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DIVISION OF BEHAVIORAL AND SOCIAL SCIENCES AND EDUCATION (DBASSE)

Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Sciences

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Agenda

- Study Process
- Five Priorities for Reducing Negative Impacts of Dementia
- Research Opportunities
- What Makes a Ten-Year Research Agenda Optimally Effective
- Recommendation and Call to Action
- Closing Remarks

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Advisory Panel Members

- CYNTHIA HULING HUMMEL, living with dementia
  Elmira, New York
- MARIE MARTINEZ ISRAELITE, care partner/caregiver
  Chevy Chase, Maryland
- JOHN-RICHARD PAGAN, living with dementia
  Woodbridge, Virginia
- EDWARD PATTERSON, living with dementia
  Clermont, Florida
- BRIAN VAN BUREN, living with dementia
  Charlotte, North Carolina
- GERALDINE WOOLFOLK, care partner/caregiver
  Oakland, California

Study Process

- What is a decadal study?
- Committee charge:
  - Develop 10 year research agenda in behavioral and social sciences;
  - Research on the burden of AD/ADRD for individuals, families, medical and long-term care systems;
  - Challenges associated with AD/ADRD care;
  - Intervention development at different stages of illness;
  - Cognitive and AD/ADRD epidemiology;
  - AD/ADRD prevention;
  - Detection of AD/ADRD-related change;
  - Causes and consequences of AD/ADRD health disparities; and
  - AD/ADRD data infrastructure needs.

Study Process

- Information gathering:
  - Committee members
  - Advisory panel
  - 4 workshops
  - White papers
  - 6 commissioned papers
- Deliberation and report development

Five Priorities for Reducing Negative Impacts of Dementia

- Improve the lives of people touched by dementia
- Rectify inequities and disparities
- Develop innovations
- Address costs, value and outcomes
- Advance research capabilities

RESEARCH OPPORTUNITIES

UNDERSTANDING MODIFIABLE FACTORS THAT CAN PREVENT ALZHEIMER'S AND RELATED DEMENTIAS OR REDUCE OR DELAY THEIR SYMPTOMS

WAYS TO FACILITATE THE DEVELOPMENT OF COMMUNITIES THAT SUPPORT PEOPLE LIVING WITH DEMENTIA AND CAREGIVERS

Deborah Blacker, MD, ScD

Understanding of modifiable factors that can prevent Alzheimer’s and related dementias or reduce or delay their symptoms

Understanding of modifiable factors that can prevent Alzheimer’s and related dementias or reduce or delay their symptoms

- The causal effects of social factors.
- The effects of health-related behaviors and their management over the life course.
- Modifiable drivers of racial/ethnic inequality in dementia incidence.
- The mechanisms through which socioeconomic factors influence brain health.

Understanding of modifiable factors that can prevent Alzheimer’s and related dementias or reduce or delay their symptoms

- Modifiable risk factors that can be the basis for precise recommendations to individuals about decision making and for population-level policies to promote brain health.
- Effective means of communicating the magnitude and degree of potential risk and protective factors to support informed decision making.

Ways to facilitate the development of communities that support people living with dementia and caregivers

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- Develop systematic analysis of the characteristics of communities that influence the risk of developing dementia and the experience of living with the disease.
- Collect data to document the opportunities and resources available in communities and evaluation of their impact.

Ways to facilitate the development of communities that support people living with dementia and caregivers

- Analyze the community characteristics needed to foster dementia friendly environments.
- Evaluate innovative approaches to adapting housing, services, and supports so that persons with dementia can remain in the community and out of institutional care.

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WAYS TO SUBSTANTIVELY IMPROVE THE EXPERIENCE OF INDIVIDUALS LIVING WITH DEMENTIA

WAYS TO SUBSTANTIVELY IMPROVE THE EXPERIENCE OF FAMILY CAREGIVERS

David Reuben, MD

Ways to substantively improve the experience of individuals living with dementia

Ways to substantively improve the experience of individuals living with dementia

- Improve screening and diagnosis, including guidance for clinicians that also addresses issues related to disclosure.
- Develop guidance to support ethical and responsible decision making by and for people living with dementia.
- Develop outcome measures that reflect the perspectives and values of people living with dementia, their family caregivers, and communities.

Ways to substantively improve the experience of individuals living with dementia

- Improve design and evaluation of nonpharmacologic interventions to:
  - Slow or prevent cognitive and functional decline
  - Reduce or ameliorate behavioral and psychological symptoms
  - Improve comfort and well-being
  - Adequately and equitably serve diverse populations

Ways to substantively improve the experience of family caregivers

Ways to substantively improve the experience of family caregivers

- Identify the highest-priority needs for resources and support.
- Identify the assets that family caregivers bring to their work, as well as their needs for supplemental skills and training.

Ways to substantively improve the experience of family caregivers

- Develop innovations to support and enhance family caregiving and address practical and logistical challenges in multiple domains, including appropriate use of technology.
- Continue progress in data collection and research methods.

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WAYS TO SUBSTANTIALLY STRENGTHEN THE QUALITY AND STRUCTURE OF HEALTH CARE AND LONG-TERM CARE

WAYS TO SUBSTANTIALLY STRENGTHEN THE ARRANGEMENTS THROUGH WHICH MOST DEMENTIA CARE IS FUNDED

WAYS TO IMPROVE UNDERSTANDING OF THE ECONOMIC IMPACT OF DEMENTIA AND IDENTIFY HIGH VALUE, COST-EFFECTIVE INTERVENTIONS

Vincent Mor, PhD

Ways to substantially strengthen the quality and structure of health care and long-term care

Ways to substantially strengthen the quality and structure of health care and long-term care

- Document the diagnosis and care management received by persons living with dementia from their primary care providers.
- Clarify disease trajectories to help health systems plan care for persons living with dementia.
- Identify effective methods for providing dementia-related services throughout the disease trajectory.

Ways to substantially strengthen the quality and structure of health care and long-term care

- Develop and evaluate standardized systems of coordinated care for comprehensively managing multiple comorbidities for persons with dementia.
- Identify effective approaches for integrating and coordinating care services across health care delivery and community-based organizations.
- Identify future long-term and end-of-life needs and available care for persons living with dementia.

Ways to substantially strengthen the quality and structure of health care and long-term care

- Describe and monitor factors that contribute to problems with nursing home quality.
- Develop and evaluate alternatives to traditional nursing home facilities.
- Improve understanding of how and when patients use palliative and hospice care and variations in available end-of-life care across regions and populations.

Ways to substantially strengthen the arrangements through which most dementia care is funded

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- Compare the effects of different financing structures on the quality of care and clinical outcomes.
- Examine ways to modify incentives in reimbursement models to optimize care and reduce unnecessary hospitalizations.
- Develop and test approaches to integrated financing of medical and social services.

Ways to improve understanding of the economic impact of dementia and identify high value, cost-effective interventions

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- Assess and quantify the total economic impact of dementia for individuals and families, including current and future national costs.
- Improve understanding of drivers of dementia-related costs.

Ways to improve understanding of the economic impact of dementia and identify high value, cost-effective interventions

- Estimate the value to individuals, families, and society of innovations in: prevention; diagnostics; and treatment, including pharmacologic treatments.
- Take advantage of all of these research opportunities which depend on advances in research methodology.

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KEY METHODOLOGICAL OBJECTIVES TO SUPPORT NEEDED RESEARCH

WHAT MAKES A TEN-YEAR RESEARCH AGENDA OPTIMALLY EFFECTIVE

GUIDELINES FOR AWARDING RESEARCH GRANTS TO ESTABLISH INCENTIVES

Tia Powell, MD

Key methodological objectives to support needed research

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- Expand data infrastructure and improved data collection.
- Improve measurement of exposures and outcomes.
- Support the adoption of more rigorous study designs, particularly in the realm of implementation science so that research findings can be successfully integrated into clinical and community practices.

Key methodological objectives to support needed research

- Develop systematic approaches for integrating evidence from disparate studies.
- Improve inclusion and representation among both research participants and researchers.

What Makes a 10-year Research Agenda Optimally Effective

- Coordinated
- Considers fundamental socioeconomic factors
- Includes pragmatic, implementation, and dissemination research
- Addresses potential policy implications

Guidelines for Awarding Research Grants to Establish Incentives

Coordinate research objectives with research agenda priorities

Interdisciplinary research and inclusion of stakeholders

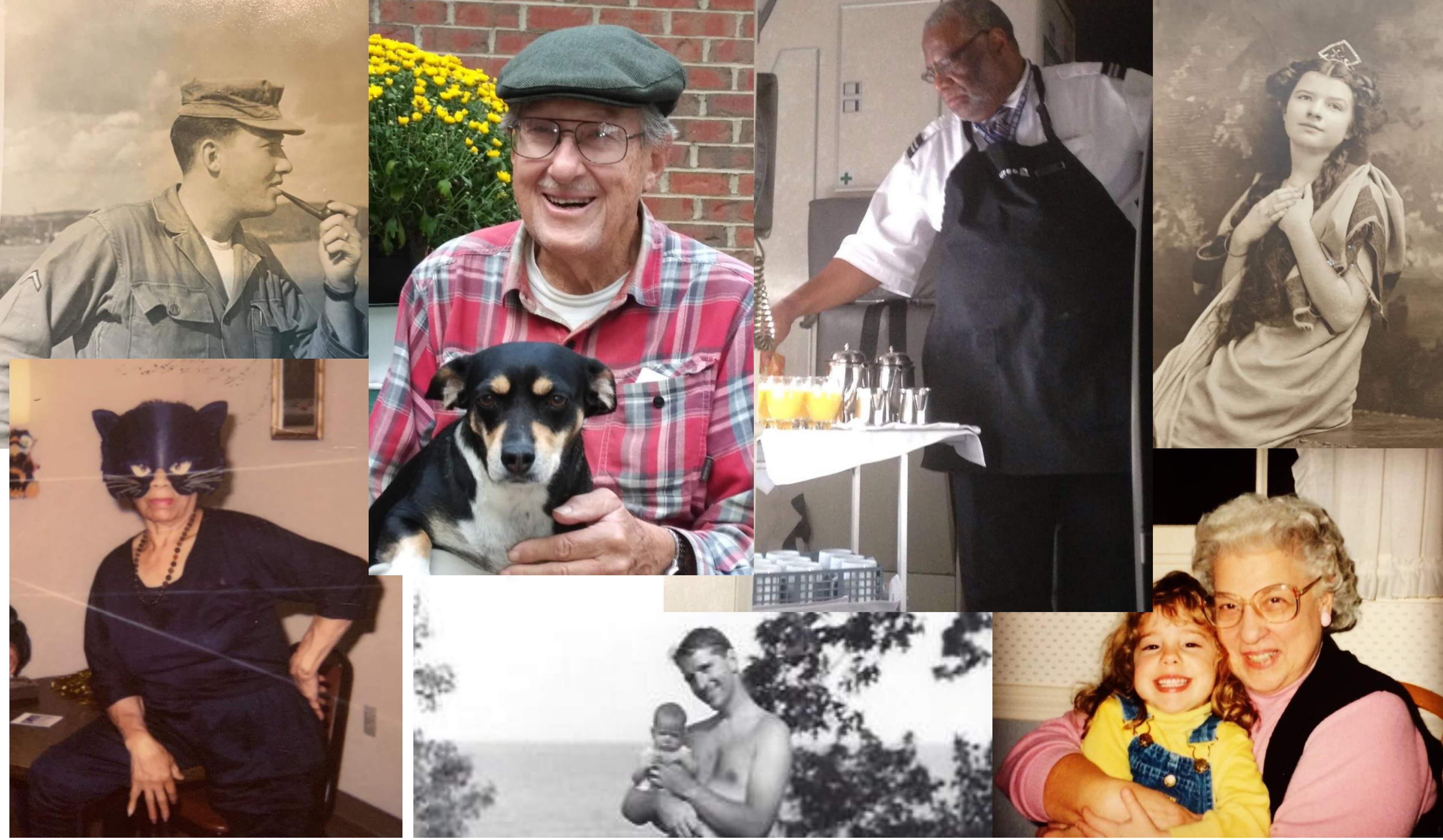
Attention to topics not typically part of medical research of importance to PLWD

Evaluation and implementation research to translate findings into programs with broad impact

Dissemination of research findings to policymakers

Thank You!

Copies of the report *Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Sciences* are available on the study website.



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