Two hundred and three children and siblings of patients with Alzheimer’s disease (AD) (age range: 30-92 years, 75% female) were surveyed regarding potential predictive testing options for the disorder. A mailed questionnaire posed various hypothetical scenarios and assessed the following variables: interest in testing, perceptions of its pros and cons, and psychological and demographic predictors of test intentions. In 5 of 6 scenarios, a majority of participants expressed intentions to pursue testing, with perceived pros outweighing cons. The most important reasons for seeking testing were informing later-life decisions and planning future AD care. Predictors of testing intentions were male gender, information-seeking style, higher perceived AD threat, and appraisal of test pros versus cons. Situational factors such as available treatment options and certainty of test information also affected responses. Results suggest a positive view of predictive testing, with its limitations and risks underrated. Study findings may inform AD genetic counseling and health education efforts.

Key Words: Medical decision-making

Anticipating Response to Predictive Genetic Testing for Alzheimer’s Disease: A Survey of First-Degree Relatives

J. Scott Roberts, PhD

Biomedical research promises eventual widespread predictive testing for Alzheimer’s disease (AD), a health care option that would pose a profound dilemma for the millions at risk for the disorder. Due to its current limitations (e.g., inadequate test sensitivity and specificity, lack of treatment options), such testing is generally not yet recommended (McConnell et al., 1998). However, given the pace of AD research, predictive testing may become a more viable option in the near future. Presymptomatic testing already occurs for families with rare early-onset (before age 65) forms of AD (Lennox et al., 1994), and genetic factors in its more common later-onset types are under investigation (Lerman et al., 1997). An apolipoprotein E allele on chromosome 19 is the first genetic risk factor for sporadic AD to have been discovered, with future findings likely to lead to genotype screening (Masters & Beyreuther, 1998). Psychological research will be critical in anticipating public reaction to testing and identifying crucial issues in its appraisal.

Such work is necessary because AD represents a unique and complex case of predictive testing. First, AD occurs more frequently than other disorders for which testing takes place. A recent study (Brookmeyer, Gray, & Kawas, 1998) estimated 360,000 new cases in 1997—an incidence rate twice that of breast cancer, the next most common disorder for which testing is available (Lerman et al., 1997). Second, AD has a later age of onset than other disorders for which testing occurs. The vast majority of cases develop after age 65, while most other disorders with testing options (e.g., cystic fibrosis) have an average age of onset of 45 or less. Third, and perhaps most important, risk information in AD testing will be more ambiguous than in most testing scenarios. Although genetic susceptibility loci for the disorder are being pinpointed, AD is not a purely genetic disease. As such, its predictive testing, even in a best-case scenario, will not yield risk estimates of the certainty found in testing for autosomal dominant disorders like Huntington’s disease (HD). Furthermore, no prevention or cure options currently exist for AD. Such
characteristics distinguish the disorder in important ways from other testing contexts, while also raising complex ethical, legal, and social issues (Post et al., 1997).

Indeed, the question of whether to seek predictive testing for AD is a daunting one. An understanding of this decision process could inform efforts in several medical domains, including physician–patient communication, genetic counseling, health education, and health policy. To this end, the goals of the current study were to (a) gauge interest in AD predictive testing, (b) describe perceptions of test benefits, limitations, and risks, and (c) identify situational, sociodemographic, and psychological factors that predict test intentions.

Literature Review

Predictive Testing for Other Medical Disorders

Psychological studies on testing for other disorders have shown that regardless of disorder, at-risk individuals express much interest in testing before it is offered (Croyle & Lerman, 1995; Lerman, Seay, Balshem, & Audrain, 1995; Meissen & Berchek, 1988). However, such intentions often do not translate into test utilization (Craufurd, Dodge, Kerzin-Storrar, & Harris, 1989; Lerman et al., 1996). Several sociodemographic factors (e.g., race, gender, years of education, health insurance status) have been found to distinguish those who pursue predictive testing from those who decline it (Lerman et al., 1996; Marteau & Croyle, 1998). These perceived pros are countered by several perceived cons, including concerns about test imprecision, the psychological burden of a positive result, and genetic discrimination from insurers and employers (Jacobsen et al., 1997). Applied work has found that illness representations—perceptions of disorder symptoms, course, consequences, causes, and cure—predict response to health threats (e.g., Meyer, Leventhal, & Gutmann, 1985; Petrie & Weinman, 1997). In addition to perceptions of illness, personality variables also influence health behavior. One example is information-seeking style, the tendency to seek or avoid threat-relevant information under stress (Miller, 1987).

Study Aims

The current study was a survey of first-degree relatives (i.e., children and siblings) of patients with Alzheimer’s disease—a population for whom the question of testing is particularly salient, given both their family experiences with the disorder and increased personal AD risk (Lautenschlager et al., 1996; Silverman et al., 1994). The survey posed various hypothetical scenarios and assessed test intentions. It was hypothesized that interest in testing would generally be great, with intentions varying according to test situational factors (e.g., available treatment options), individual coping styles (e.g., information-seeking), appraisal of test pros versus cons, and disorder-specific perceptions (e.g., perceived threat, treatment optimism).

Method

Participants

A total of 203 first-degree relatives participated in the project, 75.4% (n = 153) of whom were women. The age of participants ranged from 30 to 92 years (M = 53.5, SD = 10.9). Almost all (99.5%) had completed high school, and most (63.5%) had completed college. Most participants were White (95.6%), married (72.9%), and living with family or friends (80.2%), had health insurance (96.1%), and had an income over $40,000 (74.7%). The vast majority of participants (93.1%) had been involved either directly or indirectly in AD caregiving. Number of affected kinship groups among participants ranged from one to six (M = 1.9); almost all participants (n = 194, 95.6%) had an affected parent, but few (n = 13, 6.4%) had an affected sibling. Further description of the sample appears in Table 1.

Procedure

Participants were recruited for the study in three ways. The primary means of recruitment involved referrals from several geriatric care organizations in the state of Michigan, including hospital clinics, nursing homes, and retirement communities (n = 147, 72% of sample). A second means of recruitment was
Table 1. Description of the Sample (N = 203)

<table>
<thead>
<tr>
<th>Sociodemographic Characteristics</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>50</td>
<td>24.6</td>
</tr>
<tr>
<td>Female</td>
<td>153</td>
<td>75.4</td>
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<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30–49</td>
<td>74</td>
<td>36.5</td>
</tr>
<tr>
<td>50–69</td>
<td>114</td>
<td>56.2</td>
</tr>
<tr>
<td>70 and older</td>
<td>15</td>
<td>7.4</td>
</tr>
<tr>
<td>Racial background</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>194</td>
<td>95.6</td>
</tr>
<tr>
<td>Black</td>
<td>5</td>
<td>2.5</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>2.0</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤12 years</td>
<td>20</td>
<td>9.9</td>
</tr>
<tr>
<td>13–16 years</td>
<td>94</td>
<td>46.3</td>
</tr>
<tr>
<td>17 years or more</td>
<td>89</td>
<td>43.8</td>
</tr>
<tr>
<td>Marital status</td>
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<tr>
<td>Married</td>
<td>148</td>
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<tr>
<td>Divorced</td>
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<td>With family/friends</td>
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<tr>
<td>Alone</td>
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<td>19.8</td>
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<td>Annual household income</td>
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<td>&lt;$40,000</td>
<td>50</td>
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</tr>
<tr>
<td>$40,000–$79,999</td>
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<td>35.3</td>
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<tr>
<td>$80,000 and more</td>
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<td>Health insurance status*</td>
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<td>Private/HMO insurance</td>
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<td>Medicare</td>
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<td>14.8</td>
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<tr>
<td>None</td>
<td>8</td>
<td>3.9</td>
</tr>
<tr>
<td>Affected kinship groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>75</td>
<td>36.9</td>
</tr>
<tr>
<td>Two</td>
<td>82</td>
<td>40.4</td>
</tr>
<tr>
<td>Three or more</td>
<td>46</td>
<td>22.7</td>
</tr>
<tr>
<td>AD caregiving history</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary caregiver</td>
<td>48</td>
<td>23.8</td>
</tr>
<tr>
<td>Assistant caregiver</td>
<td>87</td>
<td>43.1</td>
</tr>
<tr>
<td>Arranged for care</td>
<td>53</td>
<td>26.2</td>
</tr>
<tr>
<td>Not involved in care</td>
<td>14</td>
<td>6.9</td>
</tr>
</tbody>
</table>

*Participants could endorse more than one response for this item.

through local newspaper advertisements and flyers posted at hospital and community sites in southeastern Michigan (n = 49, 24% of sample). Finally, the investigator's professional colleagues also referred interested and eligible personal contacts (n = 7, 3% of sample). Study participation was limited to one person per affected family. Special attempts were made to recruit African American participants through church organizations, but these efforts yielded few referrals.

In telephone contacts, the investigator verified candidates' eligibility and explained study procedures. Persons eligible for the study were those who identified themselves as having ever had an immediate blood relative (i.e., parent or sibling) affected by AD. Following questionnaire completion, participants were sent a $10 check, an AD information packet, and a letter debriefing them on the study. Of 225 questionnaires sent, 203 (90.2%) were returned. Data collection took place over a 10-month period from May 1998 to March 1999.

Measures

Although this study was largely exploratory, its design incorporated methodological critiques of previous related work. Croyle and Lerman (1995) noted that research on genetic testing intentions has tended to focus solely on sociodemographic predictors, ignoring psychological variables. Meanwhile, Leventhal et al. (1997) urged increased consideration of illness representations as an underlying cause of health attitudes and behaviors. Thus, when considering predictors of AD predictive testing intentions, it seemed useful to look beyond demographic characteristics and appraisal of test pros and cons. Its assessment of health psychological styles and illness representations distinguishes this study from most others that have examined determinants of genetic testing intentions.

The study questionnaire used both previously existing and newly created measures. New scales were refined in a pilot study of 200 persons over age 50 in the Durham, North Carolina area (Roberts, Welsh-Bohmer, & Simons, 1998). To assess order-of-presentation effects on test intentions, three separate questionnaire forms counterbalanced the order of hypothetical scenarios.

Sociodemographic Characteristics.—Age, gender, race, education level, annual household income, marital status, living arrangements, and health insurance status were assessed.

AD Illness Representations.—Two background variables were measured. Family history of AD and related memory problems were assessed by asking participants about family history of senility, significant memory loss, and/or Alzheimer's disease. Participants indicated affected family members by kinship group (e.g., siblings, grandparents). One item measured AD caregiving history in terms of extent of involvement and duration of care, using a 6-point scale.

Attitudes and beliefs composing AD illness representations were also assessed. Perceived threat was measured by a 7-item scale consisting of three sub-scales: perceived likelihood, concern, and consequences. Perceived likelihood was assessed by asking participants how likely they felt they were to develop AD, both in the next 5 years and at some point in their lifetime. Perceived concern was assessed by asking participants how concerned they were about developing AD, both in the next 5 years and at some point in their lifetime; participants also rated their concern as compared to other existing or potential medical problems. Perceived consequences were assessed by asking participants to rate how emotionally and financially stressful they believed AD would be should they develop it. Participants

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responded to each item by using a 5-point scale; higher scores indicated perceptions of greater threat. Cronbach’s alpha for the overall measure in this study was .78.

Treatment optimism was measured by a 6-item scale asking participants to rate the likelihood of future advances in AD treatment. Participants expressed beliefs concerning several potential treatment developments, including cure, prevention, and improvements in symptom relief. Participants were asked to indicate the likelihood of each development (both in the next 5 years and in their lifetime) using a 5-point scale (1 = not at all likely, 5 = very likely). Cronbach’s alpha for the measure in this study was .88.

AD knowledge was measured by a 14-item, true–false quiz used in research on public knowledge about AD (Connell, 1996). Questions covered basic facts and common misconceptions about the disorder. Sample items included “There is no cure for AD (True),” “Drugs are available to treat the symptoms of AD (True),” and “Hardening of the arteries is a common cause of AD (False).” Scores on this measure indicated the number of items answered correctly. Point biserial correlations between test items and total scale score ranged in this study from .16 to .46 (all significant at p < .05), indicating varying difficulty among test items.

AD-related distress was measured with the 7-item intrusion subscale of the Impact of Events Scale (Horowitz, Wilner, & Alvarez, 1979), which assesses frequency and severity of intrusive thoughts, worries, and feelings about a particular stressor—in this case, family history of AD. Participants were asked to indicate how often distress symptoms had occurred in the past 7 days, using a 4-point scale (1 = not at all, 4 = often). This measure has been used in previous research on predictive testing for breast cancer (Conger, 1995; Jacobsen et al., 1997). Its Cronbach alpha for this study was .88.

Health Psychological Styles.—Information-seeking style indicates the dispositional tendency to seek out (monitor) or avoid (blunt) threat-relevant information under stress. This variable was assessed with Miller’s (1987) Behavioral Style Scale, a 32-item measure posing four scenarios of physical and psychological stress (e.g., possible lay-offs at work, potential airplane crash). Eight statements describing ways of coping with the imagined stressor were provided for each scenario. Participants responded by endorsing statements that described how they might cope with the stressor in question. Separate subscale scores were derived for monitoring and blunting tendencies; Cronbach’s alpha in this study was .70 for the monitoring subscale and .51 for the blunting subscale. Blunting scores were subtracted from monitoring scores to yield an overall index score.

Health locus of control was measured with the internal locus of control subscale from the Multi-dimensional Health Locus of Control Scale (Wallston, Wallston, & DeVellis, 1978). This 6-item subscale assesses beliefs about the extent to which participants perceive control over their own health. Participants responded to items using a 5-point scale, with higher scores indicating perceptions of greater control. The measure’s Cronbach alpha for this study was .68.

Predictive Test Intentions.—Test intentions were assessed by responses to six hypothetical testing scenarios. An introductory section explained the concept of predictive medical testing and its relevance for AD. Participants were then posed six hypothetical scenarios. All scenarios described predictive AD testing as costing $200 and involving “a genetic blood test and interview about your health background.” Scenarios varied across three dimensions: (a) test accuracy (99% or 85%), (b) meaning of a positive test result (extremely high [95%] or moderately high [50%] risk, either within the next 5 years or in one’s lifetime), and (c) available treatment options (limited symptom relief, treatment to delay onset, or treatment to prevent AD). Participants indicated responses by using a 7-point scale (1 = would definitely not take the test; 2 = would probably not take the test; 3 = undecided; 4 = would probably take the test, but not immediately; 5 = would probably take the test as soon as it became available; 6 = would definitely take the test, but not immediately; 7 = would definitely take the test as soon as it became available). A sum of scores across all scenarios yielded an index of test intentions. A similar format for measuring test intentions has been used in previous psychological research on predictive testing for breast cancer (Coyne, Lepkowski, Weber, & Calzone, 1995; Jacobsen et al., 1997). The measure’s Cronbach alpha in this study was .92.

Perceptions of Test Benefits, Limitations, and Risks.—Participants rated the importance of potential reasons for seeking or declining testing, using a 5-point scale (1 = not important, 5 = very important). Both pilot data and research on predictive testing for other disorders were consulted to determine reasons listed (Jacobsen et al., 1997; Lerman et al., 1996). A perceived test pros score was derived by summing responses to eight reasons for pursuing testing, and summed responses to eight reasons for declining testing constituted a perceived test cons score. Cronbach’s alpha was .80 for the pros subscale and .73 for the cons subscale. Subtracting the test cons score from the test pros score yielded an index corresponding to the decisional balance construct developed by Janis and Mann (1977) in their classic work on decision-making. Higher decisional balance scores indicated greater eagerness to seek testing.

Data Analysis

Descriptive statistics characterized participants in terms of their sociodemographic make-up, AD background, predictive testing intentions, and perceptions of test pros and cons. A series of dependent-
variable t tests assessed whether test intentions differed by situational factors and whether perceived test pros differed in importance from perceived test cons. One-way analyses of variance (ANOVAs) were used to test for order effects on presentation of hypothetical test scenarios, as well as for gender and age group effects on test intentions and appraisal of test pros and cons. Correlation analyses identified intercorrelations among predictors and bivariate correlations between predictor variables and test intentions.

Hierarchical linear regression was used to analyze variables associated with testing intentions. Predictors were entered into the regression model in four blocks, each representing a set of predictors described earlier. Sociodemographic characteristics were entered first, followed by general health psychological styles, AD illness representation variables, and, finally, decisional balance. Those variables with significant or near-significant ($p < .10$) beta weights in the initial regression model were then included in a trimmed model.

Results

Interest in Testing

Overall, participants were enthusiastic about AD predictive testing; in five of six scenarios, a majority expressed probable or definite intentions to seek it. The scenario of least interest was one in which test result information was less certain (i.e., conveying a 50% lifetime risk rather than a 95% lifetime risk). Participants were especially enthusiastic about scenarios offering more promising treatment options than are currently available. Men expressed greater overall interest in testing than women, test intentions: $M = 30.6$ vs $M = 27.1$; $t (201) = 5.13$, $p < .001$. Men showed significantly higher ($p < .05$) test eagerness on this item than women. No significant differences in intentions were found by age group (participants younger than age 60 vs participants age 60 and older), or by order of scenario presentation. A summary of test intentions in the six scenarios appears in Table 2.

Test Benefits, Limitations, and Risks

Overall, participants rated test benefits as more important than limitations and risks, Pros: $M = 28.7$ vs Cons: $M = 19.6$; $t (200) = 13.62$, $p < .001$. Seven of eight test pros were rated on average as more important than any test con and as somewhat or very important to test decision-making. Information for future planning was considered the most important test pro, rated as such by more than 40% of participants. Guidance of one's future AD care and motivation for monitoring future treatment possibilities were also judged to be very important benefits. Meanwhile, participants did not view potential test limitations and risks as crucial to their decision-making; none of the eight cons presented were rated on average as somewhat or very important. Concern about the effect of test results on loved ones was seen as the most important reason to decline testing. No significant gender differences were found with regard to overall rating of test pros and cons. Participants younger than age 60 rated cons as more important than did participants age 60 and older, test cons: $M = 20.3$ vs $M = 17.8$; $F(1,201) = 6.60$, $p < .05$. Perceptions of test benefits, limitations, and risks are summarized in Tables 3 and 4.

Situational Predictors of Test Intentions

Situational factors influenced test intentions. Participants were more likely to express intentions of pursuit in scenarios with the following characteristics: higher test accuracy, 99% accuracy: $M = 4.14$ vs 85% accuracy: $M = 3.95$; $t (202) = 2.84$, $p < .01$; more immediately relevant risk information, risk in the next 5 years: $M = 4.56$ vs risk in one's lifetime: $M = 4.14$; $t (202) = 4.54$, $p < .001$; more certain risk information, 95% lifetime risk: $M = 4.14$ vs 50% lifetime risk: $M = 3.74$; $t (201) = 4.01$, $p < .001$; and better available treatment options, prevention: $M = 6.43$ vs treatment to delay onset: $M = 5.16$; $t (202) = 10.65$, $p < .001$; treatment to delay onset:

Table 2. Test Intentions by Hypothetical Scenario

<table>
<thead>
<tr>
<th>Hypothetical Scenario</th>
<th>All (N = 203)</th>
<th>Men (n = 50)</th>
<th>Women (n = 153)</th>
<th>Age &lt;60 (n = 147)</th>
<th>Age ≥60 (n = 56)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatment to prevent AD</td>
<td>96.1</td>
<td>96.0</td>
<td>96.1</td>
<td>98.0</td>
<td>91.1</td>
</tr>
<tr>
<td>Available treatment to delay AD onset</td>
<td>77.8</td>
<td>86.0</td>
<td>75.2</td>
<td>78.9</td>
<td>75.0</td>
</tr>
<tr>
<td>More immediate risk information</td>
<td>63.1*</td>
<td>78.0</td>
<td>58.2</td>
<td>61.2</td>
<td>67.9</td>
</tr>
<tr>
<td>Baseline (99% test accuracy; positive result = 95% risk in next 5 yrs)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less test accuracy (85%)</td>
<td>54.7*</td>
<td>72.0</td>
<td>49.0</td>
<td>52.4</td>
<td>60.7</td>
</tr>
<tr>
<td>Less certain risk information (50% lifetime risk)</td>
<td>49.5*</td>
<td>59.2</td>
<td>46.4</td>
<td>45.6</td>
<td>60.0</td>
</tr>
</tbody>
</table>

*Men showed significantly higher ($p < .05$) test eagerness on this item than women.
Table 3. Perceived Test Benefits

<table>
<thead>
<tr>
<th>Test Pro</th>
<th>% of Respondents Endorsing as Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test results would help me make important later-life decisions</td>
<td>83.9</td>
</tr>
<tr>
<td>Test results would help me and my doctors plan my future AD care</td>
<td>79.4</td>
</tr>
<tr>
<td>Knowing that I was at high risk for AD would motivate me to stay on top of future treatment/prevention options</td>
<td>78.0</td>
</tr>
<tr>
<td>My participation in testing could help researchers learn more about AD</td>
<td>71.1</td>
</tr>
<tr>
<td>Test results would give information about my children's risk of AD</td>
<td>49.5</td>
</tr>
<tr>
<td>Knowing I was not at high risk for AD would improve my quality of life</td>
<td>48.5</td>
</tr>
<tr>
<td>My family's worries about me developing AD would be reduced with a negative result</td>
<td>41.0</td>
</tr>
<tr>
<td>Getting tested would please my family members</td>
<td>16.6</td>
</tr>
</tbody>
</table>

*aWomen rated this item as significantly more important (p < .05) than women did.

*bMen rated this item as significantly more important (p < .05) than women did.

$M = 5.16$ vs limited symptom relief: $M = 4.14$; $t (202) = 9.37$, $p < .001$.

Sociodemographic and Psychological Predictors of Test Intentions

Test intentions were positively correlated with the following variables: male gender, monitoring information-seeking style, perceived threat, and decisional balance. Pearson bivariate correlations among predictor variables and test intentions are presented in Table 5 (Spearman correlations were used for associations involving gender).

Table 4. Perceived Test Limitations and Risks

<table>
<thead>
<tr>
<th>Test Con</th>
<th>% of Respondents Endorsing as Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>If I tested positive, that might upset my loved ones</td>
<td>34.7</td>
</tr>
<tr>
<td>I would not want to take a chance on my insurance companies or</td>
<td></td>
</tr>
<tr>
<td>employer finding out my test results</td>
<td>34.3</td>
</tr>
<tr>
<td>Treatment and prevention options for AD are limited, so learning my</td>
<td></td>
</tr>
<tr>
<td>risk wouldn't help much</td>
<td>32.8</td>
</tr>
<tr>
<td>Knowing I was at high risk for AD would make me worry about my</td>
<td></td>
</tr>
<tr>
<td>children's risk of the disorder</td>
<td>31.5</td>
</tr>
<tr>
<td>It would be too upsetting to learn I am at high risk for AD, so I am</td>
<td></td>
</tr>
<tr>
<td>happier not knowing</td>
<td>27.0</td>
</tr>
<tr>
<td>If I were found to be at high risk for AD, it would change how other</td>
<td></td>
</tr>
<tr>
<td>people look at me and act towards me</td>
<td>11.8</td>
</tr>
<tr>
<td>Testing is not worthwhile because I could never be totally sure if the</td>
<td></td>
</tr>
<tr>
<td>test results were correct or not</td>
<td>9.9</td>
</tr>
<tr>
<td>The testing would cost too much money and time</td>
<td>5.4</td>
</tr>
</tbody>
</table>

*aWomen rated this item as significantly more important (p < .05) than men did.

*bParticipants younger than age 60 rated this item as significantly more important (p < .05) than did participants age 60 and older.

Sociodemographic and psychological predictors of test intentions were further assessed in a hierarchical regression model. Race, living arrangements, marital status, and health insurance status were excluded from the model for a variety of reasons: (a) Theoretically, some of these factors were not thought to play a significant role in test decision-making, (b) None were significantly correlated with test intentions, and (c) In the case of certain variables (e.g., race, health

Table 5. Correlation Matrix

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Test Intentions</td>
<td></td>
<td>1</td>
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<td></td>
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Note: AD = Alzheimer's disease; Hx = history; Tx = treatment; LOC = Locus of Control.

*0 = Female, 1 = Male.

Higher scores = less caregiving. Higher scores = monitoring; lower scores = blunting.

*p < .05; **p < .01; ***p < .001.
insurance status), there was not enough variability in the sample to warrant analysis. Income level was also excluded because of potential collinearity with education level.

As a group, sociodemographic variables were unrelated to test intentions, $F(3,197) = 2.00, p = .11$. When added to the model, health psychological styles significantly increased its ability to explain variance in intentions, $ΔF(2,195) = 6.05, p < .01$. Adding AD illness representation variables also increased the model’s explanatory ability, $ΔF(5,190) = 3.85, p < .01$. Finally, decisional balance boosted explanatory power most dramatically, $ΔF(1,189) = 132.72, p < .01$. The model's explanatory ability, $ΔF(5,190) = 3.85$, was also excluded because of potential collinearity with statistical significance as predictors. A summary of the relationship between variables is shown in Table 6.

With the study’s exploratory goals in mind, and in an effort to achieve a more parsimonious model, a trimmed model was tested using five predictors. Three of these—gender, perceived threat, and decisional balance—were statistically significant, with information-seeking style and family history nearing statistical significance as predictors. A summary of the analysis appears in Table 6.

With the study’s exploratory goals in mind, and in an effort to achieve a more parsimonious model, a trimmed model was tested using five predictors. Three of these—gender, perceived threat, and decisional balance—were statistically significant, with information-seeking style and family history nearing statistical significance ($p < .08$). The trimmed model explained 50% of the variance in test intentions, roughly as much as the initial hierarchical model, and with six fewer predictors. Table 7 presents a summary of the analysis.

**Discussion**

**Summary of Findings and Implications for AD Health Care**

Results suggest a high level of interest in predictive testing among individuals at risk for AD. In five of six scenarios, a majority of respondents expressed intentions to pursue testing. Similar pretest enthusiasm was also noted before testing for HD and breast cancer became available (Lerman, Seay, Balshem, & Audrain, 1995; Meissen & Berchek, 1988). However, in those cases, most test candidates (especially those at risk for HD) did not actually follow through on their intentions (Lerman et al., 1996; Quaid & Morris, 1993). Rates of test interest here should thus be taken with a grain of salt, given that they are likely to be much greater than actual rates of utilization.

Enthusiasm for AD testing seems due in large part to perceptions that test results will inform later-life planning and future health care, motivate monitoring of treatment developments, and provide desired clarification of disorder risk. Nearly all test pros were rated as more important than any test con. Despite this generally optimistic view, a significant subset of participants expressed concerns about the effects of test results on their insurance, employment, and family's emotional well-being. Perceptions of the costs and benefits of AD testing seem similar to those of testing for other disorders (e.g., Lerman et al., 1996; Meissen & Berchek, 1988). That appraisal of its pros and cons strongly predicted AD test intentions replicates findings from breast cancer research (Jacobsen et al., 1997).

Information on test appraisal should be of use to health care professionals working with populations at risk for AD. Test limitations and risks were generally rated as unimportant (especially by participants age 60 and over), a cause for concern among medical experts who have cautioned against the premature introduction of this option. If these results indeed represent naiveté about its potential drawbacks, then physicians and other health educators may need to be more vigilant in publicizing the limits of AD testing. Also of note to health care professionals, results shed light on who might be likely to seek testing when it becomes available. Whereas sociodemographic characteristics were associated with response to genetic testing for cystic fibrosis and breast cancer (Lerman et al., 1996; Tambor et al., 1994), these factors generally did not predict in-

| Table 6. Summary of Hierarchical Regression Analysis Predicting Test Intentions |
|-----------------------------|---------|---------|-----|
| Variable                    | $b$    | $SEb$   | $β$  |
| **Step 1**                  |         |         |     |
| Age                         | .07     | .05     | .08 |
| Gender                      | 3.57    | 1.17    | .16*|
| Education Level             | .12     | .35     | .02 |
| **Step 2**                  |         |         |     |
| Internal health locus of control | .14    | .16     | .05 |
| Information-seeking style   | .25     | .15     | .09 |
| **Step 3**                  |         |         |     |
| Perceived AD threat         | .33     | .11     | .17**|
| AD treatment optimism       | .02     | .10     | .01 |
| AD knowledge                | -.23    | .30     | -.04|
| AD distress                 | .01     | .10     | .00 |
| AD family history           | -1.00   | .56     | -.09|
| **Step 4**                  |         |         |     |
| Decisional balance          | .62     | .05     | .61***|

$R^2 = .03$ for Step 1; $ΔR^2 = .06$ for Step 2 ($p < .01$); $ΔR^2 = .08$ for Step 3 ($p < .01$); $ΔR^2 = .34$ for Step 4 ($p < .001$). *$p < .05$; **$p < .01$; ***$p < .001$. 

| Table 7. Summary of Trimmed Hierarchical Regression Analysis Predicting Test Intentions |
|-----------------------------|---------|---------|-----|
| Variable                    | $b$    | $SEb$   | $β$  |
| **Step 1**                  |         |         |     |
| Gender                      | 3.74    | 1.14    | .17**|
| **Step 2**                  |         |         |     |
| Information-seeking style   | .26     | .14     | .09 |
| **Step 3**                  |         |         |     |
| Perceived AD threat         | .31     | .10     | .16**|
| AD family history           | -.98    | .55     | -.09|
| **Step 4**                  |         |         |     |
| Decisional balance          | .63     | .05     | .62***|

$R^2 = .02$ for Step 1; $ΔR^2 = .04$ for Step 2 ($p < .01$); $ΔR^2 = .07$ for Step 3 ($p < .01$); $ΔR^2 = .38$ for Step 4 ($p < .001$). *$p < .05$; **$p < .01$; ***$p < .001$. 

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intentions in the current study. One notable exception was gender, with men expressing greater eagerness to be tested than women.

The role of gender in test appraisal is not clearly understood, in part because most recent work on this topic has been breast cancer research using all-female samples. However, studies on carrier and presymptomatic tests for other disorders have shown that women are more likely than men to undergo testing (Marteau & Croyle, 1998). Results here suggest that AD may be a different case, at least in terms of initial interest. Reasons for this may be related to gender differences in test appraisal (Marteau, Dundas, & Axworthy, 1997). As stress and coping theory has pointed out, men and women differ in the ways in which they typically confront stressful situations. Men tend to utilize a problem-solving style, whereas women favor more emotion-focused coping (Lazarus & Folkman, 1984). Men may have demonstrated more test eagerness in this study because predictive testing represents a problem-focused reaction to the stress of being at risk for AD. Their tendency to rely upon denial and minimization as psychological defenses may also have led them to discount more easily the potential negative consequences of testing. Women, meanwhile, may have been more concerned about the emotional repercussions of a positive test result. Indeed, they scored higher than men did on perceptions of AD distress and threat.

Monitoring information-seeking style was, as hypothesized, a significant predictor of test intentions. That is, the dispositional preference to seek out threat-relevant information under stress was associated with interest in testing. This finding suggests that—in addition to situational factors, sociodemographic characteristics, and disorder-specific perceptions—individual personality differences may also influence response to testing.

The most significant predictor of test intentions within illness representations was perceived threat. Participants who were concerned about developing AD—and saw this possibility as likely—tended to desire testing. Although disorder-specific distress and knowledge predicted response to breast cancer testing (Lerman et al., 1996, 1997), these factors were not significant in the case of AD. Optimism about future treatment developments was also unrelated to test intentions.

It remains to be seen whether factors predicting test intentions will also predict test utilization. Although perceived threat may stimulate interest in AD testing, the HD experience suggests that threat will not prompt actual test pursuit. That participants with extensive AD family histories were less enthusiastic about testing supports this notion that high risk for a fatal, incurable disorder deters test seeking. Perceived threat, however, may help determine who would at least consider the option.

In this study, those likely to perceive AD as a greater threat were of younger age. Perhaps this heightened anxiety was because they did not feel as “out of the woods” (i.e., past likely age of onset) with regard to AD as their older counterparts, and because their long-term health care and living arrangements were not as fully resolved. Thus, although age did not directly predict test intentions, it may still be relevant to decision-making as a determinant of perceived disorder threat.

Regarding situational effects on test intentions, results showed that changes in test accuracy, nature of risk information, and (most important) treatment capacities are likely to influence interest in testing. High interest exists among those at risk for the disorder, but only assuming that testing would be accurate and risk information meaningful (i.e., with sharp contrast between positive and negative results). As breakthroughs in AD treatment and genetic research continue to be publicized in the popular press (e.g., Friend, 1996), demand for predictive testing may increase.

Study Limitations and Directions for Future Research

Several limitations should be taken into account when interpreting study results. First, the survey posed hypothetical scenarios and could not fully simulate the emotionally charged dilemma that predictive testing will pose. A more definitive understanding of test appraisal will be possible once the option is actually available. Until then, psychological studies can provide useful information by drawing upon the latest AD research to present plausible and richly detailed hypothetical scenarios (measures developed in this study may be useful in such investigations, although some of these instruments may require more formal validation). Such scenarios may prove too complicated for persons with cognitive impairment, thus it may be necessary in future studies to screen participants for such difficulties. Although survey responses in this study indicated no clear lack of comprehension, it is possible that some of the very old participants had mild impairment that affected their responses.

Another study limitation concerned the make-up of the sample, which differed in important respects from the general population at risk for AD. For example, the sample was disproportionately White and of high socioeconomic status, making it difficult to discern the effects of race and education on test intentions. Participants also differed from the general at-risk population in other notable ways. The study’s recruitment strategy, with its heavy reliance on geriatric medical care facilities for study referrals, tended to include those who were both actively involved in AD caregiving and motivated to participate in research. Such characteristics imply an interest in and experience with AD that may have influenced attitudes toward predictive testing. This selection bias may also account for the fact that so few siblings were included in the study, as siblings are less likely than spouses and children to be directly involved in caregiving (Fitting, Rabins, Lucas, & Eastham, 1986).
In order to be able to generalize results to a larger portion of the population, future research in this area should include a more representative sample of first-degree relatives. If this project is any guide, it may take special efforts to ensure adequate participation of racial and ethnic minorities, relatives not directly involved in caregiving, and persons of lower socioeconomic status. To this end, research partnerships should be sought with geriatric care facilities serving a demographically diverse range of patients with AD. Thompson, Neighbors, Munday, and Jackson (1996) provided several useful guidelines for recruitment of racial and ethnic minorities and establishment of academic-public liaisons within clinical research.

Future research would also do well to go beyond the individual level and examine how families appraise and respond to AD predictive testing. Anecdotal reports suggest that genetic information affects families in profound ways (Wexler, 1995). Leaders in the field have echoed this call for more family-based investigation of stress and coping with regard to genetic testing (Croyle & Lerman, 1995; Marteau, 1995). Such work might benefit from the use of open-ended approaches to data collection.

Conclusion

The current study offers an initial psychological investigation of AD predictive testing, a medical option that millions may one day consider. Understanding what prompts interest in AD testing may guide its eventual implementation. Before such programs can be responsibly offered, however, we must address the profound ethical issues raised by genetic testing, especially that for a prevalent, severe, incurable disorder (e.g., Annas, 1995). Safeguards will be necessary to protect against premature marketing of testing options, genetic discrimination by insurers and employers, and psychologically adverse outcomes for participants (Lapham, Kozma, & Weiss, 1996; Post et al., 1997). The ethical debate surrounding AD predictive testing may be enriched by additional studies that anticipate how those at risk for the disorder will approach this option and how they are likely to be affected by its powerful results. As the bioethicist Kahn concluded (1998, p. 2), “We have the opportunity—and more importantly, the responsibility—to create an environment that will assure the appropriate and effective use of genetic testing. But it is an opportunity whose window is open for a limited time.”

References


