Characteristics of the Healthy Brain Project Sample: Representing Diversity Among Study Participants

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Purpose: Description of study participants and documentation of the desired diversity in the Prevention Research Centers Healthy Aging Research Network’s Workgroup on Promoting Cognitive Health large multisite study designed to examine attitudes about brain health, behaviors associated with its maintenance, and information-receiving preferences among a diverse group of older Americans, to provide a foundation for developing health promotion interventions. Design and Methods: Four hundred fifty older adults in 55 focus groups at 9 sites completed a common participant survey. Using descriptive statistics, the analysis compares participant characteristics (age, sex, and race/ethnicity; rural–urban location; income and education; social activity; physical activity, nutrition, and body mass index; and self-reported measures of cognitive function) across sites and with national data. Results: Comparisons across sites document the rich diversity of the sample. Implications: The substantial representation of a variety of demographic groups suggests that the qualitative data obtained in the focus group research provide a useful basis for developing well-targeted communication interventions for promoting brain health in diverse populations.

Key Words: Demographics, Lifestyle factors, Diversity, Focus group methodology, Survey research

In 2005, the Centers for Disease Control and Prevention (CDC) and the Alzheimer’s Association (AA) began to develop a National Public Health Action Plan to Promote and Protect Brain Health. The project reviewed scientific evidence regarding the link between lifestyles and brain health and continues to identify ways that public health professionals can promote behaviors that have been associated with brain health (Albert et al., 2007). In collaboration with a variety of national organizations including the National Institutes of Health (NIH), the project produced the National Public Health Road Map to Maintaining Cognitive Health (CDC & AA, 2007). The Road Map’s priorities include identifying “how diverse audiences think about cognitive health and its associations with lifestyle factors” (CDC & AA, 2007, p. 2), and in the longer term promoting brain health through a communication intervention (CDC & AA, 2007). To address these priorities, the CDC charged the Prevention Research Centers Healthy Aging Research Network (PRC-HAN) to conduct formative research assessing diverse communities. With their partner communities, the nine PRC-HAN member centers—the project’s lead center at the University of South Carolina and member centers at Texas A&M University; University of California, Berkeley; University of Colorado Denver; University of Illinois, Chicago; University of North Carolina, Chapel Hill; University of Pittsburgh; University of Washington; and West Virginia University—undertook that formative research in the Healthy Brain Project, a large multisite study (J. N. Laditka et al., 2009).

The researchers elicited participants’ perceptions, attitudes, and awareness of topics related to brain health and the behaviors believed to be

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associated with its maintenance, as well as insights into how people in various communities currently receive relevant information and how they would prefer to receive it. A detailed description of the management of the qualitative and survey data is described elsewhere (S. B. Laditka et al., 2009). Results from the focus groups appear elsewhere (e.g., Wilcox et al., this issue). This brief report, based on a survey administered to all participants, describes the study sample, compares and contrasts characteristics by site and with related national data, and documents the distribution of participants by geography, rurality, and race/ethnicity. The analysis assesses the degree to which the larger study attained its intended diversity.

Methods

Researchers at each site independently convened between four and nine focus groups between November 2005 and August 2007, using common instruments (discussion guide and survey) and procedures. Results from earlier groups did not influence the administration of later ones. Participants completed the paper-and-pencil survey at the start of each focus group, with assistance from group facilitators as needed. The institutional review board (IRB) at each participating PRC-HAN site approved the study, and the lead center, at the University of South Carolina, obtained IRB approval for the entire project.

Study Sample and Recruitment

With the help of local PRC-HAN community advisory boards, known at some sites as community teams, researchers at each site defined a sampling frame and recruited participants. Selection oversampled minorities to ensure sufficient numbers to provide useful data, in both single and mixed race/ethnicity focus groups. Sources included senior centers, community members’ networks, churches, and regularly scheduled community activities. The sampling frames reflected characteristics of the targeted communities, not necessarily the full diversity of the United States. Recruited samples took advantage of the cultural, economic, geographical, and racial/ethnic diversity of the communities in which PRC-HAN centers are located, to provide information that would be useful for developing communication interventions for specific groups as well as for the general population.

Survey Development and Administration

Researchers from all sites and the CDC collaboratively developed a common discussion guide and a participant survey that asked about demographic and other characteristics. The discussion guide included directions for administering the survey. Pilot testing, first with graduate students and staff and then in a representative focus group, ensured that the survey questions were clear and elicited the desired information. Experienced focus group facilitators conducted the sessions and administered the survey, with assistance (e.g., note taking, logistics) from trained graduate students or community team members. Investigators ensured that participants understood the survey by, for example, conducting focus groups with Chinese Americans in English, Mandarin, and Cantonese. Including survey administration, sessions generally lasted from 1 to 1.5 hr.

Survey Measures and Derived Variables

The appendix contains the 20-item survey, which elicited information to document the diversity of the sampled populations. In many instances, existing large nationally representative surveys, such as the Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Interview Survey, provided models for the specific language of the questions. The survey asked about demographics (gender, age, race, marital status, education, income, rural/urban residence); height and weight (from which we computed body mass index [BMI]); and self-rating of memory, emotional problems, and whether a physician had diagnosed cognitive decline. It also asked about behaviors that have been associated with cognitive and emotional health, including diet, physical activity (PA), and social involvement (Hendrie et al., 2006). It is likely that a communication intervention for educating the public about maintaining brain health will refer to these factors (Albert et al., 2007; CDC & AA, 2007).

This analysis used derived variables where useful. PA questions provided data for a measure of the degree to which respondents met recommendations for PA, based on assumptions that (a) at least 30 min of at least moderate-intensity activity most days each week meets PA recommendations (CDC, 2008) and (b) PAs that “make you breathe faster, or make your heart go faster” qualify as at least moderate-intensity activities. A saturated fat consumption question corresponded closely with
readiness-to-change categories (Prochaska & DiClemente, 1983); responses were combined into two categories that suggest the presence or absence of healthy fat consumption.

Data Management and Analysis

The University of South Carolina collected information from all sites and entered the participant survey data into Epi Info 6.0, which created data sets in the Statistical Analysis Software format (SAS Institute Inc., Cary, NC). Analysis used SAS 9.1, primarily to produce descriptive statistics of the entire sample (individual unit of analysis) and by site and focus group, using chi-square tests, where appropriate, to identify differences among the group types.

Results

Demographics

Table 1 summarizes the survey data by site and in the aggregate. Across the nine sites and 55 focus groups, participants had the following demographic characteristics: 75.1% women, 77.9% aged 65 years or older, 43.3% living in rural areas, and 46.9% reporting annual income less than $20,000. Compared with 2006 estimates for adults aged 65 years or older, the study oversampled African Americans (25.6% vs. census 8.3%), Asian Americans (10.0% vs. census 3.2%), and American Indians (7.6% vs. census 0.5%; U.S. Census, 2008).

Comparisons by urban–rural residence suggest demographic differences. The rural sample was significantly older than the urban sample (85.4% aged 65 years or older vs. 72.0%, p = .001), less educated (37.0% with high school education or more vs. 52.9%, p = .001), and more likely to report income less than $40,000 (85.3% vs. 71.4%, p = .004).

Aggregate numbers mask the diversity that gives this study its richness and its usefulness for efforts...
to adapt brain health information and interventions to serve diverse communities. The following examples provide a taste of the variation:

- Focus groups in West Virginia, Colorado, and Texas took place primarily in rural areas, some with frontier status. Participants in California, Illinois, Pennsylvania, and Washington lived in urban areas. North and South Carolina samples included both settings.
- Researchers reached a widely diverse sample of races and ethnicities: African American, American Indian, Asian, Hispanic, and non-Hispanic White.
- Several centers restricted individual focus groups to a single gender.
- One center (Illinois) included a small number of moderately cognitively impaired older adults; another (Colorado) conducted one group with family caregivers of persons with dementia.

It should be noted that the study continues beyond the period reported here. Various sites are conducting additional focus groups with cognitively impaired individuals and caregivers, other ethnic groups such as Filipino, and health care providers.

**Comparisons With State-Level Data**

Compared with 2007 state-level BRFSS data for all adults (CDC, 2007; results not shown in tables), these primarily older adult participants consistently reported lower levels of PA (except for California) than that found by the BRFSS, and greater consumption of fruits and vegetables. California participants, all of whom were Asian, reported less overweight and obesity than that found in the state’s BRFSS. Elsewhere, some sites reported lower average BMI than their states’ populations; other sites reported the same or greater average obesity than their states’ populations.

**Health and Social Behaviors**

Table 2 provides information on relationships between demographic characteristics and behavioral risk factors. Physical activity, obesity, and diet factors varied by race/ethnicity. Asian participants (all in California) reported less obesity and overweight,
and greater consumption of fruits and vegetables than others, with greater readiness to reduce fat consumption in non-Hispanic Whites. African American and American Indian participants had the poorest behavioral risk profiles: more obesity and overweight than others, less readiness to reduce fat consumption (Hispanic participants also), and less consumption of fruits and vegetables. Obesity/overweight varied by sex, with more obesity in women but more overweight in men. Obesity/overweight also appeared more often among rural residents, persons with less than a high school education, and unmarried participants. Younger participants reported less social activity than those 65 years and older, but all respondents reported substantial social activity (89.3% somewhat or very active socially), across sites and focus groups, and in both rural and urban areas, possibly a reflection of willingness to participate in a focus group.

Unmarried participants and those with less than a high school education were more likely to report poor or fair memory. Although recruitment generally excluded individuals who reported having severe cognitive loss, the sample did include participants with a range of milder cognitive impairment. Overall, 27.0% of respondents reported poor or fair memory (vs. good, very good, or excellent). The percentage ranged from 9.4% in Colorado to 56.5% in California. The high rate in California may reflect cultural expectations about memory and cognition among Asian Americans, a group oversampled at that site. Reported diagnosis of memory loss by a physician also varied by site, ranging from no respondents in Pennsylvania and Washington to 30.6% in Illinois (6.9% overall).

Discussion

The purpose of the Healthy Brain Project study was to elicit information from diverse communities to inform the design of culturally sensitive and community-sensitive interventions to promote cognitive health, especially in communities whose members have not often received health information tailored to their characteristics and needs. The researchers sought to reach those communities, building on the diversity of the PRC-HAN’s partner communities. This brief report of the participants’ demographic and behavioral characteristics suggests that the recruitment attained the goal of reaching these communities.

Additionally, comparisons of behavioral characteristics across demographic categories reinforce observations that these communities carry particularly notable health risks, especially among African American and American Indian minorities and persons with less education. Although selection bias may limit the external validity of focus group research, the large number and diversity of participants increase the likelihood that the focus group results are transferable beyond these specific communities. The PRC-HAN, working with the CDC and the AA, now intends to incorporate the lessons learned into community-sensitive information and interventions to promote brain health in diverse populations.

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References


Appendix

Healthy Brain Focus Group
Participant Questionnaire

Please answer the following questions by checking the boxes or filling in the blanks. Do not put your name on this form.

1. Are you: □ Male or □ Female

2. How old are you?
   □ age 34 or younger
   □ age 35 to 44
   □ age 45 to 55
   □ age 56 to 64
   □ age 65 to 74
   □ age 75 to 84
   □ age 85 or older

3. Which best describes the place you live?
   □ Mostly Urban   or   □ Mostly Rural

4. Do you identify yourself as... (Check only one.)
   □ African American
   □ White, not Hispanic
   □ Hispanic or Latina/Latino
   □ Asian or Pacific Islander
   □ American Indian
   □ Other ________________________

5. What is the highest level of education you have completed? (Check only one.)
   □ Less than high school
   □ High school graduate or GED
   □ Some college, technical or vocational training
   □ College degree or more

6. Which best describes you? (Check only one.)
   □ Single (never married)
   □ Married, or living as married
   □ Separated, but not divorced
   □ Divorced
   □ Widowed

7. Which best describes you? (Check only one.)
   □ I am very active socially.
   □ I am somewhat active socially.
   □ I am not very active socially.

8. Please choose one statement listed below that best describes saturated fat in your diet. Examples of limiting saturated fat in your diet are drinking skim milk, eating low fat dairy products, removing skin from chicken, using spray oil, cooking vegetables without added fats, and not eating high fat desserts. (Check only one.)
   □ I limit saturated fat in my diet almost every day, and have done this for longer than 6 months.
   □ I limit saturated fat in my diet almost every day, and have done this for less than 6 months.
   □ I do not limit saturated fat in my diet, but I have been thinking about doing that.
   □ I do not limit saturated fat in my diet, and do not plan to do that.

9. Which best describes you?
   □ I eat more fruits and vegetables than most people do.
   □ I eat about the same amount of fruits and vegetables as most people do.
   □ I eat less fruits or vegetables than most people do.

10. Which best describes you?
    □ I eat fish at least once a week.
    □ I eat fish about once a month.
    □ I eat fish rarely, or not at all.

11. In a USUAL WEEK, do you do any activities for at least 10 minutes at a time that make you breathe faster, or make your heart go faster? Examples are fast walking, bicycling, vacuuming, gardening, or anything else that makes you breathe faster or makes your heart go faster.
    □ Yes
    □ No

12. If you answered ‘Yes’ to question 11: How many days in a USUAL WEEK do you do these things that make you breathe faster, or make your heart go faster for at least 10 minutes?
    □ Days per week

13. If you answered ‘Yes’ to question 11: On days when you do these things that make you breathe faster, or make your heart go faster for at least 10 minutes at a time, how much total time do you do them on an average day?
    □ Total minutes on the days I do them.
14. How would you rate your memory?
   □ Excellent
   □ Very Good
   □ Good
   □ Fair
   □ Poor

15. For how many days in the past 30 days did you feel a lot of stress, feel depressed, feel anxious, eat too much or too little, or have problems with your emotions?
   ______ Days

16. How much do you weigh without shoes?
   ______ Pounds

17. How tall are you without shoes?
   ______ Feet and ______ Inches

18. Has a doctor ever told you that you have memory loss, Alzheimer’s disease, dementia, or senility?
   □ Yes
   □ No

19. What was the total income last year from everyone in your household? (Check only one.)
   □ Less than $20,000
   □ $20,000 to $39,999
   □ $40,000 to $64,999
   □ $65,000 to $99,999
   □ $100,000 or over

20. How many people, including you, are usually supported on this income?
   ______ Number of people (including you)