

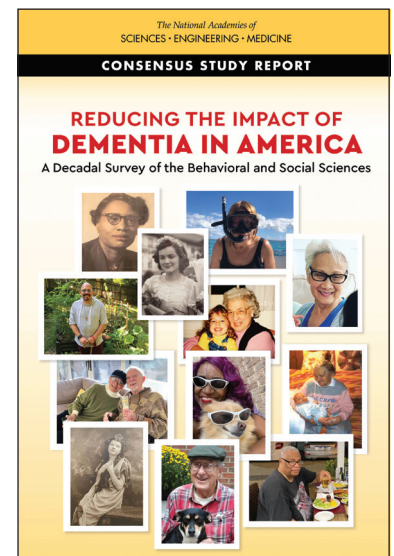


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Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Sciences Highlights

Few diseases have had as far reaching and devastating an impact on society as Alzheimer’s disease and related dementias (AD/ADRD). Nearly everyone has a direct connection to a person living with or caring for someone living with dementia. More than 6 million people in the United States are currently living with AD. For those living with and caring for people experiencing AD/ADRD, the challenges are numerous and complex, and include physical and emotional stress, loss of income, loss of function, loss of the ability to participate in valued activities, and interrupted connections to family and friends. These diseases also place a substantial demand on communities and on the institutions and government entities that support people living with dementia and their families. The COVID-19 pandemic also exposed and seriously exacerbated the long-standing challenges for persons living with dementia. In addition to the risk of serious illness and death, the virus posed challenges for persons living with dementia, regardless of whether they resided in care facilities, including social isolation and loss of access to vital resources, overcrowded and intergenerational households, shortages of care options, and risks to their care partners. Family caregivers also experienced hardship, unable to visit loved ones with dementia in facilities, and often times withdrew them from nursing homes due to fear of contacting COVID-19. The pandemic presented an opportunity to systematically examine an infrastructure that is not only vulnerable to disaster, but also inadequate in ordinary times.

The economic cost of dementia is significant, with estimates ranging from \$305 billion for 2020 in the United States, rising to about \$1.5 trillion by 2050. Recently, the drug aducanumab was approved by the U.S. Food and Drug Administration, sparking an ongoing controversy. While this drug may slightly decrease the progression of dementia, it will not eradicate the disease. The rapidly growing and diverse population living with dementia will continue to require support across a broad range of domains, and social and behavioral sciences research can help improve safeguards to provide Americans with access to effective and safe medications.



Despite these significant challenges, there is hope that research in the social and behavioral sciences will contribute to knowledge and interventions to prevent or slow the development of dementia and ameliorate the experience of living with dementia, thus substantially reducing its negative impact on society. To more fully elucidate what research is needed, the National Institute on Aging of the U.S. Department of Health and Human Services requested that the National Academies of Sciences, Engineering, and Medicine conduct a consensus study to produce a decadal survey¹ of research in the social and behavioral sciences with the potential to mitigate the negative impacts of AD/ADRD. To carry out the study, the National Academies convened a committee with a broad range of expertise in sociology, epidemiology, biostatistics, public health, geriatric medicine, psychology, psychiatry, neurology, bioethics, and public policy.

The committee's report, *Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Sciences*, offers a broad research roadmap for the behavioral and social sciences over the next decade, noting promising interventions and programs that require additional confirmatory evidence. The report also describes social and behavioral research that can provide the foundation for the development of programs and policies, as well as ethical safeguards that would serve the needs of all Americans affected by dementia. With the number of Americans living with dementia expected to grow exponentially in the coming years, the committee recommends immediate action to improve the health and well-being of those living with or affected by these diseases and to reduce the significant related economic and social costs.

KEY RESEARCH AREAS FOR REDUCING THE IMPACT OF DEMENTIA IN AMERICA

In its review of the literature, the committee looked across the potential impacts of dementia and identified the key areas below for further examination and research.

Understanding risk and preventive factors for dementia. Rigorous research is needed to determine how to prevent dementia, including how behavior changes, such as diet and exercise; socioeconomic conditions; and structural and interpersonal racism and discrimination may impact development of the disease. For example, evidence suggests that people who eat a healthy diet, exercise regularly, maintain a healthy weight, and reduce their cardiovascular risk have a lower risk of dementia. Similarly, clear evidence indicates that disparities in socioeconomic resources, negative social interactions (e.g., overt racism and discrimination), systemic racism, and other socioeconomic factors contribute to stark disparities in dementia risk across population groups. The report outlines specific research needed to assess these factors, for example, examining the effects of social factors, health-related behaviors, and modifiable drivers of racial/ethnic inequality on dementia risk. The committee also identified the need for developing effective means of communicating the magnitude and degree of potential risk and protective factors to support informed decision making.

Examining the experience of living with dementia, including diagnosis, care, and treatment. Much of the research on interventions for people living with dementia is primarily observational or conducted using conventional rather than pragmatic trials. The committee identified the need for both qualitative and quantitative research related to the needs of people at all stages of dementia that is interdisciplinary, involving ethicists, legal experts, and others, as well as clinicians and researchers. The report also describes the need for improved screening and diagnosis to identify people living with dementia, including in diverse communities. The report notes the importance of measures that assess outcomes relevant to people living with dementia and their caregivers throughout the course of the disease.

Identifying the needs of family caregivers. Although much is known about interventions that can effectively support caregivers, there are also significant gaps in the existing research. Important aspects of the caregiving experience and its effects on both caregivers and people living with dementia have not yet been studied; an example is the need for better research on differences in caregiver needs across diverse populations. Among other areas, research is needed to identify the highest priority needs for resources and support for family caregivers, including supplemental skills and training, and other resources to enhance their capacity to provide care while maintaining the safety and well-being of both care recipients and caregivers.

¹ A decadal survey is a method for engaging members of a scholarly community to identify lines of research with the greatest potential to be of use over a 10-year period in pursuit of a particular goal. The National Academies developed this type of survey to support the planning of future research for government agencies and other entities.

Understanding the role of community characteristics in dementia risk and quality of life for people living with dementia and their families. There is strong evidence that community factors shape the exposures and behaviors that influence dementia risk. Community supports are also key resources for those living with and affected by dementia. Innovative approaches to the design of communities in which people living with dementia can thrive do show promise, although their application to diverse contexts and populations has yet to be systematically demonstrated. Research is needed on the characteristics of communities that influence the risk of developing dementia and the experience of living with the disease, along with community characteristics necessary to foster dementia-friendly environments and innovative approaches to adapting housing, services, and supports so that persons with dementia can remain in the community.

Strengthening the role of the health care system and institutions that provide care to people living with dementia. People living with dementia interact with many different institutions that provide health care and social support. For example, many spend time living in long-term care facilities and ultimately receive care, such as hospice resources at the end of life, interacting with a myriad of professionals, including neurologists, social workers, geriatricians, among many others. To strengthen how people living with dementia and their caregivers interact with and are served by the health care and social service systems, the committee makes a number of related research recommendations regarding the quality and structure of health care along with long-term and end-of-life care.

While health care and long-term care systems employ millions of individuals who care for people living with dementia, examining issues that affect these workforces was beyond the scope of this study. However, the committee acknowledges that improving knowledge and correcting challenges related to workforce issues are vitally important to the research directions outlined in the report.

Understanding the economic costs of dementia. Examining the economic impacts of dementia will be key to mitigating the overall impact of the disease on individuals and society. Both reducing unnecessary costs and achieving significant improvements in health, quality of life, and other outcomes that justify the associated costs will result in economic benefit. Research needs include an assessment and quantification of the total economic impact of dementia for individuals and families, including current and future national costs; improved understanding of drivers of dementia-related costs; and estimation of the value to individuals, families, and society of innovations in prevention, diagnostics, and treatment, including pharmacologic treatments.

Strengthening data collection and research methodology. Advances in data collection and research methodology are needed to support progress in virtually every domain of dementia research. This includes the expansion of data infrastructure, improved measurement of exposure and outcomes, support for the adoption of more rigorous study designs, and development of systematic approaches for integrating evidence from disparate studies.

10-YEAR RESEARCH PRIORITIES

Recognizing that resources are finite, the committee identified the following five highest research priorities for the next decade, selected to have maximal effect in reducing the negative impacts of dementia and improving quality of life:

1. Improve the lives of people affected by dementia, including those who develop it, their families and caregivers, and their social and clinical networks, through research on factors that affect the development of the disease and its outcomes, promising innovative practices, and new models of care and policies that facilitate the dissemination of effective interventions.
2. Rectify disparities across groups and geographic regions that affect who develops dementia, how dementia is identified in different communities, how the disease progresses, outcomes and quality of life, and access to health care and supportive services.
3. Develop innovations to improve the quality of care and social supports for individuals and communities and to support improved quality of life (e.g., reducing financial abuse and stressors, finding relevant affordable housing and care facilities, gaining access to important services).
4. Ease the financial and economic costs of dementia for individuals, families, and society and balance long-term costs with long-term outcomes across the life span.
5. Pursue advances in research capability, including study design, measurement, analysis, and evidence integration, as well as the development of data infrastructure needed to study key dementia-related topics.

In addition to these broad priorities, the committee offers guidelines for the design of an effective portfolio of research. A 10-year research agenda will be optimally effective if it:

- is **coordinated** to ensure that the breadth of topics identified in this report is addressed sufficiently without redundancy and competing initiatives;
- consistently takes into account **fundamental socioeconomic factors** that influence who develops dementia, access to high-quality care, and outcomes;
- includes pragmatic, implementation, and dissemination research needed to ensure that findings can be **implemented effectively** in clinical and community settings; and
- addresses potential **policy implications** that are articulated beginning in the planning stages and assessed during the course of the investigations.

CALL TO ACTION

To support the above 10-year research agenda, sustained leadership and funding are needed. The committee therefore makes the following recommendation:

Funders of dementia-related research, including federal agencies, such as the National Institutes of Health and the Agency for Healthcare Research and Quality, along with relevant philanthropic and other organizations, such as the Patient-Centered Outcomes Research Institute, should use guidelines for awarding research grants to establish incentives for

- coordination of research objectives with the research agenda priorities identified in this report to ensure that key areas are funded without undue overlap and to foster links across research efforts;
- interdisciplinary research and inclusion of stakeholders in research partnerships;
- attention to topics that have not typically been part of standard medical research but are important to those living with dementia, including isolation, financial security, and housing options;
- rigorous evaluation and implementation research needed to translate findings into programs with impact on a broad scale; and
- dissemination of research findings to policy makers.

The report's broad research roadmap will promote progress in addressing high-priority research within the behavioral and social sciences over the next decade. This research will provide the foundation for the development of innovative programs and policies, as well as ethical safeguards, to serve the needs of those affected by dementia. By 2030, an estimated 8.5 million Americans will have AD and many more will have other forms of dementia. Those living with dementia and their caregivers deserve the support and resources needed to lead lives of dignity and well-being. To attain this goal, the time to act is now.

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To read the full report, please visit
<https://www.nationalacademies.org/our-work/decadal-survey-of-behavioral-and-social-science-research-on-alzheimers-disease-and-alzheimers-disease-related-dementias>

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