

#00:26:24.35# *[T+P talk]* *[P lowers voice again]* #00:26:45.15#

T: there is one inside the graveyard, and behind the graveyard there is also one. But the more they know. But it is not in this desa, but in neighbor desa.

I: oh that is a lot

[P talks]

T: also in the east of the market there are also a lot of patient

[P talks more]

T: so in the east of the market in the Puskesmas there are a lot of patient also and the Ibu says that when it is getting worse, the family would make a small house near the graveyard for the patient. *[P walks away]*

I: why near the graveyard?

T: I don't know.. maybe it is.. because its s little farther from the community. Because the graveyard is mostly separate from the neighborhood.

I: I would like to know.. it is hard to formulate for me in a question but maybe in conversation you can ask her this: I would like to know in marriage ceremonies there is differences, I would like to know about those special events what the difference is between a person with or without leprosy. Because in this interview she highlights some differences, so I would like to know what all the differences are.

T: So you already know about the religious gathering [I: yes] and when the wedding party, but it's.. the other community other that help we don't know about whether the family of the patient is helping a party [I: yes] something like that? And the funeral maybe? Would you like to know [I: yes and where they are buried?] *[T nods]*

I: after that I would like to know on the effect of family members from the leprosy patient. [T: I should formulate that in a question?] yes or in conversation so you won't have to ask her directly but just respond to what she says.. [T: okay okay]

[P helps customer of local store]

#00:30:50.59# [P comes back and T+P talk] #00:32:18.02#

T: so they also make a distance with the male family member with leprosy even though they look healthy, cause they is afraid of hereditary. The family of the leprosy patient is helping some wedding party the Ibu Ibu would still help to cook the family *[T check with P]* by going to the market, and getting the supplies.

[T talks with P] #00:34:04.36#

T: so the house and the family of leprosy patient held like wedding party the family itself did not join to cook, help to cook. They would do not have to do anything with the food, but if like that lots of people still don't want to eat the food. [I: but it seems that food is really important in this? Yes

[T+P talk] #00:35:25.67#

T: also when it comes to the funeral, the graveyard is different than the other. It is in the hedge. Or they would still make the distance on the people that already die. [I: still make distance when?] when they die. So the graveyard is separated?

I: will people go to the funeral?

[P nods]

T: Yes they would still go

I: are there any consequences of family members, also treated differently [T: yes] yes even though they are not infected?

T: Yes I'm sorry the Ibu already said this, even though it's healthy, ,if you are the offspring of the patient with leprosy you would still get stigma and get the exclude treatment.

I: Would she likes to know if someone has leprosy or not? *[T: what Ibu thinks]*

[T+P talk]

T: No she don't want to know, [I: she would rather not know] no she rather not know..

[T+P talk]

T: Just don't want to know.

[End interview]

April/May 2017

<i>Male contact 1 – age: 40</i>	50
Notes:	50
Transcript	50
<i>Female contact – age:</i>	54
Notes:	54
Transcript:	54
<i>Female contact 3 – age: 60</i>	60
Notes	60
Transcript	61
<i>Female contact 4 – age: 70</i>	67
Notes	67
Transcript	68
<i>Male contact 5 – age: 37</i>	73
Notes:	73
Transcript	73
<i>Male contact – age: 74</i>	78
Notes:	78
Transcript	78

Ages:

Contact 1: 40 → [CC-Pas7-B7](#)

Contact 2: 45 → [CC-Pas7-B8](#)

Contact 3: 57 → [CC-Pas7-B9](#)

Contact 4: 70 → [CC-Pas7-B10](#)

Contact 5: 37 → [CC-Pas7-B11](#)

Contact 6: 74 → CC-Pas7-B12

Male contact 1 – age: 40 CC-Pas7-B7

Notes:

Symptoms started in the (kuiten), then the arms. He is the father of the index case. His son is diagnosed with leprosy 5 years ago.

He think it can be cured, but also have come-backs. After finding out about the symptoms they went straight to puskesmas. He is in treatment for 5 years but still has reactions.

The cause is black magic, someone charmed his child. They were immediately open about it and not shy, the son is 21.

Since 5 years the son is not working, before he worked in construction
Because of leprosy he cannot work anymore.

They don't experience discrimination. No worries about exclusion. Friends are accepting.

Marriage probably won't happen because ashamed.

When his son has reactions he will not go to religious events.

He thinks you should keep get medicine and seek treatment right a way. All parents want their child to be healthy and that is possible with treatment adherence

After interview: further observation+Reflection: after this interview the researcher and translator reflect on this interview. And the research explained again the importance of sentence-per-sentence translation in order to make sure that the interviewer knows the answers better then what happened now. The translator used the interview guide to perform the interview and only translated parts of the answer. This gave the interviewer no opportunity to probe for answers and ask more questions. Also the participant was very shy. The interview took place within a Puskesmas and it the dynamic sof the conversation was influenced by the presence of a health worker. The health worker intervened a lot with the interview. After the interview, I heard that there were also a language barrier since the participant talked a certain dialect that the health worker was skilled in but the translator was not fully. So basically there were two translators in this interview. The participant was shy to answer. It seemed that he felt pressure to give the right answers. Overall, I doubt the quality of this interview.

Transcript

Translator: [talks indonesian] paks [name participant]

T: we are talking with Mr [name participant] and he is 40 years old.

#00:00:22.58#[T+P Talk]#00:01:02.55#

T: it started with tremor, when I asked what is leprosy. He says: it is tremor or.. [health worker starts talking]

I: You asked the first question?

T: Yes

#00:01:34.29# [T+P Talk] [Health workers talks also] #00:02:22.32#

T: He don't know the cause of leprosy, he only knows that yes suddenly there became white spots all over the body. He still doesn't know what the cause of leprosy is.

I: Okay

#00:02:45.82# [T+P+Health worker Talk] #00:03:32.91#

T: there is a red patches and white patches. It is like what the health worker says. [points to red skin] and then the patches become swollen en usually after that the patient dropped on the floor. Patient cannot move, cannot do activities, become very ill, cannot start there day.

I: where did the skin patches start? [silence] legs/ or arms?

#00:04:02.44#[T+P Talk]#00:04:36.77# [health worker participant and translator all talk at the same time]

T: at the leg [points to chives], and the arms, and back.

I: What is the relation? How do he know the leprosy patient, is it family or?

T: the leprosy patient is his son [I: Son?] yes

#00:05:20.03#[T+P+Health worker Talk]#00:05:35.75#

T: yes leprosy can be cured and then maybe sometime it would come back, but yes it can be cured. [I: and how?] with medicine

I: when was the first time that they were seeking help? Did they go to Puskesmas first, or what did they do?

#00:05:57.27#[T+P Talk]#00:06:13.98#

T: Went to Puskesmas [I: straight?]

T: Yes go straight to Puskesmas.

[silence]

I: and how long ago was the diagnosis?

[T+P+Health worker Talk]

T: it is now 5 years ago, but his son still get reaction sometimes.

I: okay..

[T+P+Health worker Talk for like 1 minute]

T: some people say that it is black magic

I: as the cause?

T: yes black magic, it is like charms and curses

I: how is that for the family? Has it have big impact on their family?

[T+P talk]

T: they are not making a big deal out of what people say they just ...[T+P Talk]

T: because they themselves don't believe that leprosy comes from this, so they don't make a big deal of what people are saying.

[T+P talk] [Health worker asks things in between] T: do you want to interview 1 contact?

I: well we could do two

[T+ health worker talk]

#00:10:01.67# T: yeah but this is not the common view, just there is little part of little percentage of people that say leprosy is caused from black magic, but most people just think it is a common disease

[I: okay]

[T+P Talk]

I: what did you ask here? [silence]

I: Maybe you can ask? Would they hide their son has leprosy?

T: No..

[T+P talk]

T: no they are not hiding, and the son also don't feel ashamed.

I: how old is the son?

T: 21 now

I: what is he doing? Going to school or working?

[T+P+Health worker Talk]

T: since 5 years he is diagnosed with leprosy he is not working anymore. But before that he was a worker in construction or something like freelance worker.

I: because of leprosy he cannot work anymore?

[T asks P] T: Yes, that is why.

[T asks P question, Health worker talks to]

T: they community treat normally with their son, there is no discrimination or...

[P talks]

T: he has no worries for his son gonna be discriminated because he has a lot of friends that accept him

I: okay, and how, would they think he can work again in the future or marry someone, or something like that. How do they feel towards that, towards the future?

[T+P talk]

T: Yes, but for work he really wants that he can get working again. But marriage, there is still no.. he doesn't think not yet.

I: why?

[T asks P] T: because he still have reaction sometimes, maybe he would feel afraid of himself, so self-stigma. Worrying about himself

I: so worrying about himself, how he looks?

T: yes and maybe worrying about his wife cannot accept him or so.

I: so there is still little stigma, self-stigma?

T: yes with marriage.

I: how about with other cultural events or religious events?

[T asks P]

T: if there is no reaction, he will come, if he is like 'normal', but when he still in reaction, of course he cannot go?

I: why?

T: it is painful, and cannot stand up?

I: what would he advice to other families? Many families are afraid to seek health care... [T: because it looks ugly?] Well, what would he say about that?

[T+P+health care worker talk]

T: just keep get medicine, because a lot of parents want their child don't want to become their child to become healthy again. And that is only [I: possible with treatment?] yes yes.

[P+health worker talk]

T: is this okay? Can we stop?

I: can you ask him if he has questions for us?

[T+P+health worker talk]

[health worker asks about interviewer]

I: does he has questions for us?

T: no

[End interview]

Female contact – age: CC-Pas7-B8

Notes:

Points to legs and arms when talking about symptoms

2 months ago she recognised white spots at her neighbour's skin. They were not itchy but got bigger over time.

Neighbour can do anything still, and is not discriminated.

Another neighbour she knows with leprosy is discriminated because of disability. Shows picture while telling us, he is much worse.

Example male index case (Bapak Suki): there are 4 daughters in the community of index case.

- 10 years ago it started with skin patches and he didn't want to go to puskesmas

- 2 were already married and got divorce because of leprosy, which is not something that happens soon

- no one wants to take him to puskesmas now

- daughters have quite normal life now

[laughing while telling us] of course he is treated different because he is not normal, he is not human, afraid of him. The neighbour that is just diagnosed is normal still.

She believes he is an Islamic teacher and don't wanted to get modern medicine because it is fate from God. He leaves it to God.

cause is hereditary

Transcript:

I: so who is this?

T: this person is a neighbor

I: neighbor?

T: Yes neighbor

I: who is the leprosy patient?

T: is a female patient that is 25 years old.

I: okay..

I: when did she know her neighbor has leprosy?

[T+P talk]

T: it is about two. Months ago, and first it seems not too bad. Red spots on the skin [I: red spots?]

and it did not itch or anything, but it get more over time, it get spread.

I: they get bigger?

[T asks P]

T: Yes they get bigger

[T+P talk]

T: and in the back, and on her legs.

I: itchy?

T: no it not itch.

I: what is her reaction on leprosy?

[T+P talk]

T: She says that she is a kind of health worker, she is a volunteer. She gets used with people with leprosy. [I: she is a health worker?] not a health worker like 'cutter'? Like a community member that got the information an socialization already and now volunteering in her neighborhood. When she saw the white spots on her neighbor she was curious and asks to the daughter of the patient about it, and checking it. And straight go to Puskesmas to get treatment. [I: so she initiated that she gets treatment?] yes she initiated

I: and now is the patient on treatment?

[T asks P]

T: yes

I: and how is it going now with the patient? Improving the skin patches?

[T asks P]

T: yes it is getting improved with the salt, and to clean it.

I: because she is a volunteer in her neighborhood, what is the general opinion of her neighbors on leprosy and on the patient?

[T+P talk quite long for 3 minutes]

T: they call it 'daging elek' or 'gatal-gatal'. So it is interesting, I also found this in Sumenep, that for this Ibu, Ibu [name participant], she doesn't tell to the patient that the patient got leprosy. Because she don't want people to know, or the neighborhood to know, or question herself for feel like ashamed or feel like angry, or feel angry. She just feel like the people get usual excema that itches. Even though it is not even itchy, and then just ask for the patient to go to the Puskesmas, to get checked to get medicine. [I: And the patient does not know it is leprosy?] No, but now after medicine she will reveal it. You. Have got leprosy.

I: why would she do that?

T: it is more important they get treatment, then the label. With this bus, she told first that it is usual excema. But she don't want to go, because it is usual disease, no need to go to Puskesmas. So maybe if it is usual disease people don't think it is worth it to go to Puskesmas, but finally after the Ibu tell the truth, tell it is contagious or your family can get this disease to then the patient will come to Puskesmas.

I: so the previous question they tell a lot, what did she say? She said she would not tell her neighbor or patient first? Why, because of shame or?

T: Yes, because a lot of people think that this is a hereditary disease, and a shameful disease. So people that get leprosy can come a minority in society.

I: so she wants to stimulate that it is treatable, she would just seek help and then it will be okay, so that it will not be spread?

T: yes that's what she wants?

I: that is her aim?

[T asks P]

T: Yes

I: Okay and what do people think when they hear about leprosy? Because they think it is hereditary?

T: yes...

I: what else?

[T+P talk, T asks about the myths]

[silence]

I: what did she say?

T: wait.

[T+P talk]

I: she says people think it is from about breaking a vow? [I: a promise?] yes breaking a promise, in a marriage or like saying 'I'm not stealing' but actually you are so the promise, but you still breaking the promise.

I: so immoral conduct?

T: Yes, immoral conduct.

I: how do people treat her neighbor now? Do they treat her differently?

[T+P talk]

T: treat normally

[P talks]

T: normally because the patient is not in far stage. Does not have obvious reaction, it is just some small skin patches, it is not too visible. So they still act. Normally and treat her normally

I: but does the community know?

T: yes the community already know that she has leprosy

I: okay so she is treated also the same? She can still work or?

[T+P talk]

T: yes she can do normal activity, because still it is PP or MP, it still not too severe, not disabled to do activity.

I: is her family now also treated?

[P+T talk]

T: no not yet, it is next week.

I: what does Ibu [name participant] think, how does she.. what .. how to prevent leprosy in the future? Also with other neighbors?

[T asks P]

T: keep good hygiene, but also little bit avoid the patient. [during this the participant giggles] we usually talk like this [points to our normal distance of sitting]. But with leprosy patient, after I know you are patient, I can only talk with you like this [moves chair a little bit backwards] [participant is giggling/lauhging]

I: why?

T: yes because it is contagious still, not too close.

I: how is it contagious? Or how?

[T asks P] T: it form spit form the mouth, [P talks] so you should give self-hygiene and neighborhood should also have good sanitation.

I: she feels that the neighbor, besides keeping hygiene, the neighbor can do anything? Religious events? Having children, marriage? Work? Is she still able to do anything? Or should she stay inside?

T: the patient?

I: Yes according to her opinion, can the patient still do anything he or she wants?

T: Ooh okay, yes yes..

[T asks P]

T: well this person is already married, and now she is pregnant. So yes she is having children. [T+P talk].

T: desa balonganjar is the endemic village with leprosy.

[T+P talk]

T: there was also another neighbor, and he is much worse an she got stigma. He was discriminated, because yes.. you know.. visible disability. And visible reaction.

I: and what? Can she tell us some examples where the discrimination shows?

[T asks P]

T: this Bapak has four daughters, two of them were married, two of them not. And the two married daughter are divorce by their husband because they got leprosy. [I: because the father has leprosy?] No, because they were also infected, and when the husband found out, they would leave the women.

I: and how is that in daily life?

T: when Ibu [name participant] wants to take them to Puskesmas, there was no one that want to take them with motorcycle or car, because yes, there is a chance that it is contagious?

I: what else? Is that all she said?

T: yes?

I: how does she personally feel towards her female neighbor and to the Bapak?

T: different treatment or what?

I: aya, how she herself feels towards them. If it is different?

[T asks P] [Health worker and P laugh]

I: what do they say?

T: she would treat them totally different. Because the neighbor just normal, and the other one is mostly not human. He is not human, because she is afraid of contagious, [I: afraid of him?] yes she is afraid of him.

[T asks P something]

T: But the person that live in the same household she would treat normally. So the 4 daughter, they would be treated same, they would get a normal life. Get work and socialize normally.

I: how does she think that the Bapak got leprosy? What is the cause for his leprosy?

[T asks P]

T: first it started more than 10 years ago. The Bapak don't want to go to Puskesmas? Then it became worse.. and then ya... [P says something] He, the Bapak was islamic teacher [I: oh okay!] he was like religious teacher in islam, he just don't want to get modern medicine, he just want to surrender it God, to Allah. So he don't want to get modern medicine. And then a few days ago, the health worker received a threat from the Bapak, if I take your medicine and I die, I will get you in the after world, in after life. Something like that..

I: and what do they think how it is also caused? Does he think it's from he Gods?

[T asks P]

T: she still thinks it is hereditary. The health care volunteer thinks this is hereditary [she laughs]

I: and therefore they divorced the daughters right?

[Health worker + P + T talk]

T: they think the cause for the Bapak, they suspect he have black magic and then he got promise, vow, from a [unknown word].. like religious chief. So the chief of islamic boarding school, promised to him. No I don't do black magic. But after the promise he got leprosy. So they think that the Bapak actually performs black magic: they call it Santek, this is black magic. Magic to harm other people. [I: so he is punished?] yes because he is breaking his promise.

I: okay.. [silence] Can you ask her if I can make a picture with her?

T: Yes you can, she would like that

[T+P talk]

T: she has to go now..

I: okay

[End interview]

Female contact 3 – age: 60 CC-Pas7-B9

Notes

She is the wife of the index case. Already quite old - already retired. First her husband had stroke symptoms. Then followed by itchiness and red skin all over the body. Become uncontrollable.

Now in treatment and gets better, sometimes it comes back. He drinks jamu —> gave hardly any effect.

So in January 2017 was diagnosed with leprosy and since this month receives treatment. It is now reducing but still itchy.

“What else can we do?” It is God's fate and they should receive it and try to get medicine.

She thinks that there is a difference in cause when talking about *lepra* or *musta*. *Lepra* is with deformities and worse symptoms. *Kusta* is only the itchiness. Cause is from fatty food like meat.

Itchy and stroke symptoms is part of it.

Neighbourhood doesn't ask about it, And we don't tell. Because it is just *kusta*.

They feel it is not *lepra*, fear leprosy and think it is contagious. Neighbourhood does and so does this *ibu*. Wouldn't want to know if someone has leprosy.

Lepra patients get different treatment. They are excluded. When people are not sick enough to go to the hospital, it is still okay. But when condition gets worse and you need treatment people would exclude *lepra* patient.

When there is a gathering in *desa* *lepra* patient is invited, however someone other from the family would come instead of the *lepra* patient. *Lepra* patients don't want to join. Family members are not excluded.

Her husband has *kusta* and not *lepra* so it is not that bad and maybe that is why their family is not experiencing any exclusion. *Kusta* is accepted

If you don't get routinely treatment it can become worse and can become *lepra*.

A person with leprosy is different, they fear that it is contagious and the person itself is just 'different'

Doesn't fear condition of her husband. She trust the medicine and that it prevents from getting worse.

Transcript

[many family members are gathered in the living room, also a health worker is present, and a researcher from the research team (T2) which helps to translate/explain. Translator (T1) tries to translate in the meanwhile which is sometimes hard to hear. Overall it is a very crowded setting]

I: can she tell me a little bit about herself and her family?

T1: She doesn't know her age.. So she is now getting her ID-card. [name participant]. is the name.

[rumour]

T2: she thinks she is 60 years old

[researcher and translator and participant talk]

[index case is also present, walks in]

I: [understands some Indonesian words] She is a seller of daily needs, and?

T2: yes

[silence]

I: what is leprosy, can she tell me about the disease leprosy?

[T +P talk, T translates in the meanwhile]

T1: First she saw stroke symptoms, and then that heal.. or get better. And then it got to itchy and reddish over the skin.

I: and what did they do when they found out about it?

[T2 asks P]

T1: Okay they try to go to Puskesmas but, itch is not like.. it still itch, it is not getting better..

I: okay and then?

[T1 asks P]

T2: Get better for a while. And then it come back. They also drink '*jamu*' [T1 and T2 discuss] but it did not gave any effect.

I: did they already know it was leprosy then?

[T1+T2+P talk] [P cannot hear so well, so sometimes they have to ask twice] [People walk in and out]

T1: Yes they know, even though the Ibu. [T1 and P talk]

I: can you ask it one more time?

[many people talk, including health working]

T1: the first diagnosis was in January [I: last January?] yes. And after that the Bapak didn't take the medicine. So he started again this month.

I: with the treatment?

T1: yes

I: and how is it going now?

[T1+P+index case talk]

T1: there is still itchiness but it is reduced it is better than the follow... previous month.

I: how did she feel when she found out her husband had leprosy?

[T1 asks P, T2 repeats question]

T1: It is just like, 'what else can we do?' They think it is a fate. It is God fate. So they if they want it or not, they just have to receive it and try to seek medicine.

I: what does she thinks is the cause?

[T1 asks P]

T1: they think there is a difference between 'kusta' and 'lepra'. Kusta is like the worse one, with deformities. And kusta is like the itch and reddish skin and skin patches. They think 'lepra' is the worst symptom.

I: so they know that is like the worst symptom but they see it as the same disease?

T1: no it is a different disease.

I: and what do they think is the cause?

[T2 and T1 discuss, in the meanwhile of previous translation T2 already tried to ask it so he knows the answer now]

T1: So the index case think it is from food, from eating fatty food, like mie, or meat.

[T2 laughs]

I: And does the community and neighbors know about that he has leprosy?

[T1+T2+P]

T1: No they just know it is itchiness and stroke symptoms.

I: So they don't want to tell it?

T2: what?

I: They want to keep it that way, they don't want to tell it?

T1: oh okay wait

[T1 asks P]

T1: the neighbor don't ask about it, so the Ibu will not tell it anyway. They just say itchiness.

I: and how does the community look, have views towards lepra?

[T1 ask P] [T1 and T2 discuss]

T1: The community here is like afraid if there is someone with leprosy, they think it is contagious.

I: and how does she feel about it personally? How does she see it herself?

T1: what, you mean like?

I: yes like with this view. How does she feel about that?

[T1 asks P]

T1: she feels the same.

I: same?

T1: yes

I: would she like to know if someone has leprosy or not?

[T1+P talk]

T1: It is better they know

I: are people with leprosy treated differently?

[T1+T2+P talk]

T1: yes it's treated differently, they exclude because it is contagious.

I: and at what events do you see it is different?

[silence]

I: how are they excluded?

[T1 asks P, T2 helps say it louder, takes a while]

T1: So it also happens for other disease. If the people get sick enough so they go to the hospital, then they do it. But if they are sick, but not too worse, they will not come to the hospital, then it is okay.

I: So then the exclusion is less? [T1: yes] If it is not too bad? [T1: yes] Okay but how are they excluded, can she give me an example of how?

[T1+T2+P talk, laugh a few time]

T1: The example is maybe when there is someone holding a gathering in the house, the patient's family will still be invited, but surely not the patient himself, but a member of the family. So maybe the son is then invited.

I: why is that?

T1: because they knowing it is contagious so they don't want to.. they are afraid maybe himself can be contagious to us.

I: is invitatie from the patient? Or from the?

T1: yes from the patient, they still invite it, by the community. But the one who come is often the son.

I: and the family treated different? Family of the patient?

[T1+T2+P talk]

T1: There is still.. they just don't exclude the family. [silence]

I: that's it?

T1: but maybe when her husband get worse symptoms, maybe it changes.

I: they say there is difference between kusta and lepra, is there also difference in treatment?

[T1 ask P]

T1: it is treated different. Lepra is total exclude. [P talks]

I: is there also a different cause of the two?

[T1 + P talk]

T1: When kusta is not get treatment, then it.. [P talks] when it is not get treatment continually it will get worse.

I: so kusta becomes lepra? [T1: yes]

[silence]

I: what is the general attitude towards a person having kusta or lepra?

[T1+T2+P+health worker talk]

T1: it is treated differently, they think it is different in society. Because they are afraid of contagious.

I: And now we are talking about lepra?

T2: Yes

I: So the person with lepra is seen different?

T2: Yes

I: is she afraid that the Bapak also may develop leprosy? Or she just mentions it?

[T1+P talk]

T1: is not afraid, because of the medicine?

I: does she think it can be cured?

T1: yes

I: uhm, does she know other patients with lepra?

T1: yes seeing them on the market, not personally

I: how does she feel about them?

T1: she is afraid

I: afraid?

T1: yes

I: uhm? Yes, I think I know some.. Do you know anything interesting from the things she mentioned I can ask?

[T1 starts talking] [T1 + T2 discuss]

I: can you maybe asks if there are any myths are present in the community?

[T2 asks P]

T2: There is no myth here, just hereditary

I: but he has early treatment, so not so much to ask?

T2: yes life is not so different for them

[End interview]

Female contact 4 – age: 70 CC-Pas7-B10

Notes

Ibu of this household got leprosy and was treated. Now her son and daughter got leprosy too (skin patches). She only has stiffness in the fingers. Leprosy patient is 29 and interview is with her mother (70). Leprosy patient herself is also joining the interview and so is her brother-in-law.

She didn't know about leprosy at first. But what happened to her daughter is that skin patches arises. Then it was itchy and then it seemed like excema. She doesn't know the cause.

What she does know is that the husband of her daughter (the index case) comes from a high-endemic family. So in his family many people affected by leprosy and in his desa he's from. (desa balong-nguling).

Symptoms stayed for three months they went to puskesmas.

Myth- there is the belief that leprosy is sent by bad people through witchcraft and then medicine would not work. You have to go to the shaman for a ritual. - 'brother in law' of interviewee

Ibu doesn't believe in the ritual, because she saw her daughter be cured with medicine. But also going to puskesmas was free and going to shaman costs money. So their reason then was that they could not afford shaman. Now they don't believe it works that way..

Fear in the community exists that it is contagious. and would keep distance while her daughter was in treatment.

But then after treatment skin patches reduces. Now her children are treated in early stage and don't experience exclusion at all at school. Still play with other children. Son started treatment in January and daughter in april and both improving now. They hardly have any visible symptoms.

Neighbours knew about the situation, but still come to their house. And in community gatherings food meetings they are still invited. Her daughter is still working (collecting waste) When she was in treatment the community acted differently. They were disgusted with it.

But now her daughter is living proof it can be healed. So now no longer would take distance. Community feels empathy at first. Some are okay with it and some people are discriminative. But now she is cured her neighbours treat her normal

During treatment she noticed exclusion because she feels that in a small crowd people keep distance, talk about her and back off naturally with her appearance. Wouldn't make contact.

Nowadays: when she gives food as family the community would not accept it. but she is sure future of children is okay and healthy.

She knows that many patient hide - because they are ashamed with themselves. And are ashamed when people know. Daughter also felt ashamed.

Biggest cause for this shame according to daughter is that people ask difficult questions about the disease. It is seen as a 'bad disease' Because it may be contagious and family can get it.

Treatment is important and can heal patients if it happens routinely and continually.

Transcript

[the interview was held in the household of three leprosy patients, a mother (M) with a son (S) and daughter (D). We interviewed the grandmother (P), who was also living there. Although, many answers were given similarly when the Participant and M, de index case talked. It was sometimes difficult to distinguish who gave the answer exactly. M that was first infected, but treated, is now considered ex-index case. M is also there and talks along while giving the answers. The story line of this interview is so to say from two perspectives: contact and index case.

There was one interviewer (I) and one translator (T1) and another researcher from the research team (T2) that helped making notes and translation. Also a health worker was present.

During the interview the recording gave an error so it couldn't record everything. Straight after the interview the translators and interviewer talked about the answers given, discussed field notes and try to replicate some of the answers and field notes from I and T2 were taken into account closely. The data of this interview should be used carefully and with consideration of potential researcher bias]

T: First the Ibu in this house was infected, and then his daughter and two of her daughter are also infected now and one son as well.

I: How long ago was that? Since when?

T: the Ibu has already done the treatment a few years ago but the son and daughter are now still in treatment.

I: T2, Can you also write along? Since you're here? So I can look at it later

T2: Okay yes, hahaha

I: who are we interviewing now, the sir or the mother?

[health worker and ex index case talk]

T1: wait..

T1: Ibu [name participant] [a lot of laughter]

I: what is going on?

T1: They don't know their age, so they are looking for their ID.

T2: Many people in here don't know their age.

I: Haha okay

[in the back a child is crying]

T2: still cry, haha

[stopped]

I: okay this is simulation of the recording because it failed during the interview.

I: we were at the house of. Ibu [name index case]. And Ibu [name participant]?

T1: yes

I: Ibu [name index case] was affected by leprosy but already treated, but ibu [name participant] is her mother and she was the one we interviewed, but also her grandchildren, her son and daughter?

T1: Her son and daughter were now also infected by leprosy.

I: name of the son is? [T2/T1: Farku] and Manis is the daughter [T1/T2: yes]

I: many people in the community belief, according to the brother in law, that leprosy was send by bad people through which craft and black magic [T1/T2: yes] and don't belief in medical treatment but you have to go to the Sha'man for a ritual to be cured, [T1/T2: yes] however, this Ibu went to the?

T1: this Ibu went to the Puskesmas because the reason is first, because Puskesmas is free [T2: yes free, it's free] when you go to seek the treatment by Puskesmas, but you should pay to the Sha'man [T2: yes]

I: the symptoms?

T1: the symptoms of the Ibu is uhh [I: stiffness in fingers?] first of all she feels cold, and then heat. High temperature. [I: feverish?] until like everyone is like getting that symptom. They say that everyone that has high temperature, forgetting all the people around him.. [I: so hallucinations] [T2: yes hallucinations] hallucinations, yes, [I: so really high fever] After then they get white skin patches and little itchy and the hands become stiff [T2: yes] and so on.

I: and after three months in didn't get away?

T1: yes so she decided to go to the Puskesmas.

I: She doesn't know lepra or leprosy, but she knows kusta?

T2: yes kusta, or deging elek.

T1: bad flesh

I: she does not believe it is hereditary?

T1: she says she does not believe it, but then the brother-in-law says that the problem is that when Ibu [name index case] married her husband. And her husband all of the family is affected by leprosy, and they think that is how they got infected now.

I: So although she herself does not believe it is hereditary, there still a suggesting thought. Because she married her husband from which many family members have leprosy, she got it to?

T1: yes

T2: yes

I: uhh and her husband comes from Balong,

T2: Balong is from Nguling and lot of people there are infected by leprosy. There is a myth [T2: yes yes] that even though the balong president selling chicken then no one will buy it. Living chicken.

I: So the baling people are refused? Because they have leprosy?

T1: yes

T2: yes

T1: and then the Ibu [name participant] say that there is no clearly excluded in this community, but Ibu [name index case] was still in treatment and in disease, just.. there is this, there are, there is just Ibu [name index case] that got excluded, but not the other family members. Because the other family members still have a good relationship with the community. Just when Ibu [name index case] is close, they just keep a distance?

I: you said that she felt it when walking in a crowd, she felt that people would back up?

T1: yes people would back up, but not now, now when she is treated, now people of the community treat Ibu [name index case] as normal people because they know she is already cured. [T2: cured]

I: and during treatment she felt exclusion and because there was fear in the community?

T1: yes, during treatment. There is fear of community, but she feels ashamed when people ask about her and her disease and asking [T2: yes yes] 'why do you come here when you got this disease?' Like that

I: she felt ashamed?

T1: Yes she felt ashamed.

I: And now she is no longer ashamed?

T1: Yes [T2: yes] now no longer, because all the neighbor know about the disease they know. And know: when she was cured there was no more shame and no more exclusion. So no more shame and no more exclusion.

I: uh uh, and the common view of the community?

T1: of the community, afraid of contagious disease. Yes, keep a real distance, but still keep in mind the feeling of the patient as well. So, when there is gathering, the patient will still be invited but maybe she is not come because she is afraid of herself.

I: and is it now different? Now she is cured?

T1: no it is healed, but she will don't want, like if it is helping with the food, she still don't want. But like usual gathering she will come

I: My notes say, if there is a wedding, and they prepare food, she will not come, although she is invited?

T1: yes still invited, yes not come

I: Do people visit their house?

T1: Yes, normally they do.

T2: since.. sin. [says something in Indonesian]

T1: so at first when she got the disease and get reaction and high fever, the neighborhood is come to see her too as usual. But the people still come to her house.

I: she also still works?

T1: yes [T2: yes]she is collecting waste in siduarjo

I: When she was still in treatment people felt as a disgust, also, but now no longer after she was healed. [T1: yes that was what she said] And also my notes say, community's view: some feel empathy, some are okay, some excluded

T1: yes some feel empathy so they come to her house to bring food or just see how her progress was. And some people just say; they don't and say it is just okay. Just okay. And some ibu's say I don't want to come to close.

I: and what if they give food as a family? Will people accept it?

T1: when Ibu [name index case] was still in disease they don't accept the food, but now they would want it.

I: she is sure about the future of her child?

T1: yes she is sure about the future of her grandchild, because her daughter can be cured, so she believe that her children can be cured as well.

I: and what did she say about the patient that do hide? Their family is not hiding? What did she say about those patients?

My note says: they feel ashamed of themselves, because they have leprosy?

T2: yes yes she feeling ...

T1: yes, she feels ashamed with herself because her family got that disease.

I: So the stigma is?

T1: so the stigma is people with leprosy is different [T2: yes] and it is contagious, so they treat different and we exclude it with the community, so yeah it is disgusting.

I: and also, leprosy is a bad disease?

T1: Yes she said leprosy is a bad disease, [T1: yes disease] because it can be contagious and it affects the family, [T1: yes family can be infected

I: and then what she said in the end? I wrote down: treatment is important, it can heal me if routinely and continually repeated. [T2: yes] [T1: yes she feels that]

I: anything else? Oh yes, the children are not treated differently? As far as she knows? Not exclude in playing and also not in school?

T1: the children are not treat different in school, all, most of the friend know the status but yeah they play normally, there is no exclusion. But the grandson go to friends house, and it is okay, there is no rejection from the parents.

I: symptoms are hardly visible right?

T1: yes they don't see

I: Grandson started treatment in January and the granddaughter in April. [T1/T2: yes]

I: and the neighbors?

T2: yes they know

T1: the neighbors, all the neighbors know.

I: why she didn't hide it?

T1: because from the very first time, the neighbor already know that Ibu [name index case] is infected [T2: yes] and all the neighbors, close friends, feeling empathy they go to her house and see the progress, and see how its.. and see the condition. From then, Ibu [name index case] feels like she is being cared for by her neighbors, so become open en just tell the neighborhood and also tell that she gets treatment and now it is already better, it already cured.

I: What did the mother say?

T1: neighbourhood does not know much about the disease, even though her daughter get the disease, she doesn't know either. But the people around her in the neighborhood is not exclude all the members of family, just Ibu [name index case] in treatment.

I: what was the cause?

T1: she didn't know, when we talk about the cause, and then the myth with leprosy: she doesn't live with black magic. But the brother in law say that they say that because there is Ibu there, so they don't want.. they feel hesitate to discuss about the myth.

I: because?

T1: because there was someone there from the Puskesmas. So they didn't really answer. So maybe it is the brother-in-law's opinion. We are not sure.

T2: yes they stopped talking.

[End interview]

Male contact 5 – age: 37 CC-Pas7-B11

Notes:

This is the son of the index case. He is a food seller (37).

His father started to get wounds at his nails and the wounds would spread over the feet and get worse. In 2005 he would just take care of it as it were usual wounds. But it didn't improve So he go to puskesmas and then got diagnose with leprosy.

Normal wounds happen so often because sometimes you neglect them, you work hard and have not so high economic status he says.

Thought it was usual wounds but after treatment they finally improved. He doesn't believe it is contagious because he experienced it himself. He touched infectious wounds even. but nothing happened.

He doesn't know about symptoms from other patients but know more people with leprosy.

There is this myth about overdosis. If you have an overdosis of pills that they use for gaining weight. You can get leprosy.

Also there is this belief of black magic: He doesn't believe it himself because his father became better after treatment. So, there nothing 'supernatural' about it.

They treat his father normal, no exclusion. Still invited to ceremony event but only when the wounds are clean. This is a requirement form hygiene perspective. Sometimes there is gossip because it smells not good. And then they fear its contagious they can get the smell too.

People think little less of the person because it has leprosy. This happens also with other diseases like diabetes. Disease with wounds in general cause this verbal stigma. People consider you less because you are not healthy.

cure is important, and be hygiene. But it is a lifestyle to live healthy and then it will be okay. He himself does not experience any different treatment.

Transcript

I: can you ask him his name, what he does and how old he is?

[T+P talk]

T: this is [Name] and he is a mersyon?

I: mersyon?

T: like a food seller

I: and how old is he?

T: 37

I: what is the relationship between the index case.

T: It is his son.

I: can you ask me about leprosy, what it is and how you can get it?

[T+P talk]

I: First, his father is like, gets wounds from the nails on and then after that the wounds are get wider and get like.. [I: spread] yes like spread over the hand.

[P says something]

T: it happens on 2005

I: and what, how long did it take for them to find help?

[T+P talk]

T: first they carried out like it is an usual wound, treatment of infection. Because it for several times didn't get healed or get better. They seek the help of the local health care worker, and from there they get diagnosed that it is leprosy.

I: did they get medical treatment, or other?

T: yes they went straight to medical help, but treat it first as usual wounds, not thinking about leprosy first.

I: and then his father got treatment, or what happened next?

[T+P talk]

T: Yes they get treatment

I: okay and how... [P adds something]

T: they send the father to go to leprosy hospital in Mojokerto

I: and did it improve?

T: yes it improved after that

I: Okay... does he think leprosy is contagious?

[T+P talk]

T: No he think it is not contagious because he lives in the same house..

I: and what is according to him the cause?

T: it is because of the infection of wounds, they think that is the cause.

[P talks]

T: because they come from the lower economic level, so the wounds can get neglected and he didn't care about that. So after that it get spread over the body.

I: So, at first it was just regular wounds and ..

T: yes normal wounds, so he wouldn't get special treatment and so on

I: does he know more leprosy patients?

[T+P talk]

T: yes he know a few more

I: did it start in the same way?

[T+P talk]

T: he doesn't know the cause, but it is different, it didn't come from the wounds.

I: did he know about leprosy before his father got it?

[T+P talk]

T: No he doesn't know about leprosy, but after his father get infected he just know it from the healthcare worker.

I: okay, can he tell me about the views in your community of leprosy?

[T+P talk]

T: It is like the cause, it is the cause. Overdosis of certain medicine. There is a pill for getting fat. [I: diet pills?] no pills for gain weight, not loose it. Some people think that the cause is also from the overdose of that pill.

I: okay

[T asks P something again]

T: The other people belief that it is from black magic, too

I: does he belief that too?

[T+P talk]

T: no he doesn't, because he don't believe it.. because he has prove that his father get treatment and it is healed, so it is not because of the other super natural.

I: is that view that he has the general view in this community or his neighbors?

[T+P talk]

T: not so much, there are still people that have supernatural disease.

I: okay, not so much? [T: yes] Euhm, what does the community think about the person having leprosy?

[T+P talk]

T: There is no exclusion here, it is normal...

[T+P talk]

T: It is still invited to the ceremony's even. But he said: the wound should be clean first before they go out.. just for [I: hygiene?] yes hygiene.

I: we are now talking about treatment, but the person itself, how do people see that person?

[silence, T doesn't understand question] Like we now talking about that the person is not treated differently, not excluded, still invited. But how about uhh, what do people think about people having leprosy? Is there gossip, do they see the person itself as less or?

T: oh yah

[T+P talk]

T: there are some people that are gossiping, and think less about persons with leprosy

I: how, why does that happen?

[P answers]

T: he said maybe it is from the smells

I: how does it smell?

[p talks]

T: he says it does not smell good

I: and only because of smell or?

[T+P talk]

T: they are also afraid that it is contagious, or infectious

[P says something]

[wife of participant comes in and brings tea]

I: is this also how they would treat other diseases, or is it specifically for this disease?

[T+P talk]

T: yes it also happened on the other disease, like diabetes, disease that have wounds on the skin or different appearance.

I: okay yes, is there a difference in how his family was regarded, after the father was diagnosed with leprosy?

T: how the community treat their family?

I: yes?

[T+P talk]

T: There is no different, it is just normal for the family members.

I: okay... anything else he would like to share with his experience with leprosy?

[T+P talk, health worker also, takes a while]

[wife of participant is saying something] I: what is she saying?

T: she wants her father in law, like.. cure..

I: she wants the father in law to be cured?

T: yes

I: do they think that is possible? I just want to be sure?

[T asks wife of P, P responds himself]

T: yes it can be cured but it should be balanced with a good diet, but not only infect, but also diabetes can.. can .. euehm, diabetes can also be attacked when keep diet [I: healthy live style?]

I: anything else?

T: no

End interview

Male contact – age: 74 CC-Pas7-B12

Notes:

He is the father of an index case (74). This index case is very known in his desa. Everyone knows him and knows he has leprosy. From interview with community member we found out this index case does not hide.

Started with infections in the fingers. But interviewee (father index case) says it is an allergy. Like normal allergy. his hands got wounds.

But he has lost fingers, but that is because of an accident with a chain. Not because of infection or anything. He does not have leprosy. If it would be leprosy it would heal his heart and he would be angry.

Father of index case tells us it is a rumour his son has leprosy. It is just an allergy after eating fish. Leprosy patients are excluded, and his son is not. his son has friends and can still work.

Leprosy patient have rotten skin and skin between thumb and index finger is gone. His son doesn't have that. It's just allergy. He can still eat with people. so that is proof he has no leprosy..

Skin allergy with swollen and small spots after eating seafood. Smell of kust is also different. It is the smell of blood. And neighbour would not get too close. So his son doesn't have it.

The rumour started because the health worker diagnosed him wrongly with leprosy. He started treatment but then he stopped so it didn't work.

[asked health worker from puskesmas, and he told us that this index case was not adapting well to the treatment and then refused further treatment]

Leprosy is a bad thing and for and people. Deformities and disgusting. But the early symptoms are okay.

You can get it from stepping on leprosy patient graveyard. Also on the graveyard the grass will not grow, because the soil is too 'hot'.

This does not happen to his son. Because he is still a social person. People with leprosy would stay inside and community would keep distance. They would not visit the patient because they are afraid. Shaking a hand is already disgusting. Everywhere where the leprosy patient would sit, if he walks away community would mop the floor.

He shows the medicine his son is taking, it is just medicine against itchiness. Symptoms did not improve with puskesmas treatment.

If the neighbourhood talk about his son like it is leprosy it 'hurt his heart'. He is offended and is angry. Having a social life as a lepre is hard. but my son has many friends. The issue is just a rumour and gossip and negative thinking. But only Allah can judge.

He beliefs lepra can be healed but the medicine didn't work with his son, so it is not leprosy. If it would be real, it would've worked. And also with leprosy you can see it. and my son looks great.

Transcript

[This interview was very chaotic. There were again one interviewer (I) and translator (T1), also an additional person from the research team joined and was taking field notes (T2). This person was the

father of the index case (P) and was very old. He couldn't hear very well, so T2 helped by sitting close to his ears to repeat questions. As a result P, T2, and T1 talk at the same time a lot, which made it very hard for the interviewer to follow the conversation, right after the interview follow up questions to T1 and T2 were asked to clarify the story of P at the basis of the field notes]

T2: [Name participant]

I: and his age?

T2: 74

[T2 + P Talk while T1 translates] T1: he went to junior high school, he is already on pension

I: can he tell me something about leprosy?

[T2 + T1 try to talk to P]

[while T2 and P talk] T1: he said like.. first of all, the hand of his son is getting wounded by like a.. like.. catrol and chain. Like an infection then started.... And it's, wait wait.

[P tells something]

T1: so this sir doesn't believe that his son get infected with leprosy, [P starts talking again] so when his son gets diagnosed with leprosy he gets angry. And then he is sure that his son get an allergic reaction, is this okay? Can we continue?

I: Yes but I would like to know what he is telling

T1: okay he doesn't believe it, because all of his ancestor never get a leprosy story, no one has leprosy. so he doesn't believe it.

I: what words did he use to express his anger? What did he say literally?

T1: He says, it makes me angry.

I: started with fingers and then?

T1: yes then he get allergy to a fish.

[P starts telling and talking with T1 and T2]

T1: sometimes it is swollen and sometimes it is not, because it's not treated.

I: not treated?

[T1 + T2 + P talk]

T1: he did not get the test with leprosy test, just a seeing test, visual test. So..

[T1 confirms something with P, T2 tries to explain something]

T1: it was ever .. [P starts raising voice] his son sometimes started with treatment, because they think it was not getting better so they stopped the treatment. So it was not really showing a better result.

[P is continuing talking and T1 and T2 engage in conversation again]

T1: leprosy is hereditary,

[T1 + T2 + P talk]

T1: so the leprosy start with itchiness, and scratch, becomes wounds so it get worse.

I: that is leprosy, and not what is son has?

T1: yes that is what he says

[T2 + P talk]

I: what has the son then?

T2/T1: allergy

I: and how did it come?

[T2 + T1 discuss]

I: what?

T2: skin ... allergy

T1: he has an skin allergy from eating seafood, certain fish... [P adds something] it is like small swollen.. infection.

[P keeps talking]

T1: so it starts with skin infection

I: what does he feel about leprosy then, his son does not have it, but how does he feel?

[T1 + T2 + P talk]

T1: it is different, it is not good, it is something different. And the neighbor.. they don't want to get too close, and it is like blood on the skin..

[T1 + T2 + P talk]

T1: so over there there is someone with leprosy, it is like 300 meter from here, and then [P talks during with T2] and there it is like hereditary, but not like all of the family members get it, but maybe only 5 of her children only 1 is infected with leprosy.

[T2+P talk]

T1: It is hereditary it is not a curse...

[T1 + T2 + P talk]

I: is it a bad thing to have leprosy? A bad thing?

[T1 asks question, T2 repeats question, P answers]

T2: oh sometimes..

[T1 asks P something]

[T1 + T2 + P talk]

T1: it is disgusting, they have deformities, and like is disgusting. But it is just like early symptoms it is not.

[T2 + P talk] [T1 + T2 + P talk]

T1: also there is a myth that the graveyard of leprosy patient, the grass will not grow because the soil is too hot. And there is no people that want to come to the people with leprosy but not with his son,

because his son have good socialization with his friends. So he think that his son if.. if his son is really infected by leprosy his friend is not, will not want to get close with him.

[T1 + T2 + P talk]

T1: people who have leprosy are like ashamed with himself, [T2: and deformities] and also other people in the community, the community will keep distance.

[P talks with T2] [P takes some pills out of the drawer]

T1: and there is like a solution for the itchininess patients, medicine..

[T1 + T2 + P talk]

T1: so his son takes medicine for the itchininess of allergy, just regular medicine.

[P talks]

T2: anything, anything?

[P talks]

I: his son was in treatment, was diagnosed and then no longer? What happened? Or I don't?

T1: well eeuh it is not tested, just like visible symptoms, then the health care worker say it is leprosy, but it if he ever got treatment it only was after.. [I: symptoms didn't change?] yes they think it is not leprosy they stopped treatment and go straight to Puskesmas when it begins to become itchy, and the Puskesmas just give the powder and salve to put on the skin to cure... the skin.

[T1 + T2 discuss]

T1: and then?

I: and people in the community will be treated differently?

T1: yes it will get exclusion

[P starts talking again]

I: would he have someone with leprosy have him visit.

T1: no he wouldn't, the problem..

[P talks] [T1 and T2 ask a question again]

T1: he is afraid, afraid

I: why?

[P talks]

T1: afraid when someone want to shake a hand it is disgusting

I: Does his son have leprosy or not?

T1: no the health worker said so

[P in the meanwhile talks with T2]

I: you asked?

T1: yes, and then he said he did not get the treatment well, he stopped.

I: okay?

[T2 and T1 discuss]

T1: So, if there is a leprosy patient that sit outside, like just gathering around, after that the community will like clean the floor with water. [P talks]

[T1 + T2 + P talk]

T1: if the neighbour think that his son is get leprosy, it will hurt his heart.

[P talks]

I: you just have to tell me more later, it is interesting but it is going so fast

T1: yes will do that

[P tells some more]

T1: he now says if it is really leprosy then it would be hard for his son to socialize. But my son have a lot of friends...[P talks] there is an issue with the health worker when he spread to the community a negative thinking. The only one that can judge is allah in this case.

I: so there is a rumor that his son has leprosy?

T1: yes he thinks so, it is just a rumor.

I: he is happy his son has no leprosy?

[T2 asks question, P answers, while T1 translates]

T1: yes he is happy, if he really gets leprosy he is willing to get the medicine wherever it is. [I:but it is not?] but it's not

[P talks]

T1: if we live now, leprosy can be healed. Already there is medicine.

[T1 + T2 + P talk]

T1: there is no other information, is there enough?

I: in a few minutes you have to tell me some more again, because I missed half of the conversation. Because T2 was just talking with him.

[P talks]

I: what is he saying?

T1: but if it is like real leprosy whether it is from a little bit far distance, it can already be seen, and you can see it obviously.

[T1 + T2 discuss]

[pause in recording]

I: can you tell me again what the sir said

T2: in English?

I: yes try, just everything you know. He started telling about his son.

T2: yes.. [talks indonesian]

T1: the Bapak says that his son doesn't have leprosy, he thinks that it is just some allergy from seafood [T2: yes allergy yes]

I: and his fingers?

[T2 talks indonesian]

T1: his fingers is like [T2: his fingers is not like, like this]

I: so the flesh between his thumb and index finger is still present but his finger tops are missing?

T1: yes his fingers are missing because of an accident with a chain [T2: yes [speaks indonesian]] yes with a chain.

[T2 starts telling in Indonesian]

T1: He feels happy because his son still has friends, and can gather with his friends. And the community [T2: yes the community is still..] still like receive him, accept him.

[T2 talks indonesian]

T1: but with the real leprosy.

T2: yes with real leprosy.. [speaks indonesian]

T1: and usually they are being excluded from community..

[T2 talks indonesian]

T1: and the place that they sit down is being cleaned with warm water, with real leprosy patient, but it is not happening with his son.

I: and why is it not real leprosy?

T1: because in his family there is no leprosy story [T2: yes yes]

I: and what do they think about leprosy?

T1: he thinks leprosy is a bad think and someone who caught leprosy, who is infected by leprosy will be excluded [T2: yes] and they have a different smell, smell is not good [T2: yes] and it will make people feel disgust, and then like the wounds the deformities [T2: yes wounds..], it make people disgusted and make distinct with the community. [T2 says something in indonesian] but with his son it is not like that.

I: how does it come that people think he has leprosy according to him?

T1: it is like the wounds, the deformities and the itchiness and the different flesh and different skin and like the swollen and reddish face and chicken pox like all over your body.

I: how.. but he said his son affected by leprosy is a rumor? How?

T1: yes because the health worker come to see his son and without a blood test the health worker diagnosed that his son is infected with leprosy. And then he think it is rumor because he thinks that his son does not get infected so he believed that when the health worker says it, that the health worker told the entire community. So all of the community believe that he is infected by leprosy.

I: how does that make him feel?

T1: he doesn't like that [T2: angry] he is very angry he asked.. he like.. he dare some people to proof if his son really is infected by leprosy.

I: okay, and how about any myths or?

[T2 talks indonesian]

T1: the graveyard of leprosy is very hot and the grass will not grow up in upper side of the graveyard..

[T2 tells something] and he believe that leprosy is hereditary [T2: yes] and in the 7 generation one of them.. one of them can get infected by leprosy. And by that. But in his family there is no one of his ancestor or his offspring is infected by leprosy. He was very proud of that. So he thinks that leprosy will not get into his family because it is only infected by inherditary.

[End interview]