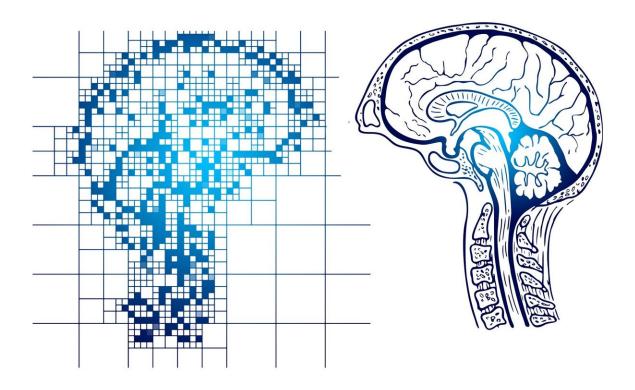


Q&A: Alzheimer's and Arab Americans—more research needed

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Middle Eastern and Arab American populations may have higher rates of Alzheimer's disease and related cognitive impairments, but researchers don't exactly know because these populations aren't



identifiable in national datasets.

That's because historically, Middle Eastern and Arab American populations haven't been included as a distinct ethnic group in the U.S. Census, making it difficult to include them in nationally representative studies. Recently, the U.S. Office of Management and Budget issued updated standards for maintaining, collecting, and presenting race/ethnicity data across federal agencies to include MENA, or Middle Eastern and North African, as a racial/ethnic category.

Previously, this population was legally classified as white, according to the University of Michigan's Kristine Ajrouch, director of the Michigan Center for Contextual Factors in Alzheimer's Disease and adjunct research professor at the U-M Institute for Social Research.

Ajrouch was recently awarded a National Institutes of Health grant to study rates of Alzheimer's disease and mild cognitive impairment among a regionally representative sample of Middle Eastern and Arab Americans. Her study will focus on the metro Detroit area, home to the largest and most visible concentration of Middle Eastern and Arab Americans in the United States.

What motivated you to start this study?

I have been studying health and well-being in the Middle Eastern and Arab American communities for more than 25 years. I began a program of research around aging among Arab Americans to understand better the strengths and challenges this ethnic group experienced.

An issue that rose to the top of people's concerns was sort of this fear about Alzheimer's and related dementias. As I began to look into the research that's been done in the area of Alzheimer's disease and related dementia, I realized that Middle Eastern and Arab Americans were not



represented.

We have had some advancements since we began this program of research in 2018. We've had research scientists at the Michigan Center for Contextual Factors and Alzheimer's Disease begin to investigate cognitive health in the Middle Eastern and Arab American populations. And what we've begun to see is that Arab Americans, especially immigrants, have worse cognitive health compared to their U.S.-born white counterparts or even foreign-born white counterparts.

And it's a really exciting time because the Office of Management and Budget has just recently named MENA, or Middle Eastern and North African, as a racial and ethnic category that federal agencies will have to report on. This is such an exciting development because they had legally been classified as white. You couldn't find MENA in large datasets because even if they were in large datasets, they weren't identified as distinct from white.

Do Arab Americans have higher rates of these diseases?

The simple answer is we don't know. But what we do know is that the research that's coming out suggests that they have high-<u>risk factors</u> for this disease.

Risk factors would be, for example, cognitive limitations, higher rates of cardiovascular disease and diabetes. From the limited research that we have, we also find they have higher rates of depressive symptoms. All of these things are risk factors for Alzheimer's disease and related dementias, but we still don't really know the prevalence levels of ADRD in this population.



What's important about studying Alzheimer's disease and related dementias, specifically in the Arab American population?

We're going to be able to identify what uniquely puts this population at risk and what uniquely protects them from Alzheimer's disease. And there may be a lot of things that are universal: what you find among the general population is also true for this population.

But we also might find some unique factors, which again, will help this community in terms of allowing us to recognize what kinds of resources we need and lobbying to get those resources because now we have the data to show it. It can also tell us what kinds of things we should be looking for in other populations that maybe we didn't think to look for in the past because this particular ethnic group had never been examined before.

The National Institutes of Health is pouring millions of dollars into understanding Alzheimer's disease. It's important for Middle Eastern and Arab Americans to be included as part of the American mosaic, and to be included in plans, programs and policies that are meant to improve the quality of life and the health of our aging families.

What are you hoping to understand by looking at rates of Alzheimer's disease and mild cognitive impairment among Arab Americans?

Looking at rates of Alzheimer's disease in this population will allow us to discern the extent to which it is prevalent. For example, do Arab Americans have similar cognitive health challenges as other minority groups, or are they more like whites? That's an important question to



answer because that then begins to lead to further inquiries such as: How can we best support this community? What can we learn from this population that can also be relevant for other populations?

I'm a real proponent of having diverse samples as a way to advance science. If you only look at one type of population in a research study, you're oftentimes missing clues, insights, and potential advances that can be made by including the diversity of the human population.

What challenges are you facing while trying to undertake this study?

We obtained the addresses of all households in the Detroit area from the U.S. Postal Service, including Wayne, Oakland, and Macomb counties. No names, no phone numbers, just addresses.

We are then randomly sending out letters to households to introduce the study and let the <u>community members</u> know that one of our <u>team</u> <u>members</u> is going to be coming by to see if they qualify to participate in this study. Then we send an interviewer out to that house because we have no other way of getting hold of them.

I think you can imagine, during these post-COVID days, that any stranger coming to your house is suspect. Once we get over that, we have to find somebody who qualifies for the study, which basically means they have to be 65 or older, they have to be of Middle Eastern or Arab ancestry, and they have to speak either English or Arabic.

Let's say we find a household that qualifies. Our challenge now is getting them to say yes. That can be difficult: They say they are too busy and often just don't understand why we want to talk to them or what benefit there is in participating in research. Sometimes, there's suspicion about



why we are asking if they are Middle Eastern or Arab. We're trying to overcome a lot of hurdles that are making it difficult for us to convey how important this research project is.

To overcome some of these hurdles, we've recruited a team of community influencers. These are individuals who are not part of our interviewing team, but they are members of the community who are known and trusted. They also have a very firm belief in the importance of research.

We've asked them to follow up with some of the individuals who qualify but haven't said yes yet to tell them about why this study is so important. These include conveying things like making sure that we're included in efforts to fight Alzheimer's <u>disease</u> and making sure that we find out what uniquely puts us at risk and what uniquely protects us from Alzheimer's. Participating in the study is totally confidential. Nobody's name or contact information will be shared with anyone outside of the study team.

We also emphasize the benefits of participating in research, including that it is a way that we can help our family, our children and our grandchildren. We try to address the suspicions around research, stating it is not the government coming in and trying to find out if you're here legally or not or to take away some kind of social program you may be on.

We want to emphasize that this is a study about health that the National Institutes of Health support, and the goal is to be able to find ways to address the needs that this particular population might have when it comes to aging well.

Related findings were <u>published</u> in the journal *Innovation in Aging* in 2018.



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