Disclosing the disclosure: Factors associated with communicating the results of genetic susceptibility testing for Alzheimer's disease

Running head: Communication of genetic susceptibility test result

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ABSTRACT

This study explored the extent to which recipients of genetic susceptibility testing for Alzheimer's disease (AD) communicated their results to others. It also examined demographic characteristics, along with beliefs about AD, associated with such communication. Participants (N = 271) in a randomized clinical trial involving genetic testing for Apolipoprotein E (*APOE*) gene variants among first-degree relatives of AD patients reported their communication behaviors 6 weeks after the results disclosure. Information on beliefs about AD and genetic testing was collected at baseline. Eighty-two percent of participants receiving *APOE* genotype information shared their results with someone. Specifically, 64% shared with family members, 51% with spouse or significant others, 35% with friends, and 12% with health care professionals. Greater AD treatment optimism was associated with communicating results to family (*OR*=1.43), spouse (*OR*=1.62), friends (*OR* =1.81), and health care professionals (*OR*=2.20). Lower perceived risk (*OR*=0.98) and higher perceived importance of genetics in the development of AD (*OR*=1.93) were associated with results communication in general. Lower perceived drawbacks of AD genetic testing was associated with results communication to friends (*OR*=0.65). Beliefs about AD risks and causes, genetic testing, and development of treatments may partly determine the interpersonal communication patterns of genetic susceptibility test results.

Key words: Susceptibility genetic testing, Alzheimer's disease, *APOE* communication, disclosure

INTRODUCTION

Genetic information is increasingly being utilized to determine individuals' risk levels for various diseases (Fontanarosa, Pasche, & DeAngelis, 2008). Genetic susceptibility testing for common complex diseases is not widely utilized within clinical health care settings, and there are ongoing debates about the clinical utility of such information (Feero, Guttmacher, & Collins, 2008). However, use of genetic testing for common complex diseases is expected to increase in the context of health care services (Emery, Barlow-Stewart, Metcalfe, & Sullivan, 2007). Currently, thousands of genetic variants are being studied as potential markers associated with increased susceptibility for common diseases that concern a large proportion of the population and have significant public health implications (Christensen & Murray, 2007). Despite concerns about providing genetic risk information without established clinical utility (Burke, 2002; Burke & Zimmern, 2004), genetic testing for some markers associated with common diseases are already available to the public through private companies (Offit, 2008; Wolfberg, 2006).

Studies describing the interpersonal communication of the results for strongly predictive genetic tests for such conditions as Huntington disease (HD), hereditary nonpolyposis colorectal cancer (HNPCC), and hereditary breast and ovarian cancer (HBOC) have been reported (Beery & Williams, 2007; van Oostrom, Meijers-Heijboer, Duivenvoorden, Brocker-Vriends, van Asperen, Sijmons, Seynaeve et al., 2007). These studies showed that recipients of genetic tests shared results with their family members (Di Prospero et al., 2001; Hughes et al., 2002; Patenaude et al., 2006), and that talking to family members may help reduce distress among them (van Oostrom, Meijers-Heijboer, Duivenvoorden, Brocker-Vriends, van Asperen, Sijmons, et al., 2007). However, there are no studies examining the communication of results for weakly predictive genetic susceptibility tests associated with common diseases.

Implications of communicating genetic test results are likely to differ between strongly and weakly predictive tests (Rolland & Williams, 2005). The likelihood of developing the illness is extremely high, in some cases 80 to 90%, among those who are identified to carry a risk version of genes through strongly predictive tests. On the other hand, the results of weakly predictive tests for common genetic polymorphism are more ambiguous because it is likely that the majority of individuals identified to carry a risk version will not develop the condition. For this reason, it is more critical for the results of strongly predictive tests to be communicated to at risk family members especially if effective preventive strategies are available (Jarvinen et al., 2000) so that they themselves may become aware of the risks and get tested. Therefore, psychological impacts of the test results may be more significant for strongly predictive tests because of their high predictability. However, the ambiguous nature of weakly predictive genetic test results also have a potential to cause confusion or distress among test recipients especially if the condition is threatening and strategies to prevent it are limited (e.g., Alzheimer's disease). Thus, investigating the less explored context of weakly predictive genetic susceptibility testing may add valuable knowledge to the literature in understanding potential differential impacts of such genetic information.

Decision to disclose private information is influenced by multiple factors including social and cognitive/emotional factors, as well as individuals' evaluation of the risks and benefits of disclosure (Petronio, 2002). Previous studies of strongly predictive tests have explored sociodemographic factors associated with communication of genetic test results. For example, it was shown that women 40 years or older who underwent *BRCA1/2* predictive genetic tests for HBOC were less likely to share results with their partners (Patenaude et al., 2006). Further, women were more likely to communicate genetic test results for Huntington's disease than men

(Taylor, 2005). Inconsistent reports exist for mutation status. Some studies reported an increase likelihood of communication with family among *BRCA1/2* mutation carriers than among those with uninformative results (Hughes et al., 2002; Wagner Costalas et al., 2003), however, others reported that *BRCA1/2* mutation carriers were less likely to communicate the results to family members (Nippert & Schlegelberger, 2003). Although, no study has compared communication patterns between racial groups, a previous study showed that African American participants were less interested in and endorsed fewer benefits of undergoing genetic testing for Alzheimer's disease compared to White participants (Eckert et al., 2006). It may be that such differences lead to less communication of the genetic test results among African Americans. Taken together, these previous studies suggest that differences may exist in communication patterns of genetic test results among subgroups of population based on age, gender, and race.

Communication of private information has both positive and negative consequences. On the positive side, interpersonal health communication involving health providers, family members, and friends may be indicative of behavioral and emotional coping processes that facilitate the well-being of individuals who have or are at risk for illnesses (Duggan, 2006). Sharing genetic test results with others can facilitate the psychological adaptation to new risk information through social support or medical support (Hughes et al., 2002). A previous study showed that recipients of genetic tests for HNPCC related genes talked about their results to non-biological kin who are not directly affected by the genetic information (Koehly et al., 2003), depicting the potential use of communication to obtain such support. Family health communication, in general, has been shown to benefit individuals' health outcomes through changes in dietary (Rimal & Flora, 1998) and high risk behaviors (Fulkerson et al., 2006). In the context of genetic testing, communicating risk information to family members in particular could

have positive implications by informing family members about their potential genetic risk and ways to reduce it. Furthermore, disclosure of private information allows the validation of the discloser's own perspective and can increase relationship intimacy (Petronio, 2002).

However, disease risk communication within the family could have negative implications as well if some family members do not wish to receive such information. Genetic risk information may influence family relationships negatively if some members feel uncomfortable about sensitive information being discussed, or feel that the information creates unnecessary anxiety within the family (Bates, 2005). The negative impacts of communicating genetic risk information for HBOC or HNPCC on family relationships were documented (van Oostrom et al., 2007). In addition, disclosure of private information also poses risks if it were to become available to unintended people due to the potential for insurance or employment discrimination and stigmatization (Clayton, 2003; Neumann et al., 2001; Wolfberg, 2006). Therefore, individuals are forced to balance their competing needs for disclosure and privacy (Petronio, 2002).

The process of disclosing genetic risk information involves weighing the perceived benefits and drawbacks (Hamilton, Bowers, & Williams, 2005; Hughes et al., 2002). Previous studies explored cognitive factors that may allow test recipients to evaluate the risks and benefits of genetic testing and associated information. It has been reported that perceived responsibility to inform family members (Forrest et al., 2003; Hallowell et al., 2005; McGivern et al., 2004), level of certainty in a given risk estimate (Forrest et al., 2003) and faith in future research (Segal et al., 2004) facilitate communication of the test results. On the other hand, concern about insurance and employment discrimination (Dugan et al., 2003), perceived ability to cope (Taylor, 2005), and desire to protect relatives from distress (Dugan et al., 2003; MacDonald et al., 2007;

McGivern et al., 2004) were found to discourage communication regarding genetic tests. Therefore, various cognitive factors about the illness and its associated genetic test are likely to influence the way individuals decide whether or not to communicate their test results.

The Apolipoprotein E (*APOE*) *ε4* genotype has been well-established as a genetic risk marker for late-onset Alzheimer's disease (AD) (Farrer et al., 1997) and cognitive decline (Bretsky, Guralnik, Launer, Albert, & Seeman, 2003; Packard et al., 2007). About 25% of the U.S. population carries at least one copy of the *APOE ε4* allele and individuals that carry one or two copies of the *APOE ε4* allele are at 2.6 and 14.9 times higher increased risk, respectively, for developing the disease (Farrer et al., 1997). Clinical use of the *APOE* genetic test for predictive purposes in asymptomatic individuals is currently not recommended due to concerns about the impact of disclosure when no disease-modifying interventions are available (Brodaty et al., 1995; Post et al., 1997; Relkin, 1996). However, the medical value of this information is likely to increase as new strategies are identified that may reduce risk of AD (Hendrie et al., 2006). Due to a lack of preventive strategies for AD and low predictive ability of the test, the implications of the results communication is unclear. However, some recipients may wish to communicate the results to obtain social support because risk information can be threatening to them.

The objectives of this report were: (1) to evaluate the extent to which individuals who received *APOE* genetic test results communicate about their results to others (family, spouse/partner, friend, health professional); and (2) to identify the AD-related cognitions or beliefs that are associated with such communication. Sociodemographic factors identified in previous research were considered as covariates and the significance of their associations with the outcomes were also evaluated. Understanding whether and with whom genetic susceptibility

test recipients share their test results, and the factors associated with such communication, can provide valuable information to the future health practices that involve genetic risk information.

MATERIALS AND METHODS

Participants and Procedures

The *REVEAL* Study is a series of randomized controlled trials that evaluate the feasibility, safety, psychological impacts, and behavioral outcomes of *APOE* genetic testing and disclosure. This paper presents the results of secondary data analyses that consider participants, in the second iteration of the REVEAL study (*REVEAL II*), who received *APOE* genetic testing and risk assessment based on age, gender, ethnicity, family history and *APOE* genotype. This trial was conducted at Boston University, Case Western Reserve University, Cornell University, and Howard University and involved adult children of living or deceased individuals with AD that developed after the age of 60. Participants were recruited through advertisement (34%), referrals from the study personnel (30%), research registries (13%), word of mouth (12%), and community presentations (11%). This study included 19% African American participants, which is notable because of the general under-representation of this population in the field of genetic research. All participants were English speaking and had screening to rule out cognitive impairment or clinically significant depression or anxiety. A certificate of confidentiality was issued to this study by the National Institutes of Health, and participants were assured of the researchers' best efforts to protect their privacy and confidentiality.

After baseline assessments were completed, the participants received genetic education and counseling followed by testing for *APOE*. Both *APOE* test results and estimated lifetime risk of disease were disclosed in either an extended (three in-person visits) or a condensed (one

in-person visit was replaced by an educational brochure) protocol with a genetic counselor or a physician. Follow-up assessments occurred at six weeks, six months, and one year post-disclosure. The randomization status of the disclosure condition was treated as one of the covariates. Participants who received a risk assessment, provided information regarding communication about the *APOE* testing results at 6 weeks, and self identified themselves as White or African American ($N = 271$) were included in the analyses. Four participants who identified themselves as Asian (2), American Indian (1), and 'other' (1) were excluded.

Measures

Communication of APOE genetic test results. These outcome variables were measured by asking "Have you told anyone the results of your *APOE* genetic test?" followed by a group of questions specifying, "Who did you tell about the results of your *APOE* genetic test: family member, spouse/significant other, friends, health professional?" Responses obtained at the first follow-up assessment (6-week) were used because there is evidence that genetic test recipients tend to share their results soon after receiving them (Segal et al., 2004).

Benefits and drawbacks of genetic testing for AD. Participants rated *benefits* and *drawbacks* of undergoing genetic testing for *APOE* using items derived from previous work (Green, Clarke, Thompson, Woodard, & Letz, 1997; Roberts, 2000). Each item assessed the extent to which participants felt a particular reason was important (1 = "not at all" to 5 = "extremely"). Levels of perceived benefits (Cronbach $\alpha = 0.84$) and drawbacks (Cronbach $\alpha = 0.81$) of genetic testing were calculated by taking the averages of respective items (9 items in each scale: see Table 1 for a list of items).

Causal beliefs. Two items were used to assess participants' perceptions of the importance of genetics/heredity or lifestyle factors in increasing the risk of AD (How important

is [genetics/heredity or lifestyle] in increasing risk of AD?: 1 = "not important" to 5 = "very important") (Roberts & Connell, 2000). These items were considered individually in the analyses.

AD treatment optimism. A six-item scale that assessed the extent to which participants agreed with statements about the likelihood that a cure, prevention, or treatment strategies would be developed within the next 5 years and during their lifetime (1 = "strongly disagree" to 5 = "strongly agree") was used (Roberts & Connell, 2000). An average was taken to obtain a scale score ($\alpha = 0.85$).

AD concern. Three previously used items (Roberts & Connell, 2000) assessed the extent to which participants agreed with statements about their concern that they would develop AD, that they would develop it in the next 5 years or at some point later in their lives (1 = "strongly disagree" to 5 = "strongly agree"). Two additional items asked about their feelings that they would someday develop AD and the extent to which participants felt that AD was the worst disease they could think of. The Cronbach alpha for this five-item scale was 0.67.

Perceived risk of developing AD. Participants were asked to rate their belief regarding their own chances of developing AD on a scale of 0 to 100%.

Demographic characteristics. Age, years of education, gender, race, marital status were assessed through self-report at baseline. The age variable was dichotomized (60 years or older vs. younger) because incidence of AD starts to increase at age 60 (Farrer et al., 1997) and test results are likely to have more immediate implications to older individuals. This decision was based on the finding of a previous study showing that women 40 years, at which HBOC related conditions can develop, or older who underwent *BRCA1/2* genetic tests were less likely to share results with their partners (Patenaude et al., 2006). An indicator variable was created for White

participants. This study had participants who were generally highly educated (about 70% with a college degree or more). Thus, the education variable was dichotomized (16 years and up) based on the distribution of the sample. Genotype status was coded to indicate whether a participant was found to carry at least one *APOE ε4* allele. Information on demographic characteristics and beliefs about AD was obtained at baseline before participants underwent genetic testing.

Analyses

Frequencies were obtained to describe the extent to which participants communicated the *APOE* test results to others. Five logistic regression models were fitted, one for each of the outcome variables (i.e. communication to anyone, family, spouse, friends, and health professional), to evaluate the associations between the outcome variables and AD beliefs, as well as sociodemographic variables. The demographic variables (age, education, gender, race, marital status) along with genotype and randomization status (i.e., extended vs. condensed protocol) were considered covariates and included in each model. The primary predictors, AD belief variables, were entered in a forward stepwise selection manner based on the significance levels of the estimated coefficients while controlling for covariates, in order to ensure that the variables most prominently associated with the outcomes are prioritized. AD belief variables that were statistically significant based on a Type I error rate of .05 were included in the final models along with all covariates, and 95% confidence intervals were constructed for all statistically significant effects. All statistical analyses were conducted using the Statistical Package for the Social Sciences, Version 14.0 (SPSS, 2005).

RESULTS

Demographic characteristics of the 271 participants considered in this study are presented in Table 2. The mean age of the participants was 58.2 (*SD* = 10.5) ranging from 33 to 86. On average, participants completed 16.1 years of education (*SD* = 2.5). A majority of the participants identified themselves as White (81.5%). Forty-one percent of the participants were found to have at least one *APOE ε4* allele, and 69% of those were under 60 years of age. Descriptive statistics for the outcome variables are presented in Table 3. Over 80% of participants reported that they had told someone about their *APOE* test results after receiving their risk assessment, among those 57% were under the age of 60 years. Participants reported that they shared their results with family members (64%), their spouse or significant other (51% overall or 82% of those who were married or had a partner), friends (35%), and health professionals (12%). Table 4 contains descriptive information on beliefs about AD. On average, participants perceived their risk of developing AD as 51% (*SD* = 22.4, ranging from 0% to 100%) prior to the education and disclosure process.

The final models of the five logistic regression analyses are presented in Table 5. Participants who perceived lower levels of perceived risk of AD [OR = 0.98, CI(0.97, 0.99), $p = .03$] and higher levels of beliefs about the importance of genetics in the development of AD [OR = 1.93, CI(1.26, 2.95), $p < .01$] were significantly more likely to talk to someone about their results. Higher perceived optimism about the development of a cure or treatment for AD was significantly associated with a greater likelihood of participants' sharing results with their family [OR = 1.43, CI(1.00, 2.03), $p = .05$], spouses or significant others [OR = 1.62, CI(1.09, 2.41), $p = .02$], friend [OR = 1.81, CI(1.22, 2.69), $p < .01$], and health professional [OR = 2.20, CI(1.20, 4.04), $p = .01$]. Participants who reported lower levels of perceived drawbacks of genetic testing for AD was significantly more likely to tell their friends about the test results [OR = 0.65,

CI(0.42, 1.00), $p = .05$]. Other types of AD beliefs (concern about developing AD, perceived benefits of genetic testing for AD, and causal beliefs that lifestyle is important in the development of AD) were not associated with whether participants communicated their *APOE* test results.

The results also indicate that female participants were roughly twice as likely as males to talk about their *APOE* test result with their families [OR = 2.03, CI(1.12, 3.69), $p = .02$]. White participants [OR = 2.67, CI(1.21, 5.92), $p = .02$], and those with more than college education [OR = 2.04, CI(1.10, 3.78), $p = .02$], were more likely to tell their friends about the *APOE* test results than African American or less well educated participants, respectively. Those with more than a college education [OR = 2.01, CI(1.14, 3.55), $p = .02$] and older than 60 years of age [OR = 1.76, CI(1.01, 3.08), $p = .05$] were also more likely to tell their family. Participants who received a condensed disclosure session were more likely to share their test results with health professionals than those who received an extended disclosure session [OR = 5.19, CI(1.50, 17.89), $p < .01$]. *APOE* genotype was not significantly associated with whether participants communicated their test results with others.

DISCUSSION

This is the first study to report patterns of results communication among the recipients of genetic susceptibility testing for a common disease polymorphism. Results of this study showed that over 80% of the participants who underwent genetic testing for *APOE* communicated about their test results with others, most frequently to family and spouse. Furthermore, various sociodemographic and cognitive factors regarding AD were associated with communication patterns.

Comparing our findings to those from other studies suggests that genetic test recipients commonly share their results with others, regardless of whether they underwent strongly predictive genetic testing (Smith, Lipe, & Bird, 2004) or a less predictive susceptibility testing such as *APOE ε4* genotyping. In our study, family members and spouses or significant others were more likely to be informed of the results by participants than individuals outside of the family. This may be due to the closeness of family members, as well as the participants' efforts to prepare family members for future illness they may encounter or the potential future heritable illness among other family members (Roberts et al., 2003). It also may reflect attempts to obtain social support to cope with the new risk information (Petronio, 2002). Regardless of the reasons, this finding suggests that provision of susceptibility genetic testing results impacts not only test recipients but also their family members through communication. When genetic risk information is shared, family members' perceptions about the health of the tested individual may be altered, or biological family members could become concerned about their own genetic risks (Rolland & Williams, 2005). Future studies may consider the possible detrimental and positive effects of genetic susceptibility information on family members of test recipients.

More than one-third of the participants reported that they had shared the results with friends. In a previous study, about 20% of the communication and support networks of individuals affected by HNPCC was non-biological social ties (Koehly et al., 2003). Having these individuals in social support networks were also found to be important to the psychological well-being of *BRCA1/2* genetic test recipients (Koehly et al., 2008). Sharing test results with those without biological links may be an indication that participants were trying to obtain social support (Hughes et al., 2002). Understanding the extent to which such support seeking behavior

occurs and the role of results communication in psychological adaptation after disclosure can help develop strategies to facilitate well-being among test recipients.

Although studies of *BRCA1/2* testing for hereditary breast and ovarian cancer (HBOC) showed that mutation carriers were more (Hughes et al., 2002; Nippert & Schlegelberger, 2003; Wagner Costalas et al., 2003) or less (Nippert & Schlegelberger, 2003) likely to communicate results to family than those who received uninformative results, in our study, genotype was not associated with whether participants shared their test results. This distinction may reflect the difference in the predictive ability of the genetic testing for HBOC versus susceptibility testing for AD or the absence of medical interventions for AD. In our study, other factors, like gender and beliefs about the disease, played more prominent roles than genotype in whether or not participants communicated their genetic testing results.

Consistent with the finding of previous studies about communication of genetic test results for HBOC (Patenaude et al., 2006) and Huntington disease (Taylor, 2005), male participants were less likely to communicate their *APOE* test results with family members. This suggests a gender difference in communication of genetic information within families regardless of the genetic risk levels. As expected based on a previous report that African American participants perceiving less benefits of genetic testing for AD (Eckert et al., 2006), White participants in our study were more likely to share their results with friends than African American participants. Further research on reasons for the lower likelihood of communication among some subgroups would help future efforts to facilitate communication if that becomes desired.

Participants who received disclosure in a condensed protocol were more likely to share test results with their health professionals. The primary aim of the *REVEAL II* study was to

assess the safety of disclosing *APOE* test results in a clinically feasible protocol (condensed). This current report shows that participants may seek additional in-person encounters with health professionals to discuss their test results when results were disclosed in this manner. The growth of consumer based genetic susceptibility testing that involves results disclosure over internet or telephone, combined with the limited availability of genetic counselors suggests that many of these consumers may turn to their health professionals for additional information and assistance. However, physicians generally report feeling uncomfortable discussing topics related to genetics or possessing insufficient knowledge to do so (Burke & Emery, 2002; Menasha, Schechter, & Willner, 2000). This suggests need for programs to assist physicians in providing accurate information about genetic testing and risks, and in addressing psychological problems test recipients may experience.

Our results showed that optimism about the development of a cure and treatment was associated with results communication to family, spouse/partner, friends, and health-care providers, suggesting that when a cure and/or treatment for AD becomes available, test recipients may more openly discuss their own *APOE* test results. Thus, genetic susceptibility information for conditions for which effective prevention and treatment strategies are available is likely to be communicated more than *APOE* results. In fact, over 90% of the *BRCA1/2* test recipients who were identified as carriers shared results with their mothers (Patenaude et al., 2006) and sisters (Hughes et al., 2002; Patenaude et al., 2006), as compared to 64% in our study that shared results with their family members.

The levels of perceived benefits of testing were not associated with communication outcomes. This may have been due to low variability as all participants had decided to undergo *APOE* testing in this study and reported rather high levels of perceived benefits. Our findings

suggest that placing more emphasis on the potential social threats associated with genetic risk information during counseling may lead to less communication. Disclosure of genetic information can potentially be harmful if the information was used to limit individuals' ability to obtain insurance or employment (Clayton, 2003). As part of the informed consent procedure in this study, participants were informed about the potential impact of testing result on privacy. Inclusion of a thorough discussion about this issue during genetic counseling may help recipients make more cautious decisions about whether and to whom they disclose their test results. A previous study showed that individuals who received positive *APOE* result were more likely to purchase long-term care insurance (Zick et al., 2005). Given that the Genetic Information Non-Discrimination Act does not protect against discrimination in long-term care insurance coverage, informing test recipients of this limitation seems important.

Although a previous survey of a random sample of adults in U.S. found that 86% of survey participants reported that they would trust their doctors with their genetic test results (Genetics and Public Policy Center, 2007), only 12% in our study shared their results with health professionals. It may be that a 6-week follow-up period was not long enough for the test recipients to visit and discuss the results with their health care providers. However, this lower rate may also reflect participants' awareness and concern about the potential privacy issue or the awareness about the limited utility in communicating the information with health care providers due to lack of preventative strategies. Issues of privacy and confidentiality are becoming even more pressing as genetic testing services are increasingly available through private companies (Offit, 2008; Wolfberg, 2006), as some have argued, genetic privacy is becoming increasingly difficult or impossible to guarantee (Lunshof, Chadwick, Vorhaus, & Church, 2008).

Previous studies on strongly predictive genetic testing have identified other predictors of communicating genetic test results such as a feeling of responsibility to inform family members (Forrest et al., 2003; Hallowell et al., 2005), quality of interpersonal relationships (Claes et al., 2003; Dugan et al., 2003), and family characteristics (Forrest et al., 2003; Koehly et al., 2003). In addition, desire to prevent psychological distress among family members was reported as one of the barriers to family communication of *BRCA1/2* results (Clarke et al., 2005). Because providing care to AD patients is a large part of life for families affected by this disease, a desire to prevent distress associated with an anticipated need for care may determine whether *APOE* test results are shared within families. Conducting studies that explore the roles of such psychosocial factors in influencing communication of *APOE* test results will enhance our understanding about the impact of genetic susceptibility testing on individuals and their families.

The survey items used in this study did not make a distinction between communicating results to biological and non-biological family members or between children and other family members. However, in other studies, results of predictive genetic testing were more likely to be communicated to first-degree relatives than to other relatives (MacDonald et al., 2007; Tucker et al., 2006). Selective communication of results was also reported among those affected by Huntington Disease (Hamilton et al., 2005). Future studies should investigate whether susceptibility genetic test recipients communicate results in a similar selective manner. Participants in this study indicated their perceived chances of developing AD in percentages. However, literature in health risk communication shows that people have limited ability to interpret risk estimates using proportions (Hoffrage, Lindsey, Hertwig, & Gigerenzer, 2000) and that people frequently misunderstand numerical information (Kahneman, Slovic, & Tversky, 1982). It has been shown that there is great variability in the way people respond to probability-

based risk information (Rothman & Kiviniemi, 1999), and little is known about how people construct their own risk estimate for developing an illness. Future studies may consider alternative ways to measure perceived risk. Finally, a majority of participants in this study were female and highly educated, limiting the generalizability of the results to a larger population who may choose to undergo *APOE* testing in the future.

Conclusion

This is the first study that empirically evaluated the extent to which individuals receiving a genetic susceptibility test communicated their test results to others. The results showed that a majority of the individuals who underwent *APOE* testing shared the results with others, especially with members of their families. The findings of this study provide insights into what the recipients of susceptibility genetic testing do with the information obtained, and suggest the need for additional research to further understand disclosure patterns by considering additional individual and social factors. Knowledge about the patterns of and factors associated with communication of genetic susceptibility information is likely to inform future public health practices as more genetic variants associated with common diseases becomes available (Feero et al., 2008; Scott et al., 2007). Conducting research on the role of communication in influencing health promoting behaviors of susceptibility genetic test recipients as well as their family members will help assess the potential utility of public health interventions using genetic risk information.

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Table 1. Items used to evaluate perceived benefits and drawbacks of undergoing genetic testing for AD

Benefits of genetic testing for AD
To prepare my family for my possible illness
To arrange my personal affairs
To start doing things sooner than I had planned to
To know more about my risk in case better treatments become available
To make arrangements for my long-term care
To give information about my children's possible risk of AD
To put my mind at ease if I found out I was not at risk for AD
To confirm the feeling that I might already be developing AD
To seek information on preventive measures (lifestyle changes)
Drawbacks of genetic testing
It would be too upsetting to find out I'm at risk for AD
Test does not give definite answer about whether I might get AD
Test procedure would be too burdensome
It could make me worry about my children's risk of getting AD
The test results might upset my loved ones
The results could change how people look or act towards me
The results could affect my employment
There is no way to cure or prevent AD
My family does not think it is a good idea for me

Note: Three benefit items and one drawback item from the original scales were excluded because the results of factor analysis indicated that they had factor loadings that were lower than a predetermined level (0.40).

Table 2. Demographic characteristics of the sample ($N = 271$)

	Yes
Age 60 years and older	41.7%
Education: 16 years or more	68.6%
Male	29.5%
White	81.5%
Married	60.9%
Carrier of ε4 allele	41.0%
Extended disclosure protocol	32.8%

Table 3. Frequencies of communication of *APOE* genetic test results ($N = 271$)

	Yes
Have you told **anyone** the results of your *APOE* genetic test?	81.5%
Who did you tell about the results of your *APOE* genetic test: **family member**?	63.8%
Who did you tell about the results of your *APOE* genetic test: **spouse or significant other**?	50.9%
Who did you tell about the results of your *APOE* genetic test: **friends**?	34.7%
Who did you tell about the results of your *APOE* genetic test: **health professional**?	12.2%

Table 4. Perceptions and beliefs about AD at baseline

	Mean	*(SD)*
Benefits of genetic testing for AD	3.51	(0.80)
Drawbacks of genetic testing for AD	1.78	(0.64)
Causal attribution of AD: genetics/heredity	4.08	(0.85)
Causal attribution of AD: lifestyle	3.50	(1.11)
AD optimism	3.66	(0.74)
AD concern	3.41	(0.69)
Perceived risk of developing AD (%)	51.35	(22.41)

Table 5. Final models: Odds ratios and 95% confidence intervals when significant at $p = 0.05$ ($N = 271$)

	Anyone	Family	Spouse/ significant other	Friend	Health professional
Age: 60 and older	1.41	1.76* (1.01, 3.08)	1.42	0.73	1.36
Education: 16 years and up	1.68	2.01* (1.14, 3.55)	1.70	2.04* (1.10, 3.78)	1.01
Female	1.39	2.03* (1.12, 3.69)	1.87	1.84	2.25
White	1.51	1.06	1.89	2.67* (1.21, 5.92)	1.18
Married	1.17	1.31	11.90*** (6.21, 22.81)	0.52* (0.29, 0.92)	0.68
Carrier of *ε4* allele	0.76	0.80	0.98	0.78	1.23
Condensed disclosure	1.23	1.37	0.89	1.44	5.19** (1.50, 17.89)
Drawbacks of genetic testing	NS	NS	NS	0.65* (0.42, 1.00)	NS
AD optimism	NS	1.43* (1.00, 2.03)	1.62* (1.09, 2.41)	1.81** (1.22, 2.69)	2.20** (1.20, 4.04)
Perceived risk	0.98* (0.97, 0.99)	NS	NS	NS	NS
Causal attribution to genetics	1.93** (1.26, 2.95)	NS	NS	NS	NS

*$p < .05$, **$p < .01$, ***$p < .001$

1. Each column represents an individual model for each outcome; 2. A horizontal line below 'Condensed disclosure' indicates the distinction between covariates (above the line) and AD-belief variables (below the line); 3. AD-belief variable that were not significant in any of the models are not presented in this table; 4. NS indicates that indicated AD-belief variable was not significant in the relevant model, thus not included in the final model.

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