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

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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

Learn about BSR’s AD/ADRD Research Priorities: https://www.nia.nih.gov/research/dbsr/ad-adrd
Traditional n=10

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

Kristine J. Ajrouch, Irving E. Vega, Tone C. Antonucci, Wassim Tarraf, Noah J. Webster and Laura B. Zahodne

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

Lucy Annang Ingram, Marilyn E. Ford, Christiana L. Johnson, Brianna Ashton-Carroll, Quentin McConnell, Daniela B. Friedman and Sue Ellen Levkoff

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

Lorraine T Dean and Roland J Thorpe Jr

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

Jennifer J. Marli, Andrea Gilmore-Bykovskyi, PhD, RN, Kacie D. Deters, PhD
Inside an AD-RCMAR

Leadership & Administrative Core

Research Education Component (REC)

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
**SCIENTIST DATA AT-A-GLANCE**

**RCMAR Cycle**

- ***RCMAR V (2018-Ongoing)***
  - Male
  - Female
  - Total: 71

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***RCMARs I-III include 6 funded centers.***

***RCMAR IV includes 7 funded centers.***

***RCMAR V includes 19 funded centers.***

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<tr>
<th>Ethnicity</th>
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**NIH National Institute on Aging**
Educational Benefits and Cognitive Health Life Expectancies: Racial/Ethnic, Nativity, and Gender Disparities

Marc A Garcia, PhD, Brian Downer, PhD, Chi-Tsun Chiu, PhD, Joseph L Saenz, PhD, Kasim Ortna, HS, Rebeca Wong, PhD


Cognitive screening with functional assessment improves diagnostic accuracy and attenuates bias

David Andrés González, MD, PhD, Mitz M. Gonzales, MD, PhD, Kyle J. Jennette, MD, Jason R. Sobel, MD; Bernard Fong, MD, PhD

Received 28 July 2021 | Revised 17 September 2021 | Accepted 21 September 2021 | Published online 7 December 2021
DOI: 10.1002/adb.32205

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

FEATURED ARTICLE | Full Access

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

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 Kewe’e’aimoku Kaholoku2, Richard F. MacLehose3, Sunshine M. Rote1

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

Mateo P. Foninha, MA, MD, Mark D. Hayward, PhD, Jung Ki Kim, PhD, and Eileen M. Commins, PhD

Journal of the Alzheimer’s Association

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The Gerontologist

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National Institute on Aging

NIH
San Diego AD-RCMAR @SD_RCRCMAR - 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/sandiegoadrcmar...

SAHAN DIEGO AD-RCMAR 2022-2023 SCIENTISTS

Lauren Brown, PhD, MPH, Assistant Professor, School of Public Health, San Diego State University
Project Title: Examining Cohort Variation in Chronic Stress, Anthropometrics, Biological, and Cognitive Function of Black and White Older Adults Across Age Cohorts

Kryssal Kiung, PhD, Postdoctoral Research Fellow, School of Public Health, Social & Behavioral Health, University of Nevada, Las Vegas
Project Title: Racial/Ethnic Disparities in Social and Gender Minority Caregivers of Individuals with Alzheimer’s Disease and Related Dementias

Sabinna Smalley, 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)

Liz Tahhan, PhD, TSRI Postdoctoral Fellow, Sinai Institute for Research on Aging, UC San Diego, Department of Psychiatry
Project Title: The Effects of Perceived Discrimination and Neatness Status on Cognitive Decline among Hispanic/Latinx American Older Adults

San Diego AD-RCMAR @SD_RCRCMAR - Jun 30, 2021
We are beyond proud of our 2020-2021 graduating cohort of scientists @Talarousansh @Hpurada @DLG12 Zivinka Zlata & 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 symposium 2021 AAC Meeting @DrLRGuerrero @Hilcv17 @RCMARCC

Kacie D and Angela Gutierrez
C. A. Mingo, PhD @MingoPhd Nov 13, 2019
Getting a great deal of valuable information from the 2019 RCMAR Recruitment and Retention of Minority Elders: An NIA Priority Area @geronosociety

Dr. Jennifer Manly @ManlyEpic Nov 13, 2019
Kristina Arocho @mcmfad has some critical lessons learned to share from her experience recruiting Arab Americans and Latin people in the Detroit metro area for research on AD/ADRD. #GSA2019

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 funds to researchers from underrepresented backgrounds who work on needful older adults. #RCMARAnnual2022

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

Dr. Tiffany Kindratt @tkindratt 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! #GAA2021 @Liz_Munoz @geronosociety @erica_dim @mccfad @izahodne @RCMARCC
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)

Questions? Contact Dr. Melissa S. Gerald
Melissa.Gerald@nih.gov
Thank you!

Melissa S. Gerald, PhD
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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
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 facilitate participation in research

Resources
- Elders
- Academic researchers
- Community Liaison
- Community Advisory Board (CAB)
- Community Organizations
- Health Care Providers & Systems

Activities
- Health education learning series
- Monthly CAB meeting
- Annual health reception
- Semi-annual newsletter
- CME opportunities

Immediate Outcomes
- Latino & Arab American adults attend activities
- Latino & Arab American adults consent to join research volunteer directory

Long-term Outcomes
- Diverse samples for ADRD research
- Enhanced understanding of ADRD
- Skilled ADRD workforce
- Healthy Society for All

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

<table>
<thead>
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<th>Y1</th>
<th>Y2</th>
<th>Y3</th>
<th>Y4</th>
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<td>117</td>
<td>70</td>
<td>35</td>
<td>99</td>
<td>321</td>
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<tr>
<td>Total</td>
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<td>187</td>
<td>102</td>
<td>239</td>
<td>745</td>
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Advance ADRD Science

• Community Based Scientists as Leaders have:
  • Trust of the community
  • Knowledge of cultural expressions
  • Awareness of local customs
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<th>Research Scientist (n=17)</th>
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<td>African American</td>
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<td><strong>Institution</strong></td>
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<td>R1</td>
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<td>R2</td>
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<td>Culturally Sensitive Care</td>
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Increase ADRD Workforce

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<td>African American</td>
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<td>Graduate Student</td>
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<tr>
<td>Post Doc</td>
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<tr>
<td>Assistant Professor</td>
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### Increase ADRD Workforce Success Indicators

<table>
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<tr>
<th>Years</th>
<th>Manuscripts</th>
<th>Grants</th>
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<tr>
<td>2018-2022</td>
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<td>39</td>
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</table>

**2019** SDI focused on ADRD epidemiology
- Modeling Cognitive Aging in Context – 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
- The Costs of ADRD – 7 manuscripts TBD
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%).
Age of Migration and Cognitive Function Among Older Latinos in the United States

Marc A. García, Kasim Ortiz, Sandra P. Arévalo, Erica D. Diminich, Emily Briceño, Irving E. Vega, Wassim Tarraf

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

Chanee D. Fabius, PhD, MA
Assistant Professor
Department of Health Policy and Management

Johns Hopkins Bloomberg School of Public Health
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

<table>
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<th>Leadership</th>
<th>Mentorship team</th>
<th>Community Liaison and Recruitment Support</th>
<th>Analysis Support</th>
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<tr>
<td>Dr. Roland Thorpe</td>
<td>Dr. Jennifer Wolff</td>
<td>Dr. Janice Bowie</td>
<td>Dr. Jeannie Leoutsakos</td>
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<td>Dr. George Rebok</td>
<td>Dr. Deirdre Johnston</td>
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<td>Dr. Joe Gallo</td>
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<td>Dr. Quincy Samus</td>
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Engagement with other scientists

Professional development series

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”

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

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.
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

PHI, 2018; 2020
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). Direct Care Worker Engagement and Experiences Caring for Older Adults with Dementia: Findings from a Statewide Survey of Direct Care Agencies.

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.
Agencies with contact information publicly available from the Maryland Department of Health
N=1,150

# of agencies mailed surveys
N=1,089

No contact (mail returned to sender AND no return call/number disconnected)
N=37

Total sample (denominator)
N=1,052

Incomplete Surveys
N=30

Completed surveys
N=177 (16.8% Response Rate)

Excluded:
- Non-Medicaid vendors (86)
- No contact information (7)
- Does not employ direct care workers (27)
- Not providing services to older adults (32)

Analytic sample:
25 agencies providing services to 1,144 adults aged 65 and older with available inteRAI HC assessment completed in 2020

Duplicates (e.g., same agency listed twice, same ownership – confirmed by research team)
N=61
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 Care Agency Participant Dementia Status

<table>
<thead>
<tr>
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<th>Dementia 53.8% (615)</th>
<th>No Dementia 46.2% (529)</th>
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<td><strong>Direct Care Agency Participant Characteristics, %</strong></td>
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<td>65-74</td>
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<td>25.7**</td>
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<td>7.6 (1.7)</td>
<td>6.7 (1.9)**</td>
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<td><strong>Participant Care Experiences, %</strong></td>
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<tr>
<td>Low Social Engagement</td>
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<td>Health care utilization</td>
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<td>Hospitalizations</td>
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<tr>
<td>Emergency room visits</td>
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<td><strong>Caregiver Care Experiences, %</strong></td>
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<tr>
<td>Caregiver is overwhelmed</td>
<td>16.9</td>
<td>8.3***</td>
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<td>Caregiver is distressed, angry, or depressed</td>
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<td>3.0**</td>
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</tbody>
</table>

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

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

<table>
<thead>
<tr>
<th></th>
<th>Low Social Engagement(^a)</th>
<th>Hospitalizations</th>
<th>Emergency room visits</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (64.6% \ (706))</td>
<td>Yes (7.8% \ (89))</td>
<td>Yes (8.4% \ (96))</td>
</tr>
<tr>
<td></td>
<td>No (35.4% \ (387))</td>
<td>No (92.2% \ (1,055))</td>
<td>No (91.6% \ (1,048))</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Dementia specific training required</td>
<td>16.2</td>
<td>11.1</td>
<td>0.02</td>
</tr>
<tr>
<td>Direct care workers assist with any health information technology</td>
<td>75.2</td>
<td>68.7</td>
<td>0.02</td>
</tr>
<tr>
<td>Direct care agency offers any supplemental services</td>
<td>83.4</td>
<td>76.7</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Caregiver is overwhelmed&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Caregiver is distressed, angry, or depressed&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Unable to continue caregiving&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes 12.9% (148)</td>
<td>No 87.1% (993)</td>
<td></td>
</tr>
<tr>
<td>Dementia specific training required</td>
<td>18.2%</td>
<td>13.8%</td>
<td>0.15*</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>p</td>
</tr>
<tr>
<td>Direct care workers assist with any</td>
<td>81.8%</td>
<td>71.5%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>health information technology</td>
<td>%</td>
<td>%</td>
<td>p</td>
</tr>
<tr>
<td>Direct care agency offers any</td>
<td>90.0%</td>
<td>79.9%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>supplemental services</td>
<td>%</td>
<td>%</td>
<td>p</td>
</tr>
</tbody>
</table>

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!
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