National Institute on Aging's Alzheimer's-related Resource Centers for Minority Aging Research (AD-RCMARs)

Melissa S. Gerald, PhD

Division of Behavioral and Social Research (BSR)

National Institute on Aging (NIA)

melissa.gerald@nih.gov





RCMAR Objectives

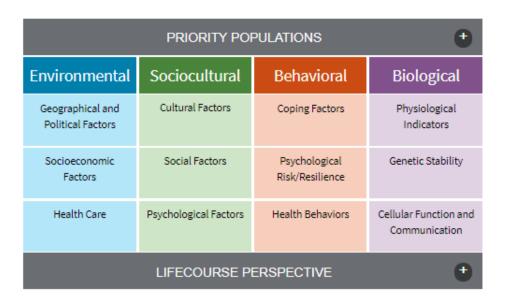
- Enhance the diversity of the aging research workforce by mentoring promising scientists from under-represented groups for sustained careers in aging research in priority areas of social, behavioral, and economic research on aging
- Develop infrastructure to promote advances to increase the number of researchers focused on the health and well-being of minority elders





NIA Health Disparities Research Framework

- Hispanics/Latinos
- American Indians/Alaskan Natives
- Blacks/African Americans
- Asian Americans
- Native Hawaiians + Other Pacific Islanders
- Socioeconomically Disadvantaged Populations
- Rural Populations
- Disability Populations
- Sexual and Gender Minorities



Behavioral and Social Research on Alzheimer's Disease and Related Dementias

Social, behavioral, psychological, and economic research at the individual, dyadic, and population level





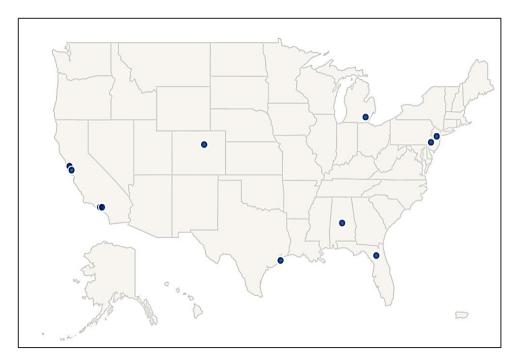


Resource Centers for Minority Aging Research Bridging the Gap between Health Disparity Research and Successful Minority Aging





AD n=8





















- The Johns Hopkins Alzheimer's Disease Resource Center for Minority Aging Research
- Michigan Center for Contextual Factors in Alzheimer's Disease (MCCFAD)
- Columbia Center for Interdisciplinary Research on Alzheimer's Disease Disparities (CIRAD)
- San Diego Resource Center for Advancing Alzheimer's Research in Minority Seniors (ARMS)
- Native Alzheimer's Disease Resource Center for Minority Aging Research (NAD)
- Carolina Center on Alzheimer's Disease and Minority Research (CCADMR)
- USC AD-Resource Center for Minority Aging Research (US)
- Rio Grande Valley Alzheimer's Resource Center for Minority Aging Research: Partnerships for Progress



RESEARCH ARTICLE OPEN ACCESS

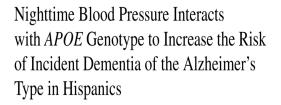
Predictors of Incident Mild Cognitive Impairment and Its Course in a Diverse Community-Based Population

Milou J. Angevaare, MD, Jet M.J. Vonk, PhD, Laiss Bertola, PhD, Laura Zahodne, PhD, Caitlin Wei-Ming Watson, MSc, Amelia Boehme, PhD, Nicole Schupf, PhD, Richard Mayeux, MD, Mirjam I. Geerlings, PhD, and Jennifer J. Manly, PhD

Neurology® 2022;98:e15-e26. doi:10.1212/WNL.000000000013017

Carrachandan

Dr. Manly jjm71@cumc.columbia.edu



Jesus D. Melgarejo^{a,b}, Daniel C. Aguirre-Acevedo^c, Ciro Gaona^a, Carlos A. Chavez^a, Gustavo E. Calmón^d, Eglé R. Silva^d, Gabriel A. de Erausquin^{c,f}, Mario Gil^{f,g}, Luis J. Mena^h, Joseph D. Terwilliger^{i,j,k,l}, Humberto Arboleda^{m,a}, Nikolaos Scarmeas^{o,p}, Joseph H. Lee^{j,o,q} and Gladys E. Maestre^{t,f,f,s,a}



SYSTEMATIC REVIEW published: 24 December 2021

Genetic Risk Factors for Alzheimer's Disease in Racial/Ethnic Minority Populations in the U.S.: A Scoping Review

Lindsey Rubin¹, Lucy A. Ingram^{1*}, Nicholas V. Resciniti², Brianna Ashford-Carroll¹, Katherine Henrietta Leith¹, Aubrey Rose³, Stephanie Ureña¹, Quentin McCollum⁴ and Daniela B. Friedman¹



Featured Article 🔓 Full Access

Differences in service utilization at an urban tribal health organization before and after Alzheimer's disease or related dementia diagnosis: A cohort study

Krista R. Schaefer 🔀, Carolyn Noonan, Michael Mosley, Julia Smith, Donna Galbreath, David Fenn, Renee F. Robinson, Spero M. Manson



Sleep and neurocognitive decline in the Hispanic Community Health Study/Study of Latinos

Alberto R. Ramos M. Wassim Tarraf, Benson Wu, Susan Redline, Jianwen Cai, Martha L. Daviglus, Li Gallo, Yasmin Mossavar-Rahmani, Krista M. Perreira, Phyllis Zee, Donglin Zeng, Hector M. Gonzalez ... See fewer authors

First published: 06 January 2020 | https://doi.org/10.1016/j.jalz.2019.08.191 | Citations: 4



Innovation in Aging
cite as: Innovation in Aging, 2022, Vol. 6, No. 2, 1–10
https://doi.org/10.1093/geroni/igab060
Advance Access publication December 30, 2021



Original Research Article

The Influence of Race and Gender on Receiving Assistance With Daily Activities Among Older Americans

Chanee D. Fabius, PhD,* Lauren J. Parker, PhD, MPH, and Roland J. Thorpe, PhD



Ethnicity & Disease

Ethn Dis. 2020; 30(Suppl 2): 765-774.

Published online 2020 Nov 19. doi: 10.18865/ed.30.S2.765

PMCID: PMC7683026

PMID: <u>33250623</u>

Partnering with Middle Eastern/Arab American and Latino Immigrant Communities to Increase Participation in Alzheimer's Disease Research

Kristine J. Ajrouch, 1 Irving E. Vega, 2 Toni C. Antonucci, 3 Wassim Tarraf, 4 Noah J. Webster, 3 and Laura B. Zahodne 5

JOURNAL ARTICLE ACCEPTED MANUSCRIPT

What Structural Racism Is (or Is Not) and How to Measure It: Clarity for Public Health and Medical Researchers 8

Lorraine T Dean **⋈**, Roland J Thorpe Jr

American Journal of Epidemiology, kwac112, https://doi.org/10.1093/aje/kwac112

Published: 05 July 2022 Article history ▼



CURRICULUM, INSTRUCTION, AND PEDAGOGY
published: 29 June 2021
doi: 10.3389/fpubh.2021.671956



Responding to the Call: Building a Training Program to Diversify the Academy in Alzheimer's Disease Research

Lucy Annang Ingram 1*, Marvella E. Ford², Christiana L. Johnson¹, Brianna Ashford-Carroll¹, Quentin McCollum³, Daniela B. Friedman 1† and Sue Ellen Levkoff³

This Issue Views 1,898 | Citations 3 | Altmetric 45

Invited Commentary | Neurology

July 6, 2021

Inclusion of Underrepresented Groups in Preclinical Alzheimer Disease Trials—Opportunities Abound

Jennifer J. Manly, PhD¹; Andrea Gilmore-Bykovskyi, PhD, RN²; Kacie D. Deters, PhD³

≫ Author Affiliations | Article Information

JAMA Netw Open. 2021;4(7):e2114606. doi:10.1001/jamanetworkopen.2021.14606

Health.Psychology Alaska.Native community.based.participatory.research workforce.needs National.Institute.on.Aging career.development Death.Rate collaborative.environment Research.Institute Hispanic-serving.Institution minority.health Diverse.Workforce Neuropsychology Cultural.Diversity brain.health Universities Underrepresented. Minority resilience New.York.City racial.minority Alzheimer's.disease.risk Textiles Family.Caregiver Scientist Arabs Resources dementia.risk Behavioral.Research Dementia Vascular.Dementia South.Texas Homes.for.the.Aged Underrepresented. Groups Alzheimer's.disease.related.dementia American.Indians social.health.determinants New.York physical.conditioning African. American Pilot.Projects Alzheimer's. Disease Latino Principal.Investigator South.Carolina recruit Older.Population Cities Minority-Serving.Institution Discipline Minority Aging education.research educational.atmosphere disease.registry Surgeon Chippewa Pacific. Island. Americans Communities older.driver Academic.Medical.Centers Observational.Study Texas health.disparity healthy.aging early.life.adversity social.culture social Medical.center ethnic.minority.population undergraduate.research Vocational.Guidance Discipline.of.Nursing health.economics service.delivery Research.Support Neighborhood. Health. Center Cognitive.aging Hispanic.Community.Health.Study/Study.of.Latinos interdisciplinary.collaboration Faculty Remunerations Study.of.Latinos Hispanic.Americans California Social.Network distinguished.professor sociodemographics community.organizations Capsicum population.based



Inside an AD-RCMAR



Leadership & Administrative Core



AD-RCMAR Scientist

Optional Cores

- Analysis Core
- Community

 Liaison and
 Recruitment

 Core



REC Resources

- Long-term mentorship and Support
- Training activities
- Educational activities
- Professional development opportunities
- Community engagement
- Networking opportunities & events



Pilot funding Primary or secondary data



Inside the CC

- Provides logistical support to RCMAR Centers
- Ensures interaction between Centers
- Oversees dissemination activities
- Maintains Program data





RCMAR Resources











Measurement



Annual Meeting Files

] Q

1 of 7

SCIENTIST HIGHLIGHTS

The RCMAR Program has now grown to over 400 scientists! Scientists receive funding and mentoring at one of our 18 sites. Meet some of our scientists and their work below.



SCIENTIST HIGHLIGHT: Lan Đoàn, PhD, MPH (CICADA RCMAR

In this week's Scientist Highlights, we feature Lan Đoàn, PhD, MPH, who became a CICADA RCMAR Scientist in In this week's Scientist Highlights, we 2021. Dr. Đoàn's work is centered on feature Luciana Mascarenhas and has focused on cardiovascular NAD RCMAR Scientist in 2020. Dr.



Scientist Highlight: Luciana Mascarenhas Fonseca, PhD (AD-NAD

the structural determinants of health Fonseca, PhD, who became an AD-



"Cynthia" Li, PhD, OTR, (UTMB-Texas

RCMAR Webinars

Getting the Most Out of Your Mentoring Relationships. Speaker: Roger B. Fillingim

Optimizing Mentoring Experiencing, Part II: Addressing Challenges that Arise. Speakers: Anna Napoles, Roger Fillingim, and Roland Thorpe

The NIH Review Process: Perspectives from a RCMAR Scientist. Speakers: Roger Fillingim, Alison Moore, Roland Thorpe, and Annie Nguyen





Resources from RCMAR Sites

Articles and other resources on topics relevant to RCMAR scientists, including: career development topics, grant writing resources, social determinants of health disparities, working with minority populations, community engagement, measurement methods and more.

YouTube Channel



The RCMAR YouTube Channel has a library of webinars, including topics like:

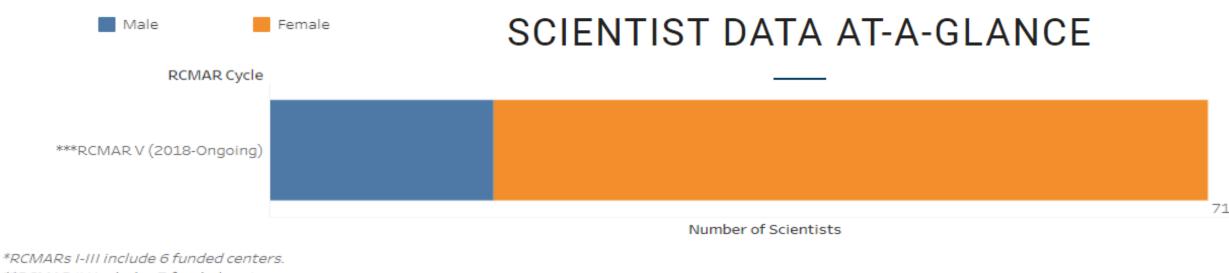
- Tools for Understanding Contextual Factors that Affect the Health of Diverse Older Adults. Speakers: Patricia Jones, NIA; Amy Kind, MD, PhD, University of WI; Jennifer Ailshire, PhD, USC-AD RCMAR
- Imposter Thoughts: Let's Talk about Them. Speaker: Ericka Boone, PhD, NIH; Roland Thorpe, PhD, JHAD-RCMAR; Brandon Brown, MD, MPH, CHIME; Mirella Diaz-Santos,
- Best Practices for Using and Obtaining Diversity Supplements. Speaker: Maria G. Carranza, PhD, NIA
- NIH Repays your Student Loans: And In-Depth Overview of the NIH Loan Repayment Programs. Speaker: Ericka Boone, PhD, NIH
- · Additional video resources from RCMAR sites

And more!

CONNECT WITH SCIENTISTS

Looking for a mentor and/or collaborators on aging studies? Connect with the individuals in our RCMAR Network!

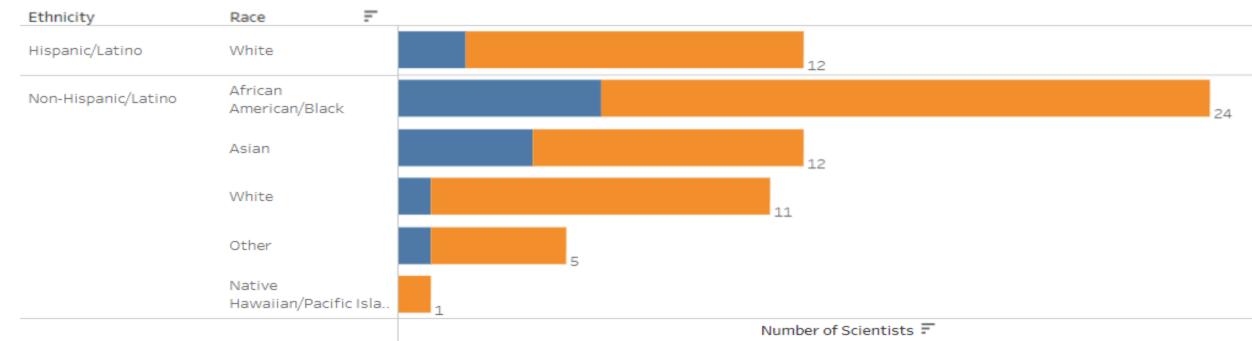
The individuals listed below are all our funded scientists – from all cohorts and across all our centers. Use the "email" function to reach out to them directly via email, or search for their current work using NIH Reporter.





^{**}RCMAR IV includes 7 funded centers.

^{***}RCMAR V includes 18 funded centers.











NIH Repays Your Student Loans: An In-Depth Overview of the NIH

Resource Centers for Minority Aging Research (RCMAR) - Online Event

Planning for Compliance with CONSORT Requirements in Cli

Resource Centers for Minority Aging Research (RCMAR) - Online Event



hard-won knowledge



Ethnicity



MCUAAAR/PRBA Summer





Have you subscribed to our YouTube Channel!? Here you can find all of our webinars, professional development series, and more...Subscribe to see what we are up to!



Getting the Most Out of Your

Mentoring Relationships

Dr. Roger B. Fillingim

Resource Centers for Minority Aging Research

RCMAR Webinar: Race and Racism in our Research Resource Centers for Minority Aging Research (RCMAR) - Online Event

Loan Repayment Programs



The Michigan Center for African American Aging Research (MCUAAAR) and Program for

Mentoring Program

Research on Black Americans PRBA) is pleased to announce its 2021 Summer Mentoring Workshop on African American Research. The workshop is virtual and will take place June 2-4, 2020. Drs. Robert Joseph Taylor, Khari Brown and Amanda Woodward are the program faculty. The



RCMAR of the Alzheimer's disea

Health Disparities in Older Adults

Marvella E. Ford, Ph.D.

Johns Hopkins Alzheimer RCMAR 5-15 Webinar The Center is based in t

Resource Centers for Minority Aging Research

Behavioral & Social Research & NIH

Clinical Trial Guidance

Dr. Partha Bhattacharyya

Dr. Lisa Onken

CCADMR Webinar: COVID-19 and the Social Determinants of

2:24 AM · Jan 14, 2021 · Twitter Web App

Michigan Center for Urban African American Aging Research

Strategies for Successful Recruitr and Retention of Minority El HAD SHIPLE BOOK AND AFTER HER PROPERTY OF THE AFTER A SHIPLE A SHIPLE AFTER A SHIPLE A SHIPLE AFTER A SHIPLE A SHIPLE

Identify successful strategies for supporting ongoing retention of minority elders in health research.

Identify successful strategies and NIA tools for supporting engagement of minority elders in health research

Describe the major barriers to participation in health research for minority elders of various race/ethnicities

Optimizing Mentoring Experiences, Part II: Addressing Challenges that Arise

"This meeting is being recorded and will be wosted to the RCMAR website in the future

Pivoting During the Pandemic: Biopsychosocial Considerations in Neurodegeneration RCMAR National Coordinating Center Starting soon! Hope you can join us. RCMAR National Coordinating Center @RCMARCC - May 21 Join us on June 11th at 9am PT for our free RCMAR webinar on Best Practices for Using and Obtaining Diversity Supplements! Register here ow.ly/xoat50ESu0n

Webinar: Best Practices for Using & Obtaining Diversity Supplements

dent careers in aging and geriatric earch and meet NIA's goal to enhance diversit Carranza will present the best practices for

MCCFAD TORS IN ALTHEINER'S DISPASE

Summer Data Immersion (SD



RCMAR CHIME and CTSI

Twenty Years, Sixty Scientists, over 500

Publications! Join the RCMAR CHIME

Summer 2021 Scientific Retreat - Register Today

WEBINAR (APRIL 23, 2021)

RC AR **TOOLS FOR UNDERSTANDING CONTEXTUAL FACTORS** THAT AFFECT THE HEALTH OF DIVERSE OLDER ADULTS

atricia Jones, DrPH, MPH, MS. amy Kind, MD, PhD ifer Allshire PhD



family as we reflect on our upcoming 20th anniversary as a center! Download Flyer Current Agenda PDF Register







Wednesday, March 24 | 1pm EST

Robert Taylor, Belinda Tucker, and Phillip Bowman

M INSTITUTE FOR SOCIAL RESEARCH

Michigan Center for Urban African American Aging Research









Journal of Racial and Ethnic Health Disparities https://doi.org/10.1007/s40615-022-01338-y

Prevalence of Dementia in American Indians and Alaska Natives Compared to White, Black, and Hispanic Medicare Beneficiaries: Findings from the National Health and Aging Trends Study

Heehyul E. Moon¹ · Joseph Keawe'aimoku Kaholokula² · Richard F. MacLehose³ · Sunshine M. Rote¹

JOURNAL ARTICLE

Educational Benefits and Cognitive Health Life Expectancies: Racial/Ethnic, Nativity, and Gender Disparities •

The Gerontologist, Volume 61, Issue 3, April 2021, Pages 330–340, https://doi.org/10.1093/geront/gnaa112



ournals of Gerontology; Social Sciences i Soc Sci, 2020, Vol. 15, No. 7, e105-e112 doi:10.1093/geronb/gbz046 vance Access publication April 25, 2019

DOI: 10

Original Article

Racial and Educational Disparities in Dementia and Dementia-Free Life Expectancy

Mateo P. Farina, MA,1.* Mark D. Hayward, PhD,1 Jung Ki Kim, PhD,2 and Eileen M. Crimmins. PhD2

Received: 28 July 2021 Revised: 17 September 2021 Accepted: 21 September 2021 Published online: 7 December 2021

DOI: 10.1002/dad2.12250

RESEARCH ARTICLE



Cognitive screening with functional assessment improves diagnostic accuracy and attenuates bias

David Andrés González^{1,2} | Mitzi M. Gonzales^{1,2} | Kyle J. Jennette³ | Jason R. Soble^{3,4} | Bernard Fongang^{2,5}





FEATURED ARTICLE ☐ Full Access

Education differentially contributes to cognitive reserve across racial/ethnic groups

Justina F. Avila, Miguel Arce Rentería, Richard N. Jones, Jet M. J. Vonk, Indira Turney, Ketlyne Sol, Dominika Seblova, Franchesca Arias, Tanisha Hill-Jarrett, Shellie-Anne Levy, Oanh Meyer, Annie M. Racine, Sarah E. Tom, Rebecca J. Melrose, Kacie Deters, Luis D. Medina, Carmen I. Carrión, Mirella Díaz-Santos, DeAnnah R. Byrd, Anthony Chesebro, Juliet Colon, Kay C. Igwe, Benjamin Maas, Adam M. Brickman, Nicole Schupf, Richard Mayeux, Jennifer J. Manly

First published: 22 August 2020 | https://doi.org/10.1002/alz.12176 | Citations: 19



Featured Article 🔓 Full Access

Longitudinal analysis of dementia diagnosis and specialty care among racially diverse Medicare beneficiaries

Emmanuel Fulgence Drabo, Douglas Barthold, Geoffrey Joyce, Patricia Ferido, Helena Chang Chui

🔼 Lesley A. Guareña 🧠 듣 📊 @l_guarena · Apr 26

San Diego AD RCMAR @SD_ADRCMAR representing at the @alzassociation #LatinoSymposium in Bonita Springs, FL!! Powerful research presented by Drs. #MonicaMDiaz #ArianaStickel #MariaAranda @solincalab



Kacie D and Ángela Gutiérrez



Getting a great deal of valuable information from the 2019 **RCMAR** Recruitment and Retention of Minority Elders: An NIA Priority Area @geronsociety

Dr. Jennifer Manly @ManlyEpic · Nov 13, 2019

Kristine Ajrouch of @mccfad has some critical lessons learned to share from their experience recruiting Arab Americans and Latinx people in the Detroit metro area for research on ADRD, #GSA2019

Lessons Learned

Dr. Jennifer Manly @ManlyEpic · Mar 31

Aging & Health Equity Scholars: Check out this YouTube playlist of completed works by **#RCMAR** Scientists! The **RCMAR** Centers around the US award pilot funds to researchers from underrepresented backgrounds who with minoritized older adults. **#RCMARAnnual** 2022

HEALTH DISPARITIES II
-ASSOCIATED DEMENT
SOUTH CAROLINA
Movique J. Brown, P.PO, NIPH
Descripted of differentiates and floatistics

youtube.com

2022 RCMAR Annual Meeting: Completed Works
Presentations



San Diego AD-RCMAR @SD_ADRCMAR · Jun 2

We are thrilled to announce the new cohort of SD AD RCMAR scientists! Learn more about them and their pilot projects here: knit.ucsd.edu/sandiegoadrcma...

SAN DIEGO AD-RCMAR RECTION SAN DIEGO

Lauren Brown, PhD, MPH, Assistant Professor, School of Public Health, San Diego State University Project Title: Examining Cohort Variation in Chronic Stress,

Anthropometric, Biological, and Cognitive Function of Black and White Older Adults Across Age Cohorts



Krystal Kittle, PhD, Postdoctoral Research Fellow, School of Public Health, Social & Behavioral Health, University of Nevada, Las Vegas Project Title: Racial/Ethnically Diverse Sexual and Gender Minority Caregivers of Individuals with Alzheimer's Disease and Related Dementias

Sabrina Smiley, PhD, Assistant Professor, School of Public Health, San Diego State University

Project Title: A Qualitative Study Designed to Explore the Experience of Social Isolation, Loneliness, and Cognitive Function among Older Black Individuals with Cocaine-Use Disorder (CUD)



Lize Tibiriçá, PsyD, T32 Postdoctoral Fellow, Stein Institute for Research on Aging, UC San Diego, Department of Psychiatry Project Title:The Effects of Perceived Discrimination and Nativity Status on Cognitive Decline among Hispanic/Latin American Older

alison moore @AlisonMooreMD · Jul 1, 2021

Hear, hear! They are bright stars whom we were fortunate to have in our program and thrilled to have as forever members of the **rcmar** community.

@RCMARCC

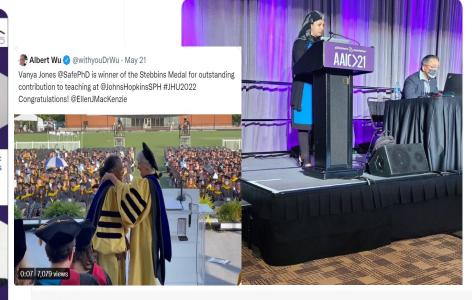
San Diego AD-RCMAR @SD ADRCMAR · Jun 30, 2021

We are beyond proud of our 2020-2021 graduating cohort of scientists @Talarousansh @Hparada @DrLG12 Zvinka Zlatar & Ariana Stickel. The future of aging research in underrepresented communities looks brighter because of you all!



Roland J. Thorpe, Jr @rolandjthorpe · Jul 30, 2021

Check out @JohnsCenter RCMAR Scientist @halima_amjad sharing results from her outstanding work at the first AD RCMAR symposius 2021 AAIC meeting @DrLRGuerrero @hillcv17 @RCMARCC



Dr. Ti

Dr. Tiffany Kindratt @tbkindratt · Nov 10, 2021

I'm so thankful to be part of this amazing group of MCCFAD Research Scientists! I am looking forward to many presentations over the next few days from other RCMAR scientists and mentors! #GSA2021 @Liz_Munoz @geronsociety @erica dim @mccfad @lzahodne @RCMARCC



Stress, Cognition, and Minority Healt

Chairs: Toni Antonucci & Laura Zahodne (University of Michigan)

Discussant: Melissa Gerald (National Institute on Aging)



GBA 2021 ANNUAL SCIENTIFIC MEE
Glasgios to Transform
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Disparities in cognition among US and foreign-born minority populations with and without diabetes

Presented by Tiffany Kindratt, PhO, MFW | November 16, 2021, Presentation Other Authoric Riverice J Clafe, PhO, MFW, Laura B Zahndee, PhO, Kristine Ayrouch, Ph

2021 G5A202

GERON SHITTS

Funding Opportunities Coming Soon!

Resource Centers for Minority Aging Research (RCMAR) Program

For details and deadlines:

Aging & AD/ADRD Centers (NOT-AG-22-023)

Coordinating Center (NOT-AG-22-024)







Thank you!



Melissa S. Gerald, PhD

Division of Behavioral and Social Research (BSR)

National Institute on Aging (NIA)

Email: melissa.gerald@nih.gov





National Alzheimer's Project Act (NAPA)

Kristine J. Ajrouch, PhD Professor of Sociology

July 25, 2022

Overview MCCFAD Goals

- Advance ADRD Science
- Increase ADRD Health Workforce
- A Healthy Society for All



ALZHEIMER'S DISEASE IN CONTEXT

Epidemiology of AD Health Economics of AD Culturally Sensitive AD Care

Executive Committee

Expert Advisory Board Community Based Older Adults, Caregivers and Health Professionals

ADMINISTRATIVE CORE

Oversight, Communication, Facilitate linkages

RESEARCH AND EDUCATION CORE

RCMAR Scientist Seminar
Mentoring and Career Development
Pilot Recruitment Plan
Pilot Studies
Core Activity Evaluation

COMMUNITY LIAISON & RECRUITMENT CORE

Share Research Results with Communities
Dissemination to Larger Scientific Community
Research Volunteer Directory

ANALYSIS CORE

Culturally Sensitive Measurement
Person and Variable Centered Approaches
Methods Dissemination

Dr. Kristine Ajrouch Director

Administrative Core Lead Community Liaison and Recruitment Core Lead

Dr. Laura Zahodne Co-Director

Research and Education Core Co-Lead Analytic Core Co-Lead

Dr. Noah Webster MCCFAD Faculty

Analytic Core Co-Lead

Dr. Briana Mezuk MCCFAD Area Expert Epidemiology of AD

Dr. HwaJung Choi MCCFAD Area Expert Health Economics

Dr. Toni Antonucci Co-Director

Research and Education Core Lead Administrative Core Co-Lead

Dr. Richard Gonzalez MCCFAD Faculty

Analytic Core Lead

Dr. Irving Vega MCCFAD Faculty

Community Liaison and Recruitment Core Co-Lead

Dr. Lindsay Ryan MCCFAD Area Expert

Epidemiology of AD

Dr. Sheria Robinson-Lane MCCFAD Area Expert Culturally Sensitive Care

Advance ADRD Science

Through a focus on unique communities Middle Eastern/Arab & Latino

Why these groups?

Risk and prevalence of AD greater compared to whites Growing immigrant communities Similar stresses & strong family ties Non/Traditionally considered underrepresented

Identify new pathways of risk and resilience



Research of, by and for the Community

Assumptions Better research through community involvement Involve community health care providers and all community members in outreach

Health education

activities will

participation in

facilitate

research

Resources

Activities

Immediate Outcomes

Long-term Outcomes

Elders

Academic researchers

Community Liaison

Community Advisory **Board (CAB)**

Community **Organizations**

Health Care Providers & Systems

Health education learning series

Monthly CAB meeting

Annual health reception

Semi-annual newsletter

CME opportunities **Latino & Arab American** adults attend activities

Latino & Arab American adults consent to join research volunteer directory

> **Health Care Providers** attend CME opportunities

Diverse samples for **ADRD** research

Enhanced understanding of ADRD

Skilled ADRD workforce

Society for All

Healthy

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

Research Volunteer Directory

RVD Members	Y1	Y2	Y3	Y4	Total
Middle Eastern/Arab	100	117	67	140	424
Latino	117	70	35	99	321
Total	217	187	102	239	745
					\ /



Advance ADRD Science

Community Based Scientists as Leaders have:

Trust of the community

Knowledge of cultural expressions

Awareness of local customs



Increase ADRD Workforce

Research Scientist (n=17)	2018-2023
Race/Ethnicity	
Arab/Middle Eastern	4
Latino	6
African American	4
<u>Institution</u>	
R1	14
R2	3
AD Area	
Epidemiology	11
Culturally Sensitive Care	6

Increase ADRD Workforce

Summer Data Immersion (SDI) n=98	2019-2022
Race/Ethnicity	
Arab/Middle Eastern	7
Latino	15
African American	22
<u>Position</u>	
Graduate Student	21
Post Doc	20
Assistant Professor	38





<u>Years</u>	<u>Manuscripts</u>	<u>Grants</u>
2018-2022	144	39

2019 SDI focused on ADRD epidemiology

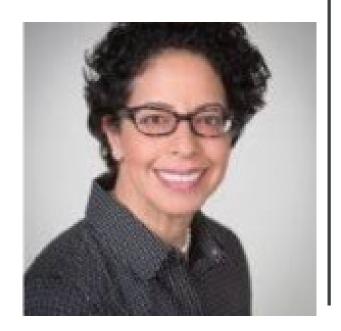
<u>Modeling Cognitive Aging in Context</u> – 5 manuscripts; *Research on Human Development*

2021 SDI focused on culturally sensitive ADRD care

ADRD Care in Context – 9 manuscripts in Journal of Gerontology: Social Science

2022 SDI focused on health economics

<u>The Costs of ADRD</u> – 7 manuscripts TBD





Study Title: The Epidemiology of Alzheimer's Disease and Related Dementias (ADRD) among Arab Americans



Innovation in Aging
cite as: Innovation in Aging, 2021, Vol. 5, No. 1, 1–9
doi:10.1093/geroni/igaa058
Advance Access publication November 24, 2020

OXFORD

Original Research Article

Prevalence of Self-reported Cognitive Impairment Among Arab American Immigrants in the United States

Florence J. Dallo, PhD, MPH,^{1,*,o} Tiffany B. Kindratt, PhD, MPH,^{2,o} and Laura Zahodne, PhD³

Research Design and Methods: We used 18 years (2000–2017) of National Health Interview Survey data (n = 228 985; ages ≥ 45 years). Weighted percentages, prevalence estimates, and multivariable logistic regression models were calculated.

Results: The age- and sex-adjusted prevalence of self-reported cognitive impairment was significantly higher among Arab American immigrants (9.7%) compared to U.S.-born and non-Hispanic White immigrants (~7.4%).



Marc Garcia, PhD
2019 Scientist
Assistant Professor
Department of Sociology
Syracuse University

Study Title: Age of Migration and Cognition: The Importance of Contextual Factors in Cognitive Aging Among Older Latinos in the United States

Age of Migration and Cognitive Function Among Older Latinos in the United States

Marc A. Garcia^{a,*}, Kasim Ortiz^b, Sandra P. Arévalo^c, Erica D. Diminich^d, Emily Briceño^e, Irving E. Vega^f, Wassim Tarraf^{g,*}

Methods: We used longitudinal biennial data from the Health and Retirement Study (HRS; 2006–2014) to fit generalized linear and linear latent growth curve models for: 1) global cognition (Modified Telephone Interview for Cognitive Status; TICS-M); 2) memory and attention subdomains of TICS-M; and 3) cognitive dysfunction. We also tested for sex modifications.

Results: In age and sex adjusted models, all Latino subgroups, independent of nativity and age of migration, had lower global and domain-specific cognitive scores and higher propensity of cognitive impairment classification compared to USB-NLWs. Differences between USB Latinos, but not other Latino subgroups, and USB-NLWs remained after full covariate adjustment. Latinas, independent of nativity or age of migration, had poorer cognitive scores relative to NLW females. Differences between all Latinos and USB-NLWs were principally expressed at baseline. Racial/ ethnic, nativity, and age of migration grouping was not associated with slope (nor explained variance) of cognitive decline.

Towards a Healthy Society for All

- Meeting the highest standards while creating new pathways
 - Recognizing need for traditional and non-traditional measures of ADRD risk and resilience
- Use non-traditional criteria to invest in future of RS from underrepresented communities
 - Not just R1, but R2 and possibly R3
 - Applied research results to realize real life impact

- Why scientists from within and without participate
 - Model collegiality, supportive networks for success
 - Navigating academia (teaching, research and service expectations)



Conclusions and Future Directions

- RCMAR model benefits/success
 - Longstanding commitment to making underrepresented groups visible in academia and research
 - Advancing the science of health and health disparities
- RCMAR Challenges
 - Underfunded compared to other NIA aging centers
 - Lack of high quality data with minority representation
- Importance of work through MCCFAD
 - Social and behavioral emphasis key to addressing ADRD disparities
 - Inclusive approach to addressing disparities by expanding categories/linking to other Centers
- Thereby Creating a Healthy Society for All



Ready to Launch: Experiences of a JHAD-RCMAR Scholar

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Johns Hopkins Bloomberg School of Public Health

Chanee Fabius















2018- Present

Areas of Research

- Racial, socioeconomic, and disease-specific (i.e., dementia)
 differences in networks of care (home care; family
 caregivers); care experiences of older adults and caregivers
- Effects of community-based long-term services and supports on quality of life across diverse groups of older adults
- Strengthening the home care workforce



Surveying Direct Care Agencies in Maryland to Examine Quality of Life of Older Medicaid Home and Community-Based Service Recipients with ADRD

Specific Aims

- 1. Survey Maryland direct care agencies about current practices, barriers, and opportunities to improve training of direct care workers of persons with ADRD.
- 2. To assess variability in Maryland direct care agencies' organizational characteristics and older HCBS recipients' quality of life outcomes.



Mentorship and Resources

Leadership

Dr. Roland Thorpe

Dr. George Rebok Mentorship team

Dr. Jennifer Wolff

Dr. Deirdre Johnston

Dr. Joe Gallo

Dr. Quincy Samus

Community Liaison and Recruitment Support

Dr. Janice Bowie

Analysis Support

Dr. Jeannie Leoutsakos



Engagement with other scientists

JHAD-RCMAR Professional Development Series: Work in Progress
"The Direct Care Workforce Supporting Medicaid-Enrolled Older Adults Living
with ADRD in the Community: Findings from a Statewide Survey"

Professional development series

Friday, March 11, 2022 1:00-2:00 pm EST via Zoom



Chanee Fabius, PhD
JHAD-RCMAR Cohort 3 Scientist

Open doors and new opportunities



• 2021 NIA IMPACT Collaboratory Career Development Award Recipient:

"Engaging and Integrating Direct Care Workers in Care Delivery for Persons Living with Dementia in the Community"

 K01 proposal: "Improving Information Sharing Between Family Caregivers and Home Care Aides Caring for Persons Living with ADRD" - submitted February 2022



Surveying Direct Care Agencies in Maryland to Examine Quality of Life of Older Medicaid Home and Community-Based Service Recipients with ADRD

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Background: What we know; what we don't know



Home and Community-Based Services

Goal is to delay or replace the need for nursing home services by allowing people to "age-in-place"

Administered through states' Medicaid programs (otherwise private pay)



The Direct Care Workforce

- Personal care aides, home health aides who help with routine daily activities
- Fastest growing workforce in the US / 4.5 million workers in the US
- Demand driven by population aging and change in supply in family caregivers
- Over-represented by women, racial/ethnic minorities, immigrants
- Low-wage job with minimal training
- Little known about direct care agencies' characteristics, supports, for direct care workers, or implications for older adults



Methods: How We Conducted This Study



Objectives

Fabius, C. D., Millar, R., Geil, E., Stockwell, I., Deihl, C., Johnston, M. D., Gallo, J., Wolff, J. L. (Revise and Resubmit). <u>Direct Care Worker Engagement and Experiences Caring for Older Adults with Dementia: Findings from a Statewide Survey of Direct Care Agencies.</u>

- 1. Compare attributes of older HCBS participants and Medicaid-financed direct care agencies in Maryland by dementia status.
- 2. Examine care experiences of older adults and family caregivers across Medicaid-financed direct care agencies.



Methods - Data: Survey of Direct Care Agencies

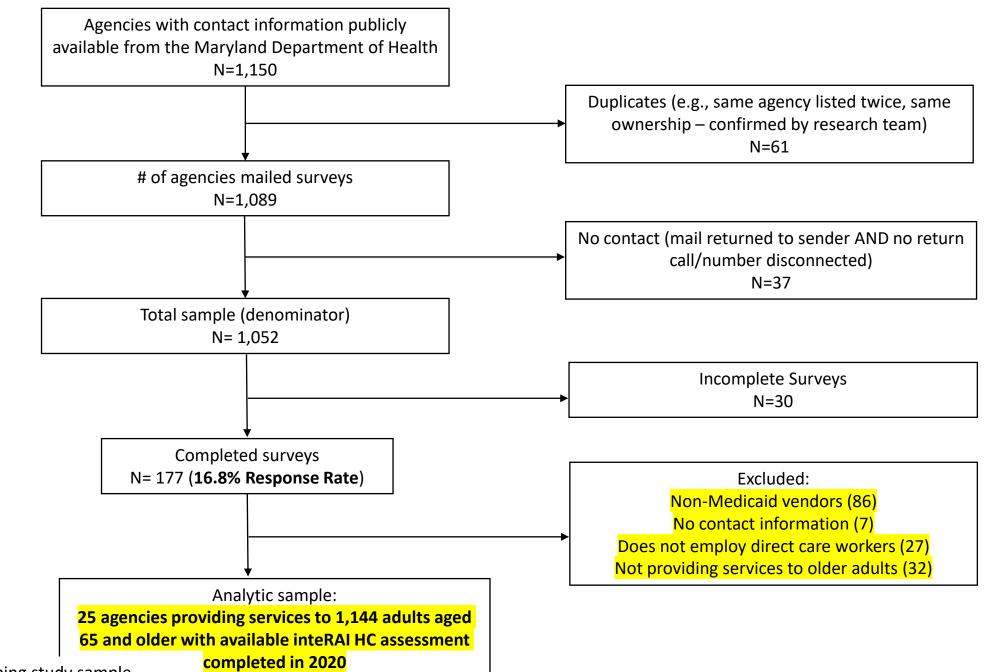
- Survey of Licensed Direct Care Agencies
 - Not Medicare Home Health; Primarily paid by Medicaid HCBS or private pay
 - Direct care agency/worker/client/ characteristics, direct care worker training requirements, roles related to health information technology, dementia-related challenges and supports
- Recruitment & Data Collection
 - Proof-of-Concept with the Maryland National-Capital Homecare Association
 - Multi-modal (e.g., US postal mail, phone, online)
 - Mailed surveys followed by two phone calls
 - February 2021 June 2021



Methods - Data: interRAI Home Care (HC) Assessment

- Completed by direct care agency nurses on annual basis
- Collects information about HCBS participants' function, social factors, caregiver burden, and health care utilization.
- Used to track changes that may warrant revisions to participants' service care plans.





Methods: Measures

Participant care experiences

- Low social engagement: 30 or more days since last able to participate in social activities of longstanding interest
- Hospitalization: any in the last 90 days
- Emergency room visit: any in the last 90 days

Caregivers' care experiences

- Feeling overwhelmed by HCBS participant's illness: yes/no
- Expresses feelings of distress, anger, or depression: yes/no
- Unable to continue caregiving: yes/no



Methods: Measures and Analysis

Participant characteristics

- Age
- Gender
- Marital status
- Race/ethnicity
- Disability
- Dementia (score of 12 or less on the Brief Interview of Mental Health [BIMS])

Direct care agency characteristics

- Agency tenure
- # of participants
- % of participants ages 65 and older
- Dementia related challenges
- Dementia-specific training
- Assistance with health information technology
- Dementia related supplemental services

Analysis: Descriptive; Pearson's chi-square and Student's t-tests

Results: Linking Direct Care Agencies to Maryland Medicaid HCBS Recipient Outcomes



Table 1. Sociodemographic, Disability, and Care Experiences, by Direct	Dementia	No Dementia
	53.8% (615)	46.2% (529)
Direct Care Agency Participant Characteristics, %		
Age		
65-74	<mark>19.2</mark>	<mark>25.7**</mark>
75-84	<mark>34.8</mark>	<mark>44.2</mark>
85+	<mark>46.0</mark>	<mark>30.1</mark>
Sex		
Male	28.6	25.0
Female	71.4	75.1
Race/Ethnicity		
Non-Hispanic White	<mark>64.9</mark>	66.4***
Non-Hispanic Black	<mark>14.0</mark>	<mark>20.8</mark>
Non-Hispanic Asian	<mark>16.8</mark>	<mark>10.6</mark>
Hispanic and other	<mark>4.4</mark>	<mark>2.3</mark>
Married Control of the Control of th	29.1	27.0
ADL Limitations, M (SD)	7.6 (1.7)	6.7 (1.9)***
Participant Care Experiences, %		
Low Social Engagement	62.9	60.3
Health care utilization		
Hospitalizations	7.5	8.1
Emergency room visits	8.9	7.8
Caregiver Care Experiences, %		
Caregiver is overwhelmed	<mark>16.9</mark>	<mark>8.3***</mark>

Note. **p<0.01, ***p<0.001. Among (N=1,144) older adults (65+) receiving Maryland Community Personal Assistance Services and Community First Choice services from (n=25) direct care agencies; Dementia defined as self-reported Alzheimer's Diseases and Related Dementias or a Brief Interview for Mental Status (BIMS) score of 12 or less; "Other" race/ethnicity includes American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, and those with more than one race selected.

3.0**

3.8**

Caregiver is distressed, angry, or depressed

Caregiver is unable to continue caregiving

	Dementia	No Dementia
	53.8% (615)	46.2% (529)
	615	529
<u>Direct Care Agency Characteristics, %</u>		
Years of operation		
Less than 1 year	2.0	2.3
1-4 years	2.9	4.7
5-9 years	12.7	9.1
10 or more years	82.4	83.9
Number of participants enrolled at this Agency		
<=50	9.1	12.3
51-100	12.5	10.2
>=100	78.4	77.5
Dementia related caregiving challenges		
Challenges managing dementia related behaviors	95.3	92.2
Issues communicating with participants with dementia	53.8	46.2
Issues with family	96.3	95.1
<u>Direct Care Agency Training and Supports, %</u>		
Dementia-specific direct care worker training	15.6	13.0
Direct care workers help with any health information technology	<mark>76.9</mark>	<mark>68.1***</mark>
View sections of electronic health record	<mark>75.9</mark>	<mark>67.5**</mark>
Perform health management tasks	12.7	11.0
Interact with clinicians	12.7	10.8
Dementia related supplemental services		
Any supplemental services	<mark>84.4</mark>	<mark>77.5*</mark>
Family caregiver dementia-specific training	<mark>15.6</mark>	<mark>11.3*</mark>
Referrals to other supportive services	<mark>78.5</mark>	<mark>69.8***</mark>
Information about other supportive services	<mark>78.4</mark>	<mark>67.1***</mark>

Note. **p<0.01, ***p<0.001. Among (n=1,144) older adults (65+) receiving Maryland Community Personal Assistance Services and Community First Choice services from (n=25) direct care agencies;. Alzheimer's Diseases and Related Dementias or a Brief Interview for Mental Status (BIMS) score of 12 or less

Table 3. Direct Care Agency Training and Supports, by Participant Care Experiences

	Low Social Engagement ^a			Hospitalizations			Emergency room visits		
	Yes	No		Yes	No		Yes	No	
	64.6% (706)	35.4% (387)		7.8% (89)	92.2% (1,055)		8.4% (96)	91.6% (1,048)	
	%	%	р	%	%	р	%	%	р
Dementia specific training required	<mark>16.2</mark>	<mark>11.1</mark>	0.02	<mark>23.6</mark>	<mark>13.7</mark>	0.01	<mark>22.9</mark>	13.7	0.01
Direct care workers assist with any health information technology	<mark>75.2</mark>	<mark>68.7</mark>	0.02	69.7	73.1	0.49	70.8	73.0	0.65
Direct care agency offers any supplemental services	83.4	<mark>76.7</mark>	<0.01	85.4	80.9	0.29	85.4	80.8	0.27

Among (n=1,144) older adults (65+) receiving Maryland Community Personal Assistance Services and Community First Choice services from (n=25) direct care agencies; Comparisons based on Pearson's chi-square tests. a. Missing data for low social engagement (n=51)



Table 4. Direct Care Agency Training and Supports, by Caregiver Experiences

	Caregiver is overwhelmeda			Caregiver is distressed, angry, or depresseda			Unable to continue caregiving ^a		
	Yes 12.9% (148)	No 87.1% (993)		Yes 4.6% (53)	No 95.4% (1,087)		Yes 4.6% (53)	No 95.4% (1,087)	
	%	%	р	%	%	р	%	%	р
Dementia specific training required	18.2	13.8	0.15	*	*	*	22.6	14.0	0.07
Direct care workers assist with any health information technology	<mark>81.8</mark>	<mark>71.5</mark>	<0.01	83.0	72.3	0.09	79.3	72.5	0.28
Direct care agency offers any supplemental services	90.0	<mark>79.9</mark>	< <mark>0.01</mark>	90.6	80.8	0.07	90.6	80.8	0.07

Among (n=1,144) older adults (65+) receiving Maryland Community Personal Assistance Services and Community First Choice services from (n=25) direct care agencies; Comparisons based on Pearson's chi-square tests. a. Missing data for caregiving is overwhelmed (n=3), distressed, angry or depressed (n=4), and unable to continue caregiving (n=4). *Unable to disclose values <10.



Discussion



Discussion

- Findings support earlier work that highlights vulnerable nature of community-dwelling older adults
- Opportunities to better include direct care workers in interdisciplinary care teams
- There are benefits of Medicaid HCBS for family and unpaid caregivers.
- Care experiences vary by dementia status.



Limitations

- Experiences of HCBS participants and caregivers in one state.
- Low survey response rate.
- Unable to determine whether surveys are completed with assistance of, or solely with caregiver.
- Unable to determine amount, frequency, and type of services older adults are receiving



Conclusion

- Findings have implications for home care delivery and way in which we understand the contribution of direct care agency and direct care worker characteristics in experiences of older adults and caregivers.
- Strengthening of HCBS is integral if policymakers and providers are to support families in the community.



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Collaborators







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Questions?

Thank you! Email: <u>cfabius1@jhu.edu</u>



