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Resilience and Psychological Distress in Genetic Testing for Alzheimer's Disease

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The relationship between resilience and psychological distress resulting from genetic testing for Alzheimer's disease among non-cognitively impaired individuals is examined in this study. Preventative genetic testing determines the likelihood of developing or passing on genetic disorders. However, receiving genetic information, especially regarding incurable diseases like Alzheimer's disease, can lead to significant psychological distress. Resilience, the ability to cope with adversity and recover quickly, is considered a protective factor against psychological distress. The purpose of this study is to investigate whether higher levels of resilience are associated with lower psychological distress from genetic testing for Alzheimer's disease and to determine if having a familial history of Alzheimer's disease influences this relationship. An online cross-sectional survey was conducted among 181 non-cognitively impaired participants (43.6% Male; 54.1% Female; M_{age}=38.1 [13.9]) using the Impact of Genetic Testing for Alzheimer's Disease (IGT-AD) scale and the Brief Resilience Scale (BRS), along with a question about family history of Alzheimer's disease. The results indicated a significant negative correlation between resilience and psychological distress, suggesting that individuals with higher resilience experienced lower distress related to genetic testing. However, family history did not mediate the relationship, meaning the protective effect of resilience was consistent regardless of familial risk. These findings have implications for developing targeted support services and resilience-based interventions to help individuals cope with the emotional impact of genetic testing for Alzheimer's disease. Further research could explore other potential protective factors and examine the long-term impact of genetic testing results on psychological well-being and behavior.

Keywords: resilience, psychological distress, genetic testing, Alzheimer's disease

The landscape of preventative genetic testing is continuously expanding, providing insights into the likelihood of developing or transmitting genetic disorders. This form of testing holds apparent significance: offering the advantage of foreknowledge about genetic diseases prior to the manifestation of symptoms, facilitating the diagnosis of various conditions, and receiving information pertaining to the potential transmission of genetic disorders to offspring (Khoury et al., 2006). Within Alzheimer's disease and related dementias, a focal point of investigation lies in genetic testing. Advanced technology is now available to analyze genetic makeup, facilitating the identification of specific genes associated with the onset of Alzheimer's disease. Consequently, some individuals are interested in procuring their genetic results (Cutler & Hodgson, 2003). As genetic testing advances and refines, its accessibility is anticipated to expand, granting individuals the choice of accessing information about their susceptibility to Alzheimer's disease and related dementias. Ethical considerations stemming from the acquisition of potential symptomatology knowledge encompass issues of hereditary transmission, lifestyle adjustments, and future life planning (Roberts et al., 2003).

Alongside the benefits of genetic testing, there are potential ramifications for those who opt to acquire genetic information, notably an increase in psychological distress. Psychological distress is characterized by a spectrum of stress-related symptoms encompassing anxiety, tension, and depression, significantly impacting overall well-being (Gooding et al., 2006). In the context of discovering that one is a carrier of an Alzheimer's disease gene, individuals may commonly be confronted with uncertainties regarding the timing and potential outcomes of their condition, thus intensifying psychological distress (Galluzzi et al., 2022). Given that Alzheimer's disease and related dementias involve irreversible brain degeneration and lack definitive curative treatments, the absence of viable long-term remedies could lead to distress among individuals experiencing cognitive impairment or a dementia diagnosis (Cutler & Hodgson, 2003). Therefore, receiving genetic information about Alzheimer's disease has the potential to induce substantial psychological distress (Bookherimer & Burggren, 2009).

Moreover, chronic stress has been shown to exert a detrimental impact on Alzheimer's disease itself. Research suggests that sustained stress can accelerate the progression of Alzheimer's disease, leading to increased neurodegeneration and the worsening of cognitive and behavioral symptoms in affected individuals (Justice, 2018). This complex interplay between stress and Alzheimer's disease underscores the need for comprehensive interventions aimed at addressing both the psychological well-being of patients and the biological factors contributing to disease progression.

Though the psychological impact of receiving a diagnosis for an incurable disease is apparent, the do-

main of potentially protective factors remains less explored. Resilience is a pivotal protective factor against psychological distress (Garmezy, 1991). Resilience, characterized by the ability to withstand or recover quickly from distress, has an established inverse correlation with psychological distress (Yasien et al., 2016). Norman Garmezy introduced the resilience theory to understand how individuals who face adversities and risk exposure can develop normally and become healthy adults (Garmezy, 1991). This theory postulates that resilience entails rebounding from emotional distress and maintaining adaptive behavior despite threats and adversities to an individual's well-being.

Resilience has been shown to impact the adjustment to genetic testing results with hereditary diseases, including cancers (Ho et al., 2010). Psychological distress from genetic testing is impacted by the severity of the disease, perceived risk, ability to control the disease, and availability of treatments (Oliveri et al., 2018). Analogous to cancer, Alzheimer's disease significantly affects quality of life and psychosocial well-being and often necessitates long-term care or interventions (Oliveri et al., 2018). Hence, further exploration is required to unravel the interplay between resilience and psychological distress from genetic testing, particularly in Alzheimer's disease.

Moreover, the influence of resilience on psychological distress may not be uniform across all individuals. Family history, which signifies whether an individual has a familial predisposition to Alzheimer's disease, has the potential to influence this relationship. A family history of a disease, particularly one with a genetic component like Alzheimer's disease, can significantly heighten psychological distress (Liu & Cao, 2014). It leads to increased awareness of one's susceptibility, fostering stress and anxiety, as individuals become more concerned about their own risk and the possibility of transmitting the condition to their descendants (Roberts et al., 2003). Furthermore, family history can impose a perceived genetic "inheritance burden" on individuals, leading to guilt and concern about implications for their loved ones or future generations (James et al., 2006). While family history can increase the risk of developing Alzheimer's disease (Liu & Cao, 2014), its role in the context of resilience and psychological distress remains underexplored.

An understanding of the psychological impact of genetic testing, particularly in the Alzheimer's context, is beneficial in identifying individuals at heightened risk of psychological distress and in devising additional coping strategies (Chung et al., 2009). Resilience-based interventions aimed at strengthening an individual's resilience, thereby mitigating distress, and at promoting emotional well-being hold the potential to significantly enhance the quality of life for individuals afflicted by neurocognitive disorders. However, more information is needed to understand how to effectively introduce resilience interventions (Wang et al., 2021), specifically in the context of receiving genetic testing results.

Purpose

The purpose of this study is to examine the relationship between resilience and psychological distress from genetic testing for Alzheimer's disease among non-cognitively impaired individuals, hereafter referred to as 'unimpaired.' Drawing from resilience theory, which posits that protective factors mitigate the adverse consequences of risk exposure (Garmezy, 1992), it is hypothesized that individuals with higher levels of resilience will experience lower levels of psychological distress when considering genetic testing for Alzheimer's disease. This association rests on the premise that individuals exhibiting higher resilience levels will experience lower levels of emotional and behavioral challenges, such as depression, anxiety, and stress (Yasien et al., 2016), compared to their counterparts with lower resilience levels.

Furthermore, family history is hypothesized to mediate the interplay between resilience and psychological distress. Instances of psychological distress, including anxiety, depression, and disease-specific distress, tend to intensify in the presence of a family history of particular diseases (Liu & Cao, 2014). Family history is projected to influence the strength of the relationship of resilience as a positive adaptation to psychological distress, given that a familial history of Alzheimer's disease is likely to amplify the psychological distress experienced by participants contemplating genetic testing for the disease. The intent of the study is to answer two key research questions:

1. Do variations in the Impact of Genetic Testing for Alzheimer's Disease (IGT-AD) scores relate to levels of resilience among unimpaired partici pants?
2. Does the presence of a family history of Alzhei mer's disease influence or mediate this relationship?

This study aims to recruit participants to complete a survey consisting of the IGT-AD survey, Brief Resilience Scale, and a query regarding a family history of Alzheimer's disease. The IGT-AD (Appendix 1) was created to evaluate the nature of genetic information and examine the impact of Alzheimer's disease risk assessment (Chung et al., 2009). The survey will measure the adverse effects of participants receiving genetic information about Alzheimer's disease. The Brief Resilience Scale (Appendix 2) will assess the perceived ability to bounce back or recover from stress (Smith et al., 2008). The variables, psychological distress from Alzheimer's disease genetic testing and resilience, will be assessed for a relationship and will determine if family history impacts the relationship. The findings hold significant implications for discerning susceptibility to psychological distress related to genetic testing and understanding the role of resilience in counteracting these psychological effects.

Method

Participant Recruitment and Selection

To address the research question, a cross-sectional survey was conducted online, leveraging the benefits of prompt participant data collection without the need for in-person administration, which aligns with the study's focus on obtaining a snapshot of characteristics at a specific moment. This research project underwent rigorous ethical review and received Institutional Review Board (IRB) approval from Tiffin University, ensuring the protection and well-being of all participants involved. Prior to involvement in the study, participants were required to complete an informed consent which provided comprehensive information about the research objectives, procedures, potential risks, benefits, and confidentiality measures.

Due to the convenience of online data collection, the internet survey platform, Prolific, was used for participant recruitment, with the study population of interest being cognitively unimpaired individuals. The survey obtained a study sample of participants who are not cognitively impaired or experiencing memory concerns through exclusion criteria. Participants who answered "yes" to the initial question regarding memory concerns and cognitive impairment: "Are you currently experiencing cognitive impairment or concerns with your memory and thinking?", were disqualified from the study. The survey was a convenience sample as the Prolific platform fills study places on a first-come, first-served basis and was distributed to all available participants. Participants were pre-screened for English as their primary language, and an inclusion criterion was implemented to obtain participants only from the United States.

Sample Size Determination

A power analysis was conducted using G*Power to determine the appropriate sample size for the expected statistical analyses. For multiple regression (f^2=.15, 80% power, α=.05) a minimum sample size of 82 and 68 participants, respectively, is required to yield meaningful results. The study aimed to recruit approximately 200 eligible participants to complete the survey, accounting for the number of participants deemed ineligible due to the initial question regarding memory concerns or cognitive impairment and their incomplete survey completion. A total of 231 participants initiated involvement in the study, and 50 participants were disqualified from the study due to the inclusion criteria. The sample size consisted of 181 responses with an average survey completion time of three minutes. Participants who completed the entirety of the survey were rewarded $0.40 as an appreciation of their time and effort.

Participant Demographics

A total of 251 participants were presented with the survey, 181 met the inclusion criteria and completed the entirety of the survey. The sociodemographic characteristics are reported in Table 1. The sample consisted of 98 females (54.1%), 79 males (43.6%), and four non-binary participants (2.2%). Participants' ages range from 19 to 73 years, with a mean age of 38.1 years (SD = 13.9). Regarding educational attainment, 1 participant (0.6%) had some high school education, 23 participants (12.7%) had completed high school or equivalent, 63 participants (34.8%) had some college education, 75 participants (41.4%) held a bachelor's degree, and 19 participants (10.5%) held a graduate or professional degree.

Survey Design

The survey consisted of a one-group design with a two-variable comparison of psychological distress from Alzheimer's disease genetic testing and resilience. Google Forms was used to generate a survey consisting of the preliminary question regarding current cognitive impairment, two embedded scales, a question regarding family history of Alzheimer's

disease: "Do you have a history of Alzheimer's disease in your family?" (Questionnaire 1), and demographic questions (Questionnaire 1). The study items were piloted among five participants to determine the appropriateness and consistency of the items.

Description of Scales

Impact of Genetic Testing for Alzheimer's Disease Scale. The first scale, Impact of Genetic Testing for Alzheimer's Disease (IGT-AD; Appendix 1), assessed the dependent variable, psychological distress from receiving Alzheimer's disease genetic testing (Chung et al., 2009). The IGT-AD scale was developed to accurately assess the psychological distress associated with genetic testing for Alzheimer's disease. While existing risk assessment scales predominantly focus on measuring depression and anxiety (Chung et al., 2009), the IGT-AD scale was formulated to gauge the psychological impact of genetic susceptibility to Alzheimer's disease, incorporating insights from other genetic testing impact assessment scales (Cella et al., 2002). This instrument is designed for clinical and research applications, providing a concise self-report measure of the psychological impact of genetic susceptibility to Alzheimer's disease (Chung et al., 2009).

This 16-item scale used a 4-point response scale where 0 was "strongly disagree," and 5 was "strongly agree." The total score ranges from 0-80, with higher scores reflecting greater psychological distress related to Alzheimer's disease genetic testing (Chung et al., 2009). In their study, Chung et al. (2009) reported a mean of 16.9 with a standard deviation of 9.9, serving as a reference point for interpretation, along with a Cronbach's α of 0.82 for the scale. The IGT-AD was assessed for construct validity by comparing the final scale to other established psychometric scales, including the Impact of Event Scale (IES), the Center for Epidemiologic Studies Depression Scale (CES-D), and the Beck Anxiety Inventory (BAI). Using Spearman's correlations, the final scale was positively correlated with all the psychometric scales indicating convergent validity (Chung et al., 2009). The assessment results suggest that the IGT-AD is a valid and reliable scale that may be a more useful and sensitive tool in measuring psychological distress specific to Alzheimer's disease genetic testing than other generalized mood scales.

Brief Resilience Scale. The second scale, the 6-item Brief Resilience Scale (BRS; Appendix 2), was used to measure the independent variable, resilience, or the perceived ability to bounce back or recover from stress (Smith et al., 2008). This 6-item scale used a 5-point response scale where 0 was "strongly disagree," and 5 was "strongly agree." The total score ranges from 0-30, with higher scores reflecting greater resilience (M=21.18-23.88, SD=4.08-5.1; Smith et al., 2018). Smith et al. (2018) reported Cronbach's α of 0.80-0.91 for the scale. The BRS was assessed for convergent validity and was positively correlated with resilience measures, including optimism, social support, and life purpose, and was negatively correlated with pessimism and negative interactions (Smith et al., 2008). The assessment results indicate that BRS is an adequate measure of resilience with good internal consistency and test-retest reliability.

Reliability and Validity in the Current Dataset

To ensure the reliability and validity of the measurement instruments in the current dataset, an analysis of internal consistency was conducted using Cronbach's alpha. The values for Cronbach's alpha in our dataset, demonstrating a high level of internal consistency (α= .82 for IGT-AD and α= .94 for BRS), were found to be consistent with previous research (Chung et al., 2009; Smith et al., 2018), affirming the instruments' sustained reliability. Additionally, the content validity of the scales, which assess the intended constructs, was confirmed as the items were adapted from previous studies with established validity.

Data Screening and Preliminary Assumptions

Statistical analyses were performed using the SPSS 28.0 statistical software. The data met the assumptions for multiple regression analysis: (a) one continuous independent variable (IGT-AD Total Scores), one continuous dependent variable (BRS Total Scores), and one dichotomous mediator variable (family history) , (b) independent observations, (c) a linear relationship exists between the independent and dependent variables, (d) homoscedasticity is present, (e) no multicollinearity, (f) no outliers, and (g) the residuals are normally distributed. A Durbin-Watson statistic was conducted to support the independence of residuals (DW = 1.743). Standardized residuals indicated approximately normally distributed errors, as did the normal P-P plot of standardized residuals. Tests for multicollinearity showed no concern (BRS total scores, Tolerance = .994, VIF = 1.006; Family history, Tolerance = .994, VIF =1.006).

In order to explore the potential mediating effect

of family history on the relationship between psychological distress and resilience, a mediator analysis using regression was applied. In the mediator analysis, psychological distress and resilience are defined as the dependent and independent variables, respectively, while family history is defined as the mediator to determine if family history impacts the relationship. The PROCESS Macro Model 4 for SPSS was utilized to apply a bias-correct non-parametric bootstrapping technique with 5000 resamples to estimate family history's direct, indirect, and total effects (Preacher & Hayes, 2008). All assumptions for the mediator analysis using regression analysis were met.

Results

Descriptive Statistics

The survey's descriptive statistics are reported in Table 2. The sample contained 52 participants with a family history of Alzheimer's disease (28.7%) and 129 participants without (71.3%). No family history was coded as 0, and family history was reported as 1 with a reported mean of .287 (SD = .454). The total scores of the IGT-AD scale ranged from 1 to 72, with a mean score of 34.3 (SD = 11.8), indicating moderate psychological distress related to Alzheimer's disease genetic testing for the sample. The total score of the BRS scale ranged from 6 to 30, with a mean score of 19.8 (SD = 5.4), indicating a moderately resilient sample.

Statistical Analyses

Multiple Regression Analysis

A multiple regression analysis was performed to investigate the relationship between psychological distress from Alzheimer's disease-related genetic testing (IGT-AD scores) and resilience (BRS scores). The model, incorporating BRS scores as the independent variable and IGT-AD scores as the dependent variable, yielded a significant negative association (Figure 1). The multiple correlation coefficient (R) was 0.415, indicating a moderate correlation between the predicted and observed values of IGT-AD scores and the predictor variable. The regression model, involving BRS scores, accounted for 17.22% of the variance in IGT-AD scores (R^2 = .172, F(2,175) = 16.057, $p < 0.001$). The unstandardized coefficient for BRS scores was -0.829 ($p < 0.001$), indicating that, for each unit increase in BRS scores, IGT-AD scores decreased by 0.829 units.

Covariate Analysis

To assess the potential influence of covariates on the relationship between BRS and IGT-AD scores an analysis of the covariates, including age, gender, and education was conducted. Education level emerged as a significant predictor (B = 1.963, SE = 0.892, β = 0.151, t = 2.202, p = .029), suggesting that individuals with higher education levels experienced higher psychological distress. The results of this analysis revealed that after controlling for these covariates, the relationship between BRS and IGT-AD scores remained statistically significant (F(22,153) = 1.877, p = .015, η^2 = .212)).

Mediator Analysis

The mediator analysis results are reported in Table 3. The analysis of family history revealed a non-significant effect on IGT-AD scores (p = .163), suggesting family history did not significantly influence the scores. The interaction term between BRS scores and family history did not significantly contribute to the variance in IGT-AD scores (R^2 = 0.011, F(1, 175) = 2.326, p = 0.129), suggesting that the relationship between BRS scores and IGT-AD scores were not influenced by the presence of family history. Bootstrap analysis further supported the regression results.

Discussion

The present study investigated the relationship between resilience and psychological distress resulting from genetic testing for Alzheimer's disease among unimpaired individuals. The findings indicated a significant negative correlation between resilience and psychological distress, indicating that higher levels of resilience were associated with lower levels of distress related to genetic testing for Alzheimer's disease, irrespective of age and gender. These results support previous research that resilience can act as a protective factor against psychological distress in the context of genetic testing for hereditary diseases (Ho et al., 2010).

The negative correlation between resilience and psychological distress suggests that individuals with higher resilience may cope more effectively with the potential implications of genetic testing for Alzheimer's disease. Resilience allows individuals to adapt positively to challenging situations and adversities (Garmezy, 1991), which may translate into reduced distress when faced with the possibility of developing Alzheimer's disease. Higher levels of resilience may enable individuals to maintain emotional well-being despite the perceived threat of the disease and the uncertainty associated with genetic testing results (Yasien et al., 2016).

The results also showed that family history did not significantly mediate the relationship between resilience and psychological distress. This suggests that individuals with higher resilience may be better equipped to cope with the emotional impact of genetic testing, regardless of their family history. While a family history of Alzheimer's disease can increase the risk of developing the condition (Liu & Cao, 2014), it did not significantly impact how resilience influenced the psychological distress associated with genetic testing for the disease.

The development and use of the IGT-AD scale were essential in measuring the psychological impact of genetic susceptibility to Alzheimer's disease (Chung et al., 2009). Previous scales primarily targeted depression and anxiety, but the IGT-AD scale provides a more specific and sensitive measure for assessing distress specifically related to Alzheimer's disease genetic testing. Using validated and reliable measures, such as the IGT-AD and the BRS, strengthens the study's validity and supports the generalizability of the findings to other populations undergoing genetic testing for hereditary diseases.

The present study contributes to the existing literature by focusing on unimpaired individuals' psychological distress related to genetic testing for Alzheimer's disease. Understanding the factors that influence individuals' responses to genetic testing is crucial, as it can help identify those at higher risk of experiencing distress and guide the development of tailored interventions. The results suggest that resilience-based interventions may be beneficial for individuals undergoing genetic testing for Alzheimer's disease, as they may help mitigate the psychological distress associated with receiving test results (Wang et al., 2021).

Limitations

The present study had some limitations that should be acknowledged. The sample consisted of a convenience sample of unimpaired individuals recruited online, limiting the generalizability of the findings to the broader population. Future research could aim to recruit a more diverse and representative sample to increase external validity. The study's cross-sectional design does not allow for causal inferences, and future longitudinal studies can better examine the relationship between resilience and psychological distress over time. It is crucial to acknowledge that the IGT-AD and BRS scales were not counterbalanced in this study, thereby introducing the possibility of order effects influencing participants' responses. Self-report measures are subject to response biases, and participants may have provided socially desirable responses, leading to potential measurement errors.

Another potential limitation arises from the reliance on participant-reported family history of Alzheimer's disease. This information could be subject to variations in accuracy, as it depends on participants' knowledge and the extent of their inquiries within their families. Some participants may have inquired about Alzheimer's disease in only a few generations, while others may have gone further back in their family tree. For future research, adopting more standardized and comprehensive methods for assessing family history may enhance the accuracy of this variable.

Implications and Future Research

The study's findings have several implications for clinical practice and future research. First, identifying individuals at higher risk of psychological distress related to genetic testing can inform the development of targeted support and counseling services to help individuals cope with the emotional impact of test results. Healthcare providers should consider incorporating resilience-based interventions as part of pre-and post-genetic counseling for Alzheimer's disease and other hereditary conditions. Such interventions may help individuals develop coping strategies and enhance their emotional well-being in the face of potential risk ultimately aiding in the reduction of stress that can contribute to the accelerated progression and neurodegeneration of Alzheimer's disease (Justice, 2018).

While the present study did not explicitly assess the temporal aspect of psychological distress, it is essential to acknowledge that distress may vary over time. Genetic testing results can trigger acute stress reactions, followed by an adjustment period. For some individuals, this psychological distress may be temporary, while for others, it may extend into a more prolonged and chronic experience. Future research could delve into the dynamics of psychological distress over time in relation to genetic testing results, examining the factors influencing its duration and intensity.

Future research should explore other potentially protective factors, such as social support, coping strategies, and personality traits, to gain a comprehensive understanding of the factors that influence psychological distress related to genetic testing for Alzheimer's disease. Longitudinal studies can also provide insights

into how resilience evolves over time in response to receiving genetic testing results and the progression of Alzheimer's disease. Additionally, examining the long-term impact of genetic testing results on psychological well-being and behavior, especially in those with a family history of Alzheimer's disease, can offer valuable information for personalized interventions.

Conclusion

In conclusion, the present study adds to the growing body of literature on psychological distress related to genetic testing for Alzheimer's disease by examining the role of resilience as a protective factor. The findings highlight the importance of resilience in coping with the potential emotional impact of receiving genetic testing results and suggest that resilience-based interventions may be beneficial in supporting individuals undergoing genetic testing for Alzheimer's disease. Healthcare providers should consider incorporating resilience-based strategies in genetic counseling sessions to enhance individuals' ability to cope with the emotional challenges of genetic testing. Further research is needed to explore other potentially protective factors and their role in influencing psychological distress related to genetic testing for Alzheimer's disease, ultimately improving support and care for individuals at risk.

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Table 1

Sociodemographic Characteristics of the Participants

Sample Characteristics	*N*	%	*M*	*SD*
Gender				
Male	79	43.6		
Female	98	54.1		
Non-binary	4	2.2		
Age			38.1	13.9
Education				
Some high school	1	0.6		
High school or equivalent	23	12.7		
Some college	63	34.8		
Bachelor's degree	75	41.4		
Graduate/Professional degree	19	10.5		

Table 2

Survey Descriptive Statistics

Survey Descriptives	*N*	%	*M*	*SD*
Family History			.287	.454
With Alzheimer's disease	52	28.7		
Without Alzheimer's disease	129	71.3		
IGT-AD Total Scores			34.3	11.8
BRS Total Scores			19.8	5.4

Table 3

Mediator Analysis

Effect	Regression Coefficient	*SE*	95% CI		*p*
			LL	UL	
Intercept	52.757	3.355	46.136	59.378	.000
BRS Totals	-.941	.161	-1.259	-.623	.000
Family History	-9.643	6.874	-23.210	3.925	.163
Interaction	.525	.344	-.154	1.204	.129

Figure 1

Scatterplot of BRS and IGT-AD Total Scores

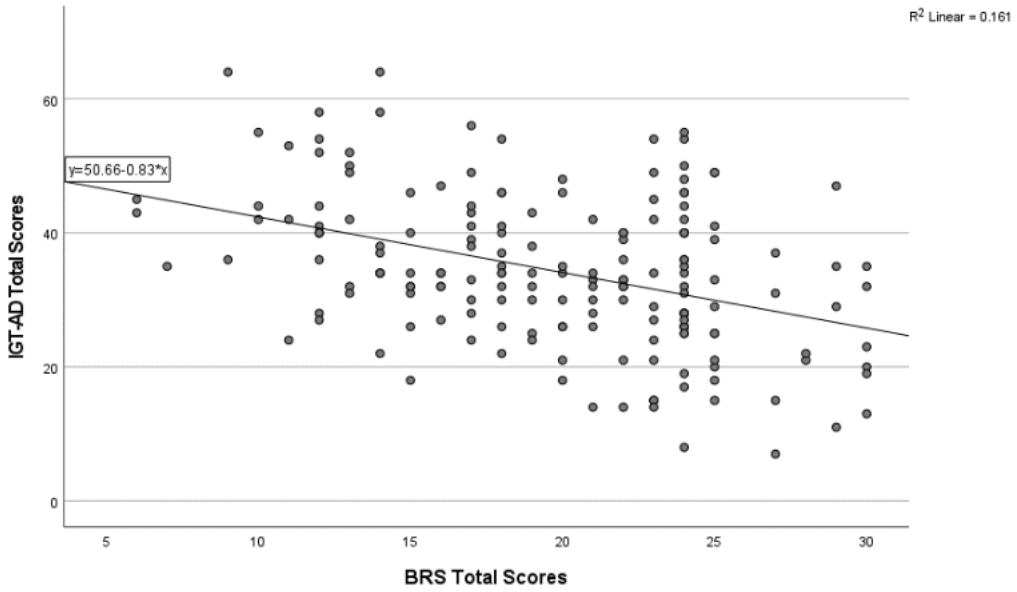
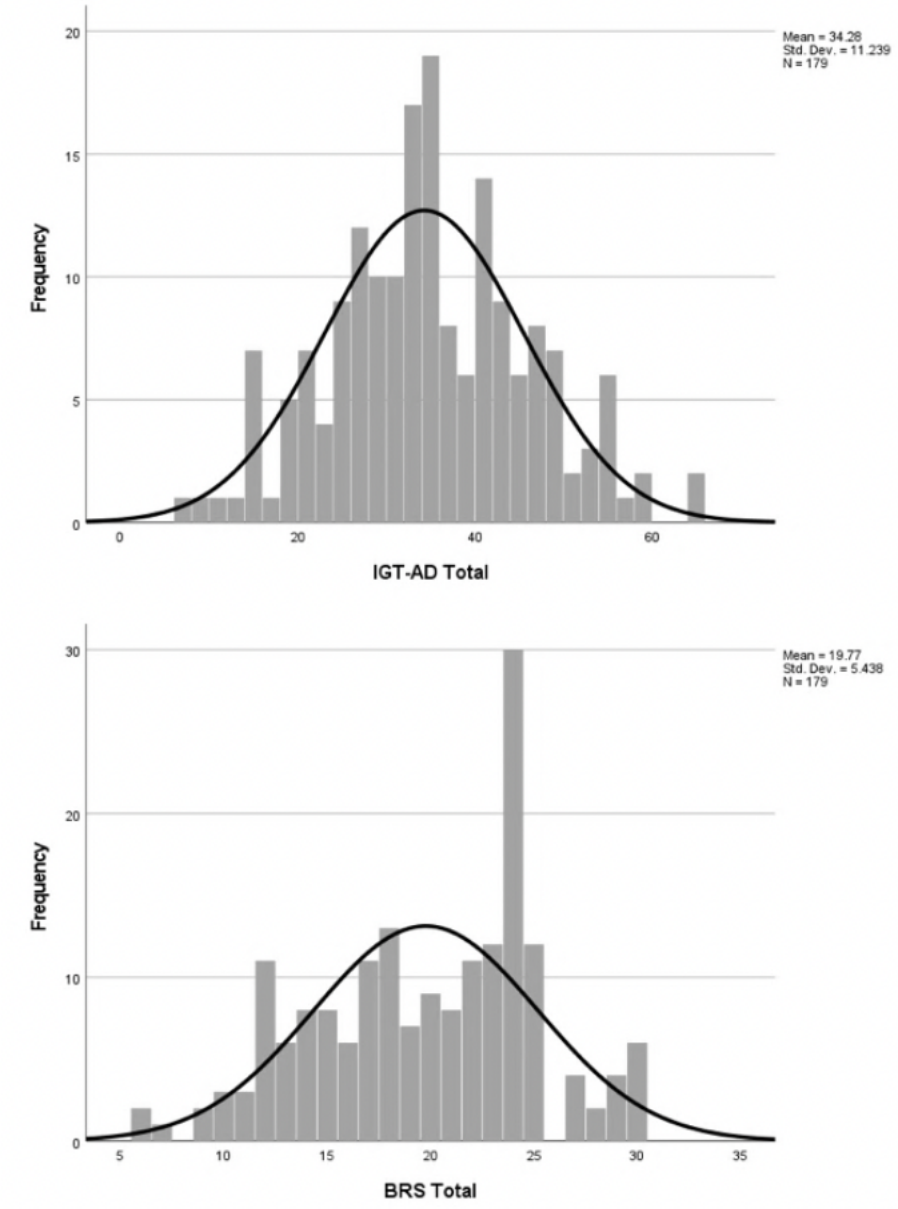


Figure 2

Normality Distribution of IGT-AD and BRS Total Scores



Appendix 1

The Reveal Impact of Genetic Testing in Alzheimer's Disease Scale (IGT-AD)

The questions below are about specific responses you may have about receiving your Alzheimer's disease genetic test results. Please evaluate your response to receiving your results and answer every question in this section. Indicate whether you strongly disagree, disagree, agree, or strongly agree with each statement, by selecting the corresponding response.

	Strongly Disagree	Disagree	Agree	Strongly Agree
I would feel upset about receiving my test result	● (0)	● (1)	● (3)	● (5)
I would feel sad about receiving my test result	● (0)	● (1)	● (3)	● (5)
I would feel anxious or nervous about receiving my test result	● (0)	● (1)	● (3)	● (5)
I would feel relieved about receiving my test result	● (5)	● (3)	● (1)	● (0)
I would feel happy about receiving my test result	● (5)	● (3)	● (1)	● (0)
I would feel a loss of control	● (0)	● (1)	● (3)	● (5)
I would have problems enjoying life because of my test result	● (0)	● (1)	● (3)	● (5)
I would feel worried about my risk of getting Alzheimer's disease	● (0)	● (1)	● (3)	● (5)
I would feel uncertain about what my test result means about my risk of developing Alzheimer's disease	● (0)	● (1)	● (3)	● (5)
I would feel uncertain about what my test result means for my child(ren)'s and/or family's Alzheimer's disease risk	● (0)	● (1)	● (3)	● (5)
I would feel frustrated that there are no definite Alzheimer's disease prevention guidelines for me	● (0)	● (1)	● (3)	● (5)
I would feel concerned about how my test results will affect my insurance status	● (0)	● (1)	● (3)	● (5)
I would have difficulty talking about my test results with family members	● (0)	● (1)	● (3)	● (5)

I would feel frustrated that there are no definite Alzheimer's disease prevention guidelines for me	● (0)	● (1)	● (3)	● (5)
I would feel concerned about how my test results will affect my insurance status	● (0)	● (1)	● (3)	● (5)
I would have difficulty talking about my test results with family members	● (0)	● (1)	● (3)	● (5)
I would feel that my family will be supportive during genetic counseling and testing process	● (5)	● (3)	● (1)	● (0)
I would feel satisfied with family communication about my genetic test result	● (5)	● (3)	● (1)	● (0)
I would feel regret about getting my test results	● (0)	● (1)	● (3)	● (5)

Note. Items 4, 5, 14, and 15 are reverse scored. To score, add the responses varying from 1-5 for all sixteen items, giving a range from 0-80.

Appendix 2

Brief Resilience Scale (BRS)

Please respond to each item by marking one response	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I tend to bounce back quickly after hard times.	● (1)	● (2)	● (3)	● (4)	● (5)
I have a hard time making it through stressful events.	● (5)	● (4)	● (3)	● (2)	● (1)
It does not take me long to recover from a stressful event.	● (1)	● (2)	● (3)	● (4)	● (5)
It is hard for me to snap back when something bad happens.	● (5)	● (4)	● (3)	● (2)	● (1)
I usually come through difficult times with little trouble.	● (1)	● (2)	● (3)	● (4)	● (5)
I tend to take a long time to get over set-backs in my life.	● (5)	● (4)	● (3)	● (2)	● (1)

Note. Items 2, 4, and 6 are reverse scored. To score, add the responses varying from 1-5 for all six items, giving a range from 6-30.

Questionnaire 1

Family History and Demographic Questions

Do you have a history of Alzheimer's disease in your family?
☐ Yes (1)
☐ No (0)

What is your gender?
☐ Male
☐ Female
☐ Other ☐

What is your age?

☐

What is your highest level of education completed?
☐ Some high school
☐ High school graduate or equivalent
☐ Some college
☐ Bachelor's degree
☐ Graduate/Professional degree