

Interviewer/Number of Interview: NK13

Date of Interview: 7/24/19

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

Year of Birth: Information is not being made available. Respondent is 18-24 years old

Gender: Female

Country of Origin: U.S.

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 was born in Wisconsin and has an older sister with a Mild Cognitive Impairment. She states the Muslim community believes differences in ability or disabilities are tests from God. She has witnessed her sister face a few hardships with bullying, watching siblings surpass the levels she can achieve, and changes in routines including going to family parties or having no one available to bring her to activities. She also states that she thinks both genders experience the same types of attitudes associated with disabilities, but was thoughtful at the question. She also shared her respite care and babysitting experiences dealing with people who were insensitive to disabilities, and believes that people should have opportunities not only to learn about them, but interact with people with a disability.

Key Themes:

Cultural aspect regarding Muslims' faulty explanations of mental illness and emotional issues. Making arrangements for care after the caregivers have died. Importance of family and extended family. Secrecy/stigma.

Needs: Respite care; knowledge of available resources; Muslim community being made more aware, informed, and sensitive; reducing ignorance in Muslim community; dismantle old beliefs; need for caregivers to understand the culture of those receiving care.

Transcription:

I: How would you identify yourself in terms of your national background?

R: Palestinian-American.

I: Ok, great. And what's the highest level of education you've completed?

R: So far just high school, but I'm in college.

I: What's your marital status?

R: I'm un-married.

I: Ok, do you currently work outside the home?

R: I do! I'm teaching summer school, and I'm currently providing respite care for some families. That's pretty much it.

I: How many hours a week do you work?

R: Well in the summer it's about 30 hours a week.

I: Ok, and do you live here full time?

R: Yeah.

I: So I have a better understanding of your situation, could you describe the difference in ability that your sister has?

R: Yeah so she has a cognitive disability. I'd say that she just processes things a little more slowly. I'd say that's pretty much it.

I: Do you know when she was diagnosed with that or when it was noticed?

R: Birth.

I: Ok, would you describe what kind of care you provide for her?

R: Nothing too intense really. She doesn't drive so the most we would do is just help drive her. And also she doesn't use big appliances like the oven or stove. So if she like wants like a boiled egg or something I'll just turn the stove on. She turns it off, she just doesn't turn it on. She doesn't use the oven. We have a toaster oven so she uses the toaster oven but if she wants something that's like in the oven we just stick it in the oven for her. But that's really it. She's pretty independent for the most part.

I: Yeah. Do you know what kind of care she receives from others? Like possibly physical therapy or occupational therapy or others of that nature?

R: She doesn't receive any therapies right now. I know we were kind of looking into it.

I: Ok, so those were all the background questions. These are more focused on the perceptions of the Muslim community. How do you think the Muslim community perceives differences of ability that are very visible? Compared to the broader US?

R: I think the Muslim community kind of thinks of it as a "test from God." They don't think of it necessarily... that's a tough one. I think most of them think of it as a test from God. I don't think many of them think of it as like a punishment. I think more people would say it's kind of God's test to that parent, or family, or whoever is like the caregiver. But, mostly that.

I: How do you think the Muslim community perceives less visible differences in ability? So like for example, a cognitive delay or mental illness. Or other things like that.

R: I would say they're not as accepting. With a cognitive delay I think it's a little different than mental illness. I feel like mental illness is something that's looked at as totally different or perceived as totally different. I like there's more of a stigma around people with mental illness than there are people with disabilities. I feel like people who have mental illnesses are looked at more like people who are incompetent, or maybe weak in their faith and that's why they're struggling mentally. Whereas a cognitive delay or physical disability or any difference in ability is looked at as like a test from God than mental illness it.

I: That's interesting. Have you, when you were with your sister, or just directed at your sister, experienced any negative remarks or discrimination because of her difference in ability?

R: Truth be told, now that I'm older I don't see it because the people we associate with are more aware of it. But looking back at when we were younger I actually forgot about it until that focus group. There were a few incidents when we were younger and we would hang out and play with kids in the Muslim community and because, my sister, if you look at her you can't tell she has a cognitive disability, you know? So sometimes when they would talk to her they would be a little rude or they would be impatient and just leave, or they would make rude remarks or whatever. But they wouldn't say anything too rude or something that really got to her. But mostly just about her looks, and not even comments but maybe just actions- they would steer clear of her. But nothing, at least that I can say that was that traumatizing.

I: Do you think that those were things that you more noticed, or that your sister noticed as well? Or were they things that she just brushed off?

R: I'd say she brushed it off. I noticed it. [She described an argument with kids from another family and their response when the respondent's sister with the cognitive delay tried to intervene.] My sister walked up and said something like, "Oh I'm 16, just saying, like I'm older than all of you so you shouldn't-" but like they didn't understand. All they heard was "I'm 16"

[and they were] like how is that relevant to them? So they all laughed and turned their shoulders to her; that's the first time I really noticed it, but that was it really. I mean nothing rude was said but actions speak louder than words.

I: Yeah definitely. Do you think that if you've ever experienced discrimination aside from that-that being Arab or Muslim had anything to do with it?

R: I mean I wouldn't say so, I mean if it did or if there was I don't remember it. But I think most of the discrimination that I saw was from within the Muslim community and not from anybody else.

I: Why do you think people have these negative judgments or negative reactions to people with differences in ability?

R: Negative reactions when they interact with them?

I: Yeah, or I guess negative opinions.

R: So I mean with [Sister with MCI] I'd say just because they are told that's God's test to them. And so I don't want to say that it's a negative, it's just that they have this unneeded sympathy. They have this sympathy for her which is not needed, right? I mean she's perfect. Yeah I mean I guess for people maybe with like a mental illness they have this negative thing like, "Oh, they're too far away in their faith!" like they are not connected with God and that's why they're suffering. And so I'm sure the older generation, I feel like the newer generation that's growing up here [in the US] is a little more aware that the older things that we are told are not necessarily true. Or not necessarily fully true. I don't know. It's a sore subject on mental illness.

I: Basically do you think there is an impact on your willingness to go out with your sister or for your sister to go out into certain situations because of the public perceptions?

R: I wouldn't say so, like we were never hesitant to take her with us anywhere. Now that she's older things are a little different because she herself doesn't want to leave. I'm not sure if that has anything to do with maybe her realizing people are aware of her disability or if she truly likes just being in the house and not leaving anywhere. But no, it doesn't really impact us going out as a family. Or us taking trips together, going to the movie theater, whatever. It doesn't. Not at all.

I: Alright. How do you think the community's perceptions impact the way you deal with the difference in ability she has and caring for her.

R: What do you mean?

I: Well like your mother had said, because of her faith and your faith, she wants to take care of her for as long as she lives and doesn't want to put her into a group home.

R: So... there's like a cultural aspect to it too, not just necessarily a religious aspect. But I mean,

right now all I do for her really are the little things like driving her or whatever. But long term, yeah I wouldn't see us putting her anywhere else than with one of the siblings. She- and not that I necessarily have a bad image of what [facilities are like]- and I know that there's independent living [facilities]. I know that there's like funding for that and whatnot. I just think, not necessarily for anyone else's approval or anything but just for her it would be better for her to live with one of us than to jump around. But it's not influenced by any outside influence or force. I think there is more of a like- it's slightly influenced by religion and culture but I wouldn't say too much. It's just overall for her well-being long-term.

I: Just maybe your particular family's values?

R: Yeah so I wouldn't necessarily- like I jump back and forth. Like yes there's a big cultural thing where it would definitely be frowned upon if she lived anywhere other than with one of us. But our decision for her to live with us isn't influenced by something else.

I: So you don't think the Muslim community has certain expectations for you to take care of her, it's more...

R: No they definitely have expectations for us; after my mother passes it's expected that she'll live with one of us. I mean like it would be an honor for me, like it's something that I've been ready to do basically.

I: Definitely. Do you think you have these expectations on yourself too of how that's going to go in the future?

R: Of myself? I don't know. I guess it sort of depends on what happens in the future with each sibling individually. But I know speaking on behalf of myself, I wouldn't want to like- if she wants to live with somebody else, one of the other siblings, I'd be more than willing. If she wanted to live independently I don't think I'd fully shoot that down. I wouldn't mind it. I mean if it's part of her funding and something that she really wants to do I don't see why not. I feel like if that were to happen she would have to be very close to her other siblings, but I don't want her to have to like see all of us move on and go and do our own thing while she is stuck with my mom or like stuck with one of us, because with her disability it's not like she doesn't understand what's going on, like she's very aware of her difference in ability and that she doesn't necessarily participate in all the things that we do. Like she doesn't drive and that was a big trigger for her. So I have a sibling between me and (sister with mci) and it was tough because she's older and she should be doing the things she's doing before her [sister without mci]. And when she passed [sister with mci] it was a bit of a rocky road. And then when I got my license, rocky road. My brother, he's fine because he takes her everywhere.

I: Do you think that she has particular expectations of you guys and of her future?

R: We haven't really talked about that. I know that when we went through and when my mom went through with the guardianship and that when she (mom) passes that she's with my brother I think that kind of got her thinking about it. It's not something we've talked about yet

because you know that's a sore subject because that's after my mom goes.

I: Yeah, right. So these next questions are about any challenges you or your family have faced in taking care of her.

R: Sure.

I: So have you noticed in yourself or your mom or anyone else who has been active in her care, that you've been stretched too thin? Not getting enough support? Having insufficient resources or education about it? Not getting enough help?

R: I mean we have definitely all kind of have had our moments. Her schedule is different every day. [Respondent described typical days and who in the family transports her sister.] I mean we definitely are spread thin but not in a bad way, right? When somebody else is not able to help in what they usually do then someone else picks it up. And so it's kind of a shared responsibility among us.

I: Do you think that the teachers that your sister has had and the doctors have provided a good enough education about expectations and options?

R: I don't know because when we were in school we went to completely different schools and we were also at different times. I know my mom maybe touched on this a little bit how when they were doing everything for like right before she graduated they had all these meetings and stuff to tell about long term care and my mom had assumed that it was for group living or one of those long term care facilities and whatnot so my mom was like, "Nope, she's living at home, she's not going anyways." So she didn't go to those meetings so she didn't know that she could get basically funding for all of [sister with mci]'s activities. So my mom has been paying out-of-pocket for things for years. And then I started doing respite care and I told my mom that we could get these things paid for. So then I looked into that and we got all that covered. But, I don't know I mean one of the teachers I think told my mom about guardianship so I mean for that that was really important but for everything else I didn't know about the funding, like the respite, any therapies or whatever, we didn't know what was covered.

I: Have there been any strategies you've used or that your family's used when you do run into an issue or something challenging?

R: Yes. It happens. Honestly? Not often, but she will get frustrated. It happens every now and then. Like with me she came to wake me up a few days ago to take her to the gym and she wakes me up at 5 in the morning to take her to the gym. So I woke up and was like no, go ask somebody else. So she came back like 10 minutes later and was like nobody's taking me to the gym. So I was like, go ask someone else again, and she came back 5 minutes later and was like *nobody's taking me*. Like you could see that she was getting frustrated. So I was like, oh God. So she gets these little angry outbursts but reasoning with her works really well if you just explain. And I feel bad, because she's older, and when we were younger we would tell our older siblings, we would yell at her, "She needs to understand, she needs to understand!" but it took

us so long to realize that she doesn't understand. Right, that there's some things that maybe she'd like want, and we just couldn't understand why when she couldn't understand [why she couldn't get what she wants.] But yeah, right now, reasoning with her works really really well. We haven't had an outburst from her in a while. The only thing that we have really with her, she does not want to leave the house unless it's like for her stuff. If she knows about it advance that's different, but just kind of spur of the moment, she hates that. So just kind of reasoning works with her but there's just sometimes we cannot get her to go.

I: Do you think that is because it is a change in her routine or because of anxiety over going out to see other people?

R: I would say a little bit of both. I don't want to say she hates social interaction because she likes talking to people. Like talking to some family members who she is comfortable with, she'll talk to them all day. But talking with, maybe like strangers is a little different, but I think mostly it's the change in routine.

I: That's interesting... have you had any particularly positive instances of getting help or support from others? Or that you've seen towards her or for your family?

R: Yeah, the art class and regular routine of going to the gym. And she recently started seeing a trainer so I feel like it helps a lot with like her anger and frustration, so I feel like that's like a good release of energy for her. Family is really helpful when there's like a last resort. [Sometimes we ask extended family to help with the transportation.]

I: That's awesome. So do you think that there are any challenges that females with a difference in ability have that males don't?

R: I don't think so. I mean me personally, I've been doing a little work with MUHSEN. I think if you have a difference in ability or disability in the Muslim community, like that's it. You have a disability. It doesn't matter if you're male or female. I don't think gender has much to play in.

I: You don't think there's more or less support for one or the other, like if it was a husband versus a wife who got sick? Or different chances for employment or marriage?

R: Oh yeah, but I think... that got me thinking. I don't know, I hadn't really thought about that. Again, I think if it's known that you have a disability or a difference in ability I think that it's known that you're not, I don't know, it's such a weird word but... eligible for marriage? I think in that way I don't have it in my mind that she thinks that way or that she will share her life with someone else, but if it was a brother or whatever I mean I'd say the same thing. I was doing respite care for a middle-aged man and he was living with his mom and his mom had done guardianship and what-not so that he would be living with his brother when she passes or as she got older. So I guess, I mean I wouldn't say gender... I mean I don't know! It depends on the situation really, and if there was a married couple and if the husband [had a] TBI (traumatic brain injury) I don't know. Yeah, that's a tough one. That really got me thinking.

I: Yeah, it's not something you have to know. It's just us wondering if you did have an opinion or did know or experience anything.

R: Honestly I don't. No experience with it either so...

I: That's totally fine. What do you think in the community or across the US- are there any changes in attitude or additional support and resources that should be made available?

R: Well I know that you know a little about MUHSEN, right?

I: Kind of.

R: It's an organization that is providing support and accommodations for Muslim families with special needs. So I've been doing like a little work with them and it's been really really helpful. I had no idea that there were so many families that had children with autism. So then when MUHSEN came around there are dozens of families getting together and sharing information and I'm just like... I had no idea! There were only a few people that I knew in the community who had a disability. So once MUHSEN came around, all of a sudden you see families becoming more comfortable sharing if their child has a disability or difference in ability. And so I think MUHSEN has been like a big blessing to our community. And just like, helping provide resources, so that's how I got connected you know doing respite care for so many families. It's actually so crazy -- I have another family that reached out to me today that I met through MUHSEN for respite care so I think it's really good. And a lot of Muslim families feel more comfortable having a Muslim respite care provider in their house, especially if they want to go somewhere, run somewhere, relax, whatever! Especially for parents with autism they need ABA therapists (Applied Behavior Analysis) all the time that are in your house and are complete strangers. So they're just [more] comfortable having a fellow Muslim in their house taking care of their child or taking them to the library or whatever.

I: Yeah, so then do you think there is additional education that people need if they are going to be in the home of someone who is Muslim? Or their doctors or?

R: I would say so. I'd say, like cultural responsiveness, is that what you mean?

I: Yeah.

R: I'd say so. Yeah I mean it's important for them to understand the culture and not necessarily for just Muslim families, but people from any cultural background. It's really important to know their background and what their values are and what their beliefs are.

I: Yeah, definitely. Is there anything you think healthcare providers or a school or anyone else should know to be supportive for you or families in a similar situation? Or just general education?

R: General education but I don't know if that's enough either. Education but also just like if you're educated about it why aren't you implementing it into your core values or belief? So a

little bit of a story time. I was doing during Ramadan, like the holy month, I was babysitting during the nightly prayers, so I wasn't praying I was just watching kids under 5 in the babysitting room. And there was one girl with autism and she came in pretty much every day. And when she came in she'd want to sleep. So we'd like, set her up in a different room, we'd turn the lights off and she'd just sleep. There was one day where- and she was like very sensitive to sound, she was, she hated sound, like the light bothered her, so many things that bothered her. And so there was one day where her mom brought her in already sleeping. And so her mom set her [down] and we didn't want to move her because her mom had already put her down, and so we lowered the speaker because in that babysitting room you can hear the prayers going on. And so we lowered the volume. It wasn't [too] low, like you could still hear it, but it was lower than it normally was and we had a mom who was praying in the babysitting room say- like she was arguing with me and the other babysitter, she said to turn the volume higher. And we were like, sorry, we can't put it that high because if she wakes up it's going to be very difficult to calm her down without her mom. And she was like I need the volume higher, I need the volume higher! And we were like sorry, she is on the spectrum and needs it lower. And she was arguing with us, and finally she was like her mom shouldn't bring her to the masjid if she has this! And I was like, seriously?

I: Wow.

R: And so like this was not, she was an educated woman, I'm not sure maybe she wasn't that educated but she seemed like an educated woman. And I didn't know her on a personal level but I was just like even with all the work that MUHSEN has done, the Muslim community has done to be maybe just a little more aware or a little more educated we still have people like this with such old beliefs. Like you shouldn't bring your child to the masjid if they have a disability. It's just... it was so upsetting to me to hear her say those words.

I: Definitely. And it wasn't even hurting her really to have the volume lowered.

R: It wasn't! It wasn't! And the only reason she was in that babysitting room was because her baby would cry every time she would leave! It's just like, maybe you shouldn't bring your kid to the masjid! You know? It was so frustrating! It drove us crazy.

I: Yeah, that sounds really frustrating. Is there anything else that you think would be helpful for us to know to help others?

R: I would say, I don't know, I'd say maybe events every now and then for the community, the Muslim community, just to be educated on how to interact with people with disabilities? I mean sure people are aware of it, they know of it, you know, they're slightly educated in it. But like when they come face-to-face with someone with a disability they are like, all of a sudden all the women don't know what to do or what to say. So maybe just interact normally or be normal with them. You don't have to pretend they're two years old, so I'd say that was a really big one for me. And also all the resources that like families can get. Like I met another lady, she has a son who has a visual impairment, and once I figured out all the resources that we could get for (sister with MCI) I was like sharing it with everybody and she goes, "Wait. I've been

paying for an Uber for my son who doesn't drive for like, 3 years". And I was like no there's a taxi service or you can get paid to drive your son, like you don't have to, because he's over 18 there's resources for him. And so I gave her the number to the Waukesha county aging and disability resource center and set her up with like a taxi service to her son. So I'd say informational sessions for like families with children with disabilities because they think if you're like, I don't know. I don't speak for everybody but I feel like a lot of families have felt like, ok maybe I'm an immigrant or you know, like I don't necessarily have the rights to those resources or whatever but it's like no, you get these resources just like everybody else. So I think that's really important.

I: No, definitely. I think the problem is people like that don't have their story heard because they don't reach out, so they don't get help.

R: Really, it's tough, because it's like a thin line too because sure, they want these resources but they also don't want to share that they have a child, sibling, whatever who has a difference in ability or disability.

I: Exactly. Do you know any other families who may want to participate in this?

R: Maybe a ton! [They shared information on how to connect with other potential interviewees.]

I: Awesome, that's super helpful. And thank you so much.