

PARTNERING WITH MIDDLE EASTERN/ ARAB AMERICAN AND LATINO IMMIGRANT COMMUNITIES TO INCREASE PARTICIPATION IN ALZHEIMER'S DISEASE RESEARCH

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Purpose: Recruitment and retention of US ethnic groups traditionally underrepresented in research continues to pose challenges. The Michigan Center for Contextual Factors in Alzheimer's Disease (MCCFAD) engages with two underserved immigrant communities in Michigan – Middle Eastern/Arab Americans in metro-Detroit and Latinos in the Grand Rapids area – to recruit and retain two Participant Resource Pools (PRP).

Procedures: We adapt an existing community-based participatory research (CBPR) approach to recruit Middle Eastern/Arab American and Latino adults of all ages for Alzheimer's disease and related dementia (ADRD) research. Using American Community Survey (2014-2018) data, we compare socio-demographic characteristics of Middle Eastern/Arab Americans and Latinos living in Michigan to our PRPs. Assessment tools and community advisory board feedback identified missteps and culturally sensitive solutions.

Main Findings: In the first year of MCCFAD activities, 100 Middle Eastern/Arab Americans and 117 Latinos joined the MCCFAD PRPs. Comparisons to state-level data showed that PRP participants were on average older and more likely to be female than the Middle Eastern/Arab American and Latino populations in Michigan. Further, Middle Eastern/Arab Americans in the PRP reported higher education levels while Latinos reported lower education levels than their respective statewide populations. Community partnerships/feedback identified the importance of connecting with community leaders, attending to matters of within-group diversity, as well as language and semantics.

Conclusion: Partnership with communities to develop culturally targeted and sensitive community health events can fill a signifi-

INTRODUCTION

Racial/ethnic disparities in Alzheimer's disease and related dementias (ADRD) are a major public health concern. According to the Alzheimer's Association,¹ more than 5.4 million individuals currently live with Alzheimer's disease, and this number is expected to triple by 2050. Health disparities in ADRD are known to disproportionately affect particular racial/ethnic groups in the US population.² More than 12% of older Latino adults meet criteria for ADRD, compared with 6.9% of non-Latino White and 9.4% of African American adults.³⁻⁵ Although data on ADRD among Middle Eastern/Arab Americans is virtually non-existent, preva-

lence rates among Arabs are reported to be higher than among non-Arabs in the Middle East.^{6,7} Furthermore, ADRD risk factors are more prevalent among Middle Eastern/Arab American Americans than among Whites.⁸

The Michigan Center for Contextual Factors in Alzheimer's Disease (MCCFAD), a newly formed Alzheimer's disease Resource Center for Minority Aging, has a targeted emphasis on social and behavioral factors related to ADRD in two ethnic Michigan communities underrepresented in research: the Middle Eastern/Arab American community in the metro-Detroit area and the Latino community in Grand Rapids. Both groups have high proportions of immigrants, within-group heterogeneity

cant gap in addressing ADRD health disparities by establishing sustainable relationships to increase participation in ADRD research. *Ethn Dis.* 2020;30(Suppl 2):765-774; doi:10.18865/ed.30.S2.765

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(eg, country of origin, cultural practices), and face significant challenges (eg, anti-immigrant sentiment/policy, negative media portrayals, etc.) from mainstream US institutions,⁹⁻¹¹ all of which result in less health care utilization as well as lower rates of research participation. Engagement with both communities is led by the MCCFAD Community Liaison and Recruit-

We report on our approach to successfully establish partnerships with Middle Eastern/Arab American and Latino adults of all ages as a means to increase interest in participating in ADRD research.

ment Core (CLRC), whose primary goal is to improve community-based and culturally sensitive research while increasing research participation of members from underrepresented ethnic groups. Our approach engages community members in an equitable partnership to address specific disparities. Here, we report on the MCCFAD CLRC approach to successfully establish partnerships with Middle Eastern/Arab American and Latino adults of all ages as a means to increase interest in participating

in ADRD research. We also describe the characteristics of the population reached and present lessons learned.

PATTERNS AMONG MIDDLE EASTERN/ARAB AMERICANS AND LATINOS

Middle Eastern/Arab Americans and Latinos have common biological, psychological and social ADRD risk profiles. Both have high prevalence of metabolic disorders and cardiovascular disease¹²⁻¹⁴ as well as depression.^{15,16} Social factors include lower socioeconomic status and English language proficiency,¹⁷ which pose barriers to accessing the health care system,^{9,18,19} and social stress due to anti-immigrant political rhetoric^{20,21} that put these groups at higher risk of developing ADRD. In Michigan, both the Middle Eastern/Arab American and Latino populations are growing, particularly in comparison to the non-Latino White and Black populations. The Middle Eastern/Arab American population in Michigan grew 47% between 2000 and 2013 and is estimated to include more than 300,000 individuals, which is 3% of the population, and concentrated in southeast Michigan, according to the Arab American Foundation Institute (2014). Likewise, Latinos comprise 5% (447,000) of the total population in Michigan.¹⁹ The presence and growth of these populations represent an untapped opportunity to establish meaningful collaborations between community leaders of both ethnic groups. The CLRC works directly with these two underrepresented communities to enhance inclusion in ongoing social, behavioral, and clinical

research, improve health care literacy, and promote healthy living behaviors.

METHODS: COMMUNITY BASED PARTICIPATORY RESEARCH APPROACH

The CLRC aims to enhance active participation of Middle Eastern/Arab American and Latino communities in ADRD-relevant health research by creating a Participant Research Pool (PRP) of 300 adults within each community. The Michigan Center of Urban African American Aging Research (MCUAAAR) recruited approximately 300 PRP members during their first five years, which guided our decision to work toward recruiting a similar number in each community.^{22,23} A PRP allows community members to become part of a self-identified group who agree to be contacted in the future about participating in research studies. Our PRP recruitment efforts focus on inclusion of all adult members in both the Middle Eastern/Arab American and Latino communities to investigate and promote healthy living practices that contribute to reduced risk of developing ADRD and advance culturally sensitive ADRD care, but we prioritize recruiting individuals with Mild Cognitive Impairment (MCI) and dementia.

Participant Research Pool (PRP) Recruitment

To achieve our aims, we adapted the community-based participatory research (CBPR) approach used by MCUAAAR.^{22,23} A CBPR approach commits to an equal partnership between academia and the communities

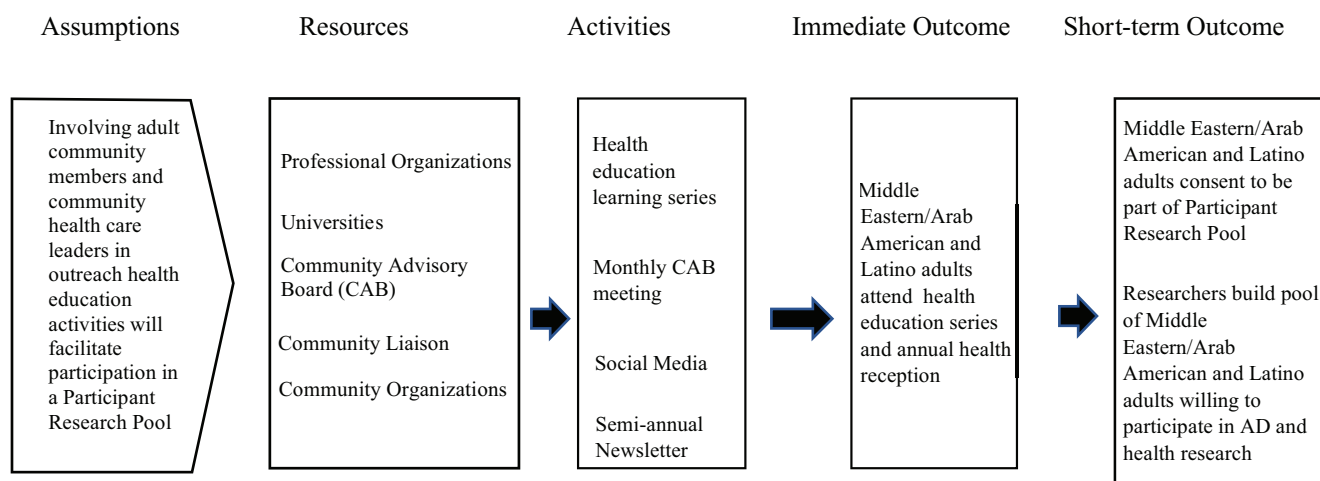


Figure 1. Logic model illustrating the recruitment process for building a volunteer registry within the Middle Eastern/Arab American and Latino communities (adapted from Chadiha et al, 2011).

in which research takes place.²⁴ Our main assumption states that involving older community members in outreach health education activities will facilitate interest and participation in a research volunteer participant pool (see Figure 1 for adapted Logic Model). Given that ADRD risk begins to accumulate early in the life course and ADRD care often involves family networks, we extended the assumption to include community members of all ages. Working directly with our community advisory boards (CABs), community organizations, professional associations and universities as resources, the CLRC activities include a regular health education learning series, monthly CAB meetings, social media (eg Facebook, Twitter) and mainstream media presence (eg, local radio, newspapers), as well as a semi-annual newsletter that highlights recent AD-related innovations, research findings, healthy living practices and available resources.

The immediate outcome is that Middle Eastern/Arab American and Latino adult community members attend the health learning events. The primary short-term outcome is to foster attendees' participation in the PRPs. The longer-term goal is to allow the CLRC to build a pool of Middle Eastern/Arab American and Latino adults willing to participate in ADRD-relevant health research.

Recruitment into the PRPs occurred at the health learning events. Participants were given an overview of MCCFAD's goal to advance research among underrepresented ethnic groups, and they were invited to complete a short survey that would indicate their willingness to become part of MCCFAD's PRP. Community volunteers and university students circulated the room at the beginning and toward the end of each event asking participants whether they had interest in completing the survey and becoming part of the PRP. The survey

collected contact information, demographic data, individual and family health histories, and suggested topics that attendees would like to learn more about at future community events.

MCCFAD Composition

The Center is led by an interdisciplinary team with complementary strengths in life course sociology, life span developmental psychology and neuropsychology. It also involves a strong multi-disciplinary group of scientists across the social, behavioral, economic, and medical sciences, benefiting from years of interdisciplinary research and partnerships within and across four universities and local communities. MCCFAD also forged key partnerships with the Alzheimer's Association. For both Middle Eastern/Arab American and Latino community activities, the Alzheimer's Association participates as a member of the CABs. However, for the Latino community activities, this partnership ex-

tends to the Latino Community Liaison being hired to work on behalf of both MCCFAD and the Alzheimer's Association. This arrangement capitalized on the Alzheimer's Association desire to connect more closely with the Latino community and ensures connections between the Latino community and AD/DRD resources beyond the grant funding period. The two community liaisons hired for the center are bi-lingual (Arabic-English and Spanish-English respectively). They each work with the CLRC leads, both of whom have strong connections to the respective communities, to identify CAB members.

Once identified, CAB members received a formal invitation from the respective CLRC lead. CAB members comprise older adults, recognized leaders representing community-based organizations, AD caregivers, and community healthcare professionals. We purposefully include community leaders and health care system representatives to help maintain relationships beyond the funding period and promote transformational actions directed toward better addressing the needs of the community. The CABs advise on the integration of results into practice and the development of culturally sensitive measures; ensure respect for the values, culture and social practices of each community; and help ensure that the target communities benefit from research. CAB members also contribute to the bi-annual newsletter, which is written by the CLRC leads and community liaisons and distributed through community organizations and listservs. Community organizations include those that provide social services, as well as re-

ligious institutions and schools that serve each ethnic group. CAB members receive a small honorarium at the end of each year of service. Monthly CAB meetings provided guiding input to our PRP recruitment. Specifically, the topic of each learning event, format (length and language of delivery), community location and strategies to publicize were discussed with the respective CAB before each event.

Assessment

Community event attendees completed a sign-in card (available in English, Arabic and Spanish) where they indicated their reason for attending, how they heard about the event, whether it was their first time attending a MCCFAD Community Health Learning event, their sex, and birth year. We also asked for zip code information, to facilitate tracking of the areas from which we drew participants (data not shown) in both communities. We use zip code information to better attend to geographic variability when planning future events. Following each event, a descriptive analysis is provided by the investigators to the CAB to brief them on who attended, and why they did so. Together, they reviewed elements of each health learning event to identify what worked and what needed modification.

To assess the representativeness of our PRPs, we compared demographic characteristics of age, sex and education reported by those who joined our PRP to statewide census data. Specifically, we used data from the 2014-2018 American Community Survey (ACS 5-year estimates) to identify Middle Eastern/Arab American (those who indicated Middle

Eastern/Arab as their first ancestry) and Latinos (those who answered yes to the Hispanic origin ethnicity question). We conducted descriptive analysis to characterize the age, sex and education distribution in each sample. Further, we conducted descriptive analysis to discern prevalence of key health characteristics of our PRP members: cholesterol level, depression, diabetes, hypertension, and concern with memory loss.

All procedures were in accordance with the ethical standards of the responsible committee on human subjects (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants included in the study. Comparing our PRP members' age, sex, and education data with statewide ACS data helped identify groups of people who are not being reached through our voluntary recruitment method. This will help expand on existing knowledge of Middle Eastern/Arab American and Latino populations while facilitating a more representative pool of potential research participants.

RESULTS

Health Event Attendees

We report on characteristics of attendees who provided self-reports when they signed in during the first year of community health learning events. Each community had four events organized and sponsored by MCCFAD. The Middle Eastern/Arab American community events occurred in November 2018, and in January,

March and May 2019. The Latino community events occurred in February, March, April and May 2019.

Middle Eastern/Arab American Community.

One hundred and eighty-three (183) community members signed in when they attended events during the first year. Of these 183, thirty-five (29%) individuals reported attending more than one MCCFAD Community Health Event. Attendees who reported their year of birth had an average age of 52 years (range 21-85). More females (63.5%) attended than males (36.5%). Participants indicated that the primary reasons for attendance were to learn more about ADRD (71.0%), followed by having a loved one with ADRD (21.3%), social networking (12.0%), and accompanying an attendee (19.1%). Participants could indicate more than one reason for attending. The most prominent channel through which news about the community health event reached participants was word-of-mouth (49.7%).

Latino Community

A total of 134 individuals signed in at the four first year events. Of these 134, eight (6.2%) individuals reported attending more than one MCCFAD Community Health Event. Attendees who reported their year of birth ranged in age from 19-97, and were on average 49.6 years old. Events drew participants representing various age groups and women (76.9%) were more likely to attend than men (23.1%). The majority (68.6%) of participants stated that they were attending because

Table 1. Community health learning event characteristics by community

	Arab American, N=183	Latino, N=134
	% (N)	% (N)
Demographics		
Average age (range)	51.9 (21-85)	49.6 (19-97)
≤19	--	5.2 (7)
20-39	24.7 (43)	35.7 (47)
40-59	39.7 (69)	32.8 (44)
≥60	35.0 (61)	26.9 (36)
% female ^a	63.5 (75)	76.9 (103)
Motivation for attending ^b		
Learn more about AD	71.0 (131)	68.6 (92)
Loved one with AD	21.3 (39)	20.1 (27)
Social networking	12.0 (22)	29.8 (40)
Accompany someone attending	19.1 (35)	11.9 (16)
Other	--	11.9 (16)
How learned about event		
Word-of-mouth	49.7 (89)	54.5 (73)
Flyer	26.2 (47)	7.5 (10)
Social media	21.8 (39)	18.7 (25)
Other	21.8 (39)	32.1 (43)

a. For the first health event, the sign-in cards did not include the sex/gender question.
 b. Participants could indicate more than one reason as to their motivation for attending the community health event.

they were interested in learning more about ADRD. Word-of-mouth was also the most prominent way people heard about the event (54.5%).

In sum, attendees from both communities were, on average, aged approximately 50 years and predominantly female. Increasing interest in ADRD is reflected through the fact that word-of-mouth is the most common way to learn about the events and learning more about ADRD was the most frequent reason cited for attending. These data provide preliminary information about the ways in which MCCFAD engagement efforts link to segments of each community.

Participant Research Pool (PRP) Characteristics

At the conclusion of year 1, the MCCFAD PRPs included 100 Middle Eastern/Arab American and 117

Latinos. These numbers exceeded expectations, as we aimed to recruit 60 people from each community per year. We briefly describe the demographic characteristics of the PRPs (Table 2).

Middle Eastern/Arab American Community PRP

Members from the Middle Eastern/Arab American community who agreed to become part of our PRP ranged in age from 19-97, and were on average 50.9 years old. Identifying Middle Eastern/Arab Americans in Michigan using the 2014-2018 five-year American Community Survey²⁵ (first ancestry; N=31,516) shows that the older population is over-represented in the PRP. While those aged ≥60 years comprise 34% of the PRP, those aged ≥60 years are only 11% of the Middle Eastern/Arab American population in Michi-

Table 2. Participant research pool characteristics by community

	Arab American, N=100	Latino, N=117
	% (N)	% (N)
Demographics		
Average age (range)	50.9 (19-97)	48.7 (20-91)
< 20	1.2 (1)	0 (0)
20 – 39	27.4 (23)	39.0 (39)
40 – 59	34.5 (29)	34.0 (34)
60 – 74	23.8 (20)	14.0 (14)
≥75	13.1 (11)	13.0 (13)
% Female	71.1 (69)	73.3 (77)
Education		
< High school	8.3 (7)	34.4 (30)
High school	16.5 (14)	19.5 (17)
> High school	75.2 (64)	23.9 (40)
US born	39.0 (32)	45.5 (49)
Health		
Seeing a physician for diabetes	10.0 (7)	22.8 (23)
Seeing a physician for high cholesterol	25.3 (19)	25.7 (26)
Seeing a physician for hypertension	14.6 (11)	20.8 (21)
Seeing a physician for depression	8.6 (6)	25.5 (26)
Concern about change in memory	23.1 (18)	20.0 (17)

health, high cholesterol (25.7%), depression (25.5%), diabetes (22.8%), and hypertension (20.8%) were reported most frequently. Yet, approximately one fifth (20.0%) of PRP members reported concern about changes in their memory.

CLRC Assessment

The first year of activities assessment identified three key principles to guide future activities: 1) the critical value of strengthening connection with community leaders; 2) the need for paying closer attention to diversity within the population; and 3) the importance of language and semantic choices made when communicating with community members.

Community Connections

Over the course of our first year, evidence from community health event attendance demonstrated that connecting with community leaders prior to events led to high impact results. Community leaders include those who are well-respected and have high-profile positions (eg, directors or administrators at city government, religious leaders, community, non-profit and profit organizations). When ethnic community leaders recognized the importance of ADRD for the community and their organization, they embraced an ambassador role, using personal means to connect with individuals, which resulted in high event attendance. It also relieved tension around the stigma that surrounds the disease and research mistrust. This observation illuminated for MCCFAD that efforts to connect with leaders should include a series of interactions that establish why the

gan. Further, men and women each comprise 50% of the Middle Eastern/Arab American population in Michigan, but almost three-quarters (73.3%) of these PRP members are female. Education level of PRP participants was generally high; 75.2% reported more than a high school education, however, the majority of Middle Eastern/Arab American in Michigan are high school graduates. The majority (61%) of our participants are born outside of the United States. In terms of health, chronic illnesses reported with the highest frequency included high cholesterol (25.3%), hypertension (14.6%), diabetes (10%), and depression (8.6%). Almost one quarter (23.1%) of PRP members reported concern about changes in their memory.

Latino Community PRP

Community members who agreed

to become part of our Latino PRP ranged in age from 20-91 and were, on average, 48.7 years old. The 2014-2018 five-year American Community Survey²⁵ (using the Hispanic ethnicity question; N=484,568) indicates that adult women comprise 49.2% and men 50.2% of the Latino population, and those aged ≥60 years are 7.8% of the Latino population in Michigan. In our Latino PRP, 71% of respondents were women and the older population (aged ≥60 years) was over-represented comprising 27%. The education of those reached through the PRP survey skewed toward lower levels relative to the overall Latino population in Michigan. About one quarter (24%) of the Latino PRP reported more than a high school education compared with 44% of Latinos in the state. The majority (54.5%) of Latinos in the PRP are born outside of the United States. In terms of

Table 3. Identified missteps and solutions

Misstep	Solution
Community connections	Identify leaders (not only organizations). Clarify MCCFAD aims and goals.
Diversity (eg, socioeconomic and religious)	Rotate location of community events.
Semantics/language use	Arabic and Spanish translations/interpretations. Do not assume bilingualism.

issue of ADRD is important and significant for their community. Community liaison activities were shifted to first identify leaders (not only organizations) that have community reach, and second, conduct a series of interactions with those leaders to clarify MCCFAD aims and goals. This approach ultimately led community leaders to recognize the importance of ADRD research and the need for representation of their communities in ADRD research. Empowering community leaders with ADRD knowledge provides sustainable engagement with the community as it establishes a foundation for future community events, and encourages community member participation in research.

Two key insights were gained from the partnership with the Alzheimer's Association (AA): 1) MCCFAD's efforts to establish a community engagement structure by capitalizing on a partnership between a non-profit organization and academia facilitates mutual support for the Latino community, providing continuity in outreach efforts in the event that either the non-profit or academia undergoes changes, challenges and/or restructuring; and 2) MCCFAD's identification of Middle Eastern/Arab Americans as an important and necessary community to recognize concerning ADRD provided a unique opportunity to

make Middle Eastern/Arab American visible to the AA. Beyond inviting a Middle Eastern/Arab American representative from the AA to join our CAB, MCCFAD invited AA educators to deliver health event talks, and provided Arabic translations for some of the AA health education material (eg, 10 early signs and symptoms of Alzheimer's). Ultimately, the partnership introduced new paths of community engagement for both communities.

Diversity

MCCFAD activities recognize that the terms Arab American and Latino represent pan-ethnic terminology referring to heterogeneous groups of people. The term Arab American represents individuals from 22 countries in west Asia and North Africa. Further, community diversity exists regarding religion (eg, both Christian and Muslim) as well as ethnicity (eg, Chaldeans), which sometimes makes using the term Arab American alone problematic.²⁶ Interactions with the community and CAB feedback revealed that in order to be more inclusive, the language used sometimes needed to shift, for example, using the term Middle Eastern in conjunction with Arab American. The Latino community includes individuals from 19 coun-

tries in North, Central, and South America and the Caribbean. Further, the US citizenship status of Puerto Ricans provides a different immigration experience compared to other Latino subgroups. Interactions with the community and CAB feedback revealed that in Grand Rapids the use of Latino or Latinx was preferred over the term Hispanic. Hence, national origin issues in need of attention within both communities emerged over the course of first year activities.

MCCFAD also considered locational diversity while assessing year one events. Two activities were undertaken to address this shortcoming. First, zip code data collected on sign-in cards were analyzed to identify the presence of geographies underrepresented at our events and in our PRPs. By rotating the location of events, we attempted to address residential socio-economic variations and, in the Middle Eastern/Arab American community, religious diversity. For example, though outreach occurred across the community, we held community events at a mosque one month, and a church the next. This approach ensured diverse segments of the community were included in our efforts. Further, broadening and expanding connections through our CABs occurred by reviewing composition and recruiting new mem-

bers. For the Middle Eastern/Arab American community, diversifying CAB membership facilitated connection to community leaders representing distinct Arabic dialects, cultural practices, and preferences. Community liaisons were also a key resource for identifying new and appropriate venues for community health events.

More effort to connect with Middle Eastern/Arab Americans from Yemen was identified as a need given

Our team successfully initiated the creation of Participant Research Pools within the metro-Detroit Middle Eastern/ Arab American and Grand Rapid Latino communities, exceeding initial recruitment goals.

that they constitute one of the most numerous national origin groups in metro-Detroit.²⁷ As a result, CAB membership changed (some members rotated off and others rotated on) following the first year to ensure Yemeni segments of the Middle Eastern/Arab American population were represented. Similarly, for the Latino community more effort connecting with Afro-Latinos was identified as an area to

increase diversity of the Latino PRP membership. Strategic partnerships with other community organizations, such as the Urban Core Collective which engages Afro-Latinos residents, were established to increase participation of Afro-Latinos and expand MCCFAD's reach. In West Michigan, we also had the opportunity to expand to Holland, a city with a large population of Latinos (22.75%).²⁸

Recognizing that lower socioeconomic populations can be hard to reach,²⁹ MCCFAD initiated new connections and partnerships with schools. Beyond religious institutions and community organizations, schools appear to serve as a familiar and welcoming space to reach a broader representation of the community.^{30,31} Holding events at places where children are served represents a convenient and accessible location that provides opportunity to connect with more socioeconomically diverse parts of the community.

Semantics and Language Use

The language used to describe topics of discussion as well as the activities planned arose as matters in need of attention during the first year. We learned at one of our health learning events that the clinical word for dementia, translated into Arabic ("kahraf"), has an insulting and derogatory meaning. Arabic speakers use the word in everyday language as a way to suggest that someone has lost their mind and therefore is appropriate to ridicule.³² This issue arose at one of our community health events when a Middle Eastern/Arab American physician used "kharaf" to refer to dementia. A community member

strongly objected. Discussions with the CAB ensued as to alternatives, which included adopting the phrase in Arabic "Alzheimer's and related diseases." Yet, MCCFAD also recognized that our role is to address and reduce stigma around dementia. Community events, therefore, now include a direct reference to the stigma by placing the word "symptoms" in conjunction with the word dementia ("symptoms of dementia" or "aerad al-kahraf"). Using the "symptoms of dementia" terminology and refraining from using "kharaf" as a descriptor is in line with person-first language that linguists advocate to be used when describing diagnosis.^{33,34} Further, as a corrective measure suggested by the CAB, MCCFAD enlisted the help of Middle Eastern/Arab American university students to develop a short skit that draws attention to recognizing dementia as symptoms of disease rather than indication of having lost his/her mind.

The language used to refer to planned community health learning events also evolved after the first year in the Middle Eastern/Arab American community. Recognizing that events were drawing highly educated participants, it was suggested that calling our event a "learning opportunity" may not resonate with many segments of the Middle Eastern/Arab American community, not only because of varying education levels, but also because of the didactic connotation a learning event implies. Discussions ensued with the CAB, and the cultural norm of visiting neighbors for coffee arose as the feeling or image to project. Coffee traditions in Middle Eastern/Arab culture

are strong,³⁵ including the history of coffee houses where men historically gathered to discuss politics, or visiting with neighbors among women where serving coffee constitutes a major and necessary part of welcoming the visit. Drinking coffee is a key means of socialization in Middle Eastern/Arab culture, and is a central part of showing hospitality.³⁶ As a result, all Middle Eastern/Arab American "community health learning events" are now referred to as "community coffee times."

Health education meetings for the Latino community were conducted in Spanish or English, depending on the clients/participants that our community partner organizations serve. At the Hispanic Center of West Michigan, the health education meeting was conducted in Spanish, but with the Latino Community Coalition and Latinx Network, which brings together young adult professionals, the activity was conducted in English. Based on the interaction with these community groups, we realized that a large proportion of younger adults are second generation in Grand Rapids and speak only English, in part, due to the stigma associated with speaking Spanish in a very conservative area of Michigan. This likely contributed to the shift to English only at home, that is, to avoid what was widely perceived as a disadvantage. This group of young adult Latinos, between aged 30 and 45 years, are monolingual (English), but highly active and vocal on issues that affect the Latino community. Thus, the expectation evolved that any educational material developed should be in both English and Spanish.

CONCLUSION

The MCCFAD team successfully initiated the creation of PRPs within the metro-Detroit Middle Eastern/Arab American and Grand Rapid Latino communities, exceeding initial recruitment goals. Assessment activities conducted during the first year provide preliminary evidence of similarities and differences between and within both Middle Eastern/Arab American and Latino communities in Michigan. Results led to an approach that recognized the importance of communicating with community leaders about ADRD risks and resources, as well as attending more closely to both within-group diversity and the effects of semantics/language use. The community based participatory research model used by MCUAAAR²¹ appears to have elements that effectively apply to both Middle Eastern/Arab American and Latino communities. Yet, unique cultural and contextual elements in each community of focus require special considerations as MCCFAD seeks to engage, recruit and retain research participation. We worked closely with community partners to quickly address and modify our methods to address unanticipated challenges as they arose. Time will tell whether PRP members enroll in future research studies. Nevertheless, our experience illustrates the utility and adaptability of the MCUAAAR model, which may be replicated around the nation as a critical step to diversifying the pool of potential research participants for ADRD studies.

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CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Ajrouch, Vega, Antonucci, Webster; Acquisition of data: Ajrouch, Vega, Antonucci, Tarraf, Webster, Zahodne; Data analysis and interpretation: Ajrouch, Vega, Zahodne; Manuscript draft: Ajrouch, Vega, Antonucci, Tarraf, Webster, Zahodne; Statistical expertise: Ajrouch, Webster; Acquisition of funding: Ajrouch, Vega, Antonucci, Zahodne; Administrative: Ajrouch, Vega, Antonucci, Tarraf, Webster; Supervision: Ajrouch, Vega

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