

Interviewer/Number of Interview: Stefan Reutter, SR27

Date: October 25, 2019

Name of Interviewee Assigned by Researcher (to protect identity): Respondent

Year of Birth: Information is not being made available. Respondent is in the range of 55 to 64 years old.

Gender: Female

Country of Origin: Syria

Year of Immigration: 1980s

Note: In the transcript, *I* refers to Interviewer, and *R* refers to respondent/interviewee. To protect the identity of the interviewee, some responses to questions are not provided. In such cases, this statement will show in the transcript: Information is not being made available. In other responses, specific details that might identify the family members are omitted or made more general.

Abstract:

The respondent is a Syrian woman currently living in Milwaukee, Wisconsin. She has an advanced degree. She has several family members who have been diagnosed with serious mental conditions, including her daughter. In the interview, the respondent discusses the impact of mental illness on her family's life. She describes the stigma surrounding mental disabilities in comparison to physical disabilities as well as what she perceives as a generational difference in openness when talking about disability and illness. She also compares the degrees of acceptance of differences in ability in the United States and Middle Eastern countries. She expresses her concerns regarding the potential dangers of medications when treating mental illnesses, and stresses the importance of trying alternative methods to improve one's wellbeing. She also described the power of her faith to deal with traumatic events and other obstacles.

Key Themes:

Alternative medicine, medication, adults with disabilities, mental illness, generational and national differences regarding the stigma of mental illness, faith, beliefs about mental illness that may affect a woman's ability to marry (relates to stigma of mental illness and gender).

Transcription:

R: My daughter was diagnosed with [a specific mental illness]. I don't think the diagnosis is correct. The problem is that her doctor – her psychiatrist – is trying many medications with her. I think this might be the sixth or seventh different kind of medication. I don't think that diagnosis is the right one, and this is because I also have another family member who is diagnosed with [the same mental illness]. I don't like to talk about this topic. You know like when you have a headache, or a stomachache? You know where it is and you can do things, but when it comes to these psychological and emotional issues, I feel that even the physicians are not sure how to diagnose them. I was with my daughter when she went to her doctor and the doctor was trying to listen to her and diagnose her from what she could tell her.

I: Right, so it's lacking that physical element.

R: Right, exactly... There's no kind of bloodwork or anything you can do to tell you exactly what kind of illness somebody is suffering from. So I may not be the right person to talk to... I do have experience with it unfortunately in my family and it is very painful for me. Sometimes I feel they are normal, nothing is wrong with them, they are perfect, I enjoy their company, they are successful in their lives, but sometimes they don't make the right decisions and all of us have to pay the price for not making the right decisions. So, I'm not sure if you know...

S: No, all of this is very helpful. The most important thing is to understand how people are feeling and how people in the community are responding to different issues, especially psychological ones since those are often the hardest to understand.

R: You know, I really don't want anyone to know about my daughter and other family members. My daughter [shared her diagnosis at a public event]. I was not happy at all to learn that she did that. This generation is more open than us. For me, I don't want anybody to know. I want to help her, but why do we want to tell people? We should take care of this. I keep saying that just medication is maybe not enough and that we need to do alternative things. [Respondent discussed alternative approaches such as nutrition, exercise, breathing techniques, acupuncture, some of which her daughter has now tried.] I think that we should try – for me personally – I should try to help her and go over this without telling people. To tell the truth, this is part of our culture and we are very sensitive to these illnesses, it's more than physical. If it's physical like being diabetic we're ok, but emotional and psychological issues are different. In the end I want her to marry a good person; sometimes people in the community talk.

S: Do you think there is a stigma in the community surrounding issues like this?

SR27: Unfortunately yes, and not just about the person himself or herself, it's about the whole family. I can't decide about what's going on right now because I feel there are many changes going on right now in the Arab world, right here, back home, and I'm not sure – right now – what's going on. For my generation, we didn't know about these things. In Syria, they diagnosed [my family member who has an emotional illness] as someone who wasn't emotionally mature, and the illness didn't have a title. We had to leave Syria and we went to another country [in the Middle East] to be away from people who knew us, because we didn't want the whole family to be stigmatized.

I: Do you think there was a greater bias in Syria? Or was it more a general desire to get away?

R: Well I think, Syria was less tolerant. And especially in our new country, nobody knew us there; we wanted to go away from our surroundings and family and whatever because I was young and my father wanted me to find a good man. In Syria, everyone would say “Oh, look at her [family member with mental illness]; she’s not feeling well so maybe the whole family is ill.” We wanted to go far from the whole thing. It is very painful for me because I went through this when I was young. My daughter, thank God, is much better than my other family member. My daughter works and goes to school, [although sometimes she feels overwhelmed]. As I said, right now I don’t want anybody to hear about my daughter because I want to help her and go over all the difficulties she’s going through, and I think about her future and finding a very good man. I don’t want her to lower her standards just because she is not feeling well. I don’t to decide for my daughter, but I want to help her to recover. Right now I’m reading about negative energy and positive energy and how to make some changes in the house to make her feel better because I want her to feel better. I actually don’t want her to take medication and that was where our relationship wasn’t that good in the beginning. She wanted to take them; I took her to many other psychotherapists and, since none of them recommended taking medication, I didn’t want her to. I want her to try something different like nutrition or the environment to help her get better.

I: In trying to help her and not wanting to use medications, do you think that Islam or your culture in general has influenced the ways you approach helping your daughter?

R: Unfortunately my daughter is not religious at all. She is not practicing. I’m fine with that it’s up to her and she’s not a little girl, but I always tell her that being religious helps a lot. I went through a lot and I felt that being Muslim and being a religious person helped me to get better and to keep going. Especially with what happened in Syria, I lost [a family member] who was

shelled and killed. I went through a lot, I lost many family members, so I keep telling her to consider some kind of relief through being religious but she doesn't want to. [Respondent described other methods she has been using to eliminate negative energy in the home.] It may not help but it does not hurt. I wish she was religious because being a religious woman helped me. I think religion, any kind of religion, helps when someone goes through difficult times.

I: In general with the community as a whole... How do you think that these issues should be approached? What kind of resources do you think would be the most valuable in helping people? Should it just be handled within the family or should the community should be involved?

R: When my daughter [publicly shared her diagnosis], I asked her why she did it and she said to me, "We shouldn't hide. We have to start telling people that we're suffering and that's not the end. We should talk openly about these things and I'm gonna be the first one." Maybe it helps, so maybe somebody who is struggling with this should say something and it can be a good thing. To tell you the truth, I don't think my generation would be able to do this, maybe the new generation, the second generation here.

I: And you think that's mostly a generational divide just from age?

R: I think so, I think so... You know for me I was thinking all day yesterday should I cancel? Should I go? What should I say? I know you won't mention my name but I still don't feel comfortable talking about this.

I: It's hard to talk about.

R: Yeah, especially with my daughter. I always tell her I will do whatever it takes to help her. I don't want her feeling overwhelmed or having anxiety attacks. I don't want to see her like this and I want her to be strong. She's very strong and very stubborn, and sometimes I feel like she's ok and she shouldn't take anything. I like many things about her personality. She's very sensitive

to unfair and unjust situations, and [is actively involved]; she's very considerate. I want her to enjoy life more. Part of not wanting to tell people is that that's what we learned from [one of my parents who was diagnosed with a serious physical illness]. My parent kept saying nothing was wrong, even after the diagnosis. [Others witnessed my parent being sick and in pain, and even then, my parent said]: *I don't want to talk about this. I want to always feel like I'm strong and I don't want anybody to feel sorry for me.* Even with physical things, not just mental, my parent gave us a good example to always be strong and not to tell people about your illnesses because you could get better and they will not forget that you were sick *laughing* so they will keep it with them. If you try to help yourself and do whatever you can to improve your situation, and people will always see you as a strong woman.

I: How do you think that the US has done comparatively in your experience here? I know you said you don't feel comfortable talking about it, but do you feel more comfortable here?

R: I think American people are more tolerant towards this, but I do not like the approach they take. They like medication and take medication, and I think lately they have been trying to change to more alternative medicine. When I came to the U.S., I felt like even a simple thing like good tea was not available just coffee, coffee, coffee, coffee! Now you can read about wellness and alternatives like herbal things and acupuncture. Recently – maybe in the last five years – American people started thinking about more than taking medications and I like that they are going towards this path. For me, I am very against traditional, or conventional, medication because I know the side effects. Cure something but the cure could hurt something else. Right now I do not take any medication and I wish that my kids did not take any medication; if anything happens I want to help them and I want them to help themselves to do something other than just taking medication.