UTILIZATION OF CONJOINT ANALYSIS TO ELICIT PREFERENCES FOR GENETIC

TESTING FOR ALZHEIMER'S DISEASE

by

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(Under the Direction of Matthew Perri)

ABSTRACT

Alzheimer's disease (AD) was the seventh-leading cause of death in the US in 2006. With the advent of predictive genetic tests, people will have the option to investigate their future risk of developing diseases like AD. This knowledge can benefit people as they can start to prepare themselves as well as their families. In order to align the clinical practice of using predictive AD genetic with patient values and preferences, this study was conducted to estimate societal preferences and perceived values placed on AD genetic tests. This study also evaluated public awareness of the Genetic Information Nondiscrimination Act (GINA) of 2008 which prohibits genetic discrimination in health insurance and employment. Consumers need to understand GINA so they can take advantage of the protections it provides against genetic discrimination.

An anonymous online survey was distributed by Qualtrics® to a general population panel aged 18-64 in April 2011. The 17 item survey included a rating conjoint analysis to assess public preferences for AD genetic testing and two multiple choice questions to measure public awareness and knowledge of GINA. A total of 295 responses were collected over four days. On average, respondents placed more importance on predictive accuracy than either treatment availability or result anonymity. Even without a cure for AD, people still placed a high

preference on a predictive test with a 100% predictive value, and were still willing to pay for it. These results suggest that patients find value in having a reasonable estimate regarding their future chance of developing AD, even without a treatment. Value may arise from having an opportunity to make informed future plans or from a reduction in uncertainty. Four groups with differing attribute importance patterns were identified using cluster analysis.

Twenty-six respondents indicated they had ever heard of GINA and only 10 people could correctly identify that GINA 2008 prohibits the improper use of genetic information in health insurance and employment. Three years after GINA 2008 was signed, public awareness of this law is low. More effective dissemination of information related to this federal law may be required to improve protection against genetic discrimination.

INDEX WORDS: Predictive genetic test, Alzheimer's disease, Conjoint analysis, Preferences, Willingness-to-pay, Genetic Information Nondiscrimination Act (GINA), Awareness

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CHAPTER 1

INTRODUCTION

1.1. Alzheimer's Disease

Alzheimer's disease was the seventh-leading cause of death in the US in 2006 (Heron et al.,

2009). The number of Americans with Alzheimer's disease is estimated to be 4.5 million and

expected to increase to 13.2 million by 2050 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003).

Alzheimer's disease is the most prevalent form of dementia and accounts for 69.9% of dementia

cases (Plassman et al., 2007). The etiology of Alzheimer's disease is unknown and the

progressive changes in Alzheimer's disease include changes in memory, orientation,

concentration and calculation ability, language abilities, the ability to draw figures and the loss of

various functional capacities (Emilien et al., 2004). Currently, there is no cure or effective means

of preventing the onset of Alzheimer's disease. Yet, several drugs have been approved by the

U.S. Food and Drug Administration for the short term treatment of cognitive deficits in

Alzheimer's disease. Further, there is some evidence that aerobic exercise, mental exercises,

foods and/or dietary supplements, moderate amounts of wine or other alcohol and medications

such as cholesterol-lowering agents may work to slow the onset of or possibly prevent

Alzheimer's disease (Caselli, Beach, Yaari, & Reiman, 2006).

1.2. Predictive Genetic Testing

Genetic testing is "the analysis of human DNA, RNA, chromosomes, proteins, and certain

metabolites in order to detect heritable disease-related genotypes, mutations, phenotypes, or

karyotypes for clinical purposes. Such purposes include predicting risk of disease, identifying carriers, and establishing prenatal and clinical diagnosis or prognosis"(Holtzman & Watson, 1999). Genetic tests generally fall into three categories: diagnostic tests, predictive tests and tests for reproductive decisions (McPherson, 2006). Predictive tests are probably the most controversial because the information usually comes with uncertainty and is difficult to understand without proper genetic consultation. Analytical validity, clinical validity, clinical utility and the ethical/legal/social implications are critical for the evaluation of predictive genetic testing (Zimmern & Kroese, 2007).

While a relatively new phenomenon in health care, there has been some research focusing, for example, on the genome-based prediction of colorectal cancer, breast/ovarian cancers, Alzheimer's disease, cystic fibrosis, type 2 diabetes, coronary heart disease, sickle cell anemia and Down's syndrome (Burke, 2002; Heshka, Palleschi, Howley, Wilson, & Wells, 2008; Janssens & van Duijn, 2009). With respect to these and other genetic tests, genetic screenings for susceptibility to these disorders lack predictive values because of a high proportion of false-positive and false-negative results (Holtzman, 2006).

The cost of genetic testing can range from under $100 to more than $2,000, depending on the complexity of the testing and whether the company holds a patent for the test (Berg & Fryer-Edwards, 2008; Holtzman, 2006). When genetic tests are recommended by physicians for a medically valid reason, the cost may be covered by private insurance (Berg & Fryer-Edwards, 2008); however, public insurance such as Medicare and Medicaid generally does not cover predictive genetic testing in the absence of past or present illness. Screening services used to

detect an undiagnosed disease or disease predispositions such as predictive genetic testing are not covered by Medicare (Center for Medicare and Medicaid Services).

1.3. Genetic Aspects of Alzheimer's Disease

Alzheimer's disease appears in two versions, early onset (familial) and late-onset (sporadic). Early onset Alzheimer's disease usually develops in the 40s or early 50s and represents no more than 5% of all AD cases. Mutations in three genes (APP, PSEN1, and PSEN2) are rare and are deterministic factors for early-onset AD. Late-onset AD is characterized as onset past age 65, and accounts for 95% of AD cases. There is only one genetic variant to date that has been established to significantly increase the risk of developing late-onset AD -- the APOE ε4 allele. The increased relative risk is about 3-fold for people who carry one ε4 allele (heterozygous), and almost 15-fold for people who carry two ε4 alleles (homozygous) when compared to those possessing two ε3 alleles; however, the APOE ε4 allele is neither necessary, nor sufficient to actually cause the disease and APOE ε4 testing is currently not recommended for disease prediction (Emilien, et al., 2004; Serretti, Olgiati, & De Ronchi, 2007; Sisodia & Tanze, 2007).

Even though genetic testing for the APOE ε4 allele is not currently recommended, it is believed that tests with higher predictive value and more effective treatments will emerge in the future (Ritchie & Lovestone, 2002; Serretti, et al., 2007; Sisodia & Tanze, 2007). This research will develop an understanding of societal preferences and perceived values placed on predictive genetic testing for Alzheimer's disease. Information from this study will provide information needed for developing screening strategies and implementation in the future.

1.4. Using Conjoint Analysis in Health Care to Elicit People's Preferences

1.4.1. Conjoint Analysis

Conjoint analysis is a method used to elicit or quantify consumer preferences for various attributes of a product/service (ISPOR Conjoint Analysis in Health Good Research Practices Task Force, 2009). It is an attribute-based survey method that estimates utility by measuring the benefits of various features. Respondents are presented with a sequence of hypothetical scenarios that vary along several attributes (M. Ryan, Gerard, & Amaya-Amaya, 2008). Within health economics, this technique has been applied in a number of areas to elicit patient/community preferences, to evaluate health states, to determine optimal treatments for patients, and to derive willingness-to-pay (Champ, Boyle, & Brown, 2003; Hanley, Ryan, & Wright, 2003).

There are several stages in the design and analysis of conjoint analysis, specifically to: 1) identify the attributes and attribute levels to include in the study; 2) choose the presentation of the scenarios (rating, ranking, or choice); 3) produce a survey instrument, 4) elicit preferences; and 5) analyze the responses (ISPOR Conjoint Analysis in Health Good Research Practices Task Force, 2009; Lloyd, McIntosh, & Price, 2005; M. Ryan, et al., 2008; M. Ryan & Hughes, 1997).

1.4.2. Applying Conjoint Analysis in Healthcare

The use of conjoint analysis in healthcare has increased dramatically in recent years (Bridges, Kinter, Kidane, Heinzen, & McCormick, 2008; M. Ryan, et al., 2008; M. Ryan et al., 2001). By using conjoint analysis, non-health outcomes (such as the benefit resulting from the provision of information, reassurance, autonomy or dignity in the provision of care) and process attributes

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(such as waiting time, location of treatment, or staff attitudes) can be incorporated into the assessment of the benefits of a particular health care service or intervention. The inclusion of non-health outcomes and process variables has augmented our understanding of utility for health care services (M. Ryan, et al., 2008).

The potential uses for conjoint analysis in healthcare include assisting in the understanding of the optimal combination of features for a product or service, the relative contributions of individual features to overall product evaluation, opportunities for products not currently offered, the effect of eliminating costly features on product demand, variations in consumer preference, and willingness to pay for a service or product (Mele, 2008). For example, Ryan used a choice-based conjoint that included the attributes "attitudes of staff toward you", "continuity of contact with same staff", " time on waiting list", "cost", " chance of taking home a baby", and "follow-up support" to elicit people's preferences for in vitro fertilization and estimated willingness to pay for this service indirectly. By using conjoint analysis, this study included the non-health attributes and found that people could benefit from non-health outcomes in healthcare service (M. Ryan, 1999).

1.5. From Individual Preferences to Public Preferences

From a societal perspective, designing genetic testing based on public preferences could result in increased usage of testing and potentially improve both health and non-health outcomes. Even though at present we do not have proven methods to prevent or cure Alzheimer's disease, patients may benefit from the knowledge that the genetic testing can provide. For example, consumers could seek to purchase medical/long-term care insurance or opt to spend more quality

time with their families if they knew they were at high risk for developing AD. Research in this field is progressing rapidly and there are many promising treatments in development. The results of a conjoint analysis will also help policy makers design optimal strategies for testing/screening for Alzheimer's disease as improved genetic testing, or perhaps even a cure, becomes available.

CHAPTER 2

LITERATURE REVIEW

Aligning the clinical practice of predictive genetic testing for Alzheimer's disease with patient values and preferences has the potential to improve healthcare delivery. Little, however, is known about community preferences for genetic Alzheimer's disease (AD) testing. In the following literature review, I discuss the issues regarding people's preference when making a decision to test for AD or not. These issues include prediction value (i.e. false-positive/false-negative results), availability of treatments that would prevent or delay onset of AD, and anonymity/confidentiality. The prediction value of the AD genetic test can help people know how confident they can be with the result. The treatment availability for AD impacts people's health outcomes, quality of life, and future plans. Another important issue is anonymity/confidentiality, which brings concerns about discrimination in health insurance and employment.

This research tests twelve different combinations of the above three features of the AD genetic test. The study results will help in understanding people's preferences, which can have implications for individual decision making such as personal affairs arrangement, purchase of insurance and long-term care, or family's preparation for possible future illness. By learning community preferences, healthcare professionals can provide services which more closely fulfill patient/customer need. Policy makers can also design optimal testing/screening strategies for Alzheimer's disease.

2.1. Predictive Value of the Genetic Testing for Alzheimer's Disease

How well the test can predict the risk of developing AD plays an important role in the decision making process. Owing to low sensitivity/specificity and uncertain causality of the disease, genetic risk information in AD testing can have predictive value as low as 42%, which means the result will be true in only 42% of cases (Saunders et al., 1996). One study asked physicians about the minimal predictive value of AD genetic tests suitable to be used in clinical practice: the responses ranged from 20% to 100% with a median of 80% (Chase, Geller, Havstad, Holtzman, & Bassett, 2002). As for the opinion from relatives of people with AD, Green et al. used a convenience sample of people ages 22 -77 and found that even if the tests were only 60% accurate, 35% of people surveyed would still choose to take the test (Green, Clarke, Thompson, Woodard, & Letz, 1997). Bassett et al. found that among offspring of people with AD, only 20% would not obtain any predictive testing and more than 40% of respondents would accept tests with imperfect sensitivity /specificity as low as 30% (Bassett, Havstad, & Chase, 2004). Neumann et al. used a general population sample and found 45% of respondents stated that they would take a predictive genetic test for AD when the test result has a 90% chance to be correct (Neumann et al., 2001).

2.2. Treatment Availability for Alzheimer's Disease

Availability of treatment options for Alzheimer's disease is also essential to people's decision regarding genetic testing for AD. To date, there is still no cure for Alzheimer's disease, but several drugs may temporarily help with the symptoms and improve quality of life for up to 24 months. Complementary options such as mental training, physical exercise, sensory stimulation

and regular leisure activity can also help to decrease behavioral problems (Richter & Richter, 2004). With the understanding of limited treatment options, 77.8% of participants still desired to take the test (Roberts, 2000). One qualitative study showed that a genetic test for AD could still be beneficial to at-risk individuals and their family by helping them cope with emotional responses and plan the future (Gooding et al., 2006).

2.3. Anonymity/Confidentiality Issue Regarding the Genetic Testing for Alzheimer's Disease

Concerns about discrimination in health insurance and employment may also influence one's decision to obtain a genetic test for AD. In a study regarding reasons for seeking genetic susceptibility testing, Roberts et al. found 34.3 % of people thought it was risky to take a genetic test for AD because their insurance company or employer might find out the test results and use them to discriminate against the patients (Roberts, 2000). Neumann et al. also found 31.8% of respondents worried about others gaining access to their test results (Neumann, et al., 2001). The previous findings pointed out that anonymity might also play an important role for decision making when obtaining a predictive genetic test for AD. Although the Genetic Information Nondiscrimination Act (GINA) signed by President Bush in 2008 forbids discrimination based on genetic information in health insurance and employment, it is not clear whether people's concerns about genetic discrimination have changed since the law passed. The studies described above were all done before 2008. GINA prohibits health insurers from requesting genetic testing from customers for decisions about coverage eligibility or premiums. It also prohibits employers from using genetic information for hiring or discharge decisions ("Genetic Information

Nondiscrimination Act of 2008," 2008b). Now is a good time to analyze whether people are still worried about confidentiality and discrimination issues and therefore prefer anonymous tests over non-anonymous tests.

2.4 Relationship Between Socio-demographics and People's Attitudes toward Predictive Genetic Testing for Alzheimer's Disease

Prior studies have indicated that age, gender, education, income, and race/cultural background may impact the decision for genetic testing for AD. Frost et al. used a college student sample and suggested that demand for genetic AD testing was likely to be low among young people (Frost, Myers, & Newman, 2001). Others have found that people below the age of 60 were more likely to seek tests compared to people age 60 and above; indicating the "baby boomer" generations might want to seek more genetic information than the older generations (Roberts et al., 2004).

Different results have been found regarding the role of gender for genetic testing for AD. Roberts et al. found that men expressed more interest in being tested than women (Roberts, 2000). Bassett et al. showed that men tend to accept tests with higher error rates (Bassett, et al., 2004). In contrast, women were the majority to take part in a clinical trial that provided free genetic testing (Roberts, et al., 2004). Other studies have suggested that gender was not associated with the desire to be tested for AD (Frost, et al., 2001; Neumann, et al., 2001).

The effect of education on the desire to obtain genetic testing for AD is unclear. In one study, Green et al. found that subjects who expressed the desire to obtain genetic testing for AD had lower educational levels (Green, et al., 1997). However, Roberts et al. found that respondents with a college level education were more likely to seek testing (Roberts, et al., 2004).

Educational level may also impact test acceptance based on sensitivity/specificity. One study showed that respondents with lower education levels were more likely to accept tests for AD which had higher error rates (Bassett, et al., 2004).

Roberts et al. found income was not associated with the desire to seek genetic testing for AD (Roberts, et al., 2004). Neumann et al., however, found that income was associated with the likelihood of seeking a genetic test. Respondents with lower incomes (household income less than $30,000) were more likely to be interested in taking the genetic tests (Neumann, et al., 2001).

There were also conflicting results about cultural effects on the desires to obtain genetic testing for AD. Binetti et al. showed that Italians were more likely to obtain an AD genetic test than Americans and indicated the culture background may influence the desire to obtain the AD genetic testing (Binetti et al., 2006). Another study suggested African Americans showed less interest in genetic testing for AD when compared to whites (Hipps, Roberts, Farrer, & Green, 2003). While these two studies found that culture may have an effect, Neumann et al., however, showed that desire to take a genetic test for AD was constant across different races which include whites, African American and Hispanic in US (Neumann, et al., 2001).

Neumann et al. also showed that people with AD family history or AD care-giving experience were more likely to take AD genetic test, although the differences were not statistically significant (Neumann, et al., 2001).

2.5. Previous Study on People's Valuation for Predictive Genetic Testing for Alzheimer's Disease

Limited study has evaluated people's willingness-to-pay for genetic testing for AD, probably because the test is still not recommended for clinical use. However, research on the community's willingness-to-pay for genetic testing for AD can have implications for research development, health policy, and clinical practice. Neumann et al. determined people's willingness to pay for genetic testing for AD by using a double-bounded, dichotomous choice contingent valuation method. Respondents were randomized to one of four bidding amounts: $100, $500, $1000, $1500 and answered whether they would or would not take a predictive test with 100% accuracy. If respondents answered yes to the initial bidding, they were asked whether they would pay double that amount. If they answered no to the initial bidding, they were asked whether they would pay half of the amount. Their study showed that respondents were willing to pay $170 for a predictive test which had a one-in-ten chance of being incorrect and $324 for a perfectly predictive test (Neumann, et al., 2001).

2.6. Contribution of this Research to the Current Literature

For diseases with high prevalence and uncertain cause such as Alzheimer's disease, it is crucial to understand the preferences for the general population. Most previous studies, however, have used small samples, convenience samples (e.g. students, samples that enrolled relatives of AD patients), or samples which were predominantly Caucasian, female and high socioeconomic status (refer to Table 2 for sample comparison). Additionally, most previous studies did not combine multiple attributes (refer to table 1) or only used an exploratory method to discuss the reasons and factors people consider when making an AD genetic test decision. As an extension of the previous work, this research project will use a general population sample to elicit

community preferences and will use a conjoint analysis approach, in which different attributes are used to create a series of scenarios. This research project will also use contingent valuation to elicit people's willingness to pay for genetic testing for AD.

CHAPTER 3

RESEARCH QUESTIONS

We seek to better understand people's preferences and willingness to pay for genetic testing for Alzheimer's disease. Our research questions are:

1) What are the important characteristics of AD genetic tests people consider when deciding whether or not to have a genetic test for Alzheimer's disease?

2) Do consumer segments exist showing different preferences for AD genetic tests and how do these segments vary by people's sociodemographic characteristics such as age, gender, education, income, race/cultural background, family history, care-giving experience, and awareness of related law?

Specific aim 1: To develop a conjoint analysis questionnaire for genetic testing for Alzheimer's disease

Literature reviews will be conducted to develop the attributes and attribute levels that will be used in the conjoint analysis. The survey will be piloted by using a convenience sample and will be revised.

Specific aim 2: To elicit people's preferences for genetic testing for Alzheimer's disease

A general population sample will be used to conduct the survey. Results will be analyzed to elicit people's preferences for genetic testing for Alzheimer's disease, as well as to determine whether

preferences vary systematically between respondents with different sociodemographic

characteristics.

CHAPTER 4

STUDY RATIONALE AND HYPOTHESES

Based on prior research, several qualitative attributes can be identified that are related to the proposed study, which include: 1) prediction value, 2) availability of treatments that would prevent or delay onset of AD, and 3) anonymity/confidentiality. Based on these of attributes, we have developed the following research hypotheses:

H01: In the aggregate decision model, consumers will place equal importance on all the attributes of AD genetic: prediction value, availability of treatments, and anonymity.

HA1: In the aggregate decision model, consumers will place different importance on all the attributes of AD genetic: prediction value, availability of treatments, and anonymity

Prediction value will be defined as the chance of test result correctly predicts the occurrence of the disease. The availability of treatments will be defined whether treatments are available to prevent or delay the onset of AD. Anonymity will be defined as the state where a person's name and other personally identifying information is not known.

To determine whether preferences vary systematically between respondents with different sociodemographic characteristics, we will group respondents according to their preference and investigate the sociodemographic constitution, which include 1) age, 2) gender, 3) education, 4)

income, 5) race/cultural background 6) family history of AD, and 7) care giving experience for Alzheimer's disease patients.

We hypothesize:

H02: The clusters will not show difference in socio-demographic characteristics: age, gender, education, income, race/cultural background, family history of AD, caregiver status, and awareness of Genetic Information Nondiscrimination Act

HA2: The clusters will show heterogeneity in sociodemographic characteristics: age, gender, education, income, race/cultural background, family history of AD, caregiver status, and awareness of Genetic Information Nondiscrimination Act

For the hypothesis, caregiver status will be defined as one who has ever personally cared for an AD patient (Neumann, et al., 2001).

CHAPTER 5

RESEARCH DESIGN

5.1. Theoretical Foundation of Conjoint Analysis

The conjoint analysis is based on Lancaster's consumer theory (Lancaster, 1966) that assumes an individual gains utility from the consumption of a good which is composed of different characteristics (attributes). It can use a rating, ranking or choice-based approach to quantify preferences (ISPOR Conjoint Analysis in Health Good Research Practices Task Force, 2009; M. Ryan, et al., 2001).This research project will use rating conjoint analysis which asks respondents to rate several scenarios composed of different attributes and levels. It will be appropriate to use rating full-profile conjoint other than choice-based conjoint for this study because rating full-profile conjoint is better for emerging markets such as AD genetic test. Using full-profile conjoint can show the whole picture about the attributes levels of the unfamiliar product/service more easily than choice-based conjoint, which can help people give reliable responses about their preference. It is usually assumed that utility is linear-in-parameters:

$U_j = \beta_1 X_{j1} + \beta_2 X_{j2} + \ldots + \beta_k X_{jk} + \varepsilon$

where X_{jk} is attribute k in scenario j, β_k is the preference parameter on attribute k, ε is the random error term with zero mean. (Champ, et al., 2003)

5.2. The Proposed Attributes and the Attribute Levels

Based on the literature review, the attributes and the attribute levels which are proposed to use in this study are listed in Table 3.

5.3. Experimental Design

There are three proposed attributes that will be used in this study with the levels specified in Table 3. A generic design (specifically, the genetic tests will be named scenario 1, 2, 3... rather than using a proprietary name) will be used instead of a labeled design. The attributes and attribute levels will result in a full factorial design of 12 (=3×2×2, levels of each attribute in Table 3) scenarios. The respondents will be asked to give preference ratings for each scenario using a 0-10 point scale based on Louviere's suggestion for 16 or fewer scenarios (Louviere, 1988). The pretest result also suggested the majority of the respondents gave ratings in 10 digits when using 1-100 scale. The respondents will also be asked to give their highest willingness-to-pay in dollar amount for each scenario as the out-of-pocket cost using open-ended questions. Instead of using market value to design the price attribute in the traditional conjoint design, using open-ended questions in this study will be better to explore people's true willingness to pay since the AD genetic tests are not used in clinical and all the scenarios in this study are hypothetical. All 12 scenarios will be shown in the same page to help respondents compare and contrast their answers between different scenarios and produce reliable responses.

5.4. Sample Size Estimation

While theoretically conjoint analysis can be estimated by one respondent as long as that respondent has a sufficient number of rating tasks, a large sample size is still required to make sure the respondents are representative of the population of interest. Generally sample sizes ranging from 50 to 200 will provide enough information regarding consumer preferences (Hair, 2010). Since this study will group the respondents into four segments for cluster analysis (based

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on three attributes), we will need to collect at a minimum 200 (=50×4) responses. Pilot study testing revealed these four clusters accounted for approximately 80% of the total variance, therefore, the final sample desired will be a minimum of 250 responses.

5.5. Study Population and Data Collection

This research project is proposed to use a sample aged 18-64 general population to elicit public preferences. This study will be a cross-sectional study by using a web-based survey. Internet surveys showed greater internal consistency and higher response rates in the short-term compared to mail surveys (Foytik, 1999). Data will be collected online using Qualtrics® survey panel via Qualtrics® online survey software tool. The majority of the Qualtrics® panelists are recruited over the internet and the demographics of the survey respondents will be examined using Chi-square test to see if they closely match U.S. population.

5.6. Data Analysis Plan

SAS and SPSS statistical software will be used for data analysis. The data analysis plan include: 1) Estimate the individual models to determine the utilities of attribute levels and the attribute importance scores using ordinary least squares multiple linear regressions. 2) Summarize the individual attribute importance scores for aggregate model to get average attribute importance scores. 3) Group the subjects with similar individual models into segments using the PROC CLUSTER and PROC FASTCLUS procedures available in SAS and analyze the preferences by segments.4) Analyze the demographic constitution of segments 5) Estimate the average WTP for each competing profiles for the whole sample, the demographic groups, and the preference

segments 6) Rank the12 scenarios by WTP and preference ratings and compare the difference. 7) Explore the relationships between preference and family history/care giving experience. 8) Explore the relationships between preference and people's awareness of GINA (Genetic Information Nondiscrimination Act).

5.7. IRB Statement

An application to use human subjects for research was submitted to the University of Georgia Institutional Review Board and was approved in February 2010.

CHAPTER 6

PUBLIC PREFERENCES FOR PREDICTIVE GENETIC TESTS FOR ALZHEIMER'S DISEASE

[1]

6.1. Introduction

Alzheimer's disease (AD) was the seventh-leading cause of death in the US in 2006 (Heron, et al., 2009). The number of US patients is currently estimated at 4.5 million, and is expected to increase to 13.2 million by 2050 (Hebert, et al., 2003). The etiology of Alzheimer's disease is still unknown. Currently there is no cure or prevention for the disease. The high prevalence and indeterminate cause make it hard to identify a target population; therefore, it is crucial to understand public preferences for AD care.

With the advent of predictive genetic tests, people will have the option to investigate their future risk of developing diseases like AD. This knowledge can benefit people as they can start to prepare themselves as well as their families. Even though genetic testing for AD is not currently recommended, it is believed that tests with higher predictive value and more effective treatments will emerge in the future (Ritchie & Lovestone, 2002; Serretti, et al., 2007; Sisodia & Tanze, 2007). Aligning the clinical practice of using predictive genetic testing for Alzheimer's disease with patient values and preferences is important. However, little is known about community preferences for genetic Alzheimer's disease (AD) testing. Techniques such as conjoint analysis and contingent valuation(M. Ryan, et al., 2001) can be used to elicit public views . This study was conducted to estimate societal preferences and perceived values placed on predictive AD genetic tests by combining rating-based conjoint and open-ended contingent valuation.

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6.2 Methods

Conjoint analysis

A rating conjoint analysis survey was used for this study. Conjoint analysis is based on Lancaster's consumer theory (Lancaster, 1996) that assumes an individual gains utility from the consumption of a good which is composed of different characteristics (attributes). In this study, the individual conjoint models were estimated using ordinary least squares regressions (PROC TRANSREG procedure in SAS). The individual attribute importance scores were calculated from the utilities in the individual conjoint models and were furthered summarized as aggregate importance scores (SAS 9.1; Excel 2010). The ordinary least squares regression model specified was:

$$U = B0 + B1i \ (Accuracy) + B2j \ (Treatment \ availability) + B3k \ (Anonymity) + \varepsilon ijk$$

where U is the rating, Predictive Value (Accuracy) is the chance of the results being correct (i=three levels for accuracy: 100%, 80%, 40%), Treatment availability is whether a cure for AD is available (j=two levels for Treatment availability: "A cure is available" or "There is no cure for AD but there are medicines to relieve symptoms and improve quality of life for up to two years" ; Anonymity refers to whether the name is recorded with the test results (k=two levels for Anonymity: "The test result is anonymous" or " The test result is not anonymous." These attributes were treated as qualitative variables. Effects coding was used to create indicator variables for all levels of all attributes.

Attribute/Levels/Rating design

The attributes used in the conjoint design were identified from a thorough literature review. (Bassett, et al., 2004; Binetti, et al., 2006; Chase, et al., 2002; Frost, et al., 2001; "Genetic Information Nondiscrimination Act of 2008," 2008a; Gooding, et al., 2006; Green, et al., 1997; Hipps, et al., 2003; Neumann, et al., 2001; Richter & Richter, 2004; Roberts, 2000; Roberts, et al., 2004; Roberts et al., 2003; Saunders, et al., 1996) The attributes included: "Prediction Value (Accuracy)" (three levels), "Treatment Availability" (two levels), and "Anonymity" (two levels). The prediction value of an AD genetic test can help test recipients know how confident they can be with the result. In this study, we used the levels of 40%, 80% and 100%. Treatment availability for AD impacts people's health outcomes, quality of life, and future plans. We defined the two levels of treatment availability as "cure is available" and "There is no cure for AD but there are medicines to relieve symptoms and improve quality of life for up to two years." Issues regarding the anonymity or confidentiality of genetic tests, carry with them concerns about discrimination in obtaining, for example, health insurance or a job. We defined anonymity for our purposes as the test result either being recorded with the patient's name or not. All together, these attributes will result in a full factorial design with 12 different scenarios (3×2×2, levels of each attribute). To rate the scenarios, respondents were asked to give preference ratings for each scenario using a 0-10 point scale (10 means definitely would want to take the test and 0 means definitely would not want to take it), which is suggested by the literature (Louviere, 1988).

Cluster Analysis

This study used a hierarchical agglomerative procedure to cluster respondents according to the individual part-worth (Distance measure: Squared Euclidean Distance; Linkage rule: Between

groups average distance approach). Descriptive statistics for each of the clusters were analyzed by each of the socio-demographic characteristics in order to identify any important factors that affected the preferences.

Willingness-to-pay (WTP)

Respondents were asked to give their highest willingness-to-pay in dollar amount as the out-of-pocket cost for each scenario using open-ended questions. Instead of using market value to design the price attribute in the traditional conjoint design, the use of this open-ended question was a better way to estimate people's true willingness to pay since the AD genetic tests are not currently being used clinically and all the scenarios in this study are hypothetical. All 12 scenarios were shown on the same page to help respondents compare and contrast their answers between different scenarios and produce reliable responses.

Pretest

The survey used in this study was pre-tested online (three iterations) during April ~ November 2010. The first version of the test was reviewed by a panel of pharmacy care administration faculty and students (n=7). The second round of the pre-test was conducted online by sending out the survey link to a convenience sample of 20 individuals who were not working in health care. The third round of the pre-test was conducted using a Qualtrics® online general population panel (n=244) in November 2010. The survey was revised during each round of the pretest. The major change of the survey during the pretest was the adoption of 0-10 scale for the rating conjoint questions. The pretest results suggested the majority of the respondents gave ratings in 10 digits when using a 0-100 scale. This adoption was also supported by the literature (Louviere, 1988).

6.3. Results

A total of 295 responses were collected over four days in April 2011. The mean age of the sample was 44.7 years (SD 12.7) and 86% indicated white/Caucasian heritage. Thirty nine percent of the respondents held bachelor's degree. There were approximately equal numbers of males and females in the final sample. Fifty three percent of the respondents had annual household incomes below $50,000 and an even distribution of incomes was shown. Fifteen percent of the respondents indicated their family had been diagnosed with Alzheimer's disease. Sixteen percent of respondents had care-giving experience for AD patients. Twenty three percent of respondents had "exposure" to Alzheimer's disease by indicating either having Alzheimer's disease family history or care-giving experience for AD patients. Only 8.81% of respondents indicated they had ever heard of the Genetic Information Nondiscrimination Act of 2008 (GINA). Table 4 demonstrated the sample demographics in detail.

The internal consistency of the conjoint model was assessed by examining the R-squared of the individual regression model. Sixty-nine percent of the respondents showed an R-squared higher than 0.7 for their individual regression model. We also included two validation tasks to assess validity. Each validation task included two scenarios which were already presented to respondents in the previous rating tasks and formed a choice set. If the ratings correctly predicted the choice of the validation task, it was called a "Hit". The hit rates of the two validation tasks were 49.15% and 64.07%, respectively.

Aggregate model

For the conjoint analysis, twenty responses were excluded because they indicated no variation in the preference ratings for the conjoint tasks. Therefore, a total of 275 responses were used for the conjoint analysis. The result of the aggregate linear regression model is below:

U=6.5215 + 1.9521 Accuracy100% + 0.4012 Accuracy 80% - 2.3533 Accuracy 40% + 0.6282Cure – 0.6282 NoCure+ 0.2548 Anonymous – 0.2548 NotAnonymous

(Where all variables = 1 or 0)

Instead of using the aggregate linear regression model to explain the preferences, we used importance scores which derived from the individual regression model and represented the relative part-worth utility range of each attribute. We calculated the importance scores for each individual and then averaged them. The importance of an attribute was equal to the part-worth range for the attribute divided by the sum of the part-worth ranges for all attributes. The averages of individual importance scores for each attribute were reported as the results of aggregate models. The importance scores results showed the most important attribute was Accuracy, contributing 64.73% to the preference rating. Treatment Availability and Anonymity contributed 20.72% and 14.59% to the preference rating, respectively. The most preferred scenario was the test with a 100% chance of being correct, a cure for AD is available and the test result is anonymous.

The average preference ratings and willingness-to-pay of the 12 scenarios were shown in Table 5. Compared to treatment availability and anonymity, predictive accuracy was the most important factor for the aggregate model regarding the AD genetic test decision. People gave

high ratings for the scenarios with 100% predictive value. Even without a cure, a test with 100% accuracy was still placed with a high preference and WTP. On the other hand, a scenario with "80% AD predictive value and a cure available" could yield similar preference ratings and the same WTP as a scenario with "100% accuracy test without a cure". A test with 80% accuracy was tolerable when a cure was available. Scenarios with 40% accuracy were all placed with the lowest preference ratings and WTP.

Subgroup model/ Cluster Analysis

The cluster analysis was performed according to individual part-worth utilities (individual preferences).The number of clusters was identified during the agglomerative clustering process. The clustering process should stop when there is a large increase in the distance coefficients, indicating more dissimilar clusters were being combined. Our cluster analysis showed the "step of elbow" was stage 262 and indicated a solution of 13 clusters (275-262). The 13 clusters included 4 big clusters and 9 smaller clusters (each with a sample size <=10). The findings were most meaningful and easier to communicate when we focused on the four large clusters. We also confirmed this by re-running cluster analysis after deleting the small clusters to make ensure there was no change in the cluster structure.

Figure 1 demonstrates the attribute importance scores for each cluster. The cluster descriptives are listed in Table 6. These four clusters incorporated 244 respondents (out of 275) from the conjoint analysis. Cluster 1 was composed of 74 respondents and Clusters 3 and 4 both had a total of 26 respondents. Cluster 2 was the largest cluster with 118 respondents.

The first cluster was termed "Comprehensive Thinkers" with 74 respondents, representing 25% of the sample. Respondents in this group took all attributes into consideration and placed a more balanced importance among the three attributes. Accuracy was the most important attribute (51.89%). Treatment availability and Anonymity were also important which accounted for 24.73%, and 23.43%, respectively. Comprehensive Thinkers considered anonymity more important than the other three groups did. The group characteristics were more male (60.81%), with lowest median income ($ 44,999.5), young (average age 43.18), and with a highest proportion of people have heard of GINA (14.86%).

The second cluster was termed "Accuracy Seekers" given that this group reported Accuracy as the most important attribute (75.92%), followed by Treatment availability (15.68%) and finally Anonymity at 8.43%. This was the largest cluster with 118 respondents which represented 40% of the sample. The group characteristics included a similar proportion of males and females, 44.07% of people had bachelor's degree, lowest proportion of Caucasian, and with the lowest proportion of people having AD care-giving experience.

The third cluster was "Accuracy Extremists." Accuracy was the dominant attribute (accounting for 90.5%). Treatment availability and Anonymity were not important factors for this group when making the decision to choose the genetic test. "Accuracy Extremists" was a small cluster with only 26 respondents representing 9% of the sample. This group included highest proportion of Caucasian (100%), a high percentage of females (61.54%), with lowest median income ($ 44999.5), with lowest education level (only 19.23% of people had bachelor's degree) and the lowest proportion of people having a family history of AD (11.54 %).

The fourth cluster (CL4) was "Treatment Seekers." Treatment availability was the most important attribute for this group with a 53.00% of importance. Accuracy was also important in this group (39.04%). These respondents included highest proportion of females (65.38%), the lowest reported education level (65.38% with higher education), the highest median income ($64999.5) , with higher education level (46.15% had bachelor's degree), were older (average age 48.96), and held the highest proportion of both a family history of Alzheimer's disease (19.23%) and care-giving experience of AD(30.77%). Only one person in this group (3.85%) reported awareness of GINA. This was also a small cluster with only 26 respondents or 9% of the overall sample.

The results of cluster analysis also suggested the accuracy was the most important attribute. Although different consumer segments had different patterns placing the importance among the three attributes, accuracy was still the most important one for three out of four clusters, which included 74% of the study respondents. Accuracy was the predominant attribute for Cluster 3 (Accuracy Extremists, with 26 respondents). This group placed 90.5% importance on accuracy and did not care about treatment availability and anonymity. Cluster 1(Comprehensive Thinkers) and 2 (Accuracy Seekers) also placed the highest importance on Accuracy (51.89% and 75.92%, respectively).

 Treatment availability was the second most important attribute on average (average importance: 20.72%). Although for the majority of the respondents, treatment availability was less important than accuracy, it was the most important attribute (55% importance) for Cluster 4 (Treatment Seekers with 26 respondents). This group was oldest, richest, with the highest

education level and included more females. This group also had the highest percentage of AD family history and the highest proportion of respondents with AD care-giver experience.

Among the three attributes, anonymity was the least important one for all four clusters (average importance: 14.59%). However, cluster 1(Comprehensive Thinkers) paid more attention to anonymity than the other three groups and placed a higher importance than average on anonymity (23.43%). This group also had the highest percentage of respondents who had ever heard of GINA.

Willingness-to-pay (WTP)

A total of 295 responses were used for the contingent valuation. 12.9% (38 out 295) of the respondents were not willing to pay any amount (indicated "zero" as WTP) for any scenarios regarding predictive genetic test for Alzheimer's disease. These responses were still included in the WTP calculation. The median WTP for the highest-rating scenario (Accuracy 100%, a cure is available, test result is anonymous) was $100 (mean WTP was $276). The median WTP for the lowest-rating scenario (Accuracy 40%, no cure but drugs for symptom relief, not anonymous) was zero (mean WTP was $34). The median WTP for the second highest rating scenario (Accuracy 100%, a cure is available, test result is not anonymous) was $75 (mean WTP was $290). WTP for each scenario is listed in Table 5. The willingness to pay for the different scenarios showed a similar pattern as the ratings. Higher-rated scenarios tended to have higher WTP. The WTP also reflected the importance of attributes and attribute levels. Regardless of the levels in treatment availability or anonymity, the scenarios with 100% accuracy always had higher WTP (median WTP $50 -$100, mean WTP $134-$290), while the scenarios with 40%

accuracy always had lower WTP (median WTP $0-$10, mean WTP $34-$76). The results showed that people were still willing to pay for a not-that-perfect test with 80% accuracy (median WTP $25-$50, mean WTP $86-$175). It also showed that even though there was no cure available for AD, respondents were still willing to pay for the test if the accuracy were at least 80%.

6.4. Discussion

This rating conjoint study focused on three factors which are relevant to AD genetic tests: predictive accuracy, treatment availability and result anonymity. On average, respondents placed more importance on predictive accuracy (average importance: 64.73%) than either treatment availability or result anonymity. The aggregate and cluster results both showed that predictive accuracy was the most important factor for the majority of study respondents when making the decision to obtain an AD genetic test. Even without a cure for AD, people still placed a high preference on a predictive test with a 100% predictive value, and were still willing to pay for it (median WTP was $50). These results suggest that patients find value in having a reasonable estimate regarding their future chance of developing AD, even without a treatment. Value may arise from having an opportunity to make informed future plans or from a reduction in uncertainty.

These results also showed that when the accuracy levels fell between 80% and 100%, people were willing to make a trade-off between "treatment availability" and "accuracy." Further, the

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scenarios with 40% accuracy always received the lowest preference ratings and WTP. These results indicate that while important to consumers, the accuracy of the tests may not need to be 100%, but higher accuracy is more highly valued. Since few tests are perfect, the 80% accuracy level may be a good enough target for AD genetic test development, which was also consistent with what suggested by physicians as the minimal predictive value of AD genetic test (Chase, et al., 2002). This is important because development and/or production costs for a 100% accurate test may be prohibitive.

Even though treatment availability was less important than accuracy to the majority of the respondents, it was the most important attribute for Cluster 4 "Treatment seekers." Respondents in this group had the highest probability of having AD family history and care-giver experience for AD patients. The experience of dealing with the disease may lead to a higher importance placed on the cure for AD over accuracy when making the decision to obtain AD genetic test. Healthcare providers counseling people with a family history of AD or AD care-giving experience should focus on providing information about available treatment options, potential future treatments, and opportunities to participate in ongoing clinical research.

Although anonymity remained the least important of the three attributes, Comprehensive Thinkers still placed 23.43% importance on anonymity. This group had the highest percentage of respondents who had ever heard of the Genetic Information Nondiscrimination Act of 2008. The awareness of this genetic related policy may lead to more attention to the anonymity issue in this group. Anonymity may become a more important issue when the public is more aware of the potential usage of predictive genetic tests to discriminate against health insurance or employment.

Policy makers, healthcare organizations, and healthcare providers should be prepared for consumers to express concerns associated with the issue of anonymity/privacy – which could lead to genetic discrimination.

CHAPTER 7

PUBLIC AWARENESS OF GENETIC INFORMATION NONDISCRIMINATION ACT

OF 2008

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[2] Huang, MY, Huston S, and Perri M. Submitted to *Journal of Medial Ethics*

7.1. Introduction

Genetics research has the potential to identify the causes of many diseases and improve medical care by developing individualized treatments and/ or prevention strategies (Francis, 2010; Hudson, Rothenberg, Andrews, Kahn, & Collins, 1995). However, genetic information may be misused to discriminate against people for health insurance and employment. It has been reported that some insurers have discriminated against African Americans carrying the sickle cell gene by charging higher rates or denying coverage (Andrews, 1987; Hudson, et al., 1995). Recent studies reported that 22-40% of respondents with a family history of genetic conditions indicated they had been discriminated against in insurance, family, and social settings (Bombard et al., 2009; Hudson, et al., 1995). Research also showed concerns about genetic discrimination were high in people at higher risk of genetic disease or who had undergone predictive genetic testing (Bombard, et al., 2009; Penziner et al., 2008). In order to *"prohibit discrimination on the basis of genetic information with respect to health insurance and employment"*, the Genetic Information Nondiscrimination Act (GINA) was signed into law by President Bush in May 2008 ("Genetic Information Nondiscrimination Act of 2008," 2008a). This signature ended a thirteen-year long congressional debate on whether and how parity between genetically high and low-risk individual should be achieved (Abiola & Chernyak, 2008; Epstein, 2007).

However, the challenge outside congressional halls may just be starting since GINA implementation is proving difficult. The law itself is hard to understand and has several limitations, which is creating confusion among insurance carriers and health care professionals(Clifton, VanBeuge, Mladenka, & Wosnik, 2010; Dressler & Terry, 2009; Payne,

Goldstein, Jarawan, & Rosenbaum, 2009; Van Hoyweghen & Horstman, 2008). The limitations of GINA include that it does not apply to life insurance, long-term care insurance, and disability insurance. Additionally, GINA applies only to asymptomatic individuals (Clifton, et al., 2010; Erwin, 2009; Rothstein, 2008). One study surveying family physicians showed that only 10.3% of physicians had a basic knowledge of what GINA protects, and about half were not at all aware of GINA(Laedtke, O'Neill, Rubinstein, & Vogel, 2011). Without complete understanding of GINA, an individual may still suffer from genetic discrimination after obtaining a genetic test. Since all individuals have some level of genetic mutation and could potentially be discriminated against through health insurance or employment practices, people need to understand how GINA can protect their genetic information. Understanding the general population's knowledge regarding GINA can inform future patient educational efforts about GINA. (Laedtke, et al., 2011). Three years after enactment of GINA, research regarding public awareness of this federal law is still scant. Hence, this study evaluates public awareness of the GINA of 2008.

7.2. Methods

An anonymous online survey was distributed by Qualtrics® to a general population panel in April 2011. The inclusion criterion was adults aged 18-64 years. The 17 question survey included two multiple choice questions to measure public awareness and knowledge of GINA and a series of demographic related questions. The respondents were first asked whether they had ever heard of the Genetic Information Nondiscrimination Act of 2008. Respondents who

answered "yes" to this question were asked to choose among four GINA descriptions and identify the correct option between : 1) The GINA (2008) requires patients to report their genetic information to the Department of Health and Human Services; 2) The GINA (2008) promotes research of genetic tests by providing federal funding; 3) The GINA (2008) prohibits the improper use of genetic information in health insurance and employment (the correct description); 4) The GINA (2008) requires a doctor's prescription to obtain a genetic test; 5) I don't know the details about the GINA (2008).

Survey pretest

The survey used in this study underwent three rounds of testing between April and November 2010. The first version of the survey was reviewed by graduate faculty and students (n=7) in Pharmacy Care Administration program at the University of Georgia College of Pharmacy. The second phase of pretesting was conducted online by sending a survey link to friends and their friends (snowball sampling, n=20) who were not biomedical/medical/pharmacy majors. The third test was conducted using the Qualtrics® online general population panel (n=244) in November 2010. The survey was revised based on feedback from each round of the pretest.

7.3. Results

A total of 295 responses were collected over four days in April 2011. Table 4 provides the sample demographics. The sample was 51% male, the mean age was 44.7 years (SD 12.7) and 86% indicated white/Caucasian heritage. Seventy-eight percent of the respondents had at least

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some college education. Fifty three percent of the respondents had an annual household income below $50,000.

Only 26 (8.8%) of respondents indicated they had ever heard of GINA 2008. When asked further about the GINA details, only 10 people (38% of those who had heard of GINA) knew that GINA 2008 prohibits the improper use of genetic information in health insurance and employment.

Chi-square tests and Fisher's Exact Test were performed to determine any possible association between respondent socio-demographics and GINA awareness. Respondents with male gender, with care-giving experience for Alzheimer's disease patients, and with a family history of Alzheimer's disease were more likely to be aware of GINA, although this was not statistically significant. There were no strong associations of any other socio-demographic factors. Data were analyzed using Microsoft Excel 2010 and Microsoft Research Web Tools.

7.4. Discussion

Three years after GINA 2008 was signed into law, public awareness is still low. Only 8.8 % of the current sample had ever heard of GINA and only 3.4% understood that GINA is intended to protect against genetics-based health insurance and employment discrimination. Low GINA awareness may be attributable to other issues that occurred in 2008 such as the presidential election or the housing and financial crisis, which drew much media and public attention. The complicated body of law related to genetics and insurance may also contribute to low public

awareness (Payne, et al., 2009). Furthermore, predictive genetic disease tests are still not clinically prevalent, which may be another reason for low awareness of GINA. However, rapid advances in genetic research will undoubtedly bring more clinical utility to genetic tests, and this should heighten awareness of GINA and the protections it offers.

One finding of this study was that people who were caregivers for Alzheimer's disease patients were significantly more likely to be aware of GINA. The reason may include that people with care-giving experience of Alzheimer's disease patients were more inclined to take the predictive genetic test for the disease (Neumann, et al., 2001) and may have paid more attention to related law's about genetic information protection. The experience of taking care of Alzheimer's disease patients may also lead these respondents to foresee the potential for genetic discrimination in health insurance or other settings and contribute to a higher awareness of GINA. With increases in Alzheimer's patients we can expect this factor alone to result in further increases in GINA awareness.

The issues associated with genetic discrimination in the area of health insurance and employment should be important to all. A thorough understanding of GINA could help consumers better protect their genetic information and their rights. Low awareness of GINA in our sample showed there is a need to disseminate information related to GINA more effectively. Since physicians are a trusted source of health information and previous research has shown awareness and knowledge of GINA to be low among family physicians, GINA information dissemination may start as part of the continuing education for physicians. Pharmacists and other

health care practitioners could also be an important source of information regarding (Laedtke, et al., 2011).

The results of this study were limited by the use of an online panel for data collection. While it is more efficient and cheaper to collect data over the internet, the Qualtrics® online panel does not perfectly represent the general population. Our sample had more Caucasians and more highly-educated people than the general population. Moreover, Qualtrics® sent out a huge number of emails and closed the survey when the desired number of responses was received. It is possible that prompt responders (who were included in the survey) may hold different opinions than slower responders (who were not included due to the survey being closed). Lastly, with low level of public awareness of GINA, which translates into a small effect size, a larger sample size is needed to identify statistical significant associations between awareness and sociodemographic characteristics.

CHAPTER 8

CONCLUSIONS

Consumers are generally much more concerned with the accuracy of genetic tests for AD than either anonymity or the availability of treatment options. Since the decision to take a genetic test, at least for now, seems to be driven by the tests ability to correctly predict disease, genetic test developers should focus on strategies that improve predictive accuracy to at least 80%. It is likely that the issue of privacy will emerge as awareness. More effective information dissemination regarding GINA 2008 may be required to improve the public's ability to take advantage of GINA 2008's protections.

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Table 1. Previous work on people's intention to seek AD genetic testing

Study	Participant recruitment	N	Hypothetical Scenario	% of respondents expressing probable or definite intentions to seek testing or went on to seek testing	Free genetic test provided
Green et al., 1997	Convenience sample from (a) family members and care givers of patients with AD attending a regional symposium (b) subjects participating in a study of past exposures to chemical s in the workplace (c) volunteers from a civic organization	176	Test accuracy: 60% 100%	35 69	No
Roberts et al., 2000	Children and siblings of patients with AD. Referral from Geriatric medical care facilities and advertising in hospital and community in Michigan	203	Test accuracy : 99% 85% Treatment availability : prevention Delay AD onset Test result information: Less certain risk (50%) More certain risk (95%)	58.1 54.7 96.1 77.8 49.5 63.1	No
Neuma nn et al., 2001	Random sample of US adults using random-digit-dialing techniques	314	Perfect test: zero chance to be incorrect Imperfect test: one in ten chance to be incorrect	N/A	No

Frost et al., 2001	Convenience sample of undergraduate students in UK	449	Test result information: More certain (90%) Less certain (50%)	N/A	No
Roberts et al., 2003	Randomized controlled trial (Risk Evaluation and Education for Alzheimer Disease--REVEAL study) Adult children of patients with AD	206	No hypothetical scenarios Intervention arm: genetic counseling and risk assessment (lifetime risk estimates based on family history and sex ranging from 13% to 57%) Control arm: risk estimates based on family history and sex ranging from 18% to 29%	77.7% went on to seek testing (overall)	Yes
Hipps et al., 2003	Convenience sample of (a) health workers/family members attending a conference in Alabama (b) healthcare workers attending a meeting in Florida (c) persons in Georgia who were participating in other public health surveys (d) members of church congregations/civic organizations and participants in support groups/health fairs in Atlanta	452	100% accurate with treatment available to delay the onset of AD 60% accurate and cost $200 100% accuracy 80% accuracy 60% accuracy	80.3 19.6 64 51 30	No

Bassett et al., 2004	Convenience sample of the adult offspring of AD patients currently enrolled in a genetic linkage study	518	Test accuracy Sensitivity(False-positive): 92% 69% 31% Positive predict value : 87% 65% 33%	76.3 68.8 59.9 65.1 55.0 47.9	No
Roberts et al., 2004	Randomized controlled trial(REVEAL study) Adult children of a person with clinically diagnosed and/or autopsy-confirmed AD	self-referred: 179 systematically contacted:110	No hypothetical scenarios Intervention arm: genetic counseling and risk assessment (lifetime risk estimates based on family history and sex ranging from 13% to 57%) Control arm: risk estimates based on family history and sex ranging from 18% to 29%	64% went on to have genotyping and received AD risk disclosure 24% went on to have genotyping and received AD risk disclosure	Yes Yes
Binetti et al., 2006	Clinical trial(REVEAL study) Italian sample: first and second degree relatives of patients from families were at least affected individuals, subject were not paid	134	99% test accuracy & 95% lifetime risk Less test accuracy (85%) Immediate risk Less certain risk information (50% lifetime risk) Available treatment to delay AD onset Available treatment to prevent AD	73.8 70.8 71.5 70.0 77.7 87.7	No

Table 2. Comparison of the sample description for previous studies

Study	Participant recruitment	N	Response rate	Mean age and range	Gender (% Female)	Race (% White)	Annual household income	AD care-giving history (% had served as caregiver)	Free genetic test provided	Mean years of education
Green et al., 1997	Convenience sample from (a) family members and care givers of patients with AD attending a regional symposium (b) subjects participating in a study of past exposures to chemical s in the workplace (c) volunteers from a civic	176	54	45 (22-77)	75	70	N/A	N/A	No	72% with some college education or above
Roberts et al., 2000	Children and siblings of patients with AD. Referral from Geriatric medical care facilities and advertising in hospital and community in Michigan	203	N/A	53.5 (30-92)	75.4	95.6	74.7% had an income over $40,000	93.1%	No	63.5 % had completed college
Neumann et al., 2001	Random sample of US adults using random-digit-dialing techniques	314	47	43.3	62.4	73.0	48.1% had an income of 30,000-75,000	24%	No	92% finished high school

Frost et al., 2001	Convenience sample of undergraduate students in UK	449	87.5	All college student	55.68	N/A	N/A	N/A	No	All college students
Roberts et al., 2003	Randomized controlled trial (Risk Evaluation and Education for Alzheimer Disease--REVEAL study) Adult children of patients with AD	206	N/A	52.8 (30-78)	72.3	94.7	Median household income: 70,000-99,999	75%	Yes	16.5
Hipps et al., 2003	Convenience sample of (a) health workers/family members attending a conference in Alabama (b) healthcare workers attending a meeting in Florida (c) persons in Georgia who were participating in other public health surveys (d) members of church congregations/civic organizations and participants in support groups/health fairs in Atlanta	452	N/A	47	78	61	Median household income: $40,000-59,999	20%	No	Median education level was college graduate
Bassett et al., 2004	Convenience sample of the adult offspring of AD patients currently enrolled in a genetic linkage study	518	78	40.4% in the range of 50-59 (18-78)	59.7	96.3	75% had a income over 35,000	25%	No	46.5% has equal or more than 16 years

Roberts et al., 2004	Randomized controlled trial(REVEAL study) Adult children of a person with clinically diagnosed and/or autopsy-confirmed AD	self-referred:179	N/A	52.5 (31-82)	78.8	91.1	Median: 70,000-99,999	N/A	Yes	16.7
		systematically contacted:110	N/A	57.9 (30-82)	58.2	97.3	Median: 50,000-69,999	N/A	Yes	15.4
Gooding et al.,2006	Adult children of people with AD enrolled in REVEAL study (REVEAL-QRI study)	60	N/A	54 (37-76)	87	95	Median: 70,000-99,999	N/A	Yes	17
Binetti et al., 2006	Clinical trial(REVEAL study) Italian sample: first and second-degree relatives of patients from families were at least affected individuals, subject were not paid

Compare to American sample(Roberts et al., 2000): one family member with AD, subjects were paid | 134 | 54.5 | 47.5 | 57 | 100% Italian | N/A | 58% | No | N/A |

| Moscarillo et al., 2007 | Convenience sample of unaffected relatives being followed as part of an ongoing genetic linkage study | pilot survey :57 | 87.7 | 73.1 (38-93) | 53 | 100 | N/A | N/A | No | 13.3 |
| | | focus group:16 | N/A | 40-70 | 68.8 | 62.5 | N/A | N/A | No | N/A |

Table 3. The attributes and the attribute levels

Attributes	Attribute levels
Prediction value	1. Test result will have a 40% chance to correctly predict AD 2. Test result will have a 80% chance to correctly predict AD 3. Test result will have a 100% chance to correctly predict AD
Treatment availability	1. Cure is available. 2. There is no cure for Alzheimer's disease, but there are medicines to relieve symptoms and improve quality of life for up to two years.
Anonymity	1. The test result will be recorded along with identification. 2. The test result will not be recorded with any identifying information.

Table 4. Sample description (n=295)

Variable	Categories	Frequency(counts)	Percentage (%)
Gender	Male	150	51
	Female	145	49
Level of Education	Less than high school	4	1
	High school/GED	63	21
	Some College	85	29
	2-year college degree	29	10
	4-year college degree	79	27
	Postgraduate or Professional	35	12
Age	18-24	17	6
	25-34	58	20
	35-44	59	20
	45-54	82	28
	55-64	79	27
Income (2010)	Under 10,000	18	6
	10,000-19999	18	6
	20,000-29,999	40	14
	30.000-39,999	36	12
	40,000-49,999	43	15
	50,000-59,999	30	10
	60,000-69,999	23	8
	70,000-79,999	16	5
	80,000-89,999	18	6
	90,000-99,999	21	7

	100K or more	32	11
Race (alone or in combination with one or more other races, may add to more than 100 percent)	White	255	86
	African American	17	6
	Hispanic or Latino	18	6
	Asian	9	3
	Native Hawaiian and Other Pacific Islander	0	0
	American Indian and Alaska Native	7	6
Care-giving experience for Alzheimer's disease patient	Yes	48	16
	No	247	84
Alzheimer's disease family history (diagnosed family member)	Yes	44	15
	No	235	80
	Uncertain	16	5
GINA awareness (heard of GINA)	Yes	26	9
	No	269	91
GINA awareness (knows GINA)	Yes	10	3.4
	No	285(16+269)	96.6

Table 5. Willingness-to-pay and preference ratings of the 12 scenarios

Level of Accuracy (The % chance of the test result being correct)	Level of Treatment Availability	Level of Anonymity (Whether the test result is anonymous or not)	Median WTP ($)	Mean WTP ($)	Mean rating (0-10)
100%	A cure is available	Anonymous	100	276	9.45
100%	A cure is available	Not anonymous	75	290	8.47
80%	A cure is available	Anonymous	50	175	7.64
100%	Drugs for symptom relief and better quality of life are available but no cure is available	Anonymous	50	134	7.58
100%	Drugs for symptom relief and better quality of life are available but no cure is available	Not anonymous	50	159	7.23
80%	A cure is available	Not anonymous	50	148	6.88
80%	Drugs for symptom relief and better quality of life are available but no cure is available	Anonymous	40	99	6.49
80%	Drugs for symptom relief and better quality of life are available but no cure is available	Not anonymous	25	86	5.95

40%	A cure is available	Anonymous	10	86	4.65
40%	A cure is available	Not anonymous	10	76	4.63
40%	Drugs for symptom relief and better quality of life are available but no cure is available	Anonymous	1.5	42	3.82
40%	Drugs for symptom relief and better quality of life are available but no cure is available	Not anonymous	0	34	3.60

Table 6. Cluster Description

| Cluster	n	Accuracy Importance (%)	Treatment Availability Importance (%)	Anonymity Importance (%)	Gender (% Female)	Education (% with Bachelor's degree)	Income (median)	Race (% White, does not include mixed race)	Age	Exposure to Alzheimer's disease (% of having family history or care-giver experience)	Have ever heard of GINA (%)
1	74	51.89	24.73	23.43	39.19 (Highest male proportion)	36.49	44999.5 (Poorest)	83.78***	43.18 (Youngest)	25.68	14.86 (Most)
2	118	75.92	15.68	8.43	44.92	44.07**	54999.5	79.66*** (less likely to be White)	45.73	22.03	6.78
3	26	90.5	5.46	4.15	61.54*	19.23 (Lowest)	44999.5 (Poorest)	100.00 (Predominantly White)	46.23	23.08	11.54
4	26	39.04	53.00	7.92	65.38* (Highest female proportion)	46.15** (Highest)	64999.5 (Richest)	92.30	48.96 (Oldest)	42.31 **** (Most)	3.85 (Least)

*Showed statistical significance when comparing with Cluster1 (p-value=0.0488 for Cluster1&3; p-value= 0.02114for Cluster1&4)

**Showed statistical significance when comparing with Cluster3 (p-value=0.0191 for Cluster2&3; p-value=0.0385for Cluster 3&4)

***Showed statistical significance when comparing with Cluster3 (p-value=0.0329 for Cluster 1&3; p-value=0.0077 for Cluster 2&3)

****Showed statistical significance when comparing with Cluster2 (p-value=0.0322 for Cluster 2&4)

Figure 1. Attribute importance score for the four identified clusters

Attribute importance for the four clusters

Cluster 1
Cluster 2
Cluster 3
Cluster 4
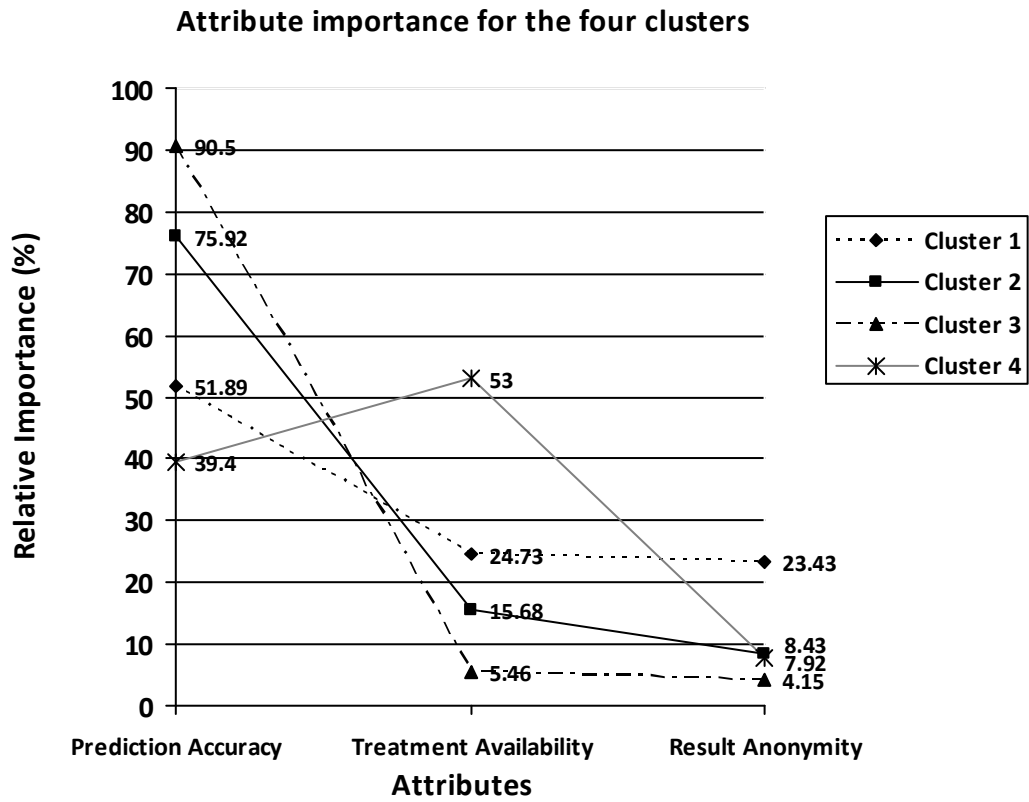
APPENDIX A: ONLINE SURVEY INSTRUMENT

Welcome! Thank you for taking this survey.

In this survey, you will be shown some imaginary scenarios. The scenarios are about predictive genetic tests for Alzheimer's disease (AD). Please rate each of the scenarios based on how interested you are in taking the test. Also, please estimate how much you are willing to pay for the test in dollars. There are 12 scenarios and 15 easy questions, which will only take you about 10 to 15 minutes to answer.

This is an anonymous survey. The answers you give will be kept in a file that is encrypted and password protected. Your participation is voluntary. You may choose not to participate or stop taking part at anytime without penalty or loss of benefits to which you are otherwise entitled. By completing the questionnaire, you are agreeing to participate in this research project.

Before we start, please answer the following question.
Have you ever been diagnosed with Alzheimer's Disease by a physician?
◻ Yes
◻ No

First, an example of how to complete the survey is provided at the bottom of this screen.
After you look at the example, move to the next screen where you will start the survey.

As you can see in the example below, the first thing to do is to rate each of the 12 different

scenarios using the 0-10 scale in the drop down list. After you rate each of the 12 scenarios, enter the dollar amount you are willing to pay for the test in the last column.

Each scenario has different features. The different features are for Predictive Accuracy, Treatment Availability, and Anonymity. Let me describe Predictive Accuracy, Treatment Availability, and Test Anonymity.

Predictive Accuracy is the chance that the test correctly predicts Alzheimer's disease. Three chance levels are used in this survey: 40%, 80%, and 100%.

Treatment Availability is whether a cure for AD is available. Two levels are shown in this survey: "A cure is available" vs. "There is no cure for Alzheimer's disease, but there are drugs to relieve the symptom and improve quality of life for up to two years".

Anonymity: An anonymous test means your name is not recorded with the test result. This means that later on no one can associate the test result with your name. Two levels are presented: "The test result is anonymous" vs. "The test result is not anonymous".

This is just an example. You don't need to answer it. You will see the real questions in the next page.

Please rate each of the following 12 different scenarios by using the 0-10 scale in the drop down list.
10 means definitely would want to take the test.
0 means definitely would not want to take it.

Please indicate the highest dollar amount you are willing to pay for the test ($). Write zero if you are not willing to pay any amount of money

Dollar amount you are willing to pay for the test ($).

Scenario 1		
The test result has an 80% chance of being correct		
Drugs for symptom relief and better quality of life are available but NO cure is available	▼	
The test result is NOT anonymous		
Scenario 2		
The test result has a 40% chance of being correct	▼	
A cure is available		
The test result is anonymous		

Below are the 12 different scenarios about a predictive genetic test for Alzheimer's disease. Each scenario has different features. The different features are for Predictive Accuracy, Treatment Availability, and Anonymity.

67

The first thing to do is to rate each of the 12 different scenarios using the 0-10 scale in the drop down list. After you rate each of the 12 scenarios, enter the dollar amount you are willing to pay for the test in the last column.

Below are the 12 different scenarios about a predictive genetic test for Alzheimer's disease. Each scenario has different features. The different features are for Predictive Accuracy, Treatment Availability, and Anonymity.

The first thing to do is to rate each of the 12 different scenarios using the 0-10 scale in the drop down list. After you rate each of the 12 scenarios, enter the dollar amount you are willing to pay for the test in the last column.

Please rate each of the following 12 different scenarios by using the 0-10 scale in the drop down list. 10 means definitely would want to take the test. 0 means definitely would not want to take it.

Please indicate the highest dollar amount you are willing to pay for the test ($). Write zero if you are not willing to pay any amount of money

Dollar amount you are willing to pay for the test ($).

Scenario 1		
The test result has an 80% chance of being correct		
Drugs for symptom relief and better quality of life are available but NO cure is available	▼	$
The test result is NOT anonymous		

Scenario 2		
The test result has a 40% chance of being correct	▼	$
Drugs for symptom relief and better quality of life are available but NO cure is available		

The test result is anonymous

Scenario 3

The test result has a 100% chance of being correct	▼	$
A cure is available		
The test result is anonymous		

Scenario 4

The test result has a 100% chance of being correct	▼	$
Drugs for symptom relief and better quality of life are available but NO cure is available		
The test result is anonymous		

Scenario 5

The test result has a 40% chance of being correct	▼	$
Drugs for symptom relief and better quality of life are available but NO cure is available		
The test result is NOT anonymous		

Scenario 6

The test result has a 100% chance of being correct	▼	$
A cure is available		
The test result is NOT anonymous		

Scenario 7

| The test result has a 40% | ▼ | $ |

chance of being correct		
A cure is available		
The test result is NOT anonymous		

Scenario 8

The test result has an 80% chance of being correct	▼	$
A cure is available		
The test result is NOT anonymous		

Scenario 9

The test result has an 80% chance of being correct	▼	$
A cure is available		
The test result is anonymous		

Scenario 10

The test result has a 40% chance of being correct	▼	$
A cure is available		
The test result is anonymous		

Scenario 11

The test result has an 80% chance of being correct	▼	$
Drugs for symptom relief and better quality of life are available but NO cure is available		
The test result is anonymous		

Scenario 12

The test result has a 100% chance of being correct	▼	$

Drugs for symptom relief and better quality of life are available but NO cure is available
The test result is NOT anonymous

Which scenarios would you prefer regarding Alzheimer's Disease genetic testing?

○
Scenario A

The test result has an 80% chance of being correct
A cure is available
The test result is anonymous

○
Scenario B

The test result has a 100% chance of being correct
Drugs for symptom relief and better quality of life are available but NO cure is available
The test result is NOT anonymous

○ There is no difference between scenario A and B

Which scenarios would you prefer regarding Alzheimer's Disease genetic testing?

○ Scenario A

The test result has an 80% chance of being correct
Drugs for symptom relief and better quality of life are available but NO cure is available
The test result is NOT anonymous

○ Scenario B

The test result has a 40% chance of being correct
Drugs for symptom relief and better quality of life are available but NO cure is available
The test result is anonymous

○ There is no difference between scenario A and B

For the previous scenarios, we focused on Predictive Accuracy, Treatment Availability and Anonymity. But we know we may not have included all of the features that could influence your decision. Are there any other factors that would be important to you if you were making a decision to obtain a genetic test for Alzheimer's disease? If yes, please list in the box below.

[ ]

Do you have any care-giving experience for someone with Alzheimer's disease?

☐ Yes

☐ No

For how long (in months) ?

[ ]

Do you have any family members diagnosed with Alzheimer's disease?

☐ Yes

☐ No

☐ Uncertain, because [ ]

Have you ever heard of the Genetic Information Nondiscrimination Act (GINA) of 2008?

☐ Yes

☐ No

Please choose the correct description regarding the Genetic Information Nondiscrimination Act (GINA) of 2008.

☐ The Genetic Information Nondiscrimination Act (GINA) of 2008 requires patients to report

their genetic information to the Department of Health and Human Services.

☐ The Genetic Information Nondiscrimination Act (GINA) of 2008 promotes research of about genetic tests by providing federal funding.

☐ The Genetic Information Nondiscrimination Act (GINA) of 2008 prohibits the improper use of genetic information in health insurance and employment.

☐ The Genetic Information Nondiscrimination Act (GINA) of 2008 requires a doctor's prescription to obtain a genetic test.

☐ I don't know the details about the Genetic Information Nondiscrimination Act (GINA) of 2008

In what year were you born?

[   ]

What is the highest level of education you have completed?

☐ Less than high school

☐ High School / GED

☐ Some College

☐ 2-year College Degree

☐ 4-year College Degree

☐ Postgraduate or Professional Degree

How do you describe yourself? (Please indicate mixed racial heritage by checking more than one option).

☐ Hispanic, Latino, or Spanish origin

☐ White

☐ Black or African American

☐ American Indian or Alaskan Native

☐ Native Hawaiian or Other Pacific Islander

☐ Asian

☐ Indian (Asian)

☐ Some other race [   ]

What is your gender?

☐ Male

☐ Female

For statistical purpose only, please indicate your approximate household income before taxes in 2010?

☐ Under 10,000

☐ 10,000 – 19,999

☐ 20,000 – 29,999

☐ 30,000 – 39,999

☐ 40,000 – 49,999

☐ 50,000 – 59,999

☐ 60,000 – 69,999

☐ 70,000 – 79,999

☐ 80,000 – 89,999

☐ 90,000 – 99,999

☐ 100K or more

How difficult is this survey for you to fill out?

Very difficult	Difficult	Neutral	Easy	Very easy
☐	☐	☐	☐	☐

Any comments?

Survey Powered By Qualtrics®