

Older adults' concerns about cognitive health: commonalities and differences among six United States ethnic groups

JAMES N. LADITKA*, SARAH B. LADITKA*, RUI LIU†, ANNA E. PRICE‡, BEI WU§, DANIELA B. FRIEDMAN||, SARA J. CORWIN||, JOSEPH R. SHARKEY¶, WINSTON TSENG**, REBECCA HUNTER†† and REBECCA G. LOGSDON‡‡

ABSTRACT

We studied concerns about cognitive health among ethnically diverse groups of older adults. The study was grounded in theories of health behaviour and the representation of health and illness. We conducted 42 focus groups (N = 396, ages 50+) in four languages, with African Americans, American Indians, Chinese Americans, Latinos, Whites other than Latinos (hereafter, Whites) and Vietnamese Americans, in nine United States locations. Participants discussed concerns about keeping their memory or ability to think as they age. Audio recordings were transcribed verbatim. Constant comparison methods identified themes. In findings, all ethnic groups expressed concern and fear about memory loss, losing independence, and becoming 'a burden'. Knowing someone with Alzheimer's disease increased concern. American Indians, Chinese Americans, Latinos and Vietnamese Americans expected memory loss. American Indians, Chinese Americans and Vietnamese Americans were concerned about stigma associated with Alzheimer's disease. Only African Americans, Chinese and Whites expressed concern about genetic risks. Only African Americans and Whites expressed concern about behaviour changes. Although we asked participants for their thoughts about their ability to think as they age, they focused

* Department of Public Health Sciences, University of North Carolina at Charlotte, USA.

† Epidemiology Branch, National Institute of Environmental Health Sciences (NIEHS), Research Triangle Park, North Carolina, USA.

‡ Department of Health and Exercise Science, Furman University, Greenville, South Carolina, USA.

§ Gerontology Program, University of North Carolina at Greensboro, USA.

|| Department of Health Promotion, Education, and Behaviour, University of South Carolina, Columbia, USA.

¶ Texas Healthy Aging Research Network Collaborating Center (TxHAN) at the School of Rural Public Health, Texas A&M Health Science Center, College Station, USA.

** School of Public Health, University of California, Berkeley, USA.

†† Carolina Geriatric Education Centre, and Centre for Ageing and Health, University of North Carolina at Chapel Hill, USA.

‡‡ Psychosocial and Community Health, University of Washington School of Nursing, Seattle, USA.

almost exclusively on memory. This suggests that health education promoting cognitive health should focus on memory, but should also educate the public about the importance of maintaining all aspects of cognitive health.

KEY WORDS – cognition, ageing, Alzheimer's disease, dementia, memory, qualitative research, focus groups, brain health.

The emerging opportunity to promote cognitive health

Significant memory loss and cognitive decline affect about 25 per cent of older adults living in the community, and are risk factors for developing dementia (Plassman *et al.* 2007; Unverzagt *et al.* 2001). The prevalence of cognitive problems increases dramatically with age (Alzheimer's Association 2008), making this issue increasingly important as life expectancy rises, and as the large baby boom cohort ages. Although evidence from randomised clinical trials is limited (van Uffelen *et al.* 2009), growing evidence from epidemiology and animal models suggests that health behaviours may influence cognitive health (Albert *et al.* 2007; Chodzko-Zajko *et al.* 2009; Hendrie *et al.* 2006; Rabins 2007). This development provides an opportunity for public health education promoting cognitive health, with appropriate acknowledgement that the evidence remains uncertain (Centers for Disease Control and Prevention and Alzheimer's Association 2007).

The central role of theory in promoting cognitive health

Successful public health interventions are most often grounded in a theory of health behaviour change. The science base supporting the possibility of promoting cognitive health has developed only recently. No unified conceptual framework or theory has been developed for understanding people's views about cognitive health, and for promoting cognitive health. This formative research, part of the Healthy Brain Study, was designed in part to provide a foundation for the development of that conceptual framework or theory.

The theories most commonly used as foundations for health behaviour change programmes all include a focus on knowledge and beliefs (Painter *et al.* 2008). Thus, those who are developing public health interventions to promote cognitive health need information about the public's knowledge and beliefs about it. In multicultural societies, the need includes specific information for population sub-groups. For example, the widely adopted stages of change theory, also called the Transtheoretical Model, suggests

that even in the initial stages of behaviour change, people need knowledge about the health status they want to promote or avoid, and motivation for behavioural change (Prochaska and Velicer 1997). If older people typically have knowledge about their considerable risk of cognitive decline, and about the potential efficacy of health behaviours that may reduce that risk, they may be more likely to contemplate taking up those behaviours, and eventually to do so.

Another commonly applied theory of behavioural change, Social Cognitive Theory, assumes that people act to produce desired health effects only when they believe that their actions can produce those effects, when they have a reasonably strong sense of 'self-efficacy' (Bandura 1986). If individuals strongly believe that serious cognitive decline inevitably accompanies ageing, or that cognitive health trajectories are determined genetically rather than by behaviours, they may be less likely to adopt behaviours associated with maintaining cognitive health. Alternatively, those designing behavioural interventions grounded in the widely applied Health Belief Model would want to know whether individuals in a given population: (a) believe they are susceptible to cognitive decline; (b) believe that their personal risk of cognitive decline is potentially serious, in terms of its impact on their lives or the lives of those in their families or social circles; (c) believe that benefits that might result from behaviour changes would outweigh their costs; and (d) have received 'cues to action', information that makes them feel the need to act on their beliefs (Rosenstock 1974). Thus, if individuals in a given population group know little about cognitive health and behaviours that have been associated with it, or if they commonly believe that they are at low risk of cognitive decline, then the likelihood that they will take up and maintain behaviours thought to protect cognitive health will remain low unless their knowledge and beliefs can be altered. In summary, if we are to design public health education for diverse groups that will effectively promote behaviours that are increasingly associated with cognitive health, we need to understand the knowledge and beliefs about cognitive health that are typical among individuals in those groups.

What is known regarding views about cognitive health?

There has been only limited information available about this knowledge and these beliefs in the general population (Anderson *et al.* 2009). Most related research has focused on individuals with Alzheimer's disease or associated disorders, or on those who care for them. In a MetLife Foundation survey that represented the adult United States population (2006), 74 per cent said they knew little or nothing about Alzheimer's

disease. In a 1999–2000 Harris Interactive survey, 61 per cent said they were somewhat or very worried about having memory loss at age 75 (Cutler, Whitelaw and Beattie 2002). One national survey suggested that about half of Americans think steps can be taken to ‘maintain a healthy memory and reduce the chances of getting Alzheimer’s disease’ (Connell, Roberts and McLaughlin 2007). In an online survey of African Americans by the Alzheimer’s Association and American Heart Association (2008), 50 per cent reported engaging in behaviours specifically to promote ‘brain health’. However, in another national survey, only about one-quarter of Americans reported making lifestyle changes to avoid developing Alzheimer’s disease, considerably lower than the proportion reporting making such changes to avoid cancer (66.3%), diabetes (72.3%), or heart disease (85.6%) (Connell, Roberts and McLaughlin 2007). This limited and mixed evidence suggests that many Americans may be concerned about cognitive health, but also that they have little information about it.

Internationally, a survey has suggested that about half of Australian adults believe that at least some recovery from dementia is possible, although about 80 per cent correctly offered that brain disease, genetics, and mini-strokes contribute to the risk of dementia (Low and Anstey 2009). That survey also suggested that about 72 per cent of Australians believe the risk of dementia can be reduced through healthy lifestyles (Low and Anstey 2009). Participants in a survey conducted in France, Germany, Italy, Poland, Spain and the United Kingdom were found to have little knowledge about early signs of Alzheimer’s disease (Rimmer *et al.* 2005). They expressed concern about Alzheimer’s disease, but expected that cancer and heart disease would affect their families and themselves more (Rimmer *et al.* 2005). This survey also suggested that about one-third of Europeans believe that Alzheimer’s disease is serious, but that it does not affect many people (Rimmer *et al.* 2005). In Japan, there is evidence that attitudes about dementia among older persons may have changed considerably since the implementation of a universal long-term care system: in 1997, between 64 and 69 per cent of survey respondents identified dementia as the ‘least wanted disease’ of later life; by 2006, the result for dementia had fallen to between 34 and 44 per cent, with increasing concern expressed about cancer and stroke (Matsubayashi *et al.* 2009). Evaluating this change in public attitudes, the authors note that disease states are experienced in many dimensions – not only scientific, but also subjective and sociocultural. This result underscores the usefulness of understanding attitudes about cognitive health, because the likelihood of taking up healthy behaviours to avoid a disease may be a function of perceptions of personal or family risk, and of the social and financial costs associated with it.

Focusing on beliefs about cognitive health among ethnic groups in the United States of America (USA), a national survey reported by Connell, Roberts and McLaughlin (2007) found that African Americans (59 %) and Latinos (50 %) were more likely than Whites other than Latinos (33 %; hereafter Whites) to agree, incorrectly, that 'Alzheimer's is the term for normal memory loss as we get older'. Surveys have found evidence that African Americans may have less perceived threat of developing Alzheimer's disease than Whites, and less worry about its possible consequences (Roberts *et al.* 2003). It has been suggested that a diagnosis of Alzheimer's disease may be of less concern to many African Americans than to Whites because African Americans have more access to support from extended families and churches, may adapt more readily to adversity, have greater resilience with positive coping strategies such as prayer and reframing of negative experiences, and value social role performance more than individual cognitive accomplishment (Roberts *et al.* 2003). Using an approach from cultural anthropology, Gaines examined characteristics that might be ascribed to Alzheimer's disease in traditional Southern culture (Gaines 1989), also suggesting that African Americans and others immersed in traditional Southern culture may place higher value on emotions and role expectations than on cognitive or intellectual abilities. From the perspective of such values, cognitive decline may have limited importance unless it becomes sufficiently severe to impair the individual's relationships and social roles (Gaines 1989).

Representations of cognitive health and disease

This approach to understanding ethnic differences in views about cognitive health is supported by work on representations of health and illness (Leventhal and Crouch 1997; Leventhal *et al.* 1997). Although developed with primary regard to managing disease by accessing medical treatment, the theory of illness representation can be applied equally well to disease prevention. Our representations of cognitive decline define its putative causes, expected symptoms, applied labels, expected potential consequences, assumed possibilities for control, and anticipated time-lines both for its development and for disability and death associated with it. Illness representations can vary across places, over times, and among groups. The theory of illness representation also suggests the usefulness of understanding the social context of health behaviours. Health behaviours spring not only from individuals' knowledge and beliefs, but also from the knowledge and beliefs held in common in their social groups. Thus, for example, if individuals in a given ethnic group are more likely to view Alzheimer's disease and related disorders as normal characteristics of

ageing, it may be less likely that they will respond to a public health promotion that suggests alternative knowledge.

There is evidence that older Whites may be more knowledgeable about Alzheimer's disease than African American, Latino and Asian older adults (Ayalon and Arean 2004). In 25 interviews with Chinese families providing care for individuals with Alzheimer's disease in the Boston area, researchers found that serious memory loss and other types of cognitive decline were considered part of normal ageing, and also that Alzheimer's disease was associated with a high level of stigma (Hinton *et al.* 2000). Families affected by Alzheimer's disease reported feeling guilt and shame, and that they might hide the affected person from society. The view that Alzheimer's disease is part of normal ageing and the association of Alzheimer's disease with strong stigma have also been found in a group of eight Vietnamese care-givers in the San Francisco area (Hinton *et al.* 2005). In interviews and focus groups, recent Chinese and Vietnamese immigrants in Hawaii said that dementia was a 'natural part of older age' (Braun and Browne 1998).

A number of studies have examined subjective cognitive complaints, which are everyday concerns about memory or thinking ability reported by people with or without cognitive impairment (Gallassi *et al.* 2008; Glodzik-Sobanska *et al.* 2007; Jessen *et al.* 2007). Research suggests that older adults are concerned that their own subjective cognitive complaints may signal cognitive decline (Gallassi *et al.* 2008; Glodzik-Sobanska *et al.* 2007). A related concept is anticipatory dementia, concern that memory changes will lead to cognitive impairment (Cutler and Hodgson 1996). Research suggests that people who assess their memory function negatively often have greater concern about developing Alzheimer's disease (Cutler and Hodgson 1996). In a study of 15 women in the United Kingdom, most expressed dread about dementia, negative attitudes about people with dementia, and particularly great anxiety about dementia and memory loss if they knew someone with dementia (Corner and Bond 2004).

Dark-Freudeman, West and Viverito (2006) examined older adults' (N = 24, ages 53–87) expectations for their future selves, with a focus on memory and cognition. Forty-four per cent mentioned a cognitive or memory-related concern, with particular focus on Alzheimer's disease. Nearly a third said cognitive decline was their greatest fear. Although some research has identified populations concerned about Alzheimer's disease who believe prevention is not possible (Welch and West 1995; Wu *et al.* 2009), in the study by Dark-Freudeman, West and Viverito (2006) over half of the older adults with memory concerns said they were trying to prevent cognitive decline through physical or mental exercise. This

result is consistent with a general finding that older people are more likely than younger people to conserve and protect their physical health (Leventhal and Crouch 1997). Consistent with health behaviour theory, it seems likely that those who perceive themselves to be particularly vulnerable to cognitive decline would be more likely to adopt risk reduction strategies (Leventhal and Crouch 1997).

The purpose of this study

This study addresses the research gap regarding cognitive and memory concerns of diverse groups of older adults using data from a large, multi-site, primarily qualitative initiative, the Healthy Brain Study (Friedman *et al.* 2009; J. Laditka *et al.* 2009; S. Laditka *et al.* 2009 *b*; Wilcox *et al.* 2009). The present study has two objectives. In the context of increasing evidence that healthy behaviours may help maintain cognitive function, we sought to describe concerns about cognitive function and memory among a diverse group of older adults in the USA, and to examine commonalities and differences by ethnicity. The study was grounded in theories of health behaviour and the representation of health and illness by individuals and groups. Researchers using surveys to study these issues emphasise limitations of surveys, and stress the need for qualitative research (*e.g.* Roberts *et al.* 2003). Previous related qualitative studies have used small samples and highly varied approaches. The present study contributes to research in this area with results from a large number of participants and focus groups representing six ethnicities, obtained using standardised focus group methods and a discussion guide that was developed through the collaboration of researchers, policy makers, and community partners in nine locations of the USA (J. Laditka *et al.* 2009). Greater understanding of concerns about cognitive function and memory may be useful for developing effective interventions to promote cognitive health.

Methods

Focus group participants and selection criteria

The study methods described below have been previously reported in detail (Bryant *et al.* 2009; J. Laditka *et al.* 2009; S. Laditka *et al.* 2009 *a*, 2009 *b*; Wilcox *et al.* 2009). The study included 42 focus groups: 19 with Whites, ten with African Americans, four with American Indians, four with Chinese, three with Vietnamese and two with Latinos, with 396 adults living in the community in nine states. The focus groups were conducted between November 2005 and August 2007. With participation

by the Centers for Disease Control and Prevention (CDC), the study was conducted by the Healthy Ageing Research Network (CDC-HAN), which includes nine research universities and their community partners (J. Laditka *et al.* 2009). Recruitment leveraged the cultural, economic, geographical and ethnic diversity of the communities in which CDC-HAN centres are located, and also the strong network of CDC-HAN community partners, to provide information that would be useful for developing health promotion interventions for specific groups as well as for the general population (Bryant *et al.* 2009; J. Laditka *et al.* 2009; Wilcox *et al.* 2009). Participants were age 50 and over, and reported no notable cognitive impairment when recruited. Although some participants may have had experience caring for a family member or friend with dementia, this was not a recruitment focus. There was no evidence in the focus group results that many participants were providing care for someone with dementia, or had done so.

Almost all of the White participants were recruited through senior centres, as were three of the ten African American focus groups; these focus groups were conducted at the senior centres. Six African American focus groups were recruited and conducted at churches. One African American focus group was recruited and conducted at a local conference. American Indians were recruited through tribal organisations. All Chinese and Vietnamese participants were recruited through community partners in the San Francisco Bay area. The Vietnamese participants were all recent immigrants (Wilcox *et al.* 2009).

Focus group procedures

A nine-item focus group discussion guide was developed (J. Laditka *et al.* 2009). This study focuses on one question of the guide. We invited each group to: 'tell us about any concerns you may have about your ability to keep your memory or ability to think as you age'. Follow-up prompts asked about the importance of the concerns, and why they were important. Participants also completed a survey that asked about demographic characteristics, health behaviours, and mental health (Bryant *et al.* 2009). One question asked, 'How would you rate your memory?' Response options were: Poor, Fair, Good, Very Good and Excellent. We also asked, 'Has a doctor ever told you that you have memory loss, Alzheimer's disease, dementia, or senility?'

Experienced moderators conducted the groups, which lasted 90–120 minutes. Moderators used comprehension probes to obtain and clarify responses. For example, moderators may have asked, 'Would you give me an example of what you mean?' All groups were audio-recorded. Most

groups were conducted in English. All Vietnamese and Chinese groups were conducted by native-speaking moderators and assistants, of the same ethnicity and language as participants, using a translated consent form, discussion guide and survey. Responses from the Chinese (conducted in Mandarin and Cantonese) and Vietnamese groups were translated into English. Due to resource constraints, some focus groups with American Indians and Latinos and half of the African American groups did not match moderator and participant ethnicity. The study was approved by the Institutional Review Board at each CDC-HAN site.

Qualitative data analysis

Audio recordings were transcribed verbatim into Microsoft Word. A detailed description of the codebook development and data coding procedures has been published (S. Laditka *et al.* 2009*a*). Briefly, transcripts were imported into ATLAS.ti version 5.2 (Muhr and Friese 2004), software that facilitates the management and analysis of qualitative data. Axial coding (Strauss and Corbin 1998) connected code categories, and identified themes. To determine inter-rater agreement, two researchers independently coded one transcript from every ethnic group from each of the nine sites. The researchers then met to determine inter-rater agreement. At least 80 per cent agreement was considered evidence of consistent coding. If 80 per cent agreement was not reached, the coders discussed the discordant codes and the passages to which they had been applied, and reached consensus regarding the most appropriate application of each code. The transcripts were then recoded and inter-rater agreement was calculated again. The few remaining coding issues were resolved by discussion and consensus among the six co-authors who met frequently to ensure the validity and reliability of coding and data analysis. Several of the researchers developed a codebook from the interview content to categorise and organise concepts (S. Laditka *et al.* 2009*a*). The constant comparison method (Glaser and Strauss 1967) was used to identify commonalities and differences among groups, comparing and contrasting themes within and across groups defined by ethnicity. All co-authors met in monthly conference calls throughout the project for quality assurance, addressing issues such as focus group procedures and data analysis.

Survey data analysis

Survey data were analysed using Statistical Analysis Software (SAS) version 9.1.3. For continuous variables, the non-parametric Kruskal–Wallis test was used. Pair-wise comparisons used the Kolmogorov–Smirnov test,

comparing each minority group with Whites. Whites were selected as the comparison group because of their large number in the focus groups, and given their larger proportion in the older US population. Chi-square tests were performed for categorical variables.

The findings

Participant characteristics

Table 1 reports participant demographic and behavioural characteristics. The mean age of participants was 71.0 (standard deviation 9.3; range 50–90). A large proportion (74.9%) were women. Nearly 40 per cent reported being high school graduates; 26 per cent graduated from a technical or vocational school, and 17 per cent from college. About half of participants reported annual household income less than \$20,000, about a third between \$20,000 and \$39,999, and 20 per cent at least \$40,000. This compares with Census estimates of median household income for the time of the survey of \$36,032 for those ages 65–69, \$40,296 for those ages 70–74, and \$31,654 for those ages 75 and over (US Census Bureau 2010).

Several characteristics differed substantially and significantly by ethnicity. Whites were older (mean age 74.4) than participants of most other groups. They were substantially older than the Latino and Vietnamese participants (61.3 and 60.6, respectively). Compared with Whites, larger proportions of Latinos and Vietnamese were married.

As Table 1 shows, across all ethnic groups, 29.2 per cent of participants rated their memory as Fair or Poor. Chinese and Vietnamese Americans were more likely to report Fair or Poor memory (47.2 and 69.3%, respectively). Although participants had reported no notable cognitive impairment when recruited, we also asked, 'Has a doctor ever told you that you have memory loss, Alzheimer's disease, dementia, or senility?' Five per cent of all participants indicated that they had been told this, with no statistically significant differences among groups excepting Vietnamese Americans. In that group, consistent with their larger proportion who reported having only fair or poor memory, 26.9 per cent of participants said that a doctor had told them this.

Thematic analysis findings

The sections that follow describe themes identified in the qualitative data, highlighting ethnic similarities and differences. Table 2 provides a summary of these themes by ethnicity; a check mark in the table indicates that the theme was commonly expressed in focus groups of the given ethnicity.

TABLE 1. Description of focus group participants in the cognitive concerns study, by ethnicity

	African Americans (N = 95)	American Indians (N = 34)	Latinos (N = 10)	Chinese (N = 36)	Vietnamese (N = 26)	Whites other than Latinos (N = 195)	Total (N = 396)
Mean age (SD)	70.0 (8.4)*	69.6 (9.9)	61.3 (6.0)**	69.0 (8.3)*	60.6 (7.7)***	74.4 (8.1)	71.0 (9.3)
Mean BMI ¹ (SD)	31.7 (8.3)***	31.0 (5.5)**	30.5 (7.4)	23.3 (3.2)***	22.4 (3.3)***	27.7 (5.5)	28.2 (6.7)
Mean stress (days/month) (SD)	4.8 (8.2)	11.6 (11.5)*	7.6 (7.0)	5.3 (8.2)	7.1 (8.1)*	5.4 (8.4)	5.9 (8.7)
	<i>Percentages</i>						
Female	88.4**	81.8	70.0	69.4	57.7	71.2	74.9
Married ²	29.5	41.2	90.0**	55.6	61.5*	39.7	41.5
Education:							
< High school	19.0	17.7	20.0	19.4	26.9	18.5	19.2
High school/ GED	37.9	38.2	50.0	22.2	38.5	40.2	38.0
Technical or vocational	32.6	26.5	10.0	25.0	19.2	25.3	26.3
≥ College degree	10.5	17.7	20.0	33.3	15.4	16.0	16.5
Annual household income:							
< \$20,000	56.5	51.6	25.0	50.0	46.2	46.6	49.2
\$20,000–39,999	32.9	29.0	25.0	25.0	38.5	30.3	30.8
\$40,000 +	10.6	19.4	50.0	25.0	15.4	23.1	20.0
Social activity:							
Very social	55.9	42.4	90.0*	30.6	11.5***	42.7	43.9
Somewhat social	38.7	42.4	10.0	58.3	38.5	50.0	45.6
Not very social	5.4	15.2	0.0	11.1	50.0	7.3	10.5
Memory fair or poor ³	21.7	27.3	20.0	47.2**	69.3***	24.9	29.2
Cognitive problem diagnosis ⁴	1.2	6.3	0.0	5.7	26.9***	3.4	5.0

Notes: SD: standard deviation. BMI: body mass index. GED: General Educational Development. 1. BMI for Chinese and Vietnamese calculated using World Health Organization (2004) guidelines for calculating BMI for Asians. 2. Compared with single, separated, divorced, or widowed. 3. Self-reported memory is compared to good, very good, excellent. 4. Participant's response to the question: 'Has a doctor ever told you that you have memory loss, Alzheimer's disease, dementia, or senility?'

Data source: Healthy Ageing Research Network (CDC-HAN), the Healthy Brain Study; 42 focus groups with 396 participants, ages 50+, conducted in four languages in nine US locations (California, Colorado, Illinois, Pennsylvania, North Carolina, South Carolina, Texas, Washington and West Virginia), November 2005 to August 2007. Statistical tests compare each group with Whites, the largest group.

Significance levels: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Concern and fear about cognitive decline. By far the most common reactions to the question regarding concerns about 'your memory or ability to think' were expressed in terms such as: 'worried', 'afraid', 'scared', 'frightened' and 'terrified'. This theme was expressed by all ethnic groups. Many participants spoke about minor memory lapses, such as losing keys or forgetting a person's name. They often then said these minor events were of great concern. For example: 'I'm worried about how that,

TABLE 2. Summary of cognitive concerns, by ethnicity

Theme	African Americans	American Indians	Chinese Americans	Latinos	Whites other than Latinos	Vietnamese Americans
Concern and fear about memory loss	✓	✓	✓	✓	✓	✓
Concern about forgetfulness	✓	✓	✓	✓	✓	✓
Concern to remain independent and avoid becoming 'a burden'	✓	✓	✓	✓	✓	✓
Concern heightened by knowing someone with Alzheimer's disease	✓	✓	✓	✓	✓	✓
Concern that cognitive decline is an expected characteristic of normal ageing		✓	✓	✓		✓
Concerns about stigma and how family treat those with cognitive impairment		✓	✓			✓
Concern about genetic risks or other predispositions for cognitive decline	✓		✓		✓	
Concern about behavioural changes associated with cognitive decline	✓				✓	

Note: A check mark indicates that the theme was commonly expressed in focus groups of the given ethnicity.

Data source: Healthy Ageing Research Network (CDC-HAN), the Healthy Brain Study; results based on 42 focus groups with 396 participants, ages 50+, conducted in four languages in nine US locations, November 2005 to August 2007.

if I'm going to lose it. You know, what do I do?' (African American). 'I'm worried about, well, do you lose it like that or does it take time, or how does it?' (African American). 'I wonder if it's going to get worse' (American Indian). 'We don't know what we'll do. That's why I think everyone is concerned. Not many people aren't concerned' (Vietnamese).

White, Chinese and Vietnamese participants compared their concerns about cognitive function to those about other diseases associated with ageing, and also to concerns about death:

For us elderly, it's mostly about heart disease and cancer. Now the Alzheimer's disease is also an important issue. Cancer and heart diseases can be treated or prevented. But with Alzheimer's, we haven't even figured it out yet. What causes it, how to prevent and treat it, and we are not clear about this. (Chinese)

And, there should be, as far as this Alzheimer's, I mean, you know, none of us don't like to pay taxes or whatever, but that's something that somebody, somewhere, ought to shake a tree and get some money loose for research. Alzheimer's, it's a terrible thing. (White)

I am really worried because right now, I have illnesses that require a lot of medication. My brain's always aching. So I'm worried. Scared. Not scared of death, but of when my mind will no longer be sharp. (Vietnamese)

Concern about forgetfulness. Participants of all ethnic groups expressed concern about being forgetful, as well as potential implications of this forgetfulness for their future cognitive health. They reported forgetting: where they left their keys, words, people's names, doctor appointments, telephone numbers, driving directions, why they went into a room, what they intended to buy at the supermarket, where they had put things, and all sorts of 'little things', such as, 'when I go to the refrigerator and I don't know what I'm doing there' (Latino). Although participants joked about mild forgetfulness, their discussions about it often expressed considerable concern. For example, a Latino participant said, 'I'm extremely concerned because I'm 53 going on 54 and I'm going like, "This can't be happening to me". It's terrible'. Another Latino participant offered: 'Sometimes I get very disappointed if I can't remember things. And then I forget that I forgot something'.

Focus group participants often expressed concern that an inability to remember something might indicate the beginning of Alzheimer's disease:

I know that every once in a while, you, when you have a, I call it a brain freeze at this age, but whenever you have some kind of a problem remembering something, you think, oh, you know, you automatically think about Alzheimer's. At least I do. I mean, I think, am I in the beginning stage, you know? I mean, you really do because it's so frightening. (White)

Concern to remain independent and avoid becoming 'a burden'. Participants in all groups voiced concern that they wanted to avoid becoming a burden to their families. As an American Indian put it, 'I don't want to live, you know, to where I'll be a burden on, on my family'. Concern about becoming a burden prompted many comments about the importance of remaining independent, which were expressed in the context of concerns about cognitive health:

You don't want people to lose their independence. You know, I mean, my whole goal in life, and being in health care as long as I have, is to be independent, to be fully independent and able to take care of themselves. You know, that's really the greatest thing that can happen. (White)

Chinese participants also asserted that they did not want to burden their children as a result of cognitive decline: 'So this is the issue I am concerned about. It is really not right to stay at home [if you have dementia]'. Other participants in the same focus group expressed agreement with this view. Many focus groups included similar discussions, with participants often stating that it is 'better to be dead' than to live with serious cognitive impairment, a 'burden' on family or on 'Medicare'.

For White participants, part of avoiding becoming a burden due to cognitive decline was recognising the need to plan for long-term care and end-of-life issues. Whites often made comments such as, 'I wonder who else is, who's gonna take care of me, you know?' Whites commented about planning for long-term care, 'while you have your right mind, while you have the choice'.

African Americans more commonly said they were concerned about the possibility of their own cognitive decline because they were responsible for the care of older family members:

Well, my concern is, my mom is, she has dementia now and she's in assisted living. And my concern is that if something should happen to me that I won't be around to more or less care about her, to see after her.

Concern heightened by knowing someone with Alzheimer's disease. One of the most common themes, expressed in focus groups representing all ethnicities with the exception of Latinos, involved observations about friends or relatives with Alzheimer's disease or another form of cognitive impairment. A Vietnamese participant offered: 'In my workplace, there's this woman who's only 50 something. She works, but she forgets this and that. One day, she was working and she just kept pushing the cart back and forth. Now she can't work' (Vietnamese). In a typical example, one White participant said:

It's my brother. He's two years older than I am, and I see, and it hurts my heart when I go to visit him. He forgets who my great-grandchild is or that he saw her last week. I see the sorrow in his face and in his eyes and it hurts me. And, I'm worried for me. Maybe I'm being selfish, worrying. I'm worried what I'm going to be. I'm 84. He's 86. Is this going to be my fate?

Concern that cognitive decline is an expected characteristic of normal ageing. Among American Indians, Chinese Americans, Latinos and Vietnamese Americans, there were frequent statements that cognitive decline is to be expected with ageing. For example, American Indians commonly expressed an acceptance of cognitive decline: 'It's called senile, but it's a natural process'. One American Indian participant said that she had attention deficit disorder, and had to struggle to memorise as a child, 'and

now that, after I have matured and gotten older, I find it kind of ironic that now it's pretty much accepted that I'm forgetting things, that I don't have to really concentrate and sacrifice to remember anymore'. American Indians typically said they expected, 'that as we get older, it's gonna be a little bit harder, you know, to remember everything'.

Offering an example of losing one's glasses while wearing them, one Vietnamese participant exemplified the common view in this ethnic group that memory loss is a normal characteristic of ageing, as predictable as the loss of physical strength: 'We're old, right? In old age, there will be changes according to our age. Like we can't carry heavy things and our memory has lessened, see?'. Another Vietnamese participant spoke of ageing and memory loss:

Then, of course, when ageing, the sharpness lessens. Following the standard model, our brain will be less sharp. For example, people say that the memory of older people is lessening, disappearing, and won't be developing like the teenage years.

There was some evidence that Latino participants may have differed from others in the way they viewed this decline. Perhaps because they considered cognitive decline to be inevitable, Latino participants commonly said they simply accepted it:

I know that her grandmother, she would ramble on, and so on and so forth, and I would sit, sit there and listen to her and just let her go, just let her talk whatever she wants to talk about. And so that's part of the, just, that's part of life. And, and you just go along with it.

Another Latino participant immediately agreed with this comment: 'Yeah. Yeah. Yeah. And it's not something that you bring up or that you make fun of, or that you – yeah, it's just part of life'.

Chinese participants tended to also associate ageing with cognitive decline:

The concern is as we age, it's bound to be, you know, definitely if you start ageing and if you're 80 and 90 years old, you cannot be as sharp as if, as if you were in your twenties, thirties, forties. So, that's a natural happening. So that's a concern.

Although generally agreeing with the idea that cognitive decline is a normal characteristic of ageing, Chinese Americans were the only group to voice hope for recovering cognitive function after its decline, with several making comments such as: 'In order to make progress, you must do what the doctor says. Don't deprive the brain from any opportunities to make progress. Then it can recover slowly' (Chinese). 'New brain cells can still grow at this stage. New brain cells. As long as you keep stimulating them, they can still grow' (Chinese).

Concerns about stigma and how family treat those with cognitive impairment. Participants in several ethnic groups expressed concern about how cognitive loss might affect the way they are viewed or treated by others, particularly family. An American Indian commented, 'Well, I don't always remember everything and my kids make remarks to me like, 'Oh mom's getting forgetful'. I don't feel like I'm that forgetful. I don't know if they're just making fun of me' (American Indian). Another American Indian commented:

Well, I remember my grandmother was, I guess she would repeat herself, so after a while they would kind of just quit listening to her and talk, talk about her, and she'd be sitting there, but they would be talking about her like she wasn't even there. I wouldn't want to be treated like that. So, it's important to me to try to remember things and not repeat things.

Vietnamese and Chinese participants also addressed concerns about ways that declining cognitive function might affect how they are treated as they age, particularly by their children or by 'young people'. Vietnamese expressed concern that, 'They [will] send me away'. Chinese participants voiced the greatest concern about how they might be treated if they were to develop Alzheimer's disease. These concerns typically involved being shunned by family members, being 'sent away', or being 'locked up':

Once someone has Alzheimer's, they lock you up in the house. This could lead to serious consequences. I have a cousin, 94 years old, living in Mainland China. In general, he functions normal, with only occasional occurrence of Alzheimer's. They locked him up in the house. So he held a pillow and jumped off the 4th floor at night. (Chinese)

Concerns about genetic risks or other predispositions for cognitive decline. African American, Chinese and White participants expressed concerns related to genetic risks or other predispositions for developing Alzheimer's disease: 'You're talking about genes and like. I'm concerned because my Mom had Alzheimer's. And I'm afraid that, you know, I will get that, too' (Chinese). African Americans did not explicitly mention genetic risks. However, they did voice concern that efforts to reduce risk might be ineffective:

You know, 'cause a lot of people come down with it and they, you know, be in good shape and do what they supposed to do and eat what they supposed to eat. But still they come down with Alzheimer's. (African American)

In some groups, genetic links were noted, but with uncertainty. For example, a typical question from an American Indian was, 'Is

the Alzheimer's, is that handed down from generation?' One White participant put it this way:

Yeah. On my mother's side, there's, there were three, well they were second cousins, and it always goes through my mind, oh, I hope it's not on this, or I hope it's not on that. Is it something that they did maybe that brought it on? Was it hereditary that brought it on? You hope it doesn't happen to you or your family. But, it's a fear. My biggest fear is Alzheimer's. It runs in our family.

Concerns about behavioural changes associated with cognitive decline. African Americans and Whites were the only groups to express concerns about behavioural changes associated with dementia. For example, one African American participant was concerned that, with Alzheimer's disease, 'you're mean to your family because you don't know them and stuff; and I would never hopefully have to do that' (African American). Typical of responses in this area was that of one White participant, who described behavioural challenges associated with Alzheimer's disease:

The wife was diagnosed with Alzheimer's and of course their retirement turned into a nightmare for him. And I would go out there and he would cry because he said this is not the beautiful woman that he was married to. And, she would have spells of being very aggressive and she was normally a very sweet person. But I saw that and I'm, I'm determined that I never want me or any of my loved ones to be like that. (White)

Discussion

There is growing evidence that healthy behaviours may help to maintain cognitive function. Given this evidence, it is useful to examine concerns about cognitive health among ethnically diverse groups of older adults, to provide a foundation for developing health communications or other interventions designed to promote cognitive health. In our study, participants in all ethnic groups expressed great concern about 'loss of memory or ability to think', often using terms such as 'worried', 'afraid', 'scared', 'frightened' and 'terrified'. This is consistent with studies that have found cognitive decline is among the greatest fears of older people (Corner and Bond 2004; Cutler, Whitelaw and Beattie 2002; Dark-Freudeman, West and Viverito 2006). All ethnic groups also voiced concerns about being forgetful, as well as potential implications of this forgetfulness for their future cognitive health. Our finding in this area is consistent with studies of subjective cognitive concerns and anticipatory dementia (Cutler and Hodgson 1996; Jessen *et al.* 2007). Participants in all ethnic groups

expressed concern that cognitive decline would make them a burden to their families, and stressed the need to remain independent (Corner and Bond 2004). Another theme commonly mentioned among all ethnic groups, excepting Latinos, was anxiety when around people with Alzheimer's disease or another form of cognitive impairment. Being around a family member with dementia may trigger feelings of anticipatory dementia (Corner and Bond 2004; Cutler and Hodgson 1996). Although the results are generally consistent with previous research, one notable difference is that surveys have found African Americans to have less perceived threat of developing Alzheimer's disease than Whites, and less worry about its possible consequences (Roberts *et al.* 2003), whereas in the present study the African American focus groups were equally likely to express concerns about cognitive health. This difference may be attributable to the differing research methods of this and previous studies. In general, however, our findings are consistent with survey research and smaller qualitative studies. Most of the latter were conducted a decade or more ago and with a variety of discussion guides. This consistency of results suggests that the ethnic or cultural differences found in this study may be pervasive and lasting.

From the perspective of the transtheoretical model of behaviour change (Prochaska and Velicer 1997), there was evidence that most participants had some knowledge about cognitive decline, and were concerned about their individual risks for developing it. The transtheoretical model focuses on stages of change in health behaviours. The stages range from one end of a continuum that is often called 'precontemplation', where the individual does not yet intend to take action in the foreseeable future, to the opposite end where the individual has made lasting changes with almost no possibility of relapse to less healthy behaviours. Only rarely did participants express that they were preparing to take up the health behaviours that have been most strongly associated with cognitive health, namely physical activity and healthier diets, or that they had actually done so. We did not ask participants about their health behaviours in the focus groups, although we did describe health behaviours that have been associated with cognitive health, and gave participants an opportunity to react to that information. We also did not ask whether participants intended to change their health behaviours within a given period of time, or had already made such changes, questions that are important in the transtheoretical model. The decision not to ask these questions responded to our emphasis on focus group methods rather than individual interviews, concerns about participant burden and the need to focus on our core research questions, and the limited resources available for our research. Thus, the data do not permit us to place participants precisely among the stages of change that

characterise the transtheoretical model. However, the brief survey that participants completed before each focus group did ask about physical activity and diet. In results reported previously, we found that two-thirds to three-quarters of participants, depending on ethnicity, did not meet national recommendations for physical activity (Bryant *et al.* 2009). On the other hand, the majority of participants in all ethnic groups were either limiting saturated fat intake, or were planning to do so (Bryant *et al.* 2009). It would be useful for researchers to examine where a large sample of older persons might be located among the stages, specifically with regard to behaviours that are thought to be associated with cognitive health. From the perspective of designing health promotion interventions, the most important finding is that most participants were knowledgeable and concerned about cognitive health. Knowledge and concern about health conditions are foundations of behavioural change.

Interpreting these results from the perspective of the Health Belief Model (Rosenstock 1974), there is evidence from this study that older adults believe: they are susceptible to cognitive decline; their personal risk of cognitive decline is potentially serious; and that the costs of cognitive decline, in terms of its effects on individuals and families, are great. Again from the perspective of the Health Belief Model, unanswered by this research is whether participants have received adequate cues to action that would motivate them to make those behavioural changes. One important expectation of the Health Belief Model is that successful behaviour change requires that people believe that its benefits will outweigh its costs. One finding of this study was that American Indians, Chinese Americans, Latino Americans and Vietnamese Americans all said that serious cognitive decline is an expected characteristic of normal ageing. Indeed, American Indians commonly expressed acceptance of serious cognitive decline, including Alzheimer's disease and related disorders. This result for Chinese, Latino and Vietnamese Americans is consistent with previous research (Ayalon and Arean 2004; Hinton *et al.* 2000, 2005). Although science does not support this belief, its persistence in these population groups poses a major challenge for those designing health interventions to promote behaviours that have been associated with cognitive health. Public health education and the weight of scientific findings can often overcome such widely-held beliefs only with great difficulty; it may be a challenge to convince those who represent even Alzheimer's disease as 'normal' (Leventhal *et al.* 1997; Leventhal and Crouch 1997) that the effort required for behaviour change is worthwhile, particularly when the science associating healthy behaviours with cognitive health remains uncertain. Viewed from the perspective of Social Cognitive Theory (Bandura 1986), individuals in these groups may share a relatively low

sense of self-efficacy with regard to cognitive health. Effective public health programmes or interventions designed to promote cognitive health in these groups will need to account for their representations of cognitive health and illness.

American Indian, Chinese and Vietnamese participants expressed great concern about stigma associated with cognitive impairment, and about how they would be treated, particularly by their children or by 'young people', if they were to develop Alzheimer's disease. This result is consistent with previous survey research (Ayalon and Arean 2004) and qualitative studies (Hinton *et al.* 2000, 2005), and also with previous research finding that Asians were more likely to view Alzheimer's disease as a form of insanity (Ayalon and Arean 2004).

Only African American, Chinese and White participants expressed concerns related to genetic risks or other predispositions for developing Alzheimer's disease. African Americans and Whites were the only groups to express concerns about behavioural changes associated with dementia. That African Americans expressed this concern is consistent with the expectation that cognitive decline may not be considered to be highly important among many African Americans until it impairs the individual's ability to fulfil social roles (Gaines 1989; Roberts *et al.* 2003). Also notable is the fact that 'ability to think' was rarely discussed; participant responses focused primarily on memory. This is particularly notable because we asked participants to discuss their concerns about 'memory or ability to think', and repeated this phrase several times during each focus group.

We recognise that the lack of a unified conceptual framework or theory for understanding people's views about cognitive health, and for promoting cognitive health, is a limitation of this study. Such a framework would likely include aspects of the health behaviour theories discussed in this study, such as knowledge, beliefs, and perceived threat, which are commonly considered in health education and health promotion programmes (Painter *et al.* 2008). It would also likely include constructs from the theory of representations of health and illness (Leventhal and Crouch 1997; Leventhal *et al.* 1997). The development of a comprehensive theory of cognitive health promotion was beyond the scope of this study.

Several additional considerations should be weighed when evaluating these results; many of these considerations have been described in detail previously (S. Laditka *et al.* 2009*b*; Wilcox *et al.* 2009). The words 'ethnicity' and 'culture' do not adequately characterise the groups that were the focus of our study, or the diversity within these groups. Differences among the responses from the groups may be associated with geographic region, or other characteristics that varied among the focus groups, rather than characterising the ethnic groups on which the analysis focused. It is

useful to note that most of the ethnic focus groups were distributed among more than one research site, and that the sites were widely distributed geographically. This reduces the likelihood that the results primarily reflect regional differences or differences in the ways that the groups were conducted at a given location. Participants represent a purposive sample of individuals who may be more socially active than typical older adults. Results may not characterise less socially active older adults. Also, the fact that an ethnic group did not mention a particular concern about cognitive function, or did so rarely, does not provide conclusive evidence that the given concern is not important to that group.

We also acknowledge that the two Latino focus groups offer a limited set of empirical data. In instances where we noted that all groups expressed a theme, Latinos did so also. However, a larger number of Latino focus groups might have revealed differences in views about some of the themes we identified, or the presence of other themes. Issues of language and translation also may have affected the results. We attempted to limit this possibility by using bilingual researchers to translate the focus group guide, the survey, and the transcripts, by conducting focus groups with native speakers, and, in the case of Chinese focus groups, by having a bilingual researcher conduct a dual-language review of all transcripts and codes.

Chinese and Vietnamese participants were particularly likely to report that their memory was fair or poor. Chinese participants were more likely to be regularly active and to have diets and other behaviours and characteristics that have been associated with better cognitive health (Wilcox *et al.* 2009). The likelihood that they would report having been told by a doctor that they had memory loss or dementia did not differ from that of most other ethnic groups. Their reporting of poorer memory may be associated with social expectations for cognitive function among Chinese Americans, or with connotations of the translated survey question and the survey's available responses. Additional research in this area would be useful. The Vietnamese participants were former refugees, mostly with limited incomes and limited social connections, although they were more likely to be married than participants in several other ethnic groups. Vietnamese participants were considerably more likely than others to report that a doctor had told them that they had memory loss or dementia. About 27 per cent of Vietnamese participants responded in that way, suggesting that results for the Vietnamese participants should be interpreted with caution. For example, the greater concern among Vietnamese Americans about stigma associated with cognitive impairment may be associated with the higher levels of reported cognitive impairment in that group, and may not be characteristic of Vietnamese Americans reporting less cognitive impairment.

Most White participants, and nearly a third of African Americans, were recruited through senior centres. Every day in the USA, nearly 11,000 senior centres serve about 1 million older American adults who live in the community, about 10 million annually (National Council on Ageing 2010). Supported by Federal, state, and local funding, they offer services designed to help older adults age successfully. Although there is little current nationally representative information about senior centre users, an earlier study found that those using senior centres were more socially involved than others, had lower income, were more likely to live alone and to be female, and less likely to be disabled (Krout, Cutler and Coward 1990). Thus, those who use senior centres may not be representative of all older Americans.

It would be useful to investigate whether concerns about cognitive health change as individuals age, and also whether they vary among age cohorts. Aside from the age 50+ inclusion criterion, the focus groups in this research were convened without regard to age. The resulting age heterogeneity within groups does not permit us to examine age differences across focus groups in concerns about cognitive health. This is a useful area for future study. It is possible that people of different ages may differ in their susceptibility to public health messages promoting cognitive health.

Conclusions

This study found that older adults are very concerned about cognitive health. Findings of this study provide a foundation for designing and implementing theory-based culturally sensitive health interventions to promote cognitive health. Interventions designed to influence behaviours of ethnic groups to promote cognitive health may be more successful when the concerns about cognition in these groups inform the design, delivery, and evaluation of the interventions (Friedman *et al.* 2009; Green and Kreuter 2005).

For American Indians, Chinese, Latinos and Vietnamese, the expectation that substantial cognitive decline and serious disorders such as Alzheimer's disease are a normal characteristic of ageing may be a barrier to taking up healthy behaviours that might help maintain cognitive health. That expectation may also be a barrier to appropriate health care that may reduce the risk of cognitive decline by controlling risk factors such as hypertension and diabetes. Communications designed for these population groups could emphasise that severe cognitive impairment is a disease process that is not a characteristic of normal ageing.

Only African Americans and Whites expressed concern about behaviour changes that can accompany serious cognitive impairment. A lack of knowledge that substantial changes in personality and behaviour often accompany serious cognitive decline may account in part for less concern about cognitive decline in several ethnic groups. Their lack of information about this issue may limit their incentive to take up healthy behaviours. Thus, it may be useful to include information about behavioural aspects of cognitive impairment in health education programmes.

In another area, African Americans much more commonly said they were concerned about their own cognitive decline because of their responsibilities to their families. Whites more commonly echoed the statements, 'I'm worried for me', and, 'who's gonna take care of me, you know?' These dramatically different concerns should inform cognitive health promotion efforts directed to these population groups. The latter concern is also of policy interest, given the substantial reduction in the level of concern about cognitive impairment that accompanied the introduction of a universal long-term care plan in Japan (Matsubayashi *et al.* 2009).

Those who study and treat cognitive health issues are likely to focus at least as much attention on aspects of cognitive health other than memory, including executive functions such as judgement, problem solving, decision making, planning, and social conduct. These executive functions depend on many cognitive abilities including attention, reaction time, perception, memory, visuospatial abilities, and language. Although we repeatedly asked participants about 'memory or ability to think', it is notable that responses emphasised memory loss. Only rarely did a participant mention some other aspect of cognitive function. Aside from the concern about behavioural changes expressed by African Americans and Whites, these rare mentions were not sufficiently common to constitute a theme. This result suggests that it may be most efficient for interventions promoting cognitive health to focus largely on concerns about memory. However, it also suggests that it would be useful to educate the public about the importance of maintaining all aspects of cognitive health.

Participants' concerns focused primarily on Alzheimer's disease and related disorders. Although participants expressed concern about even mild forgetfulness, they did so primarily because they were concerned that forgetfulness might lead to dementia. However, cognitive health and cognitive disease are increasingly viewed as a continuum. Many individuals who do not have Alzheimer's disease or a related disorder have notable cognitive impairment. They face diminished quality of life despite the absence of a disease diagnosis. A desirable goal for health promotion would be to communicate that relatively simple behaviours, such as

physical activity, healthy diets, social involvement, and avoiding risks to vascular health may help to promote cognitive health.

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Address for correspondence:

James N. Laditka, Department of Public Health Sciences,
University of North Carolina at Charlotte,
9201 University City Boulevard, Charlotte, NC 28223, USA.

E-mail: jladitka@uncc.edu