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How do older people describe others with cognitive impairment? A multiethnic study in the United States

SARAH B. LADITKA*, JAMES N. LADITKA*, RUI LIU†, ANNA E. PRICE‡, DANIELA B. FRIEDMAN§, BEI WU||, LUCINDA L. BRYANT¶, SARA J. CORWIN§ and SUSAN L. IVEY**

ABSTRACT

We studied how older people describe others with cognitive impairment. Forty-two focus groups represented African Americans, American Indians, Chinese Americans, Latinos, Vietnamese Americans, and Whites other than Latinos (Whites) (N=396, ages 50+), in nine locations in the United States of America. Axial coding connected categories and identified themes. The constant comparison method compared themes across ethnic groups. African Americans, American Indians and Whites emphasised memory loss. African Americans, American Indians, Latinos and Whites stressed withdrawal, isolation and repetitive speech. African Americans, American Indians, Vietnamese Americans and Whites emphasised ‘slow thinking’. Only Whites described mood swings and personality changes. Many participants attributed dementia to stress. Terms describing others with dementia included ‘Alzheimer’s’, ‘dementia’, ‘senile’ and ‘crazy’. Euphemisms were common (‘senior moment’, ‘old timer’s disease’). Responses focused on memory, with limited mention of other cognitive functions. Differences among ethnic groups in descriptions of cognitive health and cognitive impairment underscore the need to tailor public health messages about cognitive health to ways that people construe its loss, and to their interest in maintaining it, so that messages and terms used are familiar, understandable and relevant to the groups for which they are designed. Health promotion efforts should develop ethnically sensitive ways to address the widely held misperception that even

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serious cognitive impairment is a normal characteristic of ageing and also to address stigma associated with cognitive impairment.

KEY WORDS—Alzheimer’s disease, brain health, cognition, dementia, focus groups, memory, qualitative research, senility.

Introduction

The number of people with dementia worldwide in 2009 was estimated at 34.4 million; total costs were estimated at \$422 billion (Wimo, Jonsson and Winblad, 2010). The number of people with dementia is projected to increase to 63 million by 2030 (Wimo *et al.* 2003). In the United States of America (USA), the number of people with dementia is projected to grow from about 5.4 million in 2011 to between 11 and 16 million by 2050 (Alzheimer’s Association 2011; Hebert *et al.* 2003). One-quarter of older adults in the USA will be ethnic minorities by 2050. Some minority populations may face relatively high risks of cognitive decline, particularly African Americans (Demirovic *et al.* 2003; McDougall *et al.* 2007). Diabetes, hypertension and physical inactivity have been linked to greater risk for cognitive decline, and all are increasing in the US population (King *et al.* 2009; Rabins 2007). At the same time, growing evidence from epidemiological studies suggests that physical activity, heart-healthy diets and social involvement may help to protect cognitive health (Albert *et al.* 2007; Barnes and Yaffe 2011; Etgen *et al.* 2010; Hendrie *et al.* 2006; Saczynski *et al.* 2006; Sun *et al.* 2010). Although this evidence remains mixed (US Department of Health and Human Services 2010), it may offer an opportunity for health promotion. The purpose of this analysis is to help inform the development and delivery of relevant messages and materials to promote cognitive health by exploring how older adults perceive others with cognitive impairment, as well as how these perceptions may vary by ethnicity.

This analysis examines data from The Healthy Brain Study, conducted in response to *The Healthy Brain Initiative: A National Public Health Roadmap to Maintaining Cognitive Health* (Centers for Disease Control and Prevention and Alzheimer’s Association 2007; J. Laditka *et al.* 2009). Leading experts on cognitive health and public health developed the *Roadmap* (Albert *et al.* 2007). The *Roadmap* calls on public health professionals ‘to determine how diverse audiences think about cognitive health and its associations with lifestyle factors’, and ‘to translate research findings into community action’ (Centers for Disease Control and Prevention and Alzheimer’s Association 2007). The Healthy Brain Study, a large, primarily qualitative study conducted in four languages by researchers at nine universities and their

community partners, examined views about cognition among diverse groups of older adults in nine states in the USA.

The present research builds on a previous analysis of data from The Healthy Brain Study that examined concerns older Americans from diverse ethnic backgrounds have about keeping their ability to think and remember as they age (J. Laditka *et al.* 2011). The focus of that analysis was on concerns older people have about their *own* cognitive function as they age. Participants in The Healthy Brain Study were also asked to describe *other people* who have a loss of memory or thinking ability. Responses to that question are the focus of the present analysis. The purpose of the present analysis is to describe how older people from diverse ethnic backgrounds view *others* who *currently* experience cognitive impairment, or did so in the past, rather than a hypothesised future self who might experience cognitive decline. Thus, this analysis completes the picture of concerns about cognitive health that was begun in the previous analysis (J. Laditka *et al.* 2011). A more complete picture can provide insight into how representations of dementia may vary by ethnicity (Hashmi 2009).

Background

Views about cognitive health

Relatively little is known about knowledge and beliefs about cognitive impairment in the general population (Anderson *et al.* 2009). Most related research focuses on individuals with dementia, or their care-givers. In a MetLife Foundation (2006) survey of the adult US population (2006), 74 per cent said they knew little or nothing about Alzheimer's disease. Internationally, about 80 per cent of participants in a large telephone survey in Australia correctly identified an individual as having dementia from a brief vignette (Low and Anstey 2009). More than 80 per cent said old age, genetics, brain disease or stroke contribute to dementia (Low and Anstey 2009). In a survey of participants without cognitive impairment who were not care-givers for others with dementia, conducted in France, Germany, Italy, Poland, Spain and the United Kingdom, about two-thirds distinguished dementia from normal ageing (Rimmer *et al.* 2005).

A nationally representative survey on beliefs about cognitive health in the USA found that African Americans (59 per cent) and Latinos (50 per cent) were more likely than Whites (33 per cent) to agree, incorrectly, that 'Alzheimer's is the term for normal memory loss as we get older' (Connell, Roberts and McLaughlin 2007). Surveys suggest that African Americans may perceive themselves to be less likely to develop dementia than Whites, and may worry less about its consequences (Roberts *et al.* 2003). Some research

has suggested that this result may be attributable to African Americans having more support from extended families and churches, a greater ability to adapt to adversity, more positive coping with disease through prayer and reframing negative experiences, and a greater value placed on social roles than on individual cognitive achievements (Gaines 1989; Roberts *et al.* 2003). In another survey in the USA, all participants recognised that memory loss was a primary symptom of dementia (Connell *et al.* 2009). However, African Americans were much more likely than Whites to say that memory loss is a normal part of ageing, and less likely to worry about developing dementia. National studies have not examined Asian American views about cognitive health.

Individual representations of people with memory loss

Individuals and groups understand illness at least in part through their knowledge, expectations and beliefs (Leventhal, Nerenz and Steele 1984; Leventhal *et al.* 1997). Gaines (1989) examined characteristics that may be attributed to dementia in traditional Southern US culture, stressing folk theories of disease causation. From Gaines' perspective, people in traditional Southern US culture are more concerned with emotions and fulfilling social roles than with the individual's intellectual abilities. From this perspective, cognitive decline may not be highly important as long as a person maintains her or his ability to fulfil social roles (Gaines 1989).

Hashmi (2009), drawing on a related approach from cultural anthropology, describes the role of culture and ethnicity in perceptions of dementia. He contrasts individualistic views of self that value independence in Western Europe and the USA with the views of many non-Western cultures that emphasise social relationships. In non-Western cultures, dementia can be attributed to 'bad social relations'. In contrast, in the USA the loss of autonomy that progresses with dementia is more often viewed as a challenge to the individual's identity.

Chinese and Vietnamese families caring for individuals with dementia have reported that they consider even serious memory loss to be part of normal ageing (Braun and Browne 1998; Hinton *et al.* 2000, 2005). They also associated dementia with a high level of stigma. Chinese, Japanese and Korean American focus group participants described three categories of dementia symptoms: memory related (*e.g.* forgetfulness), cognitive (*e.g.* slow thinking) and behavioural (*e.g.* repetitive speech and personality changes); Chinese participants in the focus groups attributed dementia to genetic risks, head injury and normal ageing (Jones, Chow and Gatz 2006).

Two smaller qualitative studies have explored variations in perspectives about dementia. In a study of 14 African Americans in the USA, 'mind loss'

was associated with being forgetful, losing things, getting lost, needing supervision, repeating statements and having more anxiety (Jett 2006). In the United Kingdom, 15 middle-age and older women and men described severe memory loss as a characteristic of dementia (Corner and Bond 2004). Some said stress and inactivity can cause dementia. Some described disruptive behaviours as characteristic of people with dementia. Collectively, studies suggest that African Americans, Asian Americans, Latinos and Whites may have differing perceptions of dementia.

Objectives

Dementia is a growing public health problem that disproportionately affects ethnic minorities. Survey methods offer only limited information regarding beliefs about dementia (Roberts *et al.* 2003). Qualitative studies in this area have relied on small samples (Braun and Browne 1998; Corner and Bond 2004; Jett 2006; Jones, Chow and Gatz 2006). Their varied approaches make it difficult to compare results across ethnic groups. Also, the fact that most previous studies were conducted in a single location increases the likelihood that the results may be due to characteristics of the local population. The present analysis offers results from a large number of focus groups representing six ethnicities, conducted in multiple locations across the USA with standardised methods. The present analysis has two objectives. Using a sample of older adults who identified themselves as being in one of six ethnic groups, we sought to: (a) describe ways that older people in these ethnic groups recognise and define cognitive decline; and (b) examine how older people in these ethnic groups perceive others with cognitive decline. An improved understanding in these areas may help to develop ethnically sensitive public health messages and materials to promote health behaviours.

Theoretical framework

The theory of representations of health and illness (Leventhal, Nerenz and Steele 1984; Leventhal *et al.* 1997) guides this research. According to this theory, individuals and groups construct representations of illness based on expectations and beliefs. These representations shape health behaviours, including use of medical care and social services. Representations of health threats are influenced by language, understanding of disease symptoms, knowledge of disease and treatment options, and other factors that help to define culture and ethnicity. Leventhal *et al.* (1997) found that better communication with patients reduced fear of illness. Improved communication also increased the probability that people would respond to illness, or

the risk of illness, with problem-based responses such as improving diets or increasing physical activity, instead of fear-based responses such as crying or denial. If health threats can be described in ways that are meaningful to individuals and their groups, this may more effectively promote behaviour change.

Health behaviours are shaped by knowledge and beliefs shared by social groups, as well as by individuals' knowledge and beliefs. For example, if individuals in a given ethnic group are more likely to view even severe memory loss as a characteristic of normal ageing, they may be less likely to respond to health promotion messages that suggest otherwise, or to seek health care or other services when faced with memory loss. Thus, to enhance communication about cognitive health, it is useful to better understand how people view cognitive health and brain diseases.

Methods

Focus group selection criteria and participants

The Healthy Ageing Research Network conducted the study. This research network is a collaborative effort of the Centers for Disease Control and Prevention and nine US research universities (J. Laditka *et al.* 2009). Focus groups were conducted between November 2005 and August 2007 with adults age 50 and over who lived in the community in California, Colorado, Illinois, North Carolina, Pennsylvania, South Carolina, Texas, Washington and West Virginia. The communities selected for this research are diverse with regard to culture, economic characteristics, geography and ethnicity. We purposively selected the ethnicities studied in this analysis to take advantage of this diversity. Our local research team at each of the sites has active community partners who helped design the study, identify groups to be studied, recruit participants and interpret results.

This analysis examined responses from 42 focus groups representing specific ethnic populations: 19 groups with Whites other than Latinos (hereafter Whites), ten African American, four American Indian, four Chinese, three Vietnamese and two Latino. We recruited and conducted six of the ten African American focus groups at churches, and one additional African American focus group at a local conference. Three African American focus groups were recruited and conducted at senior centres, as were almost all of the White focus groups. We worked with tribal organizations to recruit American Indian focus groups, which were conducted on tribal lands. Chinese and Vietnamese focus groups were recruited and conducted at community partner sites in the San Francisco Bay area. All Vietnamese American participants were recent immigrants. Recruitment

and location details are available (J. Laditka *et al.* 2009; S. Laditka *et al.* 2009a; Wilcox *et al.* 2009).

Focus group procedures

We used a nine-item discussion guide developed by researchers, policy makers and community partners in nine locations of the USA (J. Laditka *et al.* 2009). This analysis focuses on one of those items. Using a standardised script, the moderator asked participants to consider ways that cognitive health might be important: 'As they grow older, some people lose some of their ability to remember things, and to learn new things. Some also lose their ability to think clearly, and even to behave in ways that are normal for them. Other people don't have these problems.' Immediately after this statement, participants were invited to provide words they 'use to describe older people who have a loss of memory or thinking ability'. Participants also completed a survey, providing information about their personal characteristics, their emotional health and their health behaviours (Bryant *et al.* 2009).

Focus groups were conducted by experienced moderators, and were 90–120 minutes. Moderators encouraged participants to offer responses and elaborate on them. We conducted most groups in English. However, we conducted all Vietnamese and Chinese groups using native-speaking moderators and assistants, of the same ethnicity and language as participants. In these groups, we used a translated consent form, discussion guide and survey. We conducted the Chinese groups in Mandarin and Cantonese, and the Vietnamese groups in Vietnamese. We translated the transcripts for these groups into English before conducting the analysis. Some focus groups with American Indians and Latinos, and half of those with African Americans, did not match the moderator's ethnicity with that of participants. This was primarily a result of limited resources. However, the researchers and focus group moderators who planned and participated in these groups were experienced in conducting focus group research with these populations. The Institutional Review Board at each of the nine study sites approved the study. Details about the focus group process have been published (S. Laditka *et al.* 2009a; J. Laditka *et al.* 2011; Mathews *et al.* 2010).

Qualitative data analysis

We transcribed the focus group audio recordings verbatim into Microsoft Word. Recordings and transcripts were compared word-for-word to verify accuracy. Using the discussion guide as a framework, two focus group transcripts, one African American and one White, were selected to develop

an initial set of codes. Four researchers read each transcript, assigning semantic codes to text segments. During this ‘open coding’ process, we reached consensus about the definition of each code. Next, two researchers organised the lists to form the initial codebook. The two transcripts were re-coded using this codebook. New codes were developed as needed. Transcripts were imported into Atlas.ti version 5.2 (Muhr and Friese 2004), software that helps researchers manage and analyse qualitative data. ‘Axial coding’ connected code categories and identified themes (Strauss and Corbin 1990). The constant comparison method (Glaser and Strauss 1967) compared themes within and across groups defined by ethnicity. Details of the analysis process have been published (S. Laditka et al. 2009a).

To ensure coding consistency, we determined inter-rater agreement for transcripts of each ethnic group from each of the nine research sites. Two coders met in person and counted the number of times their codes agreed or disagreed, line-by-line for each transcript. The number of agreements was divided by the number of disagreements plus agreements. This fraction, multiplied by 100, is the per cent agreement. We considered a percentage agreement of at least 80 per cent to indicate consistent coding (Miles and Huberman 1994). When coding did not agree at the 80 per cent level or higher, our coders discussed the relevant passages and their approaches to coding, and reached consensus on the most appropriate application of each code. The transcripts were then recoded and inter-rater agreement was calculated again. This process resulted in 100 per cent coding agreement for all themes, and nearly complete agreement for all sub-themes.

Survey data analysis

We analysed the survey data using Statistical Analysis Software (SAS) version 9.1.3 (Cary, NC, USA). We used the non-parametric Kruskal-Wallis test for continuous variables, and the Kolmogorov-Smirnov test for pair-wise comparisons (comparing results for each minority group with those of Whites). Whites were selected as the comparison category because of their larger proportion in the older US population. For the same reason, the largest number of focus groups was conducted among Whites. Chi-square tests were performed for categorical variables.

Results

Participant characteristics

Table 1 reports demographic and behavioural characteristics of the 396 participants in the 42 focus groups. Participants’ mean age was 71.0

TABLE 1. Characteristics of focus group participants, by ethnicity (N=396)

	African Americans	American Indians	Latinos	Chinese	Vietnamese	Whites other than Latinos	Total
Groups (participants) ¹	10 (N=95)	4 (N=34)	2 (N=10)	4 (N=36)	3 (N=26)	19 (N=195)	42 (N=396)
Age, mean (standard deviation)	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)
Variable:	<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 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	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
Diagnosis of cognitive problem ⁴	1.2	6.3	0	5.7	26.9***	3.4	5.0

Notes: GED: General Education Development. 1. Statistical tests compare each group with Whites, the category with the largest number of focus groups. 2. Compared with single, separated, divorced or widowed. 3. Self-reported memory, compared to good, very good, excellent. 4. Diagnosis of cognitive problem is 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: Centers for Disease Control and Prevention Healthy Aging Research Network (CDC-HAN), The Healthy Brain Study; results based on 42 focus groups conducted November 2005 to August 2007, with 396 participants, ages 50+, in nine US locations.

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

(standard deviation 9.3; range 50–90). Three-quarters were women. Nearly 40 per cent reported having graduated from high school, 26 per cent from a technical or vocational school, and 17 per cent from college.

Ethnicity was significantly associated with several participant characteristics. A larger proportion of African Americans than others were women. White participants were significantly older than those in most of the other groups. About 30 per cent of all participants rated their memory as fair or poor. This rate was higher for Chinese and Vietnamese Americans. Participants said when we recruited them that they were not cognitively impaired. In the survey, we asked, ‘Has a doctor ever told you that you have memory loss, Alzheimer’s disease, dementia or senility?’ Five per cent of participants responded that they had been told this. Vietnamese participants were more likely to say that they had only fair or poor memory; consistent with that result, nearly 27 per cent of them responded that a doctor had told them they had memory loss, Alzheimer’s disease, dementia or senility.

Qualitative results

Overview. When asked to describe older adults who have a loss of ‘memory or ability to think’, participants described characteristics of others with cognitive impairment. Participants also described causes of cognitive impairment, and provided words or phrases they associated with it. In our presentation of results, themes and their sub-categories are organised from the most frequently to the least frequently mentioned. [Table 2](#) shows a summary of themes, by ethnicity. A tick in the table indicates that the theme was identified in the focus group results representing the given ethnicity. Consistent with the most prominent goal of our focus group selection criteria, the presentation of results highlights ethnic similarities and differences.

Characteristics of people with memory loss. Minor forgetfulness to severe memory loss. By far the most common characteristics participants described were being forgetful and having memory loss, ranging from minor episodes of forgetfulness to severe memory loss. African Americans, American Indians and Whites made statements illustrating this theme more often than other groups. Latinos and Chinese Americans made such statements, but less often. Many participants spoke of general forgetfulness, ‘forgetful, yeah, forgetting everything’ (Latino). Participants frequently spoke about others forgetting medications, dates and the location of their keys. One African American commented, ‘Forgetting if they took their medications that morning. And some of them take it again ’cause they can’t remember if they

TABLE 2. Summary of descriptions about others with cognitive impairment, by participant ethnicity

Theme	African Americans	American Indians	Chinese Americans	Latinos	Vietnamese Americans	Whites other than Latinos
Characteristics of people with memory loss:						
Minor forgetfulness to severe memory loss	✓	✓	✓	✓		✓
Socially isolated or out of touch	✓	✓		✓		✓
Repetitive speech	✓	✓		✓		✓
Slow thinking	✓	✓			✓	✓
Severe mood swings, major personality changes, and other disruptive behaviours						✓
Causes of memory loss:						
Anxiety or stress or having a lot on the mind	✓	✓	✓			✓
Health-related causes: diseases, surgery, head injury						✓
Genetics or heredity			✓			✓
Words or phrases to describe others with memory loss:						
Alzheimer's	✓	✓	✓	✓	✓	✓
Dementia	✓	✓		✓		✓
Euphemisms, e.g. 'senior moment'	✓	✓	✓	✓	✓	✓
Senility, and pejorative terms associated with mental illness, such as 'crazy' or nuts	✓	✓		✓		✓

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

Data source: Centers for Disease Control and Prevention Healthy Aging Research Network (CDC-HAN), The Healthy Brain Study; results are based on 42 focus groups, conducted November 2005 to August 2007, with 396 participants, ages 50+, in nine US locations.

took it.' Many spoke of forgetting names, 'They'll remember a face, but they can't remember the name' (White). A Chinese American said:

It's like in a Chinese proverb that says things escape your mind because you don't put your heart to it. Like my wife – once, my daughter-in-law asked her to turn on the burner, keep an eye on the soup, and turn it off when the soup was brought to boil. My wife could turn on the burner. However, she couldn't keep track of when the soup was boiling, and forgot to turn off the burner.

African Americans and Whites mentioned the ability of others to recall past events, but not recent ones. An African American said:

One of the things I noticed too that a lot of people, when they get older they can remember things that happened a long time ago, but not present events. You know, things that happened like last week or two days ago. But they can go back, way back 20 or 30 years ago and be just alert with that time.

A number of participants spoke about connections between Alzheimer's and memory: 'I thought Alzheimer's [is] when you're totally out of memory' (White). Some participants spoke of progressive loss of memory or forgetfulness:

I've been trying to think what the word that we call it when she, she progressively lost a lot of her memory and they've had to sell her home and put her in an apartment. They finally diagnosed her with Alzheimer's. But, for so many years before then, they had started to see her slowly, like she'd be in a car wash and drive off, you know, while they were washing the car. Or, end up on the other side of town or forget names of family members. (American Indian)

Participants spoke about losing the ability to recognise family members as dementia progressed: 'My mother had it just prior to her dying. She basically lost her memory, even forgot who I was. She thought I was her brother' (White). Participants also mentioned severe forgetfulness in advanced stages of dementia:

My mother-in-law had Alzheimer's and she passed away. Oh, that is a terrible, terrible disease to me. Because, you know, when she got it she was just healthy as a horse and finally it just got to the point where she would even forget to eat. You know, she'd forget how to chew or swallow or anything. (White)

Socially isolated or out of touch: The second most common way participants described others with memory loss was that they were socially isolated. African Americans, American Indians, Latinos and Whites mentioned this theme. Participants spoke of others with memory loss as 'withdrawn'. 'I think, too, they kind of withdraw. We would go to visit her and she would just sit. She wouldn't talk because she was afraid she was going to say something wrong or forget something' (White). Several African Americans offered: 'I say a person is not in good contact'; 'What about out of touch?'; 'Anti-social'.

Several participants described others with cognitive impairment as increasingly withdrawing, becoming more socially isolated as the dementia progressed:

I noticed a dear friend of ours, at the beginning he's like in the middle phase now of this Alzheimer's, but he, he became more detached from the situation. Like if he was in a group of people, he was quieter, he became quieter. But he went through various phases and he was very social, but began to withdraw, sit quietly, then at the end get angry and get physical and it was just sort of like a progression. (White)

Several American Indian participants commented about the importance of memory for social activities. A representative comment was:

I think that the person in that position is isolated because memory is every bit the part of how you live every day, and if somehow you forget so many parts of that day, you are not in that day. And that's what I would say it's actually, it's almost like losing your hearing and your eyesight at the same time. (American Indian)

Repetitive speech: The next most common characteristic of others with memory loss was repetitive speech, saying the same phrase or asking the same question repeatedly. African Americans, American Indians, Latinos and Whites mentioned this theme. Latino participants commented, 'They repeat'; 'Dementia is thinking over and over'; 'That's the way my mom started, repeating and repeating'. African Americans said, 'They say the same thing over and over and over'; 'Repeat themselves'. Referring to her aunt, a White participant said, 'If that's how dementia's defined, I mean my aunt was the same way. She'd say something to me and five minutes later, the same sentence, the exact same sentence would come back at me.'

Slow thinking: African Americans, American Indians, Vietnamese and Whites described 'slow thinking' as a characteristic of others with memory loss. Several African Americans described others with memory loss, saying, 'It's when brain activity [is] slow, slows down'; 'Your brains slow down when you don't think'. Several Whites commented, 'It's slowed down'; 'Slow and forgetful'; 'Then their brain stops, too'. A number of participants described slow thinking as a normal characteristic of ageing, 'Well, when you get older, you're not as fast as you used to, your mind don't work as fast as it usually do' (White). One White participant drew an analogy between memory and a computer, 'We used to have a fellow that said it's still up here. He says his computer is just having a hard time finding it.' A Vietnamese participant commented, 'The people who slowly sit at home, it seems like they've slowed down and are doting.'

Severe mood swings, major personality changes, and other disruptive behaviours: White participants in several focus groups mentioned severe mood swings, personality changes, or depression as characteristics of others with memory loss. Most participants spoke of severe personality changes occurring among

people with memory loss, describing the change as, ‘totally, total personality change’ (White).

In almost all instances, these participants spoke of negative personality changes associated with memory loss. A White participant described it this way: ‘I know one of my friends and church members that seems as though it just come up on him all of a sudden. He didn’t know where he was at and he, he actually got violent’ (White). Several participants said that personality changes were the first sign of dementia:

When my mother started going into dementia, that was one of the first things that we noticed about her. She was so negative about everything and everybody. That was the first. That was when she started. We knew something was wrong. (White)

Causes of memory loss. Anxiety, or stress, or having ‘a lot on the mind’: African Americans, American Indians, and Whites mentioned anxiety, stress, worry or having too much on the mind as causes of memory loss. Several White participants commented, ‘Too much stress’; ‘When you have a lot to worry [about]’; ‘Sometimes aggravation cuts off your memory, too. Or over-stress’; ‘I think you can overcrowd your brain’. An African American commented, ‘Sometimes it can be caused by having like a nervous system. Their body is very nervous and they not dwelling with what’s going on in something too much, and then they just go kind of forgetful.’ An American Indian said, ‘having too much on your mind’. A Chinese participant advised, ‘Don’t fill your head with a lot of unimportant things. You need to prioritise, and concentrate on the most important thing.’

Health-related causes: diseases, surgery, head injury: Primarily Whites mentioned causes of memory loss in this category. Several White participants spoke of memory loss following a stroke. One said, ‘My wife had serious loss of memory. She had five by-passes and then a stroke and she remembers none of it’ (White).

Others mentioned head injuries as a cause of memory loss: ‘Now they’re saying Alzheimer’s can be caused – sometimes if you had a bad knock in the head or something and some of those concussions and things that used to think that didn’t really matter, you know?’ (White). Others asked about memory loss being associated with diabetes, ‘If you’re a diabetic, doesn’t taking your medication help? It’s like sugar doesn’t help your brain’ (White). Other White participants spoke of memory loss associated with chemotherapy; one commented, ‘When you’ve had chemotherapy, it appears to affect your memory and some ways that you might perceive a situation, and people joke about it.’

Genetics or heredity: Chinese and White participants commonly mentioned genetics or heredity as causes of memory loss. A Chinese participant said, ‘So, physical health contributes to a healthy brain. In terms of us elderly

getting sick, I think 30 per cent of it is genetic, 70 per cent of it is what we do.' A White participant commented, 'I think, too, if you have people in your family that has Alzheimer's or has a problem, I think, you, you ought to get concerned yourself.'

Words or phrases to describe others with 'loss of memory or ability to think'. Alzheimer's: Participants in all ethnic groups used 'Alzheimer's' to describe people with memory loss. Some participants said that the term Alzheimer's was used less in the past, 'Years and years ago, I know that my grandparents, or both grandparents, had never heard the word Alzheimer's' (White). Often, Alzheimer's was described in combination with other words to describe those with memory loss: 'Well, they're just senile. And of course, it, and it may have been Alzheimer's then, but they may not know what it was' (White). A Chinese American participant commented: 'Before, years ago, you never heard of Alzheimer's and we do forget different things. So that's normal, normal ageing, but it can also be later on the Alzheimer's.'

Dementia: African American, American Indian, Latino and White participants mentioned 'Dementia'. Vietnamese did not mention this term. Chinese used it rarely. Some participants said the meaning of 'dementia' was unclear, 'And so people use the word dementia or dementing, somebody's dementing, has a dementia, but they can't tell you exactly what it means, I suppose. There is a technical definition of dementia and then there's how people use it in the streets' (White). Several participants used dementia and Alzheimer's in the same phrase. Many expressed uncertainty about differences between the terms. For example, two White participants commented: 'Isn't dementia the beginning of Alzheimer's?'; 'I don't know where is the line between Alzheimer's and dementia'. An American Indian said, 'They call a lot of dementia Alzheimer's, you know.'

Euphemisms: Many participants in all ethnic groups used euphemisms to describe people with memory loss or loss of ability to think. African Americans, American Indians, Latinos and Whites used the term 'senior moment', as in the following exchange among two White women:

Female 1: Then all of a sudden, you stand there a minute; it's gonna come to you.

Female 2: Or you go back where you first thought about it.

Female 1: Ah, I say, 'What did I come in here for?' You know.

Female 2: Open the refrigerator and put your pocketbook in it.

Female 1: That's a senior moment; it'll come to you in a minute.

A number of African Americans and Whites used the terms, 'Old Timer's' or 'Old Timer's disease'. African Americans, American Indians and Whites used the phrase, 'Absent minded'. Only Vietnamese participants mentioned being 'confounded and dreamy', as in: 'I'm afraid of being dreamy.'

I'm afraid of being confounded.' Several Latinos used the phrase, 'poor person'.

Senility, and pejorative terms associated with mental illness such as 'crazy' or nuts': African Americans, American Indians, Latinos and Whites used the words 'senility' or 'senile'. These terms were mentioned commonly, but less often than 'Alzheimer's' or 'dementia': 'They get senile and they think they know but they don't know' (African American). 'It's called senile, but, it, it's a natural process' (American Indian). Several participants spoke of hearing this term from a physician. For example, a White participant commented, 'Many years ago, I took care of my mother-in-law who was described by the doctors as having premature senility.' Several participants also used the terms 'crazy' or 'nuts' to describe others with memory loss.

Discussion

This analysis of data from The Healthy Brain Study provided an opportunity to hear directly from a large and ethnically diverse group of older people about their perceptions of others with memory loss. Characteristics of others with cognitive impairment mentioned most frequently were: forgetfulness and memory loss, social isolation, repetitive speech, slow thinking, and severe mood swings and personality changes. Words used most commonly by most ethnic groups were 'Alzheimer's', 'dementia', 'senile' and a variety of euphemisms. Consistent with previous research, participants expressed uncertainty about distinctions between Alzheimer's and dementia (Jones, Chow and Gatz 2006; Rimmer et al. 2005). Participants also used the words 'crazy' or 'nuts' to describe people with memory loss, reinforcing the stigma that often accompanies cognitive impairment (e.g. Hinton et al. 2005; Low and Anstey 2009; Rimmer et al. 2005). Without regard to ethnicity, characteristics and words used to describe others with cognitive impairment were relatively consistent with those reported in international surveys (Low and Anstey 2009; Rimmer et al. 2005).

There were ethnic differences in views of others with cognitive impairment. African Americans, American Indians and Whites emphasised forgetfulness. African Americans, American Indians, Latinos and Whites emphasised social isolation and repetitive language. Only Whites mentioned behaviour changes. Only African Americans, American Indians, Vietnamese and Whites mentioned thinking ability. As for causes of cognitive impairment: African Americans, American Indians and Whites emphasised stress; Whites pointed to illness and head injury; Chinese and Whites emphasised genetics. These ethnic differences are consistent with previous research (Braun and Browne 1998; Corner and Bond 2004; Jett 2006;

Jones, Chow and Gatz 2006), although previous studies often asked about aspects of dementia identified by the researchers, rather than by participants (Connell *et al.* 2009; Corner and Bond 2004; Jett 2006; Low and Anstey 2009; Rimmer *et al.* 2005; Roberts *et al.* 2003). The Healthy Brain Study, which produced the data examined in the present analysis, used open-ended questions, an approach that is more likely to elicit a full range of participant views. The Healthy Brain Study and the present analysis also had a greater representation of diverse populations than previous studies.

Findings from the present analysis complement those of an earlier analysis of The Healthy Brain Study, which focused on individuals' concerns about their *own* cognitive health. Those concerns largely focused on individuals' imagined future selves (J. Laditka *et al.* 2011). The present analysis focused on the same individuals' views about *others* who *currently* experience loss of memory or the ability to think, or who did so in the past. Participants in the previous analysis said they were frightened about becoming cognitively impaired, even 'terrified' (J. Laditka *et al.* 2011). This reaction was not common when the same participants described others. Several common perspectives about others' cognitive problems in the present analysis were not even mentioned when people described their own future selves, including concerns about social isolation, mood swings or repetitive speech.

Revisiting the conceptual framework that guided this research, illness representations (Leventhal, Nerenz and Steele 1984; Leventhal *et al.* 1997), the most common characteristics ascribed to people with dementia were mild to severe forgetfulness, social isolation and repetitive speech. Most ethnic groups described others with dementia as having 'slow thinking', and some White participants described behaviour problems that would interfere with social interactions. For the most part, however, participants did not mention important aspects of cognition that are often called executive functions, including planning, thinking abstractly, learning, and initiating appropriate actions and inhibiting inappropriate actions (Hendrie *et al.* 2006). While it is tempting to conclude from this finding that those specialising in health promotion should seek to make the public more aware of important executive brain functions, the results of the present analysis of data from The Healthy Brain Study suggest that a more effective goal for promoting cognitive health may be to appeal to the ways that people construe its loss, and to their interest in maintaining it. The findings point to specific items that may be useful to highlight in health promotion messages and materials, such as reducing the risk of becoming forgetful or socially isolated.

We acknowledge several limitations related to the design of The Healthy Brain Study. Most of these limitations affect all analyses using data from that study. Participants were a convenience sample of older adults living in the

community who were largely recruited through social settings such as senior centres and churches. Results may not characterise less socially active older adults. Neither the word 'ethnicity' nor the categories of ethnicity that participants reported can adequately characterise the groups we studied. Geographic region, years living in the USA since immigration, level of acculturation or other differences among the groups we studied may account for the results, rather than ethnicity. Study design features may reduce these effects for some issues. For example, in most cases the focus groups representing a given ethnicity were conducted at several research sites, which were widely distributed geographically. In addition, the discussion guide, the participant survey and the focus group procedures were consistent across sites. The local focus group activities at the nine sites were discussed frequently across sites throughout the project, to ensure standardised data collection. In another area, we have limited confidence that the results for Latinos would be unchanged if we had conducted more Latino focus groups. Future research with additional Latino focus groups would be useful, as would representation from specific Latino groups such as Mexican Americans. Language translation may have influenced the results for Chinese and Vietnamese participants. Chinese and Vietnamese participants reported fair or poor memory more often than others. Chinese participants had health behaviours and characteristics associated with better cognitive health (Wilcox *et al.* 2009). They may have been prompted to report poorer memory by social expectations among Chinese Americans. Connotations of the translated survey question and its available responses also may have affected their responses. Further research in this area would be useful. The considerations just described have been acknowledged in previous analyses based on The Healthy Brain Study (*e.g.* J. Laditka *et al.* 2001; S. Laditka *et al.* 2009b; Mathews *et al.* 2010). In another area, those who care for people with dementia may have different perceptions about cognitive impairment than others (Low and Anstey 2009; Rimmer *et al.* 2005). We did not ask if participants had been care-givers. There was no evidence in the transcripts that many participants had provided dementia care.

Chinese participants offered substantially fewer comments about others with dementia than did individuals in other ethnic groups, reflected in the fewer quotations from Chinese Americans that are presented in our results. Our data do not provide information that would enable us to identify factors associated with this difference. Researchers have suggested that Chinese persons who develop dementia may often be considered in Chinese culture to have a moral failure (Hinton *et al.* 2000; Zhan 2004). Chinese culture may also commonly view dementia as mental illness, which often may be accompanied by stigma (Liu *et al.* 2008; Zhan 2004). Individuals with dementia in Chinese culture in some instances may be concealed by family

care-givers, to avoid the stigma associated with mental illness (Liu *et al.* 2008; Zhan 2004). Social contacts may also be limited due to fear that the dementia might be contagious (Liu *et al.* 2008; Zhan 2004). All of these characteristics of dementia in Chinese culture can be associated with shame (Braun and Browne 1998; Zhan 2004). Thus, the Chinese American participants in our focus groups may have been hesitant to speak openly about dementia. Doing so might imply a family experience with dementia, an implication that could bring stigma or shame to the participant and her or his family. On the other hand, Chinese participants have spoken more freely about dementia in related research (Jones, Chow and Gatz 2006). The same Chinese Americans included in the present analysis offered many more responses to other questions in The Healthy Brain Study (*e.g.* S. Laditka *et al.* 2009b; Wilcox *et al.* 2009). Our phrasing of the question that asked about dementia may have limited the number of responses by Chinese participants. Translation issues may also have influenced this result. Our data do not permit a detailed examination of these possibilities.

Similarly, for all of the ethnic groups represented in this analysis, the ways that individuals describe others with dementia may very well be influenced by experiences, norms, words and other symbols, customs, and expectations that are broadly shared within each group. There is considerable evidence from anthropological investigations that different cultures view dementia differently (Hashmi 2008). A consideration of the present research is that the focus group approach and study design, which identified focus group participants based on their self-identified ethnicity, did not allow us to examine alternative cultural pathways that might have contributed to the results. The ethnic groups represented in our research were also likely to have had considerable within-group heterogeneity. Although members of a given ethnic group may often share a variety of characteristics and experiences, for example, each individual may also participate in a variety of distinct cultures. Moreover, each individual's internalisation of her or his socio-cultural context can incorporate the totality of that individual's experiences as well as the cultures in which she or he is immersed (Goodenough 1981). The unique characteristics of each person's experiences can result in highly individualised interpretations of the individual's primary culture. These unique characteristics can also result in highly individualised interpretations of the ethnic group, or ethnic groups, with which the individual identifies. These interpretations, of both culture and ethnicity, may include highly individualised views about dementia. We have no expectation that the individuals who participated in our focus groups necessarily represented uniform 'African American' or 'Chinese' cultural views about dementia, for example, views that might apply consistently across individuals in each of the ethnic groups we studied. All of these sources of

heterogeneity are unmeasured in our research, and may have affected the results.

An extension of this research focused on ways that culture may affect beliefs about dementia within ethnic groups would be useful. For example, it would be useful to conduct a large enough number of focus groups with African Americans in rural areas of the south-eastern USA, and also in other US regions such as the urban industrial areas of the northern mid-west, to examine how culture may affect beliefs about cognitive health among African Americans. Such research would help those who design public health interventions promoting brain health for ethnic groups with higher risk of developing dementia to adjust the interventions to address cultural variation. Refining our understanding of differences in views and beliefs about dementia among ethnic and cultural groups for this purpose is a major goal of *The Healthy Brain Initiative* (Centers for Disease Control and Prevention and Alzheimer's Association 2007; J. Laditka et al. 2009).

The findings of the present analysis also suggest the usefulness of considering representations of illness (Leventhal, Nerenz and Steele 1984; Leventhal et al. 1997) across ethnic groups to develop messages and materials to promote cognitive health. Differences among ethnic groups in the language used to describe cognitive health and cognitive impairment underscore the need to tailor public health messages so that the terms used are familiar, understandable and relevant (Kreuter and Wray 2003). For example, participants in all ethnic groups were familiar with the term 'Alzheimer's'; most identified memory loss, forgetfulness and social isolation with Alzheimer's disease. Thus, these characteristics and the word 'Alzheimer's' are likely to be useful for health promotion messages and materials. Health communication messages might also usefully address the stigma that often accompanies cognitive impairment, as well as the fatalism that individuals in some groups tend to accept when family members are diagnosed with dementia (Hashmi 2009; J. Laditka et al. 2011). These messages should acknowledge perceptions among diverse groups about memory loss and cognitive decline, and inform people that referring to those with memory loss as 'nuts' and 'crazy' or 'slow thinkers', as mentioned by some older adults in these focus groups, may perpetuate stigma associated with dementia. In addition, health communication efforts should develop ethnically sensitive ways to address the widely held misperception that serious cognitive decline is a normal part of ageing.

Coupling the findings of the present analysis with those of the previous work on individuals' concerns about their own memory and cognitive function (J. Laditka et al. 2011), it is useful to understand that many older adults are frightened about the possibility that they might become cognitively impaired. Despite that fear, our research (J. Laditka et al. 2011)

suggests that people do not typically describe their future selves using terms such as 'Alzheimer's' or 'dementia', or 'nuts' or 'crazy.' They also do not typically describe their future selves as having severe mood swings, or behavioural disorders associated with brain problems. As the present analysis suggests, those are characteristics that may apply to others. Although many older adults are concerned at some level that they may some day develop dementia, the ways that they represent their future selves do not typically include most of the characteristics of dementia. Thus, health promotion efforts that focus on reducing the risk of developing these negative characteristics may not be relevant or meaningful to many people. A larger opportunity for future research may lie in health message development that principally focuses not on avoiding cognitive impairment, but on promoting cognitive health, as a way to maintain or enhance the positive characteristics that many individuals already ascribe to their current and future selves.

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