Interviewer/Number of Interview: MG08 Date: February 4, 2018 Name: Anonymous Year of Birth: 1975 Gender: Female Country of Origin: Palestine Year of Immigration: 1991

## Abstract:

This individual, a female from Palestine, who lived in Jordan for 10 years before migrating to the United States in 1991. She is currently caring for a family member, her son, with mental illness, specifically depression and schizophrenia. Her family has been unable to provide proper care for this individual because he is refusing care. He currently lives at home with the interviewee. She discusses her own coping mechanisms as a caregiver and the social effects of her son's illness on her, her family, and his future. She also speaks about the stigma surrounding disabilities and mental illness.

Key Themes: Mental health, mental illness, depression, schizophrenia, mental health stigmatization, caring for a family member with mental illness

I: So I will just begin by asking just a little bit of background information about you, so your name, your age, and the place you were born?

R: My name is \_\_\_\_\_ and I was born in Palestine and I am forty-four.

I: Okay. Since you were born in Palestine, when did you move to the United States?

R: Um, 1991.

I: And what was your reasoning for moving to the United States?

R: First of all, because of the political situation in Palestine, we lived under occupation. I got married and moved to Jordan where I lived for 10 years before migrating to the US. There were no job opportunities for me or my husband, we moved first to Jordan but then decided to come to the US.

I: So how far were you in your education when you moved to the United States?

R: I finished my undergrad.

I: Okay. So when you moved to the United States, where was the rest of your family? Did your parents move with you, or just your husband?

R: From my husband's family, only my husband. They stayed in Palestine, some also in Jordan. From my family's side, I have some family members here, a brother and sister. My parents stayed in Palestine.

I: So when you moved to the United States, did you move right to Milwaukee?

R: Yes.

I: And what was your reasoning for moving here?

R: Because my husband had some relatives here and he wanted to join them.

I: How many siblings do you have?

R: I have three brothers and one sister.

I: Are they all still in Milwaukee?

R: No, I only have one brother lives in Milwaukee.

I: So, how do you define yourself in terms of a national background? Do you consider yourself

- American or Palestinian or both?
- R: In terms of national background, I identify myself as Arab, Palestinian, and American.
- I: What is your marital status?
- R: I'm married.
- I: And how many children do you have?
- R: I have three sons and two daughters.
- I: And what are their ages?
- R: My daughters is 29 and 27, my sons 24, 25 and 18.
- I: Are they all relatively near to Milwaukee?

R: My daughter lives in another state and two of my sons live with me.

I: And do you currently work outside the home?

R: I do.

I: So to better understand your situation, are there any differences in abilities that you have or someone in your family has?

R: Yes, I have a family member who has a disability. And I have relatives who have children with disabilities.

I: Would you consider yourself the main caretaker?

R: Me and my husband.

I: And is this difference in ability for your family member physical, mental, or emotional?

R: Mental.

I: And what are the living arrangements for the person you care for?

R: He lives with us. And unfortunately he is refusing to get any treatment. And we tried a lot of things to do, but we feel like we're at the end of the tunnel.

I: How would you describe the disability?

R: We think he has schizophrenia.

I: And when did this begin?

R: It began in 2015. When his condition started. But it started, when he was in high school, he had kind of depression and we didn't know what was going on so we sent him to a psychologist, and for a while, they said that there was nothing wrong with him and that he was okay, it was just his teenage years and he would grow out of that. So, yeah.

I: So, where there any factors that he or the psychiatrist has explained that may have led to this? R: So he was a great student, however, the last year in middle school he started experiencing a lot of discrimination from his fellow students as well as his teachers in the school. this period was after after September 11. The following years in high school, he struggled with school and also with his relations with us, his family. We were still not sure what is going on and thought he just going though his teen years and things will get better. he was trying to nivigate and form his identity as an American, Arab, Palestinian, Muslim, and non-white.

I: Okay. So, first of all, I am so sorry to hear about that. As a mother it must be so hard to see your child going through that type of thing. When did you see that evolution to the depressive state to his schizophrenic state? And just to contextualize, he was in middle school and high school in the early 2000s?

R: Yeah so in high school he started to skip school and he became 18 when he was in last year high school so this also make him not share with us things and the school would not share with

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us when he skipped school because he was 18. He struggled the last year but he did finish high school with a lot of struggle. And then we were thinking that it's also identity issues, because he is known as an Arab and a muslim and for him he was unable to navigate this kind of identity, so he wanted to detach himself from this identity to be more American and associate himself with friends who are known as his core, and dress in a way that expresses these teenage years. And listen to rock and roll, heavy metal, and feel more gothic in his way of dress. But he was still reading a lot and writing a lot during these years as well. He started going to college but unfortunately we didn't know what he was going through and that he is developing something like that. And I did not think he is developing mental illness. We started to feel like we had failed as parents in raising him. And we were so disappointed and we had tried best to give him everything we can. And our expectation for him was a lot. But I guess one of the things was he got into a lot of trouble because of the way he feels and the group he associated with. And I know now there is a correlation between drugs and mental illness, and he started using. And we thought he was a bad boy, and he is taking bad decisions because he is old enough to be making good decisions but he is doing this, and he is betraying us as parents. So in 2014 he moved to out of state, and we thought this was good for him, like a better environment and things like that. And he stayed where he was for a while and he was doing well. But all the sudden, he came back, as his mental condition deteriorated. We tried to convince him to seek help, we tried a lot of things, we even got a court order, but the system also failed us. Because he is over 18, he has rights and we cannot force him, and we are in a circle with the legal situation, with how much as parents we can do.

I: So right now, is he using any drug, prescription or non prescription, and is he facing addiction or anything?

R: No, so he was using, but now he is living with us and he doesn't have a job so he doesn't have money or a car so he doesn't even really leave the house. So he is clean, he used to smoke cigarettes and now he does not even smoke cigarettes, so I would say he is clean, but I am not sure for how long this will last. He is refusing to take medication, I think this is part of his condition, he thinks that medicine is poison, he doesn't trust the medical institution or medical health system.

I: And he is refusing to see a psychiatrist or therapist as well?

R: Yes we tried. We tried to bring a therapist home to talk to him and we asked the county to come and they've sent us two people a few weeks ago. And they asked him if they can come back because they are trained to deal with that situation but he said no. So we are trying to convince him to do this but at this point, I don't know. I know he has to go all the way down, as some people tell me, to get better, like hit rock bottom.

I: How has it impacted your family, like your other sons that live at home and your husband? R: Yeah, my other sons are trying to deal with it the best they can. He is the older brother and they have always looked up to their older brother, but they also keep themselves busy with work, writing, going to the games and stuff like that.

I: Good. So in focusing on the prejudice or the discrimination he faces, how does the Muslim community perceive his differences in ability or mental illness? Have you been able to talk to anyone in your family about this?

R: I am not open to this from even my own family because, for my own family, there is a blaming game usually in these situations. And there is also secrecy, and I am apart of this too. But there is secrecy. And I know our society and our community in general does not accept these issues. And I know overseas they keep it secret too. There is a self-denial in families when a

family member is suffering from mental condition including depression. In many cases that I know, families just refuse to admit or tell the rest of family members.

I: I was going to ask, so you didn't know?

R: No, and if I was told that this is the situation, that he was at some kind of risk, maybe I would rethink a lot of things and help my son deal with the other kind of discrimination he faced as a student after September 11. but the thing is I didn't know about the schizophrenia. I was not familiar with schizophrenia or what schizophrenia was. So our community, especially if it is something visible, no one can hide it. So if my son is paralysed, that's it. Everyone knows. And I would be very open about it and I would deal with it and the community would deal with it. And I don't think the community views all disabilities in the same way. I think mental illness is more stigmatized than, for example, physical disabilities.

I: Yes, really outside of the Muslim community, anywhere in the United States it is stigmatized. R: Yes, so it's the same thing. but the thing is also the judgement, and the implication of what is going on in this family on the other members of the family, because they will judge the other members of the family. it's like corporate punishment. You know what I mean? if one has a mental illness, then maybe the whole family has one too. So yeah we are not open to it to talk about it and address it and start talking about it. How can we make the family who is suffering with these things feel included in the community and feel supported by the community, etcetera etcetera. So if it is a female suffering from depression, they will be hiding that and not seek help because of the stigma and because they think they won't be able to find a marriage partner or something like that. So from my own experience and from the people I know that have members, like a mother of four kids and her sister is suffering from mental health conditions, and she cannot talk about this. She talks about it with me but she does not really talk about it because she

is scared about the other implications, that it will affect other family members.

I: So would you describe the discrimination within the Muslim community worse than even just the general American community?

R: I will not address it as discrimination, I will address it as a stigma that is culturally structured. Especially among the immigrant generation. And I say the immigrant generation because the second generation now is more open to talking about it and everything but the immigrant generation, you know, brought their cultural baggage from back home with them. That is why I say things may get better in a generation or so, but for now, it is more of a stigma and ignorance. Like ill-treatment of the situation. And since every family wanted to be cleared from something like that, so they are judgemental on others who have this situation.

I: Given the mental illnesses of your son, and the community's perception, whether it is Muslims or just the general American or Arab community, are there any impacts on your willingness to maybe go out in public with your son or have people over to your home?

R: When there is a community wedding or family or related family member's wedding or function, I try my best to take him if he agrees. And I will be very cautious of the way he talks and how he acts and about him getting into, because he doesn't feel comfortable with people asking him questions, like what are you doing. I mean he's 25 years old and he still hasn't finished college and he can't keep a job. All of that. And that is why he avoids people and also for me I want him to interact, and he needs to learn how to interact when he agrees to take medication and seek help. But for me I avoid going to places sometimes so I don't leave him home because I know he feels better when someone is home. Or for my husband and I, we cannot leave for vacation together, one of us has to stay home.

I: Do you think it has had implications on your marriage or your whole family dynamic? Like

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your children as well?

R: I love my husband and he loves me, and even with everything that is going on we try to support each other. We try to find ways to overcome this and help one another. I know my husband is suffering a lot. And part of it is our experience with our oldest son, which started as a I told you a long time ago. And I also have health issues that might be related to the stress that I have with my son. So I really cannot say if it is, but I would say mentally, me and my husband are also suffering from anxiety and things like that. And I think it is related to what we face. As mother and father we want the best for our children. And seeing him suffering like this, it's killing us.

I: Yes. Do you feel like there are expectations as a mother, as a caregiver, and how has that played into this anxiety of what is going on with your son?

R: I am very, and this is probably not similar in other families, but I am very fortunate to have a husband like mine. Meaning that he has taken a lot on to try to make it easy for me. Like he's handling more when it comes to my son situation, he is the one dealing with communicating with the county and the doctors and the pharmacists. So he is the one dealing with these things and not me. And I know that this is not typical, in Arab and Muslim families. Even though we are sharing, we are doing our best, both of us, to deal with him, but I would say my husband does more than me. But this is not common in Arab and Muslim families.

I: Mhm. So it sounds like if you were to have any pressure coming out of the expectations of your role as a mother it would not be from your family, it would be more of a societal perception, what you're trained to expect out of yourself.

R: Yes.

I: That's good that you have that support at home, especially from your husband. That's very

important.

R: So what are some challenges that you personally face caring for your son on a day to day basis?

I: Like the daily stuff, convincing him to eat, because he doesn't like to eat with us, and he doesn't eat much. So just convincing him to eat, to bathe, to take care of himself, he, because of his situation he will not sleep in his bed he will sleep on the floor, so it's just part of the situation. So just keeping up with these things and keep convincing him, I keep talking to him and his dad keeps talking to him, that he needs to seek help and find someone to talk to, to see a therapist and get help and do that. We try our best to do this, so just dealing with him and convincing him to get treatment.

R: Have you considered moving out of Milwaukee, and like I don't know the implications of checking him into in patient because he is over the age of 18, but have you considered moving? I: I did, I did. And sometimes I think about finding a job in another state where they have a better healthcare system where they can, I know that the legal system in every state is different too, so going to a state where I can easily get court-order or force him for treatment. but it is very hard, especially if we want to relocate and find another jobs. And I love Milwaukee, I've been here since I migrated in 1991, I don't think I'll fall in love in another city. But yes, you know, if I know there is a way to get him help by moving, I will.

R: Are there any other people or ways in which you are able to get help emotionally, outside of your family?

I: I have a couple friends that I talk to and they are great. I do exercise, try to eat healthy, and I think these are ways for me to cope with what I'm going through.

R: Do you feel hopeful for the future and what will happen with your son? And how has your

faith been impacted by this?

I: I always have hope. The way I think, I thank God for everything. I am a Muslim first, so my faith in God and God's will is very strong. And God wanted these things to happen for some reason, and I am accepting it. But also, I believe with God's help, that things are not going to stay the way they are for long. And things will get better. I am hopeful that things will get better with God's will.

R: Do you have anything else surrounding this situation, or any other thoughts on the discrimination or stigmatized part of your life that your son may feel or you may feel that you want to tell me?

I: Just that I wish that there is more awareness about these issues, especially about the mental health issues that has struck our new generation. And I know that many of these are environmental, and it happens because of different reasons. Some of these reasons, for example in the immigrant generation, dealing with the second generation can be very hard, dealing with balancing their own cultural expectations and our society's, or American culture's expectation, so our young generation, they are going through a lot. The young generation trying to balance between these two cultures. We need to make more efforts to reach this young population so they can deal with their depressions and mental health issues.

R: Do you see your son as someone who has been in touch with his faith throughout his life in different ways or at any point in his life?

I: When he was young, we would take him to Sunday school. But his experience in Sunday school back then was not really great. The people there, they did not really know how to deal with the young generation, they were dealing with him in verbally abusive ways. And my son hated going there. And now they are better in many levels, they have new Imams, very young

Imams, second generation Imams that understand the situation more, so I think we are starting to understand the situation more and how to deal with the young generation. And of course I don't generalize, I am just talking about my son's experience. but he didn't feel good, and he didn't feel belonging to the community or to the Mosque community. He has Arab friends, but not many. But yeah, I guess that's what I want to say.

R: Especially, as you said, he faced a lot of discrimination after 9/11--

I: Yeah, and he was aware of what was going on. People were like like "I don't want to play with an Arab," as a child, how do you deal with something like that? The thing is, my son, he is great, he didn't share these things with me until later on, until years after. And I don't know if this is typical for younger generation that they don't share what is happening in school with their parents.

R: That sounds very much like a teenager not wanting to share with their parents what is really going on, yes.

I: Yeah.

R: Well thank you for doing this and speaking with me today, I really appreciate your time.I: Yeah thank you.