



Interview with Providers: Gendered Differences of Abilities and U.S. Muslims Arab and Muslim Women's Research and Resource Institute (AMWRI)

Interviewer/Number of Interview: SW5

Date: August 4, 2021

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

Year of Birth: 1983

Gender: Male

Country of Origin: Pakistan

Year of Immigration: 1993

Current State in which respondent resides: Illinois

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 respondent or name of employer are omitted or made more general.

Abstract: The respondent is a licensed clinical psychologist and assistant director of the clinic where he works. He has been working with Muslim caregivers/individuals with ability differences for about seven years. He shared some of the challenges their patients report in the clinical setting. The biggest challenge is getting support, sensitivity, and understanding from their loved ones. The other challenge is acceptance of the individual, because they have so many other strengths. For example, when someone learns you're depressed or have anxiety, there's often automatically a stigma and people start judging others. The respondent also discussed challenges they face as a provider of care. These include lack of resources and being stretched too thin with waiting lists. Everyone should have access to quality care and counselling as preventative care in addition to reactive care. Other challenges are not having enough therapists who can offer spiritually integrated psychotherapy, not having enough "brown" therapists in general, and the need for more education and awareness. We need resources for providers, especially more centralized resources for providers, including how to get find someone to consult with. Yet, he also reported that awareness of mental health has increased in the last few years, which offers us hope. Lastly, he identified several resources that AMWRI's might want to include in its webpage.

Key Themes: motivation to change and work on self, patients exhibit culturally specific symptoms of depression, anxiety, etc. Culturally sensitive and religion centered approaches to therapy. Stigma and prejudice of mental health disorders. Need for services for both patients and providers. Importance of

self-care for providers. Compassion fatigue. “With knowledge is awareness, with more knowledge and awareness come less stigma.”

Transcript:

I: It should have started recording. Yes, good. So, I sent you a description of the project, but I'll just fill you in a little bit again. So, the project seeks to understand the weight of cultural beliefs about ability differences, and to explore ways of influencing cultures by spurring dialogue with Islamic scholars and Imams, educators and healthcare, human service providers, our goal is to bring down barriers experienced by Milwaukee Muslim women and through them the community at large. So we're interviewing people who provide services for Muslims with ability differences or their caregivers. And this can include language, instructors, teachers, health care professionals, counselors, community, service workers, etc. We'll just begin with a few brief biographical questions, your name, I have. Could you share your year of birth?

R: 1983

I: And your gender?

R: Male.

I: Your country of origin.

R: Pakistan.

I: And the year of immigration?

R: 1993.

I: Perfect thank you so much. And the current state in which you reside?

R: Illinois.

I: OK ,great. So the first question is demographic and background and it asks what services you provide to Muslims with ability differences or their caregivers and your role in the population.

R: Sure, so I mean I provide general mental health services - so individual counseling, family counseling, couples counseling. And although my services aren't geared towards that specific population, but you know, I think that that factor comes up; can come up in in the people that I serve.

I: And how long have you been working with this population?

R: So, I would say with the Muslim community ever since 2014.

I: Great.

R: So that would be 7 years almost.

I: Thank you. And with whom is it that you work with -- Muslims with ability differences, their caregivers, or both?

R: Mostly, I would say caregivers. Out of the clients that I receive, I can't remember the last time I had someone with ability differences. Can you define what do you mean when you say ability differences right?

I: Good so uhm, this is the next - this is the next portion. So, differences of ability could refer to mental health differences, intellectual differences, physical substance disorder, learning disorder, etc.

R: Yes, I do work with them as well.

I: Great, and your position title?

R: I'm a licensed clinical psychologist.

I: Thank you, thank you. So this is a question where you explain the types of differences of ability that the Muslims in your care have, and so there are seven categories. I'll just list them and then after each one if you could share what kind of conditions you have come across. Mental health conditions.

R: So, just generally speaking, mental health conditions; I mean anxiety disorders, trauma, mood disorders, and sometimes mental health differences are secondary to like family conflict. I mean personality disorders as well, although those are rare, or they might be secondary to mental health issues. Let's see, very rarely schizophrenia and bipolar disorder as well. Schizophrenia and OCD as well - obsessive compulsive and related disorders.

I: Thank you. In terms of intellectual differences of ability?

R: Oh, so those would be – now, like if you check in the book, - intellectual differences, so we will have some that actually meet the criteria for complete intellectual disability. So, they have low IQ and they also have low adaptive functioning. It's rare to find those, but we'll frequently have people with low IQ, but I think that's because the IQ test is standardized on Americans and when you give it to those who are not Americans, they'll often score low on it. So I wouldn't consider those intellectually disabled. And then very rarely we would have someone who was born with intellectual disability and coming in for services because we don't specialize in that. So, generally we refer them out to agencies that specialize in that kind of care.

I: I think intellectual differences also refer to Down syndrome, fetal alcohol, ADHD, and autism.

R: Yeah, ADHD is frequent, but ADHD is also over-diagnosed, so it's hard to know if it's truly ADHD or they're just meeting the criteria based on symptoms, but we will have people with ADHD very frequently. Not so much with autism or Down syndrome or fetal alcoholism, because we don't

specialize in those services. So, we would rather have someone take care of them outside, and if the family still needs a Muslim consultation every now and then, we will provide those but direct services we generally don't provide.

I: Thank you. The third category is physical differences.

R: Physical differences, does that mean like physical disabilities?

I: Physical disabilities such as amputation, stroke, cerebral palsy, deafness and heart condition.

R: Yeah, very rarely, like stroke - I've treated at least two people that I can think off the top of my head with stroke in the past history, but yeah, that's rare. So someone may have physical - like would that also include someone who's like wheelchair bound because of old age?

I: Sure.

R: Sure, yeah. So yeah, I guess that's also kind of rare, but it does happen.

I: The 4th category is substance disorder.

R: So, that's very rare, you know, like because, again, we don't specialize in that. So like, maybe like once every two years or so somebody would come in. All those secondary substance disorders do exist, so if somebody comes in with substance disorder and they don't have a primary mental health disorder, we'd refer them out. But if they have a primary mental health disorder, we will treat the mental health disorder.

I: Then we have learning differences, speaking, reading, writing, reasoning or math skills.

R: Yes, yes. I've treated this.

I: And chronic illness such as seizures, diabetes, kidney disease, arthritis?

R: Yes, absolutely.

I: And then the last type of difference, speech and language such as voice disorders, stuttering aphasia or articulation.

R: I mean, very rarely. I can probably count one person - think of one person that I treated that qualified for that.

I: I see, thank you. Is there anything that you want to say about the general types of differences that your Muslim patients present with?

R: I think mental health is probably the most common one that we treat. I mean, other than that, they're kind of rare to see.

I: Thank you. So the next set of questions focuses on perceptions about people with differences of abilities and experiences of prejudice or discrimination. Have you observed any prejudice, negative remarks, or discrimination directed towards Muslims with differences of abilities?

R: I have, I have. I mean, I think even family members can be insensitive. You know, if somebody is like, suicidal, they might say “oh she's faking it.” Or you know, like this one person would have depression and depression was actually caused by low vitamin D deficiency. But you know, they were just saying “he's making an excuse because of school. Doesn't want us, you know he's lazy” or something. Or like related to medication, like if somebody is suicidal and we want them to go on medication because of their severe depression, then the comment is also like you know “it's not going to work because this person doesn't really care about getting better” things like that. I think calling people “crazy”, calling people “retarded”. So yeah, I think it happens. I mean, I think it's getting better, like even those individuals who make these comments once they're informed about it, they are able to modify their perspective and even, you know, use more sensitive language. But initially that's noticed.

I: So do you think these prejudices and negative judgments are from not having awareness or education?

R: Yes, I think most of it's because of not having the awareness. Once they become aware of these issues, you know then they're able to be more sensitive. I think in almost all cases it's due to lack of awareness and education.

I: Thank you, the next group of questions focuses on the challenges that Muslims with ability differences face (or their caregivers) and your suggestions for addressing their needs. From your perspective, what are the biggest challenges that they face?

R: Yeah, I'm I guess being accepted, especially if the issue may be like normal or they are high functioning. So, when I say ‘normal’ I mean like everybody has anxiety. With COVID everyone had anxiety, right? So, there is a little bit of like acceptance of OK this is just, you know, everyone's feeling this way. So, I think that's the challenges, like even something that might be normal, like anxiety because of COVID, you know, people can be insensitive to it. The other challenge would be like acceptance of the individual, because they have so many other strengths. So like you know if somebody is considering someone for marriage or something and they find out that this person has a history of depression. You know like and the person is motivated to seek help and get better so you know, the idea that that they can actually get better, or you can live with somebody that has depression and you know like that's just, that's just how the world works. I think that's the part that people have difficulty accepting. I think it's the biggest, one of the biggest challenges because they when you hear ‘depression’ when your anxiety when you hear these clinical terms, people get the automatic - there's automatically a stigma and people start judging others.

I: Thank you and do your patients report being stretched too thin or having insufficient resources or information quality care?

R: So yeah, I think in terms of resources, absolutely. I mean, even now we're stretched too thin because we're we have a wait list in all of our offices and we don't have enough competent providers, you

know, to help them because people come to us looking for spiritually integrated psychotherapy. And so we don't have enough of those providers to give services. So, we have wait lists and then clients, also because they don't have that resource. So, so most people that come to us because of Muslim background almost always want some kind of an element of spirituality or religion as part of the therapy. We have our own data on this. I think it's like 90 some percent of the people you know said it was it was extremely important or somewhat important to have their Muslim a therapist and almost the same percentage said that they want Islam integrated incorporated into therapy. So, you know, I think finding those types of providers is very challenging for Muslims. Even finding Muslim providers in general or even brown providers in general, like I think it's just you know overall then you add every time you add a layer, it's more complicated. Uh, so absolutely. I think that that's a challenge. As for other challenges like finances and stuff, our organization makes sure that we don't turn anybody back, especially if they're suffering from something we want to help them. So, we have a policy of, you know, service over fee, so we help everyone regardless.

I: Thank you. Could you describe some of the emotional challenges that your patients report experiencing such as depression or hopelessness, sadness, a spiritual crisis?

R: I think perhaps the biggest emotional challenge would be not having that emotional support so you know trying to help the their family member understand what they're suffering from and how to effectively help them is a challenge in its own, and I think that's probably one of the bigger challenges that they have, emotionally speaking. I think most patients, if they have some level of motivation, they are able to eventually overcome their own emotional challenges; they're able to work on themselves and help themselves through that. But if they don't have the support you know, then it makes it makes it twice as hard for them.

I: And you mentioned earlier physical health that health conditions that might be secondary to and an emotional one. Could you share a little bit about this, such as lack of sleep or physical challenges in staying involved in life activities?

R: So physical is secondary to emotional. I think obviously you know like, for example, depression can cause problems with motivation, energy level. So, not being able to get certain things done, and then if people are kind of stuck inside of their house, they don't have that push to get out of bed and then sleep is disturbed with obviously both anxiety and depression. So either there's less sleep, more sleep, or sleeping too much. If they have something like OCD, then the physical challenges would be getting things done on time because they're just so caught up in compulsions that they're often stuck. Or maybe there's trauma associated with something like being traumatized at their home or with certain family members. Then there are physical challenges, like not being able to go to -- or avoiding -- certain places or individuals that also poses somewhat of a physical barrier.

I: Thank you, could you share a little bit about counseling or relationship kind of support that you provide? What are the conditions or challenges that your patients report in that sector?

R: Like with marital counseling, I think the same category which is basically that they don't feel like their partner or their family member doesn't truly understand them, and so one challenge is that for them to accept that their partner will never really, truly understand them, because it's not them. So that's a challenge in its own. And then the second would be like getting the partner to understand them

and what they're struggling from. So, I think both of those kind of go back on the client, unfortunately.

I: And do your clients or patients report any language barriers? Have you experienced any language barriers?

R: I mean, Alhamdulillah we have the providers to overcome the language barriers. So even if there are any, for the most part we we've had somebody who spoke that language. So for us this issue is really not there. The only rare times that we will see that is like if you have parents that don't speak fluent English and children that do, and you're trying to help them, and there's a language barrier between the parents and children, for example.

I: And do you have any difficulties with the kind of cultural translation of ...I guess this is what your specialty is in a way, but you know, the kind of cultural literacy, the cultural translation of between Western diagnosis and the particularly Islamic uptake. Or translation into the language? Could you say something about that?

R: So yeah, I mean, obviously, that is our, our area of expertise. We do, you know, we want to make sure we provide culturally sensitive, culturally informed care. Oftentimes, I think, well, there's two parts to it, one is understanding that sometimes, some of these disorders can manifest differently in different cultures, like anxiety disorders manifested with physical symptoms like somatic symptoms with a lot of brown individuals: Indian, Pakistani, Bangladeshi individuals, Afghani. So instead of anxiety symptoms they're having, like headaches and stomach problems and back pains, you know, like ulcers and whatnot. So, that's one part of it; which is making them understand that when you're having these issues, it can be a manifestation of your anxiety. There's a psychological component to it. The second challenge could be like, in terms of how they interpret their illness, so there is a belief of like evil eye, or, you know, demon possession, djinn possession, so that can also come in when you're trying to work with them and trying to motivate them to change or work on themselves. If they kind of have this belief that, oh, this is because of evil eye or whatever, then they don't - there is a lack of motivation. And then kind of rarely, I think we have some challenges of like treatment. So, as we're providing treatment, is the treatment culturally sensitive? Will the person be open? So if somebody has OCD and we're trying to do exposure therapy with them, are they going to be open to that kind of exposure, if they already have a certain belief from their culture or religious background.

I: Thank you, what additional support help or changes in attitudes are needed? What is needed to make things better for your patients?

R: Well education is the first thing. I think education and awareness - making therapy accessible for everyone. So, whether they're suffering from a disorder or not, they should be able to have access to a counselor, and everyone should see a counselor, even if they're suffering from something you know that's not that big of an issue, more preventative care rather than like intervention or reactive, but yeah, it all comes down to education and awareness. So, you know, whether it's - I mean, a lot of these people are watching, like still watching their TV channels from back home, right? So, maybe I think some of the work needs to be done back in those countries where you know, like some of the awareness can come from there, but definitely here, like in mosques and community centers and within families, the idea that, you know, these are mental illnesses and they need to be worked on.

I: Thank you, that's very helpful. AMWRRI is gathering information on resources and services that might be helpful for this population so that they can be included on our website. Are there any resources or services that you suggest should be included?

R: There's the Institute of Muslim Mental Health, which has a directory and it puts up articles and blog posts that are very helpful. There's another organization called SEMA or SEEMA, or maybe there's 2 E's in there. But if you search for SEMA mental health, you'll find it. They also have a directory. They also put up a lot of resources. There's the Muslim mental health lab from California and that does put a lot of resources so, I think a lot of these places are doing work, including us. We also have our website. We try to bring a lot of awareness. I think that could be very helpful.

I: Thank you, that's very helpful. The next group of questions focuses on the challenges that you face as a person who works with, or provide services for Muslims with ability differences or their caregivers, and your suggestions for improvement. So, what are challenges that you face as a provider?

R: Challenges that I face - I think I don't have enough time to work with some of these individuals. I think that would be, you know, for sure a challenge for me. I think, I mean, oftentimes I do struggle with self-care, but I've gotten better at that, so being able to make sure that I take care of myself; and that I don't get burnt out. Obviously, compassion fatigue could be a challenge for us as well. And then not having enough resources, so it's hard to say no to people. You know, people were suffering, and then you're like – “I can't see you”, and they're like, “well, can somebody in your organization see you?”, “Well, they can't because we have a wait list” and you know, they're like: “what are we supposed to do?” and it's kind of hard to say no. But you know, I mean, that's a challenge. What can we do about it, right?

I: Do you find any challenges in terms of training for non-Muslim practitioners who might be interested in integrating a spiritual dimension or understanding better spiritual dimensions from Islam for their patients?

R: I mean, there's going to be a national challenge anyway, like I think that's just a given. So, if you're not a Muslim, and you're trying to do Islamically integrated work or spiritually integrated work, it's a challenge. Unless you are very highly educated in Islamic theology and terminology and understand it, there's going to be that challenge on your end. On the other end, and the receiving end, if the person realizes that you're not a Muslim, they're automatically going to reject you. I mean, in fact, I think you could probably be a convert who may know more about Islam and about the work that they're doing, than someone who is Muslim-born, but I think that people are automatically going to reject you because of that, unfortunately.

I: Thank you, that's interesting and helpful for the project. What additional support, help or changes in attitudes are needed and what is needed to make things better? This is for you as a practitioner.

R: I think having like more centralized information about resources - you know, like if I need to find someone, I mean, I think there are some organizations that are trying to do there, but it's still challenging. So, like a place where if I needed resources, I could go find them. I think definitely we

need more for consultative groups and even support groups for providers, right? Because of the like I said, compassion fatigue and all these other challenges that we experience.

I: Thank you. The last question is if there is anything else that you would like to share with me about your experiences with the Muslim population and their conditions or with your work and experiences.

R: I mean, I, I think the good thing is that there's definitely more awareness. I think we've seen even within our own clientele, that we have a lot more people seeking services, so that's a good thing. There's actually hope, right? I think that we definitely can't talk a lot about negative things and challenges. I think there's definitely hope, and I would say that that's, that's good. I mean, compared to how things were like seven years ago, a lot has changed - more people are seeking services, more people are aware, you know, there's more like premarital coaching happening. That was a rare phenomenon back in the day. Now, every other week, I'm doing someone's premarital coaching, So, I think there's definitely hope, and I would say that's probably the feedback that I want to give.

I: Great thank you. Do you think that that is because there's a diminished amount of stigma, or ignorance about the importance of mental health?

R: Yes, absolutely, absolutely. I mean that plays a role in and ties into the knowledge and awareness as well, right? So, with knowledge is awareness, with more knowledge and awareness comes less stigma. And I think that's definitely helpful.

I: Perfect thank you so much. The last thing I want to mention is that we would like to interview more providers as well as Muslims with ability differences or their caregivers. So if you know of someone we might contact, could share my name. Probably better my name and email address with them or and ask them to contact me. That would be helpful for our project we are trying to reach and speak with as many people as possible.

R: If you send me kind of a small blurb, just briefly describing what you're doing, not going into too much detail and then your contact information, I will forward that to some people I know. So, on the blurb, state that if you're interested, they can contact you by....

I: Super, I will definitely do that and also forward the survey. There is an anonymous survey for all people. It's on the AMWRRRI website and I'll send that with you in a follow up email. Thank you so much for your time and energy and sharing your experiences and your suggestions. You've been a tremendous help. And when we sponsor public events, we will be sure to invite you when the website is up and running. And hopefully with this project and the publications that come from it and the social community awareness, these things will inspire more resources to blossom and support the community.

R: Sounds good.