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| Participant's Group: Local | | Audio File No. ( ) | |
| Level: Locality | | Interview Date: | |
| Participant's Work Place: Ministry of Education | | | |
| Age: 43 | Qualification: University Graduate | | Job Title: Elementary Teacher |
| Period Spent working the job: 18 years | | | |

Researcher: okay Miss, when we say this person has healthy lungs, what does that mean to you?

Participant: that means a healthy person whose respiratory system works very well and lives in a healthy environment.

Researcher: Good. And what does it mean to you when we say someone has bad lungs?

Participant: means someone who us suck and has trouble breathing and their respiratory system is defective or any problem related to breath and breathing.

Researcher: so here in XXXX if someone has a problem in their lungs for a long period of time, is there something specific that you call them?

Participant: yes, in the old days we used to say that this person has (sadriya = chest disease)

Researcher: What does "Sadriya" mean?

Participant: someone who has asthma or allergy, our mother's used to call all that chest disease. That means that they cannot distinguish between asthma and tuberculosis. If someone is coughing, it means that their chest is sick so they called it "Sadriya", so only of your coughing continues for a while it's said that you have "Sadriya", which means tuberculosis and such diseases.

Researcher: how long have you dad asthma?

Participant: I've had it for exactly one year. It started in the middle of last winter, February last year onwards.

Researcher: okay so I want you to tell me about your symptoms in detail. What did you feel when you got the asthma?

Participant: I used to have sinusitis back in the day, and when seasons change it affects my nose and my voice changes, and it’s been there for a long time. I saw a doctor and he gave me medications and told me it's sinusitis and I got better. Last year the kids spilled a sack of beans hay and the dust got into my lungs and coughed so hard. After that I felt suffocated and had dry cough for a few days. I thought it was just normal pneumonia or sinusitis or allergy and I took medications but I didn't get better, so I went to a specialist and I took my medications with me and I told him everything and did some examinations and X-Rays and lung functions and gave him the results, so he told me that I have asthma and chronic allergy and he told me that I have constricted lung capacity and he prescribed me medications to treat my allergy but he didn't prescribe me an inhaler. Another doctor before prescribed me an inhaler for daily use at night for a month when I had sinusitis before it became asthma. He gave me a medication that gave me nervous breakdowns which is six tablets per day; two after breakfast two after lunch and two after dinner. I couldn't stand after taking the pills so I went back to the doctor and told him about it and he told me that this is the side effect of the pills at first. I started using local medicine such as honey and sesame oil and olive oil in addition to the doctor's medications. I got a bit better but I wasn't entirely cured, so I relapse because of the smallest amount of dust, especially the fine dust on curtains and so on. That whole year was like this. One day I was cleaning a room last January and I haven't been well since.

Researcher: what do you think is the reason of your sickness?

Participant: as for sinusitis, I think it's irritation caused by perfumes and other things, but now I'm convinced that the hay is the reason because it gets worse whenever I smell it or when rain falls on animal feces or so, and also when the weather is dusty and I was wearing a mask this morning because there was a lot of dust. The good thing is that I don't suffocate I only cough and pain and constriction in the chest and my chest actually becomes hot.

Researcher: how did this allergy affect your daily life?

Participant: it did. A lot.

Researcher: how did it affect you?

Participant: it affected me a lot. For example, if there was any dust it makes me tired all day and I cannot leave bed and I feel like all I want to do is sleep. Anything that I inhale, even of it wasn't dust, it hurts me. I'm always anxious and nervous. I cannot even prepare food for the kids and I cannot do my daily activities. My life isn't the same anymore but thank God I don't fear illness any my family, my kids and their father, are very understanding.

Researcher: what are the things that you were able to do once and now you can't?

Participant: first of all cleaning inside the rooms and the fine dust it makes, the same dust that I used to mob without any problems, now any small effort tires me. Earlier I used to normally wash blankets and clean the yard and all parts of the house, now I cannot even walk long distances and I get tired very fast.

Researcher: what about your social life?

Participant: I used to normally sit when there are odors and smoke but now if any fire is lit I cannot breathe. Any strong odor affects me, even if I chop onions without good ventilation, and I try not to directly inhale it. It affected my social activities and relations with people.

Researcher: I learned that you're a teacher. How did this affect your career?

Participant: it affected my career because I cannot go to work the day after I smell fine dust because I get sick, and sometimes I take more than one day off and I cannot work for long periods of time. The good thing is that the people at work are understanding and I have supportive workmates.

Researcher: as a person with allergy, how do you feel about your illness?

Participant: sometimes I just thank God as the doctor told me because some people have it worse and they can't take it. We're humans after all, one sometimes gets fed up but I remember God and that I'm better than some others, because some people cannot even stand and some breathe using an inhaler. Some suddenly go breathless and pass out, but I thank God anyway.

Researcher: did it mentally affect you?

Participant: of course it did. All illnesses do.

Researcher: how so?

Participant: for example, sometimes when I need to do Henna I suffer because of the strong smell of Mahlabiya and I try to avoid the dye and Dukhan. I'm a wife and I need to use perfumes and such things, but I cannot because of this illness but thank God anyway, sometimes I try to find my way around it.

Researcher: do you have someone close that you talk to about these things?

Participant: I don't have daughters but my relationship with my sisters is very strong, maybe because I'm their older sister so I'm like their mother and father, so I do talk to them. I also have a doctor niece that I talk to and she talks to me, and sometimes when I feel like I'm too much she prescribes me medications and tells me what to do and she stays with me for hours and if I don't show up she asks about me. Also my brother and his wife and my cousins and all the people around me are very caring.

Researcher: so the matter of having a relative with a chronic disease in Sudan has a financial impact. Did it financially affect you?

Participant: of course. I'm a teacher and I'm dependent on my salary, but medications are very expensive and so is the doctor's appointment, in addition to the original expenses of life in general. Some way or another it'll affect you because the cheapest medicine is worth a month's salary. And even if I want to go to Khartoum or [state capital] to see a specialist, I'd need to pay 1000 SDG for transportation only, and that's almost my salary, let alone the doctor's fee and medications and tests. Of course it financially affects you.

Researcher: don't you have medical insurance?

Participant: I do but most of the medications are not available under insurance, even some emergency medications sometimes I find them uncovered by insurance. For instance, I have to have a preventive inhaler that I bought only once and I stopped buying it and decided to just be careful instead, unless something happens against my will.

Researcher: did the financial aspect of the illness affect your agreement at home?

Participant: of course it did. Because we're both teachers we combine our salaries to purchase our monthly supplies. We're also part of a "community fund" and we took money for treatment, so I've been spending money on treatment for four months now, so sometimes I feel like we cannot buy some things for the house because we don't have enough money. Now we only do the important things such as food and so on and if we need new furniture or if there's something that needs repair we just leave it for another time.

Researcher: okay. So of course there's a difference between before and after you felt the symptoms. How did you adapt with this change?

Participant: it's necessary to adapt. Once I was a healthy woman but after I got this attack I tell myself every day that I'll get better, and now I think that I'm better than before, thank God. And whenever I get a new attack I just adapt and I got used to it because I know that I'll never go back to what I used to be before so I just learned to live with it.

Researcher: is there any of your neighbors that has the same problems that you have?

Participant: a lot. At some point we never had this illness in the family except for my niece that I told you about who had sinusitis, but it was a normal thing. Now I have another niece who has the same thing as me as she has sinusitis that is giving her hard time. Back in the day my father had three yards, one for cows and one for goats and a third for kids. I loved animals and I used to go with him and touch them and work with sorghum until I got married and up until 2010 I used to be okay and I didn't feel any pain but now I feel like this illness is affecting more people. Many people in the neighborhood have it now and my brother's little children also have bad allergies. It's become more lately.

Researcher: why do you think it's more now? What do you think is the reason for this increase?

Participant: maybe it's because the immunity of the people deteriorated or maybe because things used to be more natural back in the day. I remember in the 70s we used to stay around animals a lot and their feces didn't affect us but now I feel like it's full of chemicals that either entered our systems or the systems of animals. Also I think the polluted air contributed to this.

Researcher: how do you deal and interact with other people with allergy in the neighborhood?

Participant: the one that I deal with the most is XXXX (her neighbor who is asthmatic). We understand each other very well in regards to what affects us.

Researcher: they share the same things with you

Participant: yeah. You understand them and it's more comfortable to talk to them because they know what you feel and you know what they feel. It's better to deal with them.

Researcher: do you talk to each other about being upset with being sick?

Participant: sometimes we communicate only in tears. I feel like I can't talk and just want to cry. They tell me that I'm a believer this shouldn't happen. They remind me that I have to be strong. I suffer a lot when I get the asthma attacks and I feel like I just want to cry.

Researcher: so after you started getting these symptoms you're talking about, what did you do?

Participant: what did I do about what exactly?

Researcher: did you treat yourself at home or did you go to a doctor?

Participant: when I first got it, after the first and second day I thought it was a normal thing, but after a week I decided to go see a doctor and the doctor gave me medications at that time. I went to a General Practitioner at first.

Researcher: here at the local hospital?

Participant: yes. And it was a General Practitioner not a Specialist. And I love asking questions so I asked him what it was and what is this dry cough? When I figured that he's not that good I decided to see a Specialist who started treatment and gave me medications.

Researcher: so in the week before you go to hospital, did you try any local remedies or seek any other sort of treatment?

Participant: no. I just think to myself it's normal allergy and I only take Panadol and rest. Sometimes I use sesame oil and olive oil. We have local sheikhs and healers who you go to that may read Quran to you or press back your chest.

Researcher: so after you felt the symptoms, did you go to one of those?

Participant: no. At first I didn't go. I only went after I saw the doctor because some people say that there's something misplaced in your chest, and some tell you to drink raw eggs. Sometimes you feel a lot of pressure from others who tell you if this isn't working for you, you should switch to this and that because it worked for another person. They tell you it won't do you any harm anyway.

Researcher: so in the first week before going to the doctor, you said you used sesame oil and these things, why did you decide to use them?

Participant: I thought that my chest was dry so I oiled it externally. Back in the days when someone is sick in their chest we used to use these oils in addition to (Garad = Acacia Nilotica). These things are local remedies that ancestors used and we still use these for our children.

Researcher: and after a week you went to the hospital, right?

Participant: I went to hospital after like 5 days when I saw that I'm not making any progress and that the cough is getting worse.

Researcher: so tell me exactly what happened when you first got to the hospital

Participant: I told the doctor that I have bad fever and a sore throat and a headache and cough. We tested for Malaria and Typhoid and he gave me medications and asked me for an x-ray and he told me they don't have that here but take these medications and he gave me an antibiotic that I took in syringes. I took 8 shots. I didn't feel any progress and the cough is still there. The fever and headache were cured but the cough was still there and I coughed all night to the morning. I went back to the doctor and he said this might not be pneumonia and it could be sinusitis, so he gave me sinusitis medications but there wasn't any progress also so I stopped it and went to see a specialist.

Researcher: what are the tests that he asked you to do?

Participant: he asked for an x-ray to know what is wrong and what is causing this cough.

Researcher: what did he tell you that you have when he gave you the medications?

Participant: he sad it's pneumonia and that I tested negative for Malaria and Typhoid. When he heard sounds from my lungs he said that this is a case of pneumonia and gave me hourly medications.

Researcher: you said that his medications didn't help you…

Participant: yes the response was very slow and very little.

Researcher: do you know anyone from the neighborhood who has allergy and do not see a doctor?

Participant: I don't believe so. Most of the people I know go to doctors. Their diagnosis might not be complete but I don't think if anyone has such an annoying cough wouldn't go to a doctor. They do go to doctors but the problem is that we don't know if their diagnosis is correct or not. The good thing about doctors here is that they refer you if you don't respond to treatment because there are some people who were referred. That's why they ask us to go get x-rays in [district capital], so one thinks of they go to [district capital] for an x-ray the might as well take it to a specialist there or in Khartoum or [state capital].

Researcher: so if we assume that someone has lung problems and they don't go to a doctor, what do you think would be the reason?

Participant: I don't think there would be any reason other than financial affordability. From what I feel, I don't think anyone could take all this pain, when it comes to breathing particularly, because this pain is unbearable. I'd go to a doctor even if I had to ask people for money. And in our community, if you're financially unable you'll find people helping you without you asking. But anyone who wouldn't go to a doctor, they're either uneducated or they gave up.

Researcher: so what do you think we should do to make people go to doctors?

Participant: we should go talk to them and tell them that this disease has treatment.

Researcher: what would you say to a person who is with you now and doesn't go to a doctor?

Participant: if I knew that someone is suffering this pain I'd tell them to go to a doctor, even if it's the local hospital, even if people had to collect money for them. For example, my neighbor is a bit poor but her family gave her money and told her to go to [district capital]. That's the simplest thing people could do, to collect money for a person so they would get treatment.

Researcher: as a person with allergy, what do you think are the services that allergy patients need?

Participant: first thing I wish if there could be a specialist in this hospital because there are children who have it too. The other thing, I hope these medications would be included in insurance. Also the medications and the tests for these diseases should be made available in the local hospital as a big rural hospital. All these things are not available here. The rest depends on us and we need to be careful, but a specialist is a must.

Researcher: why do you think there's no specialist in this hospital?

Participant: if you analyze the data and see who goes to specialists in [district capital] you'll find out that our area needs one, but specialists don't come to these rural areas.

Researcher: why do you think they don't come?

Participant: I think because the financial return isn't high. Plus they probably have regulars where they used to be. Also we fear getting into new high costs. A specialist in [district capital] may have 20 to 30 patients but they don't know how many patients they would get if they come here.

Researcher: what do you think we could do to help allergy patients?

Participant: spreading awareness and making awareness campaigns in schools and mosques and health symposiums and making people familiar about the disease and its negative aspects. More awareness is always better for us.

Researcher: why did you say what you just said?

Participant: because I think our community has very little knowledge about lung diseases, and I think they spread more in the past period in a very concerning pace and every few days there's someone who's taken to hospital with lung disease, and this specialization is neglected unlike Obstetrics and Gynecology and Pediatrics, because lung disease is socially stigmatized.

Researcher: why is it stigmatized?

Participant: because the person with lung disease is singled out and people fear them and try to stay away from them, but now people are more understanding of asthma, like look at tuberculosis for example, people do fear it a lot.

Researcher: so we have discussed the medical aspect, but you said that there should be awareness and such things. Regarding the psychological aspect, what could we offer allergy patients to help them get better?

Participant: they should be made feel like it's a normal disease like any other disease, and people should make them hear kind words like this can be cured and nothing is hard to be treated and there's a solution for everything and that they shouldn't be afraid because people deal normally with all other types of diseases. They need to know that it's not a dangerous disease and it can be dealt with.

Researcher: so on the physical aspect, how do you think we could help allergy patients?

Participant: doctors know this aspect better. They should tell us what type of sport we can do and what we can and can't eat and our weight and all these things a doctor should tell us about.

Researcher: if we choose people from this community and gave them training on how to figure out the symptoms of people with allergy so they could tell a person that should see a doctor and they could assist people with allergy. Do you think this would make a difference?

Participant: of course it would.

Researcher: how would it make a difference?

Participant: first of all people would tell you how dangerous it could be. And that if people listen to advice and do something early it would be better for them. Avoiding what stimulates your disease would also be good.

Researcher: does your local hospital have the requirements for examination? And to know what causes lung problems? Would that make a difference?

Participant: of course it would make a difference. First thing, financially, so a person wouldn't need to do these tests somewhere else. And if there's some specialist here, they would tell you what to do, even if they just chatted with you, you would learn something that could help you. So if I found the doctor here it would be more convenient and saves me effort and money. Now you can only find a few of these tests here but for the rest you get referred to [district capital] or Khartoum. If we could find these things here it would be very convenient.

Researcher: in your opinion, if the hospital here is able to provide medications that would help people with lung problems and make them feel better if they would take them regularly, do you think that's a good thing?

Participant: yes, very.

Researcher: why?

Participant: because if I could do my tests here and see my doctor here and buy my medications here this would be perfect. Treatment is hard so it would be better if we could find everything in one place. There are some medications that we get from abroad or in Khartoum. You might have a pill that you need to take continuously and you suddenly can't find it, that would be a problem. When you can find all your medications you wouldn't be worried and you would be comfortable. Like, I can go get my medications, but if I was told that I need to get it from somewhere else, even if it wasn't very far, I would be upset.

Researcher: we are done chatting with you. Thanks a lot for the information and for your time

Participant: you're welcome. At the end it's a way to help and you're here trying to help us, regardless of what you get in return, it still makes a difference. It makes me happy when I see people doing such studies because we need it.