

**Qualitative baseline data focus group discussions and in-depth interviews - LRI funded project (705.17.30) about developing a family-based approach for prevention and self-management of disabilities**

**FGD1: Group discussion with persons affected by leprosy**

Question. How do you know you are diseased? How do you accept it the disease? What other people said about the disease? What is/are the impact of NTD on personal and family life? What are the involvement of family members in managing the NTD?

Number 1: I knew during long time ago. My leg became wounded. I was in the city of Injibara, and I went to the hospital and I got treatment. I accept the disease it is from God. People considered as the disease was my personal problem.

Number 2. I used traditional medicine for the long period of time and during that we lost huge resources for the treatment. Later I was treated in the clinic. Peoples thought the disease would be transmitted through the genes. My father as well as I assumed that the disease will transmitted to my children but the reality is not that because my children are not affected still now. We have a problem with farming because of the disease.

When we are in contact with soil our problem worsened. We hurt when we got up. We cannot able to send our children to school for learning as like the healthier people. We cannot able to chop wood. Usually we are not doing our work instead we employee daily laborer to do our work. That leads us for economic crises.

Question. What said your community?

Number 2. They said diseased person.

Questions. What impact happen because of the disease?

Because of our illness, we cannot hold hot things. We cannot even lift a hot boiled potato.

Number3: The impact of the disease, as we go to wedding ceremony there is abuse there. Even in the past during Derg regime our friends got land for farming from the government but for me no one give rather they said we cannot give for him he can beg and eat. On the other hand, when we wanted to married the disease had great impact. Peoples are not accept easily and we got marginalization by the community.

Currently am working in Leprosy association mill house here and peoples harass me during this time I became extremely angry and during this time I preferred to die.

We cannot go far distance. It is fine if we got diagnosis for our illness. Now we're in good condition. It is better if we have homemade in the same area in the town for all of the leprosy patients.

Number 4. I had a visit for treatment because people considered the disease is related with blood. Even once up on a time one traditional healer burrowed herbal medicine with my leg by assuming that as bad wound.

It is new thing happened in my body and I thought I was going to die. People had no awareness about the disease but they insult us. There are many peoples with the disease but not got treatment. There is an exclusion from participation of events.

The pain reoccur again because I myself had taken two times the treatment. There is no good investigator to diagnose the disease in this area so we are forced to go to other area for treatment. We sold our

property to go and get treatment from other area. I myself get treatment in the near past and cured from the disease.

Question. How do you take care for yourself?

For the question in related to care taken to ourselves I wash and care for myself.

The pain hurts the family. It can cause economic deprivation.

No. 5. The disease was occur when I go to other area.

The disease also picked up three times my finger nail.

I went to holy water. I've gone to a cultural expert also.

People assumed us not like them because of our illnesses. It was consider us like a dog. Currently, the disease creates a challenge when we go to work because our body became changes.

When we left the drug the pain is so bad. Cold and snow prohibit us from doing work.

Number 6. When I saw a sign on my body, I went to the doctor's office and found medicine, so I found a good chemotherapy.

Before that because of the illness, one of my finger lost. I cannot hold axe because of the sickness.

Verse 7. When the disease happen my foot throbbing, then it holds my hand also.

To get relief from the disease I went to hot spring water but I had not recover from the illness. Instead, the pain went to severe condition.

As a result, my younger brother even never asked me in the nearby by assuming the disease transferred to him.

One person told me my case is leprosy because he had the illness before and he had get treatment and recovered from the disease. Then I went to one clinic for the treatment but in that clinic I had get referral paper and I went to Addis Ababa and got treatment and recovered from the illness but now the pain reoccurred.

Q. Who helped you in the family?

Number 7 - I could not plough. My wife only supported me.

Number 8. When the disease started, my thigh became white then later my body skin becomes leopard. During this time, one person said that, "I think this is Leprosy so that better you go to Injibara (Name of a Town) and seek treatment there" what he advised me. I went to Danigla and got treatment. But I did not get any change instead my swollen leg became burst and the illness goes to my fingers too.

I took the medication but my fingers lost then I went to Danigla again and got treatment there and recovered from the illness.

Now there is no wound in my leg but there is a feeling of pain.

It is good if the government help us. In the past time we had taken ointment from the government for our skin but now that one is not available. It's good if the government help us. During the past time, we had taken ointment for our skin but now that one is not available.

Question in related to daily life.

Question- What looks like your daily activities? Social contacts? Leisure? Needs? Obstacles and opportunities in daily life?

Number 2. We had get treatment and recovered from the disease.

So, we have a day to enjoy and celebrate with peoples in different gatherings but previously we had not because of our illness.

Nevertheless, the problem happened when the event occurred in a far distant because we cannot able to walk far. Even if from our family if a person died we had not participate in the funeral ceremony because of far distance.

If there is an access of car we can go by paying money.

On the other hand, if also joyful gathering of the family in far area I did not participate because when I go there I may get one day satisfaction from the event instead, I exposed myself for two or three month illness. I faced this like problem many times. So, when I balance this I preferred to leave participation of the event.

Nonetheless, most of the time regarding to our daily life we feel immoral rather than happiness.

Number 3. Truly we are Leprosy patient. What I feel if our cattle go into another cabin. They said this are lost finger person cattle take them away. They harassed us in many ways.

In our daily life what enjoyable thing is by leprosy victims association established here in Injibara.

Even in public gathering if I forward my opinion regarding the agenda they are not accepting rather they said lost finger's person idea.

They mistreated us when we go to another meeting place also.

Number 5. Peoples gave us a nickname like lost finger and other harassing words day to day. Things are not easy for us. But, thanks to God for our journey what have been before and for the future.

Number 4. What challenge we faced day to day when we go to other place by assuming this is near place in between we might face with the rain. That is not good for us, our illness may occur or aggravated.

On the other hand, if other peoples do their own work we feel bad due to ourselves incapability.

I am excited when I give my idea to people in the meeting and if gets acceptance.

I do mediation if there is disagreement with peoples and this one is good thing too.

I enjoy by the job of the leprosy affected person association work here in Injibara.

I am happy to be able to save money with my capacity in this association monthly. I like it when I work here. It's also fun peoples said they (leprosy affected people) have a mill.

Currently, in our project (Mill house) five leprosy affected association members employed.

Other area leprosy affected persons associations were awarded eight cows but they sold and took the money.

On the other hand, we have enough land or place taken from the government. Fortunately, we have three areas /terrestrial/ here in Injibara by the name of the association and it is good if we able to build home and creates work opportunity to other association members too and benefited by that.

That makes happy the members because they think that they capable to do a work. That refreshes their (the leprosy affected persons) mind.

Being entrepreneur is important thing because after 50 years of age nothing comes unless we do such like things.

Number 8. It is good this like advice and idea (like this focus group discussion). We can say we are employer because we gave you an idea as like this forum. It is a good when we give our idea or opinion on the meeting and it gets acceptance.

It is better if the higher government body support us, in order to make us joyful. They (the government bodies) get acknowledgment from us.

Why the government or other concerned bodies train the leprosy patients?

Why give us lecture regarding to the disease?

What's wrong with the government if we enter the urban area from where we live now in the rural area?  
We had get enough place in the urban area but what is the problem the government build home to us?

Number 5. In the past, we had been taken an exercise book, pen and pencil for our children and also ointment for us too but nowadays, we have not get it.

Number 6. We felt that we are guilty. We are less powerful if we go with the healthier people. The community discriminate us.

It was better if our home would be in the urban area. Land grants have been given to us by the Cities of the State, but, it is good if home builds to us in that area.

Number 7. My home is far from this town.

I came from that area for the monthly meeting and the like but it was better if I get home in the town.

I cannot build home here in this town because I do not have money.

As a result, we pay five birr (about 5 birr) when come to here and Five birr when we go to our home.

Number 9: In our area there is no too much crop production instead peoples plant, cultivate and sell piece of wood as a source of income, but I cannot bear to carry and sell it. The disease is broken me once.

Number 10. There is work, but we cannot able to do the work and live. As I wash my feet with soap I become fine. But when once begins the wound it worsens.

I came from far distant it took one hour walking time so it is hard to come to here, however to live in the town I do not have money to rent house.

Question Regarding to Family-based approach

Question- What have the opportunities for the family support you get? What are the possible elements of a family-based-approach? What are the possible obstacles or opportunities for a family-based approach? What is/ are the desired outcome of a family-based approach?

Number 10. I do not have a family who supports me. My first kid dropped out in the 8th grade and went to another area looking for a job. When I ask him “why you drop your education”, he said that “you are powerless so who helped us?”

Now, I worried about his health because he went to a desert place in that area there are different disease like malaria and others too.

Thus, my wife is the only one who assist me.

Number 5. Families cannot help me anything.

Number 4. If our family helping as by keeping our cattle, wash our feet, prepare food and feed us as well as if they provide coffee for us was good. However, our family not wash our clothes.

But in our home there are kids which do not perform the listed activities / refuse to do/ instead they are going to school. Again after going to school they observe other students and they said buy clothes for us as like our friends unless we are forced to drop out from participation in school. At this time, we are in a difficult situation to sell our property to fulfill the students’ requirement instead of helping us.

I have daughter who learn in the university I send 300 Birr per month but this one not satisfied her. She said “the money is too less amount.” Because, of this instead of my family helping me, I helped my family with my limited capacity.

There are also other diseases affected person rent their land and on the money earned educate their children.

Our kids do not help us instead they leave us and go to school. In the past they helped the family, but now they focus on education as they want to become self-sufficient. Currently, children said that “we want to study instead of doing your work”.

Even when we order them to sell wood and to buy coffee they are not willing to do it. You know that even if we are not interested to send our children to the school, the government body forced us to send our children to the school.

Number 2. In the past, when my illness was not worsened I sent my children to school.

I have son and he said that I want to buy a big shoe by three hundred birr like other children I said I cannot able to do that. During this time he dropped out from Grade seven. One of his teacher called me and asked me “why your child dropped out from his education? I replied to him it was my interest to teach my child” and I told him what I said to my child that, “please better to learn, do not stop your education as much of our capacity we help you but not compare us from other healthier peoples”. He was not willing to hear me. At this time, his teacher advised him. During that time, he said that ok I left from the school so I want to do daily work to earn money and support my brothers.

But, our child advised us (father and mother) to rent our land for rich people and earned money and live by that.

Number 3. Truly our leprosy affected people association leader is blessed man what he advised us in order to go to Addis Ababa and ask land for building home in the urban area from the government body even if we are not performed it.

Even I myself became died if I am not come to here and employed in the mill house of the association. But, my family is there in the rural area. Now, I am fine only I go to the family in rural Kebele in festive time. Even my wife harassed by people “you are lost finger wife” what they said her.

Question- What are the possible obstacles or opportunities for a family-based approach?

Number 4. Good opportunity is if our child learn and employed then if they help the family that is good. Another opportunity is if child planting tree, sell it and help the family.

But, the challenge is that if not able to do that they are left to other area for searching job.

Number 5. What challenge we faced cold and hoarfrost lead to exile. We were rich by planting tree. But, when a person becomes powerless, he migrates to another place/area.

Children want to learn rather than helping us.

Children help the family when they are helped by the family in a mutual way but we are not capable enough to help our children.

Question -

Other concern you want to raise? Response: No new thing we add they said.

*If it so thank you very much we are finished our discussion.*

## FGD2: Group discussion with family members of persons affected by leprosy

Question. How the affected person knew he/she had diseased? How the affected person accepted the disease? How the affected person family accepted the disease? How the community accepted the affected person disease? What were the impact of disease on the affected person? What are the impact of disease on the affected person family?

Response

Number 4. He knew infected by the disease from the health institution. The community abuse the patient by saying disease person and the like.

Number 1. He told me he had leprosy disease after diagnosed in the health institution.

Number 2. He became ill during plough when in contact with the soil and the mud. The family said do not complain about the pain faced simply wash by hot water your feet then massage by Vaseline and tide by a piece of cloth during this time get relief. Again in this time he also sleep.

Then after when he went to the health institution he knows the case is Leprosy.

After that he got treatment and recovered from the disease. But he could not able to do farming activity. On this time he migrate from the rural area to urban area by leaving our mother, brothers and sisters (our family) too.

Number 3. When he exposed to cold weather he became ill. When he went far distance as well as exposed to the mud the illness aggravated. Then he knew infected by leprosy from the hospital.

Number 5. I do not know how he knew he was with the disease.

Question- How the family accept the disease?

Number 2. We accepted as it is but we are not participated in coffee ceremony with our neighbors. They said that “this disease is transmittable to us so that do not approach with us.”

They discriminated, stigmatized us from them. If we have a chance of participation we have separate coffee cup for ourselves, we do not used by them.

Number 4. The family accept the disease as it is. Because we cannot do anything for him unless otherwise giving care for him.

Number 3. The community marginalized us. They are considering us weak persons.

Number 5. The community accepts them as like any person.

Number 1. He cannot able to do farming activity. What he gave the land for others in order to farm and share the crop what they cultivate.

Even currently his feet swell. So we helped him by washing his clothes, feet and apply massaging by Vaseline that was good for him. But currently, we couldn't get the Vaseline. Hence, he suffered a lot by the disease.

Number 6. The community accept the disease person and they live harmoniously.

Question - What impact the disease causes on the affected person?

Number 2. There is great impact on him. He couldn't properly work as like other healthy people. Thus, he has in hunger because he couldn't work, as well as not move place to place easily.

He is not also benefited from different things. He cannot able to help the family. Even if he couldn't able to do for himself rather than helping the family.

We help him by doing daily work.

Number 5. There is no visible impact. He can able to do all activities without any problem. He is equal with the community member.

The impact on the family is that we are forced to do other activities beyond our usual work learning in order to get money because our father not support us very well.

Number 3. If he was healthy he supported us but because of the disease we are forced to help to him rather than getting help from the father. We left our education in order to support the family by doing daily work.

Number 4. If he was healthy he do many activities so that we were not in challenge of economy. We were learn without any challenge.

Number 6. There are work he did not perform with the effect of the disease.

Question – How the leprosy affected person take care for himself?

Number 3. He go to hospital to get treatment. On the other hand, he bought soap for himself to wash his clothes and his feet.

Number 2. When the affected person facing illness, he wash his feet then apply Vaseline, this give relief from the pain. If he sustains his personal hygiene, he will not encounter with the illness.

Number 4. He take care for himself by taking prescribed drugs. Again, the patient do not go far distance by walking. He polish his foot by ointment after washing.

Number 5. He wash his feet and massage by Vaseline.

Number 1. He take care for himself by avoiding walking long journey, because, this activity expose him for aggravating the illness.

Number 6. He wash his feet when he became ill.

Question – What are the contribution of the family members to minimize the effect of the disease on the affected person?

Number 6. We take care for him, giving respect for him. Not marginalized him.

Number 3. We advised them to avoid doing work. Additionally, if he faced harassment from the community we advised him to take it as easy in order to avoid the feeling of bad on his mind. The family members also support him by saying not to feel bad as well as not to anger.

Number 2. Similar with the idea of number 3 just we advised him psychological support in order to minimize the harm of feeling bad. If he harassed by people he became angry and after a while faced illness. We support him by keeping his personal hygiene, we give food on time.

Number 1. Similar with the others too.

Number 4. We wash his feet daily.

Question in related to daily life.

Question- What looks like the affected person daily activities? Social contacts? Leisure? Needs? Obstacles and opportunities in daily life?

Number 2. If on the day of religiously not work day, he goes to the near area of eventual activity and recreate, participate in the event if he can. However, he couldn't go without the family member. Because, we feel he encounter with the accident if he go himself only. On the other hand, we are not allowed him to go far distance because this aggravates his illness.

Number 4. His daily activity is going to church, meeting place if it is near distance and also far distance if there is transport access.

Number 5. By considering himself as a diseased person he do not stop performing his work. But in culturally/religiously work prohibited days he plays with his friends, enjoys as much as he can.

Number 6. He cannot able to do heavy work.

Number 3. He cannot go far distance on his daily activity, but he participated in community activity aroused in the near territory.

Question – How do you see the affected person’s need fulfillment?

Number 2. If we have we can fulfill his need. Sometimes he needs banana, orange and the like. Therefore, if we had money we accomplished his needs.

He spent most of his time sitting in the home. Hence, he needs many things, his request is various, and if we are not fulfill that he became aggressive. He assumed that all things are cheap because he cannot observe that, he cannot know the market condition. He behave as like of children. If we cannot fulfill his need he abused us.

Number 3. Similar with number 2 idea.

Number 1. Similar with number 2 idea.

Question – What are the good opportunity and obstacles in related with fulfilling the need of leprosy patients?

Number 4. Lack of money is the obstacles in order to fulfill the need of the patient.

Number 2. The obstacle in order to fulfill the need of the patient is lack of money.

If he need many things from the market and if we haven’t money for that, where it comes? This is a great challenge.

Question – Opportunity

Number 2. As much as our capacity we are willing to fulfill his need. This is a good opportunity.

Number 6. As much as his capacity he eat and drink.

Number 5. Even if we are not living similar with other community we are not passing night without food. Other good opportunity is we are collecting money for our survival even if it is not that much suffice.

Obstacles-

Number 5. Lack of or shortage of money.

*Now, my question goes to the family member life related issues*

Question- Is there a patient’s family member work as a government employer other than farming and daily laborer?

Number 3. No

Number 1 and 2. No.

Number 6. We are doing daily work. There is no family member working on better job.

Number 4. No family member work in a governmental institution, only we do farming and related with farming.

Question- What looks like the leprosy patient relation with the family members?

Number 2. He has not shown good behavior. But we tolerate him because we know what makes him as like this (the disease).

When he abused us we indicated a smile face for him and also if we gave advice for him, during this time he accepted us.

Number 3. He has good relation with the family member. He knew that the family member give him support in every aspect of his life.

Number 4. He has get a respect for the family members and the family members also respect him.

Number 5. He has no good relation with the family especially with his wife.

Number 6. The family members live harmoniously.

Question- What looks like other family member /other than you/ support for the affected person?

Number 4. Helping him by doing work, washing his foot and giving care for him.

Number 2. All other family members as much as their capacity support him.

Number 1. Similar with number 2 idea.

Number 5. We give care for him by keeping personal hygiene. We prepare and give food on time if he gave as money.

Question – What are desired outcome of a family-based approach for the leprosy patient?

Number 2. My father has not able to plough so he live here in the urban area with me by renting house but my mother and other families live there in the rural area.

Thus, our desired is that the family living together here in urban area. Because, if they live here together my father get follow up in the health institution. However, to do this we do not have enough money to rent big house which accommodate the whole families.

In order to send him with her (his wife) is impossible because, he cannot do any work there.

Number 4. If he became cure that is the desired of the family.

Number 1. The interest of the family is to live here in urban area together. Since, in urban area they keep their personal hygiene very well as compared with the rural area.

Other wish of the family is if the patients cure from his illness.

Number 6. Our desire is to cure from the disease.

Question – What looks like the leprosy patients family member relation with the community?

Number 1. We live in a good relation with the community. Even if, they abuse as we overlook the event as not happened because, if we give a response for them we don't have good relation for the future.

Number 4. We have good relation with the majority of the community but some individuals abused us by saying "lost finger son" and the like. This happen when we disagreed with them by different things.

Number 5. We have good relation and there is no discrimination.

Number 6. Sometimes there are abused us because of the disease.

Number 2. Relation with community is not that much. They said that, "diseased person, lost finger daughter and the like". They abuse as very much.

Number 3. Similar with number 2.

Question on family related care for the patient

Question – What possible opportunities do you have for a family-based approach for the patient?

Number 1. No good opportunity to support him because I am daily laborer so I am out from home early in the morning and returned back during the night time. I have a shortage of time.

But, if he want something from the market I purchase for him. On the other hand, if he has work and if ordered me, I do that job by leaving my daily work.

Number 4. Helping him by doing work. Try to keep him by facilitating his personal hygiene. Giving advice for him in order to avoid walking long journey.

Number 2. As much as my capacity, I give care for him. I wash his clothes and foot.

Number 5. Keep his personal hygiene. Giving advice for him in order to avoid conflict with his friends.

As much as our capacity allows we should try to fulfill his needs.

Number 6. If capacity allows change patients cloth and shoes. As much as our capacity try to fulfill his needs. We try to give him care and support.

Question – What possible obstacles do you have for a family-based approach?

Number 6. Lack of capacity/money/.

Number 4. Our capacity is limited to support him what he want. We do not have enough money to help him in a satisfactory way.

Number 2. We (the families) are not living together creates challenge in our daily life.

The other obstacles is shortage of money.

Number 5. We are not able to fulfill his need as like other friends. Other concern he is not will to hear our advice.

Question – What is the desired outcome of a family-based approach for the patient?

Number 2. Our care for them in order to minimize the sufferance of the disease person. Our desire is patients cure from their illness.

Number 4. Our care is to avoid worsening of the disease.

Number 5. Our needs regarding to the patient is cure from the illness.

Number 6. Similar with number 5's idea.

Question - Additional idea if you have? Response all of them said no.

I thank you for giving this information and spending your time with me.

### FGD3: Group discussion with persons affected by podocniosis

Questions. How do you know you are diseased? How do you accept it the disease? What other people said about the disease? What is/are the impact of NTD on personal and family life? What are the involvement of family members in managing the NTD?

No 1. I confirmed from going to the health center. I fall the ground because I could not reach to my home. During this time my family took me to the health institution.

No 7. It pierce my knee. I cannot go far distance. If I do this activity I become sick and spent two days. How do you accept the illness?

No 4. We accept as it is. This comes due to God.

No 8. As it is. But due to illness we might spent three days in bed.

No 6. It comes due to God.

No 3. It comes due to walking in my bare foot.

No 1. I do no where it comes. Just I know when it happens the case.

Question. What it looks like your relation with the family and the community?

No 5. Family not feel of boring but others (community members) harassing me.

No 4. The community harassing us just like the diseases created with us.

No 7. Family given care for us. They are inviting us to drink tea and coffee. Where us community members insult us.

No 1. It is similar the community insult us. But no discrimination from the family.

Question. What kind of impact happen due to the diseases?

No 7. We cannot able to go far distance, similarly unable to do much and also we cannot equally with healthy people.

No 5. During cold time when we walk our foot become red and swollen. But during recovering our skin exfoliate. The color of our skin become black. It looks like flamed by fire.

No 4. The impact is preventing me from eating food. I feel myalgia (muscle pain).

No 6. When illness starts I spent in my bed, I cannot able to speak.

No 1. When illness starts the swelling holds pus. But when I took drug from health institution I recovered from the illness.

Question. What is the impact of the diseases on your family?

No 1. Community members stigmatized us and our children.

No 4. Similar with number one idea.

Question. How do you take care for yourself?

No 7. During night time I wash my foot with soap. We wear shoe.

No 5. I wash my foot with soap. I bath my feet with water and salt.

No 3. I did not spent night without foot washing. But I recovered from my illness when I got injection.

No 2. I wash my feet.

No 8. Similar with no 8 idea.

Question in related to daily life.

Question- What looks like your daily activities? Social contacts? Leisure? Needs? Obstacles and opportunities in daily life?

No 7. We collected fire wood. We go to mill house.

No 8. We condensed traditional alcohol.

No 2. We do agricultural work.

No 5. We cannot able to plough. But I can work in mill house.

Regarding to social network

No 5. We have local religious association. We live in harmony with peoples. We did not discriminate from local social and religious network.

No 6. They are insult us. They did not shaking our hand.

No 3. In our locality they are insulted us.

What is your need?

No 2. I want to be cure and wish to work equally with my friend.

No 4. If any kind of help available it is good if we get.

No 3. I want a person who help me.

No 7. If we get house work we can able to do because we have power as little as much.

No 8. I live in disintegrated home so I want if my home amended.

No 5. It is good if it is available any help because I am becoming old in my power in order to accomplish my day today activities.

No 7. If we have ability we can do unless we spent in bed.

No 4. Similar with No 7's idea.

No 1. After going to do work out of my home if my illness become started I went back to my home and spend in bed.

Question. How family help you?

No 5. She helped me by preparing traditional beer, wash cloth and wash my foot as well.

No 6. If I become sick my family took me to health institution in order to get treatment. They purchase drug to me, wash my cloth until I become recovered my illness they are not do other work.

No 7. My son fetch water after return from school and also collected fire wood from the field or from the forest.

No 8. My family helped me buying sheep/ got during festive time to eat meat. If they get money they helped me.

Question. What it looks like families day today activities?

No 8. My son helped me before he became ill but now he has not healthy.

No 1. They helped me by doing farming activities.

No 2. They helped me by washing my clothes.

Family relation

No 5. Previously I had health insurance but in this year I have not.

No 4. The government body secured me health insurance freely.

Your need

NO 5. I want become cured after get treatment.

No 3. By doing daily work we got money we pay for private institution to get treatment.

Based on this it is good if we got free health care service.

#### **FGD4: Group discussion with family members of persons affected by podocniosis**

Questions. How the affected person knew he/she had diseased? How the affected person accepted the disease? How the affected person family accepted the disease? How the community accepted the affected person disease? What were the impact of disease on the affected person? What are the impact of disease on the affected person family?

No 1. They know based on their feeling. They accept because not capable to do nothing.

No 2. They know due to swelling

No 5. Just it comes due to willing of God.

No 6. Diseases comes due to willing of God.

No 2. Family considered nothing different.

No 3. We considered it came due to heredity.

No 1. Family considered as the diseases came due to their sin. Just it happens without any reason.

No 2. Peoples considered as skin diseases.

Questions. What impact happen because of the disease?

No 1. Stigmatized from other person. Not able to work as like others. Feeling of illness.

No 2. Presence of acute attack and wound.

No 5. Presence of acute attack.

Questions related to Family life, Family activities, Family interactions, Family support and Family needs.

Family interaction with the community

No 1. For diseases person it is pain for us it is stressful.

No 2. Feeling of inequality.

No 4. Limitation of wanted supply for the patient.

Question in related to daily life.

Question- What looks like your daily activities? Social contacts? Leisure? Needs? Obstacles and opportunities in daily life?

No 2. We may spend to take care of them when they become sick.

No 1. When the sick person go to long distance their illness may be aggravated.

Interaction with community

No 2. Impact may or may not happen. There may be stigma and discrimination.

No 1. May be they cannot able to move from place to place.

No 1. We spent time by undermining ourselves.

No 2. If they can able to do they do work unless if they cannot they do not do anything.

Question Regarding to Family-based approach

Question- What have the opportunities for the family support you get? What are the possible elements of a family-based-approach? What are the possible obstacles or opportunities for a family-based approach? What is/ are the desired outcome of a family-based approach?

Question – What are the good opportunity and obstacles in related with fulfilling the need of leprosy patients?

No 1. We are willing but we may not have capacity.

No 3. I do not have idea.

No 6. They cannot able to do work simply the disease affected person spent their time in bed.

No 2. Supporting family is good but it is not feeling comfort unequal with other people.

Family living condition

No 6. They cannot do daily work and purchase and eat. If the acute attack aggravated they might spend two weeks in bed.

No 2. Those who able to work trade do trade and those able to farm they plough.

Interaction with family

No 2. There is good and bad relation with the family.

Family support

No 1. There is family support for the disease affected person.

No 2. There is support and fulfilling the required thing as much as possible.

No 5. There is family support.

Family wish

No 2. It is good fulfilling the needed thing. If there is command it is good to transfer the order/command.

No 6. If the affected person get they eat if not they sleep in their bed.

No 3. We want the patient cure from their illness.

Family based care and support

Good opportunity

No 2. Family prepared food, fetch water, if patient became ill take him to treatment place, if water needed give to him and do home activity.

No 3. Support by washing clothes and foot.

What type of care is possible?

No 1. Fulfill needed things. Search wound healing or curing drug.

No 2. Similar with No 2's idea.

Obstacles

No 2. Lack of money.

No 1. Lack of health and disagreement

Good opportunity

No 2. If money available and the other if care giver is healthy good to give care.

No 1. If there is knowledge supporting family might be easy.

What is/ are the desired outcome of a family-based approach?

No 3., No 2., No 1., No 4 and No 5. Have similar idea which is wish to cure ill person.

## In-depth interviews

### Patient #one

Disease: podoconiosis

1. Background information
  - Sex: F
  - Age--70
  - Family size ---3,
  - Role---head of household
  - Education---not educated
  - Occupation---traditional cotton preparation for weavers
2. Experiences with podoconiosis:
  - Diagnosis-- *"it started with itching followed by papules erupted and finally my leg swelled...the swelling is increased to today"*.
  - Acceptance---*"I accept as it is from God not from the people"*
  - Reactions family and community—*"my family also accepts the same, but the community discriminates me from social life, I have no social relationship in the community"*
  - Impairments due to NTD---*"after I became sick by this disease, I become poor and I lose my social life..."*
  - Impact of NTD on personal and family life---*"limited relationship with neighbors"*
  - Self-care----*"I wash my feet daily and my clothes weekly"*
  - Involvement of family members in managing the NTD---*"they advise me to keep my personal hygiene"*
3. Daily life:
  - Activities----*"I walk to near places such as toilet, market and church"*
  - Social contacts----*"my social contact is limited to my families"*
  - Leisure---*"I enjoy with my children meanwhile I do my usual work...traditional cotton preparation"*
  - Needs—*"I have needs of money, clothes and different food items"*
  - Obstacles and opportunities in daily life---*"limited relationship with the community and relatives...but no opportunities are there"*
4. Family life:
  - Family activities---*"daily laborers"*
  - Family interactions---*"we live in harmoniously in the house"*
  - Family support—*"my daughters help me"*
  - Family needs—*"My family needs are also similar with mine"*
  - Family interaction with the community---*"like me they have limited relationship with the community because of my disease"*
5. Family-based approach:
  - Opportunities for family support---*"no opportunity other than my children"*

- Possible elements of a family-based-approach---“my family supports me by washing close, cook food and collect firewood from forest”
- Possible obstacles or opportunities for a family-based approach---“my children supports me by their full potential”
- Desired outcome of a family-based approach –“support me psychologically”

#### Family members for patient #1:

2. Background information
  - Sex—m
  - Age--38
  - Family relationship: child
  - Education—grade 3
  - Occupation---farmer
3. Experiences with podoconiosis of the family member:
  - Diagnosis—“as the disease starts she was sick critically at least weekly, slept in the house, poor appetite...”
  - Acceptance---“the same to her”
  - Reactions family and community ---“the family members accept it but when the community insult her as *‘swollen leg’*, she feel sad in the house”
  - Impact of NTD on personal and family life---“she experience pain monthly or every two months that hidens her daily activity”
  - Involvement of family members in managing the NTD—“keeping personal hygiene and food preparation”
4. Daily life:
  - Activities—“in addition to her usual work (traditional cotton preparation) she also visit her sister and look after the vegetables”
  - Social contacts—“ not healthy there is discrimination against social life”
  - Leisure---“visit her sister”
  - Needs---“she needs support from gov’t and wish to breed ships”
  - Obstacles and opportunities in daily life---“due to the disease the food she is not comfortable with the food she eat”
5. Family life:
  - Family activities—“farming”
  - Family interactions—“good support”
  - Family support----“good support”
  - Family needs---“we need money”
  - Family interaction with the community----“limited relationship”
6. Family-based approach:
  - Opportunities for family support—“NO”
  - Possible elements of a family-based approach---“moral support”

- Possible obstacles or opportunities for a family-based approach—“there is shortage of materials to help her”
- Desired outcome of a family-based approach—“we desire to live together and longer”

### Patient #two

Disease: LF

#### 6. Background information

- Sex: F
- Age--20
- Family size ---7
- Role---child/student
- Education---Grade 4
- Occupation--- student

#### 7. Experiences with podoconiosis:

- Diagnosis—“*it started with feeling of dislocation followed by pain of left leg then in my right leg too and I realize my disease*”.
- Acceptance---“I accept as it is from God not from nothing”
- Reactions family and community—“my family and the community shows no discriminations, we live harmoniously”
- Impairments due to NTD---“I cannot continue my education like my partners because of my disease that is why I repeatedly interrupt my education”
- Impact of NTD on personal and family life---“ my families spent a lot of time in caring me when I sick including taking to health facility”
- Self-care----“I wash my feet daily, wash my close and feed food that my family provide me”
- Involvement of family members in managing the NTD---“take to health facility and encourage me to take the medications”

#### 8. Daily life:

- Activities----“I work both outdoor and indoor with my families”
- Social contacts----“no problem of social relationship in the community and in the school”
- Leisure---“No more leisure, I spent the day with fetching water, collect fire wood from forest and play with my friends”
- Needs—“get the treatment and to continue my education like any of my friend”
- Obstacles and opportunities in daily life---“unable to continue my education due to my disease and when there is work load my leg become febrile and my inner thigh is swollen. I see as good opportunity when I become well”

#### 9. Family life:

- Family activities---“farmer”
- Family interactions---“we live in harmoniously in the house”
- Family support—“ take to medical care”

- Family needs—“My family needs are also similar with mine”
- Family interaction with the community---“they have good relationship and my friends also approach me because of my families acceptance in the community”

10. Family-based approach:

- Opportunities for family support---“my family status in the community is respected”
- Possible elements of a family-based-approach---“buy close and shoe”
- Possible obstacles or opportunities for a family-based approach---“there is no obstacle except the disease”
- Desired outcome of a family-based approach –“to be cured from the disease”

*Family members for patient #2:*

7. Background information

- Sex—m
- Age--73
- Family relationship: grand father
- Education—not educated
- Occupation---farmer

8. Experiences with podoconiosis of the family member:

- Diagnosis—“when she was grade one she told me as inching and as she grew up her leg swells”
- Acceptance---“the same to her”
- Reactions family and community ---“the community insult her as ‘*swollen leg*’ by calling her name”
- Impact of NTD on personal and family life---“only her disease condition, not on family”
- Involvement of family members in managing the NTD—“she did not tell to her parents when she became sick rather will told me first”

9. Daily life:

- Activities—“support family and sometimes school”
- Social contacts—“ No problem”
- Leisure---“play with her friends”
- Needs---“to be cured from the disease”
- Obstacles and opportunities in daily life---“sometimes when become ill she is depressed”

10. Family life:

- Family activities—“farming”
- Family interactions—“good support”
- Family support----“good support”
- Family needs---“we need her treatment”
- Family interaction with the community----“good”

11. Family-based approach:

- Opportunities for family support—“yes, her siblings and her share the same father and mother”
- Possible elements of a family-based approach---“medical care”
- Possible obstacles or opportunities for a family-based approach—“there is shortage of materials to help her”
- Desired outcome of a family-based approach—“continue her educations”

**Patient #Three**

Disease: podoconiosis[s]

11. Background information

- Sex: F
- Age--28
- Family size ---2
- Role---mother
- Education---Not educated
- Occupation--- farmer

12. Experiences with podoconiosis:

- Diagnosis—*“it started with itching in one leg at that time I was not aware of the swelling, I used to look after goats”.*
- Acceptance---“I used to go different holy waters—religiously, but my family told me as it was hereditary disease then I accept as it is from God not from nothing”
- Reactions family and community—“my family accepts the problem but the community insult me as **“swollen leg” ‘Egire Abata’ in Amharic** in every encounter we had”
- Impairments due to NTD---“discrimination from the community”
- Impact of NTD on personal and family life---“ I cannot fully engaged in work because of my pain aggravates when I serious work”
- Self-care----“I wash my feet daily in the night, I prepare food what is available from home”
- Involvement of family members in managing the NTD---“They asked me to take Addis Ababa for treatment but I refused since my belief that I cannot be cured”

13. Daily life:

- Activities----“I work both outdoor and indoor with my families for agricultural activities unless I became sick”
- Social contacts----“I practice ‘some’(limited) social life in the community”
- Leisure---“I go to my relatives house and I usually make coffee...we enjoy with it”
- Needs—“I wish I become cured either by medication or any treatment”

- Obstacles and opportunities in daily life---“some people insult me that make me unhappy in my life but my husband is always on my side and he advise and reassure me”

14. Family life:

- Family activities---“farmer and daily laborer”
- Family interactions---“we live in harmoniously in the house”
- Family support---“ my husband and me support each other no other family members help u”
- Family needs---“My family needs are also similar with mine”
- Family interaction with the community---“we have limited social life”

15. Family-based approach:

- Opportunities for family support---“they provide daily needed consumable materials”
- Possible elements of a family-based-approach---“buy close and shoe”
- Possible obstacles or opportunities for a family-based approach---“when food items in house are deficit I forced to work and then become sick, no opportunity except my husband”
- Desired outcome of a family-based approach ---“to be cured from the disease and seen by the local community”

**Family members for patient #3:**

12. Background information

- Sex---m
- Age---25
- Family relationship: husband
- Education---Grade 3
- Occupation---farmer

13. Experiences with podoconiosis of the family member:

- Diagnosis---“I do not know the cause of her leg swelling because we married after it happened already”
- Acceptance---“Since I love her I marry even if I know her leg is swollen”
- Reactions family and community ---“No family member support her except me but we live harmoniously with the community”
- Impact of NTD on personal and family life---“her disease condition lead me to work alone when she is sick”
- Involvement of family members in managing the NTD---“I advise her to keep her hygiene and to wear shoe”

14. Daily life:

- Activities---“she perform household works”
- Social contacts---“ it not bad”
- Leisure---“spent with me”

- Needs---“to be cured and become healthy”
  - Obstacles and opportunities in daily life---“shortage of consumable food in the home and I see as opportunity her ability to move around even if her leg is swollen”
15. Family life:
- Family activities—“farming”
  - Family interactions—“good support”
  - Family support----“good support between her and me”
  - Family needs---“we need change through hard work if she is healthy”
  - Family interaction with the community----“good”
16. Family-based approach:
- Opportunities for family support—“material support for daily utilizations”
  - Possible elements of a family-based approach---“keep personal hygiene, shoe wearing”
  - Possible obstacles or opportunities for a family-based approach—“shortage of financial issue to fulfill daily life needs”
  - Desired outcome of a family-based approach—“we need her to be cured”

#### **Patient #Four**

Disease: podoconiosis

#### 16. Background information

- Sex: F
- Age--60
- Family size ---8
- Role---mother
- Education---Not educated
- Occupation--- daily labor

#### 17. Experiences with podoconiosis:

- Diagnosis—“*it started with itching then swollen like you now(very big foot)*”.
- Acceptance---“ I accept as it is from God”
- Reactions family and community—“both my family and the community supports me, they love me”
- Impairments due to NTD---“No”
- Impact of NTD on personal and family life---“ No”
- Self-care----“I keep my personal hygiene”
- Involvement of family members in managing the NTD---“only of my daughter help me from her daily labor work pay”

#### 18. Daily life:

- Activities----“I walk to market and coffee ceremony at my neighbors ”
- Social contacts----“I have good relationship”
- Leisure---“coffee ceremony in the home, church and visit my children’s home”

- Needs—“I wish I become cured either by medication or any treatment”
- Obstacles and opportunities in daily life---“No obstacle except the disease and my family and the community support is good opportunity”

19. Family life:

- Family activities---“daily laborer”
- Family interactions---“we live in harmoniously”
- Family support—“ they support me what they can--financially”
- Family needs—“money”
- Family interaction with the community---“good”

20. Family-based approach:

- Opportunities for family support---“they wash my close and collect firewood from forest”
- Possible elements of a family-based-approach---“wash close and prepared food”
- Possible obstacles or opportunities for a family-based approach---“when food items in house are deficit I forced to work and then become sick, no opportunity except my husband”
- Desired outcome of a family-based approach –“to live together”

**Family members for patient #4:**

17. Background information

- Sex—F
- Age--45
- Family relationship: Daughter
- Education—Grade 8
- Occupation---Merchant

18. Experiences with podoconiosis of the family member:

- Diagnosis—“started in small swelling and increased later”
- Acceptance---“as will of God”
- Reactions family and community ---“we are unhappy because of her disease suffered every month at least once and she never leave her shoe since she fear the community insult-swollen leg”
- Impact of NTD on personal and family life---“she cannot buy whatever she need in the market and cannot go church whenever she is sick”
- Involvement of family members in managing the NTD—“help her to wear shoe and keep her leg clean”

19. Daily life:

- Activities—“she used to move around but now a days she become weak and hard to move”
- Social contacts—“ it not bad”
- Leisure---“spent in her house”
- Needs---“money”

- Obstacles and opportunities in daily life---“lack of money especially for holiday spent”
20. Family life:
- Family activities—“small scale trade and daily labor”
  - Family interactions—“good support”
  - Family support----“not this much”
  - Family needs---“close, shoe”
  - Family interaction with the community----“good”
21. Family-based approach:
- Opportunities for family support—“no”
  - Possible elements of a family-based approach---“keep personal hygiene, shoe wearing, clean her house”
  - Possible obstacles or opportunities for a family-based approach—“shortage of financial issue to fulfill daily life needs”
  - Desired outcome of a family-based approach—“we need her live comfortable”

### **Patient #Five**

Disease: podoconiosis

#### 21. Background information

- Sex: M
- Age--60
- Family size ---6
- Role---Father
- Education---Not educated
- Occupation--- Farmer

#### 22. Experiences with podoconiosis:

- Diagnosis—“*it started with itching and swollen in one leg then two of them*”.
- Acceptance---“ I accept as it is from God”
- Reactions family and community—“both my family and the community supports me we live social life in mourning, church.., but some people think as I am lower than them”
- Impairments due to NTD---“I cannot work like my friends because of my disability”
- Impact of NTD on personal and family life---“ I cannot fulfill my family spending due to my inability to work with my full potential”
- Self-care----“wash my leg every night and feed what is available in the house”
- Involvement of family members in managing the NTD---“No family support except my own care”

#### 23. Daily life:

- Activities----“I move around and work when there is pain but if pain arose I cannot move...slept”

- Social contacts----“I have good relationship with family and community members”
- Leisure---“sometimes I go to town and relax by coffee, tea ”
- Needs—“I wish I become cured either by medication or any treatment”
- Obstacles and opportunities in daily life---“I am under my colleagues due to the disease and cannot move when I become sick and no comfort at all”

24. Family life:

- Family activities---“Farming”
- Family interactions---“we live in harmoniously”
- Family support—“ they did not support me rather they need my support”
- Family needs—“No need”
- Family interaction with the community---“good”

25. Family-based approach:

- Opportunities for family support---“when the prepared food”
- Possible elements of a family-based-approach---“my family members do whatever I ordered including wash my close, leg, shoe”
- Possible obstacles or opportunities for a family-based approach---“I cannot work with my full potential and cannot change my life”
- Desired outcome of a family-based approach –“to live in life”

**Family members for patient #5:**

22. Background information

- Sex—F
- Age--45
- Family relationship: Wife
- Education—Not educated
- Occupation---farmer

23. Experiences with podoconiosis of the family member:

- Diagnosis—“when get married the disease started and as we live together we have children...then the pain and the swelling is increased now”
- Acceptance---“I am aware of his disease but I need the man so that I married ”
- Reactions family and community ---“the family accept as the will of God but some of the community members see him as he is inferior”
- Impact of NTD on personal and family life---“Unable to work fully”
- Involvement of family members in managing the NTD—“I support him in personal hygiene-I wash his feet and help him wear shoe, we take him to health facility when sick seriously but if the pain is mild we buy him some drug from town”

24. Daily life:

- Activities—“unless his pain arose he can move in the nearby places”

- Social contacts—“ it is good”
- Leisure---“sometimes he go to town”
- Needs---“he likes coffee, tea and other soft drinks”
- Obstacles and opportunities in daily life---“ most of the time he is not happy with usual food in the house but when I prepare for him like ‘**Beso**—prepare from barley, **Atmit**—made from Oats and other cereals”

25. Family life:

- Family activities—“agricultural activities”
- Family interactions—“good support”
- Family support----“has good support with the available resource”
- Family needs---“his cure”
- Family interaction with the community----“good”

26. Family-based approach:

- Opportunities for family support—“no”
- Possible elements of a family-based approach---“keep personal hygiene, , clean his shoe, wash legs and prepare food he most likes”
- Possible obstacles or opportunities for a family-based approach—“shortage of financial issue to fulfill daily life needs”
- Desired outcome of a family-based approach—“we wish he is cured and take of his family”

## Patient #Six

Disease: podoconiosis

26. Background information

- Sex: F
- Age--70
- Family size ---3
- Role---Mother
- Education---Not educated
- Occupation--- Farmer/rent land as livelihood

27. Experiences with podoconiosis:

- Diagnosis—“*it started with itching, thorn like appearance then burst and swollen legs*”.
- Acceptance----“ first I was complaining later I accept as it is from God”
- Reactions family and community—“both my family and the community supports me we live social life in mourning, church. And when become sick they take me health center”
- Impairments due to NTD---“yes because of my disease/pain but no other impact”
- Impact of NTD on personal and family life---“No”
- Self-care----“wash my leg every night and feed what children made available”

- Involvement of family members in managing the NTD---“they take to health facility when I become sick”
- 28. Daily life:
  - Activities----“I move around and work when there is pain but if pain arose I cannot move...slept”
  - Social contacts----“I have good relationship with family and community members”
  - Leisure---“I used to visit my sister but now I become weak and I cannot so that I spent totally in my home ”
  - Needs—“any help”
  - Obstacles and opportunities in daily life---“because of my disease and age no opportunity other than my children”
- 29. Family life:
  - Family activities---“all children are students and they do labor work after school”
  - Family interactions---“we live in harmoniously”
  - Family support—“ they support me by daily work income”
  - Family needs—“Money”
  - Family interaction with the community---“like me my children also live in good relationship with the community”
- 30. Family-based approach:
  - Opportunities for family support---“when the prepared food, collected fire wood, cleans my house...”
  - Possible elements of a family-based-approach---“ wash my close, leg, prepare food”
  - Possible obstacles or opportunities for a family-based approach---“no obstacle and I see my children a opportunity to care me and our house”
  - Desired outcome of a family-based approach –“to cure from the disease”

### **Family members for patient #6:**

#### 27. Background information

- Sex—F
- Age--45
- Family relationship: Daughter
- Education—Not educated
- Occupation---Small scale trade

#### 28. Experiences with podocniosis of the family member:

- Diagnosis—“I did not know how it started but as I grew up I see as her leg is swollen”
- Acceptance---“she sometimes complain as ‘why God make me sick while I am not sinful’ reported the daughter”

- Reactions family and community ---“mother is mother-(“*Enat atitelam’ in Amharic*) sometimes when she is sick her behavior changes but we treat her based on the condition and some of the community live with us like family members but few may be discuss about her disease out of her sight/hear”
- Impact of NTD on personal and family life---“she is not happy when we cannot earn our livelihood, when she is not well she frequently complain of the disease that disturbs the whole family”
- Involvement of family members in managing the NTD—“first we gave her traditional medicine (*Yrhabesh medahnit*) in Amharic” but no improvement then we took her to health facility and they give her some relief drugs”

29. Daily life:

- Activities—“unless her pain arose she can move in the nearby places during hot time and when the weather is cold she sit in the house ”
- Social contacts—“ it is good”
- Leisure---“she visit the vegetable when she is fine”
- Needs---“to be cured from the disease”
- Obstacles and opportunities in daily life---“she perceived as she is inferior to other people even to visit her relatives who live away from her and the care given by her children is good opportunity”

30. Family life:

- Family activities—“students and daily labor”
- Family interactions—“good support”
- Family support----“has good support with the available resource but family members are poor”
- Family needs---“needs money from government”
- Family interaction with the community----“good”

31. Family-based approach:

- Opportunities for family support—“we help her to stop her alcoholic habit and provide her fruits so that her pain seems relived”
- Possible elements of a family-based approach---“take to health facility, provide food, wash her close, give psychological support”
- Possible obstacles or opportunities for a family-based approach—“shortage of financial issue to fulfill daily life needs”
- Desired outcome of a family-based approach—“to make her happy and make free from stress”

## Patient #Seven

Disease: LF

### 31. Background information

- Sex: F
- Age--18
- Family size ---4
- Role---Daughter/student
- Education---Grade 10
- Occupation--- student

### 32. Experiences with Lymphatic Filariasis (LF):

- Diagnosis—“when I was playing with my friends I feel pain in one leg and followed by itching than the other leg is also swollen”.
- Acceptance---“ I feel sorry, I become sick by this age and cannot play with my friends”
- Reactions family and community—“my family also reacts as how it comes while we have no hereditary in this disease? There is good relationship with the community”
- Impairments due to NTD---“I feel inferior from my friends”
- Impact of NTD on personal and family life---“seen as inferior than my friends”
- Self-care----“I always wash my feet and wear shoe, I feel pain without shoe”
- Involvement of family members in managing the NTD---“they take to health facility when I become sick and sometimes give me traditional medicine”

### 33. Daily life:

- Activities----“I move around and work, play with my friends”
- Social contacts----“I have good relationship with family and community members, friends but I feel as I am inferior ”
- Leisure---“play with my neighbors and friends ”
- Needs—“ I need medication that cured me”
- Obstacles and opportunities in daily life---“because of my disease and there is no opportunity”

### 34. Family life:

- Family activities---“agriculture”
- Family interactions---“we live in harmoniously”
- Family support—“ take me to health facility when I become sick and give me priority from the family when there is any problem”
- Family needs—“the need if I cured only”
- Family interaction with the community---“ we live in harmoniously also live in good relationship with the community”

### 35. Family-based approach:

- Opportunities for family support---“supportive family members”
- Possible elements of a family-based-approach---“buy close, shoe, and avail necessary food”

- Possible obstacles or opportunities for a family-based approach---“no obstacle”
- Desired outcome of a family-based approach –“to cure from the disease and live in life”

### **Family members for patient #7:**

#### 32. Background information

- Sex—F
- Age--60
- Family relationship: mother
- Education—Not educated
- Occupation---Small scale trade

#### 33. Experiences with LF of the family member:

- Diagnosis—“start with simple and now grew as big as you can see it is swollen”
- Acceptance---“accept as the will of God”
- Reactions family and community ---“we accept as gift of God and the community also has good relationship”
- Impact of NTD on personal and family life---“no”
- Involvement of family members in managing the NTD—“psychological support”

#### 34. Daily life:

- Activities—“move around ”
- Social contacts—“ it is good”
- Leisure---“she play with her friends and family mebers”
- Needs---“to be cured from the disease”
- Obstacles and opportunities in daily life---“being diseased”

#### 35. Family life:

- Family activities—“daily labor”
- Family interactions—“good support”
- Family support----“has good support with the available resource”
- Family needs---“no except her disease”
- Family interaction with the community----“good”

#### 36. Family-based approach:

- Opportunities for family support—“support each other”
- Possible elements of a family-based approach---“buy close, provide food, wash her close, give psychological support”
- Possible obstacles or opportunities for a family-based approach—“shortage of financial issue to fulfill daily life needs”
- Desired outcome of a family-based approach—“to make her happy and make free from disease”

## Patient:# eight

1. Basic information
    - Age 18
    - sex: M
    - Family Number: 6
    - Type of sickness: LF
    - The family membership: Child
    - Education Level: 10
    - Employment / Student / Student
  2. Concerning the disease
    - 2.1. How to know if you have it and how it first blighted me, and then a small swell grows up. Finally, I went to Chagniy Health Center and did not change.
    - 2.2. How did you get the disease? Initially it was small / small / bitter. Then, in my lifetime, the creator of this disease gave me a thankful response that I did not die.
    - 2.3. How did your family receive the disease? They took me to the doctor's office, right after I was sick.
    - 2.4. How did the community accept the disease? The public or my friends are so sorry because of this disease. They also encourage me to go to the hospital and try to be healed.
    - 2.5. Impact of the disease? When I feel sickness, my lymph node is enlarged (inner thigh) and when I drunk local beer (**Tela** in Amharic) it worsens.
    - 2.6. The impact of the disease on your family? The effect for me is that the impact of this illness, including my father, my mother, and myself, form those of 6 in the family, 3 of us are diseases, no worse than this disease.
    - 2.7. Self-care? I get the shampoo every day, I wash my clothes, and I do not eat meat because of my disease is worsen. But I'll eat the meals that are eaten inside the house /available in the house.
    - 2.8. What can your family members do to reduce the impact of the disease? They took me to treatment and advise me not to do harden work;
- Daily life?**
- 3.1. How is your daily routine or activity? I work or do local activities, even I am doing some light work.
  - 3.2. How are your social connections? The community is so friendly. We also have our own jokes with friends.
  - 3.3. How do you spend your leisure or vacation time? Some Pools are fun with my friends. And I also go through various movies.
  - 3.4. Your needs? I like to be cured and live with my friends like my friends.
  - 3.5. What are the things that are not right? I'm not particularly ill-influenced by people like my friends or friends. In fact, I am very depressed about psychology.
  - 3.6. If You Have opportunity? When I had a complete meal and kept clean every day
4. How is your family life?
    - 4.1. Your family's work? Agriculture / Farms /
    - 4.2. How Do You Treat Your Family? We live in love rather than the disease is the problem.
    - 4.3. How is your family support? They are very supportive in the home and while we are in the

field.

4.4. What is your family's interest? They want me to be saved for them and for the community.

4.5. How are your family connected to the community? They will live with the community on good and good.

5. How are your family's participation?

5.1. Is there a good place to take care of your family? When they reassure me, you will be saved.

5.2. What kind of care do your family care for you? A lot of care takes care of what's in the house. I can wear the available-clothes, shoes, and other entertainment.

5.3. Can there be some barriers and good things to take care of in your family?

Obstacles: I have a problem with sleeping problems and my family is not willing to buy a lot of clothing. Good things-I have nothing good.

5.4. What is the main purpose of your family care? I'm not sick or injured.

## Patient #Nine

Disease: podoconiosis

### 36. Background information

- Sex: F
- Age--32
- Family size ---5
- Role---mother
- Education---Not educated
- Occupation--- farmer

### 37. Experiences with podoconiosis

- Diagnosis—“first starts in small swelling in my right leg and then expand to my left leg....”
- Acceptance---“ I accept it as from God”
- Reactions family and community—“both my families and the community support me and they always think of my disease to be cured”
- Impairments due to NTD---“due to this disease I have also other problems like I have big swollen in my abdomen”
- Impact of NTD on personal and family life---“I am unable to work with my full potential”
- Self-care----“I always wash my feet in the night and prepared food what is available in the house,”
- Involvement of family members in managing the NTD---“they give me hot drinks and that relive my pain”

### 38. Daily life:

- Activities----“I move around and work, play with my friends when I am not feeling pain”

- Social contacts---“I have good relationship with family and community members in coffee ceremony and others”
- Leisure---“if I get time and well I go to my relatives house and play with them ”
- Needs—“ I need if the government supports me”
- Obstacles and opportunities in daily life---“because of my disease am unable to work in the house and outside any farming activities”

#### 39. Family life:

- Family activities---“daily labor”
- Family interactions---“we live in harmoniously”
- Family support—“ even if we are poor we live with love and support each other”
- Family needs—“the need support of close, food...”
- Family interaction with the community---“ we live in harmoniously also live in good relationship with the community”

#### 40. Family-based approach:

- Opportunities for family support---“two of my children support me from what they got from daily labor”
- Possible elements of a family-based-approach---“they fetch water from the river, wash my close, ”
- Possible obstacles or opportunities for a family-based approach---“poverty is my obstacle”
- Desired outcome of a family-based approach –“to cure from the disease and live in life”

### Patient #Ten

Disease: podoconiosis

#### 41. Background information

- Sex: F
- Age--45
- Family size ---5
- Role---mother
- Education---Not educated
- Occupation--- farmer

#### 42. Experiences with podoconiosis

- Diagnosis—“first starts in small pain and become severe and sudden following it the swollen worse”
- Acceptance---“ I accept with tearing but it as from God”
- Reactions family and community—“they are sorry for me and both my family and the community live in love”
- Impairments due to NTD---“due to this disease I cannot move to distant place, mourning and field work unlike my counterparts”
- Impact of NTD on personal and family life---“even I cannot buy from the nearby shop because of my pain and waiting for my children to serve me”

- Self-care----“I always wash my feet in the night using water and soap if I miss a day I will be sick seriously,”
- Involvement of family members in managing the NTD---“my children care me to be cured and advise me how to live”

#### 43. Daily life:

- Activities----“when I become sick I did no move but when I feel good I move around my crops surrounding the house”
- Social contacts----“I have good relationship with family and community members”
- Leisure---“if I get time and well I go to my relatives house and play with them ”
- Needs—“ I want to be cured”
- Obstacles and opportunities in daily life---“because of my disease am unable to work in the house and outside any farming activities and there is no opportunity except my children”

#### 44. Family life:

- Family activities---“Agriculture/farming ”
- Family interactions---“when I feel pain and did not cook food for my children they sometimes feel bad”
- Family support—“ my children support me but others did not rather they expect from me”
- Family needs—“money support
- Family interaction with the community---“ we live in harmoniously also live in good relationship with the community”

#### 45. Family-based approach:

- Opportunities for family support---“when I prepared food and try to taka to farm my children help me not to go there, one of them will come and take their lunch to farm”
- Possible elements of a family-based-approach---“support me in finance and food preparation”
- Possible obstacles or opportunities for a family-based approach---“poverty is my obstacle then sometimes there are luck of food in the home”
- Desired outcome of a family-based approach –“to live with them in life and decrease my suffer”

### **Patient #Eleven**

Disease: Leprosy

#### 46. Background information

- Sex: M
- Age--60
- Family size ---6
- Role---Father
- Education---Not educated
- Occupation--- serve in the church/priest

#### 47. Experiences with leprosy

- Diagnosis—“first it start me when I swim in the river by scabies like rash in my whole body and it was itching finally the wound start from my foot and widespread to whole body, then felling senseless finally it eats my fingers and I lose my fingers”
- Acceptance---“ I accept it as it was from God”
- Reactions family and community—“since I spent most of the tiem in home, my family and the community feel sorry for me”
- Impairments due to NTD---“lose of half figures and cannot do usual work”
- Impact of NTD on personal and family life---‘I fell sorry from my inability to work like my friends”
- Self-care----“I cannot take care of myself due to I become weak,my children wash my feet and closes”
- Involvement of family members in managing the NTD---“my children care me to be cured and advise me how to live, they take me to health facility when it aggravates”

##### Daily life:

- Activities----“when I become sick I did no move but when I feel good I move around my crops surrounding the house”
- Social contacts----“I have good relationship with family and community members, they support me psychologically”
- Leisure---“I cannot move away so that I spend my time in the home and surroundings, sometimes I listen radio ”
- Needs—“ I wish if this disease does not progress further than this”
- Obstacles and opportunities in daily life---“because of my disease am unable to work in the house and outside any farming activities and there is no opportunity except my children”

##### Family life:

- Family activities---“Agriculture/farming, our relatives support the family”
- Family interactions---“I cannot live without support”
- Family support—“it is good”
- Family needs—“they need if I get cured and live together”
- Family interaction with the community---“ we live in harmoniously also live in good relationship with the community”

#### 48. Family-based approach:

- Opportunities for family support---“when I prepared food and try to taka to farm my children help me not to go there, one of them will come and take their lunch to farm”
- Possible elements of a family-based-approach---“support me”
- Possible obstacles or opportunities for a family-based approach---“my disease only”

- Desired outcome of a family-based approach –“to live with them in life and decrease my suffer”

## Patient #twelve

### Basic information

- Disease type LF
- Family Responsibility-----mother
- Age 70. Sex - F
- Educational status not educated
- Family size--- 1
- Occupation/livelihood--- small scale trade

### 2. Experience with disease

just as it starts with itching and my legs began to grow, and I went to the doctor's house to get treatment. First was worried about it and then people say you are not the only person affected by the disease and I start to accept it as the gift of God? (I live alone, nobody is good). The community advise me to visit the doctor. The pain aggravates every month I used to work some of the various jobs before, but now I have to stay at home. I wash my feet at night, wash my clothes once a week, prepare meals at home and eat meals. Immediately, they took me to a doctor when started the disease, but now they have left me and I will be deserted.

### 3. Daily Like

I move to a neighbourhood, or a nearby area, without going far. We live in love with the community. I got to my neighbours home for coffee otherwise simply stay in home. From my top priority, It's the shoes I need. I did not feel good when the illness rises I have not got anything to be comfortable with this disease.

### 4. Family life

I sell different small scale trade namely local alcohol (Areke) and tea. When there is any celebration/religious and called by my elder children I visit them. Otherwise there is no support from my families. We have interest to get close such as blankets.

### 5. Family based approach

There was a brother who had taken care of me, but now I have nothing my obstacle for daily life is as my energy decrease today, I have struggled to do all kinds of work. I have nothing good support.

## Patient #thirteen

### 1. Background information

- -Disease type--- LF
- Age-----70
- Family size---4
- Role-- Mother
- Education---not educated
- Occupation----farmer

### 2. Experiences with LF

When I was look after our lives talks, a bull kicking my leg, and then went home and washed my feet. Eventually, my legs began to swell, and then both of them become big leg. I was in the lament, but finally, I was saved, and I accepted the gift of God. My families do not say anything about me when I get out and sit in or get together with my local community very well received and together we live together. I bothered by the fact that the pain rises. I stay clean at home. Whenever I feel sick my family members take me to health centre and the community supports it.

### 3. Daily life

I take care of the nearby fields crops, and I plant them. We meet with the community in good faith without any problems. I went to the city with my friends and visit crops I need If the government provides me financial support. I fell nothing comfortable with my disease.

### 4. Family life

our family ways of life Agriculture (Farming). I have no problem with other families outside of my family. But my family need some help from me so they can have no support for me. We need to grow and grow my families are they are in good condition with other people

### 5. Family-based approach

my families cook meals and wash my clothes and shoes. Sometimes we may fail to seek out necessities at home. I have nothing to be considered as opportunity for my disease. The main purpose of my family care is let me live in my life

## Patient #14

### 1. Background information

- Disease type--- LF
- Age 70
- Sex - M
- Family size --1
- occupation—guard

## **2. Experiences with LF**

First it starts with itching and start from my ankle and it grew into hard swells. I pray for God as I would never give up. My families are not worried about me since they are living alone.

The community told me If there is medicine to take and get cured. I feel pain in my inner thigh once a month and cannot move even. Nothing is happed on me as a result of this disease by the community. If I want to keep my general hygiene, sometimes I prepare my food. There is no contribution from my family.

## **3. Daily life**

I try to bring some light jobs, such as repairing fence, cut tree from the forest. We live together with love and support with the community. As a school guard, I spend time visiting the school compound and occasionally going to the city for tea/coffee. I need medicine / medication to save me

## **4 Family life**

serve as guard of the school and prepared different ferries including plough, knife..... my elder child sometimes brings me some food. Even if my family members did not live with me they have good relationship with the community in there locality.

## **5. Family based approach**

Currently no family is supporting me except sometimes my son visits me with food. My great obstacle is poverty in addition to my disease. I want to live in my life.

## **Patient #15**

### **1. Background information**

- Disease—LF
- Age--25
- Family size---5
- Education---Grade 10+3 (Diploma)
- Occupation—Teacher

### **2. Experience with the disease**

First, I feel serious pain in one of my testis. It was severe in day and night so that I went to health centre and they gave me drug then referred me to Bahrdar Felege Hiwot referral hospital and the doctors done me surgery and told me as the disease was “hydrocele”. I assumed as the disease was caused by my exposure to sun in the river while I wash washing my body. I did not tell to my families since I feel ashamed. But as the health professionals refer me to Bahrdar, I told them. The disease affect my daily activity ( I cannot walk, I feel pain in my leg too and I cannot take my grade ten examination on time). My families spent a lot of money from my treatment. Even now I feel pain while I walk.

### **3. Daily life**

I am working in the rural school and I have to walk distance every day. When I feel pain I sat down in the tree and take rest. I did not go to health facilities. I feel pain as I urinate and teach my students for long time. Since no one is aware my disease status in the community and my students, I live as any one healthy. I wish I become cured through medication and or any other means so as to work my job fully. I see my rural job that demands long distance to walk and stand for long time to teach as obstacle for my health.

#### **4. Family life**

My families are farmers. As I disclose them my disease they used cares me through taking to hospital and provides me necessary care.

#### **5. Family based approach**

Even if I did not tell them on time they care me afterwards. Now I am living alone and no one support me for my disease. They are not also aware my current status.

### **Patient #16**

#### **6. Background information**

- Disease—Leprosy
- Age--62
- Family size---6
- Role---father
- Education---not educated
- Occupation—farmer

#### **7. Experience with Leprosy**

It has been start more than 30 year back. Begin as my body is becoming senseless. I went different holy waters but no treatment was found. I accept as it was from God. My families also worried as it was new disease in our family/heredity. Now the disease impact is my foot figure is cut down, I am unable to work my previous agricultural activities. I become poor in economy since I cannot work as previous. My body feels numbness. The community thinks for me. My wife wash my feet and my children care me through other works. I also wash my foot with soap every day in the night.

#### **8. Daily life**

I look after the sheep and advise my children on work. My social activity is limited. We have leprosy affected people association and even in that association people considered us like we are not equal. For example some did not bring their powder to our grinder. I cannot withstand the muddy life in rural and I need to come to town and live. My disease worsens in the rural. My great obstacles are looking after live stalks, collect fire wood and travel long distance to come to the association. I see as good opportunity what is available in the association and government support through different mechanisms to mention (give land in the town).

#### **9. Family life**

My families work in daily labor and agriculture. My wife cares me and she assured that when we get married as I was healthy. There is no social relationship problem for me and my family in our locality.

#### **10. Family based approach**

My family support me by washing my leg, close, prepare food and wishes to be cured. My great opportunity is my wife's care

## Patient #17

### 1. Background information

- Disease—Leprosy
- Age--60
- Family size---10
- Role---father
- Education---not formal education and he is priest.
- Occupation—farmer

### 2. Experience with Leprosy

It starts in 1986 E.C and become fully symptomatic in 1999 E.C. since I am priest I visit many holy waters and cannot get treatment. It starts with numbing and on my knees, elbow and neck. Then I went to Bahrdar hospital and the doctor told me as I need surgery (amputation of my leg and hand). But I refused and come to my home and sleep in my home for two months. And I hear as there is leprosy association in Injibara and some people told me to go and ask them. Finally the head of the association diagnose me as “leprosy” and took me to the nearby health center for treatment. Then I took my medication and further exacerbation is stopped. My relatives insult me and my children are also the victim of it. Other priests in the church feel discomfort and I left the ‘kidase” service for other and engage in other spiritual one. I some time encounter a problem when I found wife for my children. I care of myself in shoe wearing wash close and wear shocks.

### 3. Daily life

I pray from 6 pm to 12 pm in the night always and sometime more than this in my bare foot in the church. Even if it is not like the previous I also engage in agricultural activities with my children. I look after my cows and oxen. I need if government support in loan to have sheep. My figure is cut down and unable to work with my full potential. Whenever I use fire to protect my coldness my body swells and bursts.

### 4. Family life

Most of my children are students and they also do agricultural works. As a result they repeatedly interrupt their education. We love each other in the family. When the community insult my child they leave them simply since we feel we are inferior. My children needs to continue their education but poverty,

### 5. Family based approach

My family support me by preparing food, building house, look after cows and oxen and work with their potential.

I want to remind the government to bring medications that cure/eliminate from the body. The disease is like fire in the ash not cured even if we finish treatment.

## Patient #18

### 1. Background information

- Disease—Leprosy
- Age—56
- Sex--F
- Family size---10
- Role---mother
- Education---not education.
- Occupation—farmer and art (cotton and traditional food handling material preparation)

### 2. Experience with Leprosy

It starts me when I was 40 years old and I diagnosed from Addis Ababa Alert hospital as it was leprosy. I feel sorry by my luck and divorced with my husband. My family and the community did not accept it as disease rather it was seen as something I brought because of my sine. He married another wife and born two additional children. My right foot fingers are cut down and still there is repeated wound. My families cannot produce enough food because of we are separating and they were too young. I care my wound by immersing with salt water, wash with soap, and using baslin.

### 3. Daily life

I work hand craft (cotton preparation for close and prepared traditional food handling materials) since my hand fingers are well. It was worst situation in the last times to live with the community but now it is improved. I feel shamefully when people care me in any social interaction. They respect us and the awareness created by our association is helpful. I cannot do my previous agriculture because of my disease. If exposed to soil and mud my wound aggravates that make me poor. I thank God my hand is well. I want get loan and have sheep or hen in my capacity.

### 4. Family life

My children are elders and they are busy of caring theirs'. I used to support by exercise book and pen my grandchild from our association in turn he helped me but now the support is interrupted due to the association rule to support only child. Sometimes we enjoy coffee if there is occasional ceremony.

### 5. Family based approach

I need if my children supports in collecting fire wood from forest, fetching water from river and make coffee.

## Patient #19

### 1. Background information

- Disease—Leprosy
- Age—55
- Sex--m
- Family size---8
- Role---father
- Education---grade 4.
- Occupation—farmer

## **2. Experience with Leprosy**

It started me before 35 years and I visit money holy waters. I also went to Addis Ababa with the help of my brother. The doctors diagnose as leprosy and give me some drugs taken a year. That shows some improvement but not cured. As you can see me now I cannot even handle things with my hands. I thought I will be cured but impossible. My brothers told me as the disease is hereditary and as I get from my father. The community attitude was not good in earlier times and now gets improved. My children and my wife support me in agricultural work and personal care including food preparation, wash close, give psychological support. I also take care of myself in keeping personal hygiene and visit doctors when I feel sick. There is no negative impact on my family except economically I cannot support them.

## **3. Daily life**

I look after our cows and oxen collect firewood from nearby forest. I cannot walk distance place because of my disability. I need to have job in the town like small shop. I give advice to my children on agricultural job. My children are good opportunity for me.

## **4. Family life**

Most of my children are students and work in the farm to support our family. They have good relationship between them and among the community. They need more money to expand their agriculture.

## **5. Family based approach**

My children and my wife take care of me. They said you pay more suffer for us and now you should be get rest. They wash my leg, close and prepare food.

## **Patient #20**

### **1. Background information**

- Disease—Leprosy
- Age—68
- Sex--m
- Family size---5
- Role---father
- Education---not educated
- Occupation—farmer

### **2. Experience with Leprosy**

It started me before 40 years and I spent more than a year in holy waters. I accept it as it is punishment from God. My wife's family tries to divorce her because of my disease. I feel as I am inferior to my friends. In the beginning the communities reject us from social relationship and now more improvement is observed. My fingers are not normal. I wash my legs with ash and soap every day. I cannot work my previous farming since it aggravates the wound. My children support me especially in holidays by money.

### **3. Daily life**

I did not work in the farm and I look after our cows and oxen. We have good social contact. I need to live in the town where there is no mud and long distance walk. When I exposed to mud and soil the pain aggravates. Also when I become Waite and try to dry by fire it worsen the wound. I see as solution being

live and work in the town. My disease is obstacle for my routine work as a result I become poor in economy. My children advise me to cut my alcohol and keep my personal hygiene.

#### **4. Family life**

Most of my children are students and work in the farm to support our family. They wash close, my legs, and clean house and prepare food. But sometimes some people insult me out of witness.

#### **5. Family based approach**

My children and my wife take care of me. They said you pay more suffer for us and now you should be get rest. They wash my leg, fetch water, cloth and prepare food. We have good relationship with the community.

### **Patient #21**

#### **1. Background information**

- Disease—Leprosy
- Age—33
- Sex--F
- Family size---5
- Role---Mother
- Education---not educated
- Occupation—farmer

#### **2. Experience with Leprosy**

When I was young I become sick and my families took me to the doctor. My families believe as the disease is hereditary and they mentioned as my elder brother was sick by this disease. The community also believes the same. My parents agree me to marry for someone and after preparation the groom left me unmarried due to my disease. Now we have good relationship with the community. Now my legs are become senseless and I cannot walk long distance, I cannot prepare food by fire (prepare with difficulty). I sometimes quarrel with my husband as I cannot work in the farm. If I work and exposed for soil and mud my pain/wound aggravates.

#### **3. Daily life**

I cannot clean wastes of horse and donkey since it aggravates the disease. I work in the house like food preparation for my family, go to market. I need to live in the town where mud and soil related work is minimal unlike the rural one. I always bother as I will lose my fingers like other people I know.

#### **4. Family life**

My husband works both farming and daily labor in the town. We have good relationship with the family and the community. My children/girls cannot complete their studies due to our economic incapability. In early times of my disease it was hard to live social life with the community but now days there is improvement. My worry is my children will contract the disease. Sometimes people called our association as it is disables (yekomatoch) association.

#### **5. Family based approach**

We have a half hectare land and we are living using it. Our big aim is living out of soil and mud work. The greatest obstacle is economic inability. My husband sometimes warns me to work in the field and since I become ill I am not volunteer. Since I can care of myself my families support is minimal.

## Patient #22

### 1. Background information

- Disease—Leprosy +podoconiosis
- Age—55
- Sex--m
- Family size---5
- Role---Father
- Education---can and write
- Occupation—farmer

### 2. Experience with Leprosy

It was before more than 30 years it diagnosed in Addis Ababa alert hospital. First I believe I got from my father since he was also affected by the disease. My elder families and communities also support the idea of the disease is hereditary. My families are afraid of acquiring the disease and leave my house as they become 'independent'. My wife also worries as she will be diseased. I keep my personal hygiene. I have problems to buy soap and basline for my wound care. I always worry as my disease is worse than my friends.

### 3. Daily life

I limit my daily work to few hours when there either too hot or cold. I have good relationship with the community. However, it is usual to discuss about our situation in hidden circumstance. I need loan from government or others to start other businesses that can be managed by my capacity such us sheep, hen farming. I want to live in the town to decrease my vulnerability due to soil and mud exposure.

### 4. Family life

We have few animals we look after. My children already leave the house due to fear of the disease and stigma except my wife. Some people insult both my families and me when there no witness.

### 5. Family based approach

My wife washes my leg, my close, clean the house. One of my sons also works in the farm and he sometimes support me with money from his daily work income.

## Patient #23

### 1. Background information

- Disease—Leprosy
- Age—45
- Sex--m
- Family size---6
- Role---Father
- Education---grade 3
- Occupation—merchant

## 2. Experience with Leprosy

It has been more than 5 years since I diagnosed as leprosy from Bahrdar hospital and referred to Addis Ababa Alert hospital. I stay 2 years in Alert hospital getting the treatment. The disease was severe in generalized across my body. I was almost with no hope to become cured but now I am cured from that worst case. My wife repeatedly asks me to be divorce and even she was lost for more than 2 weeks. Then I beg her with elders and priests in the town and come back. Especially her relatives forced her to leave me. I used to beg money for the transport expense to Addis Ababa. Our association/leprosy helps me to negotiate with my wife. Many of my neighbors used to say we cannot entered to his house, they separate me from coffee too, sometimes whenever I say hello for kids their parents were not happy, few of them warn me not to touch them. That was the worst time during my illness. Now there is good change of behavior of the community. Some people support our association. Once up one a time when I was near to fire during cold season, my body bursts and I went to health center and they give me treatment for my wound. Afterwards, I did not expose to fire. When people are discussing about my disease and prevent from social life my wife asked me to divorce. Two of my brother are died of this disease.

## 3. Daily life

I have art ( I made simple farmers shoe and bed) I also highly participate in the association affaires. I also grind powder. Now we have good relationship with the community. I spent most of my free time in the leprosy association work. I need baselin for night use and loan to work by horse cart. My house is getting old and I also need support to repair it too,

## 4. Family life

My wife prepares local alcohol (Areke) and support the family. My elder daughter also supports us through daily work from neighbors. We live in good relationship with the community. My families support me in work to share some burden. We need some loan/grant to work on small scale trade.

## 5. Family based approach

My children are my great opportunity to care me in addition to my wife. They wash my sock, shoe, close and prepared food. My draught buys coffee from her money by fetching water. They also advise me not drink alcohol. My house in the town is great opportunity than mu counter parts.

## Patient #24

### 1. Background information

- Disease—Leprosy
- Age—60
- Sex--m
- Family size---8
- Role---Father
- Education---grade 4
- Occupation—guard

### 2. Experience with Leprosy

My disease starts me more than 30 years back. First my friend noted on back of my neck while I was working in irrigation farm. It stars with senseless and sometimes sharply painful. There was no nearby

treatment center during that time. My father told me as I have hereditary disease from my mother's relatives. I asked my father what the disease is and he told me as it is like beggars in the road. Then I was shocked and ask him to find some solution. He was so wise and assured me as there is traditional medicine (Yehabesh medahnit). Meanwhile our neighbor who was similarly affected by the disease told me as there is drug in the nearby town called Dangila and we went there. They gave me the treatment and I took over 15 years. They diagnose as leprosy and after I complete my treatment they took sample from my ear and declared as I am free from the disease. But still the sequel in my left hand and leg is not reversed. I remember one day someone insult me as 'you are dirty beggar' and I try to harm him with spear. Finally when 1 year drug come to treatment I took it also. The local governing body did not give me land as equal as my friends since they believe I cannot fuse it. That was serious harm for my family. I get divorced four wives due to my disease and now I am living with my 5<sup>th</sup> wife who accepts my condition. I keep my personal hygiene; I did not walk long distance.

### **3. Daily life**

I spent 24 hours in the association grinder as guard and also help while grinding powder. We live with our neighbors with good relationship. We need money to start honey bee farm. I see as great opportunity to live in the town in addition to my children support. If I get loan I plan to expand my honey bee farm.

### **4. Family life**

My wife engages in honey bee farm in the rural. And most of my children are students. I have two children who complete their university education. There are some people still who undermine my family, for example this year when I plan to marry my daughter for someone the interrupt it and give her for other man.

### **5. Family based approach**

My children are my great opportunity to care me in addition to my wife. They wash my sock, shoe, close and prepared food. Being in town also is good.

## **Family member for Patient #24**

### **1. Background information**

- Disease of indexed case—Leprosy
- Age—24
- Sex--F
- Family size---8
- Relationship---Daughter
- Education---grade 10
- Occupation—merchant/Tella seller

### **2. Experience with the patient as a child and care giver**

The disease has been long time. It aggravates in the night especially when was farming. we have some information as the disease si not hereditary since we can read what is given in their association. The community discriminate our family based on our fathers illness but now it is decreasing. We wash his legs, tell him to wear shoe, take him to health center as he fell pain and care him we our capacity. We cover his leg with cloth and tie it when the pain is worse that help to him relive the pain.

His daily activity is working both as guard and grinder in the cereal grinder of the leprosy association. He is also management committee of the association. Now the disease get improved and we (my mother and children) care him what we can.

## **Patient #25**

### **1. Background information**

- Disease—Leprosy
- Age—38
- Sex--m
- Family size---8
- Role---Father
- Education---not educated
- Occupation—daily labor

### **2. Experience with disease**

It started me with chilling. It was stricken, and it was like common cold and I used to wash in the morning in the river for several days. I had to grasp my leg, feeling of 'cut off', and then started to fall. Then I went to the doctor and diagnosed it with leprosy. Then they gave me a 12-month course of medication. I could not get cured by the medicine. I do not know where the disease came from. There is no such disease in our hereditary. My family also does not think so. I was fine but progress in a short time, I would hand it to my feet, but I would do it for them. So, unfortunately, this happened to me. I did not believe as the disease is from God. My neighbors and the community thought me as with bad chance, you become seriously sick. The impact is bad, I cannot work since my hands are disabled so that I cannot afford to my family daily livelihoods including lack of money for house rent. There is an occasion my home renter told me to leave his house since I cannot pay on time. I was forced to leave his house with my children however; my neighbours pay me for the rent. And the damage is not so easy. My family has been unemployed because I have been unemployed. I have been treated for extreme hardship and I have been sick with them. I used to care of myself by selling my sheep and all my goats, but now I have nothing to sell and even my neighbours lend me money for holy water and other expenses. My eldest daughter help by serving in others' house and took me to Addis Ababa for treatment. Others are helping me with the disease as much as they can.

### **3. Daily activity**

I was unable to move even toilet in the last a year and eight months. And Now, I just get a bit improved and at least I can get to toilet. We live in good relationship and enjoy coffee together. But the relationship is not the same as it was two years ago. How can I have leisure time in these condition (lose my fingers and bedridden). The people around me helped me what they can, and now I want the government to help me. I would like to eat my salvation. What's so unpleasant at home is loss of money.

### **4. Family life**

My children support me with day-to-day work and I become good as you see me. They did not show me any other characteristics I did not know in the future but they did not have anything to this day prepare meals, wash my close and I exist my their support.

#### **5, Family based approach**

my wife and children cook a meal and washing my clothes. Just they want to save my life.

### **Family member/wife of patient #25**

#### **1. Background information**

- Disease of indexed case—Leprosy
- Age—36
- Sex--F
- Family size---8
- Role---mother
- Education---not educated
- Occupation—daily labor

#### **2. Experience with the patient**

We saw as his hands and legs were swollen. I do not know where this come from, may be from God. We have good relationship with the community; my neighbours even help when he was sick, including for the rent. The impact of the disease is his hand was leaned in his feet and he could not even eat food. He could not walk. He was supporting hid family before he was sick. And now he was in trouble with the house. We are also in fear of contracting the disease. For more than one year and 8 month I wash his feet, hands, take care of his urine and fences and feed him. Now he starts care himself. We took him to holy water and hospital but there is no change and he is not cured.

#### **3. Daily life**

He simply sleeps and spent time in the home. He cannot move distant and only get into toilet by his own recently. I start to go to the nearest house for coffee after he comes back from holy water. There is nothing suitable for the poor, we are in trouble. Both our kids and me are working day-to-day as daily labour to support the family.

#### **4. Family life and family based approach**

We wash his clothes, feed food, wash his hand, we are doing our best, we live with peace and reconciliation with the community. We have never been in trouble. They help us and say that they care with us. The first kid is busy doing a lot of stuff. so we have a financial problem

## Patient #26

### 1. Background information

- Disease—podoconiosis
- Age—40
- Sex--F
- Family size---6
- Role---mother
- Education---not educated
- Occupation—beggar

### 2. Experience with the disease

Initially start me in itching, and then it became very red, and after that I was badly wounded I accepted the name God gave me. My families also accept the same. Some people say God's punishment," and others say, "You're going to be tested." I become beggar and my children also cannot work and Waite my hand. My children cannot get school because of poverty. Some people insult me and also they insult my children as off I 'buy' the disease.

### 3. Daily life

I went to church and beg some money. If I get I will come back home and eat what we get with my children and if no, we spent the night in hunger. My social life is not good. People in the wedding let me to stay outside of the tent and they did not treat me as I was healthy. They are afraid of my disease not to be transmitted to them. How can be equal with this disease, I sometimes agree with what they did. No, my friend is as weak as me, as my suppliants. I also did not connect with my relatives. They were just as sick as I was when the church chanted and drove me out of Marriage as a priest. I'm not with them, only with my kids. Since we are weak the community and the government better help us. My husband is also beggar.

### 4. Family life

my husband is also beggar. One of my daughters is working day by day and helping me. One of my daughters went school her friends insult her as your mother is beggar, "komata' and now she did not go to school.

### 5. Family based approach

When God gave me the disease, he gave me a baby, and he gave me a drink of water. When I drink breaks down, the pain is gone. They are doing all their deeds, and they want to help me, as long as we are together. They want us to be saved and to be saved by medical cure. They say they always say, 'We are going to get you far and wide,' and you say, 'We are going to save you.' But they lose their sense of humour for us.

## Family member/daughter #26

### 1. Background information

- Disease of the index case—leprosy
- Age—18
- Sex--F
- Family size---6
- Role---daughter
- Education---Grade 8
- Occupation—student/daily labor

### 2. Experience with disease

My dad and my mother were not born before I was born, and I did not know that the sickness had begun. I do not claim my mother and father who suffer by disease while they grew up me.

How did your father, mother, and your mother-in-law get all the sickness? We all have good family support. People seem forget that of disease come from God. Rather they insult as my father and mother are abusing the church property, they also insult me as beggars' child. Two reasons for leaving my education are: One is because I have to work day by day to care for my family, and the second is taking a toll on the harsh words at school. in spite of my abusive comments, I was struck by the insults at the police station.

### 3. Daily life

We have at times a lower standard of living than human kinds. Most of the damage was that I interrupted my school, and I lost consciousness when I learned to work as a laborer at this age. One of my brothers has become a street child. There is no family to continue his education. Mom and Dad are also begging because they cannot work. If the disease did not come, we would have had a good life,

### 4. Family life and family based approach

some people hire me and supports. But few people insult me and I usually are in quarrel with. I wash my mam and Dad clothes, take my mam to market and prepare food for the family.

## Patient #27

### 1. Background information

- Disease—LF
- Age—40
- Sex--F
- Family size---1
- Role---mother
- Education---Grade 4
- Occupation—small scale trade

### 2. Experience with disease

Question: What do you do when the illness begins?

When it starts to bite me, it bumps me red and it loses in slowly and loses in the morning.

Question: Do you believe the disease is from?

A: I think I'm going to bet that I'm going to blow up once, and it'll be OK another time. What do you know about this, and I'm not saying that I'm just giving pic to go with Akim

Q: How do you tell if the family received the disease?

The answer is, yes, I have the same shoe in the morning, but when I started, there were other families with my mother.

Q: Do you and your family support the disease? Where is the neighboring community from?

No, I do not know what to say

Did the question come from a race, or did it not say that God's wrath was the Father's father?

I do not know if I did not hear or not

Q: Is there a problem caused by a problem?

Answer My leg was very wounded and leaped when I was leaping from the leopard. It switched on my throat and my leg was too high.

Question: What if the effect of the disease on you and your family affected your family?

Answer: Yes, when I could not work I sat down and sat down alone

Was there a question of marriage and that the divorce was caused by the divorce?

Answer: Yes, yes, who can eat me when I can not work?

Question: Are you caring for yourself?

And I always kept my integrity. As I told you, I always kept kissing and washed with water, then dried up in salting. I sat down and kissed my bed, kissed my legs, and slept all night.

### **3. Daily life**

ANSWER: I really crave for what I do. Because of the illness, I often have a break at home at tea

## **Patient #28**

### **1. Background information**

- Disease —podoconiosis
- Age—35
- Sex--M
- Family size---7
- Role---Father
- Education---Grade 4
- Occupation—daily labor

Question: How did you know that you have the disease / sickness?

Answer: As soon as blood blew me off, it blew up because of blood

Question: How did families receive the sick as a result?

Answer: - Receive the sun because of the sun

Question: How did the neighbors receive the disease?

Answer: They saw that he was coming

Question: What caused the injury?

I could not go out but I could not swallow, and my face swelled and became fatter.

Question: Is there a problem with your family?

Answer: I ended up with my family's financial problems with drinking and medicine

Question: How can you protect yourself?

Answer: I live clean, wash with soap, wash with salt while I wash it with water.

Question: What can the family do to reduce the risk?

ANSWER: They provide me with soap and so on.

Question: How was your day worked?

I was working and I was sick because I was sick and I was unemployed and I worked for a day job.

Question: How is it related to neighbor?

Answer: Villagers insult me when they are abducted

Question: How do you spend your holidays on holiday?

As an opportunity my friends call me, I go, but I go to the forest

Question - What do you want?

Answer: If I have this disease, I want to live as a human being

Question-What Will You Want to Be Saved?

A. I want to be saved by both physician and apologist

Question: Unconscious things?

ANSWER: Living with the disease, I have no money to pay for transportation for medical treatment

Question-friendly?

Answer - I have a doctor because I have a soap and a baby billet for shelter

Question: Family work

Answer-day work

Question: Relationships with family?

Answer: We live in harmony

Question: How do families support you?

Answer-washing clothes, drinking water and making a laundry machine when I get sick

Question: Family Interest?

Answer - They want me to be saved with them

Question: Did your family communicate with neighbors?

Answer: We live in peace with the community

Question: What opportunity do we have to look after in the family?

Answer: My brother is there with me because he helps me out oral with treatment

Question: What care can a family take care of?

Answers: They pay me for clothes and they take me to the office and they take me to the office

Question: What prevents you from caring for a family?

Answer: The problem of poor living conditions and treatment

Question: What was the purpose of the family?

ANSWER: I've worked well with my crew to live with them

## Family member for Patient #28

### 1. Background information

- Disease —podoconiosis
- Age—35
- Sex--M
- Family size---7
- Role---Father
- Education---Grade 4
- Occupation—daily labor

Question: Where do you come from?

ANSWER: As you bleed as a result, it was sun-drenched in sunshine, not sunburn

Question: How do neighbors respond?

The neighbors know that they come for a real reason

Question: Is the disease caused by the disease?

It's difficult to get a faint-fired injection

Question: How does it affect the disease?

Answer: There is no work at all but a day's work and no bread

Question: How can you cure the patient?

Answer: By putting on a clotheskin, I'll give it a cigarette and give it to him. I'll take care of it and treat him as I need it.

Q: How do you contribute to reducing the risk?

Answer: In the illness, I take him to a doctor's hospital and care for him.

Question-Is He Working Every Day?

Answer -It's a day's work and it's going to lie down

Question: Relations with neighbors?

Answer: We will live in harmony and live in peace

Question: How do you spend a day without work?

ANSWER: When playing with friends, it is fun to play with family

Question-What Was It?

Answer: We want to work in the field of irrigation, farming, cattle husbandry

Question: Unfair conditions?

Answer: The sickness can not be processed because of the disease, so live with the disease and poverty

Question-friendly?

Answer: When a brother becomes ill, he or she gets to a place of treatment or a place of evacuation. It is best to live well with a sick person who is sick without sickness.

QUESTION: What do you have to eat?

Answer-day work

Question: Relationships with family?

Answer: We will live in love /

Question: Family Support?

Answer - We get dressed, ssi, when we get sick, we will take him to the treatment place

Question: Family Interest?

Answer: To be free from disease

Question: Are you dealing with a neighbor?

Answer: We live in peace in love

Question: Is it a good time to take care of your family?

Answer: An elaborate brother takes him to the treatment room for an illness

Question: What can you look out for in your home?

Answer: We will dress it up, when we get sick, we will take it to the hospital

Question: What prevented you from taking care?

Because of economic hardship, we were facing a challenge

Question: What is your role?

Answer: We want to be able to work like people

## Patient #29

### 1. Background information

- Disease —LF
- Age—40
- Sex--M
- Family size---4
- Role---Father
- Education---not educated
- Occupation—Guard

Question: How did you know when it started?

ANSWER: Initially, he pummeled me both at once and my father treated me with a pesticide and then a swollen lump and I became very sick.

Question: Where do you think it is from?

ANSWER: We got our mother in maternity With that leg of a feline, I was sitting on my lawn and sat down and then passed away

Question: Where does your family come from?

Answer: We have a command of the Lord and we have a seed

Question: Neighbors accepted it

Answer: They say that they are a disease caused by your mother

Question: What went wrong with the disorder?

A: I had been taking the pills for Nursing Pills, and I also had a hot stomach and had a very serious infection.

Question: How did the disease affect the family?

My answer: I have been a refugee, a shortage of money

Question: How do you handle yourself?

A: I go to the treatment room. I wait and wash. I do not walk without shoes

Question: How did the family deal with the harm caused by the disease?

There is nothing that I can do

Are you doing two-day work?

Answer: I am able to get up and sit

Question: What relationship to neighbors?

Answer: I live in the smallest human being while I am an abusive child

Question: How do you spend the holiday day / vacation?

I do not have anything to wear because it's a stupid job

Question: What do you need?

Answer: If I can fix my leg like people, I need help from the government

Question-What do you think?

Answer: What's Wrong With My Wage And My Wages Are Not Enough My Mum's Weak And My Children Are Children

Question-What Did Not?

Answer: Poverty and the disease

Question-to-Use?

ANSWER: My husband is working day by day and we will be safe

Question: Where is the relationship between the family?

Answer: Went to wash clothes and work well and work well

Question: What do your family want?

Answer: I want my salvation to live like people do for me

Question: How do you and your children live with neighbors?

Answer: As they live in peace, they bludgely blaspheme, saying, "Sweet are you!"

Question: What good opportunity do I have during my courtship at home?

ANSWER: My wife is doing a lot of work and getting sick while washing her clothes and curing meals and it's a good thing to be there with her.

Question: What care do they take in the family?

Answer: When I get out of bed and get dressed up, she gives me a warming fire

QUESTION: What happens when you go to the bathroom / restroom?

Answer - Poverty / Lack of Finance /

Question: Why are they cared for at home?

Answer: To make my work work

## Patient #30

### 1. Background information

- Disease —podoconiosis
- Age—40
- Sex--F
- Family size---4
- Role---mother
- Education---Grade 7
- Occupation—daily labor

Question: How do you know the disease?

Answer: It started to sweat, and then began to sneeze.

Question: How did the disease get him?

Answer: I accepted my transgression by having inherited the disease because of my father's condition

Question-Did You Receive a Family?

Answer: Because my family was affected by the disease, I accepted that you were also crippled

Question: How did the neighbors receive it?

Answer: Where do you come from? Where do people come from? I think I'm from the Desire of my father.

Question: Is the harm caused by disease?

Answer: I can not work because when the disease starts, it does not stir up

Question-Family Influence?

A: I'm not able to work on my own pain when I have a headache. There is no impact on family impact

Question: How to care for yourself?

Answer: When I get up, I go to the hospital and use my penis to wash my feet with soap and water.

Q: What do you do to reduce the incidence of the disease?

Answer - Medicine buys me to go to the doctor's office

Question: How do you work every day?

When I lie down, I lay down and I eat and drink and work day by day

Question: How do you tie in with the neighbors?

Answer: They do not want to stay in touch with the community because they do not want to touch it, so they do not ask me to be upset, crumpled, countless.

Q: How will you spend your spare day / daytime?

Answer: In the afternoon of tomorrow, I do the job saying that the disease is up, I do not have any entertainment

Question: What do you want to say?

Answer: I want to be saved by the one hundred lives I live and mock me

Question: Things that are not comfortable at home

A: My illness did not work because I did not have to pay the rent because I did not pay the rent.

The questions-things that are convenient

ANSWER: It hurt me when my brother fell ill

Question: Family work / Livelihood /

Answer-leave me alone, and I get up and walk away

Question: Relations with neighbors?

Answer: We live in peace in love

Question: What is the relationship between family?

They get me a dress, they buy shoes for me to dive. I take them to the treatment place. They treat me with pain and wash my feet.

Question: Family interest

Answer: I want to be updated with my friends in prayer and medical treatment

Question: Relationship to neighbors (Families)?

ANSWER: They blaspheme my parents A sullen boy slanders younger people

Question: Is it a good time to take care of your family?

Answer: -stam they take me to the hospital they pay me clothing and help me to get health care treatment to avoid wasting money in sickness.

Question: What care can you take in the family?

Answer: When the disease rises, they cook meals, they take me to treatment, and they make me domestic hygiene.

QUESTION: What is hard to take care of in the family?

Answer: If money costs me when I have money, I will save money to buy enough to buy it. In general, poverty /

Question: What is the purpose of family planning?

Answer: My parents want to work with my friends to help me recover from the illness.

### Family member for Patient #30

#### 1. Background information

- Disease —podoconiosis
- Age—36
- Sex--m
- Family size---4
- Relationship--brother
- Education---Grade 7
- Occupation—Grinder

Question: How do you know her illness?

Answer: I know it after I get sick

Question: How did you get the illness?

Answer: I will agree to come to the family of their father through their father

Question: How did families receive it?

Answer: Mother's family came from her father's family

Question: How did the neighbors receive the disease?

Answer: As he came from the seed of his father

Question-How Do You Look After It?

I need help when I get sick when I get sick

Question: What has been done to reduce the harm caused by the disease?

We recommend that you wash your hands with water and soap

Question: How does it work each day?

ANSWER: She'll be back to work when she goes to work, she'll be back to work and she'll do some simple things.

Question - What do you want?

Meles: We want you to live with us

Question: How is family support?

Answer - When we get sick, we care for you

Question: Is there a good opportunity to care for family members?

ANSWER: I care for her while I'm with her

Question: What can you do to draw out a family?

When I answer a doctor, I will take her to a doctor and get her a meal.

Question: What are some of the obstacles to take care of?

Answer-Money Problem / Poverty /

Question: What is the main purpose of care?

ANSWER: Just to be saved

## Patient #31

### 1. Background information

- Disease —podoconiosis
- Age—50
- Sex--m
- Family size---6
- Role --father
- Education---not educated
- Occupation—beggar

Question: How did you know when the disease began?

Answer: When I was a young man, when I started out as a boy, hugging my fingers became very unhealthy. Afterward, I washed my whole body and circled me to my limousine.

Question: How did you receive the disease?

Answer: I accepted it from the Father God

Question: How did the families get the disease?

Answer: My family came to complain that it came from the father of the father or the descendant, who came from the father of the father.

Question-Community / Neighbors / How did you get the disease?

Answer: Accept him as coming from the Father of the Father

Question: Is the disease caused by the disease?

ANSWER: I turned my back on my first marriage and made it to a different country.

Question: What is the effect of the disease on you and your family?

Answer: The family is orphaned and homeless

Question: How to care for yourself?

Answer: I wash with soap and water on my feet

Q: What family members do you take to help reduce the disease?

ANSWER: I do not care about you. I live on my own

Question: How do you work day after day /

Answer: I can sit down, I can just do farming and do hard work

Question: How is a relationship with a neighbor?

Answer: I have no relationship with neighbors and relatives because I have been living or living in another country because of the disease.

Question: How will you spend it on a holiday day?

Answer: What do I have to rest and what if I'm happy if I'm happy?

What do you want to ask for?

Answer: If the medicine is good and the medicine is not good, then I would want the government to help the weak

Question-What Is Unrealistic? Answer-Living With Sickness Poverty

Question - convenience

Answer: My husband is married to me

Question: Family

Answer / Answer /

Question: How Is the Family Relations?

A: I also cheered with my family, and both my children and my husband spent the day with the begging money and the money that they brought, and we drank together and drank together.

Question: How is family support?

Answer: my parents / my son / caregiver brings me to my home and gives me a washbasin to keep me safe.

Q. What is family interest?

Answer - I need a helping hand like working overtime

Question: How does the family relate to the community?

ANSWER: They slanderously claim to be a bully, an abusive son, a scoundrel

Question: What opportunity do we have to look after in the family?

Answer: Have my kids build me a house and take care of me

Question: What can you take care of in the family?

Answer: When you are sick, you can buy medicines while you are sick

Question: What are the obstacles to caring for a family?

Answer-Poor Resources / Poverty /

Question: What is the primary purpose of caring for a loved one?

Answer: I and the disease will not stay together.

## Patient #32

### 1. Background information

- Disease —Leprosy
- Age—45
- Sex--F
- Family size---1
- Role —mother
- Education---not educated
- Occupation—beggar

Question: How do you know when you start the flight?

Answer: By the time I went to work, there was a spontaneous flow of water between my pelts

Question: You know what's coming from the fugitive

Answer: We have no predominance of what happened to us / God's wrath /

Question: How did families receive it?

A: Tell us where it comes from

Q: How did the local community receive the salad?

Answer: Tell us what happened to her sickly and tell her what happened, and leave me alone

### Patient #33

#### 1. Background information

- Disease —podoconiosis
- Age—60
- Sex--F
- Family size---1
- Role –mother
- Education---not educated
- Occupation—daily labor

Question How to get in and know how to get it started

Back home, I started to swell as I was cold in my temper

How did your family get it?

Answer: We saw what went down over but nothing

Question How were the neighbors / communities?

There is nothing good in the community

Question: What disease did you have?

When we answer, we do not have any water to eat, but our legs get fed, and we get upset

When it is impossible, it can not be saved

Is there a question from the family?

Answering can not prevent my family, but if they get sick, they will not have a doctor for them

I gave medical assistance to the doctor

Q. How do you look after yourself?

There was no money when I was using a pesticide pill every month and every week

Because I'm not going to medical treatment, I wash my feet with soap and water.

Q: How do families deal with the disease?

Answer: I'm self-helping, but it's my help again

We care

How is the question in everyday life?

I get tired when I get tired

Q. How is the relationship between social / neighbors?

Reply with the community, I agree and live by love

Question: How do you date a holiday / holiday / holiday?

I'm not happy with the people, waiting for a blanket, because I'm sick

What do you want to ask?

Answer Over time, there's no help from the government since I changed my work I want.

What were the conflicting questions?

I do not understand anything good about the low salinity

QUESTION: What is family composition?

Answer Day job

Question with family connection

Answer I do not have any clothes to wear because my family is in agreement. It is unacceptable and we have no connection

Q: What kids will do for you.

Answer My workday support and support I do not support them.

Q: Do you want children to make it?

God does not say that even if he does not want to be anything, he does not want to be God

What is their wish unless it is like eating their own?

I do not know.

Question: What is the relationship between families and neighbors?

Answer: Your family will live in harmony with neighbors and neighbors

What is the good chance from your home?

No good luck

The question can be what care

Answer I am going to make myself available by presenting myself

Q: Are there gaps in family care?

ANSWER: My children are not caring for us.

### Family member for Patient #33

#### 1. Background information

- Disease —podoconiosis
- Age—60
- Sex--F
- Family size---1
- Relationship with the case—daughter
- Education---Grade 5
- Occupation—daily labor

You know how disease is a disease

I do not like it

How did you receive the question?

What is my answer?

How did the quorums receive him?

She was recently back from good health

Question: The damage the disease has caused

The answer is that my leg is comfortable and does not move around

Question from family problems?

She could not teach us how to teach

How did she receive him?

When she answers by washing her clothes, we will bring her with water

What will you do to lessen your symptoms?

We advise you to go to the pulpit

Question How is day day activity?

She only reacted when she heard that she was reacting

Question: How is the relationship with neighbors?

We have no problem.

How will she spend on the day of the holiday?

ANSWER: She likes to play with children when they are dating

What you want is what you want

You do not know

What is so unthinkable?

Answer Poverty / Financial Crisis /

What is a career setting?

Answer We are working from day-to-day work

Q. How is a family relationship?

Answer: The peace of love we live together

Question: Do you support family support?

Answer: You can wash clothes by drinking water

How are the needs of the family?

Just answer us to be equal to people and people

Question: How are they related to neighbors?

We have no problem

What is the best opportunity to ask questions?

When she answers, we will bring her water to her.

What are some barriers to caring for in her beta?

Answer Poor financial / poverty /

Question: What is your main purpose?

Well, good luck to stay with us

## Patient #34

### 1. Background information

- Disease —LF
- Age—58
- Sex--M
- Family size---3
- Role –Father
- Education---not educated
- Occupation—Grinder

Question: How do you know when disease begins?

Answer I just got up early to swallow with my neck and joints

And I was hungry for medicine, then pulled my feet to the feet and squirmed

It hurts me

Question How did you get the disease?

The answer is I have not eaten a bite-sized disease

How did the families receive?

Answer: Answer: The doctors in Mali are sick, and I accept him as the one who came here

How did the neighbors respond?

Answers come as a result of contamination. Communities say this is a disease

Question: What has been the problem with this illness?

When I answer, it sinks me with water, it scratches from the top

Not wearing shoes

How Did the Question From the Family Affect?

I did not understand why I did not think they would go to the family

Question: How do you take care of yourself?

Reply I washed soda with soap and soap and did not shake without shoes

Q: What helps the family to reduce their disability

Answers get me for treatment and feet and socks

How was the question from day two?

I can not do hard work because of the irregular movement

I can get up.

Question with neighbor?

Answer as well as today and today much different from what happened after a sickness

Larger than average because it does not equal with the average person

You will get a question on a painting / vacation / time

ANSWERING I spent playing in a campfire camp

What do you want to ask?

Answer Work, work, eat, and get help from work

I want.

Q: Is there anything in the wrong place?

Answer: The shortage of money / poverty / rent payments

Questionable circumstances

ANSWER: My wife is wearing a foot and clothes for washing

Q. What is family development?

Answer: I am working on a project, and families are staying away.

Q. What is the relationship between the family and the family?

Can We Understand Conviction and Agree?

Is there any help from family support?

Answer: We need to understand the money that they take to me when they want to wash

It supports us

Question your family relationships with neighbors

When I'm back, I'm working cooperatively

An opportunity to be cared for within the family

ANSWERING She worked and lived by my husband while living with me

What can you take care of within the family

They crave me for treatment when they have an answer

Q What are some barriers to caring for a family?

Answer The shortage of money / poverty /

Question: What is your main goal of not caring for your family?

My answer is to work as my laborers

## Family member for Patient #34

### 1. Background information

- Disease —podoconiosis
- Age—48
- Sex--F
- Family size---3
- Relationship with the case—daughter
- Education---not educated
- Occupation—daily labor

Question How did you know when the disease began?

The answer is, it seems that the disease has begun, I am a model

Question: How did you get the disease?

ANSWER: I think the disease came from God's wrath

They do not have around

And how do neighbors ask!

No answer, this is a phenomenon in the phenomenon of God's anger

Question: Is there a risk of this disease?

When he answers, he swells and flips to the top and does not need shoes or even fever

It melts.

How Did the Family Get Answered?

It was absurd because it was a day job because it was a day job, and it was the family

Managing capacity is too short.

Question: How do you care for yourself / the cats /

Answer I bring soap and water and salts and go to the treatment

I'll let him go.

Question: What helps a family to reduce injuries and hurts?

Answers foot and mucus wash and get well and go to the treatment

How to ask a question from both activities?

Okay, we can not do hard work

Getting up is better than getting it

Q. How is the relationship with neighbors / community?

Answer is like no other people / as healthy as it is

Ask questions on a day / day off / day

Answer: In the absence of an employee, no maintenance work is done

What do you want to ask?

An answer-saving pill does not work well, but he needs help from the government

Q: What's so unpleasant?

Answer The shortage of money / poverty /

Question There are no obstacles to care for in the family.

ANSWER: Pensioner / Poverty /

## Patient #35

### 1. Background information

- i. Disease –leprosy
- ii. Age—40
- iii. Sex--m
- iv. Family size---8
- v. Role—father
- vi. Education---not educated
- vii. Occupation/means of living---cannot work due to his illness

### 2. Experience with the disease

It started with fluid swelling in my hands and feet that was painless. Then I went to holy water and when it relives I start my work. When I hit with stone, bite by thorn, even by knife... it does not feel pain. When I have been provided food and want to eat I was unable to eat because of my numbness. I cannot feel weather it cold or hot. When my families ask me to feed me I did not agree because I feel as I am inferior and weak. I used to eat with two of my servants. Now my fingers (both hand and foot) are cut down and unable to carry out my routine activities. May be it is gift of God and I accept it with no further complain. As it worsens I went to hospital and they gave me medication to apply on my wound but no improvement and went again to hospital then they diagnose me as leprosy patient and give one year drug. I also went to holy water in between. Following my medication my sense start to improvement now I can identify what is hot and cold. The disease aggravates if I drink alcohol (local beer and Areke) so that I left it now. My families accept it like me but the community discussed as I went to wizard house while I was in holy water. I gave my livestock to my relatives while I was in holy water for long time. However, they were tired of look after my livestock and I sell all of them. Even the community perceive as I am affected by not leprosy but also HIV. The impact of the disease is huge, I lost my digits, I cannot work like the previous, I cannot grasp and hand things due to my loss of fingers. I was one of among top ten10 farmers who have been praised by the government but now I spent most of my time in the holy water and health facility, I cannot work like my previous status. Now I become not only ill but also poor. Even I cannot support my families. My children are continuing their education with limited resource.

### 3. Daily life

When I feel pain I go to holy water and if I feel good I look after my livestock. I am in quarrel with children to help me to wash my cloth. I advise my children how to work and lead life since I cannot help them in fiscal work. My wife and children did not satisfy me by their help in washing my cloth. They urge me to

sell what is available in our house and get treatment. My children are insulted by the community because of my illness. The community insults me as drunker and my behavior change as the disease progress, even I did not go for coffee ceremony as previous in my neighbors. Now I did not identify when work day is and when is non-work day because I did not work totally. I have no leisure time since things are not good for me.

#### **4. Family life**

Since I cannot work I rent my lands and my wife start market to sell some materials. My children did not comply with my order it is the character of today's children. But my wife and my children strongly wish if I become well by selling all what we have. They take me to health facilities when feel sick.

#### **5. Family based approach**

One of my daughters is student I did not force her to care me. My wife also spend much of her time in market and I mostly taker of myself (wash cloth with difficulty). If the pain worsens they took me holy water by borrowing money from other people and prepare food. The main purpose of home based care is to restore my illness not to prevent further deterioration.

### **Patient #36**

#### **1. Background information**

- i. Disease –podoconiosis
- ii. Age—50
- iii. Sex--F
- iv. Family size---3
- v. Role—mother
- vi. Education---not educated
- vii. Occupation/means of living---daily labor

#### **2. Experience with disease**

It started with rash and I went to holy water. Soon I left my husband and leave him. He begged me to live together but I feel I am sick and I did not deserve as his wife. But after many years I marry other man and now I have three children. My second husband accepts my status and we live in love together. The communities also think for my disease and they encourage me. My children provide me necessary support from their income by doing daily labor. The disease impact in my life is immense since I did not work due to my disease. I wash my leg, I use holy water and I visit doctors but no improvement of the disease. My families take me to holy water.

#### **3. Daily life**

I cook food and work light work but I cannot work some hard works. My neighbors did not call me for coffee unlike the previous. They discriminate me as I buy the disease. They insult me as leper. I did not think to enjoy life since I am disabled. I become very poor and dependent on my children for daily lives. My children interrupt their education and taker of me. My children are also insulted as a child of leper, daily laborer but we accept it as from God.

#### **4. Family life and family based approach**

I am unable to support myself and my children. They work in daily work to support our daily spending. They take me to holy waters, wash my cloth, feed me and take me to health centers. They buy to me soap and other as much as they can.

### **Family member for Patient #36**

#### **1. Background information**

- i. Disease of indexed case –podoconiosis
- ii. Age—17
- iii. Sex--F
- iv. Family size---3
- v. Role—daughter
- vi. Education---grade 5
- vii. Occupation/means of living---daily labor

#### **2. Experience with the disease**

The diseases start her before she born me. The disease is from God. Some people insult us due to her leg disease. She spent the day and night in her house not able to move, she wait for our help. She suffers a lot because of her disease. I interrupt my education and my brother too to help our mother and serve ourselves as the result of her disease. We buy her cloth, shoe, food and wash her cloth. We buy drug when her pain worsens.

#### **3. Daily life**

She sits down in the house and depends on our daily income. She prepare food when we brought her tin the home. We live in good relationship with the community except some children insult us because of her disease. We wish if she can got treatment and cured. We keep her hygiene and ours if we get time.

#### **4. Family life**

We have scarcity of money to take her to treatment in the other parts of the country. We did not use soap that was used by our mother; we did not use materials she used. She also tells us not to expose ourselves to her contacts. She told as the disease is communicable and we are taker of that issue.

#### **5. Family based approach**

We support her by money, buy cloth, shoe and others she need. We take her to health facility if she experience illness. I and my brother are her opportunity and poverty is great challenge in our house. Our main aim of to decrease further deteriorations.

### **Patient #37**

#### **1. Background information**

- i. Disease of—Lymphatic filariasis
- ii. Age—25
- iii. Sex--F
- iv. Family size---5
- v. Role—mother

- vi. Education---not educated
- vii. Occupation/means of living---daily labor

## **2. Experience with disease**

It started like wart in my body and increase from week to months. It has been 14 years since started. The disease starts me because of my exposure to sun/mich. I cannot move my leg (I cannot extend and reflex). It aggravates in cold time. As the disease worsens I took medication from drug store. I wash my leg using soap and water and I wear my shoe. My families take me to health center and holy water.

## **3. Daily life**

As the pain relive I move in and out of house for daily work and if worsen I slept in my home. My neighbors and the community assure me as the disease is not hereditary. I play with my children. I need if I got curable drug. My great barrier is poverty, I have no money for treatment and holy water to treat my disease.

## **4. Family life and family based approach**

My children are serving us in daily work. Some of our neighbors insult me and my children as 'leper'. My children are too young to give me care but they give me water and food when I become sick.

## **Family member for Patient #37**

### **1. Background information**

- i. Disease of indexed case—Lymphatic filariasis
- ii. Age—30
- iii. Sex--m
- iv. Family size---5
- v. Role—Father
- vi. Education---not educated
- vii. Occupation/means of living---daily labor

### **2. Experience with disease**

The disease starts her as we were visiting our relatives who gave birth in distant place. She was exposed to meal smell that let her sick. The community also agrees on the cause of her illness. Due to the disease in her leg, she is unable to work. Since we have no big children we are in trouble for food preparation when she is sick. I take her to health center.

### **3. Daily life**

In the day time she works daily work and in the night she feels pain. She plays with our children especially when she feels fine. Since both of us are daily laborers we have no opportunity to support each other. If we get treatment and she became well is our dream. Some people insult my children as a child of leper.

### **4. Family life and family based approach**

We did not give care since I am also working as daily laborer but my children provide her water and food as she become sick. Our main aim of support is to get her cured but our main obstacle is poverty.

## Patient #38

### 1. Background information

- i. Disease ---podoconiosis
- ii. Age—35
- iii. Sex--F
- iv. Family size---3
- v. Role—mother
- vi. Education---not educated
- vii. Occupation/means of living---daily labor

### 2. Experience with disease

First started in one of my leg and the second was swell as well. It aggravates at least month and my inner thigh is swelling. We have such hereditary disease. I did not use traditional medicine and holy water. Some people insult me as leper and beggar. The impact of the disease is I am unable to work due to the disease and some peoples insult. I get divorced from my husband due to my leg disease that hinders my previous work performance. I wash my leg every night with soap and salty water. My brother takes me to health Centre as my pain aggravates.

### 3. Daily life

I work daily when I am free from the pain and I sell local Areke too, I collect fire wood from the forest, I live with good relationship with the community in the market place and other social relationships. Even, though some people insult me due to my leg.

### 4. Family life and family based approach

Both my elder brother and I work daily labor in the town. He provides me some money for house rent and other expenses. I wash my feet with soap and water then immerse with salty water.

## Family member of Patient #38

### 1. Background information

- i. Disease ---podoconiosis
- ii. Age—25
- iii. Sex--m
- iv. Family size---3
- v. Role—brother
- vi. Education---not educated
- vii. Occupation/means of living---daily labor

### 2. Experience with disease of indexed cases

I guess the cause of her disease is lack of personal hygiene since she was grew up without mother she did not keep her cleanness. We have no such hereditary disease. She is divorced from her husband after they have one child due to her disease. Some of the people in our village said her disability is as a result of God punishment. She cannot walk long distance and cannot work like the previous times. I support her in money and idea to keep her personal hygiene.

### 3. Daily life

If she feels fine she collects firewood from the forest, fetch water, prepare local alcohol/Areke and prepare our food. She has good relationship with the local community and relatives. Her great barrier is lack of money for house rent and whenever she feel sick expense for health facilities.

#### **4. Family life and family based approach**

I support her to pay house rent, keep her personal hygiene and to wear shoe consistently. However, I have no money to take her to holy water. She cares herself as she washes her cloth, wear shoe and washes her leg every day.

### **Patient #39**

#### **1. Background information**

- i. Disease ---LF
- ii. Age—18
- iii. Sex--F
- iv. Family size---10
- v. Role—child/daughter
- vi. Education---grade 9<sup>th</sup>
- vii. Occupation/means of living---daily labor

#### **2. Experience with the disease**

The swelling starts below my ankle and it were not known for me. My families told me as it become swell and I recognize later. I have no idea where the disease comes from since we have no such hereditary disease and I did not touch bad things by my feet. I stop my education due to frequent attack of the disease. My families took me to holy water and hospital including Bahrdar but no change is made from my disease.

#### **3. Daily life**

I go church every morning and help my families in household work. Some of young children are discussing about my leg and seems irony on me. I sometimes work hand art (made traditional cloth decoration). Since I am very young I can work and change my life if I become cured.

#### **4. Family life and family based approach**

My families are farmers. We live in love and great support. They wash my cloth, take me to holy water and health centers/hospital. My families are sometimes discussed to leave this area to change air that may aggravate the disease. My great opportunity is my mother, father and siblings. They try to restore my health and prevent further progression.