

Interviewer/Number of Interview: EG29

Date: 12/15/2020

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

Your Date of Birth: Information is not being made available. Respondent is in the range of 55-64 years old

Gender: Male

Country of Origin: Palestine

Immigration Date: Late 1970s

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 55-64 years old and immigrated to the U.S. from Palestine in the late 1970s. He is a husband and a father to several adult male and female children. One of his sons suffers from schizophrenia, which runs in his family. The interviewee shares many of the challenges that he and his family face, including financially funding his son, lack of success in getting his son to follow through with treatment, caring for not only his son but his son's wife who also has mental health issues, and family tension. He discussed the challenges he and his family face, which prevent them from socializing and being open in the Muslim community, as they fear the judgment and stigma that might come with the truth. He identified several key needs, such as: information on resources; emotional support; changes in the law regarding HIPPA and getting medical help for adult children with mental illness who don't want it; better education on the issue in the Muslim community; and more openness, understanding and sympathy from the Muslim community. The respondent also discussed his son's strengths, especially his big heart, sweet character, honesty, and commitment/compassion for his wife.

Key Themes:

Mental health; schizophrenia

Denial

Financial responsibility

Family stress; impacts on other children

Genetics and schizophrenia that runs in families

Community judgment within the Muslim community; stigma; community expectations
Secrecy about the mental health issue
Social and religious isolation
Lack of support in the Muslim community and people's ignorance about mental health issues
Marriageability of family members who have a relative with an emotional issue
Need info on resources
Severe difficulty getting help for adult child with mental health issues; HIPPA laws; legal issues regarding getting residential treatment when the child doesn't want it.

Transcript:

I: [Interviewer introduces herself.]

I: And what is your age?

R: [In the range of 55-64 yours old.]

I: Okay, and where were you born?

R: I was born in Palestine.

I: Palestine, okay. And when did you move to the U.S.?

R: [Late 1970s]

I: Okay and why did you move to the U.S. at that time?

R: For better opportunities; part of my family were here already. I just followed and you know for better opportunities, studying, and even better jobs and stuff like that.

I: Okay, of course yes. Were your or your family's health condition a factor in the immigration process?

R: No.

I: Okay, and how do you identify yourself in terms of national background?

R: I'm a Palestinian-American.

I: Okay, and what is the highest level of education that you've completed?

R: [High school degree and associate degree]

I: Okay, nice and what is your marital status?

R: I'm married.

I: And do you have any children?

R: [Respondent has several male and female children who are adults.]

I: Okay, great full household!

R: Yeah.

I: And do you currently work outside the home?

R: You, I'm self-employed.

I: Okay, and uh how-what would your title be? Or what uh occupation?

R: I own a supermarket; I also own a rental property.

I: And how many hours per week do you typically work?

R: Right now there is no set hours but not less than 50 hours every week right now.

I: Gotcha, alright busy. Alright, so the next set of questions focuses on the different types of differences of ability that you or the person you care for has, we are interested in the following types of differences of abilities- here is a list for you but I'll go through it so don't get overwhelmed with the list- it's physical, chronic illness, learning, intellectual, mental health, speech and language and addition. So...

R: Mental health.

I: Mental health and is that for you personally or someone else in your family?

R: My son.

I: Okay, and could you elaborate on your mental health status?

R: I'm doing great actually, I am in great shape. No issues whatsoever.

I: Okay good, and would you categorize your mental health as depression, or different- or what uh title would you give it?

R: I think I'm normal; sometimes when I deal with my son's illness and I have to deal with issues, I get down and depressed sometimes because I'm overwhelmed with responsibility. But other than that, I'm just a normal regular with ups and downs.

I: Yeah.

R: I think like everybody else.

I: Okay, and when you say your son's illness can you expand on that?

R: You know what I have a mental health son and I have been dealing with this illness actually for the last 20 years since when he was like 14, 13, 14 years old. When it started, we were thinking that he's just a rebel son. He didn't listen, follow directions, or do what's right -- always making bad choices in life and stuff like that and just fighting him on and trying to show him the right way, and what to do. Instead he's not listening, not doing it and then it just became obvious that it was a health issue when he was 15, a mental issue. And then I tried to set him up with a therapist; he went for 2-3 times and then he refused to go again. He has so many issues and many health stuff problems --you know, related to mental health.

I: Mhmm.

R: You know, his picking up bad choices, bad decisions and me always trying to bail him out because his bad decisions can get him a lot of trouble. A lot of times, it's just me coming in fixing things for him. I'm fighting him constantly – I don't mean physically fighting him. But you know, talking and trying to show him what's right and what's wrong. And he spends and wastes money, making bad decisions. It's just overwhelming, and especially puts a strain on my life and his mom's life, and his siblings. It's constant arguing and fighting verbally between us and him when he's making bad decisions. We try to tell him "This is bad; don't do this, don't do that; do that better" and him just not listening and just always making wrong choices and doing the wrong things in life. So that takes a toll on a family. Do you know what I'm saying?

I: Of course.

R: And you know sometimes it's depressing for me or his mom. And sometimes you want to make decisions with your heart or you want to make a decision with your mind. You know what I'm saying? It's just- you don't have the heart to let him- when he makes bad decisions just let him make that decision; let him affect himself and let him be surprised for making that decision, but in the back of your mind you can't because you're always thinking that his mental disease is what is making him do that. He's sick so you just can't say "I'm going to let him go for good then, you know, to hell with it."

I: Mhmm.

R: So you know, it's tough like that.

I: Mhmm.

R: For 20 yours it has taken a toll on anyone, you know what I'm saying?

I: Of course.

R: I mean at the same time, we're trying to not show it to the public and not facing the community with it; "nothing is wrong." You don't want to go out there and say "I have a sick son who is misbehaving or doing bad things or doing wrong things." Of course, you always have in the back of your mind what the community thinks, what the community is going to say. So you're just putting on a show that everything is dandy and it's good, you know. And you know behind the scenes, it's not, it's always a struggle.

I: Mhmm.

R: And financially, it's just overwhelming. When I was young I was making more, I was working harder but you get to the point where you know it's like I- if his- his illness and his decisions is not just affecting him it's affecting us and it's taking the family down with him, too.

I: Mhmm.

R: Especially mentally and physically, you know.

I: Of course yes.

R: Okay.

I: Did he ever receive any of diagnosis about his mental health state? Any?

R: You know what I always had uh had a hard time- we always fought him take him to doctors, so many doctors we took him, so many uh hospitals. You know uh the thing is that is hard for him to follow up.

I: Mhmm.

R: Because he-the doctor give him an appointment one, two and three and he would keep missing it for three, four, five sometimes six months before he decide to go to- and I am always trying to push him but you know he's a young man you cannot force him to do what he doesn't want to do. You know what I'm saying?

I: Yes.

R: So sometimes it takes six, seven months for him to go and see a doctor. Diagnosis I honestly don't know because he refused to let me go and speak to the doctors. Okay, he won't give me permission. I don't know exactly but it's like anxiety, uh bipolar. What is it called? You know, when he's always thinking untrue things, that people are out to get him and..

I: Oh, schizophrenia?

R: Yes.

I: Okay, gotcha.

R: Because we have-I have [siblings] with that disease too- condition. [Respondent described others in his extended family who have schizophrenia, and it goes back to previous generations.]

I: Okay. I'm going to move on with questions but we'll kind of go back and touch on that in a couple minutes. What is the current living arrangement with uh your son? Does he live at home? Does he have his own place?

R: No he has his own place right now. I mean he's been out and in, he's living with his wife and that's one of the main things, too. His wife is sick, too, and needs help herself, and he's not capable of taking care of himself. But you know, it makes it harder for us to guide him because she's in the picture, she's a liability and he's not able to take care of himself, and he brought another loss to him -- another responsibility on himself to try and help. His wife is sick and she needs help. So that makes the situation even a lot worse than it is, for us and for him you know.

I: Mhmm, yes.

R: But, he's living on his own right now; but I'm paying -- I'm helping them out financially you know.

I: Okay, gotcha.

R: Like I-I gave them last month almost like 2,000 dollars you know.

I: That's a lot on you as well.

R: Yeah.

I: Do they have any children or not at this time?

R: No, no.

I: Okay, gotcha and uhm you talked a little bit about how uh this mental health has been present in him since a young age. Is there any timeline, other than what you kind of gave me that you could describe?

R: You know what, even when he was 10 and 11 he uh always missed -- he never found direction. You understand what I'm saying? It's hard for him to concentrate and stick with one agenda. Because one day he'd want to do this -- or you know, he'd do good on one thing and he'd do it for a week, two weeks, three or four and then he'd get bored and be done with it and move on, and start misbehaving again.

I: Mhmm.

R: All his life we always struggled, starting when he was 10 and 11 you know.

I: Mhmm.

R: Him not following directions, not listening, not you know doing what parents- what your parents ask you to do and in the back of our mind, but I had experienced it with my brother..

I: Mhmm.

R: But we would always -- in the back of my mind, it was like I knew there was something wrong, but it's like we were in denial.

I: Yeah.

R: My wife and I don't want to believe that our son has a disease, or he's gonna be sick, you know. But it's like it's a taboo. We don't want to label him at a young age, you see, because we forget that you know we say he's sick and go to doctors and take medication that it's going to affect his life growing up and his chances in the community -- chances of jobs or finding another wife, you know. So that you know it's really hard on him. So it was like we were in denial you know.

I: Of course. You mentioned genetics potentially playing a role in your son's mental health status. Do you think there are any other factors, maybe including traumatic experiences that might have contributed to his mental health?

R: You know what I'm thinking is that it's genetic. I mean it's in there.

I: Mhmm.

R: Where-where the DNA is in you not insulated or strong enough with your DNA from being in a traumatic experience that will make it worse on someone who's that don't have their DNA with that disease.

I: Mhmm.

R: Because if they encounter any traumatic experiences in their life will not affect them as much if you have that DNA in you. You understand what I'm saying?

I: Yes.

R: This is my conclusion but I mean every child, I mean I sit with them -- I sit with him and try to see what traumatic experience they might have had. And sometimes it's like, I don't know, sometimes you know, do you blame yourself?

I: Mhmm.

R: Just like maybe you didn't handle it well, with him misbehaving, or maybe I was tough more than you know and didn't understand that it wasn't him. It's always thinking that he's bad and misbehaving and understand that maybe that's what it is -- maybe that part of him is his disease and that's what's making him being bad or making wrong decisions or stuff like that. And sometimes, as a parent, no matter what you always think you did things wrong, you always question yourself and your judgment. You know what I'm saying?

I: Mhmm. You as a parent.

R: You start blaming yourself for part of that, but I think the DNA has a big part to do with it you know.

I: Yes, gotcha.

R: But I have my other kids. They're fine and they were raised in the same house, with the same parents, with the same rules, other than them being affected and my wife and me because of his issues. Do you understand me? The fighting and the arguing, you know.

I: Yeah. Okay so this next set of questions focuses on perceptions about people with differences of abilities and experiences of prejudice or discrimination. So, the first question is do you think the Muslim community is more critical of disabilities that are visible, like amputations or things that you physically can see, or more critical of disabilities you can't see like mental health?

R: I think they're more critical of mental health issues and disabilities that they don't see and they don't understand. They're not exposed to them, and it's like a taboo for families to talk about it between themselves and put it out there in the open. I mean I think the community is more sympathetic to physical disabilities.

I: Okay.

R: It's one of the hardest things to understand and for us to deal with mental health issues when you have it in your kids. You want to talk to people and get feedback and help and stuff like --

but always in the back of your mind, you don't want to be labeled as that family with that mentally sick child.

I: Mhmm.

R: But there is the DNA in that family. I hate to say it in the community and this is bad. In the Muslim community, if one of the children has a mental disease, I think it will affect the perceptions in the community. It will affect the rest of the families, the girls and the boys: "Oh like don't go marry" you know "in that family or one of those daughters or the boys because that family has a mental issue and their kid" you know "their kids are going to have mental issues" and so on and so on. So that issue is always in the back of your mind, where you want to hide it and keep it under the rug where you don't want to expose it out there to the community. And this is all lack of knowledge, lack of people talking about it in the community.

I: Mhmm.

R: About the lack of someone to have the courage to go up there and address it and address the issues and be open about it. Who is going to take that first step -- to go out there and explain it to the people, and say that anyone could have this disease? I'm sure lots of people in the community are out there being affected.

I: Of course.

R: And go about with this disease, and no one knows about it.

I: Mhmm. Who do you think should take that first step? Who do you think that falls on?

R: That is the reason for my doing this interview. I always thought about doing it in the back of my mind. How can I help? How can this change? What can I do? And I always thought about ways to get it out there. And even sometimes I wanted to go to the Imam and ask him if he'd give me the chance to be on stage and explain it to people and talk about it in front of the community and tell them "this disease is out there, we have to be open about it, we have to talk about it, we have to find ways where.." I always struggle where to get the resources or the help I needed or the advice how to deal with it; I'm always scared to go and talk to people about it, you know. I just didn't know where to start or how to do it, do you understand me?

I: Mhmm.

R: I think the leaders around our community, the families that are being affected about this, they need to go out there and reach out and find a way where we get this issue addressed in the community. This way it will make it easier on the person with the disability.

I: Mhmm.

R: Live with it and not be ashamed of it and the family themselves. Where it makes it easier for them to get the help they need and the support they need from the community and from other resources you know, where they don't think it's a shame on them to have a mentally sick child and you know to go out and ask for help, you know.

I: Mhmm, you. That is ideally what our project is hopefully going to help with.

R: And this is the reason why I am putting it all out there, you know.

I: You know we appreciate that.

R: And help this way -- maybe this is the first step.

I: Mhmm, you for sure. Let me flip the page here. Given your experience with the community's perception, the Muslim community, is there any impact on your willingness to be in public situations with your son or maybe fear about a stigma or anything like that?

R: Yes, yes, yes.

I: Okay.

R: Because you know the way my son is, right now his life is [unintelligible]. What he's doing -- his looks -- it matters so much to people and to us, and I hate to say it. Where sometimes I mean it's like he's disheveled or not taking care of himself, where I don't want him to be seen in public. And you know it's a terrible to say, the way he is now, because people are not going to think -- especially people who don't understand what the mental disease is -- that [my son] has a mental issue and that's the reason he's looking like that or that his hair is not cut or his beard is not shaved or the way he's dressed. [Instead], they're going to judge you for his being a "bad person" -- "as a parent, you didn't do a good job."

They don't understand what mental issues are, why the reason he is the way he is because there is a mental issue. There's a disease, there is dysfunction in his brain system or in his mechanical system -- that's what's making him choose wrong things.

I: Mhmm.

R: Again, and that stigma is why I don't want to be out there with my son, showing him to our -- to my -- community because I think it puts a shame on me. They're going to shame me for it, or their going to look down on me for it, or they're going to look down at my son. But at the same time, I love my son. It breaks my heart for me to be like that.

I: Mhmm.

R: It makes me cry so many times -- who I am because I am ashamed of my own son in public, you know. Otherwise, I understand the disease; I love my son, and I give him so much. But [for many years] it affects me financially and mentally, but I'm there for him, you know.

I: Mhmm.

R: I'm fighting for him.

I: Yes, of course.

R: Get him on the right path and you know get right treatment and do right, but sometime it's-it's you know, I just don't want him to be out there in the community where they're going to laugh at

him or look down on him, or say something is wrong with him and stuff like that. So it does affect us.

I: Yes, of course. Would you say that the Muslim community is more critical, in comparison to the greater U.S. society?

R: Uh I think so, yes.

I: Okay, do you feel more comfortable in public in the general community rather than the Muslim community?

R: You know it's the same, but I feel the general community is less judgmental.

I: Okay do you think that's partially because those people might- are not part of your Muslim community and might not share that with other people?

R: Yes, I think that's it.

I: Okay. From your experience, do you think that the Muslim community has any expectations of you as his father caring for him and kind of guiding him through this process of mental health?

R: Yeah, yeah. You know, what it's like is they judge without them understanding the full picture.

I: Mhmm.

R: It's like you know what it's like in the beginning him and his wife okay- I mean my son I try to bring my son in but his wife is just- I don't think it's fair for him and you know he's mentally ill..

I: Mhmm.

R: And it's costing me so much mentally, physically and financially, for him to go and bring in someone else, another child.

I: Mhmm.

R: Another family's person and put her weight on me and his mom. Where we are supposed to support her and take care of her, too? Do you get what I'm saying?

I: Mhmm.

R: If you're not capable of taking care of your own self and if you're mentally ill and if you need help yourself, why would you go and bring another person or wife that is mentally sick. She's incapable of taking care and you're not capable of taking care of her and yourself. I thought it's not fair. But I get this sense from some people in the Muslim community that it's your child and his wife, and you need to bring them into your household and take care of them and make them live with you. And you know they don't understand that if you do that, they're [son and his wife] aren't going to listen to you and they're not going to follow direction, and they're just going to

misbehave. It's not that you're not helping them -- that it's going to affect your lifestyle, make you, your wife and other kids live and walk on eggshells.

I: Mhmm.

R: Where you're always scared what's going to happen the next minute or watch what I'm saying?

I: Yeah.

R: It's going to destroy the whole complete household, for you sacrificing for them. You know, and it's not going to make a difference, it's not going to change, it's not going to get better. And I did that -- and it's like the community's response is "Oh, you're in charge, you're supposed to do that." But you know, sometimes I came to the point where I need to sacrifice one son. Let go. Or I'm going to take down the whole family -- my other kids, myself and my wife -- to destruction.

I: Mhmm.

R: And I let him go live on his own, so I said I better help financially and be there and help him to get his own place, rather than having him live in our house 24/7. And after that I even-I feel so bad I brought him and his wife into our household to live with us. I, my wife and his siblings decided that we're going to give them a chance -- were giving them a chance to build their life, a place with no responsibility, no bills, no expenses you know eat, sleep, eat free food. You know what I'm saying?

I: Mhmm.

R: For them to at least have them under our roof where we tell him to go to the doctor, take your medicine, take this and that and don't forget that. We thought it would work. It worked for like a week or two weeks, and they start giving us hell.

I: Mhmm.

R: What their suspicions were you know -- they think that we are talking about them, that we are spying on them. We're this and that, because of their disease. You know what I'm saying?

I: Mhmm.

R: It started driving us crazy and I had to put him out there again. I had to try to give them some financial support; they are unable to go out there and get their own place and help. I don't know, I think the community thinks that if your son is out there in the streets or on his own and he's not looking well and this and that, that you're a bad parent for letting that happen. But they don't understand that you know that you tried your heart out -- you tried every other option that is available to you to help and set him straight, but he refused; he chose the lifestyle that he wanted. And it's not because you're bad or you don't care -- because sometimes I and my wife we cry. I mean, when he's out there, we cry. When it's our son out there and he's not eating, he's not sleeping in a clean place or he's not being well, do you understand me? It affects us!

I: Yes.

R: You know, but sometimes you just have to sacrifice one for the sake of the other. You know what I'm saying?

I: You can't enable them either, it's a hard balance. For his wife, is she part of the Muslim community as well?

R: No, no she's not.

I: Okay.

R: White American. And I think -- I mean my son is sick, I'm sure. But I think 70% of the issue of the problem where my son is not being able to get the help he deserves and the help he needs and the things he needs is because she's in the picture.

I: Mhmm.

R: Okay, because if she wasn't in the picture that would make life a lot easier on him, for him to be with us here. And for him to listen to our ways and we tell him go to the doctor, take medicine or do this do that but she's a bad influence on him. At the same time, with his disease, I can't blame her for the whole thing.

I: Yeah.

R: And-and then she's like a liability on his life.

I: Mhmm.

R: They have to get a better life than the one he's living right now.

I: Gotcha and do you think she also has the same mental health problems as him?

R: Yeah, yeah, yeah. Even her own family doesn't want her, you know what I'm saying?

I: Oh okay.

R: It's like- because I tell him "[son's nickname] you know let-let- you know come over more, come back home, let her wife go by her family you know for a few months. We'll get you started, get you treated for your disease, and get you help".

I: Mhmm.

R: "Less-less stressed out or worried about your next dollar or where your meal is going to come from. Where you know we'll treat you and send you to the doctor and duh duh duh duh this and that but listen" and he said "No. I will not do that. I will not let my wife be on the street because her family don't want her. I will not -- I will sacrifice myself, my life. I'd rather be on the street with her than just me coming home and letting [son's wife's name] be out there." But I tell him "You know you're your first responsibility -- because if you don't fix yourself and you don't help yourself, you're not going to be able to be any help to her."

I: Exactly.

R: Do you understand? “So instead of you sacrificing both of yourselves, you need to save yourself for you to be able to save someone else first you know.” But he won’t listen.

I: You, that’s a hard place to be in. Uhm so okay. So the next group of questions focuses on the challenges that you have faced with issues we’ve been discussing, and we’ve touched on a lot of them already. So we will just kind of go through the list kind of one by one. Uhm so the first challenge is being stretched too thin. Do you feel like that is something that applies to you?

R: Yes.

I: Okay.

R: Yes.

I: Uhm would you say that it’s in regard to time and energy, your household.

R: Time-time and energy. Financially.

I: Mhmm.

R: Uh you know it’s like sometimes being depressed and you know it’s affecting my other kids. Because always our mind -- me and my wife -- is on that child, where sometimes we ignore our other kids’ accomplishments or being there and being handy for them.

I: Mhmm.

R: And I-so it-it’s a lot and financially I mean you know I spent so much money on you know trying to get his life started where you know, in the end, it affected me so much.

I: Mhmm.

R: [Respondent disclosed the hefty sum that he has spent on his child over the last few months, and what he has spent it on.]

I: Is your son currently working or able to hold a job at all?

R: He worked [in a part-time, sporadic job]. Sometimes he’s able to work and sometimes he’s not -- like it’s on and off. And the thing is, sometimes he works and he’s making money but it’s just a bad leg of the bad-bad decision he made.

I: Hmm.

R: With his money, he lacks management. It’s like, if I have \$200, what’s most important? But he spends \$30, \$40 on take-out food and his phone bill is due and it’s going to expire. But he needs that phone for his work, or where his car insurance bill is due and he put that off and buys a t.v. or buys a game. You understand what I’m saying?

I: Yeah.

R: I throw so much money at him, always trying to bail him out and this and that and it all ends up doing nothing; it's just always bad decision, bad decision, bad decision.

I: Mhmm.

R: He has lack of control and management, what to do. What's the right thing to do, it's like you know and it's like. You understand what I'm saying?

I: Yeah.

R: And I think this is part of his disease too.

I: Of course. You talked a little bit about getting treatment and medical care. Do you think there are insufficient resources, or information, or quality of care or more just his lack of ability to follow through with care?

R: I think it's the lack of his ability to follow care.

I: Okay okay gotcha, but do-you do feel..

R: It's hard- it's hard to get the help.

I: Yup.

R: It's not easy, resources out there.

I: Okay.

R: If you are able and you know you can get it you can find it but the thing is with his disease and lack of ability to follow and see you know and go to the doctor appointment and you know find a place where he needs to get help or you- find a place where he can get medication and it's- it's like both combination all together I think.

I: Mhmm, gotcha okay. Alright, so to deal with these challenges what are some of the strategies that you've used that have worked, if any?

R: Uh so far nothing (R and I laugh).

I: Okay, gotcha.

R: I'm sorry (R laughs).

I: Okay what about for your own wellbeing, is there anything?

R: I tried, I tried so many ways, so many things. I tried to you know to give, to throw money at him.

I: Mhmm.

R: To get him setup, two or three time, I'd get him a new apartment or money uh I've given him a car, I give him a place to stay- I pay his debt whatever he owes...

I: Hmm.

R: To get him to start from zero.

I: Yeah.

R: You know and uh it didn't do good. In the end it stopped being- where he started- and I tried to cut him off where I completely cut him off and you know that's it where I hoped (R clears throat) that maybe me cutting him off would you know uhh- where he's gonna learn, he's gonna get so much on the street that he's gonna relent and follow my ways and listen to me when I tell him go to the doctor or listen to me when I say you know do this or do that and uh it got to the point where one time he was going to be on the street..

I: Mhmm.

R: And he you know he won't listen- he won't listen he- but me and my wife- I guess it's like you know I guess maybe we failed where we couldn't -we couldn't live with our son on the street. You understand what I'm saying?

I: Yeah, mhmm.

R: You know it's like even if it's like no matter what we-we just wanted- couldn't let it happen. So I-I – and we try and take you know accept his wife or- for what she is and be there for her as another family, but it didn't work- it didn't work. None of those things- I tried so many ways, so many things and none of those worked- none of them would work until now.

I: Hmm, okay.

R: So I-I-I got to the point where now I just take it one day at a time. I just don't know whether- what's going to happen the next day.

I: Gotcha and you talked about how it has affected your family and your marriage. Is there anything else you can share about how that has impacted your family as a whole?

R: (R sighs) You know what I mean; it's in public when me and my wife go out into the community. We look at other families and other kids, where when we are so depressed and down where me and my wife we just don't want to be in the community because then you have to socialize.

I: Mhmm.

R: You understand what I'm saying?

I: Yes.

R: You have to socialize and talk and this and that, and in the back of our mind 24/7 is our son. It's like we're a failure, he's a failure. Like you know, we have a son like that and you know we-we couldn't be comfortable in the community or socializing.

I: Mhmm.

R: And the same thing with our kids. They've seen us sad. And they go off and say to us "let him go -- just throw him out." In a way, it affected them and when I brought him and his wife to live with us for a month or two, you know my other kids don't want to come and visit no more, do you understand?

I: Mhmm.

R: They don't want to come and visit. They don't want to be around him; they get depressed you know. They see us depressed then they get depressed. They're not happy and one of my children was living with us here and said "I cannot live with this. You know I'm always scared about what they're gonna do and what they're gonna do next. I'm gonna leave." So it got to the point where we're going to sacrifice the whole family or sacrifice one person. You know, it affected us in so many other ways. My other kids -- thank god for each one of them -- they all have college degrees and all of them are holding their own jobs, their own households. You know what I'm saying?

I: Yeah.

R: But I thought, now it's like me and my wife should be able to slow down, after years of working and taking responsibility; and I thought we'd be able to travel and do this and that or move somewhere else. Now it's like we can't because he's always in the picture.

If we move away, who's going to take care of him, who's going to be there for him, whose going to do this and do that? So it has changed our plans for our old age you know. Think you're going to retire or slow down or this and that but now he's in the picture. It seems like this would never happen to us. [He discussed the financial impacts of taking care of his son and how that has affected his and his wife's future.]

When you're a family, a lot of people don't understand that when there is a disease, it's like a tree. A branch of a tree gets affected, the whole tree gets affected. It's the same thing with this disease. The whole family-I-I- you know I hate to say that a lot of people out there don't understand you know they judge you, they think you're a failure, they think you did something wrong, they think you didn't raise your kids well. You know what I'm saying? So that's a burden too you know.

I: Yes, yes.

R: And you know there's that fear where you know you don't want to put your feelings out there in the community or to show weakness or to show- you know what I'm saying?

I: Mhmm.

R: We have to put on that happy face, and you know strong will and this and that you know.

I: Mhmm, mhmm (R sighs) you. Umm a- next question would be do you think it's harder for females or harder for males who have a disability within the Muslim community?

R: Is it harder for females or males you mean?

I: Yes...within the Muslim community specifically?

R: I-I-you know what I think- I don't know- I think it's equal actually.

I: Okay.

R: I mean to me at least, that's how I think.

I: No that's totally fine. Uhm you uh do you-how do you feel, if there is any difference, uhm feel free to share your own opinion about marriageability for males versus females with a disability, how that impacts that?

R: You know when it comes to- I mean to me I think it makes it a lot easier.

I: Okay.

R: Then a female.

I: Mhmm.

R: But I mean, I think it's-it's equal, I mean it's a stigma where for both a female or for a male it's in- you know what I'm saying?

I: Of course.

R: I think it's a little bit easier for a male if he has a disease than for him to find someone to marry than a female is and not much different, I think.

I: Okay.

R: But I think-I think a female with a mental disease uh in the Muslim community not-not now with this young generation I think, I think it's a little bit better now.

I: Yes.

R: For the kids that are living in this country.

I: Mhmm.

R: But you know they're more intelligent, they're more open to social media and this and that, you understand what I'm saying?

I: Yes, you.

R: Especially- and before it's like where the marriage is like between families, they fix it, you know what I'm saying?

I: Yeah, arranged.

R: Now a lot of these girls and boys are marrying themselves.

I: Mhmm.

R: In colleges, in the work place, they're meeting people. Especially for females, when she meets someone and they fall in love, I think they tend to forget about other issues, like oh she's a little bit mentally sick. [With arranged marriages,] if I have a daughter who is ready for marriage but she has a mental issue then the boy's parents would never take their son and go to a family with a mentally ill girl.

I: Mhmm.

R: So you know to ask for her hand for your son, there are zero chances of that. Some families mainly now make it a lot easier I think. There are better chances because the girls and the boys found each other. You know what I mean? They're finding their own mates now. But I think maybe there's a little less chance for girls -- you know, a better chance for a male than a female.

I: Okay.

R: On the scale a little bit more challenging for her.

I: Gotcha. The next question is what are things that you would tell healthcare providers who are treating Muslim patients especially with mental health issues? What would you like them to know so that they can be culturally competent?

R: ...I don't know, I don't know that's the million-dollar question. What would I tell them?

I: You, maybe for them to better understand your community?

R: I think uh because it's like -- uh I don't know- you I think they have to have some understanding of the community, of the culture too.

I: Mhmm.

R: Because you know to understand where I- you know I sent my son when he was 14-15 to therapy.

I: Mhmm.

R: His therapist was a white American lady and you know he come to me and is like- she made judgment from just listening to him, she didn't try to uh- you know if you know if you tell him I want to do this or you know I wanna smoke weed it's like oh if that's what you want it's fine cause you're old enough where you have the choice to make your own choices. If that's what makes you happy then go ahead and do it, don't listen to your father. Do you understand? They give the choice to sick people to make their own choices and it's fine if that make them happy, even if it's wrong. So, do you understand what I'm saying?

I: You there's a balance there.

R: It's like they don't try and take feedback. From the parents, what the real issue is, what is right and what is wrong and there is always- when you know you're over age, I think consent age where you know you cannot share with the parents what going on. I think that makes it so hard for the person to get the right health providers; they're not listening to the other stories, to the parents' stories. You know what I'm saying?

I: Mhmm.

R: They need to get the full picture of that child who is sick -- why he has that disease and what's wrong and what's the right way and the right path to treat him. And that's a big liability because you know it's like sometimes I had issues- I wanted to get my son committed to a hospital, right?

I: Mhmm.

R: And he wouldn't listen but I knew he's breaking down. And he needed help. But he couldn't be forced to get it. The law here in this country is you can't force someone. If someone wants to be on the street and hungry and this and this, that's their choice. You understand what I'm saying?

I: Yeah.

R: But someone needs to talk about these laws and to change them so that it is right for the providers or doctors to be able to discuss with that child's or man's parents so that they understand the full picture, and to do that without the adult child's consent.

I: Mhmm yes, that does make it a little muddy (of a) situation.

R: Yes and it makes it hard if you wanted to go to court, you have to take control, it's hard to prove.

I: Yeah.

R: For a judge to approve for your son to go to a hospital, you know usually 10% chance that he will approve that. And I've tried, and I've been there.

I: Mhmm, gotcha. Throughout this interview you talked about your experience with other relatives who have mental health problems as well. Could you explain their kind of journey and where they are now with their mental health?

R: [The respondent described the journeys of some of relatives with schizophrenia.]

I: Gotcha. One of the questions I wanted to ask you is what kind of supports or people have you been able to reach out to, and how that has kind of worked for you and your family?

R: No one (R laughs), no one I went to support to- go to support to.

I: Okay, do you look internally within your family for support?

R: I look for- well internally my wife.

I: Okay, gotcha.

R: (R laughs) I hate to say that, it's just me and my wife.

If you look at other families, I'm sure each family has their own issue they have to deal with and it's like you listen and I mean you- they listen to you and they sympathize with you but at the end of the day it's like when you-they just move on you know what I'm saying?

I: You.

R: Not much support there. I tried one time to reach out to uh you know- an organization- a Muslim organization to get help for my son.

I: Mhmm.

R: I called- I mean you know- I called them and I talked to someone and they were supposed to call me back, nobody called back about that I called this and that so. There-there, I hate to say it, in the Muslim community when it comes to mental issues I-I-there is no support system out there for families to go to or be able to talk to, this and that. But to ask for how-ways to get more help, resources for your child, you know for your sick child or other family member. I hate to say it but there is nothing out there where you're able to go to, you know.

I: Okay. Is there anything, as we kind of conclude this interview, is there anything else you would like to share about your experiences or kind of hopes that you have?

R: You know what I hope? I hope that people -- families and the community -- are able to talk about this mental issue with openness, with understanding, and with sympathy.

I: Mhmm.

R: Understand that it's not about putting a liability on your family. People need to understand and be taught about mental health issues. When someone does bad stuff or makes bad choices, sometimes it's not that person, and it's not a bad person. My son has the biggest heart in the world, you know what I'm saying?

I: Mhmm.

R: He's so honest, even with his disease and mental issues; he's the sweetest kid there is. I mean he's willing to sacrifice his life, be on the street just not to abandon a needy person and he's in need himself. You understand what I'm saying?

I: Yeah.

R: A lot of people don't understand that. I wish people would understand mental issues: what it is and where the community is able to sit down and have that talk, and talk to each other. We need support systems and organizations where you're able to get the help you need, where there's a community organizer who can show you and be there and support you and a place where you can find out about resources and how to get the help you need. You know? That's my biggest wish -- I wish we were able to do that.

I: Yeah, okay.

R: And look into medically where we able to find organizations to get someone who, with these medical profilers or doctors, would study the DNA issues. Are these mental issues related to the DNA? Or is it just experiences these kids have had?

I: Mhmm.

R: All their life what they become sick or is it just you know in the family move on from one father to son, from father to son? Or is it maybe- sometimes I wonder is it because we were raised in a mentally you know challenging uh father and brothers where it affected us and when we raise our kids we affected our kids and that's why it keeps on moving from one generation to another? Do you understand what I'm saying?

I: Yeah.

R: Someone to do a study. Try and understand what's the problem, what is the issue, what's the reason of this keep happening.

I: Yes. Find some more answers, for sure. Anything else?

R: No.

I: Okay.