A Direct Comparison of Popular Models of Normal Memory Loss and Alzheimer’s Disease in Samples of African Americans, Mexican Americans, and Refugees and Immigrants from the Former Soviet Union

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OBJECTIVES: To understand how people differentiate normal memory loss from Alzheimer’s disease (AD) by investigating cultural models of these conditions.

DESIGN: Ethnographic interviews followed by a survey. Cultural consensus analysis was used to test for the presence of group models, derive the “culturally correct” set of beliefs, and compare models of normal memory loss and AD.

SETTING: Chicago, Illinois.

PARTICIPANTS: One hundred eight individuals from local neighborhoods: African Americans, Mexican Americans, and refugees and immigrants from the former Soviet Union.

MEASUREMENTS: Participants responded to yes-or-no questions about the nature and causes of normal memory loss and AD and provided information on ethnicity, age, sex, acculturation, and experience with AD.

RESULTS: Groups held a common model of AD as a brain-based disease reflecting irreversible cognitive decline. Higher levels of acculturation predicted greater knowledge of AD. Russian speakers favored biological over psychological models of the disease. Groups also held a common model of normal memory loss, including the important belief that “normal” forgetting involves eventual recall of the forgotten material.

CONCLUSION: Popular models of memory loss and AD confirm that patients and clinicians are speaking the same “language” in their discussions of memory loss and AD. Nevertheless, the presence of coherent models of memory loss and AD, and the unequal distribution of that knowledge across groups, suggests that clinicians should include wider circles of patients’ families and friends in their consultations. These results frame knowledge as distributed across social groups rather than simply the possession of individual minds. J Am Geriatr Soc 2011.

Key words: memory loss; Alzheimer’s disease; lay beliefs; ethnic differences; cultural models; consensus analysis

The Alzheimer’s Association estimates that approximately 5.3 million Americans have Alzheimer’s disease (AD) and that African Americans are approximately two times as likely and Hispanics 1.5 times as likely as whites to have AD or other dementias.1 Furthermore, both groups show significant delays in diagnosis seeking after first noticing possible symptoms.2–6 Of the many factors involved in delayed diagnosis, one is the extent to which the primary symptom of the disease—memory impairment—is described as “just old age.”7,8

Research on beliefs about “normal memory loss” generally shows that people expect memory loss as they age,9–11 that complaints about memory loss increase with age,12 and that, in light of public concern about AD, some older adults engage in “symptom seeking” behaviors,13 but these studies provide little information on whether minorities were included in the samples (with the exception of a study that compared Koreans and Canadians11), and this warrants more-focused attention on the beliefs and attitudes of minority populations.

Research on beliefs about AD in ethnic minorities in the United States shows that people generally perceive memory loss as an important symptom. In a recent study of blacks and whites in Boston and Atlanta, 90.8% of blacks and 89.4% of whites believed that “the primary symptom of AD is memory loss.”14 Similarly, in a study of four ethnic groups in the San Francisco area, 83.3% of African Americans, 70.0% of Asians, 59.5% of Latinos, and 90.6% of whites affirmed that “the major symptom of AD is memory loss.”15 The problem is that memory loss is also a fact of
normal aging. Thus, in a recent national survey of blacks, whites, and Hispanics, normal memory loss and AD were linked in the following item, “Alzheimer’s disease is the term for normal memory loss as we get older.” Significantly more whites (67.3%) answered the item correctly (FALSE) than blacks (41.1%) or Hispanics (49.5%).

This article directly compares common beliefs about normal memory loss and AD in African Americans, Mexican Americans, and refugees and immigrants from the former Soviet Union (FSU). Knowledge about normal memory loss and AD was addressed by eliciting beliefs about both domains from cultural informants in each of the groups, formally testing for group models of normal memory loss and AD, assessing within-group variability in knowledge of the models, and comparing beliefs about normal memory loss and AD. Finally, given that ethnic groups in U.S. society share a common minority status but have unique cultural characteristics and historical trajectories, the study sought to go beyond the documentation of variability in knowledge to address potential predictors of variability. These included level of acculturation, education, age, and sex.

This approach differs from previous research because knowledge was treated as a group resource rather than simply a feature of individual minds. Participants’ articulations of their beliefs (vs scientific/clinical articulations) were prioritized in their original languages, and these articulations were then employed in a survey instrument administered to larger groups. This approach is based on cultural consensus analysis, which assesses whether the beliefs that members of a group articulate form a coherent model, what the “culturally correct” beliefs are, and how knowledge of that model is distributed throughout the group. Previous cross-cultural applications have addressed asthma, acquired immunodeficiency syndrome, breast and cervical cancer, the common cold, and antibiotic therapy.

**METHODS**

**Recruitment and Participants**

Participants (N = 108) were recruited using purposive sampling in the Chicago area (36 African Americans, 36 Mexican Americans, 36 immigrants or refugees from the FSU). Local consultants (one from each ethnic group) and bilingual research assistants, coordinated the recruitment of participants from community groups, ethnic organizations, and churches and religious institutions. Mexican Americans were purposely recruited instead of “Hispanics” to attend to the cultural distinctions within the latter category, and immigrants and refugees from the FSU were sampled to attend to ethnic differences within the larger category of “whites.” To ensure a range of acculturation experience, the African-American and Mexican-American samples were stratified according to neighborhood such that half (n = 18) came from ZIP codes where that group was predominant and half (n = 18) from ZIP codes in which that group was the minority. FSU participants were too few within ZIP codes to pursue this strategy, and these were stratified according to proficiency in English. That is, in response to a question on English proficiency, half answered that they spoke English very well or well, and half answered not well or not at all. Individuals aged 40 and older and who would represent a range of income and education were targeted. Individuals who were trained or licensed as healthcare professionals were excluded. Participants were given a $15 gift card to selected local businesses. The institutional review board of the Leonard Schanfeld Research Institute, Chicago, Illinois, approved the project.

Table 1 shows the demographics of the total sample and each group. In general, half or more of the participants were female and in their early 60 and had household incomes less than $30,000 per year, with no significant differences between groups on income (Kruskal-Wallis one-way analysis of variance (H) = 1.07). Of Mexican Americans, 12 were born in the United States and 24 in Mexico and had spent approximately one-third of their lives in the United States. The immigrants and refugees from the FSU were from Belarus, Russia, Tajikistan, Ukraine, and Uzbekistan. All were Russian speaking and born in their respective countries of origin and had spent approximately one-quarter of their lives in the United States. Nonparametric analyses of variance and post hoc comparisons showed that more African Americans than FSU refugees and Mexican Americans and more Mexican Americans than FSU refugees worked in the health field (H = 19.99, P < .001). In addition, more African Americans had friends and family who worked in the health field than Mexican Americans and FSU refugees, with no differences between these latter two groups (H = 8.26, P < .05). Finally, although the Kruskal-Wallis one-way analyses of variance (H-statistics) suggested omnibus differences in means, post hoc multiple comparisons did not show differences between groups in terms of whether participants had family members or friends with AD (H = 6.11, P < .05), whether participants self-identified as caregivers (H = 7.56, P < .05), and whether participants had contacted an outside organization for information about AD (H = 15.94, P < .001).

**Instruments**

**Beliefs Questionnaire**

The first research goal was to elicit articulations of group beliefs about AD and normal memory loss, and the second goal involved using these articulations in a survey that would test for formal models. Thus, the survey questionnaire was developed from open-ended, qualitative interviews with 30 informants, with 10 carefully selected from each group based on reputational case selection (i.e., “Who around here is not a clinician but is knowledgeable about aging in the community?”) and maximum variation sampling (i.e., “Who around here has opinions that differ from yours?”). Interviews (in English, Spanish, and Russian) lasted approximately 60 to 90 minutes and began with typical, ethnographic “grand tour” questions (e.g., “Tell me about African-American views on aging”) and were followed by more-focused questions. Items were extracted from these interviews, in their original wordings, and piloted with the same 30 individuals.

The final questionnaire included 81 items about AD (Spanish: la enfermedad de Alzheimer; Russian: болезнь Альцгеймера). Questions about AD were divided into three sections: statements, causes, and possible treatments. (A methodological presentation of consensus analysis using these data on AD may be found in a forthcoming...
Questions about normal memory loss were divided into two sections: statements and causes. For the sake of comparability, the current study excluded the questions about treatments for AD and compared statements about and causes of AD (69 items) with statements about and causes of memory loss (55 items). All items were rewritten to fit yes-or-no answer formats, balanced across likely yes-or-no responses based on data from the pilot. Questionnaires were prepared in all three languages and administered in written form to the new sample of 108 participants. All of the African Americans responded in English, all of the FSU immigrants and refugees responded in Russian, and 72% of the Mexicans responded in Spanish.

**Experience with AD**

All participants were asked to provide information on age, sex, education, and income. Experience with AD was operationalized as a binary variable in response to the question: “Do you have friends or family who have received a diagnosis of AD?”

**Measures of Acculturation**

In general, acculturation describes the process of affirming, adapting, negotiating, modifying, and accepting or rejecting beliefs, customs, values, attitudes, and behaviors of the dominant culture while simultaneously maintaining or withdrawing from those of one’s ethnic group.37,38 (For a critique, see39) This research was particularly focused on the extent to which identification with the culture of origin affected knowledge of local models of AD and normal memory loss. Hence, measures that specifically assessed identification with culture of origin were selected.

African Americans completed the African-American Acculturation Scale-33,40,41 a 33-item instrument in which each item is worded so that high scores indicate greater adherence to, or agreement with, specific African-American beliefs and customs. The 10 subscales composing the instrument are preference for things African American, religious beliefs and practices, traditional foods, traditional childhood, superstitions, interracial attitudes and cultural mistrust, falling out, traditional games, traditional family values, and family practices. Mexican-American and FSU participants completed the Ethnic Society Immersion (ESI) subscale of the Stephenson Multigroup Acculturation Scale (SMAS).42 The 17 items of the scale query use of ethnic language, social interaction with co-ethnics, media preferences in the native language, behaviors, and attitudes. The English SMAS was translated and back-translated in Spanish and Russian. Because the two instruments employed different metrics, scores were standardized within groups to create the acculturation variable for the regression analyses.

**Analysis**

Data from the survey were analyzed using cultural consensus analysis,20,21 which determines whether, within a group, there exists a consistent series of beliefs in a particular knowledge domain—a single cultural model; which beliefs are part of the model and which are not—the culturally correct answer key; and how much each individual knows about the model—each person’s cultural knowledge
or competence. Methodologically, consensus analysis is a minimum residuals factor analysis of a respondent-by-respondent agreement matrix.\textsuperscript{20,21} The matrix was constructed by calculating agreement levels between each pair of respondents using the covariance method. High factor loadings and an absence of negative loadings on the first versus the second factor indicate the presence of a single model (a 3:1 eigenratio is the standard). Participant loadings on the first factor represent cultural knowledge scores for each individual.

Consensus analysis makes the assumption that individuals with higher levels of shared agreement about the series of beliefs know the model better than those with lower levels of shared agreement. Consequently, if a single model emerges, the culturally correct answer key can be generated using Bayesian analysis of the weighted answers from this more-knowledgeable subgroup.\textsuperscript{20} This has implications for sample size. If a single set of answers emerges (the “one culture assumption”), then sample sizes need not be large.\textsuperscript{22} For instance, for a moderate mean agreement level of 0.50 and classification of survey responses at a confidence level of 0.95, a sample of 23 individuals is necessary.\textsuperscript{20,43,44} With a total sample size of 108 and subsamples of 36, the current study well within the sample requirements for the method. All analyses were performed using UCINET (Analytic Technologies, Harvard, MA) and ANTHROPAC (Analytic Technologies, Natick, MA) software.

Response data from the questionnaires were pooled across groups to test for whether a shared model existed overall within the whole sample and then divided according to ethnic group to test for within-group models. Between-group agreement (pairwise) on the group answer keys was then assessed using a kappa coefficient. Kappas range from 0.0 (no agreement) to 1.0 (complete agreement), controlling for chance agreement.\textsuperscript{45} Finally, six predictors of variation in cultural knowledge scores were tested: ethnicity, age, sex, education, acculturation, and experience with AD.

RESULTS

The Common, Core Model of AD

Although there were some differences between ethnic groups on individual items, there was clearly one common model of the disease across groups. Consensus analysis of the pooled data showed a single overarching pattern of agreement, evidenced by a first- to second-factor eigenratio of 4.53, with 45% of items deemed TRUE. On average, the pooled participants knew just under half of the model (0.47 ± 0.17). Similarly, each group showed a single pattern of responses, with respondents knowing approximately half of the models (eigenratio, mean cultural knowledge score ± standard deviation: African Americans, 6.88, 0.48 ± 0.17; Mexican Americans, 5.69, 0.47 ± 18; FSU participants, 5.85, 0.50/ ± 0.17). Across groups, the proportion of TRUE responses ranged from 42% to 46%. To confirm the common model, the group answer keys were compared using kappa coefficients, and these indicated high levels of pairwise agreement (African American and Mexican American, 0.62; African American and FSU, 0.74; Mexican American and FSU, 0.64).

Predictors of within-group variation in cultural knowledge were tested for by regressing the first-factor cultural knowledge scores on the six predictors mentioned above (F(6,101) = 5.06, P < .001). Ethnicity did not emerge as a significant predictor (beta = 0.05), nor did age (beta = 0.17) or sex (beta = 0.01), but more years of education (beta = 0.24, P = .01), higher levels of acculturation (beta = 0.21, P = .02), and having a family member with AD (beta = 0.22, P = .2) predicted more knowledge of the model. Variation inflation factors were uniformly low (<2.3) for all predictors and indicated no threat of multicollinearity.\textsuperscript{46}

Statements About AD

Table 2 lists the statements and “culturally correct” answers for the pooled data and for each group separately. The models include the beliefs that AD is an incurable disease (not equivalent to senility), as evidenced by deterioration of the brain and cognitive decline, and that symptoms depend on which parts of the brain are affected. The cognitive decline occurs over several stages, although people can be in the early stages for many years. The disease cannot be diagnosed with a blood test, and it is not true that the only way to know for sure whether someone has AD is based on an autopsy after death. According to the model, keeping busy (going for walks, playing games, doing crossword puzzles, reading) can help prevent the disease, but having an intellectual versus physical occupation does not.

Causes of AD

Causes of the disease (Table 3) include neurological problems and psychiatric problems and possibly psychological trauma and high amounts of aluminum in the brain, but many physiological conditions were excluded as causes, including viruses, diabetes mellitus, high blood pressure, heart disease, and high cholesterol. It is not the result of the following specific stressors: a difficult life, a heavy work schedule, a monotonous life, loneliness, or the “syndrome of tiredness,” nor is it related to lifestyle factors such as excessive use of alcohol, poor diet, or lack of exercise.

Intercultural Variation on Individual Items

Group differences on particular items suggest that the FSU model shows a more biological or physiological perspective on the disease, whereas the Mexican-American model shows a more mental or behavioral perspective— with the African-American model in between. Thus, in the FSU model, AD is not seen as a mental illness, and engaging in mental activities has no effect on the progression of the disease, but this is not so in the African-American and Mexican-American models. Also, whereas AD is associated with plaques and tangles in the FSU and African-American models, it is not in the Mexican-American model. Furthermore, in the Mexican-American model (but not the others), personality and social context can alter the course of the disease.

The Common, Core Model of Normal Memory Loss

A common model of normal memory loss is also evident in the pooled data. The eigenratio of first to second factors was 3.04, with 64% of the items deemed TRUE, although on average, participants knew 39% of the model. Similarly, analysis according to individual group showed single models, again with low mean cultural knowledge scores.
Table 2. Statements About Alzheimer’s Disease (AD) Grouped According to “Culturally Correct Answers”

<table>
<thead>
<tr>
<th>Statement</th>
<th>Pooled</th>
<th>African American</th>
<th>Mexican American</th>
<th>Refugees and Immigrants from the Former Soviet Union</th>
</tr>
</thead>
<tbody>
<tr>
<td>Descriptions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AD affects brain cells, is cognitive decline, is deterioration of the brain; AD symptoms depend on which parts of the brain are affected; AD has been around a long time but remained hidden in families.</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>AD is curable, is the same as senility.</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>AD is a mental illness.</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>AD is caused by plaques and tangles in the brain.</td>
<td>T</td>
<td>T</td>
<td>F</td>
<td>T</td>
</tr>
<tr>
<td>Course</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AD gets worse with time, has several different stages; the first stage can last many years; AD patients need help maintaining independence.</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>How AD affects a person depends on their personality.</td>
<td>F</td>
<td>F</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>Positive attitude slows down the progression of AD.</td>
<td>T</td>
<td>F</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>Mental activities (e.g., crossword puzzles, reading) can prevent behavioral problems associated with AD.</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AD can be diagnosed with a blood test; the only way to know for sure is via autopsy after death.</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>AD is rarely diagnosed in people under 50; it’s important to go to the doctor when signs first appear.</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>Many doctors don’t know about AD.</td>
<td>F</td>
<td>T</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Risk and prevention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People get AD no matter what their cultural or ethnic background; keeping busy (e.g., going for a walk outside, playing games, doing crossword puzzles, or reading) can help prevent AD.</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>AD is normal for old age; getting AD is a punishment for a bad life; the risk is equal whether a person does physical or intellectual work, having a good family can prevent AD.</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>True (T) and false (F) answers are Bayesian posterior probabilities estimated by weighing individuals’ responses by their cultural knowledge level (the participants’ loadings on the first factor of the consensus analysis).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Row headings Description, Course, Diagnosis, and Risk and Prevention) have been added to the table and were not included in the survey.</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

(eigenratio, mean cultural knowledge score ± standard deviation: African Americans, 3.49, 0.46 ± 0.19; Mexican Americans, 3.22, 0.40 ± 0.18; FSU, 8.69, 0.45 ± 0.18. Across groups, the proportion of TRUE responses ranged from 58% to 65%. To confirm the presence of one common model, pairwise comparisons were made of group answer

Table 3. Causes of Alzheimer’s Disease Grouped According to “Culturally Correct Answers”

<table>
<thead>
<tr>
<th>Statement</th>
<th>Pooled</th>
<th>African American</th>
<th>Mexican American</th>
<th>Refugees and Immigrants from the Former Soviet Union</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological or medical</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Virus, diabetes mellitus, chronic diseases, high blood pressure, high cholesterol, heart disease, falling, taking too many medications, side effects of medication</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Neurological problems</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>Head injury or trauma</td>
<td>F</td>
<td>T</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Psychological</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having psychiatric problems</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>Loneliness, syndrome of tiredness</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Psychological trauma</td>
<td>T</td>
<td>F</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>Lifestyle and exposure</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drinking alcohol, bad diet, lack of exercise, having a difficult life, a heavy work schedule, monotonous life, pollution, radiation, poisons in the environment</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>High amounts of aluminum in the brain</td>
<td>T</td>
<td>T</td>
<td>F</td>
<td>T</td>
</tr>
<tr>
<td>True (T) and false (F) answers are Bayesian posterior probabilities estimated by weighing individuals’ responses by their cultural knowledge level (the participants’ loadings on the first factor of the consensus analysis).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Row headings Biological or Medical, Psychological, and Lifestyle and Exposure have been added to the table and were not included in the survey.</td>
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</tbody>
</table>
keys. Kappa coefficients ranged from moderate to low: African Americans and FSU participants, 0.61; African Americans and Mexican Americans, 0.48; Mexican Americans and FSU participants, 0.39.

To test for interpretable variation in the cultural knowledge scores, the first factor loadings were regressed on six predictor variables ($F(6,101)=3.11$, $P=.008$). Only experience with AD was a significant predictor of knowledge of the model (beta = 0.25, $P=.01$). Ethnicity did not emerge as a significant predictor of knowledge of the model of normal memory loss (beta = 0.01), nor did sex (-0.11), age (-0.11), education (0.16), or acculturation (0.11). Variation inflation factors were uniformly low (<2.2) for all predictors and indicated no threat of multicollinearity.

### Causes of Normal Memory Loss

In addition to aging, memory loss is also associated with stroke, mental illness, physical trauma to the head, “nervous breakdown,” and emotional trauma (Table 5). It is not caused by infections or chronic conditions (e.g., diabetes mellitus, high blood pressure, high cholesterol). It is not associated with loneliness or being shy or introverted. Alcohol abuse causes memory loss, but other lifestyle factors such as diet, poverty, and family disturbances are not associated with memory problems.

### Intercultural Variation on Individual Items

Again, the FSU model seemed to take a biological or physiological perspective on memory loss, affirming in contrast to the other groups that it is caused by a physical disease and that it is “curable.” Furthermore, in the FSU and Mexican-American models, memory loss is seen as a disease (whereas in the African-American model it is not). Concerning causes of memory loss, Mexican Americans were most often at variance with the other two groups, but no clear interpretation of these results is apparent.

### DISCUSSION AND CONCLUSION

Three findings characterize the results of this study. The first finding is that the groups in the study had fairly clear models of what AD is and what causes it. On the whole,
participants understood that AD is a brain-based disease, reflected in irreversible cognitive decline over a series of stages and that it is uniquely associated with, although not necessarily an inevitable part of, aging. Nevertheless, higher education, a less-traditional cultural orientation, and having a family member with AD predicted greater knowledge of the popular model. The departures from scientific or clinical wisdom are minor. Science, for instance, still sees the autopsy as the only true, definitive diagnosis, but lay people do not. Also, diabetes mellitus, hypertension, and high cholesterol may be risk factors, but in the lay model, these diseases are not seen as such.

Taken individually, these beliefs replicate previous research showing that African Americans and Hispanics know and understand the important facts about AD, albeit with some minor variations.14,15,18 What is unique in the current approach was culling statements about the disease from the participants themselves (instead of from scientific or clinical models) and then testing for how much people knew their own “folk” models. That respondents knew only about half of their own group models may seem surprising, but within the explicitly sociocultural framework proposed, it is not important that everyone at any one time understand the workings of AD but rather that the knowledge be present and available somewhere in the group when people need it. One study found that, in African Americans, Chinese, and Latino families, the first source of advice and social support was from family and community members.8

The second finding is that there exists a cultural model of normal, age-related memory loss. However, whereas previous research on beliefs about memory focuses almost exclusively on particular memory abilities,9–11 the questions used in the current study explicitly addressed normal versus pathological memory loss and popular notions of causal factors. Thus, a unique finding was that people believe that “normal” forgetting involves eventual recall of the forgotten material, suggesting a useful lay criterion for what counts as “normal.” In terms of causality, group models confirmed that, in addition to age, likely causes of memory loss included stroke, head trauma, alcohol abuse, and possibly emotional trauma. Finally, the model included the belief that older people remember remote events better than recent ones (a pattern scientifically associated with mild cognitive impairment and early AD47). The only predictor of greater knowledge of the popular model of normal memory loss was having a relative with AD. Perhaps this experience triggers greater reflection on the difference between the “normal” and the “pathological.” People seemed to know less of the model of normal memory loss than the model of AD. This may reflect the success of public health efforts and pharmaceutical advertisement in educating the public about AD.

The third finding is that, although acculturation level emerged as a predictor of knowledge of AD (more-acculturated participants knew more of the model), there were no marked differences in the content of African-American, Mexican-American, and FSU models of AD or normal memory loss. Thus, although there were differences between groups on individual beliefs, these were not distributed within or across groups so as to suggest distinct models. The one exception seems to be that the participants from the FSU highlighted biological or medical themes over mental or psychological themes more than the other two groups. These emphases may have to do with higher levels of education and knowledge about the physiological causes as well as the stigmatization of mental illness during the Soviet era.48

There are four points of clinical relevance in these findings. First, the fact that ethnic minority groups possess a core model of AD that is largely consistent with clinical models means that patients and clinicians are at least speaking the same “language” in their discussions of diagnosis, prognosis, and treatment. Nevertheless, the unequal distribution of knowledge about AD suggests that as large a circle as possible be included in the communication of the diagnosis and that patients and families be encouraged to

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**Table 5. Causes of Memory Loss Grouped According to “Culturally Correct Answers”**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Pooled</th>
<th>African American</th>
<th>Mexican American</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Biological or medical</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke, hitting your head</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>Infection, diabetes, high blood pressure, high cholesterol</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Being physically sick</td>
<td>F</td>
<td>T</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Taking too many medications, side effects of medication, heredity or genetics</td>
<td>T</td>
<td>T</td>
<td>F</td>
<td>T</td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having mental illness, nerves or nervous breakdown, emotional trauma</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>Loneliness, being shy or introverted</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Depression, grief</td>
<td>T</td>
<td>T</td>
<td>F</td>
<td>T</td>
</tr>
<tr>
<td><strong>Lifestyle and exposure</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consumption of alcohol, lack of brain use</td>
<td>T</td>
<td>T</td>
<td>T</td>
<td>T</td>
</tr>
<tr>
<td>Bad diet, poor living conditions, problems with family</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Stress</td>
<td>T</td>
<td>T</td>
<td>F</td>
<td>F</td>
</tr>
</tbody>
</table>

True (T) and false (F) answers are Bayesian posterior probabilities estimated by weighing individuals’ responses by their cultural knowledge level (the participants’ loadings on the first factor of the consensus analysis). Row headings Biological or Medical; Psychological; Lifestyle and Exposure have been added to the table and were not included in the survey.
speak with others in their networks after the clinical interview. This should have the effect of bringing group knowledge to bear on the possibly limited perspective of patients and family. Second, regarding cultural differences, the finding that FSU immigrants were more likely to favor biological models of the disease may indicate the need for counseling about social and psychological stimulation of the patient in the family setting (e.g., appropriate conversational engagement) to counter a sense of biological inevitability about declines. Third, in the case of normal memory loss, the finding that people have rules of thumb (“what is forgotten, eventually comes back”) might provide an entrée to discussion about the kinds of memory impairment that patients experience. Fourth, and perhaps most broadly, the analysis of group models suggests that communicating with patients is more accurately conceived as communicating with a social network (vs the individual patient), which in turn activates wider group knowledge.

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Author Contributions: Dr. Iris guided the overall project from which the data were obtained, including coordinating all phases of the research—interview and survey design, recruitment, data collection, interview training, and data management. She also assisted in interpretation of the data and preparation and editing of the manuscript. Dr. Schraft assumed primary responsibility for preparing the manuscript, as well as leading the data analysis and interpretation of the findings. He was also involved in the design of the research.

Sponsor’s Role: None.

REFERENCES