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| --- | --- |
| RESEARCHER | When we say that this person has a healthy lung, what does that mean? |
| PARTICIPANT | It means it is good |
| RESEARCHER | Yes, but what does that mean? |
| PARTICIPANT | It means good |
| RESEARCHER | Good how? |
| PARTICIPANT | Very good, meaning not sick |
| RESEARCHER | So, it means not sick? |
| PARTICIPANT | Yes. |
| RESEARCHER | And what does it mean when I say to you that a person has an unhealthy lung? |
| PARTICIPANT | It means they are sick |
| RESEARCHER | Sick with what? What illness could he have? |
| PARTICIPANT | He could have water in his/her lung (pulmonary edema) and a sever infection, this is how I see it |
| RESEARCHER | Alright, what does people in your village a person who has chest related illness for too long? What does the people call this disease? |
| PARTICIPANT | I honestly don’t know. When I had my first boy who is now 26 years old, we had Asthma, people would tell me to give him Sesame oil and warm water. We would get very sick, close to dying before we get better. Then when I had my second daughter, we started going to the doctor he gave me pills and penicillin shots that you take until you become addicted. Then when I came back here where the air is different, I didn’t get the Asthma any more. A great time passed without me having an asthma attack but when I had my son who is 18 years old now it came back to me and we went back to the hospital. |
| RESEARCHER | So, it affects you during pregnancy? |
| PARTICIPANT | During childbirth and breastfeeding and first 40 days after giving birth (Nifas). They give me Oxygen and this old big shot that I don’t recall the name of. |
| RESEARCHER | Alright, what were your symptoms? What did you feel? |
| PARTICIPANT | I get something similar of a flu. I get this very sever cough that refuses to go away, then I have trouble breathing. I mostly get it during cold times. It comes and goes and I just continue to cough until I can no longer breathe. |
| RESEARCHER | For how long have this continued? |
| PARTICIPANT | Here? |
| RESEARCHER | I mean has your symptoms persisted for a long time? |
| PARTICIPANT | Of course! I told you I first had them with my first son who is 26 years old now. |
| RESEARCHER | 26 years? |
| PARTICIPANT | 26 years old is how old my eldest son is. |
| RESEARCHER | If I asked you what do you think the reason for that is? |
| PARTICIPANT | I don’t know a reason for it. I first had it when I gave birth to my first boy, I had what resembled a flu and after it was gone, I started getting trouble breathing. My family would say I should go to the doctor, some of them say give her warm water, others say sesame oil and some say acacia plant. I would use them for three days, staying up the whole time until I feel better, but when I came here to Aljazeera I started going to hospitals and getting oxygen. |
| RESEARCHER | Why didn’t you go to the hospital? |
| PARTICIPANT | Even if I did, they wouldn’t have given me oxygen |
| RESEARCHER | Alright |
| PARTICIPANT | They would only give me a shot that would relieve me momentarily and the same night I’ll get sick again |
| RESEARCHER | You’ll get sick at night? |
| PARTICIPANT | Yes, I always get sick at night, then they give me acacia and what not until my husband said we should move to Aljazeera, and ever since I came here, I’ve felt better. I think it has been two years since I got sick. |
| RESEARCHER | Alhamdullah. |
| PARTICIPANT | That’s up until recently when I started getting it all the time. Last Ramadan I was hospitalized in Khartoum Shaab hospital for a month. They told me I had pulmonary edema and they gave me this big shot that I don’t know the name of (penicillin) 3 times a day, at 6 AM, at 12 PM and at 10 PM. They told me I should get an operation but it was too expensive, 30,000 SDG, and I stayed in the hospital for a month waiting for them to gather the money, and after they went to the office of Zakat and were able to get the money the hospital told me they needed my national number and I didn’t have one at the time. |
| RESEARCHER | You didn’t have it? |
| PARTICIPANT | I didn’t. they said I needed the national number to do the surgery. My cousin came and took me by a car to get the national number, on the way back, I vomited heavily, and it had a greenish color. After I returned to the hospital the doctor ordered some scans for the operation, and when the results came back, he said I don’t have pulmonary edema and they discharged me from the hospital. I think it was that stuff that came out of me. After they discharged me the cough didn’t go away. I started this cycle of getting the cough, taking the medication, getting better then getting worse again after the medication is over. Up until now. |
| RESEARCHER | The doctor in Khartoum only said you had pulmonary edema, he didn’t say that you had asthma or anything? |
| PARTICIPANT | He said that I didn’t show signs of asthma only pulmonary edema, sever dizziness and trouble breathing |
| RESEARCHER | Alright. How does these breathing problems and cough affect your house chores? |
| PARTICIPANT | The dust. Sometimes the dust gets me agitated. |
| RESEARCHER | Are you able to perform your house chores or not? |
| PARTICIPANT | I do my house chores. The girl wearing Ebaya you see there is my daughter, she goes to Khartoum university. We cook together and do everything together until I suddenly get this cough that doesn’t stop and it my end in me vomiting and going to the hospital, but other times I’m perfectly normal, I do my Dokhan, Hinna and Mahlabila and everything and I’m perfectly fine, until I just suddenly get this cough. |
| RESEARCHER | So, what you mean is when you are sick you can’t work? |
| PARTICIPANT | Yes |
| RESEARCHER | Alright, since these symptoms started, what are the things you can do around the house and what are the things you can’t. |
| PARTICIPANT | The house work. I can’t do Oowasa (make Kisra) |
| RESEARCHER | Why not? |
| PARTICIPANT | Smoke is not good for me and the smell of onions gives me infections so I can’t cut onions |
| RESEARCHER | So, what you are saying that inhaling the smoke of Acacia wood is fine with, and it doesn’t cause any allergies |
| PARTICIPANT | Yes |
| RESEARCHER | So, the normal activities … |
| PARTICIPANT | We do Dokhan! |
| RESEARCHER | And how come the smoke from Oowasa affects you? |
| PARTICIPANT | Subhan Allah! When I do Dokhan I feel nothing at all, even if I’m having my cough, I’ll do my Dokhan (الدخان) normally and continue the rest of my day normally. But when I do Oowasa (العواسة), I don’t know if it’s because of the Acacia wood or the sugarcane used but I get terribly irritated and it causes sever cough. I’ve stopped Oowasa and my daughter does it now. |
| RESEARCHER | And are you able to satisfy your personal needs in terms of taking a bath and doing similar things, or do you need help? |
| PARTICIPANT | No, I do it by myself. |
| RESEARCHER | Alright, what about the social occasions in your community, if your neighbors have a wedding or a funeral or something, does your symptoms prevent you from going or not? |
| PARTICIPANT | You see now after the two months I spent at the hospital, whenever I go to an occasion I’ll only participate in the conversation, I can’t help and serve as I used to. I used to help with cooking the food and washing the dishes, but now even the conversation might start a coughing seizure for me. |
| RESEARCHER | Alright. You said you don’t work, right? |
| PARTICIPANT | Yes. I used to work in the fields but I gave that up ever since I got sick. Now I just stay at home and cook for my kids. |
| RESEARCHER | Alright. How do you feel when you experience those symptoms? |
| PARTICIPANT | Honestly, I have no special feelings about it. It just happens. |
| RESEARCHER | I mean would you feel upset about the state you are in or would you be normal or what? |
| PARTICIPANT | About this disease? |
| RESEARCHER | Yes |
| PARTICIPANT | No, I don’t feel upset about it at all. I thank god and pray to him in the middle of the night, and if someone comes to visit me while I’m sick, I’ll encourage myself to set and chat with them and not have them know that I’m sick. I’ll prepare coffee for them even though I have diabetes and I don’t drink it, but I do it just so they don’t feel that I’m ill. Sometimes I would get hospitalized and people will be chocked saying they were just with me and we had coffee together. |
| RESEARCHER | Alright. |
| PARTICIPANT | I just encourage myself so that people don’t feel awkward around me. When I’m sick I can’t even talk but I force myself. Sometimes I can’t even eat my breakfast but I say Alhamdulillah. |
| RESEARCHER | Alright. Do you have someone close to you that you can talk to about your illness? |
| PARTICIPANT | I have no one here, all my relatives are in XXXX, here I have only my neighbors and my friends. |
| RESEARCHER | What about someone you feel comfortable with, someone you can complain to? |
| PARTICIPANT | Well I do have my friend XXXX, she is very good to me, and whenever she comes over, I tell her about my illness and ask her to take care of my kids if something happens to me. |
| RESEARCHER | May god grant you health. |
| PARTICIPANT | Thank you and alhamdullah. |
| RESEARCHER | Alright. It’s known that an illness of a family member affects the family’s financial situation. How did your illness affect your family’s financial situation? |
| PARTICIPANT | The family? |
| RESEARCHER | Yes |
| PARTICIPANT | Was my kids affected by me or not? |
| RESEARCHER | In terms of money, how did it affect you? whenever a person is sick, they will have to go to the hospital many times, buy many medications with a lot of money. |
| PARTICIPANT | Yes, off course. All my family members came from XXXX bringing money to help us collect the operation fees of 30,000 the doctor requested. We got help from the office of Zakat who gave us 12,000 and the Thawab Bank ( a TV show that presents cases of sick people in need) and they have promised us a donation that will be transferred to the hospital, so when he canceled the operation saying the pulmonary edema is not there, we had nothing left at home, their father had nothing, he worked for a day by day fee. |
| RESEARCHER | Alright, can you tell us about the cost of the diagnosis and doctor visits. |
| PARTICIPANT | I don’t know how much because I was bed ridden and I didn’t have any money, my sisters came from XXXX and philanthropists/good doers who came to great me in Khartoum because the one siring they give me costs … and they gave me 3 in a day. People who came gave us a 100, a 50, a 30 SDG and such. A day doesn’t go by without someone coming to check in on us and help with something. A relative who works in Khartoum electricity company came everyday and gave us 200 to eat with and asked us to call her if we needed anything |
| RESEARCHER | What about the cost of access to the doctor. You traveled from here to Khartoum. |
| PARTICIPANT | I didn’t come to Khartoum because I was sick, I came because we had an occasion to attend and I got sick while I was there. When I got sick, they said I should go to the hospital and get checked, that’s when they said I had pulmonary edema and I needed to get hospitalized to prepare for an operation. |
| RESEARCHER | Alright. A disease can change a person’s life system, how were you able to adapt to that? You, a person who has Asthma, |
| PARTICIPANT | I have asthma and kids |
| RESEARCHER | Yes, how were you able to adapt to that? |
| PARTICIPANT | And I was in need and living in a rented house. What I’m saying is that all of this was happening and continues to happen to us, we are still living in a rented house, we don’t own a house, and we have our children’s living and study to take care of, and their father only works on a day by day job, so one day we will eat Kisra with water, the next we would eat Balilah. |
| RESEARCHER | Alright, what I meant was, how did you adjust with the change that happened to your life in the sense that there were things you were able to do that you no longer can do? |
| PARTICIPANT | I just surrendered my self to God and prayed for his help, encouraged myself and just ate and drank what was offered to me. |
| RESEARCHER | Alright, do you know anyone here in your neighborhood who has lung problems as well? |
| PARTICIPANT | No, I didn’t hear anything |
| RESEARCHER | No one with allergy or asthma? |
| PARTICIPANT | Well, a lot of people tell you, you have an allergy |
| RESEARCHER | No, do you know someone with lung problems such as yourself? |
| PARTICIPANT | Just here in the neighborhood? |
| RESEARCHER | Yes |
| PARTICIPANT | No, I don’t know all of them |
| RESEARCHER | Haven’t you ever met someone you recognized from the neighborhood who has asthma? Are you the only one who has asthma in XXXX? |
| PARTICIPANT | Honestly, I meet them here in the hospital and they say they have asthma, but none of my neighbors have asthma. |
| RESEARCHER | You mean you don’t know them personally? |
| PARTICIPANT | Yes, but none of my close neighbors has allergy or asthma. |
| RESEARCHER | Alright. XXXX, you started telling me previously about the first times you started showing symptoms, what you did and where did you go, can you say that again, what did you do the first time you started showing symptoms? |
| PARTICIPANT | From the beginning |
| RESEARCHER | Yes |
| PARTICIPANT | I told you that in the beginning we didn’t go to the doctor, I told you I had just gave birth to my son and I would have to stay up all night, treated with sesame oil and acacia fruit as a scrub and to drink as well as soaking “frankincense” as a herbal treatment, we have the trees here and you probably don’t know about it but they would grind those trees for me and boil it for me in water |
| RESEARCHER | What tree? |
| PARTICIPANT | A tree called Suri and another tree they bring from the fields, they grind it and soak it for me to drink, we have a tree called Aldomur and we also drink its water for two days and then we are all better. |
| RESEARCHER | Alright, why didn’t you go to the doctor from the beginning when you first felt the symptoms, why did you decide to use sesame oil and trees? |
| PARTICIPANT | This is what our elders say. All my family are Chadians coming from the west, they would say that I have an aunt there who has the same symptoms and this is how they treated her, they don’t have the courage to go see a doctor. When I gave birth to my son who is now 26 years old, I had a cousin who came from Khartoum and asked them why haven’t they taken me to see a doctor, their answer was that they don’t trust doctor and they trust their treatment more, she scolded them for leaving me sick day and night and told them they had to take me to a doctor, that’s when they got a Karroo (a carriage that is pulled by a horse or a donkey) and took me to see the doctor. |
| RESEARCHER | Alright, what happened after you went to see the doctor? |
| PARTICIPANT | The doctor tested me with his stethoscope and prescribed for me some pills and injections, he told me to use them whenever I get an attack like this and told me that what I have is called asthma. So, whenever I have the asthma attack my family would take me to the doctor who would give me this injection and those small pills to take. This continued until I had my two sons, and it persisted every autumn, with the rain season because XXXX is very rainy. So, my husband said that we should move and so we came to Al-Jazeera and Alhamdullah I remained healthy for two years until I had my other son and the attacks came back and we went to the hospital and got the treatment and the oxygen. A long time would pass between attacks, a time that would allow me to regain my health and rest very well. I continued like this until I had all my 8 children. |
| RESEARCHER | May god grant you health |
| PARTICIPANT | Yes, Alhamdullah. |
| RESEARCHER | Alright. About the first doctor who diagnosed you with Asthma, did he just examine you with a stethoscope or did he use another device? |
| PARTICIPANT | Only the stethoscope, and he told me that I had something called asthma |
| RESEARCHER | And you felt that the treatment was good? |
| PARTICIPANT | Yes, I’m all better |
| RESEARCHER | It worked well for you? |
| PARTICIPANT | Yes, I became well and regained my health and was able to resume my work in the fields, until I get the attack and have to take the medication again. |
| RESEARCHER | What did you use to do in the fields? |
| PARTICIPANT | I plant and harvest sesame and millet and bring it home. After a while, the doctor prescribed asthma spray for me that we couldn’t find on our area and had to get from a place called XXXX but after they got it for me and I started using it caused me a sever cough and the doctor told me to stop using it and use the injections instead, but now I’ve started using it again |
| RESEARCHER | You are using the spray now? |
| PARTICIPANT | Yes |
| RESEARCHER | One or two? |
| PARTICIPANT | Two, an inhaler and a spray to be used on need bases only |
| RESEARCHER | Alright. On the first time you visited the doctor and he preformed the heck and prescribed you the medications and have you the shot, what was the positive thing about that time? |
| PARTICIPANT | As soon as he gave me the shot, I was instantly relieved. |
| RESEARCHER | Alright, and what was the thing you didn’t like? |
| PARTICIPANT | These pills they prescribed for me, (she’s upset with the use of pills and quantity of medication) they are too many and I my body is shaking and I believe they are the reason |
| RESEARCHER | What about the doctor and nurses’ treatment of you, was it good or bad? |
| PARTICIPANT | Good. We had a doctor here called XXXX, he was a very brilliant doctor who was very good to me, he used to say to me, “XXXX, if you felt anything come straight to the hospital even if you don’t have a dime.” He gave me --- shots which made me much better, but it has been a long time now since they gave me the shots, they give me pills and drinking portions instead but today I asked them to give me a shot because I couldn’t sleep all night because of the cough. |
| RESEARCHER | Alright, if there is a person in your community who has lung problems like you and doesn’t go to the health unit, why would you think that would be? |
| PARTICIPANT | I would say that he is probably using herbal treatment |
| RESEARCHER | You said earlier that you don’t know anyone close to you who has asthma correct? |
| PARTICIPANT | Yes |
| RESEARCHER | Before when you lived in XXXX you didn’t know what asthma was and your people called it “shortness of breath”. Do you know anyone who is close to you who has the same thing and didn’t go to the doctor? |
| PARTICIPANT | Here? People in XXXX go to the doctor, no one stays at home and practice self-medication. |
| RESEARCHER | They come directly to the doctor? |
| PARTICIPANT | Yes. No one ignores it. Anyone who has allergies goes to the doctor and their allergy is different from mine. |
| RESEARCHER | How? |
| PARTICIPANT | I mean if they complain from something as simple as a sneeze, they say they have allergies. I used to have a neighbor who moved to Khartoum now who used to complain of an allergy but she went to the doctor always. I mean none of them have reached my level |
| RESEARCHER | Alright, in your opinion, what are the things a person complaining of chest problems such as yours would need when they come to the hospital? |
| PARTICIPANT | They would only need treatment and to be healthy, what else? |
| RESEARCHER | What else should the hospital provide? |
| PARTICIPANT | It should provide medication, especially chest treatment. It’s important a person coming to the hospital finds it |
| RESEARCHER | Why is it important |
| PARTICIPANT | They can’t breathe, where else can they take him? They have to come to the hospital to get oxygen. When my daughter suffers from shortness of breath, I bring her to the hospital. |
| RESEARCHER | Your daughter too? |
| PARTICIPANT | Yes, she is young but when she gets shortness of breath, we bring her to the hospital to take oxygen and gets all better Alhamdullah. |
| RESEARCHER | Does your daughter have asthma or allergy? |
| PARTICIPANT | Allergy, or so the doctor said. He said she is showing early symptoms of allergies and that we needed to treat it early and not allow her to get distressed. Now I brought her with me complaining of cough that she couldn’t sleep all night. |
| RESEARCHER | Alright. Are there other things that need to be provided in a hospital for a person to be treated other than what you said? |
| PARTICIPANT | From chest problems? |
| RESEARCHER | Yes. |
| PARTICIPANT | What other things? It’s only shots and oxygen, the medications for each illness must be provided for sick people to be treated. My relatives don’t care about doctors at all, they don’t take sick people to hospitals. My cousin would be very sick but she says not to take her to the hospital. |
| RESEARCHER | Why doesn’t she want to be taken to the hospital? |
| PARTICIPANT | They say they don’t want to go and they have never been treated by a doctor. |
| RESEARCHER | Do you think this is right? |
| PARTICIPANT | No, it’s wrong. Because I’ve seen it on myself. I used to suffer for three days, staying at home, before I feel relieved at the forth day. But when they take me to see the doctor, I feel relieved instantly after taking the shot. |
| RESEARCHER | Alright. How can we change the perception of people such as your cousin who refuses to go to the hospital and says she wouldn’t forgive you if you take her? What can we do to get her to the hospital? |
| PARTICIPANT | Well, we have to take her and try |
| RESEARCHER | But she says she wouldn’t forgive you if you do? |
| PARTICIPANT | I didn’t take her because she said that |
| RESEARCHER | How can you convince her? |
| PARTICIPANT | How can we convince her? |
| RESEARCHER | Yes. |
| PARTICIPANT | I talked to her saying “your illness will not be treated mother if you continue just laying here, it will only get worse, but when we take you to the doctor, even if you don’t want to take the pills they can give you shots in the veins that will make you feel better, and there is a medication they can give you through IV injections but she swears that she is not going regardless of how long I talk to her. She says she wouldn’t take the pills or the portions and I say okay, just take the shots and she also refuse. So, we never took her to see a doctor, she just gets sick and gets better on her own, staying at home. |
| RESEARCHER | May god grant her health |
| RESEARCHER | Alright, you mentioned earlier that a sick person needs treatment. What else could he need from the surrounding community for example? |
| PARTICIPANT | He needs? |
| RESEARCHER | Yes. Meaning, what can the community offer him to help in his recovery? |
| PARTICIPANT | That could only be through monetary help. He could also use the company, someone to go with him to the hospital. |
| RESEARCHER | And what about the psychological aspect, what can they do to insure he is in the best mental state? |
| PARTICIPANT | Not to upset him? A sick person should not be upset or unpleased. They should prepare for him the food and drinks he likes and persuade him to take them to get better. |
| RESEARCHER | Why did you say that people shouldn’t upset the sick person, and they should support him? |
| PARTICIPANT | Because being sick increases the illness of the sick person. When a person is sick and upset, they tend to think about many things but when someone else talks to you about how it is all part of gods plan for you and that only he can cure you and that you need to help yourself get better by seeing a certain doctor. I for example was told to go to Khartoum and then [district capital] to get some weather change but my circumstances didn’t help. When I’m sick, I think about many things but when someone visits, they take my mind of things. |
| RESEARCHER | Alright. If we brought some people from the community as a team, and we chose someone and we trained him on the symptoms of chest diseases so that he can identify when a person complains of similar symptoms to the ones you have and he can convince the sick person to go see a doctor or transfers him to a hospital or health center to get treated. Do you think that would make a difference for this person? |
| PARTICIPANT | No |
| RESEARCHER | You mean it would be better if people like this were available and offered service to the people or what? |
| PARTICIPANT | It would better if people could find someone who tells them to go to the health center and encourage them to get treated. |
| RESEARCHER | Why do you think that is better? |
| PARTICIPANT | So, you can find the cure. I took many medications back in XXXX but still I was sick, and when I came to Khartoum, they told me I had Namonin and they changed my entire treatment plan, they gave these long syringes that I don’t know the name to and found them to be better. |
| RESEARCHER | Alright. In your opinion, if your hospital here can provide you with good examination and good treatment, would that be good or bad for you? |
| PARTICIPANT | Good |
| RESEARCHER | Why? |
| PARTICIPANT | Because I’ll be staying at my hometown and close to my kids, not having to travel and finding the best treatment. I can go by foot and my kids can visit me, that would definitely be much better for me. |
| RESEARCHER | Alright. How about if your hospital became able to improve on writing prescriptions and providing medication and for you to have all that ready at hand and to feel better if you were to take it on regular basis, do you think that is good or bad? |
| PARTICIPANT | Good |
| RESEARCHER | Why? |
| PARTICIPANT | It’s good because then I would find treatment and feel relieved thank god |
| RESEARCHER | Thank God. We want to thank you XXXX for your time even though you are tired, do you have any question or addition? |
| PARTICIPANT | No |
| RESEARCHER | Thank you and may god grant health |

Notes: The patient spoke about changing her residence from Gadarif to Aljazeera where she received care and oxygen in comparison to Al Gadarif where they only gave her shots.

Her condition worsened during pregnancy and breastfeeding

She was very engaged in the conversation and consistent in her body language

She complained that smoke from cooking (making Kisra) troubles her while she can perform her activities normally (women beautification smoke doesn’t trouble her)

In the financial influence question, she took a pause then said that they don’t have money and that her husband is a labor worker

She spoke excessively about the financial influence and how she received support from social and family relations.