Promoting Cognitive Health: A Formative Research Collaboration of the Healthy Aging Research Network

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Abstract:
Purpose: Evidence suggests that healthy lifestyles may help maintain cognitive health. The Prevention Research Centers Healthy Aging Research Network, 9 universities collaborating with their communities and the Centers for Disease Control and Prevention, is conducting a multiyear research project, begun in 2005, to understand how to translate this knowledge into public health interventions. Design and Methods: This article provides an overview of the study purpose, design, methods, and processes. We examined the literature on promoting cognitive health, convened a meeting of experts in cognitive health and public health interventions, identified research questions, developed a common focus group protocol and survey, established quality control and quality assurance processes, conducted focus groups, and analyzed the resulting data. Results: We conducted 55 focus groups with 450 participants in 2005-2007, and an additional 20 focus groups and in-depth interviews in 2007-2008. Focus groups were in English, Spanish, Mandarin, Cantonese, and Vietnamese, with African Americans, American Indians, Asian Americans, Hispanics, non-Hispanic Whites, physicians and other health practitioners, rural and urban residents, individuals caring for family or friends with cognitive impairment, and cognitively impaired individuals. Implications: The data provide a wealth of opportunities for designing public health interventions to promote cognitive health in diverse populations.

Article:
Cognitive impairment in older adults is a major cause of disability. It greatly reduces quality of life for affected individuals and their families. It is also costly to communities, employers, and governments. The public's interest in protecting brain health is likely to grow as our population ages, and as more people have experiences with cognitive decline, Alzheimer's disease, and related disorders. Public demand for information about brain health will also be fueled by knowledge that relatively simple health behaviors may help to maintain it (Hendrie et al., 2006). This article provides an overview of a large research project designed to respond to public interest about brain health and to the knowledge that healthy behaviors may help to maintain it. Conducted by the Prevention Research Centers Healthy Aging Research Network (PRC-HAN), the project provides a foundation for translating basic science into public health interventions that may reduce rates of cognitive decline, Alzheimer's disease, and related disorders in the U.S. population.

In 2005, the Centers for Disease Control and Prevention (CDC) and the Alzheimer's Association began a project to promote brain health. Experts were convened in 2006, to review the scientific evidence suggesting that healthy lifestyles may help to maintain brain health, and to examine how public health organizations might motivate the public to adopt these lifestyles (Albert et al., 2007). The expert consensus was that an adequate science base exists to support public health interventions to promote brain health. The meeting suggested that lifestyle changes in mid- to late life could be beneficial, while recognizing that healthy behaviors begun earlier may have greater benefits. Thus, the aging of the large baby boom cohort offers an important public health intervention opportunity.
A product of the expert meeting and associated activity was the National Public Health Road Map to Maintaining Cognitive Health, released in June 2007 (CDC, 2007). The Road Map was intended as a “call to action and a guide for implementing an effective coordinated approach to moving cognitive health into public health practice” (CDC). One of 10 priority areas identified in the Road Map was to “determine how diverse audiences think about cognitive health and its associations with lifestyle factors,” with the charge “to translate research findings into community action” (CDC). This brief report describes research designed to address that priority and that charge.

Overview of the Healthy Brain Project

Formally titled Prevention Research to Promote and Protect Brain Health, the Healthy Brain Project is a subset of the national initiative led by the CDC and the Alzheimer's Association (Anderson et al., 2009). The project is an activity of the PRC-HAN, funded by the CDC's Healthy Aging Program (Lang et al., 2006). The PRC-HAN was created in 2001, to develop partnerships and create a research agenda promoting healthy aging. Working at the individual, organizational, environmental, and policy levels, the nine universities in the network use their expertise in aging research to collaborate with their communities and other partners to better understand determinants of healthy aging in older adult populations, identify interventions that promote healthy aging, and translate this research to create sustainable community-based public health programs throughout the nation. The PRC-HAN Workgroup on Promoting Cognitive Health began its research in 2005, participated actively in the 2006 expert meeting, and contributed notably to the Road Map (CDC, 2007).

The goal of the Healthy Brain Project was to establish a science base that will support the development of public health interventions to promote brain health in diverse populations. Although healthy lifestyles appear to benefit both cognitive and emotional health (Hendrie et al., 2006), this project focuses primarily on cognitive health. This focus was selected because our research suggests that the public views brain health primarily in terms of cognitive function, including “sharp” thinking and memory. To establish the science base, the project first sought to understand public attitudes about cognitive health and about the health behaviors associated with its maintenance.

At each PRC-HAN university location, community partners help to guide the research and, in some instances, participate as coinvestigators. The University of South Carolina is the project's lead center. Other participating PRC-HAN sites are as follows: University of California at Berkeley; University of Colorado, Denver; University of Illinois at Chicago; University of North Carolina at Chapel Hill; University of Pittsburgh; Texas A&M University; University of Washington; and West Virginia University. Individuals at other universities and organizations also contribute to the research as PRC-HAN members. Researchers and contributors who participated in the Healthy Brain Project are listed in the Appendix. In 2005–2007, the project team convened 55 focus groups with 450 participants that broadly represented the U.S. population of age 50 years and older (Bryant, Laditka, Laditka, & Mathews, 2009). Another 20 focus groups and in-depth interviews were conducted in 2007–2008.

Focus Group Guide and Participant Survey Development

The PRC-HAN developed a nine-item focus group discussion guide. Table 1 shows its essential features. Extensive prompts in the guide are not shown in the table. Moderators also used comprehension probes to obtain and clarify responses, such as, “Would you give me an example of what you mean?” (Laditka et al., 2009). The guide was translated for use with a variety of ethnic groups (Hispanic, Chinese American, Vietnamese American) and revised for use with individuals who care for those affected by cognitive impairment. The guide elicited participants’ perceptions, attitudes, and awareness of several topics related to brain health, and sought to identify language used to describe cognitive health and related issues. The discussions addressed aging well: terms used for memory loss, sound memory, and ability to think; personal concerns about memory loss and thinking ability; thoughts on keeping the brain healthy; media messages about brain health; maintenance of brain health through diet, physical activity, and social involvement; motivators for health behavior change; and ideas for brain health promotional materials and messages. To ensure
standardization, the researchers developed a detailed narrative script, with introductory and concluding comments.

Table 1. Healthy Brain Study Focus Group Discussion Questions, Prompts, and Topic Areas

<table>
<thead>
<tr>
<th>Question/item</th>
<th>Topic area</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Without mentioning a name, please tell us about someone who you think is aging well. Prompt: Describe characteristics. What words do you use to describe seniors/older people who do have a loss of memory or thinking ability?</td>
<td>Aging well</td>
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<tr>
<td>2. What words do you use to describe seniors/older people who do not have a loss of memory or thinking ability? Tell us about any concerns you may have about your ability to keep your memory or ability to think as you age. Prompt: Importance? Why Important?</td>
<td>Terms for memory loss/dementia</td>
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<tr>
<td>3. Describe the things that we can do to keep our brains healthy and keep our memories or our ability to think as we age.</td>
<td>Concerns about memory loss</td>
</tr>
<tr>
<td>4. What sort of things have your heard from TV, radio, newspapers or magazines, the Internet, and so forth about keeping your brain healthy? Introduction of the concept of brain health prevention through having a heart-healthy diet, being physically active, and being socially involved. Participants are then asked: What do you think/feel about what I just said? Prompt: What changes regarding your diet, activity level, or social involvement are you willing to make? What do you think would be the most effective ways to motivate you, or other people, to keep your brain healthy in terms of diet, physical activity, and social involvement? If we put you in charge of getting the word out to others about the importance of a healthy diet, physical activity, and being socially involved for healthy brains, what would you do to make sure everyone knew about it? Prompt: Specific examples of promotional materials. Prompt: Types of messages or slogans. Prompt: Where to place materials and messages? Used for relevant focus groups only:</td>
<td>Knowledge of brain health and prevention</td>
</tr>
<tr>
<td>5. Awareness of media messages regarding brain health and prevention Reactions to current scientific studies; feelings about preventive health behaviors and brain health; willingness to change health behaviors Motivators for healthful behaviors related to brain health Social marketing, health communication message, and material ideas ETHNICITY SPECIFIC what people think about when they hear about memory and brain health in their community. Ethnically specific brain health terms, concerns, knowledge, and social marketing</td>
<td>Terms for memory loss/dementia</td>
</tr>
<tr>
<td>6. 9/10. Is there anything else that you would like to talk about?</td>
<td>Concerns about memory loss</td>
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<td>7. 9/10. Is there anything else that you would like to talk about?</td>
<td>Concerns about memory loss</td>
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<td>10. 9/10. Is there anything else that you would like to talk about?</td>
<td>Concerns about memory loss</td>
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</tbody>
</table>

Participants also completed a 20-item survey, which asked about demographics (gender, age, race, marital status, education, income, rural/urban residence), height, weight, diet, physical activity, social involvement, emotional health, memory quality, and diagnosed cognitive decline. Bryant and colleagues (2009) provide details and survey results.

The discussion guide and survey were pretested in fall 2005, with two groups of doctoral students at the lead center. The sequencing of several questions was changed following the pretest. In November of that year, the guide and survey were pilot tested with a focus group of African Americans.

Selecting Focus Group Participants and Convening the Focus Groups
To ensure that the research represented diversity, PRC-HAN researchers identified various American groups for inclusion. With the help of local community advisory boards, known at some sites as community teams, researchers at each site defined a sampling frame and recruited participants. Selection oversampled minorities. Sources included senior centers, community members’ networks, churches, and regularly scheduled community activities. It was not expected that the sampling would represent the full diversity of the United States. A project goal was to leverage the cultural, economic, geographical, and racial/ethnic diversity of the PRC-HAN
communities, to provide useful information for developing interventions for specific populations as well as for the general public. Some focus groups were convened to represent race/ethnicity, such as African Americans, American Indians, Hispanics, Asian Americans (Chinese, Vietnamese, Indian), and Whites. Others focused on rural or urban residents, gender, or areas of varying socioeconomic status (Wu, Goins, Laditka, Ignatenko, & Goedereis, 2009). Bryant and colleagues (2009) describe the sample and suggest that the study was successful in representing diversity. Laditka and colleagues (2009) provide additional details about the focus groups.

In the second and third years, additional research was conducted with those populations, including focus groups in Spanish, and also focus groups and in-depth interviews with physicians, physicians’ assistants, nurse practitioners, and those who care for individuals with Alzheimer’s disease or related disorders. Health care providers were included because they may contribute importantly to an effective intervention. Caregivers were included because of their relatively high risks for health problems, including cognitive decline.

Institutional Review Board Process
The institutional review board (IRB) at each participating PRC-HAN site approved the study. The lead center also obtained approval for the entire project from the IRB at the University of South Carolina. Of note for researchers who might be interested to conduct similar multisite qualitative research is the substantial variety of approaches taken to such research by IRBs. The study protocols and instruments, used in common among all participating sites, were approved as exempt from human subjects requirements in less than a day at one site. Time to approval for the same methods and instruments varied notably among sites, in some cases requiring several IRB application revisions and more than 6 months. To permit common methods at all sites, the instruments were adapted to address the requirements of all IRB reviews. Although this process delayed data collection, it affected the data characteristics only modestly. For example, questions about age were ranged, rather than asking for age in years. The larger lesson for researchers planning multisite studies is that IRB processes for evaluating qualitative research can vary substantially. Adequate time should be budgeted for obtaining IRB approvals, based on previous experience with IRB evaluations of qualitative research at each study site.

Discussion
A number of factors contributed to the project's success. More than two dozen researchers and several doctoral students contributed substantial effort to the project, led at each site by the named authors of this article. Most researchers devoted substantial in-kind support to the project. Many other PRC-HAN members and their community partners also provided input into the project's design, ongoing quality control, and interpretation of the results, as did representatives of the CDC, the Alzheimer’s Association, the National Institutes of Health, the Administration on Aging, the American Association of Retired Persons, and other organizations. The discussion guide was informed by a broad panel of experts on cognitive health, health communications, nutrition, physical activity, effects of social involvement and communities on health, and public health interventions.

The discussion guide was pretested and pilot tested, to ensure that it elicited useful information and provided standardized procedures. Recruitment and informed consent were coordinated across the research sites. General participant characteristics of the groups were largely identified prior to conducting any focus groups. The principal investigator ensured open lines of communication throughout the project, through frequent individual e-mail and phone conversations. Conference calls were convened monthly throughout the project. Participants met formally in person twice yearly, as well as informally at major national conferences focused on aging and public health. Experts in aging, public health, and cognitive function at CDC and the Alzheimer's Association were active collaborators (Anderson et al., 2009). Detailed processes were established for processing audio recordings from the focus groups, to prepare the resulting qualitative data for analysis. These processes included substantial quality assurance and quality control efforts involving all sites (Laditka et al., 2009). For example, researchers at the lead center reviewed focus group audio recordings as they were received and provided rapid feedback to sites in a few instances that suggested a need to further standardize focus group procedures.
As illustrated in this special issue of The Gerontologist, the qualitative and quantitative data collected by the PRC-HAN provide a wealth of opportunities for understanding healthy aging and for designing effective public health interventions to promote cognitive health among diverse populations.

There is now a sufficient body of evidence to suggest that the time has come to promote brain health to the American public. The messages to be conveyed are relatively simple. Be physically active; eat a heart healthy diet; be socially involved (Hendrie et al., 2006). The difficult challenge will be to communicate these messages to diverse communities in ways that effectively change behaviors. This research by the PRC-HAN provides a foundation to advance that science.

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**Appendix**
Researchers and Contributors Participating in the PRC-HAN Healthy Brain Project

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Notes: a The PRC-HAN is the Prevention Research Centers Healthy Aging Research Network; the Healthy Brain Project is formally titled “Prevention Research to Promote and Protect Brain Health.”

b James N. Laditka was the principal investigator during the study period reported in this research; Daniela B. Friedman became the principal investigator in May 2008.

c At the time this research was conducted, James N. Laditka and Sarah B. Laditka were members of the faculty at the University of South Carolina.

Reference


