

Alzheimer's Disease

Diversity and Disparities in Family Caregiving:
Progress and Future Directions

MAY 3, 2017 | UC DAVIS CONFERENCE CENTER



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HEALTH

CONFERENCE AGENDA

WEDNESDAY, MAY 3RD, 2017 | UC DAVIS CONFERENCE CENTER

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: <i>Building Community Partnerships to Develop Culturally Appropriate Dementia Care Interventions</i> 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 <ol style="list-style-type: none"> <i>The Burden of Alzheimer's Disease for Families and Society from 2010 to 2050</i> Julie Zissimopoulos – University of Southern California <i>Diversity and Alzheimer's Disease Caregiving: Insights from the National Academies of Sciences, Engineering and Medicine, Report on Family Caregiving for Older Adults</i> Ladson Hinton – University of California, Davis
10:50 AM – 11:00 AM	BREAK
11:00 AM – 11:45 AM	Funders Panel: <i>Key Areas of Interest/Opportunities for Support</i> <ol style="list-style-type: none"> Carl Hill – National Institute on Aging Jessica Núñez de Ybarra – California Department of Public Health Liz Schwarte – The Rosalinde and Arthur Gilbert Foundation Oanh Meyer (Moderator) – University of California, Davis
11:45 AM – 12:45 PM	Lunch + Poster Session
12:45 PM – 1:30 PM	Afternoon Keynote: <i>The Role of Technology in Reducing Disparities Among Family Caregivers</i> Sara J. Czaja – University of Miami
1:30 PM – 2:00 PM	<i>Advancing Scientific Methods for Delivering Behavioral Interventions in Community Settings to Reduce Health Disparities</i> Anna M. Napoles & Anita L. Stewart – University of California, San Francisco
2:00 PM – 3:45 PM	Paper Presentations #2: Interventions for Diverse Populations <ol style="list-style-type: none"> <i>Adapting a Dementia Caregiver Intervention for Vietnamese Communities</i> Oanh Meyer – University of California, Davis <i>Race and Dementia Caregiving: A Way Forward</i> Fawn A. Cothran – Rush University <i>Advancing a Community-Based Model to Address Dementia in Native Communities</i> Meghan A. Jernigan – Partnerships for Native Health / Washington State University <i>Developing a Self-Directed Learning System for Chinese Dementia Caregivers</i> Hongtu Chen – Harvard University <i>The Care Ecosystem: A Dementia Care Program Designed for Diverse Communities</i> Jennifer Merrilees – University of California, San Francisco
3:45 PM – 3:55 PM	BREAK
3:55 PM – 5:05 PM	Final Panel: <i>The Future of Alzheimer's Disease Family Caregiving Interventions and Support for Diverse Populations: Where Do We Go From Here?</i> <ol style="list-style-type: none"> Dolores Gallagher-Thompson – Stanford University Peggye Dilworth-Anderson – University of North Carolina, Chapel Hill Sara J. Czaja – University of Miami Maria Carrillo – Alzheimer's Association William A. Vega – University of Southern California Heather Young (Moderator) – University of California, Davis
5:05 PM – 5:10 PM	Closing Remarks / Adjourn
5:10 PM – 6:30 PM	Reception

POSTER SESSION PRESENTATIONS

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

- 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 Apeso-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. Edand – 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

SPEAKER BIOS

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MARIA C. CARRILLO, PhD, is Chief Science Officer, Medical and Scientific Relations, at the Alzheimer's Association. Dr. Carrillo has a wide range of responsibilities, including oversight of the Association's grant making process and communication of scientific findings within and outside of the organization. Dr. Carrillo directly manages several Alzheimer's Association initiatives, including the Research Roundtable, the World-Wide Alzheimer's Disease Neuroimaging Initiative, and the Global Alzheimer's Association Interactive Network. She is co-author of the National Institute on Aging-Alzheimer's Association revised criteria for the diagnosis of Alzheimer's, and the Appropriate Use Criteria for Amyloid Imaging. She is on the Advisory Committee for the World Health Organization Dementia Setting Priorities & Portfolio Analysis.

HONGTU CHEN, PhD, is a senior scientist and Assistant Professor at the Department of Psychiatry, Harvard Medical School, and also Director of Research at the Environment and Health Group, a company devoted to developing products and services using health information and communication technologies for elders with dementia and other chronic diseases. His research areas focus on implementing evidence-based and innovative behavioral health interventions in real world settings. Chen served as Project Director and Principal Investigator on a number of major research projects funded by U.S. governmental agencies. He received the Fulbright Scholar Award to develop a training curriculum for health care professionals in Thailand to deliver to family caregivers of elders with dementia. He also serves as the Executive Editor for the peer-reviewed journal Ageing International, and is the founding director of the Global Initiative on Caregiving for the Elderly at the Harvard University Asia Center.

FAWN A. COTHRAN, PhD, RN, GCNS-BC, is an Assistant Professor with Rush College of Nursing and a 2013-2015 Claire M. Fagin Fellow with the National Hartford Centers of Gerontological Nursing Excellence. Dr. Cothran completed her PhD in Nursing and a Master's of Science in Gerontological Nursing at the University of Michigan. Originally from Washington DC, she received a Bachelor's of Science in Nursing with a minor in Psychology from Howard University. Dr. Cothran has worked in long-term care, corrections, and acute care, but her clinical work with older adults in long term care and community based care transitions informed her research in dementia caregiving in the African American community. The long term goals of Dr. Cothran's program of research are to develop and test culturally tailored behavioral interventions for African American dementia caregivers to promote their healthy physical and mental well-being. Dr. Cothran's work is interdisciplinary and she has collaborated with experts in social work, psychology, public health, sociology, religion, as well as community partners.

SARA J. CZAJA, PhD, is a Leonard M. Miller Professor of the Psychiatry and Behavioral Sciences, and has secondary appointments in Industrial Engineering, Psychology and Neurology at the University of Miami. She is also the Scientific Director of the Center on Aging at the University of Miami Miller School of Medicine and the Director of the Center on Research and Education for Aging and Technology Enhancement (CREATE). Funded by the National Institute on Aging, CREATE focuses on older adults and technology systems. Dr. Czaja's research interests include: aging and cognition, aging and healthcare informatics, caregiving, older workers, human-computer interaction, training, and functional assessment. She has received continuous funding for her research from the National Institutes of Health as well as numerous foundations. She is a fellow of the American Psychological Association (APA), the Human Factors and Ergonomics Society and the Gerontological Society of America. She is also a member of the National Academy of Science Board on Human Systems Integration and a member of the Executive Committee of the Human Factors and Ergonomics Society. She is a recent Past President of Division 20 (Adult Development and Aging) of APA and recently served on the Institute of Medicine Committee on Healthy Cognitive Aging and the Institute of Medicine Committee on Family Caregivers of Older Adults.

CHARLES S. DECARLI, MD, FAAN, is Victor and Genevieve Orsi Chair in Alzheimer's Research, Professor of Neurology, and Director of the Alzheimer's Disease Center (ADC) and the Imaging of Dementia and Aging (IDeA) Laboratory at the University of California at Davis. He has a strong interest in behavioral neurology, with specific emphasis on dementing disorders, including degenerative dementias such as Alzheimer's disease and frontal dementias. He also focuses on dementias related to movement disorders and vascular disease, as well as cognitive impairment after closed head injury. His research interests are divided into two areas: using neuroimaging techniques to understand the relationship between brain structure and function with aging and disease; and studying the role of brain antioxidant systems, primarily quinone oxidoreductase, on the pathophysiology and potential treatment of Alzheimer's disease.

PEGGYE DILWORTH-ANDERSON, PhD, is Professor of Health Policy and Management in the Gillings School of Global Public Health at the University of North Carolina Chapel Hill (UNC). Her areas of expertise include family caregiving to dementia patients, minority aging and health, and chronic disease care and management in cultural context. Her overall research focus is on health disparities with an emphasis on building knowledge to inform, researching, translating and disseminating information on chronic disease care in medically underserved populations. Her current research includes collaborating with international colleagues on a project related to building community capacity to address Alzheimer's disease and care. She received the Ronald & Nancy Reagan Alzheimer's Research Award for her research contributions on Alzheimer's disease in underserved populations. She has served on numerous boards and committees that address aging issues and healthcare outcomes including the National Research Advisory Council of the Institute on Aging/NIH, the Forum on Aging, Disability & Independence- Institute of Medicine of the National Academies, the Global Council on Brain Health, the Robert Wood Johnson National Advisory Board for the Clinical Scholars Program, and the board of directors of the Alzheimer's Association Eastern North Carolina Chapter. She has taught courses in aging, qualitative research methods, and translational health disparities, and has dedicated many years to mentoring graduate students, fellows, and junior and mid-career faculty. In recognition of her mentoring, she received the Minority Task Force Mentor Award from the Gerontological Society of America and the UNC Faculty-to-Faculty Mentoring Award from the Carolina Women's Leadership Council.

DOLORES GALLAGHER THOMPSON, PhD, received her PhD in clinical psychology from the University of Southern California about 30 years ago. She trained at UCLA's Neuropsychiatric Institute as well as with Tim Beck of the Academy of Cognitive Therapy. Her career has focused on clinical research and practice – primarily with older adults with a wide range of depressive disorders, and family caregivers of persons with dementia from ethnically and racially diverse backgrounds. Intervention research is her specialty- she's developed programs that are now considered evidence-based and have been adapted for use with several minority groups, including Latino dementia caregivers. She has over 200 peer reviewed publications, and 2 books currently in progress: the 3rd ed. of the Ethnicity and Dementia book (edited with Gwen Yeo) and the 2nd ed. of CBT for Late Life Depression (written with Ken Laidlaw of Univ. of Edinburgh). She has volunteered for over 20 years with the local Alzheimer's Association chapter – first as co-founder of what is now the "Diversity and Inclusion" Committee and then as a long term member of the Program Committee. Dolores is strongly committed to culturally tailoring evidence-based interventions for diverse groups and hopes to continue this research well into the future.

CARL V. HILL, PhD, MPH, is Director of the National Institute on Aging's (NIA) Office of Special Populations. After completing the Master of Public Health at Morehouse School of Medicine (Atlanta), Carl joined the charter class of the Centers for Disease Control and Prevention's (CDC) Public Health Prevention Service (PHPS) in 1997. Carl matriculated to the University of Michigan-Ann Arbor in 2001 where he completed doctoral studies in public health, with a focus on health disparities and the influence of ethnicity and culture on health. Dr. Hill joined the National Institutes of Health (NIH) in 2005, working initially with the National Institute on Minority Health and Health Disparities (NIMHD) and later with the Eunice Kennedy Shriver National Institute on Child Health and Human Development (NICHD).

LADSON HINTON, MD, is Professor and Director of Geriatric Psychiatry in the UC Davis Department of Psychiatry and Behavioral Sciences. He is also Principal Investigator and Director of the Latino Aging Research Resource Center (UC Davis RCMAR) and serves as Director of the Outreach and Recruitment core for the UC Davis Alzheimer's Disease Center. He is a co-author of the National Academies of Sciences, Engineering and Medicine report entitled Families Caring for an Aging America which was published in 2016. Over the past two decades, he has conducted interdisciplinary research to understand the cultural and social dimensions of family caregiving for older adults with Alzheimer's disease and to apply this knowledge to advance community-based services and interventions. He also conducts research to develop innovative family-centered models of depression care for older adults in primary care settings.

MEGHAN JERNIGAN, MPH, is a Staff Scientist at Partnerships for Native Health, Washington State University. Her research work is primarily focused on characterizing health knowledge and belief systems within American Indian and Alaska Native (AI/AN) communities. She has lead a number of projects advancing this effort including her recently funded pilot award examining the cultural views and perspectives that underpin participation in clinical research. Mrs. Jernigan is a member of the Choctaw Nation of Oklahoma, where she was born and raised. She received a BA from Oklahoma State University and an MPH in Sociomedical Sciences from Columbia University.

JENNIFER MERRILEES, RN, PhD, is a Clinical Nurse Specialist at the UCSF Memory and Aging Center and Associate Clinical Professor in the School of Nursing. Her clinical work focuses on management of problematic dementia behaviors and strategies to promote caregiver well-being. Jennifer is co-investigator on grants focused on dementia family caregivers: one study examines the emotional experience of dementia family caregivers and the impact on their burden and depression, and the other explores the benefits of positive emotion on caregiver stress. She is a lead researcher for a study funded by the Centers for Medicare and Medicaid Services entitled “Care Ecosystem: Navigating Patients and Families through Stages of Care”. She directs the Caregiver Module of the Care Ecosystem. Jennifer founded and directs the Memory and Aging Family Advisory Council, comprised of dementia family caregivers who provide feedback and guidance regarding clinical innovations.

OANH MEYER, PhD, MAS, received her PhD in social psychology and her Masters in Advanced Study in Clinical Research at UC Davis. She studies cognitive and mental health disparities in racial/ethnic minorities and older adults from a broad, population level and also at the individual level. Her current research interests include dementia caregiving and mental health, social determinants of cognitive decline associated with dementia, and geographic disparities in mental health for older adults. Dr. Meyer is currently funded by the Alzheimer’s Association and the National Institute on Aging to develop and implement a program to help Vietnamese Americans taking care of a family member with dementia or problems with memory loss.

ANNA MARÍA NÁPOLES, PhD, MPH, is a Professor and behavioral epidemiologist in the Department of Medicine, Division of General Internal Medicine at the University of California San Francisco (UCSF). She is Principal Investigator of the UCSF Center for Aging in Diverse Communities funded by the National Institute on Aging and is affiliated with Redes en Acción: The National Latino Cancer Research Network and UCSF Helen Diller Family Comprehensive Cancer Center. Her research focuses on cancer health disparities, psycho-oncology, patient-clinician communication, quality of life of family caregivers, and community-based models of research in ethnically and socioeconomically diverse groups. She has built community-academic research partnerships to develop and test evidence-based behavioral interventions for ethnically diverse adults in community-based settings. With community partners, she completed a randomized controlled trial testing a peer-delivered cognitive-behavioral stress management intervention for Latinas with breast cancer called Nuevo Amanecer that was effective in improving quality of life and reducing depressive and somatic symptoms. Her team is conducting three trials testing peer-delivered and mHealth interventions to improve symptom management among ethnically diverse, low-income cancer survivors through cognitive-behavioral stress management and/or walking, including translation into rural communities.

JESSICA M. NÚÑEZ DE YBARRA, MD, MPH, is Board Certified in Public Health and General Preventive Medicine and a Fellow of the American College of Preventive Medicine. She serves as the Chronic Disease Control Branch Chief in the California Department of Public Health (CDPH). In 2014, she and a multi-disciplinary team authored the California Wellness Plan, the state chronic disease prevention and health promotion plan, to support and expand upon the priorities of the Let’s Get Healthy California Task Force by creating a detailed road map for CDPH and its partners to promote health, eliminate preventable chronic disease and promote health equity. Jessica previously worked for CDPH’s Division of Communicable Disease Control facilitating internal public health communications, training and preparedness activities to address emerging infectious public health threats, including establishing and overseeing the CDPH Laboratory Directors Training Program (LabAspire). She currently serves as interim Program Director for CDPH Preventive Medicine Residency Program and as volunteer Assistant Clinical Professor at University of California Davis School of Medicine Department of Public Health Sciences. Since 2015, she has served as a member on the California Medical Association’s Council on Science and Public Health. She also serves as President of the Sacramento Latino Medical Association (SaLMA).

LIZ SCHWARTE, MPH, Principal at Ad Lucem Consulting, has 20+ years experience in strategic planning, initiative design, philanthropic advising, program evaluation and research. Her areas of expertise include Alzheimer’s disease, caregiving, chronic disease prevention, public health leadership and practice, social and emotional health and wellness, and community engagement. Through Ad Lucem, Liz provides strategic consultation to a range of clients including foundations, public health departments, healthcare providers, and non-profits. Liz approaches projects with a partnership model that facilitates identification of priorities, development of strategies, and clear linkages to impacts. In her role as consultant to The Rosalinde and Arthur Gilbert Foundation (TRAGF), Liz serves as program officer for Alzheimer’s Disease and Caregiving grantmaking. In the area of Alzheimer’s disease, TRAGF focuses its grant-making on the advancement of research by junior investigators in the United States and Israel and investments in Alzheimer’s disease caregiving. Liz holds a Master’s in Public Health from the University of North Carolina, Chapel Hill. She serves on the boards of Bethany Center Senior Housing and Ruth’s Table, a community creative arts program, both in San Francisco.

ANITA L. STEWART, PhD, is Professor with the Institute for Health & Aging at the University of California San Francisco and also with the Center for Aging in Diverse Communities (CADC). Although her expertise has been in developing concepts and measures of health and health-related concepts, since joining CADC 20 years ago, she expanded this to specialize in methods for developing measures for diverse populations. She has been PI of the CADC Measurement and Methods core (now known as the Analysis Core) since its beginning, and helped to advance methods and measures for minority aging and health disparities research. Behavioral interventions for older adults are also an area of interest. She developed an intervention to increase physical activity in older adults, and after joining CADC, she learned to diffuse it into minority communities to reach vulnerable seniors. She also conducted a lifestyle intervention to reduce risk of diabetes in low-income, minority older adults. The project used a randomized controlled design implemented in local community settings. Based on her experiences, she and Dr. Nápoles have worked together to develop a methodological framework with guidelines on translating behavioral interventions into disparity communities, and they continue to refine and advance these methods to be useful to others conducting interventions in community settings.

WILLIAM A. VEGA, PhD, is Provost Professor at USC with appointments in social work, preventive medicine, psychiatry, family medicine, psychology and gerontology. Vega is also Executive Director of the USC Edward R. Roybal Institute on Aging and an Emeritus Professor at the University of California, Berkeley, School of Public Health. Prior to joining the USC Roybal Institute, he was director of the Luskin Center on Innovation and an Associate Provost at UCLA. He is an elected member of the National Academy of Medicine. His work is focused on multi-cultural epidemiologic and services research, work that has been funded by multiple public and private sources. He has published more than 200 articles and chapters, in addition to several books. In 2006, the ISI Web of Science listed him in the top half of one percent of the most highly cited researchers worldwide in social science literature over the past 20 years, and currently in the top 97.5% overall by Research Gate. He is the recipient of many awards including the Community, Culture and Prevention Science Award from the Society for Prevention Research and the Rema Lapouse Award from the Mental Health, Epidemiology, and Statistics Sections of the American Public Health Association.

HEATHER M. YOUNG, PhD, RN, FAAN, is a nurse leader, educator and scientist and a nationally recognized expert in gerontological nursing and rural health care. Dr. Young is Associate Vice Chancellor for Nursing (UC Davis Health), Dignity Health Dean's Chair in Nursing Leadership, and Professor and founding Dean of the Betty Irene Moore School of Nursing at UC Davis. Dr. Young's research and clinical interest is the promotion of healthy aging with a particular focus on the interface between family and formal health-care systems. Her research has focused on family caregiving and the use of telehealth and community-based strategies to promote health for older adults and increase organizational capacity to serve older adults and their families. Dr. Young conducted several longitudinal studies of caregiving and a series of studies on long term care policy addressing nurse delegation and self-directed care. Her findings shaped state regulations. She serves as co-director of the UC Davis Latino Aging Research Resource Center and co-director of the Family Caregiving Institute.

JULIE M. ZISSIMOPOULOS, PhD, is Associate Professor in the Sol Price School of Public Policy at the University of Southern California (USC). In addition to her faculty appointment, she serves as Vice Dean for Academic Affairs at the Price School, Director of Education and Training at the Leonard D. Schaeffer Center for Health Policy and Economics, and Co-Director of the Resource Center for Minority Aging Research, funded by the National Institute on Aging. Topics of special interest are pharmaceutical innovation in Alzheimer's disease, caregiving and health care costs of Alzheimer's disease, racial disparities in medication adherence, medical expenditures, savings and wealth, labor force behavior, financial and non-financial support between generations of family members. Dr. Zissimopoulos' research sponsors include the National Institute on Aging and the Social Security Administration. She is a frequent speaker on the economics of aging and her work has been featured in the Los Angeles Times, on California Public Radio, PBS Newshour, and other media. Dr. Zissimopoulos received her B.A. *summa cum laude* from Boston College, her M.A. degree in international affairs from Columbia University, and a Ph.D. in economics from the University of California, Los Angeles.

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UC Davis Latino Aging Research Resource Center (LARRC)
UC Davis Alzheimer's Disease Center (ADC)
Betty Irene Moore School of Nursing at UC Davis
National Institute on Aging (NIA) Office of Special Populations

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.

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