Population Science Methods and Approaches to Aging and Alzheimer's Disease and Related Dementias Research

Edited by
Chau Trinh-Shevrin, DrPH

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PREFACE

The energy of the mind is the essence of life.
–Aristotle

The way you think, the way you behave, the way you eat, can influence your life by 30 to 50 years.
–Deepak Chopra

Aging begins at birth. Yet most people only begin to recognize and struggle with the aging process when they observe and experience a loss of their own youthful vitality, the breakdown of their bodies, and changes in their appearances. The effects of aging become more apparent to us as we watch our parents and loved ones endure advancing chronic conditions, comorbidities, isolation, and heightened vulnerability. In parallel, we see the reflection of these effects within our neighborhoods, communities, and society at large, producing new challenges for families and caregivers, health care providers, researchers, and policymakers. While national policies and programs, such as Medicare, are pivoting to become more cognizant and inclusive of aging-related conditions and the treatments and support needed by aging Americans and their care partners, there is an urgent need to focus attention and investment on population health approaches to address the unmet needs, sociocultural contexts, and health trajectories of older people.

While a vast array of aging-related conditions can impact the daily activities and well-being of older people, Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) are among the most feared of these conditions. These diagnoses portend a complete loss of self, including one's own identity, purpose, and autonomy as well as one's loss of self in relation to others. Profound memory loss eats away the connectedness of relationships spanning decades, rendering loved ones strangers – and, at times, strangers to be feared. As AD/ADRD advances, acute fear gives way to chronic anxiety, anger, and withdrawal. Caregivers of people living with AD/ADRD may find the most painful aspects of this process to be observing their loved ones suffer and become mere shells of the people they once were. It is important to distinguish dementia from AD. Dementia is not a specific disease; rather, it is a term that describes a set of symptoms including memory loss and

confusion as well as the breakdown of daily life functioning and the ability to communicate and interact with others. AD is the most common cause of dementia, accounting for about 70% of patients diagnosed with dementia. Other forms of dementia include vascular dementia, dementia with Lewy bodies, frontotemporal dementia, Cruetzfeldt-Jakob disease, Huntington's disease, normal pressure hydrocephalus, and mixed dementia (i.e., a combination of two or more sources of dementia). Typically, this group of diseases is referred to as AD/ADRD. In addition to degenerative diseases, like AD or Parkinson's disease, other causes of dementia may include chronic drug use, depression, infections, stroke, and vascular disease. For some causes of dementia, there may be treatments to reverse cognitive impairment or slow down the progression of dementia symptoms. AD is a disease of the brain and is progressively degenerative, impairing areas of the brain that include learning, thinking, and bodily functioning and leading to debilitation over time. AD is currently irreversible.

Over the last two decades, there have been increasing and substantial investments in identifying and testing therapeutics to treat and potentially reverse AD. For example, researchers have focused on the role of plaque-forming beta-amyloid in the brain in accelerating AD-associated deterioration, leading to the development of monoclonal antibodies to the immune system to help clear beta-amyloid from the brain. An example of this type of drug is lecanamab (i.e., Lequembi), which received accelerated approval by the United States (US) Federal Drug Administration (FDA) in early 2023; previously, aducanemab (i.e., Aduhelm) was approved in 2021. Evidence from available trials does not yet establish definitively the effectiveness of these drugs in improving cognition (Ackley et al., 2021). Other drugs in development focus on preventing destruction of synapses and halting memory loss (e.g., saracatinib), while still others focus on blocking production of beta-amyloid (i.e., beta- and gamma-secretase inhibitors). None of these currently available therapies, however, has proven beneficial to all of the individuals who have participated in drug trials or to those who have been given these therapies in health care settings, indicating the need for more investment and focused research to better understand the mechanisms and expression of AD.

Increasingly, researchers and advocates are raising attention to the role of prevention and social factors in healthy aging. For example, the role of the microbiome and the significance of the mind–gut relationship have been demonstrated to influence the risk for depression, anxiety, and dementia. What we eat and the health of the microbial environment in our digestive systems are connected to inflammation in our organs, including our brains, and thus impacts the processes for aging and sense of balance and well-being. In addition, social isolation and loneliness can impact risk for depression, cognitive decline, and risk for AD/ADRD. More research is needed to understand how social and environmental determinants impact healthy aging and the role of nutrition and the microbiome on preventing and mediating the risk for dementia.

As research progresses, including more diverse communities in biomedical and community-based research is an urgent imperative. Clinical trials conducted to date have failed to achieve meaningful representation by minoritized and low-income communities, leading to results that are not generalizable to many of the Americans in greatest need of these therapies. Reducing health disparities among older people is critical to slowing or reversing the physical impacts of AD/ADRD and improving the health of older people overall. Toward that end, financial resources and community-engaged strategies are needed to

ensure that the promise of biomedical research and clinical trials is available to all. Population health approaches offer ways to work hand-in-hand with diverse communities to address a range of aging-related conditions, including AD/ADRD, and are critical to informing the development of primary and secondary prevention strategies that aim to increase health equity for all Americans.

These challenges are daunting – but not insurmountable. This Handbook aims to provide a starting point for clinicians and other practitioners eager to take on these challenges in innovative, meaningful ways, particularly in minoritized, limited English proficient, and low-income communities. The topics included here range from population health trends and approaches to understanding community and patient engagement to caregiver perspectives and emerging trends. The Handbook aims to serve as a primer, introducing fundamental aspects of population health and participatory approaches to reducing health disparities and advancing health equity in the context of aging-related research. Our hope is that this introduction to the landscape of aging research in the most vulnerable of our communities will facilitate creativity, compassion, and meaningful next steps in biomedical and socio-ecological research, community support, and clinical care.

Chau Trinh-Shevrin, DrPH
Professor, Departments of Population Health and Medicine,
NYU Grossman School of Medicine

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THE EDITOR

CHAU TRINH-SHEVRIN, DrPH is Professor in the Departments of Population Health and Medicine, Vice Chair for Research, Director of the Section for Health Equity, and Institutional Review Board Chair at NYU Grossman School of Medicine. For over 25 years, her research focuses on the rigorous development and evaluation of multilevel strategies to reduce health disparities and advance health equity among low-income and across diverse racial and ethnic groups.

Dr. Trinh-Shevrin is multi-principal investigator (MPI) of a National Institute on Minority Health and Health Disparities (NIMHD) Center of Excellence, the NYU Center for the Study of Asian American Health (CSAAH), and a National Institute on Aging (NIA) Engagement in Longevity and Medicine Research Collaborative. Dr. Trinh-Shevrin also led a Centers for Disease Control and Prevention (CDC) Research Center for over a decade and currently leads a CDC Cancer Prevention and Control Research Network Center. Building on her expertise in community-based participatory research and longstanding relationships with national and local community partners, she is MPI of a National Institutes of Health (NIH) Community Engagement Alliance to End COVID-19 Disparities and associate director of Community Outreach and Engagement for the Perlmutter Cancer Center, a National Cancer Institute-designated Comprehensive Cancer Center.

Dr. Trinh-Shevrin is dedicated to mentoring junior faculty and students in minority and health disparities research. She is involved in many NIH-funded research training and education programs and leads an NIA Academic Leadership Award to support mentored research opportunities in healthy aging and health disparities research.

Dr. Trinh-Shevrin earned her doctorate in public health from the Mailman School of Public Health, Columbia University, and masters in health policy and management at the State University of New York at Albany. She has coauthored more than 150 peer-reviewed publications and is coeditor of three textbooks, *Applied Population Health Approaches for Asian American Communities* (Jossey-Bass, 2023), *Asian American Communities and Health* (Jossey-Bass, 2009), and *Empowerment and Recovery: Confronting Addiction during Pregnancy with Peer Counseling* (Praeger Press, 1998).

THE CONTRIBUTORS

JEANNETTE MICHELE BEASLEY, PhD, MPH, RDN, is an Assistant Professor in the Departments of Nutrition and Food Studies and Medicine at NYU. She trained in biology at the College of William and Mary (BS), nutrition at University of North Carolina-Chapel Hill (MPH, RDN) and epidemiology at the Johns Hopkins Bloomberg School of Public Health (PhD). Her research focuses on understanding the role of nutrition in chronic disease prevention, particularly in furthering the understanding of the role of nutrition in the prevention of cardiovascular disease in diverse populations and refining recommendations regarding the protein needs of older adults. This work has resulted in over 75 peer-reviewed publications and 8 books or book chapters. She has received funding from National Institutes of Health, Centers for Disease Control, and private foundations. She serves as an Associate Editor for BMC Public Health and as a peer reviewer for over 20 other academic journals. She previously held academic appointments at Group Health Research Institute, Fred Hutchinson Cancer Research Center, and Albert Einstein College of Medicine.

ABRAHAM AIZER BRODY, PhD, RN, FAAN, is the Mathy Mezey Professor of Geriatric Nursing, Professor of Medicine, and Associate Director of the Hartford Institute for Geriatric Nursing at NYU. His work focuses on the intersection of geriatrics, palliative care, quality, and equity. The primary goal of his research, clinical, and policy pursuits is to improve the quality of care for older adults with serious illnesses wherever they reside through the development, testing, and dissemination of real-world, technology, and informatics-supported quality improvement interventions. He is the principal investigator of multiple large-scale pragmatic clinical trials to improve the quality of care and quality of life for persons living with dementia and their care partners living in the community, and leads the Pilot Core for the National Institute on Aging (NIA) IMPACT Collaboratory, which is a collaboration with NIA to move evidence-based practices for persons living with dementia from research to practice. He maintains an active practice on the geriatrics and palliative care consult services at NYU Langone Health.

OMONIGHO MICHAEL BUBU, MD, PhD, MPH, is an Assistant Professor and physician scientist at NYU Grossman School of Medicine, in the Departments of Psychiatry and Population Health, with a programmatic research focus on sleep, aging, and Alzheimer's

disease (AD). Dr. Bubu has graduate, internship, and fellowship-level clinical and research training in neurology, neuro-epidemiology, and public health. His research examines how age-related and age-dependent sleep changes, and vascular risk, impact cognitive decline and AD risk, and how they drive AD-related disparities.

MIRNOVA E. CEÏDE, MD, MSc, is an Assistant Professor of Geriatric Psychiatry and Geriatrics at the Albert Einstein College of Medicine/Montefiore Medical Center, the Assistant Program Director of the Montefiore Geriatric Psychiatry Fellowship, and Associate Director of Psychiatry at the Montefiore Center for the Aging Brain. She completed her Geriatric Psychiatry Fellowship at SUNY Downstate and joined the Geriatric Psychiatry Division at Montefiore Medical Center in 2013. She has presented at national and international meetings on behavioral risk factors for dementia and models of psychiatric integration in health care. In 2018, she completed the Albert Einstein Clinical Research Training Program and attained a Master of Science in Clinical Research. She completed a Columbia Center for Interdisciplinary Research on Alzheimer's disease Disparities (CIRAD) Pilot Project Grant to further apathy and cognition in a racially and ethnically diverse clinic population. Most recently, she was awarded a National Institutes of Health Diversity Supplement to study apathy as an early risk factor for dementia in a multicountry cohort of older adults.

RUIJIA CHEN, ScD, is a social epidemiologist and a postdoctoral scholar in the Department of Epidemiology and Biostatistics at the University of California, San Francisco. She received her Doctor of Science degree in social epidemiology from Harvard University and master's degree in social policy from the University of Pennsylvania. Her research focuses on applying advanced epidemiologic methods to understand how psychosocial determinants across the life course influence social disparities in late-life cognitive outcomes.

JOSHUA CHODOSH, MD, MSHS, is Director of the NYU Division of Geriatric Medicine and Palliative Care and the inaugural endowed Michael L. Freedman Professor of Geriatric Research at NYU Grossman School of Medicine. He is also Staff Physician at VA NY Harbor Healthcare System. As Professor of Medicine and Population Health, Dr. Chodosh joined NYU in 2015 after a productive research career at UCLA and the Greater Los Angeles VA. At NYU, he has built the Freedman Research Center on Aging, Technology and Cognitive Health supported by investigators that cross several departments including medicine, population health, surgery, and emergency medicine and multiple institutions across the United States. Dr. Chodosh is PI or MPI of multiple National Institutes of Health R01s and a VA multisite Merit. He is also PI of the Centers for Disease Control and Prevention BOLD Public Health Center of Excellence on Early Detection of Dementia and