

Interviewer/Number of Interview: Stefan Reutter, Interview 1 (SR04)

Date: November 12, 2018

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

Year of Birth: 1963

Gender: Male

Country of Origin: Syria

Year of Immigration: Mid-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 man from Milwaukee, Wisconsin. He is a small business-owner, teaches at a local university/college, and is currently completing a PhD. He has a teenage child and two other children who are young adults (one is a female who suffers from high anxiety). He also discussed his own sports-related injury. He offered perspectives on how these issues are treated in the United States and Middle East. Although he had never witnessed discrimination against himself or his family related to differences in ability, he noted the importance of giving as much care as you can, and how in predominantly Muslim countries care towards differences in ability is not publicly displayed. He describes care as a strongly familial practice, but he emphasizes that people need to understand the stresses that other people endure in order to better accommodate their needs.

Key Themes:

Caregivers, physical injury, anxiety, accommodation, understanding, adults with disabilities, critical thinking in assessing credibility of information and sources, secrecy around mental/emotional ability differences, learning curve in becoming educated and taking action

Interview:

I: So the first question is: How old are you?

R: 55.

I: And where were you born?

R: Syria

I: And when did you move to the US?

R: Mid-1980s.

I: And why did you move to the US?

R: For studying, for school.

I: And so the next question is were your or your family's health conditions a factor in moving but if you came for school then I suppose not.

R: Well yeah I mean not for coming here.

I: Ok. So how do you identify yourself then in terms of your national background? Do you see yourself more as an American or as a Syrian or...

R: I would say Arab-American.

I: Ok. What is the highest level of education you have completed?

R: I am currently finishing a PhD. [Additional information is not being made available.]

I: Wow. In what might I ask?

R: [Information is not being made available.]

I: Oh wow that's really cool. So what is your marital status?

R: Married with three children.

I: Three children... How many females and how many males?

R: I have two boys and one girl.

I: And how old are they?

R: One is a teenager and the other two are young adults.

I: So, do you work currently outside of the home?

R: Yes, I teach at [a local university/college] and I have a small business.

I: And how many hours a week do you work?

R: I would say 50-60.

I: So this is where this list here plays in (Refers to types of differences in ability sheet). Let's see... So what kind of differences in ability out of this list would you say--

R: Myself?

I: Yourself or any of your children.

R: Well lately I have had two surgeries for injuries to my leg. So now I am officially, in most cases, a limping man (Laughs). So I have a limp because my ankle and my injuries really never came back completely. So I used to be a runner and now that's difficult so uh... Other than that physically I mean I don't have any other impediments.

I: And so for the kids anything?

R: The kids are in general fine, my daughter has high anxiety she's, you know, she has to deal with it basically, but beyond that, I can't really point to anything.

I: And then what is your daughter's living arrangement?

R: Well she lives at home and she goes to [a local university/college] to finish her undergraduate degree. She has her own car and transportation. She does work at [a local non-profit].

I: So this is pertaining to you and the leg injury -- do you have any kind of rough timeline of when you suffered the injuries or when you were treated for them?

R: In the past two years. [He has had two surgeries in the past two years.]

I: So what kind of factors do you think contributed to that?

R: I mean these were sports injuries so...

I: And what about the timeline for your daughter? Was she ever diagnosed or when?

R: I'm not sure about the diagnosis but I mean she kinda manages her stress mostly. I mean she's being seen but she's not categorized as a severe case. It's something she manages.

I: And this kind of goes more into prejudices regarding differences in ability. Say compared to US society as a whole, how would you say that the Muslim community perceives differences in ability that are visible or obvious to the eye?

R: I would say that to be honest, I haven't had much experience with that. If you're talking about physical -- I think that they are more or less novices in the protocol of accommodating for that. I guess the idea is that they come from societies where there is not careful attention for disabled people. For example, handicap accommodations are not, as far as I can remember, I will note here that I have not lived in the Middle East for a while now, but as I remember part of the building code. So accommodations are usually personal or familial. So I think if one comes with that kind of mindset they need a transition period to become aware of such things. I would say for example in the Islamic Centers, because of the fact that it is a public area, even just the visibility of the accommodations would make people begin to think about the accommodations and special needs. I would say in general here in the United States, because of the social awareness of it that comes from surroundings, that comes from public services, that comes from just living in a society that makes it an issue to accommodate. I think their awareness is heightened.

I: And do you think that the Muslim community in the U.S. I guess treats disabilities differently based off of whether or not they are visible or immediately strike you?

R: Well I mean, ok, so that's a good distinction: visible or not visible. Because the issue of stigma is very sensitive because of the fact of psychological issues -- impairments that have to do with depression or any kind of problem that is related to family or... These are, there is a high threshold of secrecy that is usually is the practice within the societies that they come from. So I would say that stays with them. Again this is all anecdotal. I have not really dealt with something like this, but I would expect that there is still a distance to be traveled where there is an acknowledgment of these kinds of illnesses and I feel that treatment is not a stigma it is something that is needed. So there's really that and again all of these are impressions I'm not speaking out of solid experience.

I: So these questions are essentially saying: Do you think being an Arab or a Muslim contributes to being discriminated against in terms of your difference in ability?

R: Well I would say, not connected to disability, you will have discrimination based on race or ethnicity. I would say these are in place regardless of ability or disability. Now if you combine them, then you'll have a double problem, but I have yet to see that. I mean the only thing I can think of, to be honest with you is the example of when... Like my wife is visibly Muslim, she wears the scarf. Now when she is dealing with issues that have to do with... Cus' she takes, for example, our daughter to get her care, and I think there is an assumption, from what I sensed from their experience, there is an assumption that there is a contribution to custom, to problems like the one my daughter has. I would say that's probably the only way that I can kind of veer in that direction.

I: Do you think that the way, I guess, how present those prejudices are, do you think that they kind of impact the way you give care to your daughter or pursue your own care?

R: Well I'm aware of them. The general sense of this becoming more attentive to them. I guess the way I can put it is because of my lack of experience with the issues my daughter is facing, I assume that there is a lot that I don't know and that I have to be attentive to. I'll tell you that doesn't work all the time because you can't really tell, and there will be instances and times when things should have been done or should have been said or should have been paid attention to and I find out that more should have been done. More than what I did. So I guess you know there is a learning game, there is a learning process here. We are still going through it on a personal level. Mentally you have the kind of remark to be on high alert, to be attentive, but practically you find out it is short, it's not enough. So there is a learning process that needs to be happening.

I: So do you think that the Muslim community has any expectations of you as a caregiver or anyone in your family as a caregiver?

R: I would say if you talk about family, of course, there is an expectation that people need to be cared for, meaning if you don't know, learn. If there is not something you have experience with then do you research. An example being medication. It's something I don't know much about because I have never had to use it. That would be an area where I would have to ask: what is it that is being prescribed? As a rule in the family, we try to avoid medication as much as we can. We always assume that there is a quick resort to it so we try to slow that down. But even you know, there is a point where it is necessary so that would be one thing. As far as the community is concerned I really did not have that kind of an interaction or communication that I can really add any value with.

I: In kind of the same vein: As a Muslim yourself, do you have any kind of expectations of yourself as a caregiver through that religious lens?

R: Well I mean the general guideline is that of giving more. It's I guess the general guideline is to be caring and to be merciful. That issue of mercy as a trope or as a frame is something that compels you to do more. So I would say as general, but people are limited by their perception of how serious the problem is. That's where it really gets important to give awareness, enough awareness, of it. Because by default a father is always concerned, but a father who doesn't know will not know how to be concerned. There is that element that needs to be stressed in. I would say in a study like this one of the benefits would be that value, of widening the scope of what people think needs to be done.

I: The next couple of questions are going more into being a caregiver itself: So what are the biggest challenges you have faced or I guess you and your wife have faced in terms of being a caregiver?

R: Well I guess staying, answering with the limited experience that I have, vigilant in terms of -- you see, what happens is that you make an effort, a certain effort, and you are usually convinced that you have done enough. I said this before but it's really this kind of moving target you really need to be vigilant and try to reassess always. You need experience with this kind of need and the second thing is really an inability to completely understand. This is not an issue as far as I'm concerned, you don't always know what to do. There are two things, you need to know where to go for help, and you have to preempt more need. There is always the assumption that more is really needed. So that's the struggle because there have been situations where after the fact you discover that it wasn't enough and that you need to do more, you have that gap to fill.

I: And so you say that it's always like you need more in terms of...

R: Right because you know it's very difficult to gauge the need since there is no experience, that's where that deficiency comes from.

I: So do you ever feel like you've been spread too thin or that you don't have enough resources available in terms of treatment?

R: Well maybe not spread too thin but just not knowing. Not knowing what or how to tackle, what the nature is. All of that is new. You need to get a grip on what it is and what it needs. That's really the challenge to me.

I: And so you say it's not really a lack of resources you face but have you have considered moving from Milwaukee due to a lack of resources?

R: No, no, and I can't say that there is not a lack of resources because I didn't get to the point where I probably needed the resources. Maybe I need to know how to ask for that or to know what's available. So I wouldn't say that is an area that either failed or there is not enough, I wouldn't know. But moving from Milwaukee specifically for that no it did not come to that point.

I: So to go with not knowing or dealing with new things, what kind of strategies have you used to compensate for that, I guess, initial lack of knowledge?

R: Well I mean, the standard thing to do now is google it (laughs). So you begin there I guess, now, of course, there is the problem that, I as a teacher face too. My students are doing projects and there is so much information out there that there is an inability to gauge what is useful. So I face that too, you need to know where you're getting advice from, how accurate or complete or unbiased it is. Are you reading something from a pharmaceutical company that has motivation to sell something? So I mean really it's, again, you know it's a learning process that needs clever attention to what you're doing. But I would say the first thing to do is gather information. The second thing, of course, is to try to I would say, not to completely surrender to professional handling because one of the things that can happen is in the medical profession there is a lot of

guessing. So you really have to fight against that, there are sometimes conclusions that are too quick or too convenient, or maybe the provider is swamped and doesn't have the time to take a closer look and you end up burdened with the responsibility of caring or covering that job. So I mean beyond researching it you really have to be vigilant. How do you accept advice, diagnosis, treatment? All of that.

I: And so you mention treatment and so, from who and where do you think you get the most help, and how does that help impact you? Do you have positive experiences from receiving help from others in terms of care?

R: The experience is not there yet. But, I guess there are friends and family who care, but again this goes back to what I said before. These issues, there is a very high level of discomfort in sharing them. I guess unless you are talking about very very very close family, there isn't that experience of gauging what kind of help you're getting. I'm not sure how useful that is as an answer but (laughs).

I: All answers are good answers. I'm not sure how much experience you might have with this, but have you noticed if females and males with differences in ability face different challenges respectively within the community or just in general that you have observed?

R: I mean I'm assuming that there is more of a burden... I mean I guess it goes back to the gendered way that we look at things. So there are certain things that women are better at and that they are given more leeway in, and there are certain things that men are privileged in or disadvantaged at. So in general in this thing by itself I would say that it's really hard to kind of pin down where, if you're talking about this kind of a problem that has to do with psychology or wellbeing in that sense, I have a feeling that it is equally -- I'm not sure how much gender plays in that, but I would say that if I had to make a judgment that it's equally problematic for both

sexes. Again I don't have much to stand on to give you an example or informed response, but in general, I would say the stigma is common if it is there.

I: And I suppose going off of that from either experience or just speculation, do you think that there need to be any changes in attitudes regarding either gender or differences in ability pertaining to gender or anything like that?

R: Well I would say that you know it's really before you get to the issue of gender, you know mental illness in itself requires a bit more awareness in general. If you assume that and then there is something to be talked about in terms of gender I don't know. That really is a good question I can't really think of anything that I can gauge that with. Maybe, but I'm not sure.

I: Is there anything that you think that healthcare providers or schools or just society, in general, should know in order to help you or your daughter or really anyone that has a similar issue?

R: I mean only that we as a group, as a minority, Muslims in America are in the crosshair. That can be good because one of the consequences of that is that it brought people together, you know being under pressure kind of helped bring them together. But you know that's the positive but the negative is that you're always in the crosshair, so I would say that in general people should understand the pressure that people can get under and maybe accommodate that.

I: Is there anything else that you'd like to tell me? Any closing remarks?

R: I mean I'm not sure how valuable this insight was (laughs) but the issue itself is very important so I am happy that there is attention to it. I guess we need to come up with more creative ways of bringing up this issue in the Muslim community I would say. Because I'm thinking while I'm answering these: who else, how would they answer these questions? So yeah, I guess more creative ways of getting details out. But I'm not sure with how someone who doesn't have experience or something to go off from, how would they be able to look at these

issues? It's still open. I'm imagining if someone really has problems in the family or a history in the family of mental illness or dealing with anxiety or depression or something like that, which I failed to provide in this interview, I'm just wondering how can you take a response and branch into something, even if it's not scripted, off of responses and be able to probe more and more, and that's something that should be paid attention to.