



## Oral History Project Interview

### Arab and Muslim Women's Research and Resource Institute (AMWRI)

Interviewer/Number of Interview: KV 1.00

Date: March 7, 2019

Name: Anonymous

Year of Birth: 1957

Gender: Female

Country of Origin: Palestine

Year of Immigration: 1966

**Abstract:** A 62-year-old woman born in Palestine and immigrated first to Ohio, then to Wisconsin. She takes care of her husband who suffered from a subdural hematoma around three years ago. She feels like her Muslim community supports the two of them, but when she really needs help, she can only rely on her children. They attend social events at Sakina Center, where she feels more interviewees may be found. She states that she thinks women with a difference in ability would be treated much differently than a man with the same difference, and that women would be viewed as less marriageable. In terms of support, she wishes that there was someone she could talk to about hard life choices, such as when and if she should put her husband into a nursing facility. She finds strength through her faith and hopes that the future generation has an easier time than she has had.

**Key Themes:** Caretaker, counseling, older adults/elderly, community support

**Note:** In the transcript, “I” refers to Interviewer, and “R” refers to Respondent/Interviewee.

I: Where were you born?

R: I was born in Palestine, and I moved here in 1966.

I: Was there a reason why or did you family just—

R: My dad was here, and some of my siblings were here. So, we moved, my mom and my other siblings moved to be with them.

I: Was any of your family member’s health conditions a factor in moving here?

R: No.

I: Did you move directly to Milwaukee?

R: No, to Ohio, a town named Youngstown.

I: Okay, and then when did you move to Milwaukee?

R: 1976.

I: Was there a reason why you moved here?

R: Yeah, my husband moved because his family is here to work with them, help out with the business with his brother.

I: So how do you identify in terms of your national background?

R: Well, American but originally from Palestine.

I: So, Palestinian-American or American-Palestinian?

R: Yeah.

I: What is the highest level of education you have received?

R: Highschool

I: Ok and when did you complete it?

R: It was in Youngstown, 73-74.

I: Okay, and I am assuming you're married

R: I hope so!

I: [laughs] Do you have any children?

R: Yes.

I: Yeah, you've talked about your daughter.

R: I have three daughters and a son.

I: Oh wow, those are beautiful pictures.

R: Thank you.

I: So, if you don't mind, could you tell me the ages of all of them?

R: Let's see, one is forty-five, forty-three now, and thirty-seven and thirty.

I: Is it your son who's thirty?

R: No, my son is forty-three.

I: Do you currently work outside your home?

R: Retired.

I: So now I am going to focus these next questions on the differences in ability that you, or anyone in your family, has so that I have a better understanding of your situation. So, how would you describe the difference in ability? Is it physical, a chronic illness...?

R: Well, my husband has a disability which is a subdural hematoma. Now he has dementia and heart problems, and all that. I have arthritis and diabetes.

I: So, your living arrangement is you both live here and you kind of take care of him.

R: Yes.

I: Right, no one else comes to the home.

R: Well, once in a while the kids come.

I: Right, what I meant more is like a nurse coming.

R: To help? No.

I: Okay, let's see.

R: I'm the caregiver.

I: Right! Would you describe the timeline, so when the subdural hematoma—

R: Happened?

I: Right.

R: About December, three and a half years ago.

I: Do you think there were any factors that contributed to that?

R: Yeah, the coumadin. He was on blood thinners, and I guess he fell and that's what caused it.

I: Would you describe the nature of care you provide?

R: Everything. From taking him to doctor's appointments, from taking care of him here, from providing, cooking, cleaning.

I: Do you help him get dressed in the morning too?

R: Dressed? No. He can dress but I have to, like, if we go out, I pick his clothes.

I: Right, okay. You already said you don't have a nurse that comes here; does he just go to the doctors for check-ups or prescriptions?

R: Yeah

I: He doesn't do physical therapy or anything?

R: Not anymore, he used to when he had that problem. He had physical therapy, speech therapy, comprehension, all that stuff. And that's it.

I: Thank you. Now, these next questions are on the perceptions that people have about you guys.

So, compared to the broader U.S. society, how do you think the Muslim community perceives differences of ability that are very visible.

R: The Muslim community?

I: Yeah, the Muslim community.

R: Well, there's some educated people. They understand what's going on, but in this society in the United States if you have the insurance, you have the ability, the doctors, you don't need anybody else really. They can give you support by talking to you, whatever, but it's not the same if you're on your own at home. They can talk as much as they want but if you're not in the house, and if you don't know the situation just by seeing it, it's not the same as you're doing it. So, there's a difference between someone giving you— maybe they're trying to make you feel better, but after you go home it's... yeah. They try to give you support, like friends and family and the community, "oh yeah, you need help? If you need anything we're here for you." But you know...

I: It's different than having someone over every day.

R: Yeah.

I: How do you think the Muslim community perceives differences that are not very noticeable? So, like looking at someone, you can't tell if they have a disability, or difference in ability.

R: Some people you can't, and sometimes you don't want to ask, because you don't want to hurt that person. You don't want to be in their business.

I: Do you think that in the Muslim community that people perceive it as a negative, or as something that a person—

R: No, they see it as that this is from God, and nobody is covered. Everybody is going to get sick, everybody has their own issues. You know, this person has a subdural hematoma, this person has a heart [problem], you know this is accepted because this is part of life.

I: Have you ever experienced and prejudice, negative remarks, or discrimination because of your husband or you having to care for him?

R: No, support.

I: That's wonderful to hear! Do you think, given your experience with the Muslim community, is there any impact on your willingness to be in public situations with your husband?

R: No, I try to go with him. I want him to socialize. And the Muslim community has like a senior citizen place, three days a week we get together and they provide us with coffee, drinks, sometimes like cooking together a meal, just to be together, to support one another and to let the day pass by. So that helps a lot, I take him there a lot. And they bring us speakers of different topics to keep us not bored. And like they got us from Mount Mary College, "Eat Better, Feel Better," they come to them to teach us what to eat each week, how to exercise.

I: How does the community's perceptions impact the way you deal with your husband's difference in ability? So, for example, you said having that community involvement, you really wanted him to go and socialize. So, do you think the community encourages you to go out with him more?

R: Yes, they want us to go. They try to make it fun so you can go there, and easy for us. And when we go to the mosque or whatever, everybody is friendly, they like to see him because they've known him for a long time. He was a businessman.

I: Yeah, I was just going to ask if it's the same mosque you've been going to since you've moved here.

R: Well, when we moved here there wasn't a mosque.

I: There wasn't? Oh.

R: The community, it's part of us and the community. We all pitched in and opened it.

I: That's really wonderful! I am not from the area, so I wasn't aware, sorry.

R: Oh, that's okay.

I: From your experience, do you think that the Muslim community has expectations of you as a caregiver?

R: Well, it's part of our culture I should say, and part of everybody's culture. When you are married, for better or worse, sick, or poor. So, if it was reversed, same thing. So, this is part of me and part of our faith. It's expected of me, and I don't think I would have someone else come in and do it while I am just sitting down. I'd feel so like... just, it's expected.

I: What are your expectations you hold for yourself as a caregiver to him?

R: I am happy that I can do it because I am glad God gave me strength. And I keep praying for God to give me strength to keep doing what I am doing because he is my husband, he is the father of my kids, you know? And I want him to get better.

I: Exactly. Thank you so much.

R: No problem

I: So these next questions are going to go over any challenges you might have faced, and like I said before, if you feel uncomfortable answering a questions you can definitely tell me, although it does go towards trying to put into place things to help better support care in the future. So, if you could tell me what do you think some of the biggest challenges you've faced as a caregiver for your husband?

R: I think I didn't know what to expect. I am taking it day by day. Sometimes it's hard because it's his comprehension, he doesn't comprehend as well, and he doesn't hear as well, either. So that's the thing, is the understanding. And that's kind of difficult sometimes. You just try to be patient and you try with God, Allah, strong faith will give us support. There are difficulties, as there are difficulties in any situation.

I: Right, do you ever feel maybe like you're stretched too thin, like you do need more support

from your family?

R: See, the only problem is I have to make the decisions. Nobody is here to make the decision or help me make the decision. Like the other day he got sick in the middle of the night. I was wondering, should I call 911? Or what should I do? Is he that bad for me to take him to the hospital? So, God gave me strength. I called my daughter, her husband is a doctor, she didn't answer, she is on medication, so she didn't hear. She told me next time keep calling or call him directly. Then I said you know what? I called the emergency, hospital, spoke to the nurse. So, I made my decision talking through the nurse. So, these things, those are the time when you need somebody to help you because you don't know, God forbid, but you try to do whatever you can. But thank God, in the states you can call the hospital you can call anybody.

I: Yeah, right and it's twenty-four hours.

R: Yeah

I: So, you were saying making the decisions is hard for you, do you feel like you haven't been given enough information about how to deal with those types of situations or how to help him in general?

R: Okay, so like the hospitals, once he is discharged he is discharged. They don't tell you the long term. They just tell you he needs speech, he needs this, that's it. They don't know what's going to happen after that, so this is your own decision you have to do. Your own decisions financially, your own decision on everything. So, nobody is there to help you to do that. So, I know, I can always ask my son. He tries to support and help but he is busy and sometimes I say okay, I am not going to bother him.

I: Do you feel like the hospital, or the doctors gave you the proper information for you to have the right expectations for caring for him by yourself?

R: Honestly, the doctors tell you "Oh, he is going to deteriorate more and more." Okay, what's



next? How long? They don't know either. Every person is different. They don't know. We have our good days, sometimes we have our bad days. So, you don't know what to expect. Nobody knows what to expect. The only person that sees it is the caregiver. Even his own kids, they don't know that to expect.

I: I am sure that was really hard but thank you for sharing with me. Have you ever considered moving away from Milwaukee because you feel like there are not enough resources here?

R: No. It's the opposite. We go overseas every year, vacation, and never think about moving.

I: So, you feel like the community here is—

R: Yeah, I feel like the doctors here, because they know his history, and I think the help here is better than anywhere else. Why [would] you want to start somewhere else, and they don't know anything about you and about [your injury].

I: Yeah, that's true. Here they have his whole case history. So, to deal with any challenges you've experienced, what are some of the strategies that have helped you.

R: Faith. Faith and talking to my kids, my girls, and my grandkids, they help. Like I invite them every week for dinner. Try to invite them every week, every Friday, so they can be here, around him, so he won't forget. I try taking him to Virginia, that's where my daughter lives, one of them, so he won't forget them. Facetime, you know with the kids.

I: Yeah, I bet that technology is really helpful.

R: Yeah, it helps and this way he keeps track.

I: Do you think you have any strategies that have helped you in dealing with doctors or other medical professionals?

R: Really, I just go, like I said, make appointment, go. That's, I try to work my month in the schedules.

I: Who specifically do you get help from for yourself?

R: How? Like, kids if I need it. If I need to go to a doctor or hospital or have an appointment, I have to call them.

I: Do you have any friends or neighbors or people in the—

R: Yeah, I have friends but I rather, instead of friends, his kids are responsible. Before the friends.

I: Have you had any positive experiences getting help from others?

R: You know once you are home, they think you are okay, you're okay. That's it. See, at this age, friends, they are having their own issues. So, his best friend, who I trust dearly, he has his own health issue. He can't even leave the house so he can't, everybody has their own issues. I can't call and say, here, come and do this for me. No. And when you really need somebody, they are always busy. So, I just rely on myself and my kids.

I: And your kids come over and help you?

R: Yeah, my daughter, and if I have health problems or issues, I don't want to call the doctor. I call my son-in-law.

I: Yeah, because he's a doctor too?

R: Yeah. And that helps. And my son, and even our primary doctor is a friend, so I have his cell number and text and call anytime.

I: That's really nice that you're able to do that. So, this is more of your opinion, do you think that there are any challenges that females with a difference in ability could face that would be different than males with the same—

R: Oh yeah. Yeah, females, if they're down, the husband can't do what the wife does. He needs help more than she does. Because if she's down, who's gonna cook, who's gonna clean. Men they don't know how to multitask. I don't know if it's me or if it's in general, but they don't.

They get so nervous, they want to do something. Us, we just take it easy. Don't worry, it's gonna

get done. We do it. So, it's a lot.

I: Do you think that there would be a lack of support for a female with the same—

R: Yeah. You know it's not like a support, you know like its mom. But when it comes to you know the dad, he was strong, he was this... what happened. But with the mom you know she was home, she is used to staying at home. It's different, I think.

I: Do you think there would be differences, if it were a younger person, education or work opportunities taken away from them or not available to them if it was a woman with the same difference in ability? Do you think it would be harder for her to get education or work experience?

R: Because I was raised here, I am more American than Palestinian, but we worked together, we had our own business so we both worked. In America he didn't know how to speak English, so I taught him how to speak it with work. So, we always were working together. So, some ladies who come from overseas, their husband already been here and working so they have to rely on him. And they just become a stay [at] home mom most of them. They don't want to do anything because everything is provided for them. Those types of people, it is hard for them. If something happens to them or to their spouse, it is going to be hard.

I: Do you think that a woman with a difference in ability or disability would be less marriageable?

R: If she's not married? Yes, of course. Of course. Nobody wants to take somebody who needs help. Yeah, but the other way around? Yeah, a lady would marry somebody who has like an illness or whatever.

I: So, what do you think in general, within the Muslim community, or the larger US community needs to change in the way they support people, help people, or just their attitudes in general?

R: I'm gonna say maybe a long time ago they used to help more, but these days with a busy life

everybody is busy, they tell you go online. Everybody is telling you go online, even when you call a doctor. What you hear? The message. Nobody is talking to you anymore. Everything is electronic. So, what if somebody doesn't know how to read or write, or somebody doesn't know how to go online, what is going to happen to those people? I should tell you. There's no one on one anymore. And to me, one on one is better than no. It doesn't matter where you're at. In the states, they have everything, but if you don't call or ask to demand you want to talk to somebody, the machine talks to you. I don't want to talk to a machine. twenty years ago we used to call, you talk to a human being, that's all. And it understands you. But now there's nothing. Really the support is not as well as before.

I: What do you think that doctors, schools, or your community could know to help support you more?

R: Well, I don't know how they are going to help you when you're in that. I think I got so used to being the way I am the last three years, you know. I am used to taking care of him because I took care of his mom before. And then it was her daughter, she was too busy, her sisters were too busy, so I took care of her. She stayed with me a few months. But they're too busy, they could talk to you, "Okay if you ever need anything, call me," but what are you going to tell them? "Excuse me, would you like to come while I go grocery shop?" "Oh, okay, when? Oh today I am busy." You can't. I can't rely on anyone, really.

I: Do you think that more programs like that social program—

R: Yeah, that helps a lot. I think I like that kind of program. But what I'm thinking is, I like that program but there's facilities like for older folks, like live-in facilities. But I don't like the living facilities like a nursing home. I like the fifty-five and above, I don't know if you've ever heard of them.

I: Yeah, I think they do a lot of those communities in Florida, right? Where it's just—

R: Yeah, fifty-five and up, right. I wish there was something like in this area. So instead of living in this house, buy a house in that community, that area, and they can take care of around the house for you, whatever. That's, they lack it here. I wish they had something,

I: Yeah, that would be interesting to see implemented.

R: You understand what I am saying?

I: Yeah, I do.

R: Because now I am thinking okay, I want to move because this house is too big for me. And the all the yardwork is too much for me. And I want to move closer to my son, because if something happens, I can call him, and he can be there in a few minutes. So, it's hard to find a house by him even. If they had that fifty-five years in that area, it would help a lot.

I: Or would it be helpful to, you said like if you needed someone to come over while you went grocery shopping, like someone you could—

R: You see he is so attached to me, he won't accept, let's say, if I asked you to come, he would say, "No, I'll go with you." He won't. "Why did you call them?" you know. He's been sick with bronchitis the last few days, I took him in on Monday. And I had to change the antibiotics because it didn't work with him. The next day I had to text the doctor and say this was going on and he said no problem, I'll get you a different one. So, I said, "do you want to stay here?" I don't leave him. I don't like to. He said, "I'll go with you, five minutes, I'll go with you". I take him with me everywhere. Even when it was cold, but I had to take him. So, he would rather go with me than stay with anybody.

I: Would it be helpful to have a delivery service for that type of thing?

R: Yeah, I think sometimes it helps when you have delivery, but the problem is if you want to buy vegetables or whatever, you don't know what they are gonna pick. They are gonna pick

anything. I'd rather see things and feel things, you know. I'm old fashioned when it comes to that.

I: I know exactly what you mean, make sure it's the right looking tomato or whatever.

R: Yeah.

I: Is there anything else you can think of that you'd want to tell me that you think could help people in the future or help people understand currently what you go through?

R: You know I always wish like, the hospitals, when there's something like this, that once in a while they call you and see if you need anything, or [have] questions or whatever. Or like a social worker, somebody, you know? Maybe sometimes like you have something in mind and you can share it with them, but once you are gone, you're gone. But like I said, you have to have faith in order to keep going. I think the faith and going to the Islamic community helps a lot. And like socially when we go to that it helps a lot.

I: Yeah, having the same people you go and see.

R: Yeah, and he sees them all the time. He is more comfortable with them, and they understand what's going on with him. That they're not going to make fun of him.

I: Are either of you concerned about people making fun of him outside of that community.

R: Well, it's not like... they don't know he's sick. [His] lack of hearing or lack of comprehension, like they will be talking about something and he's talking about something else. Because sometimes I notice like whatever he's thinking, he blurts it out. It doesn't make sense to others but to me, it does make sense because I am with him.

I: Right, like it could be something from earlier that day.

R: Or something, yeah. So, that's what I am saying. I don't like people who don't understand,

but like the community, the Islamic community, most of them they knew when he was in the hospital, when he got sick. Because they know him from before.

I: Exactly. Is there any other information you think would help you in the future?

R: I am taking it one day at a time honestly. I am thinking of the future, what's gonna happen and how long is it going to take for him to really forget us. And what is gonna happen then, you know? These things you think about. Do I put him in a nursing home? [Are] those nursing homes safe? You hear so much on the news. So, these things you do, I don't know who can make it comfortable for you and tell you, oh there's a good place and safe place. You don't know. You don't know where to go and who to ask.

I: So maybe if there was someone who you could meet with about that, who was like available through the hospital or through the doctor or through the mosque even, where you could meet with them to talk about those types of things, like advice—

R: Honestly, I'm like thinking about asking the Islamic community to do a nursing home or something for Muslim people because I am not against any religion or anything, but Muslims pray together, they know where to pray. If he's not doing it, [they can say] "oh, let's go pray here, did you pray yet?" They'd understand. And about the food, how we eat the food. Because our food, no pork or lard or you know? You go to a facility like mixed, they going to feed you whatever. And we are not there to enforce it and to see what he's eating.

I: Right, and if he can't advocate for himself, it would be difficult.

R: Those are the things that I'm struggling with in the future with what's going to happen. Like somebody who cooks for you. And to tell you the truth, our culture [it] is expected of us, the kids, they have to take care of the parents no matter what. No matter what age, like my daughter, her father-in-law has dementia, Alzheimer's, they don't know, he doesn't remember things. So, his wife passed away a long time before he even got sick and his son and his wife couldn't take care of him anymore, so they put him in a facility, but his son has to go every day between him and his sister to take care of the dad, feed him, and change him. Give him showers. Even though

he's there, because the nurses didn't want to deal with it anymore. Or they notice that if they go and come back, he's still in his filth, so they still have to do it, the nurses are not doing it. So, these things are making me think, do I want to put him in a place like this? And if you want to put him in a real good place, five thousand dollars a month, my daughter was telling me. Where am I supposed to get him \$5,000 a month? Social security doesn't pay for all of that.

I: That's really a tough situation.

R: See, those things you have to think about.

I: So, like a nursing home, Islamic nursing home maybe. I think there's a Jewish care facility.

R: Yeah, but Jewish is different too.

I: Right, but something similar.

R: Yeah, so we are trying to do something hopefully in the Islamic community. Hopefully we try to do something like that. And hopefully I won't need anybody, hopefully between me and my kids we can handle it. But if it comes worse to worse, you know if I can't do anything to handle it maybe I'll hire somebody to come and help me. Thank God, I am grateful, he's okay now.

He's making his own coffee.

I: Yeah.

R: So yeah, when he's home he comfortable. He does not like to go anywhere else. He's not happy anywhere else.

I: Well that's good that he has this place where he can recuperate.

R: He knows where things are, sometimes he forgets. But he's comfortable. And that's another thing, thinking of moving, is it a good time? As a [speech] therapist, maybe you know or maybe you don't, I don't know, is it a good time to move or isn't it a good time to move? Because he's so used to this house. If we move, is it gonna make it worse on him?

I: I can see your dilemma, and I'm not sure.



R: That's, who do I talk to about that? Maybe his doctor?

I: Yeah, I think that's something, like how to know who you can talk to about that. And in general, to have someone to talk to about that.

R: Yeah.

I: So, we are looking for more Muslim people to interview who either have a difference in ability or are caretakers to someone with a difference in ability, like you are. Do you know anyone else that might want to talk to us or might be able to talk to us?

R: You know what, let me talk to those senior citizens, the one we go to. Because there's a clinic there, in the same place, clinic plus that, maybe you can talk, come, and ask.

I: What's the name of the place?

R: It's called Sakina Center. MCHC. They brought in somebody to talk to us about stroke. They brought a nurse in to see the signs, what the signs are for stroke.

I: Thank you so much.

R: Maybe you can talk to somebody there.

I: Yeah, that would be really helpful. Now I'm all out of questions unless you have anything else you want to say or add.

R: Whatever you want to ask, I want to answer. Did I help?

I: You did, you really did. Thank you so much for all your energy and sharing things that I know are very personal.

R: Yeah, but if that helps others, why not? You know you have to help others. If that's going to help the future maybe, you know your generation, you can find something social workers, or somebody can start helping about these things. Maybe they can start getting in touch with people, or even in the hospital, you know? Asking, they should assign a social worker when somebody leaves.

I: Yeah, they could have a bookend program so that there's not a question that could endanger your safety.

R: Yeah, thank God, I said, I knew how to talk, I knew what to do. God gave me brains I guess to think about it, but somebody else like I said, who doesn't know how to speak English, what's going to happen to them?

I: Yeah, to them or their families.