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Editorial

The Future of Dementia Care, Caregiving, and Services Research

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With the aging of the baby boomers, the numbers of Americans living with or affected by dementia will rise dramatically. By 2025, an estimated 7.2 million Americans are expected to have Alzheimer's disease, which is the most common cause of dementia, accounting for 60–80% of cases.¹ In the absence of medical breakthroughs, the prevalence is expected to climb to 13.8 million by 2060, more than doubling the number currently affected.¹ To prepare for this coming crisis, the National Alzheimer's Project Act was signed into law in January 2011 followed by the 2012 release of a National Plan to address Alzheimer's disease that includes 5 goals to: prevent and effectively treat Alzheimer's disease and related dementias by 2025, enhance care quality and efficiency, expand supports for people with Alzheimer's disease and related dementias and their families, enhance public awareness and engagement, and improve data to track progress.

As part of the federal effort to accomplish these goals, additional funds have been directed to the National Institute on Aging (NIA) to support Alzheimer's research, rising from \$986 million in fiscal year 2016 to \$2.398 billion in fiscal year 2019.² With this increased funding, since 2016, the NIA has utilized a higher pay line for Alzheimer's Disease/Alzheimer's Disease-Related Disorders (AD/ADRD) investigator-initiated research. As part of NIA's effort, a series of Summits has been held on Alzheimer's Disease (2012, 2015, 2018) and Alzheimer's Disease-Related Dementias (2013, 2016, 2019). In 2017, sponsored by the US Department of Health and Human Services (HHS) and private sector organizations, the first National Research Summit on Dementia Care, Caregiving, and Services was held. These Summits have resulted in the identification of AD + ADRD Implementation Milestones that guide funding opportunities and priorities. In particular, the first Dementia Care Summit brought attention to the importance of research on dementia care, identifying 464 recommendations within 12 categories, which have resulted in 26 funding opportunities, 4 Notices of Special Interest, and 129 new NIA care-related awards.³ An interdisciplinary Consortium to Improve Care

and Outcomes for Persons Living with Alzheimer's and Dementia and the NIA Imbedded Pragmatic Alzheimer's Disease and AD-Related Dementia Clinical Trials (IMPACT) Collaboratory have been funded.

Building on this momentum, planning for the second Dementia Care, Caregiving, and Services Summit, sponsored by the NIA and the Office of the Assistant Secretary for Planning and Education (ASPE), US Department of Health and Human Services, began in March 2019. Guided by a 19-member Steering Committee, preparation followed a deliberate process of information gathering from the public and stakeholders, including ASPE, which obtained input from 5 Stakeholder Groups (persons living with dementia, family caregivers, service providers, workforce developers, and payers). The Summit was organized around 6 Themes plus one integrated Theme and an Emerging Topics session (Table 1). Each Theme's Summit session included research presentations that provided scientific background followed by introduction of draft research "Gaps and Opportunities" to advance the science within the Theme. Sessions concluded with reactions from diverse panelists and questions from the audience. The Summit was to be held in-person on March 24 and 25, 2020 but due to COVID-19, was converted to 3 virtual sessions held on July 10, July 21, and August 13, 2020. Recordings of the Summit sessions, including a virtual poster session can be viewed at <https://www.nia.nih.gov/2020-dementia-care-summit>. After the Summit concluded, draft Goals and Opportunities were revised based on feedback and further discussion among the Steering Committee to create a final set <https://www.nia.nih.gov/research/summit-gaps-opportunities>. A final report describing the process and agendas for the sessions and containing the Gaps and Opportunities has been posted <https://www.nia.nih.gov/sites/default/files/2021-01/DementiaCareSummitReport.pdf>.

The materials available on the NIA website provide valuable summaries of the process and outcomes of the 2020 Summit, but do not contain the rich background research that guided the development of the Gaps and Opportunities. To disseminate this important information, the *Journal of the American Geriatrics Society* and *The Journal of Post-Acute and Long-Term Care Medicine* have agreed to publish 8 papers (5^{4,8–11} and 3^{5–7} respectively) that contain content from the scientific background presentations for each Summit theme as well as the Emerging Topics session.

Though none of these background papers are comprehensive reviews, we believe that they contain succinct information that can help researchers, clinicians, and policymakers quickly grasp the current state of evidence on key areas within each theme. When coupled with the Gaps and Opportunities, scientists can begin to develop research questions and design studies to be submitted for NIA funding to advance the

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Table 1

Themes, Background Research Presentations, and Cross-Cutting Themes of the 2020 Dementia Care, Caregiving, and Services Summit

- Theme 1: Impact of Dementia⁴
 - Population trends of Alzheimer's disease and related dementias
 - Disparities in health, services, and interventions for persons living with dementia and family caregivers
 - Economic impact of Alzheimer's disease and value of delaying onset for individuals, caregivers, and society
 - Theme 2: Long-Term Services and Supports (LTSS) in Home, Community, and Residential Care* Settings for Persons Living with Dementia and their Care Partners⁵
 - Evidence-based person-centered practices for persons living with dementia and their caregivers: What do we know, where to next?
 - Understanding the long-term care workforce in a new way
 - Organization and financing of long-term supports and services for persons living with dementia
 - Theme 3: Services and Supports in Medical Care Settings for Persons Living with Dementia⁶
 - Providing high-quality care in medical care settings
 - Care of persons living with dementia and with multiple chronic conditions
 - Financing the care of persons living with dementia
 - Integration of Themes 2 and 3: The Present and Future of Integrated Long-Term and Medical Care^{*7}
 - Building the Case for Integrating LTSS and Medical Care and their Financing for Persons Living with Dementia and their Families
 - Signals on Successful Approaches to Integrating LTSS and Medical Care for Persons Living with Dementia
 - Theme 4: Participation of Persons Living with Dementia and their Care Partners in Research⁸
 - Reporters, data sources, and outcomes
 - Nomenclature: Challenges, issues, and a plan
 - Persons living with dementia and caregiver research engagement
 - Theme 5: Intervention Research, Dissemination, and Implementation⁹
 - Developing and disseminating evidence-based care models
 - Current challenges in implementation science, and implications for improving the care of persons living with dementia
 - Learning health systems
 - Theme 6: Research Resources, Methods, and Data Infrastructure¹⁰
 - Identification of people living with dementia for population and health care research
 - System level research: Pragmatic clinical trials in dementia
 - Consent for research involving persons with dementia: Ethical considerations
 - Emerging Topics¹¹
 - Emotional functioning in persons living with dementia and their care partners
 - Technological reserve in persons with dementia: The promises and pitfalls of smart systems for health, well-being, and independence
 - Implications of identification at preclinical stages of dementia
- Cross-cutting Themes
- perspectives from PLWD and their care partners
 - health disparities
 - ethics
 - technology
 - etiologies

*Papers published in The Journal of Post-Acute and Long-Term Care Medicine.

evidence base and ultimately improve dementia care quality and services for person living with dementia and their caregivers.

Author Contributions

DBR: concept and design and preparation of manuscript. JLW: concept and design and preparation of manuscript.

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