Dementia Family Caregiving:

Recommendations from the University of California Davis Conference, Alzheimer's Disease Diversity and Disparities in Family Caregiving: Progress and Future Challenges

October 2017

Prepared by:
Oanh Meyer, PhD, MAS
Ladson Hinton, MD

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Oct. 31, 2017

SUMMARY

The goal of this one-day conference was (1) to present and discuss the current caregiving climate for individuals caring for family members with Alzheimer's disease and other dementias and how to foster resilience, particularly in diverse populations, (2) to present cutting-edge research, evidence based interventions, and novel cultural adaptations for diverse caregivers and their families, and (3) to articulate future directions in the field of disparities in caregiving. This Pre-Summit activity was an opportunity to hear scientific presentations from leading experts in the field of dementia caregiving in diverse communities as well as to have scholars, funding agencies, and associations network with one another. The conference also included a poster session featuring work on theory, research, practice, and training/education issues in dementia caregiving, particularly as it related to diversity and disparities.

BACKGROUND

Older racial and ethnic minorities are one of the fastest growing segments of the population (U.S. Department of Health and Human Services, 2012). Compared to non-Hispanic Whites, some minorities have a higher prevalence of functional limitations and Alzheimer's disease (Haan et al., 2003; Mayeda, Glymour, Quesenberry, & Whitmer, 2016; Mehta & Yeo, 2017; Sinclair & Gomez, 2006; Tang et al., 1998). Consequently, the number of minorities engaged in caregiving for an older adult with impairment is also increasing rapidly. A meta-analysis found significant ethnic differences among dementia family caregiver populations, with racial/ethnic minority caregivers providing care for more hours per week and reporting more caregiving tasks compared to non-Hispanic Whites (Pinquart & Sorensen, 2005). Thus, there is a critical need for dementia caregiver interventions that meet the needs of underserved caregivers. Currently, there are effective interventions for diverse ethnic minority caregivers (Napoles, Chadiha, Eversley, & Moreno-John, 2010), but even these are limited in their representation of minority caregivers (e.g., Asian Americans), and there is not a good understanding of how to adapt current interventions so they are culturally appropriate.

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[1] This Conference was designated as a Pre-summit activity to inform the 2017 Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers. Members of the National Alzheimer's Project Act Advisory Council on Alzheimer's Research, Care, and Services recognize the value of activities such as this.

Below is a set of recommendations put forth by conference speakers to advance the field of dementia caregiving for underserved and diverse dementia caregivers.

RECOMMENDATIONS

Beginning an Intervention
1. Begin the intervention development and implementation process by identifying and engaging the community of interest and key stakeholders and building upon local resources, values, and knowledge.

The People Involved – Participants and Researchers
2. Include sufficient numbers of diverse and underrepresented populations in caregiving intervention research to allow for meaningful analysis of outcomes across groups. This will allow us to examine whether interventions are effective across populations and to identify subgroups for whom tailoring or modification of approaches or development of novel interventions may be needed. Subgroups may exist within a population (e.g., Hispanics are not a single ethnic/cultural group). It may also help identify previously unknown mechanisms of health disparities. Diversity extends beyond race/culture to include other underrepresented groups such as LGBT individuals.

3. Promote an interdisciplinary team science approach in conducting research with diverse populations. Teams should include researchers who represent the target population as well as lay representatives from those groups.

4. Prioritize the recruitment and training of research investigators and staff that reflect the ethnic and cultural diversity of the cohorts being studied. Outreach could start as early as high school to engage students to foster interest in internships and other educational experiences in the field of dementia care and research.

Conceptualizing the Problem/Theorizing
5. Develop new conceptual models to guide the development of interventions that incorporate the social determinants of health and that reflect the structural inequality, disparities, and racial/gender gaps that exist for diverse communities. Caregiving does not exist in isolation and broadening the scope of interventions to address social determinants may improve outcomes. These new models can build upon and expand existing models (e.g., Aranda & Knight, 1997; Knight & Sayegh, 2010; Montoro-Rodriguez & Gallagher-Thompson, 2009) to more comprehensively address caregiving needs in diverse communities. Models should also describe where the intervention might be most effective along the caregiving trajectory.

6. Advance theoretical frameworks and methods for the translation/adaptation process that are appropriate for underserved communities. Also, continue advancement of theoretical models and conceptual frameworks of the underlying mechanisms/pathways that produce health disparities among caregivers and their care recipients and the interventions that might reduce these disparities (mediators and moderators of effect). The intervention

evaluation should document how social determinants are affecting the efficacy of the intervention, and duration of positive outcomes, to inform our understanding of how negative effects may be anticipated and offset.

Intervention Development, Measures, and Adaptation

7. Consider alternatives to the randomized clinical trial to test and implement interventions that may be more appropriate for community settings and underserved communities, e.g., cluster randomized trials, pragmatic trials, and rigorous quasi-experimental designs.

8. Document cultural adaptations of interventions in a systematic fashion and include this information as part of the methods of the published results and technical manuals designed to inform replication and dissemination efforts. This includes description of the translation approach and documentation of specific changes made.

9. Assess the cultural and psychometric equivalence and validity of commonly used measures in diverse populations (e.g. measures of caregiver distress/burden, dementia-related behavioral symptoms) and where needed, modify items, adjust scoring, or develop new measures.

Analytical Models and Evaluation

10. Utilize advanced analytical models and designs that take into account multiple caregivers, intervention costs, etc. For example, studies usually focus on an individual family caregiver and do not consider more complex patterns of family caregiving in which multiple caregivers may be involved, which may be especially relevant for certain cultural groups with a more collectivistic orientation. In such situations, interventions might be more effective if delivered to multiple caregivers and their outcomes assessed.

Use of Technology

11. Technology based approaches are a promising approach to caregiver intervention research because they may make interventions more efficient and more accessible. In addition, technology (e.g. wearables) may provide a novel approach to measuring stress and other outcomes. Certain challenges may be more common in diverse populations (e.g. lack of meaningful access to the internet due to contextual, socioeconomic constraints) and need to be addressed. It is likely that for vulnerable populations, technological approaches will need to be combined with proven personal approaches, e.g., delivery of interventions by community/lay health workers. More rigorous research is needed with diverse populations to fully understand the opportunities, positive outcomes and challenges associated with technology-based approaches.

Sustainability

12. Embed the intervention into existing care delivery and community settings (e.g. primary care, hospitals, community-based organizations) so that they are more likely to be sustained over time. This also requires that interventions align with the goals, ongoing initiatives and priorities of the organizations and communities and incorporates successful local caregiver support models. Impediments and facilitators related to intervention acceptance and implementation should be documented and reported.

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2. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. Alzheimer's & Dementia: The Journal of the Alzheimer's Association 2016 03; 12(3):216-224.

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Appendix 1: AGENDA

Alzheimer's Disease Diversity and Disparities in Family Caregiving: Progress and Future Directions

Wednesday, May 3rd, 2017 | UC DAVIS CONFERENCE CENTER | DAVIS, CA

Time	Session/Activity
8:15 AM – 8:45 AM	**Registration & Breakfast**
8:45 AM – 9:00 AM	**Welcome Remarks** Ladson Hinton, Charles DeCarli, and Heather Young – University of California, Davis
9:00 AM – 9:05 AM	**Morning Keynote Introduction** Carl Hill – National Institute on Aging
9:05 AM – 9:50 AM	**Morning Keynote:** *Building Community Partnerships to Develop Culturally Appropriate Dementia Care Interventions* Peggye Dilworth-Anderson – University of North Carolina, Chapel Hill
9:50 AM – 10:50 AM	**Paper Presentations #1: Current Landscape of Disparities & Alzheimer's Disease Caregiving** 1. *The Burden of Alzheimer's Disease for Families and Society from 2010 to 2050* Julie Zissimopoulos – University of Southern California 2. *Diversity and Alzheimer's Disease Caregiving: Insights from the National Academies of Sciences, Engineering and Medicine, Report on Family Caregiving for Older Adults* Ladson Hinton – University of California, Davis
10:50 AM – 11:00 AM	**BREAK**
11:00 AM – 11:45 AM	**Funders Panel:** *Key Areas of Interest/Opportunities for Support* 1. Carl Hill – National Institute on Aging 2. Jessica Núñez de Ybarra – California Department of Public Health 3. Liz Schwarte – Rosalinde and Arthur Gilbert Foundation 4. Oanh Meyer (Moderator) – University of California, Davis
11:45 AM – 12:45 PM	**Lunch + Poster Session**
12:45 PM – 1:30 PM	**Afternoon Keynote:** *The Role of Technology in Reducing Disparities Among Family Caregivers* Sara J. Czaja – University of Miami
1:30 PM – 2:00 PM	*Advancing Scientific Methods for Delivering Behavioral Interventions in Community Settings to Reduce Health Disparities* Anna M. Napoles & Anita L. Stewart – University of California, San Francisco
2:00 PM – 3:45 PM	**Paper Presentations #2: Interventions for Diverse Populations** 1. *Adapting a Dementia Caregiver Intervention for Vietnamese Communities* Oanh Meyer – University of California, Davis 2. *Race and Dementia Caregiving: A Way Forward* Fawn A. Cothran – Rush University 3. *Advancing a Community-Based Model to Address Dementia in Native Communities* Meghan A. Jernigan – Partnerships for Native Health / Washington State University 4. *Developing a Self-Directed Learning System for Chinese Dementia Caregivers*

	Hongtu Chen – Harvard University 5. ***The Care Ecosystem: A Dementia Care Program Designed for Diverse Communities*** Jennifer Merrilees – University of California, San Francisco
3:45 PM – 3:55 PM	**BREAK**
3:55 PM – 5:05 PM	**Final Panel:** ***The Future of Alzheimer's Disease Family Caregiving Interventions and Support for Diverse Populations: Where Do We Go From Here?*** 1. Dolores Gallagher-Thompson – Stanford University 2. Peggye Dilworth-Anderson – University of North Carolina, Chapel Hill 3. Sara J. Czaja – University of Miami 4. Maria Carrillo – Alzheimer's Association 5. William A. Vega – University of Southern California 6. Heather Young (Moderator) – University of California, Davis
5:05 PM – 5:10 PM	**Closing Remarks / Adjourn**
5:10 PM – 6:30 PM	**Reception**

Appendix 2: POSTER SESSION PRESENTATIONS

1. ***Medication Takeovers: Regimen Adjustment Work, Covert Druggings, and Social Control in Households Facing Alzheimer's***
   Presenter: Brandon Berry – University of California, Davis
   Co-Author: Ester Carolina Apesoa-Varano – University of California, Davis

2. ***Increasing Resilience in Ethnically Diverse Dementia Caregivers***
   Presenter: Marika Blair Humber – Palo Alto University
   Co-Authors: Ann Choryan Bilbrey – Stanford University
         Dolores Gallagher-Thompson – Stanford University

3. ***Raising Dementia Awareness in the Latino Community through Promotoras***
   Presenter: Iliana Garcia-Ruiz – Stanford University
   Co-Authors: Ann Choryan Bilbrey – Stanford University
         Angelica Ceja – Stanford University
         Nusha Askari – Stanford University
         Dolores Gallagher-Thompson – Stanford University

4. ***STAR-C-Telemedicine: Extending the Boundaries of Caregiver Support***
   Presenter: Allison Lindauer – Oregon Health & Science University
   Co-Authors: Nora Mattek – Oregon Health & Science University
         Katherine Mincks – Oregon Health & Science University
         Jeffrey Kaye – Oregon Health & Science University
         Linda Teri – University of Washington

5. ***Neuropsychiatric Behaviors Among Hispanic Persons with Alzheimer's Disease: Caregiver Relevance***
   Presenter: Ann M. Mayo – University of San Diego
   Co-Authors: Guerry M. Peavy – University of California, San Diego
         Steven D. Edland – University of California, San Diego

6. ***Perceived Stress in Older Caregivers of Spouses with Dementia***
   Presenter: Guerry M. Peavy – University of California, San Diego
   Co-Author: Ann M. Mayo – University of San Diego

7. ***Meaningful Activity and Quality of Life in Older Latinos with Dementia***
   Presenter: Adriana Perez – University of Pennsylvania
   Co-Author: Nancy Hodgson – University of Pennsylvania

8. ***Understanding the Health Information Needs and Barriers of Older Adults: Implications for Caregiver Interventions***
   Presenter: A. Susana Ramirez – University of California, Merced
   Co-Author: Tashelle Wright – University of California, Merced

9. ***The Equine Guided Support Pilot Study***
   Presenter: Sarah Tomaszewski Farias – University of California, Davis
   Co-Authors: Paula Hertel – Connected Horse
         Nancy Schier Anzelmo – Connected Horse
         Claudia Sonder – University of California, Davis

10. ***Paired Integrative Exercise for People with Dementia and Caregivers***
    Presenter: Maria Ventura – University of California, San Francisco

Co-Authors: Wolf Mehling – University of California, San Francisco
              Deborah Marks – University of California, San Francisco
              Robin Woodstock – University of California, San Francisco
              Jason Flatt – University of California, San Francisco
              Margaret Chesney – University of California, San Francisco
              Deborah E. Barnes – University of California, San Francisco

Dementia Family Caregiving: Recommendations from a Conference to Advance Interventions in Diverse Populations

Oanh Meyer, PhD, MAS and Ladson Hinton, MD

University of California, Davis School of Medicine

October 2017

Alzheimer's Disease
Diversity and disparities in family caregiving: Progress and future directions

WEDNESDAY
May 3, 2017

8:30 a.m. – 5 p.m.
UC Davis Conference Center
550 Alumni Lane
Davis, CA 95616

Register today!
Registration is FREE and includes continental breakfast and lunch.

Registration:
http://bit.ly/2jWvgij

Poster submission:
http://bit.ly/2ktiuLe

Registration will remain open until Saturday, April 15th, or until the event capacity has been reached.

Contact Dr. Lauren Berger (lkberger@ucdavis.edu) with registration questions.

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UC Davis Latino Aging Research Resource Center

WITH GENEROUS SUPPORT FROM:
UC Davis Alzheimer's Disease Center, The Betty Irene Moore School of Nursing at UC Davis and NIA Office of Special Populations

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HEALTH

Conference attendees will learn:

- The current caregiving climate for Alzheimer's Disease caregivers and how to foster resilience
- Cutting-edge research, evidence-based interventions and novel cultural adaptations for diverse caregivers and their families
- Future directions in the field of disparities and caregiving

Additional conference highlights include:

- Scientific presentations by leading experts
- Networking opportunities for scholars, funding agencies, and associations
- A poster session featuring work on theory, research, practice, and training/education issues in Alzheimer's Disease caregiving, particularly as it relates to diversity and disparities (Contact Dr. Oanh Meyer (olmeyer@ucdavis.edu) with poster questions)
- The participation of multiple NIA Resource Centers for Minority Aging Research (RCMARs) and Alzheimer's Disease Centers (ADCs)

Note: The conference has been designated as a Pre-Summit activity to inform the National Summit on Alzheimer's Research, Care, and Services to be held in Washington, DC in October 2017.

Conference Speakers

Maria Carrillo, PhD
Hongtu Chen, PhD
Fawn Cothran, PhD, RN, GCNS-BC
Sara J. Czaja, PhD
Charles S. DeCarli, MD, FAAN
Peggye Dilworth-Anderson, PhD
Dolores Gallagher-Thompson, PhD
Carl Hill, PhD, MPH
Ladson Hinton, MD
Meghan Jernigan, MPH
Jennifer Merrilees, RN, PhD
Oanh Meyer, PhD, MAS
Anna Maria Napoles, PhD, MPH
Jessica M. Nunez de Ybarra, MD, MPH
Liz Schwarte, MPH
Anita L. Stewart, PhD
William A. Vega, PhD
Heather M. Young, PhD, RN, FAAN
Julie M. Zissimopoulos, PhD

Bolded names contributed directly to the writing of the recommendations.

Main Themes/Domains

1. Beginning an Intervention

2. The People Involved – Participants and Researchers

3. Conceptualizing the Problem/Theorizing

4. Intervention Development, Measures, and Adaptation

5. Analytical Models and Evaluation

6. Use of Technology

7. Sustainability

Recommendations

- The People Involved
  - Diverse and underrepresented populations
  - Recruit and train diverse investigators

- Conceptualizing the Problem/Theorizing
  - New conceptual models that incorporate social determinants of health

- Intervention Development, Measures, and Adaptation
  - Equivalence of measures; Alternatives to the RCT

Recommendations

- Analytical Models and Evaluation
  - Advanced analytical models – multiple caregivers, family-centered approach

- Use of Technology
  - Opportunities for reaching underserved populations

- Sustainability
  - Embed the intervention into existing systems of care

Acknowledgements

- Full set of recommendations can be found at [https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers]

- Sponsors
  - UC Davis Latino Aging Research Resource Center
  - UC Davis Alzheimer's Disease Center
  - UC Davis School of Nursing
  - National Institute on Aging

- Caregivers and their families