

## The Public's Perceptions About Cognitive Health and Alzheimer's Disease Among the U.S. Population: A National Review

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### **Abstract:**

The present review assesses the public's perceptions about cognitive health and Alzheimer's disease among adults in the United States. We searched the published literature and Internet, and contacted experts in the field to locate surveys assessing the public's perceptions about cognition. We found 10 eligible surveys and abstracted data concerning the public's knowledge, beliefs, concerns, and sources of information. Most of the surveys were conducted in the 2000s and focused on Alzheimer's disease rather than cognitive health. Based on the findings from the surveys, most adults were found to be aware of Alzheimer's disease but lacked specific information about the disease and its treatments. Most respondents did not perceive themselves as being very knowledgeable about Alzheimer's disease. Although we could classify the findings into several overarching domains, such as knowledge, we found considerable variability among surveys in the questions asked. Additional work is needed to understand the public's perceptions about cognitive health. Moreover, we also lack studies that help us understand perceptions about cognition across diverse demographic and cultural groups. Only by addressing these gaps can we develop targeted and effective strategies to enhance knowledge and beliefs about cognitive impairment and health.

### **Article:**

During the past several decades, we have witnessed significant scientific progress in understanding cognition and dementia, including Alzheimer's disease (Anderson & McConnell, 2007; Hendrie et al., 2006; Khachaturian, 2006). For example, the National Institutes of Health's Cognitive and Emotional Project (Hendrie et al., 2006), which reviewed the scientific evidence on factors that influence the maintenance of cognitive and emotional health, points out the importance of specific risk factors such as cardiovascular risk factors and cognitive function. Given these scientific developments, there are several compelling reasons for conducting a review of the literature on efforts to assess the public's perceptions about cognitive health and Alzheimer's disease among the adults in the United States.

There are increased calls to understand the public perceptions about cognition. Indeed, the first-priority recommendation of the Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health ([www.cdc.gov/healthybrain](http://www.cdc.gov/healthybrain)) is to “determine how diverse audiences think about cognitive health and its association with lifestyle factors.” A National Public Health Road Map to Maintaining Cognitive Health serves to focus the nation's attention to guide action and to develop a coordinated approach to move cognitive health into public health practice (Centers for Disease Control and Prevention [CDC] & Alzheimer's Association, 2007). The recommendations of the Road Map reflect the culmination of an 18-month process involving stakeholders at the national, state, and local levels. The rationale underlining this recommendation was to help promote the development of messages and inform the design and implementation of strategies addressing cognitive health.

Another compelling reason to understand the public's perceptions about cognition is because of the lack of consensus on how to define cognition (Hendrie et al., 2006). However, most experts agree that the components

of healthy cognitive functioning include language, thought, memory, executive function, judgment, attention, perception, remembered skills, and ability to live a purposeful life (National Research Council, 2000). Much like physical health, cognitive health can be viewed along a continuum—from normative functioning to mild cognitive impairment to severe dementia. Similarly, the definitions of “mild cognitive impairment” or “cognitive impairment no dementia,” both terms coined in 1997, have not reached consensus yet (Gaines & Whitehouse, 2006; Golomb, Kluger, Garrard, & Ferris, 2001; Graham et al., 1997; Peterson et al., 1997, 2001; Plassman et al., 2008; Richie & Touchon, 2000; Whitehouse & Moody, 2006). Generally, these terms refer to a condition in which a person has problems with memory, language, or other mental function severe enough to be noticeable to other people and to show up on tests but not serious enough to interfere with daily life. Occasionally, the minimal decline is noticed primarily by the person him/herself. Because the problems do not interfere with daily activities, the person does not meet criteria for being diagnosed with dementia. In specialty clinics, however, diagnoses such as mild cognitive impairment and cognitive impairment no dementia are rendered to patients with these very minor and as yet not agreed upon categorizations of cognitive decline. As a result, important issues to examine are the public's perceptions of such terms and development of language that communicates current knowledge and advances being made in these areas.

Finally, given the focus of this special issue of *The Gerontologist*, “Promoting Cognitive Health in Diverse Populations of Older Adults,” our review summarizes what is currently known and was proposed to help set the stage for the articles that follow. Our review summarizes the current state of the science regarding what is known about the U.S. public's perceptions about cognition. We include perceptions about cognitive health as well as Alzheimer's disease. As part of this review, we summarize the research designs, populations studied, and the major domains and findings related to cognition. We also provide recommendations for advancing work in this area.

### *Methods*

We used an iterative approach to identifying eligible reports for this review. Our approach involved a search of the published literature in consultation with experts in the field. Given that our interest was in describing the state of the evidence on what is known about the U.S. public's perceptions of cognition, we included both published studies and reports that provided original data (e.g., reports on the Internet). Eligible reports were published in English and conducted in the United States. We did not impose any restrictions with respect to publication date. The end date for inclusion of eligible studies to our review was June 19, 2008. Reports or surveys concerning the perceptions of health care providers; family caregivers (defined as unpaid family members, friends, or neighbors) providing care to someone who is, to some degree, incapacitated and needs help (Family Caregiver Alliance, 2005); and persons diagnosed with any form of cognitive impairment were excluded.

Two strategies were used to identify potentially relevant reports. First, we conducted a database search using PubMed, which includes and other life science journals for biomedical articles that searches back to the 1950s ([www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed)), and PsycInfo. Key words for searches focused on cognition (i.e., brain health, cognitive health, dementia, Alzheimer's disease, cognition, cognitive decline, or cognitive impairment), knowledge, beliefs, attitudes or perceptions, and the general public (i.e., the public, laypersons). We also conducted an Internet search for reports of surveys identified by experts and accessible in the public domain. After we identified published articles and reports, we reviewed references of relevant articles to retrieve any possible additional studies.

For each eligible survey, information was collected on the following: (a) the study design, including type of study (i.e., qualitative or quantitative, market research, or academic study), data collection method(s), and study period; (b) sample (i.e., number of participants, demographic characteristics, sampling [sampling and weighting of data]); and (c) study findings related to four categories (knowledge, beliefs, concerns, and sources of information). Two authors (Kristine L. Day and Lynda A. Anderson) independently reviewed all eligible studies. We then characterized study findings into four domains: (a) knowledge, (b) beliefs, (c) concerns, and (d) sources of information. Knowledge refers to awareness about an idea or proposition (Griffin & Ohlsson,

2001). Examples of such findings include reports of “being aware of Alzheimer's disease” and “Alzheimer's disease is not the term for normal memory loss as they get older.” Within the knowledge category, issues were subgrouped to examine the focus of the question, including awareness of Alzheimer's disease or facts about cognition or Alzheimer's disease. Beliefs (i.e., prospective beliefs, distinct from perceptions about being an actual caregiver) refer to the perceptions about the truth-value associated with the proposition or object (Griffin & Ohlsson). Examples of findings related to beliefs were, “I believe there is nothing a person can do to help maintain a healthy memory” and “I am well-prepared for handling a diagnosis of Alzheimer's disease.” Beliefs were further subgrouped to examine perceptions about Alzheimer's disease, risk factors, and lifestyle modifications to avoid cognitive impairment, or potentially caring for someone with a cognitive impairment (i.e., prospective beliefs, distinct from perceptions about being an actual caregiver). Concerns refer to emotional responses such as fears or worries related to cognition, as in the following example: “I am very afraid of developing Alzheimer's disease.” Concerns were further subgrouped to examine as concerns about declines in cognition, Alzheimer's disease, or potentially caring for someone with the disease. The final category, informational sources, refers to places or people used to gain knowledge related to cognition.

## Results

A total of 10 surveys are summarized in this review article. The Connell, Roberts, and McLaughlin's (2007) data were taken from the Alzheimer's Association survey of 2003 (Alzheimer's Association, 2003). We cite data from both reports but to avoid duplication, we only report on distinct nonduplicative findings from the Alzheimer's Association survey and the Connell and colleagues' publication. Copies of the surveys are available from the authors.

For the purposes of this article, we organized the study findings by domains: knowledge, beliefs, concerns, and informational resources. Of the 10 eligible surveys, 7 examined knowledge, 4 surveyed beliefs, 8 investigated concerns, and 2 explored informational resources (Table 1). Of the 10 surveys, half ( $n = 5$ ) addressed only one of the four overarching categories, examining either concerns or knowledge. The majority of surveys involved telephone interviews conducted by marketing agencies. All the surveys were cross-sectional using convenience samples. Based on the available reports, we could find no information on sampling frames or weighting of the data for national estimates. Sample sizes ranged from 209 participants to more than 3,000 participants. The age range of respondents varied across the surveys, starting at 18 years of age and older.

**Table 1.**  
Study Characteristics by Categorization of Study Findings

Author(s) (year): name of the study/survey	Study type and timeframe	Sample and characteristics	Categories of study findings			
			Knowledge	Beliefs	Concerns	Information sources
Steckenrider (1993): What people know about Alzheimer's disease: A study of public knowledge	Telephone interviews; October–November 1985	$N = 1,498$ ; age: 45+ years	X			
Ayalon & Aréan (2004): Knowledge of Alzheimer's disease in four ethnic groups of older adults	Interviews	$N = 209$ ; race/ethnicity: 48% White, 18% Hispanic, 14% Asian, 15% African American, 5% ethnically unidentified; age: 55+ years; English or Spanish speaking	X			
Alzheimer's Association (2003) <sup>a</sup> : Alzheimer's Association survey of American's knowledge and opinions about Alzheimer's disease	Market research from Synovate; telephone survey; December 2003	$N = 600$ ; age: 35+ years	X	X	X	
Connell et al. (2007 <sup>a</sup> ): Public opinion about Alzheimer's disease among Blacks, Hispanics, and Whites	Market research from Synovate; December 2003; 3,815 households selected, 1,217 successfully contacted	$N = 1,176$ household members; criteria: English speaking; age: 35+ years. Oversampled: 55+ years; Hispanic and African American	*	*	*	
American Society on Aging and MetLife Foundation (2006):	Market research from Harris Interactive;	$N = 1,008$ adults; age: 18+ years; sex: 50% female	X	X	X	

Author(s) (year): name of the study/survey	Study type and timeframe	Sample and characteristics	Categories of study findings			
			Knowledge	Beliefs	Concerns	Information sources
Attitudes and awareness of brain health poll	January 2006					
Alzheimer's Association and American Heart Association (2008): Findings from the African American heart and brain health survey	Richard Day Research; online survey; February 2008	N = 2,214 adults; 1,210 African Americans and 1,004 non-African Americans	X		X	
MetLife Foundation (2006): Americans fear Alzheimer's more than heart disease, diabetes or stroke, but few prepare	Market research from Harris Interactive; telephone interviews; April 2006	N = 1,000 residents; age: 42+ years	X	X	X	X
Roberts et al. (2003): Differences between African Americans and Whites in their perceptions of Alzheimer disease	Survey	N = 452; 61% White, 39% African American; age: 22–90 years, mean age 47 years; 78% women; X median education level: college graduate			X	X
Cutler et al. (2000): American Perceptions of Aging in the 21st Century	Harris Interactive; telephone interviews; December 1999 to March 2000	N = 3,048; age: 18+ years; female = 1,708. Oversampled: older adults (65+ years) and minorities			X	
Alzheimer's Association (2004): Alzheimer's disease and American's fears. National survey results	Market research from Opinion Research Corporation; telephone survey; September 2004	N = 1,020 adults; no descriptive information available			X	
PARADE/ Research!America (2006): What Americans think about aging and health	Public opinion poll	N = 1,000; age: 18+ years			X	

- Note: <sup>a</sup>Findings are based on the same dataset.

<sup>\*</sup>Same categories as the Alzheimer's Association (2003).

X indicates that a specific category of study findings were identified from a report or published study and classified into a specific domain by the study authors.

## Knowledge

In terms of awareness of Alzheimer's disease, Steckenrider (1993) reported that 90.7% of respondents aged 45 years and older had heard of Alzheimer's disease, which is similar to the survey findings reported elsewhere (MetLife Foundation, 2006). The MetLife Foundation found that 93% of respondents aged 45 years and older were aware of Alzheimer's disease. The survey reported by the Alzheimer's Association (2003) also examined knowledge about Alzheimer's disease. The Alzheimer's Association found that 75% of respondents aged 35 years and older correctly stated that Alzheimer's disease is not the term for normal memory loss as they get older. They also found that 44% of respondents correctly reported knowing that there are several treatments available to ease the symptoms of persons with Alzheimer's disease. Connell and coworkers (2007) publication, which analyzed data from the Alzheimer's Association 2003 survey, reported no differences across racial or ethnic groups with the exception of the following: “Alzheimer's is the term for normal memory loss as we get older.” For this statement, White respondents were significantly more likely to answer correctly (67.3%) compared with African Americans (41.1%) and Hispanics (49.5%).

Of the four surveys employing knowledge “tests” or facts, Steckenrider (1993) reported that the mean number of questions answered correctly was 9.1, or 54% (of a maximum of 17). She further divided questions into general knowledge and specific knowledge, and found that about 72% of respondents had general knowledge, whereas only 11% of respondents had specific knowledge about Alzheimer's disease. Connell and colleagues (2007) reported that about 50% of respondents answered the five knowledge questions correctly. Additionally, several surveys also explored whether there were differences in knowledge between identified racial and ethnic groups. Roberts and colleagues (2003) reported that White respondents endorsed more knowledge items correctly compared with African American respondents. Ayalon and Aréan (2004), studying adults aged 55



years and older in clinical settings, examined racial and ethnic differences in knowledge about Alzheimer's disease. They reported that White respondents had a higher mean total score on knowledge of Alzheimer's disease (10.41) compared with African Americans (8.36), Asians (4.96), and Hispanics (4.56).

### *Beliefs*

In terms of beliefs, two surveys examined perceptions about Alzheimer's disease. In the report by Connell and colleagues (2007), they found that 13.6% of respondents “believed they were very knowledgeable about what causes Alzheimer's disease.” The MetLife survey (MetLife Foundation, 2006) found that 74% of respondents aged 18 years and older reported knowing little or nothing about Alzheimer's disease. In terms of differences between racial and ethnic groups, Connell and colleagues found no significant differences, reporting that 17.2% of African Americans, 15.8% of Hispanics, and 10.5% of Whites considered themselves “very knowledgeable” about what causes Alzheimer's disease.

Three reports looked at beliefs about modifying lifestyles related to “brain health” or avoiding the development of Alzheimer's disease. The Alzheimer's Association (2003) reported that 17% of respondents believed there is “nothing a person can do to help maintain a healthy memory and reduce the chance of Alzheimer's disease.” In subsequent analysis, Connell and colleagues (2007) reported that 25.6% of respondents indicated making changes to their diet or lifestyle to avoid developing Alzheimer's disease. The survey reported by the American Society on Aging and MetLife (ASA-MetLife) found that 88% of respondents aged 42 years and older believed they could do something to keep their “brains fit” (ASA-MetLife, 2006). Subsequently, the survey by the Alzheimer's Association and American Heart Association (AA-AHA) found that 50% of respondents to an online survey reported “doing things in their lives specifically for brain health” (AA-AHA, 2008). In both the ASA-MetLife and the AA-AHA surveys, respondents identified participating in mental activities (puzzles) and eating a healthy diet as among the types of activities they believed were helpful for brain health.

Regarding beliefs about being prepared to handle a diagnosis of Alzheimer's disease in a family member, Connell and colleagues (2007) discovered that about 23% of respondents reported believing they were “well prepared.” Another survey found that 81% of respondents believed it was important to have a plan to address the possibility of having Alzheimer's disease (MetLife Foundation, 2006).

### *Concerns*

Three surveys examined concerns about declines in cognition or memory, with two of these surveys focusing on memory loss or lost mental capacity. Cutler, Whitelaw, and Beattie (2002) reported that 61% of respondents aged 18 years and older were “very or somewhat worried” about memory loss at age 75. Across selected subgroups of age, sex, race/ethnicity, and education level, memory loss was consistently reported as producing the most worry. Similarly, the PARADE/Research!America (2006) public opinion poll reported that 62% of respondents aged 18 years and older feared losing their mental capacity compared with 29% who feared having diminished physical ability. The third survey, reported by ASA-MetLife (, 2006), found that 30% of respondents believe “most people start to worry about their memory between the ages of 41 and 60 years old.”

Among the three surveys examining concerns about Alzheimer's disease (Alzheimer's Association, 2004; AA-AHA, 2008; Connell et al., 2007), the percentage of respondents concerned about developing Alzheimer's disease ranged from 26% to 49%. The MetLife survey found that 20% of respondents identified Alzheimer's disease as the most feared illness out of five major conditions, including cancer, heart disease, stroke, and diabetes (MetLife Foundation, 2006).

Two surveys reported on respondent's concerns about developing Alzheimer's disease among different racial and ethnic groups. Roberts and colleagues (2003), with a mean sample age of 47, reported that Whites perceived Alzheimer's disease as a greater threat compared with African Americans, whereas the online survey reported by AA-AHA (2008) reported no differences between racial/ethnic groups.

In terms of concerns about caring for others with Alzheimer's disease, the Alzheimer's Association (2004) reported that 49% of respondents to a telephone survey were equally afraid of taking care of a loved one with Alzheimer's disease as of getting the disease themselves. The 2006 MetLife survey reported that 63% of the respondents to the telephone survey were concerned about having to provide care for someone with Alzheimer's disease.

### *Sources of Information*

Two surveys explored the number of sources and where respondents would seek out information. The survey reported by ASA-MetLife (2006) found that the top two sources of information “about the brain and how to keep it fit” were “medical professionals” (72%) and “the media” (59%). Roberts and colleagues (2003) reported that Whites listed a larger number of information sources (4.6) than African Americans (3.1).

### *Discussion*

What does this review tell us about what is known about the U.S. public's perceptions about cognition? Although we found one published study from the early 1990s, most of the identified surveys were conducted in the past few years. Generally, this body of work documented that most adults in the United States are aware of Alzheimer's disease. About 90% of adults reported having heard about Alzheimer's disease in 1985 when the first survey was conducted (Steckenrider, 1993) as a more recent survey conducted 20 years later (MetLife Foundation, 2006). Although we could classify the findings into several overarching domains, such as knowledge, we found considerable variability among studies in the questions asked. Additionally, we found that most surveys focused on Alzheimer's disease rather than cognitive health. The majority of studies indicated that the U.S. public lacks specific information about Alzheimer's disease and current treatments. Consistent with these findings, most studies reported that the respondents did not perceive themselves as very knowledgeable about Alzheimer's disease, with generally 75% of respondents reporting not being knowledgeable. Although several reports documented that survey respondents expressed a great deal of concern about the disease, both from a personal perspective and the potential of caring for someone else, the perceived impact of cognitive impairment in U.S. households is still not clear.

Caution is needed in comparing the findings across surveys. The research included a variety of age groups, with several surveys including persons 18 years of age, whereas others included only persons 55 years and older. The differences in populations studied in addition to the age group comparisons within studies made it impossible to contrast these findings across studies. Most reports did not examine demographic variables, such as education or income, that may be associated with the public's perceptions about cognition. Most of the surveys were cross-sectional and provided only descriptive statistics. Other factors, such as wording of the survey questions and different data collection methods, could also yield various study results. Most reports did not account for oversampling among specific groups due to convenience sampling. Future work must focus on the research methods to establish critical baseline data that can be used to monitor the public's perceptions about cognition and its impact on households in the United States over time.

Despite these limitations, this review was critical in identifying gaps that future research needs to address. One gap is that we lack consistent or well-defined terms or validated measures regarding perceptions about cognition. For example, several of the studies examined concerns about “memory loss,” whereas other studies explored concerns about Alzheimer's disease specifically. Given that memory loss was not defined for participants, or information provided about how participants conceptualized this concept, it is not possible to compare across studies. Additionally, we found few items assessing respondents' beliefs about cognitive health compared with perceptions about Alzheimer's disease. Although this might be in part because of the recently evolving science about cognitive health (Anderson & McConnell, 2007), this is clearly an area in need of further attention. Data on how the public defines cognitive health and their perceptions about it could help inform population-based messages and communication interventions. In addition, the use of qualitative methods or the combined use of qualitative and quantitative methods is necessary to illuminate work in this area.

Another research gap is assessing the public's perceptions of cognition across various social and cultural perspectives. As demonstrated by this review, relatively little is known about the perceptions of different ethnic groups within the United States. Although we must be careful not to make generalizations within diverse population groups in the United States, there is a clear need to better understand how social and cultural beliefs influence perceptions about cognition. For example, as Elliott and colleague (1996) point out that traditional Chinese explanations of dementia contrast sharply with the Western biomedical model, with symptoms interpreted as reflecting an imbalance of “yin” and “yang” energy forms, and treatment is sought through herbalists or acupuncturists rather than physicians. There has also been a limited amount of research conducted on cultural perceptions of dementia among American Indians. An interesting qualitative study by Henderson (1994) with the Oklahoma Choctaw population suggested the following beliefs to be part of its cultural explanatory model of dementia: the notion that dementia is a part of the normal aging process, and the idea that dementia-related behaviors are a means by which the older person communicates with the afterlife in a period of transition to the next world. Within the African American population, “folk” beliefs about memory loss and aging have been demonstrated to vary considerably from those of their White counterparts (Fox, Hinton, & Levkoff, 1999). More studies with diverse populations are clearly needed to advance our understanding.

Several efforts to address the gaps in knowledge about cognitive health have already begun, initiated, and sponsored by a variety of organizations and agencies. The Centers for Disease Control and Prevention (CDC) in collaboration with the Alzheimer's Association and several stakeholders are in the process of developing a set of measures to monitor the public's perceptions of the impact of cognitive impairment that could be included in a state-based surveillance system ([www.cdc.gov/BRFSS](http://www.cdc.gov/BRFSS)). The National Institute on Aging is pursuing research on factors influencing cognitive health and cognitive impairment, and developing a toolkit for researchers on measures to assess cognitive performance. Another set of studies are being undertaken the Healthy Aging Research Network (HAN), a network of Prevention Research Centers supported by CDC's Healthy Aging Program. The HAN has recently completed formative research to identify how diverse groups of older adults, caregivers, and health care providers understand cognitive health. The results of some of that research are reported in this special issue.

Several national efforts are taking place that are designed to promote awareness of cognitive health, an area where there is an emerging research base. We provide a few examples of these efforts. The Alzheimer's Association is continuing to offer their basic awareness workshop, Maintain Your Brain®, through their chapters ([www.alz.org](http://www.alz.org)). More recently, they have launched a 5-year community-based demonstration project to promote cognitive health designed to affect knowledge and attitudes among African American baby boomers. The AARP is also partnering with the Dana Alliance for Brain Health to increase awareness about cognitive health through their Staying Sharp® program ([www.aarp.org](http://www.aarp.org)).

Several factors should be considered when addressing the findings of this review. Although we used complementary approaches to identify surveys, it is possible that we did not uncover every item concerned with cognition in the literature. We consulted with experts who conducted seminal surveys in this field and facilitated contact with other survey researchers who provided additional studies. Thus, the likelihood that we missed surveys that contained data that were significantly different from those that we characterized is small. It is important to note that we excluded studies that examined potential discrimination about persons with Alzheimer's disease and experimental studies concerned with memory and aging stereotypes (Hawley, Cherry, Su, Chiu, & Jazwinski, 2006; Ryan, 1992; Ryan & See, 1993; Werner, 2005). Another consideration is that we only characterized surveys that were performed in English, and our findings might not apply to surveys that were directed toward non-English speakers. Finally, our review reflects the data on U.S. samples, and we did not characterize studies from other countries. Based on our review of the literature, we found several investigations on the public's perceptions that were conducted in numerous countries, such as Australia, Canada, the United Kingdom, Brazil, Israel, Norway, and Turkey. Other investigators might consider reviewing the broader literature. However, given the current limitations in survey methods among U.S. studies, such a review presents several potential methodological challenges.

Critical next steps are needed to better understand knowledge, beliefs, and concerns about cognition among the general public, particularly in diverse social and cultural groups. Additionally, this research should be expanded to examine issues such as early diagnosis and care-seeking behavior. Future work is also needed to understand the perceptions of health care providers and family caregivers. Only by addressing what people know and understanding their perceptions can we develop targeted and effective strategies to enhance knowledge and beliefs about cognitive impairment and health. If the public's cognitive “health literacy” is not improved, this may impede public acceptance and successful implementation of evidence-based strategies addressing cognitive health, as well as early diagnosis, treatment, and management of cognitive impairment.

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### *Conflict of Interest*

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the CDC or other institutions with which the authors are affiliated.

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