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ORIGINAL ARTICLE

# Opportunities for New Insights on the Life-Course Risks and Outcomes of Cognitive Decline in the Kavli HUMAN Project

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**Abstract**

The Kavli HUMAN Project (KHP) will provide groundbreaking insights into how biological, medical, and social factors interact and impact the risks for cognitive decline from birth through older age. It will richly measure the effect of cognitive decline on the ability to perform key activities of daily living. In addition, due to its family focus, the KHP will measure the impact on family members, including the amount of time that family members spend providing care to older adults with dementia. It will also clarify the division of caregiving duties among family members and the effects on caregivers' work, family life, and balance thereof. At the same time, for care that the family cannot provide, it will clarify the extent to which cognitive decline impacts healthcare utilization and end-of-life decision making.

**Key words:** aging; cognitive decline; population research

## Introduction

Dementia is a common and feared aging-related condition characterized by declines in memory and other cognitive functions that are severe enough to cause the loss of independent function and difficulties with activities of daily living. Dementia has a large and growing impact on older adults, their families, and government programs in the United States and around the world. About 4.2 million adults in the United States, and more than 35 million worldwide, had dementia in 2010,[1] with an estimated economic impact in the United States of about $200 billion[2] and $600 billion worldwide,[3] including a large burden of unpaid caregiving provided by families. Because of the sharp increase in the incidence of dementia at older ages and the expected growth in the worldwide elderly population in the decades ahead (from about 600 million in 2015 to 1.5 billion in 2050), the number of dementia cases is expected to triple by 2050, absent new interventions to prevent or slow the trajectory of cognitive decline.[1,4]

Recognition of the growing impact of dementia has led governments around the world to prioritize expanding the collection of data on individuals and populations to understand, address, and track better the current and future impact of the dementia epidemic. For instance, the National Alzheimer's Project Act (NAPA) was signed into law by President Obama in 2011 in order to expand U.S. government efforts to improve treatment and prevention, and to collect data to track progress of these efforts in the future. The G8 Dementia Summit was held in London in 2013 in recognition of the growing global impact of Alzheimer's disease (AD) and dementia, and to begin to coordinate efforts for international collaboration and data sharing. The World Health Organization also recently identified dementia as a "public health priority" that should be on all countries' public health agenda.[4]

While the large growth in the number of older adults in the coming decades will lead to an increase around the world in dementia cases, a number of recent studies have suggested that the age-specific risk of dementia has actually decreased in high-income countries over the last 25 years, possibly due to more aggressive

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treatment of cardiovascular risk factors that increase the risk of cognitive decline (e.g., diabetes, hypertension, and high cholesterol), as well as a worldwide boom in educational attainment, which is thought to increase the "cognitive reserve" of older adults.[5] However, it is unclear whether the recent large increase in the prevalence of obesity and diabetes around the world will cause a slowing or reversal in this optimistic trend, and it is also unclear whether there has been a similar or opposite trend in low- and middle-income countries.[6,7]

Over the last two decades, the conceptualization of the cause for cognitive decline and dementia in older adults has evolved from a focused derangement of a few biological pathways (e.g., the amyloid cascade of AD; multiple strokes causing vascular dementia) toward a fuller life course, multifactorial syndrome that results in overlapping brain pathologies ("mixed dementia" from amyloid plaques, vascular insults, and Lewy-body pathology) due to both biological and social stressors from the womb through old age. In this way, dementia is a prototypical health condition that requires a "life-course" perspective because of the exquisite sensitivity of the development of brain cells and the healthy wiring of brain networks to both daily biological and social stressors.[8]

The intensive longitudinal daily data collection planned for the Kavli HUMAN Project (KHP) will provide new opportunities for ground-breaking insights into how biological, medical, and social factors interact to increase or decrease the risks for cognitive decline from birth through older age, including: (a) the transmission of "brain health" across generations (e.g., maternal health and brain gestation; early parent–child social interactions and the building of "cognitive reserve"); (b) how education, cognitive stimulation, and daily cognitive activity (reading text, smartphones, the Internet, etc.) are linked with brain health and the risk for later-life cognitive decline; (c) how key cardiovascular risk factors, such as hypertension, diabetes, vascular disease, and physical inactivity, affect the risk for cognitive decline; and (d) how social life and social interactions are related to brain health and the risk for cognitive decline.

In addition to providing new and unique data regarding the complex interaction among biological, medical, and social risk factors for cognitive decline, the KHP will provide an unprecedented opportunity to understand better the wide-ranging impact and outcomes of cognitive decline on individuals, their families, and the wider social networks in which they live their daily lives, including: (a) changes in the ability to perform key activities of daily living; (b) the amount of time that family members spend providing daily care to older adults with dementia, as well as the trajectory caregiving time as cognitive impairment worsens; (c) the dynamics of the division of caregiving duties among family members, and how caregiving affects the work and family life of caregivers; and (d) healthcare utilization and decision making at the end-of-life.

There are many key measurement opportunities and challenges involved in developing the ideal data set. A key set of factors to be measured are maternal activities during gestation. There are also important early-life interactions and opportunities to be measured. For example, more educated parents likely speak with their children in different ways than less educated parents, perhaps leading to different levels of "cognitive reserve" and, therefore, different levels of risk for late-life cognitive decline. In regard to measurement, a number of studies have used in-home recordings of parent–child conversations to identify the quantity and "quality" of cognitive stimulation for kids. It is also increasingly possible to track daily cognitive activity (reading text, smartphone use, Internet use, etc.), including how labor force participation affects risk for cognitive decline in later life.

Another important set of risk factors to measure relate to physical activity and biological markers. In addition to simple measures of how sedentary individuals are, it is important to track exercise patterns. Going further, it is important to measure such cardiovascular risk factors by monitoring blood pressure, related diseases, and the extent to which programs to control these are implemented (diabetes control, etc.). Other risk factors to measure include dietary choices, alcohol use, and use of other substances that are psychoactive and may contribute either positively or negatively to cognitive abilities in later life. It is also important to track mental health directly, including ongoing anxiety, depression, and more severe conditions, along with the measures and substances taken in an effort to rectify such conditions.

Given that the ultimate object of study is cognitive decline, it is also important to monitor and improve understanding of possible early warning signals. These may include changes in financial activities and patterns of decision making, such as "giving up the checkbook." There may be a concomitant pattern of increased risk of being a victim of financial fraud, so that key financial transactions must be monitored. There

are also possible telltale patterns of movement, such as constriction of daily geography (e.g., not venturing far from familiar places). It is also important to track changes in the frequency and types of social interactions, as well as changes in speech patterns.

### Implementation in the KHP

A key advantage of the holistic approach that KHP liberates is the ability to track the impact of cognitive decline on a large number of outcome variables. In the medical arena, it is important to track how cognitive decline is caused by and contributes to general health, function, and well-being in later life. It is also important to monitor the impact of cognitive decline on families and social networks. Of particular interest is the impact on labor-force participation of individuals and their caregivers. It is also important to track the economic cost of healthcare utilization, long-term care, and informal caregiving.

To achieve these ambitious targets, the KHP will develop a rich set of methods for measuring and tracking cognitive function. It is proposed that standard cognitive screening batteries be undertaken at yearly intervals. This will be combined with daily measurement of aspects of cognitive function with smartphone apps and other monitoring devices. GPS information will be used to gauge how daily "life space" changes as cognition declines. There may also be occasion to conduct explicit brain images at regular intervals and at key moments of change. Finally, there may be need for proxy (informant) assessments of cognitive and other functions as individuals become less able to participate in survey or other self-report data collection.

Overall, investigation of factors that contribute to cognitive decline from birth through older age would utilize the following KHP data sets, amongst others. (a) Medical information on the mother's health, pregnancy, and birth of the baby would be available from the medical history and records going forward (EMRs, doctors' notes, hospital records, dental records). Prescription data would be gathered via the New York State Prescription database. This information would be complemented by the SPARCS database and the KHP's own tests: blood tests (blood metals, vitamins, lipids, glucose, and other biomarkers) together with urine and hair tests (smoking, alcohol, and substance use) every 3 years. (b) Exposure to toxins and other chemicals would be measured via silicone wristbands worn periodically. (c) Formal education data would be available via participants' record cards, standardized test results (e.g., No Child Left Behind, ACT, SAT), and New York City Department of Education databases on student progression and school rankings. (d) Information on informal education would be gathered by KHP field teams via questionnaires on extracurricular activities and by counting the number of books in participants' homes. (e) Time parents spend together with children would be measured using Bluetooth-based presence sensors in the home and by smartphone apps that measure social interactions. (f) Data on caregiving by family members would be available via questionnaires, Bluetooth-based presence sensors in the home, and a smartphone app that measures social interactions. (g) Mobility and activity level information would be collected by activity trackers and smartphone apps. (h) Time spent on digital devices would be measured by apps on smartphones, tablets, and PCs. (i) Dietary data would be collected via periodic food diaries, complemented by mining for food purchases in financial data (credit cards, debit cards, checks). (j) Information on financial status and participation in government assistance programs (SNAP, Social Security, TENF) would be available via financial data gathered using a combination of automated and survey-based methodologies. (k) Information on smoking and alcohol use would be collected on an ongoing basis by mining for purchases of tobacco products and alcoholic beverages in financial data, in addition to the triennial tests using biological samples.

The impact of various factors on cognition and genetics would be analyzed via the following KHP data sets, amongst others. (a) Cognitive function levels would be measured via self-administered psychology questionnaires/tests on smartphones and tablets at intake and periodically thereafter. (b) Information on genetic variation—individual and family—would be gathered via whole genome sequencing of blood samples for adults (saliva for children) performed at study intake. In addition, data on epigenetics would be gathered via triennially performed assays. (c) "Giving up on the checkbook" could be measured indirectly via analyzing trends on the quantity and types of financial transaction individuals perform over time.

### Author Disclosure Statement

No competing financial interests exist.

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**Abbreviations Used**

NAPA = Nahcnal Alzheimer's Project Act
AD = Alzheimer's disease
KHP = Kavli Human Project

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